

THE ATTITUDES OF TYPICALLY-DEVELOPING CHILDREN TOWARDS PARTICIPATION WITH THEIR SIBLINGS WITH SEVERE SPEECH AND LANGUAGE DISABILITIES

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ABSTRACT

Sibling relationships and the interaction within these relationships play a central role in children's general development and will therefore impact on functional outcomes of children with severe speech and language disabilities. Siblings of children with disabilities have often felt excluded from family interactions, possibly causing negative attitudes towards participation with their siblings, in turn impacting negatively on the functional outcomes of their siblings with disabilities. The main aim of this research is to determine the attitudes of typically-developing children towards participation with their younger siblings with severe speech and language disabilities in four everyday life situations, namely: play (major life areas), communication, activities of daily living as part of domestic life and interpersonal relationships (time and responsibility issues). Twenty-seven older, typically-developing siblings of children with severe speech and language disabilities were selected to complete the measuring instrument (SAS). The results indicated that the participants held the most positive attitudes towards participation in play (major life areas) but that they held less positive attitudes towards communication participation and that they were least positive about participation in interpersonal relationships (time and responsibility issues). This study succeeded in documenting attitudes of siblings towards participating in four everyday life situations with their younger sibling. It is envisaged that these results will provide tentative guidelines for how activity-based interventions can best be structured to support both the child with a disability and their sibling.

KEY WORDS

- Attitudes
- Everyday life situations
- Functional outcomes
- International Classification of Functioning, Disability and Health-Version for Children & Youth (ICF-CY)
- Participation
- Severe speech and language disabilities
- Siblings
- Typically-developing children

OPSOMMING

Interaksie tussen sibbe binne die konteks van sibbeverhoudings speel 'n sentrale rol in die algemene ontwikkeling van kinders in verskeie areas van ontwikkeling en sal dus 'n impak hê op die funksionele uitkomste van kinders met ernstige spraak- en taalgestremdhede. Sibbe van kinders met gestremdhede het tot op hede dikwels uit gesinsinteraksie uitgesluit gevoel. Dit kon moontlik 'n negatiewe effek op hul houdings teenoor interaksie en deelname met hul sibbe met 'n gestremdheid gehad het wat verder kon veroorsaak het dat die funksionele uitkomste van hul sibbe ook negatief beïnvloed is. Die hoofdoelwit van hierdie navorsingstudie was om die houdings van tipies-ontwikkende kinders teenoor hul sibbe met ernstige spraak- en taalgestremdhede in vier alledaagse lewensituasies te bepaal, naamlik: spel (kern lewensareas), kommunikasie, aktiwiteite van daaglikse lewe en interpersoonlike verhoudings (tyd- en verantwoordelikeheidsaspekte). Sewe-en-twintig ouer, tipies-ontwikkende sibbe van kinders met ernstige spraak- en taalgestremdhede was geselekteer om die meetinstrument (SAS) te voltooi. Die resultate het getoon dat die deelnemers hoogs positiewe houdings het teenoor deelname tydens spel (kern lewensareas), en dat hul minder positiewe houdings het teenoor deelname tydens kommunikasie. Hul het die minste positiewe houdings teenoor deelname tydens interpersoonlike verhoudings (tyd en verantwoordelikeheidsaspekte) getoon. Hierdie studie het geslaag daarin om die houdings van ouer sibbe teenoor deelname met hul jonger sibbe in vier alledaagse lewensituasies te dokumenteer. Dit word beoog dat hierdie resultate tentatiewe riglyne vir aktiwiteitsgebaseerde intervensie kan verskaf om sodoende beide ouer kinders sowel as hul sibbe met gestremdhede te ondersteun.

SLEUTELWOORDE

- Houdings
- Alledaagse lewensituasies
- Funksionele uitkomst
- Internasionale Klassifikasie van Funksionering, Gestremdheid en Gesondheid-Weergawe vir Kinders & Jeug
- Deelname
- Ernstige spraak- en taalgestremdheid
- Sibbe
- Tipies-ontwikkellende kinders

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LIST OF ABBREVIATIONS

WHO	World Health Organization
ICF-CY	International Classification of Functioning, Disability and Health-Version for Children & Youth
ADL	Activities of Daily Living
SAS	Sibling Attitude Scale
PCS	Picture Communication Symbols

CHAPTER 1 : INTRODUCTION TO THE STUDY

1.1 PROBLEM STATEMENT AND RATIONALE FOR STUDY

Functional and meaningful outcomes in intervention with children with severe speech and language disabilities entail the involvement of all family members, including siblings. Sibling relationships and the interaction within these relationships play a central role in the general development and functional progress of children with severe speech and language disabilities.

Interactions within the core family system provide a child with his/her first opportunity to build and maintain interdependent relationships. It is also within these relationships that children learn crucial social, emotional, cognitive and communication skills that are necessary for interaction and participation in the broader community. This especially holds true for sibling relationships. Within the core family system, sibling relationships are one of the closest and strongest relationships (McHugh, 2003) and span a lifetime, resulting in ever-changing levels of participation and interaction in family activities.

From a systems theory perspective (Bronfenbrenner, 1977) the family constitutes a dynamic system of unique individuals. These individuals are interdependent and constantly influence each other in various aspects of family life. Therefore, the presence of an individual with a disability within the family system will impact on the entire family system and subsequently on the sibling relationship as well (Opperman & Alant, 2003). The impact of the disability on the sibling relationship depends on the unique challenges and opportunities presented by each of the individuals involved in the sibling relationship, as well as on barriers and opportunities posed by the contextual or environmental factors.

In view of the above, it becomes apparent that the impact of disability on the sibling relationship cannot be assumed to be similar for all siblings. It therefore necessitates an approach that will allow for the delineation of the strengths and needs of the children involved as well as the environmental factors that impact on the functional and meaningful participation of both of the siblings in the relationship. This will allow for the facilitation of a supportive family environment that will subsequently

enhance functional and sustainable outcomes for the child with a disability as well as their typically-developing sibling.

The World Health Organization (WHO) (2007) provides a conceptual framework in the form of the International Classification of Functioning, Disability and Health-Version for Children & Youth (ICF-CY) (WHO, 2007), in which the functional participation and interaction of a child is viewed as a non-linear, dynamic process resulting from an interaction between the child and the environment. Implied in the definition of 'environment', are the people involved in the disabled child's life as well as these people's attitudes. According to WHO (2007) participation can be defined as the individual's level of involvement in any given life situation. It is, therefore, the amount of time an individual spends interacting appropriately with the social and physical environment (Almqvist, Uys & Sandberg, 2007). According to Almqvist et al., (2007), positive experiences through active interaction as well as active involvement in life situations underlie the concept of participation. It is, therefore evident that the involvement and attitudes of participating and interacting partners are crucial to the child with a disability's daily functioning in life situations (Almqvist et al., 2007).

The ICF-CY (WHO, 2007) conceptualizes participation within nine domains which specifies a range of life areas in which children are expected to function in. These activity and participation domains include: (i) learning and applying knowledge, (ii) general tasks and demands, (iii) communication, (iv) mobility, (v) self-care, (vi) domestic life, (vii) interpersonal interactions and relationships, (viii) participation in major life areas, e.g. playtime or school-time as well as (ix) participation in community, social and civic life (WHO, 2007). In the context of the sibling relationship, the attitudes held by either of the siblings will not only impact on the quantity, but also on the quality of meaningful interaction and participation which, in turn, will affect the functional outcomes of the sibling with a disability (Ylven & Granlund, 2009) within and across each of these domains. Sibling relationships can, therefore, be viewed either as a potential strength in the process of facilitating functional and sustainable outcomes within these domains, or as a potential barrier to the entire process.

Given the impact of a typically-developing sibling's attitude towards participation on the functional outcomes of a child with a disability, it is of cardinal importance that the attitudes of typically-developing siblings of children with a disability be understood. Literature suggests that these typically-developing siblings often feel inadequately supported and excluded from the intervention process, resulting in unique family participation and interaction patterns (McHugh, 2003; Opperman & Alant, 2003). This may lead to less positive attitudes towards siblings with disabilities that, in turn, may possibly have a negative effect on sibling participation as well as on the intervention outcomes. Therefore, in order to fully utilize the sibling relationship as an asset in promoting positive outcomes for the child with a disability, one must have adequate knowledge of typically-developing siblings' attitudes, specifically as it pertains to the quality and quantity of participation and interaction in everyday life situations. Obtaining this knowledge may enable the intervention team to address the emotional, behavioural, as well as the cognitive and informational needs of the typically-developing siblings as key stakeholders. In addressing these needs, more positive sibling attitudes might result in the creation of a more supportive family environment. This will allow for the facilitation of functional outcomes for the child with a disability.

Limited published information exists in the current body of knowledge regarding the attitudes of typically-developing children towards their disabled siblings, especially with regard to interaction and participation in everyday life situations. The question therefore arises: 'What are the attitudes of typically-developing children towards participation with their younger siblings with severe speech and language disabilities?'

The aim of this study is, therefore, to determine the attitudes of typically-developing children towards participation with their younger siblings with severe speech and language disabilities. The sibling attitudes will be explored and described within four everyday life situations, typical to children, which can be seen as exemplifying four of the nine ICF-CY activity and participation domains. For the purpose of this study, the everyday life situations (WHO, 2007) that were selected are: (i) play (participation in major life areas), (ii) communication participation, (iii) participation during activities

of daily living (ADL) as part of domestic life and (iv) interpersonal relationships (time and responsibility issues).

1.2 DEFINITION OF KEY TERMS

Activity and Participation

Activity is defined as the execution of a task or action by an individual, whereas participation can be defined as the individual's level of involvement in any given life situation (WHO, 2007). In this study, the quality and quantity of sibling activities and participation is viewed as one of the key factors impacting on functional outcomes in a child with a disability.

Attitude

An attitude is a state of readiness or a tendency to respond to certain stimuli in a specific way when confronted by it (Oppenheim, 1998). According to Oppenheim (1998) attitudes are reinforced by beliefs (the cognitive component), and often attract strong feelings (affective component), which may lead to specific actions (behavioural component). In this study, 'attitude' refers to the attitudes held by typically-developing children towards participation with their sibling with a severe speech and language disability, by looking at all three components.

Everyday life situations

Everyday life situations can be defined as both the physical and social contexts wherein an individual is expected to perform daily activities (WHO, 2007). In this study, four everyday life situations central to sibling interaction and participation were selected as the focus of the study.

Functional outcomes

Functional outcomes can be viewed as the achievement of intervention goals either within the individual's physical or social contexts that subsequently contribute to the improvement of quality of life (Johnson, Baumgart, Helmsetter & Curry, 1996). It relates to the improvement of an individual's performance in everyday life situations (WHO, 2007). In this study, typically-developing siblings are viewed as key stakeholders in the facilitation of functional outcomes for their siblings with severe speech and language disabilities.

Severe speech and language disabilities

A severe speech and language disability refers to a delay or atypical acquisition of pre-verbal (e.g. imitation, eye-contact, gestures) as well as verbal communication skills (the production and use of single words and sentences) during the reception and expression of thoughts and ideas (Owens, 2000). A delay of this nature impacts on an individual's communicative competence (Light, 1997) and subsequently on his/her social functioning and participation (McLeod & McCormack, 2007). In this study, this term is used to describe the degree or severity of speech and language disability of the siblings with disabilities, in order to emphasize the impact of such a disability on participation in life situations.

Sibling participation

Sibling participation is one type of possible participation in the life of a child with a disability. Sibling participation is described by Powell and Gallagher (1993) as a continuous process persisting throughout a person's life and influences the social behaviours and personality development of family members. Sibling participation is strongly influenced by the subsystems of family life; this includes the parent-child, the sibling-sibling and the spouse-spouse subsystems (Powell & Gallagher, 1993). In this study, sibling participation is viewed as a factor that might either be a potential barrier or an opportunity in the facilitation of functional outcomes for children with disabilities within both the family and the greater social environment.

Typically-developing children

According to Owens (2000) the term 'typically-developing' refers to children who reach their developmental milestones within the parameters and norms as determined through the use of formal measuring instruments and developmental checklists or questionnaires. In this study it refers to the sibling without any diagnosed disabilities.

1.3 OUTLINE OF CHAPTERS

Chapter 1 serves to outline the justification for the study and provides definitions of key terms used in the chapters that follow.

Chapter 2 provides an overview of the typical relationships and dynamics that exist within the family. It also provides a discussion of the nature of sibling relationships, the influence of disability on family life, the influence of sibling attitude on sibling participation and the concept of functional intervention for these families and siblings. It also serves to describe the different theoretical frameworks used to conceptualise disability in the past as well as in current literature and research.

Chapter 3 is a detailed description of the methodology used in this study. It includes the aims, the research design, the pilot study, the participants, the materials used in the study, data collection procedures, and finally the data analysis and statistical procedures.

Chapter 4 provides a description of the results in accordance to the aims of the study. Firstly, the results are presented in terms of the findings across the four everyday life situations. This is followed by a description of the findings across the three attitude components.

Chapter 5 provides a discussion of the results in accordance to the aims of the study. This discussion highlights the core results as it relates to sibling participation in the four everyday life situations as well as the core findings as pertaining to the three components of attitude.

Chapter 6 provides a critical evaluation of the study in terms of its results, limitations and strengths. Recommendations for future research are also included in this chapter.

1.4 SUMMARY

This chapter provided justification for the study. It also highlighted the importance of sibling participation, within everyday life situations, in the development of communication, social, as well as cognitive skills, in children with severe speech and language disabilities. This chapter concluded with definitions of key terms and a chapter outline of this dissertation.

CHAPTER 2 : LITERATURE REVIEW

2.1 INTRODUCTION

The aim of this chapter is to provide an overview of the relevant literature pertaining to the attitudes of typically-developing children towards participation with their siblings with severe speech and language disabilities. The focus is on the typical relationships and dynamics that exist within the family system, the impact of disability on family life, the nature of sibling relationships and the facilitation of functional and sustainable outcomes for the child with a disability within the family context. Different theoretical frameworks used to conceptualise disability within the family context, in the past as well as in the current literature and research, will be discussed.

2.2 FAMILY DYNAMICS AND RELATIONSHIPS

No child is able to develop socially and cognitively, or in any of the other developmental domains, without the involvement and participation of people in his/her immediate environment. Establishing relationships and participating functionally in daily activities, are of the core aspects of the human experience.

The family is the primary group in which young children communicate, interact and explore (Powell & Gallagher, 1993). According to Ross, Stein, Trabasso, Woody and Ross (2005) the family consists of a network of interconnected individuals that must be viewed as a dynamic system of interacting and adapting relationships that change as a result of child and parental ageing and also because of social contact outside the family and changes in the community (Powell & Gallagher, 1993). Family dynamics, as defined by Tomlinson, White and Wilson (1990), is the unique way in which individual family members relate to one another. According to Powell and Gallagher (1993), family dynamics occur within and between three semi-independent family dyads, including: spouse-spouse, parent-child and sibling-sibling. Any one family member involved in these dyads exerts influence on his or her relationship with every other member of the family. This in turn influences the relationships between other family members (Powell & Gallagher, 1993), as alluded to in systems theory.

For the purpose of this study the focus will be on only one of these three dyads, namely, the sibling-sibling dyad. Sibling relationships stand central to the social and cognitive development of individuals (Furman & Buhrmester, 1985). According to the system theoretical model, family interactions can be conceptualized as taking place in eight bipolar dimensions throughout the family lifecycle (Barnhill, 1979). Of these eight dimensions, six dimensions are of importance to sibling relationships: (i) individuation-enmeshment; (ii) mutuality-isolation; (iii) flexibility-rigidity; (iv) clear communication-unclear communication; (v) role reciprocity-role conflict; (vi) stability-disorganization. Table 2.1 provides definitions for each of these dimensions (Hakulinen & Paunonen, 1995) and highlights the relevance of each dimension to this study.

Table 2.1: Six bipolar dimensions relating to sibling relationships

POSITIVE DIMENSION	NEGATIVE DIMENSION	RELEVANCE TO THIS STUDY
1. Individuation: Independence and autonomy of self and one's thoughts, feelings emotions and responsibilities	Enmeshment: Poorly delineated boundaries of self	This dimension relates to the development of each sibling's thoughts and views, which can be linked to the cognitive component of attitude (Oppenheim, 1998). This dimension will impact on the attitude held by siblings, in turn affecting the quality and quantity of their functional participation in family activities and interactions.
2. Mutuality: Sense of emotional closeness and intimacy	Isolation: Disengagement from family relationships	Emotional closeness between siblings can be associated with the affective component of attitude (Oppenheim, 1998), and therefore impacts on sibling participation.
3. Flexibility: Capacity to be adjustable and resilient during the process of change	Rigidity: Lack of flexibility and unresponsiveness to change	This dimension closely relates to the behavioural as well as the cognitive aspect of attitude (Oppenheim, 1998). Siblings' ability to adapt to change, in the presence of various influencing factors, such as disability, will greatly impact on sibling participation.
4. Clear communication: Successful exchange of information between family members; understanding each other's meanings and intentions	Unclear communication: Confused exchange of information, impeding on the understanding of others' intentions	This dimension relates to both the cognitive and behavioural aspect of attitude (Oppenheim, 1998). Clear communication is one of the core factors of sibling relationships and will have an influence on the quality and quantity of sibling participation.

POSITIVE DIMENSION	NEGATIVE DIMENSION	RELEVANCE TO THIS STUDY
5. Role reciprocity: Mutually agreed upon behaviour patterns in which an individual compliments the role of his interaction partners	Role conflict: Lack of clearly agreed upon behavioural patterns between family members	This dimension strongly relates to the behavioural component of attitude (Oppenheim, 1998). It can be linked to the definitive roles siblings assume during participation with each other.
6. Stability: Consistency and security in family interactions and responsibilities	Disorganization: Lack of predictability and clear responsibility	This dimension can be linked to both the cognitive and behavioural components of attitude (Oppenheim, 1998). Clearly defined responsibilities and predictability of family interactions will, most likely, positively impact on sibling participation.

The shift in balance within these dimensions occurs on a constant basis as siblings move through different stages in their relationship life cycle (Becvar & Becvar, 1996). This in turn affects the roles, responsibilities and relationships of siblings at any given time (Barnhill, 1979). Therefore, a healthy sibling relationship may be characterized as the siblings being able to balance these dimensions (Barnhill, 1979) when the demands of growth and change increase and, subsequently, to modify their behaviour in order to achieve new balance (Hakulinen et al., 1999). Change in any part of the system will affect the entire system and the relationships involved.

The balance referred to above is influenced by various factors that impact on family dynamics and in turn on sibling relationships. These include, but are not limited to, the following: *culture* (Becvar & Becvar, 1996; Iwakuma & Nussbaum, 2000), *family size* (Whiteman, Bernard & McHale, 2009), *child temperament* (Hakulinen, Laippala & Paunonen, 1998), *age of parents* (Whiteman et al., 2009), *marital status* (Beck, Cooper, McLanahan, & Brooks-Gunn, 2010; Butler, 2002; Pong, Dronkers & Hampden-Thompson, 2003; Sun & Li, 2008; Thornton, 2009; Usdansky, 2009; Yu, Pettit, Lansford, Dodge & Bates, 2010), *parity, health and disability* (Altieri & Von Kluge, 2009; Dodd, Zabriskie, Widmer & Eggett, 2009; Heiman, Zinck & Heath, 2008; Tadema & Vlaskamp, 2009; Tomasselo, Manning & Dulmus, 2010; Tsibidaki & Tsamparli, 2009), *education* (Beck et al., 2010; White et al., 2009) and *socio-economic status* (Hakulinen et al., 1998; Hennessy, 2009; Tulman & Fawcett, 1990).

From the above, it is evident that there is no linear way of describing the impact of stressors on family functioning and in turn on sibling relationships. Individual needs and difficulties of a sibling with a disability cannot be viewed in isolation, but rather as impacting on all family relationships within the dynamic system of family functioning (Becvar & Becvar, 1996). For the purpose of this study, one variable impacting on family dynamics and sibling relationships, namely disability, is discussed in more detail below.

2.3 THE IMPACT OF DISABILITY ON THE FAMILY

Having a sibling with a disability is associated with increased needs, responsibilities and demands on the family system (Martin & Baker, 2002). According to Williams, Williams, Graff, Hanson, Stanton, Hafeman, et al. (2002) families of children with disabilities share common difficulties and challenges. These difficulties include long-term care giving burdens, strains on family resources (financial and emotional), as well as interaction and communication problems within the family and the community (Martin & Baker, 2002). Very often, these long-term care-giving responsibilities ultimately fall upon the shoulders of siblings, because improved medical technology and medical care often cause children with disabilities to outlive their parents (McHugh, 2003). This longevity greatly impacts on the sibling relationship as well as on participation and interaction between siblings.

Previous research has aimed to explore the impact of a sibling with a disability on the sibling-sibling dyad (Aksoy & Bercin-Yilidirim, 2008; Breslau, 1982; Fowle, 1968; Lobato, 1990; McHale & Gamble, 1987; McHale, Sloan & Simeonson, 1986; Stoneman, 2001; Williams et al., 2002). Fowle (1968) implemented the use of the Role Tension Index in order to investigate the roles and adjustment patterns of children with a sibling with a disability, specifically in the case of the sibling with a disability being institutionalized. This research (Fowle, 1968) indicated positive outcomes, especially for older sisters, as the increased care giving responsibilities often assumed by older sisters were lessened by the involvement of an institution. These results were sharply contrasted by Lobato (1990) who found that extra care giving responsibilities often lead to an increase in the quantity and quality of interaction between older sisters and their siblings with a disability.

In a study done by Breslau (1982), she found that in the childhood years the disproportionate amount of time and attention given to a disabled sibling by parents may have a negative impact on the other siblings' psychological development. This finding was supported by McHale and Gamble (1987) who reported that older brothers experienced high levels of anxiety and lower levels of perceived competence in the areas of social acceptance. Stoneman (2001) also indicated that the relationships between parents and children change while parents try to cope with a child with disabilities. As a result, older siblings often experience a decrease in positive attention from their mothers (Stoneman, 2001). Despite these research results, Aksoy and Bercin-Yilidirim (2008), McHale et al. (1986) as well as Stoneman (2001) have found that the relationship between typically-developing children and their disabled siblings were usually positive.

Williams et al. (2002) pointed out that not only the relationships within the family are affected by a child with disability, but also the relationships outside the home environment and in the community. Parents and siblings often avoid certain community or public settings that may not be accepting of a child with a disability, thereby decreasing their community participation (Williams et al., 2002). From the above it becomes clear that having a child with a disability impacts emotionally, financially and socially on the entire family, especially on the sibling relationship and sibling participation. As siblings play such an important role in the development of crucial life skills (Furman & Buhrmester, 1985) it is cardinally important to include them as key partners in the process of facilitating functional and sustainable participation outcomes for their sibling with disabilities.

2.4 SIBLING RELATIONSHIPS

Sibling relationships have been described as emotional ties, existing in most children's lives and that are commonly second in strength only to those between parents and children (Furman & Buhrmester, 1985). Sibling relationships are a source of companionship and emotional support; it is during sibling interaction and participation that children acquire many social and cognitive skills that are central to health and social development (Furman & Buhrmester, 1985). Sibling relationships should also be viewed as transactional in nature, because each sibling influences the

other/s over time and this special relationship stands as a potential resource and support not only for siblings, but for the entire family (Caro & Derevensky, 1997).

Sibling relationships have been the topic of several past research projects spanning more than three decades (Buhrmester & Furman, 1990; Furman & Buhrmester, 1985; Karos, Howe & Aquan-Assee, 2007; ; Klein, Zarur & Feldman, 2003; Minnett, Lowe-Vandell & Santrock, 1983; Opperman & Alant, 2003). These studies were aimed at identifying the factors that impact on sibling interaction and the interaction patterns and social roles and responses that result because of it. Minnett et al. (1983) found that birth order, age, spacing and gender affect sibling relationships, interaction and roles assumed by siblings during interaction. Older siblings (7 to 8 years of age) were identified as being more likely to praise and teach their younger siblings and to act more aggressively towards a closely spaced (less than 2 years apart) sibling. Girls were more likely to praise and teach their siblings than boys. Minnett et al. (1983) also reported that the occurrence of cheating, aggression and dominance were more likely in same-sex sibling relationships.

Subsequent studies were undertaken with the aim to describe the nature of sibling relationships in the presence of a child with disability in the core family (Aksoy & Bercin-Yilidirim, 2008; Caro & Derevensky, 1997; Martin & Baker, 2002; Stoneman, 2001). These studies established that, the less competent children with disabilities are, the more difficult it is for them to engage with their siblings in joint interaction (Stoneman, 2001). The findings, however, showed that the relationships between children with disabilities and their siblings are usually positive (Aksoy & Bercin-Yilidirim, 2008).

Opperman and Alant (2003) investigated the coping responses of adolescent siblings of children with severe disability. Their results seem to contradict the results of previous researchers, since they found that adolescent siblings (12-16 years) experienced feelings of guilt regarding their siblings (10-18 years). The study also noted that limited family interaction was prevalent in families with children with disabilities and that siblings did not receive adequate information or guidance with regard to coping with a sibling with a disability.

It becomes apparent that various factors impact on sibling relationships and that the impact of these factors on the sibling relationship changes over time (Powell & Gallagher, 1993). It also becomes clear that each sibling relationship is unique with its own assets and challenges and that the impact of this relationship on the family system is different for each family (Ross et al., 2005). From the above it therefore seems important to structure intervention programmes that have relevant, functional and sustainable goals and outcomes for each family unit and the individuals involved, using every possible resource, especially siblings, to support the child with a disability to develop functional skills. Attempting to understand each individual involved in this process would entail an investigation of their beliefs, feelings and actions.

2.5 ATTITUDE AS AN ENVIRONMENTAL FACTOR IMPACTING ON PARTICIPATION

Children's beliefs and feelings impact heavily on their actions and interactions in daily life situations. In viewing sibling relationships against this background, one may assume that attitudes held by typically-developing children towards their siblings with disabilities will affect the quality and quantity of their interaction and participation during activities important to social, emotional, cognitive and communication development. Vignes, Godeau, Sentenac, Coley, Navarro, Grandjean et al. (2009) stated that attitude is formed in the early childhood years, and that model attitudes of parents and other adults impact greatly on the future attitudes of children. Research indicates that even as early as pre-school, children perceive peers with physical, communication, and/or cognitive disabilities as being different from themselves (Ryan, 1981). These perceived differences often lead to segregation of the children with disabilities, as they tend to form a separate social sub-group with altered social interactions (Rice, Snell & Hadley, 1991).

Morrison and Ursprung (1990) stated that exposure of children to positive experiences with people with disabilities in early childhood will establish lifelong favourable and positive attitudes towards disability. In recent years the international commitment to the inclusion of people with disabilities has brought about marked changes in the provision of equal opportunities for children with disabilities (Timor & Burton, 2006). Current legislation advocating inclusion of children with disabilities into mainstream

classrooms (Bornman, 2006) has led to more heterogeneous classroom contexts and earlier exposure to disability and diversity on an academic and social level for many children. Within this era of inclusion, Bornman (2006) aimed to determine the perceptions of non-disabled Grade 1 learners of peers with a disability. The results did indicate positive attitudes towards peers with a disability, but also an awareness of possible social exclusion and isolation (Bornman, 2006). These findings seem to support the views of Morrison and Ursprung (1990) regarding children's attitudes towards disability.

As siblings function in much closer proximity to one another on a daily basis and are exposed to various family related factors that also impact on their relationship, the attitudes held by siblings might be different from those of peers who merely share their classroom and playground experiences with children with disabilities. According to the bio-ecological model (McDougall, DeWit, King, Miller & Killip, 2004) the environment not only includes the larger social and physical setting of a child with a disability, but also includes the attitudes, needs, relationships and barriers for all family members affected by the child with a disability. This holds true, especially for sibling relationships that form the basis for the development of so many crucial life skills. Determining the attitudes of typical-developing children towards their sibling with a disability could therefore play a central role in the process of facilitating functional and sustainable outcomes for the child with a disability and his/her family. By fostering more positive attitudes towards their siblings with a disability, the involvement of typically-developing children may be viewed as a potential strength within the family system. They can facilitate more positive outcomes for their sibling with a disability.

Limited published information exists in the current body of knowledge pertaining to the attitudes of typically-developing children towards their siblings with speech and language disabilities, especially with regard to interaction and participation in daily life. Researchers have succeeded in documenting the factors that impact on typically-developing children's attitudes towards a peer with a speech and language disability (Beck & Dennis, 1996; Blockberger, Armstrong, O'Connor & Freeman, 1993; Burke 1994; Langevin 2009). According to Beck, Fritz, Keller and Dennis (2000) knowledge of these factors will assist clinicians in intervention planning. Intervention

planning and the facilitation of functional goals for the child with a disability includes various spheres of life and a multitude of individual and social participation areas that these children, on a daily basis, are expected to function in. Therefore, merely having knowledge about the factors influencing children's attitudes, especially only with peers, will be of little value in the clinician's attempt to provide holistic and meaningful intervention. For this reason it is crucial that the attitudes of typically-developing siblings towards participation in various life situations be investigated in order to allow for holistic intervention planning.

Attitude measurement, especially in younger populations, poses unique challenges. In the past, researchers and clinicians alike have attempted to obtain information regarding younger children's views and opinions mainly through questionnaires to parents and sometimes to teachers, and also from school reports (Allen, 1994). These methods proved to be inaccurate in reflecting the child's point of view because most children, when questioned by adults, tend to not express negative affect or anger in an attempt to appear socially more acceptable (Kazdin, 1990). Additional difficulties experienced in attitude measurement in young children include the impact of developmental differences in designing instruments that are applicable across a wide age range. One such developmental issue includes vocabulary development and/or reading level (Allen, 1994), which influences not only the comprehension of test items but also the accuracy of the information provided by the child in response to items. Attitude measurement necessitates the measurement of all three components of attitude which, according to Oppenheim (1998), includes the affective (feelings), behavioural (actions) and cognitive component (beliefs). The challenge, therefore, lies in designing an instrument that not only measures all of these components, but that also includes enough response items to ensure reliability for each component.

In view of the above, the researcher decided to design a measuring instrument that utilized a three-point scale, with a contained number of items, thereby reducing the cognitive demand on the participants. An additional adaptation to allow for the accurate determination of the typically-developing siblings' attitudes was the use of the 'Talking Mats' procedure during data collection. The Talking Mats procedure is a low-technology communication framework developed by Joan Murphy, to assist people with communication difficulties to express their views or indicate their

feelings more effectively using simple picture symbols (Murphy, Gray & Cox, 2007). Even though the participants in this study were typically-developing children, due to their age, this procedure was deemed appropriate for assisting the young participants in expressing their thoughts and feelings.

When attempting to determine the attitudes of typically-developing children towards participation with their sibling with a severe speech and language disability, it is crucial to measure their attitudes towards activities and interactions that are central to sibling relationships. According to Powell and Gallagher (1993), sibling interactions centre on various activities accompanying domestic life, play, communication and family recreation. Therefore, in order to accurately measure attitudes towards sibling participation, these areas need to be incorporated into the measuring instrument. This necessitates the use of a conceptual framework that will allow for the delineation of these key life situations as well as the impact these situations have on functional and sustainable outcomes for the child with a disability.

2.6 FUNCTIONAL AND SUSTAINABLE OUTCOMES

Functional and sustainable outcomes must incorporate many different contexts, missions and desired outcomes over a long period of time (Granlund, Blackstone & Norris, 1996). According to Granlund et al. (1996) outcomes may be changes in attitude, beliefs, behaviour, physical environment, social environment and/or economy as well as the effects of these changes on a person's interaction with others. As discussed earlier, the family is the core structure in which a child with a disability functions, interacts and participates. It is therefore crucial that not only the child with the disability, but also the family environment, their daily activities and their level of participation be taken into account when planning the outcomes of a holistic intervention programme.

This holistic approach, therefore, requires the use of a conceptual framework that allows for the documentation of the rapidly changing difficulties and challenges involving functions and structures of the body, activity limitations and participation restrictions that occur as a result of a child's disability (WHO, 2007). The framework proposed by the WHO (2007) that will enable professionals involved in childhood

intervention to achieve this goal, is the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY).

Much of the currently available research surrounding the ICF-CY centres on the validation and critical evaluation of its use and application. Use of the ICF-CY as an assessment and intervention tool has been documented by various authors (De Polo, Pradal, Bortolot, Buffoni & Martinuzzi, 2009; Francescutti, Martinuzzi, Leonardi & Kostanjsek, 2009; Ibragimova, Granlund & Björk-Åkesson, 2009; Kostanjsek, 2009; Leonardi & Martinuzzi, 2009; McDougall & Wright, 2009; McLeod & McCormack, 2007; Meucci, Leonardi, Zibordi & Nardocci, 2009; Zikarova-Engstrands & Granlund, 2009).

McLeod and McCormack (2007) implemented the ICF-CY in the assessment and intervention of children with speech impairment. They found that the ICF-CY enabled holistic assessment and intervention. These results were confirmed by Meucci et al. (2009) who used the ICF-CY in order to structure intervention for children with Gilles de la Tourette syndrome. The authors concluded that the ICF-CY enabled the clinician to determine the actual lived experience of a disability. According to Kostansjek (2009) the ICF-CY also emphasizes the strengths or assets of children and the environment they function in, in planning their management programmes.

In a study done by De Polo et al. (2009) the researchers utilized the ICF-CY as a means to compile Individual Educational Plans (IEP's) in order to facilitate increased participation of learners with disabilities in the mainstream school environment. The researchers found that the use of the ICF-CY in compiling IEP's allowed for a shared language amongst professionals and parents in the goal setting process that allowed for the identification of environmental barriers to participation. There were, however, also some questions regarding the use of the ICF-CY. In a study done by Ibragimova et al. (2009), the authors concluded that the ICF-CY was a feasible tool in assessment and intervention, but that the development of age-specific measuring instruments might be useful, especially in clinical practice. Zikarova-Engstrand and Granlund (2009) also found that more research needs to be done in order to investigate the use of the ICF-CY in detecting cultural differences and attitudes.

Another issue that has been identified in the critical evaluation of the ICF-CY involves the debate that is documented in current literature regarding the distinction between the concepts of activity and participation within the ICF-CY (Badley, 2008; Coster & Khetani, 2007; Whiteneck & Dijkers, 2009). Researchers have been attempting to distinguish between these concepts, leading them to divide the nine activity and participation domains as specified by the ICF-CY (WHO, 2007) into activity domains or participation domains. This would allow researchers to improve the measurement of activity or participation as well as the documentation of rehabilitation outcomes (Whiteneck & Dijkers, 2009).

Although the ICF-CY is still subject to scrutiny a firm theoretical basis exists for its effectiveness as a conceptual framework in the assessment and intervention of children with disabilities (Ibragimova et al., 2009). Within this framework a child's participation or 'involvement in a life situation' within a specific environment or context resulting from their disability can be described (WHO, 2007). The ICF-CY further conceptualizes participation as occurring in the following nine domains: i) learning and applying knowledge, ii) general tasks and demands, iii) communication, iv) mobility, v) self-care, vi) domestic life, vii) interpersonal interactions and relationships, viii) major life areas and ix) community, social and civic life (WHO, 2007). This framework, therefore, ensures that the focus of intervention and outcome planning encompasses not only the individual, but also his/her physical, social and attitudinal environments (Bornman, 2004).

In the ICF-CY, the WHO (2007) further specifies that a child's ability to be engaged and interact socially develops as a result of participation with others such as parents, siblings and peers in the immediate environment, thereby emphasizing the importance of including families in the intervention process as a strategy to ensure functional and sustainable outcomes. Little research relating to the ICF-CY and its use, specifically with sibling participation, exists. However, some researchers have endeavoured to determine parent and peer participation using the ICF-CY framework. In terms of parents and the use of the ICF-CY, a study done by McCormack, McLeod, Harrison, and McAllister (2010) to explore the perceived impact of speech impairment in childhood as seen by the parents as well as the speech-language therapist. They used the activity and participation component of the ICF-CY as a framework for their

study. These researchers concluded that the use of the ICF-CY allowed for holistic identification of factors impacting on the participation of a child with a disability. They also found that parents and professionals have very different perspectives on the impact of a speech impairment on a child's level of participation. A study focusing more on peer participation was done by Ajovalasit, Vago, Usilla, Riva, Fidani, Serra, et al. (2009), who investigated the social inclusion and participation for children and adolescents affected by a brain tumour. They made use of quality of life questionnaires in conjunction with the ICF-CY. They found that social life and relationships are crucial for defining children's disability level and that formal and informal relationships are crucially important to improved functioning. They also indicated that intervention is often focused on treatment of individual needs, while the important aspect of participation in daily life is often being neglected.

In the light of these studies one may conclude that if parent as well as peer participation play such an important role in the outcomes of a child with a disability, sibling participation could also impact on the attainment of functional and sustainable outcomes. Up to date, the early intervention process has primarily focused on informational and training support for parents involved in the process, whereas siblings have, to a large extent, been excluded (Powell & Gallagher, 1993). The insufficient provision of information to and training of siblings in order for them to become facilitators of intervention goals has been identified as possible causes of negative sibling attitudes towards their brother/sister with a disability (Powell & Gallagher, 1993). These negative sibling attitudes can potentially cause an environmental barrier to participation (Johnson et al., 1996) in many of the domains specified by the ICF-CY.

Because siblings play such an important role in terms of companionship, emotional support, and the development of social and cognitive skills (Furman & Buhrmester, 1985), it is important that current and future research endeavours are aimed at determining the attitudes of typically-developing children toward their siblings with disabilities; this aim could possibly be extended to include their informational and psychological/emotional needs. Such an inclusive endeavour may ensure the inclusion of intervention goals that are aimed at increasing the quality and quantity of family and sibling interactions. This will, in turn, ensure functional and sustainable

outcomes not only for the child with a disability, but for the entire family system (WHO, 2007).

2.7 CONCLUSION

The aim of this chapter was to provide a discussion of the relevant literature pertaining to the attitudes of typically-developing children towards participation with their siblings with severe speech and language disabilities. This entailed a discussion focusing on the relationships and dynamics that exist within the family, the impact of disability on family life, the nature of sibling relationships and the facilitation of functional and sustainable outcomes for the child with a disability within the family setting. Different theoretical frameworks which attempt to conceptualize family interaction and individual participation within the family context were also discussed.

CHAPTER 3 : RESEARCH METHODOLOGY

3.1 INTRODUCTION

In this chapter the research methodology is discussed. It starts by specifying the main aim and sub-aims of the study, followed by a discussion of the research design and research phases. Following this, the material and equipment used during data collection is described. The pilot study is presented in terms of the results obtained as well as the recommendations for the main study. The context of this study as well as the participants are also described. In closing, data collection procedures and data analysis procedures are outlined.

3.1.1 Aim of the study

Main aim

The main aim of this study was to describe the attitudes of typically-developing children towards participation with their younger siblings with severe speech and language disabilities in four everyday life situations, namely: play (major life areas), communication, activities of daily living as part of domestic life and interpersonal relationships (time and responsibility issues).

Sub-aims

In order to address the main aim, the following sub-aims were formulated:

- To develop a measuring instrument that will determine the attitudes of typically-developing children towards participation with their younger siblings with severe speech and language disabilities in the following everyday life situations:
 - participation during play (major life areas)
 - participation during communication
 - participation during activities of daily living (ADL) as part of domestic life
 - participation in interpersonal relationships (time and responsibility issues)
- To apply the measuring instrument in order to determine the attitudes of typically-developing children towards participation with their younger siblings with severe speech and language disabilities.

- To describe the results obtained from the measuring instrument as it pertains to the attitudes of typically-developing children towards participation with their younger siblings with severe speech and language disabilities in the above mentioned everyday life situations.

3.2 RESEARCH DESIGN

A non-experimental, descriptive survey design within the quantitative framework was used to realize the research aim (McMillan & Schumacher, 2006). The school, from which the participants were sampled, was selected using a purposeful sampling method (Leedy & Ormrod, 2005). Data was collected by means of a survey, the Sibling Attitude Scale (SAS). The use of a survey allowed the researcher to collect a large amount of data in a relatively short period of time, but may have resulted in inadequate description of some of the more in-depth issues related to the research topic (Kelley et al., 2003).

3.3 RESEARCH PHASES

This study involved three phases. The aim of phase one was to develop the measuring instrument. This entailed a review of past and current literature as it pertains to attitude measurement, sibling relationships, as well as literature on participation in everyday life situations. The literature review enabled the researcher to compile a list of affective, behavioural and cognitive response items (Feldman, 1993) representing four core everyday life situations that form part of sibling relationships. This list was reviewed by an expert panel of professionals who selected the response items they deemed most relevant to the current study. The expert panel reviewed 40 response items and selected 31 items to be included in the preliminary measuring instrument. The nine items that were not included were identified as being redundant and not directly related to the aim of this study. During phase two the preliminary measuring instrument was tested during a pilot study. The pilot study entailed the involvement of three separate groups: an expert panel of ten individuals, 30 siblings of typically-developing children and four child participants similar to the target population of this study. The results and recommendations obtained from the pilot study enabled the researcher to refine the measuring instrument. Finally, phase

three involved the implementation of the measuring instrument during the main data collection process. The research phases are schematically presented in Figure 3.1.

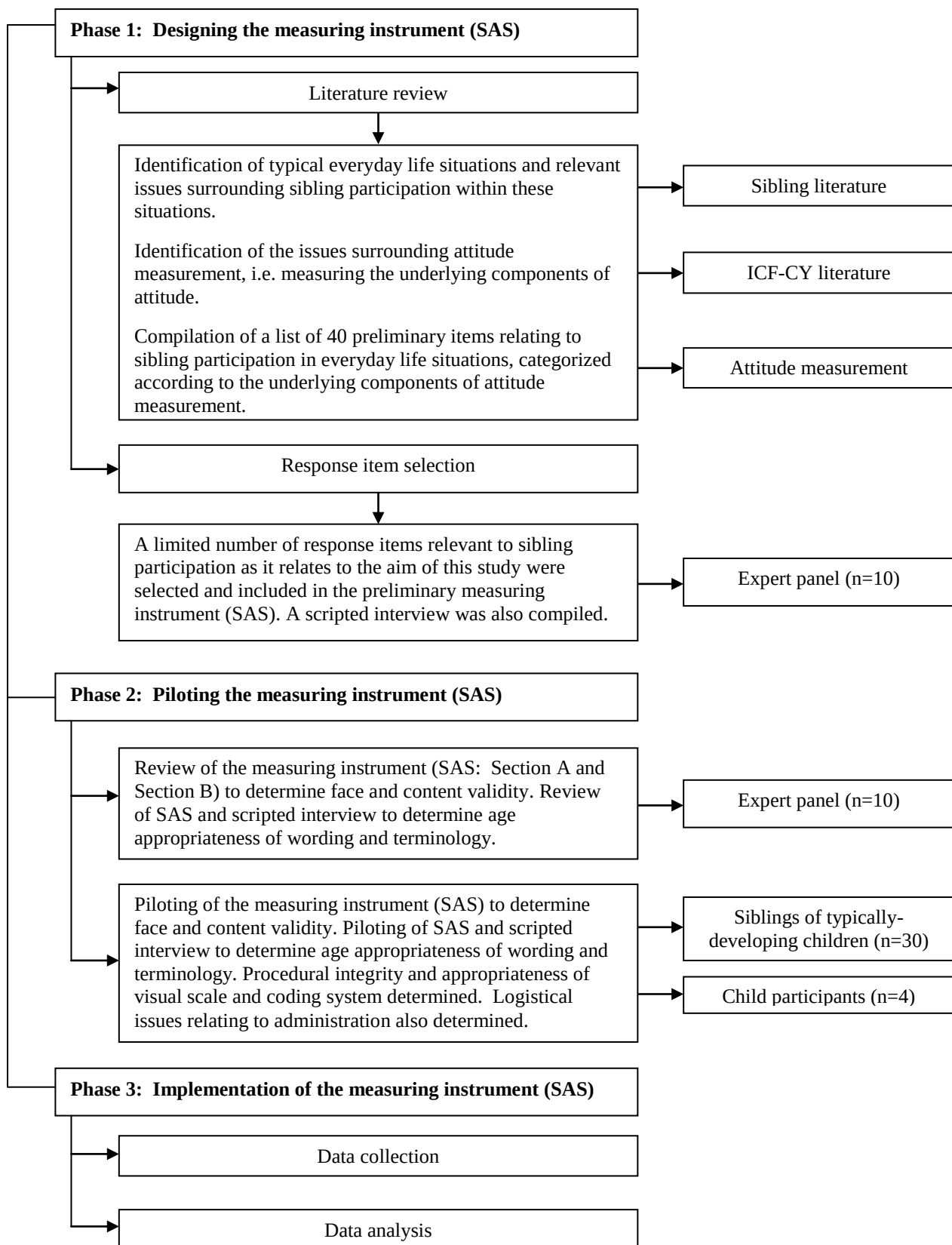


Figure 3.1: Schematic representation of the research process

3.4 MATERIAL AND EQUIPMENT

3.4.1 Designing the measuring instrument

This study entailed the design and compilation of a Scripted Interview (Appendix F) and the SAS (Appendix G) that enabled the researcher to specifically measure the attitudes of typically-developing children toward participation with their younger sibling with severe speech and language disabilities. The measuring instrument was administered by the researcher during individual one-on-one sessions with the participants, using the Scripted Interview.

A comprehensive literature review was conducted in order to identify the key factors relating to typical sibling participation, children with disabilities, attitudes towards people with disabilities as well as factors influencing individual attitudes as identified by previous researchers. The researcher obtained descriptive definitions as well as previously validated and implemented measuring instruments that related to the measurement of attitudes, interaction and everyday life situations. This aimed to promote the content validity of the measuring instrument (Maxwell & Satake, 2006).

Based on the information obtained from the literature review, the researcher compiled:

- a preliminary list of 40 items that tapped into the affective, behavioural and cognitive aspects of attitude (Feldman, 1993) to be included in the proposed attitude scale; which acted as measurement instrument
- items to be included in the biographic information section of the attitude scale, and
- dialogue and instructions to be included in the scripted interview.

The preliminary measuring instrument contained items to specifically probe the affective, cognitive and behavioural aspects of attitude measurement (Feldman, 1993) as well as additional information necessary to draw conclusions and make inferences about the attitudes of typically-developing children towards their younger siblings with severe speech and language disabilities.

The preliminary measuring instrument was judged by a panel of experts in order to ensure that the vocabulary and wording were free from jargon and on the appropriate language level for the target population (Maxwell & Satake, 2006). The expert panel comprised of three speech-language therapists, five remedial teachers, and two occupational therapists, who are familiar with children with disabilities. Thirty-one of the 40 items reviewed by the professionals were included in the preliminary SAS, after which, the instrument was subjected to a pilot study. The aims, methods, results and recommendations of the pilot study are presented in Table 3.10 to Table 3.12. Recommended changes to the measuring instrument were made on the basis of the pilot study, prior to its implementation in the main study.

3.4.2 The Sibling Attitude Scale (SAS)

- **SECTION A: Biographical information**

The purpose of this study was to investigate children's attitudes towards participation with their younger sibling with a severe speech and language disability. For this reason specific biographical information pertaining to the typically-developing siblings was needed. This information enabled the researcher to compile specific descriptive participant information that allowed for more comprehensive analysis and interpretation of the results obtained from the attitude scale (SAS). Biographical information was obtained through the use of the biographical information section (Section A) of the SAS, which included questions regarding age, sibling spacing and gender, as these factors have been identified in the literature as factors influencing the formation of attitudes (Gorenflo & Gorenflo, 1991). The biographical information section (Section A) of the SAS was completed by the researcher for each participant prior to the individual scale administration sessions. The information needed to complete this form was obtained from the disabled sibling's case history forms. The biographical information section was attached to each participant's attitude scale (Section B). The biographical information section was subjected to a pilot study after which some changes to this section were made in order to conduct the main study. The results of the pilot study are summarized in Table 3.10 to Table 3.12.

• **SECTION B: The attitude scale**

The use of a Likert rating scale has been documented in the literature as being a reliable and valid method for the measurement of attitudes (Oppenheim, 1998). Using the Likert scale as a foundation in the development of the response format for the attitude scale section (Section B) of the SAS, other scales including the Attitudes Toward Augmentative/Alternative Communication (AATAAC), developed by Beck et al. (2000) as well as the Sibling Interaction Scale (SIS), developed by Caro and Derevensky (1997) were used to develop an attitude scale specific to the purposes of this study. Table 3.1 reflects the summary of the existing scales used to compile the SAS.

Table 3.1: Summary of existing scales used in the development of the SAS

EXISTING SCALE	REASON FOR USE	DESCRIPTION	HOW IT INFORMED THE CURRENT STUDY
Attitudes Toward Augmentative/Alternative Communication (AATAAC) , developed by Beck et al. (2000).	The AATAAC is a well-developed, reliable and valid tool in the measurement of attitudes within the three aspects relating to attitude measurement i.e. affective, behavioural and cognitive components (Beck et al., 2000). According to Beck et al. (2000), the AATAAC demonstrated good internal consistency, test-re-test reliability, content validity, concurrent validity and construct validity. This test, however, focuses specifically on attitudes towards the use of AAC and not on sibling participation.	In the study done by Beck et al., (2000), the AATAAC was used to determine the attitudes of school-aged children toward their peers who use augmentative and alternative communication (AAC). The participants ranged between the ages of 7-11 years. The AATAAC consists of 36 items. A five-point Likert scale format was used and response categories were represented by Picture Communication Symbols (Mayer-Johnson, 2003). Participants viewed a commercially produced videotape depicting school-aged children using various AAC techniques. After viewing the videotape, participants had to complete the AATAAC.	This instrument allowed the researcher to evaluate and consider the wording and sentence structure of items relating to the three underlying components of attitude measurement. It also provided an example of a measuring instrument designed for a young population (7-11 years) similar to that of the target population of the current study. Furthermore, it also utilized the Mayer-Johnson PCS to represent the response categories, therefore providing an example of possible response categories to be used in the current study.

EXISTING SCALE	REASON FOR USE	DESCRIPTION	HOW IT INFORMED THE CURRENT STUDY
Sibling Interaction Scale (SIS) , developed by Caro and Derevensky (1997).	The SIS yielded reliable and valid information pertaining to sibling interaction patterns and interaction characteristics (Caro & Derevensky, 1997). The SIS consists of four sub-sections including: <i>frequency</i> of interaction, <i>roles</i> assumed by siblings, <i>positive</i> behaviour of typically-developing children, and <i>negative</i> behaviour of typically-developing children. According to Caro and Derevensky (1997), the SIS proved to be an easily administered clinical tool with high internal consistency. This tool was, however, designed to be administered during the observation of sibling interactions over several sessions.	In the study done by Caro and Derevensky (1997) the SIS was used as an observational tool to investigate the interactions between siblings with and without disability. Participants included in this study ranged from infant, pre-school and school-aged programmes. The SIS was completed by the researcher and special educator during 45 minute observation sessions in the home environment. Siblings were observed unobtrusively and were allowed to simply interact.	This measuring instrument allowed the researcher to identify key elements relating to sibling interaction. The target population this instrument was designed for was sibling pairs where one sibling was typically-developing and the other a child with a disability, similar to that of the target population of the current study.

In view of the age of the target population of this study, the measuring instrument had to consist of a limited number of response items. Thirty-one items were selected from a pool of 40 preliminary items by an expert panel, as they were deemed to represent core aspects relating to sibling interaction. The nine items that were discarded were deemed by the panel to be redundant and not specifically related to the focus of this study. Furthermore, a 3-point response category format was used, as the target population (young children) could easily use and understand this. The response categories were represented by three Picture Communication Symbols (Mayer-Johnson, 2003). These pictures were reflected on the attitude scale, which was completed by the participant and the researcher, as well as in a 5cm x 5cm symbol format that was used as part of the Talking Mats procedure (Murphy et al., 2007).

The Talking Mats procedure is a low-technology communication framework, developed by Joan Murphy, in order to assist people with limited verbal skills to express their views or indicate their feelings more effectively using simple graphic symbols (Murphy et al., 2007). The pictures included the following symbols pertaining to the individual response categories:

Table 3.2: Symbols used to represent response categories on the attitude scale.

RESPONSE CATEGORY	PCS SYMBOL TO BE USED
Definitely, Yes!	The PCS of a thumbs-up and a smiling face. 
Not sure	The PCS of a man shrugging his shoulders 
Definitely, No!	The PCS symbol of a thumbs-down and a sad face. 

Response items were developed and selected by the researcher based on a literature review as well as the results obtained from the expert panel in order to heighten content validity (Leedy & Ormrod, 2005). The response items were then subjected to a pilot study. The results obtained from the pilot study are summarized in Table 3.10 to Table 3.12.

The following theoretical constructs were used in the design of the attitude scale and its response items:

- **Attitude**

An attitude is a state of readiness or a tendency to respond in a specific way when confronted with a certain stimulus (Oppenheim, 1998). According to Oppenheim (1998) attitudes are reinforced by beliefs (the cognitive component) and often attract strong feelings (affective component) which may lead to specific actions (behavioural component). The underlying components of attitude were used as the sub-sections in the SAS.

- **Sibling participation**

Sibling participation is described by Powell and Gallagher (1993), as a continuous process, spanning throughout life, and that influences the social behaviours and personality development of family members. Sibling participation is strongly influenced by the sub-systems of family life; this includes the parent-child, the sibling-sibling and the spouse-spouse sub-systems (Powell & Gallagher, 1993). In order to compile the response items that were included in the measuring instrument the construct of sibling participation was further divided into the typical everyday life situations that exist in sibling interaction and family life (McHugh, 2003). The items were categorized into the affective, cognitive and behavioural components of attitude as specified by Feldman (1993). These attitude components served as the sub-sections of Section B of the measuring instrument. Relevant constructs relating to sibling participation were represented by an item/s under each of the sub-sections. These items were distributed amongst the respective sub-sections of Section B of the SAS.

The typical everyday life situations exemplifying four activity and participation domains specified in the ICF-CY (WHO, 2007) that enabled the researcher to render these theoretical constructs in the attitude scale operational, are set out in Table 3.3 below.

Table 3.3: Sibling everyday life situations used in the development of the attitude scale

EVERYDAY LIFE SITUATIONS	DEFINITION	USE	EXAMPLES OF ITEMS FROM THE SAS
1. Participation in play (major life areas).	Play participation is regarded as the vehicle for learning. It provides an environment free from pressure where children learn about language, social rules and interaction roles (Owens, 2000).	Items pertaining to participation during play and recreational activities were included under each sub-section of Section B of the SAS in order to determine the typically-developing child's attitude toward play participation with his/her sibling with disabilities.	Affective item: 'I like playing with my brother/sister.' (A1)
			Behavioural item: 'I always include my brother/sister in games I play.' (B1)
			Cognitive item: 'My brother/sister enjoys playing with me.' (C12)

EVERYDAY LIFE SITUATION	DEFINITION	USE	EXAMPLES OF ITEMS FROM THE SAS
2. Communication participation.	Communication participation is an interactive and reciprocal process whereby participants exchange ideas, needs, desires and information. It forms the basis of human interaction (Owens, 2000).	Items pertaining to communication participation (understanding and using language) were included under each sub-section of the SAS in order to determine the typically-developing child's attitude toward communication participation with his/her sibling with disabilities.	Affective item: 'I enjoy talking with my brother/sister.' (A3)
			Behavioural item: 'I ignore my brother/sister when I don't understand him/her.' (B2)
			Cognitive item: 'My brother/sister understands everything I say.' (C4)
3. Participation during activities of daily living (ADL) as part of domestic life.	According to McHugh (2003), activities of daily living include basic grooming activities, as well as chores in and around the house that children are expected to participate in.	Items pertaining to participation during ADL were included under each sub-section of the SAS in order to determine the typically-developing child's attitude toward participation with his/her sibling with disabilities during ADL.	Affective item: 'I feel proud to be my brother/sister's helper.' (A8)
			Behavioural item: 'I help my brother/sister do jobs around the house.' (B6)
			Cognitive item: 'My brother/sister pretends to struggle with easy tasks.' (C8)
4. Participation in interpersonal relationships (time and responsibility issues).	According to Whiteneck and Dijkers (2009), general interpersonal interactions focus on establishing and maintaining relationships and more particular interpersonal relationships focus on social roles, such as friend or family member. Children with disabilities often have limited opportunities to interact with other children, therefore their interpersonal interactions with their siblings take on increased importance (Powell & Gallagher, 1993).	Items pertaining to joint-participation time, alone-time and time spent with parents were included under each sub-section in order to determine the typically-developing child's attitude with regard to time and responsibility issues relating to their sibling with disabilities.	Affective item: 'I like spending time by myself sometimes.' (A10)
			Behavioural item: 'I want to spend more time alone with Mom and Dad.' (B5)
			Cognitive item: 'Mom and Dad let me spend time by myself.' (C11)

It is important to note that the researcher did not use the specific ICF-CY activity and participation domains per se but instead opted to use the domains as guidelines to identify typical everyday life situations that siblings participate in. This was done as not all of the items included under each everyday life situation could be theoretically categorized into an activity or participation domain, according to the Cieza rules (Cieza, Geyh, Chatterji, Kostanjsek, Utsn, & Stucki, 2005), due to the fact that most of the items required the participants to reason and think about their relationship with their sibling, which therefore places most of these items in domain D1: learning and applying knowledge (WHO, 2007). Another theoretical aspect that needs to be mentioned here is the fact that the ICF-CY (WHO, 2007) allows for the coding of the attitudes of people in the environment, labelling it as E4: environmental factors, which also made the categorization of the response items according to the Cieza rules (Cieza et al., 2005) challenging. Some of the items were also simply not codeable using the Cieza rules (Cieza et al., 2005), e.g. ‘My brother/sister enjoys playing with me’, but were deemed by the researcher to provide important information with regard to the main aim of the study. For this reason items were categorized according to the everyday life situation they represented and aimed to exemplify the activity and participation domains specified in the ICF-CY (WHO, 2007).

Subsequently, a preliminary format of the SAS was compiled. In order to decrease the occurrence of response bias, positively and negatively worded items were included (Oppenheim, 1998). More items were positively worded in order to minimize the number of items that could have been perceived as derogatory toward children with disabilities (Beck et al., 2000). The preliminary format of the SAS was also subjected to a pilot study. The aims, methods, results and recommendations obtained from the pilot study are summarized in Table 3.10 to 3.12. Based on the results, modifications were made to the attitude scale prior to the main study.

3.4.3 Scripted Interview

A Scripted Interview (Appendix F) was developed by the researcher for use during the scale administration sessions. The use of a Scripted Interview aimed at ensuring procedural integrity and providing similar information and instructions to the participants while administering the SAS. The instructions were concrete and concise (Oppenheim, 1998). The instructions were also free from jargon and at the

appropriate language level for the participants (Maxwell & Satake, 2006). The preliminary Scripted Interview was subjected to a pilot study. This allowed the researcher to make minor modifications prior to the main study, as based on the results obtained from the pilot study. The aims, methods, results and recommendations obtained from the pilot study, specifically relating to the Scripted Interview, are summarized in Table 3.12.

3.4.4 Equipment

The following equipment was used in this study:

- Equipment used in Talking Mats procedure

The data collection was done by using the Talking Mats procedure, which entailed the use of the following items:

- Response categories were graphically represented by three Mayer-Johnson (2003) Picture Communication Symbols (PCS) in a 5cm x 5cm format. Response items were also individually represented by using a 5cm x 5cm format of the PCS.
- The attitude components, used as sub-sections of Section B of the SAS, were printed on cards and laminated together with an additional card that allowed the researcher to indicate the participant number to allow for accuracy. These cards were placed on the mats prior to the picture of the mat being taken.
- Velcro backing for each of the individual PCS cards and sub-section cards, as well as Velcro strips on cardboard to ensure organized picture placement.
- A textured mat, measuring 48cm x 33cm used to place each item under the desired Likert-scale option.
- A video camera, for video recordings of the individual sessions in order to allow for subsequent inter-rater reliability measures.
- Digital camera to photograph the completed Talking Mats of the participants, to allow accurate data collection and capturing.

3.4.5 Ethical Considerations

Two main documents were compiled in order to ensure ethical research procedures:

In order to ensure that all participants and their parents were fully informed regarding all aspects of the research (Leedy & Ormrod, 2005), the researcher compiled a letter requesting informed consent from the participants' parents (Appendix D). This letter contained information regarding: the importance of the study, the need for participation in the study, the rights of the participants, participation requirements, logistical matters, as well as contact details of the researcher. This section of the letter could be kept by the participants' parents for future reference. Furthermore, the letter contained a reply slip which needed to be completed by the participants' parents in order to obtain written consent for participation in the study.

A letter requesting assent from siblings (Appendix E) was also compiled in order to obtain written assent from the participating siblings (McMillan & Schumacher, 2006).

This letter contained the same information, as the one supplied to the participants' parents, but was, in terms of wording and language level, adapted to be appropriate for the participants themselves. This aimed to ensure full understanding of the critical aspects relating to this study (Maxwell & Satake, 2006). The letter also contained a sibling assent form. This form was adapted, using pictures in order to promote better understanding of the critical aspects. The sibling assent form was completed during the researcher's scale administration sessions with the participants.

3.5 PILOT STUDY

According to Maxwell and Satake (2006) a pilot study is a smaller, preliminary version of the planned study employing only a few participants who have similar characteristics to the target population to check the feasibility of a proposed study and to refine the research design.

The purpose of the pilot study was two-fold: firstly to determine whether the SAS and the Scripted Interview were appropriate for use with the target population (children 5-10 years) and, secondly, to refine the measuring instrument (SAS) and data collection procedure in order for it to be used with older siblings of children with severe speech and language disabilities. In order to address the aims of the pilot study the researcher made use of three groups of participants, including: an expert panel (n=10), 30 siblings of typically-developing children (n=30) and four child participants (n=4).

Therefore, the Scripted Interview and the SAS were used during a pilot study, which enabled the researcher to determine if the interview format, biographical information section (Section A), the attitude scale (Section B of the measuring instrument) and the procedure was comprehensive, appropriate and functional for the purposes of this study (Leedy & Ormrod, 2005).

3.5.1 Aims

The pilot study had two main aims. The first was related to the measuring instrument and the second to the data collection procedure.

Regarding the measuring instrument, three sub-aims were set:

- to determine the face validity and content validity of the SAS and the Scripted Interview
- to determine whether the language, wording, content and administration process of the instructions and response items are age appropriate for the target population
- to determine whether the visual scale used for the response categories are easily identifiable and if they yield reliable responses

Regarding the data collection procedure, three sub-aims were set:

- to determine the soundness of the procedural integrity of the researcher's scale administration
- to determine whether the researcher creates an appropriate administration environment and allows sufficient time in which to complete the scale
- to determine whether the coding system allows for accurate and systematic data collection and organization during the administration session

Both the expert panel (n=10) and child participants (n=4) were provided with a pilot study feedback form (Appendix C). These forms were similar in content but were adapted in terms of language level to accommodate the two populations. The results and recommendations obtained from these forms used in the pilot study enabled the researcher to refine the Scripted Interview as well as the SAS in order to increase the validity and reliability of the measuring instrument as well as the data collection procedure that was used in the main study (Leedy & Ormrod, 2005).

3.5.2 Participants in the pilot study

In order to address the aims of the pilot study the researcher made use of three groups of participants. The three groups of participants were as follows:

i) Expert panel (n=10)

Ten professionals who work with children with severe speech and language disabilities were asked to critique the Scripted Interview and the SAS. Each professional was supplied with a pilot study feedback form in order to structure the feedback (Appendix C).

Table 3.4 details the descriptive information of the expert panel who participated in the pilot study. The entire expert panel was female. They all had tertiary qualifications; in the case of additional qualifications, these were specifically noted in the table.

Table 3.4: Pilot study participants: Expert panel (n=10)

PARTICIPANT NUMBER	OCCUPATION	AGE	REASON FOR INCLUSION
001	Remedial teacher	30-39 years	She has more than 15 years of experience as a teacher in the remedial context. She has insight into the impact of disability on the family and was able to comment on the face validity, language level and content of the Scripted Interview and the SAS.
002	Remedial teacher	30-39 years	She has been working as a remedial teacher for more than 15 years and was able to critique the Scripted Interview and the SAS in terms of face validity, language level and content.
003	Remedial teacher	20-29 years	She has a bachelor's degree in Psychology, as well as a post graduate Certificate of Education, specializing in special needs. She has been working as a remedial teacher for five years. This participant has both the theoretical and practical knowledge to comment on the face validity, content and language level of the Scripted Interview and the SAS.
004	Remedial teacher	60-69 years	With almost 40 years of experience working with children in both the mainstream and remedial setting, she has great insight into the impact of disability on the family. This made it possible for her to critique the Scripted Interview and the SAS in terms of language level, content and face validity.

PARTICIPANT NUMBER	OCCUPATION	AGE	REASON FOR INCLUSION
005	Remedial teacher	40-49 years	Fifteen years of experience in the remedial context, including working with pre-school and foundation phase children, enabled her to comment on the language level, content and face validity of the Scripted Interview and the SAS.
006	Speech therapist and audiologist	30-39 years	With more than 15 years of experience working with primary school as well as preschool children within the remedial context, she has great insight into the impact of various speech and language disabilities on families, enabling her to comment on the face validity, language level and content of the Scripted Interview as well as the SAS.
007	Speech therapist	60-69 years	With almost 40 years of experience working with children with severe speech and language difficulties, as well as being qualified as both a teacher and a speech therapist, she was able to critique the Scripted Interview as well as the SAS in terms of language level, content and face validity.
008	Speech therapist and audiologist	20-29 years	With almost five years of experience within the remedial context, mainly in the foundation phase, she was able to comment on the face validity, language level and content of the Scripted Interview and the SAS.
009	Occupational therapist	20-29 years	This therapist is trained in Sensory Integration and has been working with children with severe speech and language concomitant difficulties for just over six years. She also has her own private practice that includes older children with various occupational therapy needs. Her experience and training gave her the insight to comment on the face validity, language level and content of the Scripted Interview as well as the SAS.
010	Occupational therapist	30-39 years	With almost 15 years of experience, this therapist is trained in Sensory Integration and Neuro-developmental Therapy. This enabled her to critique the face validity, language level and content of the Scripted Interview and the SAS.

In summary, Table 3.4 shows that 50% of the expert panel were remedial teachers, 30% were speech therapists and 20% were occupational therapists. In terms of age, three of the expert panel participants were aged 20-29 years, four participants were aged 30-39 years, one participant was aged 40-49 years and two participants were aged 60-69 years. With regard to experience, 30% of the expert panel had just over

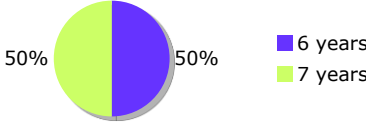
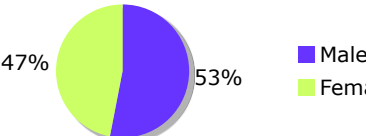
five years of experience, 50% had more than 15 years of experience and 20% of the expert panel had almost 40 years of experience working with children.

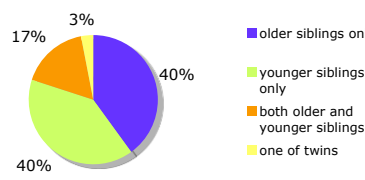
The feedback and recommendations received from the expert panel are summarized in Table 3.10 to Table 3.12. These recommendations enabled the researcher to modify the Scripted Interview as well as the SAS.

ii) Siblings of typically-developing children (n=30)

For this phase of the pilot study, 30 grade 1 learners with a typically-developing sibling were asked to complete the SAS with the help of their class teacher. A booklet with the same Mayer Johnson (2003) Picture Communication Symbols (PCS) used in the SAS was compiled in order to allow for easy use by the participants in this group. Table 3.5 details the descriptive information of the participants in this group.

Table 3.5: Pilot study participants: Siblings of typically-developing children (n=30)

DESCRIPTIVE INFORMATION	RESULTS
1. Age of participants: From the results, it was determined that fifteen of the participants (50%) were 6 years of age. The other half (50%) of the participants were 7 years of age.	Age of participants (n=30)  ■ 6 years ■ 7 years
2. Gender of participants: According to the results, more than half of the participants (53%) were male, while 47% were female.	Gender of participants (n=30)  ■ Male ■ Female

DESCRIPTIVE INFORMATION	RESULTS
3. Birth-order of typically-developing siblings: As calculated from the results, 40% of the participants had older siblings only and another 40% had younger siblings only. 17% had both older and younger siblings and 3% of the participants was one of twins.	Age of typically-developing siblings (n=30)  ■ older siblings only ■ younger siblings only ■ both older and younger siblings ■ one of twins

The results obtained from this group are summarized in Table 3.11. The results obtained from this group allowed the researcher to make necessary changes to the attitude scale section (Section B) of the SAS, including changes recommended by a qualified statistician, with regard to the coding system.

Furthermore, the participants' responses (n=30) were statistically analyzed, firstly by using the means procedure (McMillan & Schumacher, 2006), and secondly by using the Friedman Two-Way Analysis of Variance (Steyn, Smit & du Toit, 1998). The results obtained from these analyses are reflected in Table 3.6 to 3.8. This information was thought to prove useful in the comprehensive discussion of the results in Chapter 5. Table 3.6 reflects the results from the pilot study participants as calculated using the means procedure (McMillan & Schumacher, 2006).

Table 3.6: General overview of the attitude means across the four everyday life situations: pilot study participants (n=30)

EVERYDAY LIFE SITUATION	MEAN (X)	STANDARD DEVIATION (SD)
Play (major life areas): (7 items)	2.66	0.21
ADL as part of domestic life: (11 items)	2.47	0.33
Communication: (7 items)	2.35	0.20
Interpersonal relationships (time and responsibility issues): (6 items)	2.06	0.32

Subsequently, further analysis of the data was performed. Firstly, the means obtained for each individual everyday life situation, as shown in Table 3.6 were analyzed using inferential statistics. The Friedman Two-Way Analysis of Variance (Steyn et al., 1998) was used to analyze the data in order to allow for the comparison between the four everyday life situations included in this study. The results are reflected in Table 3.7.

Table 3.7: Comparison of the attitude means obtained for the four everyday life situations: pilot study participants (n=30)

EVERYDAY LIFE SITUATIONS								p-value
PLAY (MAJOR LIFE AREAS)		COMMUNICATION		ACTIVITIES OF DAILY LIVING AS PART OF DOMESTIC LIFE		INTERPERSONAL RELATIONSHIPS (TIME AND RESPONSIBILITY ISSUES)		
Mean	SD	Mean	SD	Mean	SD	Mean	SD	
2.66 ^a	0.21	2.35 ^{bc}	0.20	2.47 ^{ab}	0.33	2.06 ^c	0.32	<0.0001*

* Significant difference at the 5% level

Following the comparison across the everyday life situations, the Friedman Two-Way Analysis of Variance (Steyn et al., 1998) was further used to allow for the comparison across the affective, behavioural and cognitive components for each of the four situations included in this study. The results are reflected in Table 3.8.

Table 3.8: Comparison between attitude components within the everyday life situations: pilot study participants (n=30)

EVERYDAY LIFE SITUATIONS	ATTITUDE COMPONENTS						p-value
	AFFECTIVE		BEHAVIOURAL		COGNITIVE		
	Mean	SD	Mean	SD	Mean	SD	
Play (major life areas): Chapter d8	2.46 ^a	0.36	2.93 ^b	0.22	2.68 ^{ab}	0.53	0.0003*
Communication: Chapter d3	2.21 ^a	0.33	2.70 ^b	0.65	2.56 ^b	0.29	<0.0001*
Participation during activities of daily living (ADL) as part of domestic life: Chapter d6	2.70 ^a	0.51	2.78 ^a	0.28	1.78 ^b	0.67	<0.0001*
Interpersonal relationships (time and responsibility issues): Chapter d2	2.27 ^a	0.41	1.70 ^b	0.92	1.92 ^{ab}	0.60	0.0247*

* Significant difference at the 5% level

The information obtained from this pilot study group (n=30), therefore, not only allowed the researcher to make necessary changes to the attitude scale section (Section B) of the SAS (See Table 3.11), but also allowed for more comprehensive integration of the results, as discussed in Chapter 5.

iii) Child participants (n=4)

Four participants, who complied with the set selection criteria for the main study, but whose younger siblings with severe speech and language disabilities came from a different educational context (a similar pre-school in a different geographical area), participated in this part of the pilot study. Table 3.9 details the descriptive information of these participants.

Table 3.9: Pilot study participants: Children (n=4)

PARTICIPANT NUMBER	AGE	GENDER	REASON FOR INCLUSION
001	8 years 11 months	Male	Has a younger brother with severe speech and language difficulties. This qualified him to complete the SAS and comment on the procedure, language level and content.
002	9 years 1 month	Male	Has a younger brother with severe speech and language difficulties. This qualified him to complete the SAS and comment on the procedure, language level and content.
003	6 years 10 months	Female	Has a younger sister with severe speech and language difficulties. This qualified her to complete the SAS and comment on the procedure, language level and content.
004	7 years 8 months	Female	Has a younger sister with severe speech and language difficulties. This qualified her to complete the SAS and comment on the procedure, language level and content.

The results obtained from these participants are summarized in Table 3.11 and Table 3.12. These results allowed the researcher to adapt the Scripted Interview, the SAS as well as the data collection procedure. Modifications made on the grounds of these participants' input ensured that the measuring instrument could be used with the target population of the main study.

The aims, methods, results and recommendations specifically pertaining to the expert panel (n=10) in the pilot study are presented in Table 3.10 to Table 3.12. Furthermore, the aims, methods, results and recommendation obtained from the 30 siblings of typically-developing children (n=30) are presented in Table 3.11, and those obtained from the four child participants (n=4) are summarized in Table 3.11 and Table 3.12.

Table 3.10: Pilot study, SAS - Section A: Expert panel (n=10)

AIMS	METHODS	RESULTS	RECOMMENDATIONS
THE SIBLING ATTITUDE SCALE (SAS): SECTION A – BIOGRAPHICAL INFORMATION			
1. To determine whether the biographical information section of the SAS has face validity and is user-friendly.	An expert panel comprising of ten professionals who work with children with severe speech and language disabilities were asked to critique the face validity of this section. These professionals included five remedial teachers, three speech therapists and two occupational therapists.	The professionals unanimously agreed that the biographical information section of the SAS elicited the important biographical information needed to aid in the analysis of the information obtained from the attitude scale. They commented on the letter colour of the date of birth blocks as being too dark.	The letter colour of the blocks where date of birth had to be specified was changed from <i>black</i> to <i>grey</i> in order to increase legibility of the information written in these blocks easier.
2. To determine whether the biographical information section of the SAS was comprehensive enough in order to obtain all of the relevant information needed.	The researcher used this form in order to summarize the relevant case history information of the participants, which might have implications with regard to the research results.	Four of the professionals commented that in some cases there may be more than two other siblings in the family and that the form did not allow for such an occurrence.	Space for a third sibling's details was added in the biographical information section to ensure that all possible data in this regard could be collected.

Table 3.11: Pilot study, SAS - Section B: Expert panel (n=10), Siblings of typically-developing children (n= 30), Child participants (n=4).

AIMS	METHODS	RESULTS	RECOMMENDATIONS
SIBLING ATTITUDE SCALE (SAS): SECTION B – THE ATTITUDE SCALE			
1. To determine whether the attitude scale section (Section B) of the SAS has face validity.	Ten professionals who work with children with severe speech and language disabilities were asked to critique the face validity of the scale. These professionals included five remedial teachers, three speech therapists, and two occupational therapists.	The professionals agreed that the attitude scale section to included relevant and important aspects relating to sibling participation. They specifically commented on the use of pictures for this specific population, as it would allow them to express their feelings and ideas more accurately.	The suggested attitude scale remained the same for the main study.
2. To determine whether the attitude scale section of the SAS has content validity.	The researcher conducted an extensive literature review in order to ensure content validity. Ten professionals were asked to critique the content.	All of the professionals judged the scale to be comprehensive in addressing the relevant and important information relating to sibling participation.	The items included in the attitude scale remained the same for the main study.
3. To determine whether the language and terminology used in the attitude scale section of the SAS is unambiguous and age appropriate for the target population.	The four participants in the pilot study as well as 30 siblings of typically-developing children were asked to indicate whether the wording and the language of the questions were easily understandable, following the administration of the attitude scale. During the administration session the researcher noted the items that participants found difficult to understand.	3.1 The placement of item A5 and A6 directly following each other made it difficult for both groups of participants to discern the difference between the questions.	The researcher re-ordered the items in the <i>Attitude</i> section in such a way that A5 and A6 did not follow each other directly. Item A5 was changed to A12 and item A12 was moved to item A5.
		3.2 Three of the four child participants found it hard to understand the concept 'daily tasks' in item B6. This was not the case with the 30 siblings of typically-developing children, as this concept forms part of their <i>Life Orientation</i> curriculum in school.	The researcher decided to re-word the question by changing 'daily tasks' to 'jobs at home' which left no room for misinterpretation.
		3.3 Three of the four child participants had difficulty with item C3. They found the idea of 'understand', difficult to comprehend. This was also the case with the 30 siblings of typically-developing children.	The researcher decided to change 'I <i>understand</i> why my brother/sister can't talk as well as I do' to 'I <i>know</i> why my brother/sister can't talk as well as I do'.

		3.4 All four of the child participants, as well as the 30 siblings of typically-developing children had difficulty with item C6, because it was stated in the negative form.	Item C6 was changed from the negative to the positive form. 'My brother/sister doesn't talk a lot to other people' was changed to 'My brother/sister talks a lot to other people'.
		3.5 All four of the child participants had difficulty with the concept 'expects' in item C10. This was true for the 30 siblings of typically-developing children as well.	The word 'expects' was replaced with 'wants', e.g.: 'Mom and Dad expect me to spend all of my time with my brother/sister' was changed to 'Mom and Dad want me to spend all of my time with my brother/sister'.
		3.6 The wording in item C11 caused some confusion, since three of the child participants requested explanations for 'I am allowed'. The 30 siblings of typically-developing children did not have any difficulty with this item.	The researcher re-worded the entire question, changing it to: "Mom and Dad let me spend time by myself", to enable younger participants to also understand the question.
4. To determine whether the visual scale used for the response categories of the attitude scale section in the SAS are easily identifiable.	The four pilot study participants were asked to indicate whether they thought the symbols accurately represented the response.	All participants indicated that they easily understood the symbols used for the response categories. This was also evident in their use of the response categories during the administration of the scale.	The researcher retained the visual scale.
5. To determine whether the coding system used in the attitude scale section of the SAS allows for accurate and systematic data collection.	A completed scale, as well as the captured data in Excel spread sheet format, was presented to a qualified statistician.	The coding system of the attitude scale was found to be adequate and was also judged as allowing accurate and systematic data collection.	The coding system remained the same as was originally planned.

Table 3.12: Pilot study, Scripted Interview and Procedure: Expert panel (n=10) and Child participants (n=4)

AIMS	METHODS	RESULTS	RECOMMENDATIONS
SCRIPTED INTERVIEW & PROCEDURE			
1. To determine whether the language and wording of the Scripted Interview is unambiguous and age appropriate for the target population.	The four participants in the pilot study were asked to indicate whether the language and wording of the Scripted Interview was clear and understandable. The researcher also used the interview format during the pilot sessions and noted which of the instructions were difficult to understand.	The participants understood the instructions clearly. Most of the questions posed by the participants related to confidentiality issues and not to the clarification of instructions.	The researcher decided to keep the instructions the same.
2. To determine whether the procedural integrity of the administration process is sound.	An inter-rater was asked to view the four video-tapes of the pilot study's administration session to evaluate the procedural integrity. A standardized checklist was provided in order to evaluate the procedural integrity.	The inter-rater noted that the researcher's procedural integrity was sound. She did, however, comment on the fact that the researcher did not summarize every section for every participant before moving on to the next section.	The instruction in the Scripted Interview that related to summarizing each section was highlighted.
3. To determine the adequacy of the administration environment.	The researcher informally observed the effect of the surroundings on the participants.	The pilot study was conducted after school in the researcher's therapy room. Occasionally children were playing outside, this distracting the participants. One of the participants was quite fatigued after a long day at school.	The sessions for the main study will be scheduled over a weekend, preferably in the mornings, as this will aid in eliminating the effect of fatigue, and will also ensure a quiet environment.
4. To determine whether the researcher allows sufficient time for the administration of the scale.	The researcher completed the scale with the four participants in the pilot study and measured the amount of time needed for each participant to complete the scale.	The sessions lasted approximately 17-20 minutes. Ten minutes were needed for the researcher to clean up and re-arrange the materials for the next participant.	The researcher decided to allocate 30 minutes for each participant's session and to enlist the help of an assistant in order to help with logistical issues, e.g. arranging forms and materials.

3.5.3 Conclusion from pilot study

From the tables above (Table 3.10 to Table 3.12) it is clear that minor modifications to the Scripted Interview, the SAS and the data collection procedure were needed before the main study could commence.

3.6 MAIN STUDY

3.6.1 Context

For the purpose of this study, children with severe speech and language disabilities with older siblings were identified from the case load of a well-established, special needs pre-school within the private sector in the suburban Johannesburg area, using purposeful sampling. The school provides an integrated assessment, intervention and preschool environment for ambulatory children with severe speech and language delay and average IQ. The population in this specific context is culturally, racially and socio-economically diverse.

The school has a multi-disciplinary team of 20 professionals, including teachers, speech therapists, occupational therapists, physiotherapists and educational psychologists. All intervention is provided on-site and family members are actively involved as core team members and key decision-makers.

3.6.2 Participants (n=27)

Thirty-five potential participants who met the selection criteria were identified from the school's case load and were approached by the researcher to participate in the study. Eight parents of potential participants refused consent. Only 27 older, typically-developing siblings of children with severe speech and language disabilities who met the selection criteria consented to participate in the study. None of these participants were excluded during the data collection process as all of the participants assented and proved to understand and use the Talking Mats procedure correctly.

3.6.3 Criteria for the selection of participants

The selection criteria for the typically-developing siblings are set out in Table 3.13.

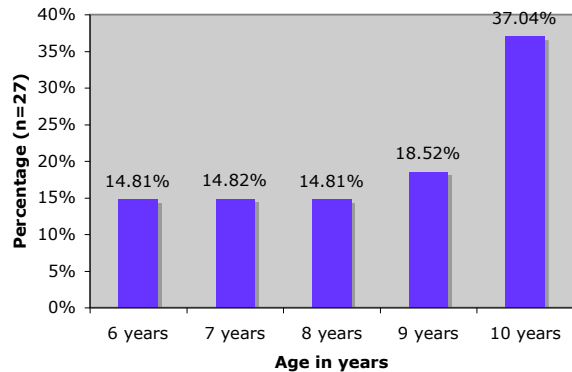
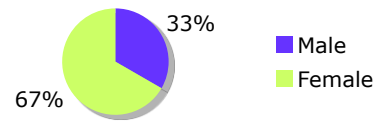
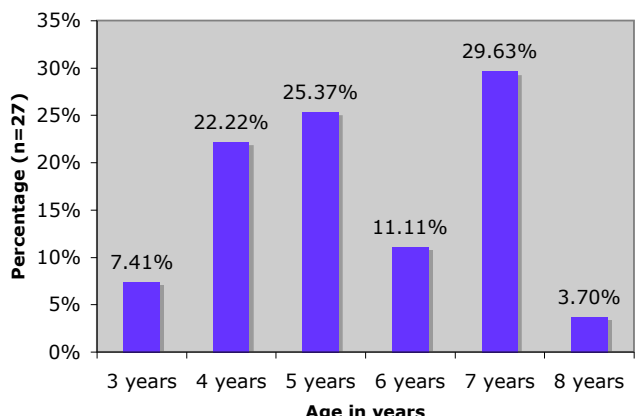
Table 3.13: Selection criteria for typically-developing children (n=27).

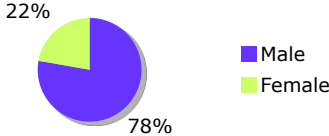
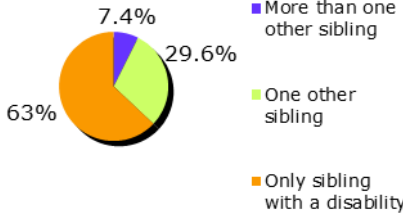
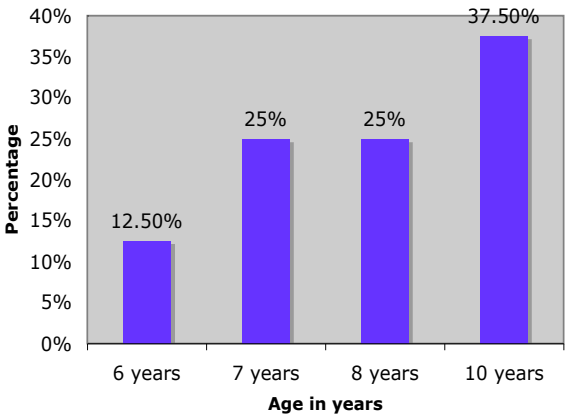
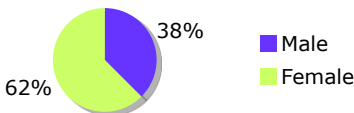
CRITERIA	JUSTIFICATION
Between 5-10 years of age	Age plays an important role in the development and change of attitudes over time (Beck & Dennis, 1996). Previous studies, relating to attitudes and disability have mainly focused on the attitudes of adolescents (Beck & Dennis, 1996), young adults (Gorenflo & Gorenflo, 1997) and older adults (Gorenflo & Gorenflo, 1991). Little information exists regarding the attitudes of younger children towards disability. Previous studies show that as early as preschool, children perceive peers with disabilities as being different and therefore they discriminate on these grounds (Beck et al., 2000).
English first language	All items on any measurement instrument should be relevant and easily understood since misinterpretation of items, due to a language barrier will lead to unreliable responses and results (Maxwell & Satake, 2006).
Older sibling of a child with a speech and language disability	Older siblings find it harder to cope with a younger sibling who was born/diagnosed with a disability because of factors relating to the acceptance of the individual and his/her condition within a typical family system (McHugh, 2003).
Participating in an early intervention, pre-school environment	Early intervention programs aim to help parents cope with their child's individual needs (McHugh, 2003). In some cases siblings are involved in these programs through participation in some play sessions to encourage their brother/sister to learn, but in general siblings feel excluded from the process (McHugh, 2003). This may influence their attitude towards interaction with their sibling with a disability.
Permanently residing with the child with a disability	Permanent residence implies continuous interaction between the typically-developing child and his/her sibling with a disability (Powell & Gallagher, 1993). This may include interaction during activities of daily living, family outings and participation in recreational/community activities (Bambara & Browder, 1991). This may impact on the attitude of the typically-developing sibling.
Not diagnosed with any form of disability themselves and never before failed a year as school.	The research goal of this study is specifically aimed at determining attitudes of typically-developing children towards their younger siblings with a disability, therefore the older sibling could not have a disability themselves. Furthermore, as the scale, used in this study, is a measure of attitude, the receptive and expressive vocabulary skills of the participants should match the level of language comprehension and expression required in the specific test items. Language difficulties will impact negatively on the test results and may have a negative impact on the validity of the results (McMillan & Schumacher, 2006). Never having failed a year at school could therefore be viewed as an indicator of age appropriate language skills.

3.6.4 Description of participants (n=27)

The descriptive information of the participants (n=27) as presented in Table 3.14 was obtained from the participants' case history forms and was recorded by the researcher in the biographical section (Section A) of the SAS.

Table 3.14: Descriptive information pertaining to the participants (n=27)

DESCRIPTIVE INFORMATION	RESULTS														
1. Age of participants: From the results, it was determined that ten of the participants (37%) were 10 years old. Five of the participants (18.5%) were 9 years old, four participants (14.8%) were 8 years of age, four participants (14.8%) were 7 years of age and the remaining four participants (14.8%) were 6 years old.	Age of participants (n=27)  <table border="1"> <thead> <tr> <th>Age in years</th> <th>Percentage (n=27)</th> </tr> </thead> <tbody> <tr> <td>6 years</td> <td>14.81%</td> </tr> <tr> <td>7 years</td> <td>14.82%</td> </tr> <tr> <td>8 years</td> <td>14.81%</td> </tr> <tr> <td>9 years</td> <td>18.52%</td> </tr> <tr> <td>10 years</td> <td>37.04%</td> </tr> </tbody> </table>	Age in years	Percentage (n=27)	6 years	14.81%	7 years	14.82%	8 years	14.81%	9 years	18.52%	10 years	37.04%		
Age in years	Percentage (n=27)														
6 years	14.81%														
7 years	14.82%														
8 years	14.81%														
9 years	18.52%														
10 years	37.04%														
2. Gender of participants: According to the results, more than half of the participants (67%) were female, while 33% were male.	Gender of participants (n=27)  <table border="1"> <thead> <tr> <th>Gender</th> <th>Percentage (n=27)</th> </tr> </thead> <tbody> <tr> <td>Male</td> <td>33%</td> </tr> <tr> <td>Female</td> <td>67%</td> </tr> </tbody> </table>	Gender	Percentage (n=27)	Male	33%	Female	67%								
Gender	Percentage (n=27)														
Male	33%														
Female	67%														
3. Age of siblings with severe speech and language disabilities: Only one participant (3.7%) had a sibling that was 8 years of age. Most of the participants (29.6%) had siblings that were 7 years of age. Three participants (11%) indicated a sibling that was 6 years of age. Almost equal numbers of participants had a sibling aged 5 (25.4%) and one aged 4 (22.2%). Only two participants (7.4%) had siblings aged 3.	Age of siblings with severe speech and language disabilities (n=27)  <table border="1"> <thead> <tr> <th>Age in years</th> <th>Percentage (n=27)</th> </tr> </thead> <tbody> <tr> <td>3 years</td> <td>7.41%</td> </tr> <tr> <td>4 years</td> <td>22.22%</td> </tr> <tr> <td>5 years</td> <td>25.37%</td> </tr> <tr> <td>6 years</td> <td>11.11%</td> </tr> <tr> <td>7 years</td> <td>29.63%</td> </tr> <tr> <td>8 years</td> <td>3.70%</td> </tr> </tbody> </table>	Age in years	Percentage (n=27)	3 years	7.41%	4 years	22.22%	5 years	25.37%	6 years	11.11%	7 years	29.63%	8 years	3.70%
Age in years	Percentage (n=27)														
3 years	7.41%														
4 years	22.22%														
5 years	25.37%														
6 years	11.11%														
7 years	29.63%														
8 years	3.70%														

DESCRIPTIVE INFORMATION	RESULTS										
4. Gender of siblings with severe speech and language disabilities: Only 22.2% of the siblings with severe speech and language disabilities were female. Most of the siblings with severe speech and language disabilities (77.8%), were male.	Gender of siblings with severe speech and language disabilities (n=27)  <table border="1"> <thead> <tr> <th>Gender</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Male</td> <td>78%</td> </tr> <tr> <td>Female</td> <td>22%</td> </tr> </tbody> </table>	Gender	Percentage	Male	78%	Female	22%				
Gender	Percentage										
Male	78%										
Female	22%										
5. More than one sibling: 5.1 Participants with other siblings: Of the 27 participants, eight participants (29.6%) had one other sibling apart their sibling with a disability. Of these eight, two participants (7.4% of the 27 participants) indicated that they had more than one sibling apart from their sibling with a disability. None of the participants had more than two other siblings.	Participants and other siblings (n=27)  <table border="1"> <thead> <tr> <th>Sibling Status</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Only sibling with a disability</td> <td>63%</td> </tr> <tr> <td>One other sibling</td> <td>29.6%</td> </tr> <tr> <td>More than one other sibling</td> <td>7.4%</td> </tr> </tbody> </table>	Sibling Status	Percentage	Only sibling with a disability	63%	One other sibling	29.6%	More than one other sibling	7.4%		
Sibling Status	Percentage										
Only sibling with a disability	63%										
One other sibling	29.6%										
More than one other sibling	7.4%										
5.2 Ages of other siblings: 37.5% (three of the other siblings) were aged 10 years. An equal number (25%) of additional siblings were aged 7 and 8 years. Only one of the additional siblings (12.5%) was aged 6.	Ages of other siblings  <table border="1"> <thead> <tr> <th>Age in years</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>6 years</td> <td>12.50%</td> </tr> <tr> <td>7 years</td> <td>25%</td> </tr> <tr> <td>8 years</td> <td>25%</td> </tr> <tr> <td>10 years</td> <td>37.50%</td> </tr> </tbody> </table>	Age in years	Percentage	6 years	12.50%	7 years	25%	8 years	25%	10 years	37.50%
Age in years	Percentage										
6 years	12.50%										
7 years	25%										
8 years	25%										
10 years	37.50%										
6. Gender of other siblings (n=8): Of the eight participants that indicated siblings other than their sibling with a disability, 62.5% of these were female and 37.5% were male.	Gender of other siblings in the family (n=8)  <table border="1"> <thead> <tr> <th>Gender</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Male</td> <td>38%</td> </tr> <tr> <td>Female</td> <td>62%</td> </tr> </tbody> </table>	Gender	Percentage	Male	38%	Female	62%				
Gender	Percentage										
Male	38%										
Female	62%										

3.7 DATA COLLECTION PROCEDURES

The following procedures were followed during the data collection stage of this study:

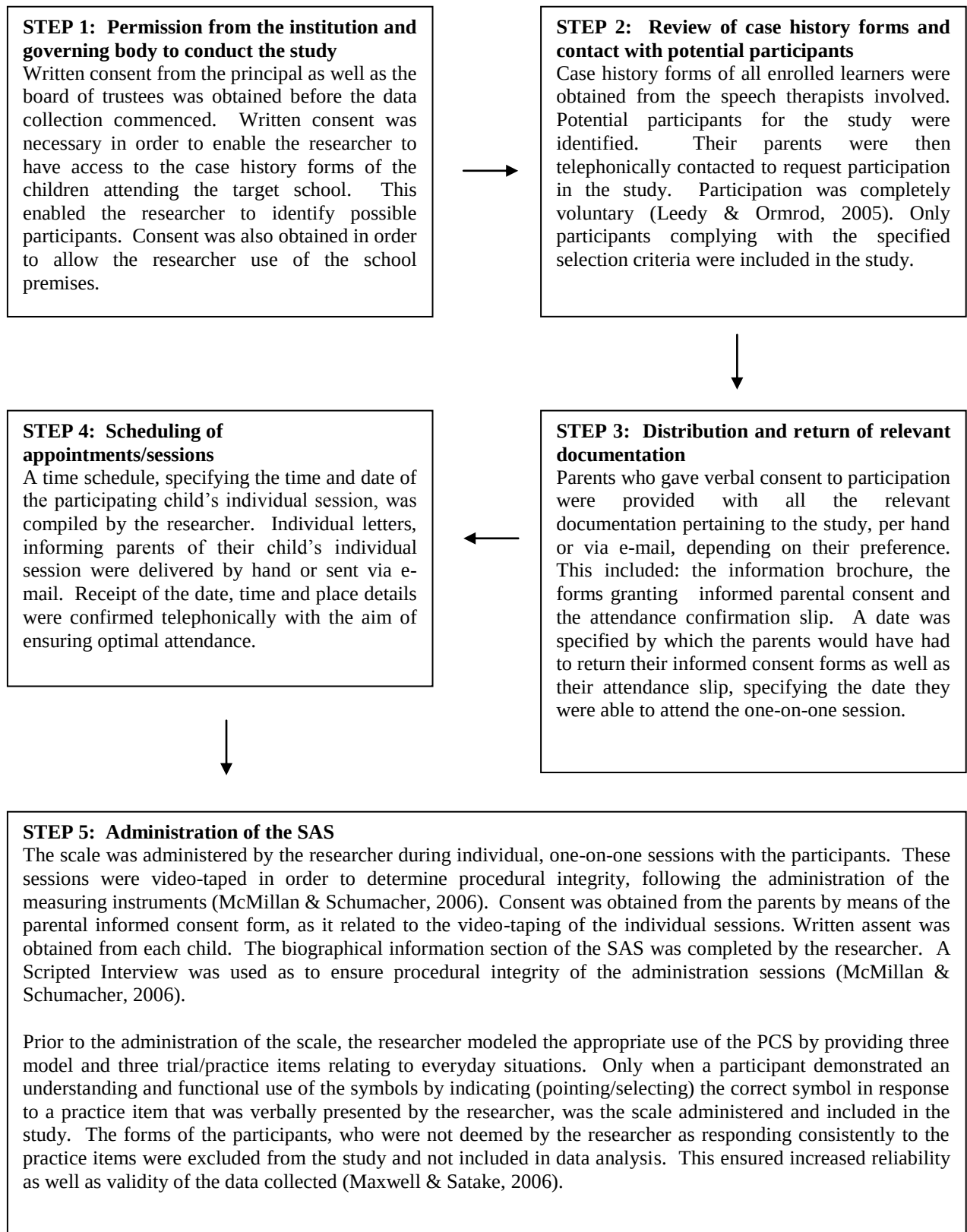


Figure 3.3: Data collection procedures

3.8 DATA ANALYSIS

Within the quantitative research design, data is frequently summarized using descriptive statistics (McMillan & Schumacher, 2006). In terms of the measuring instrument, the favourable response 'definitely, yes', was awarded the highest score, i.e. 3, 'not sure' was awarded a score of 2 and the unfavourable response 'definitely, no' was awarded a 1. The item scores were added up to obtain a total score for each participant. The possible range of total scores were calculated, e.g. 31 items with 3 possible responses = 93. The total score range was therefore between 31 (minimum/negative score) and 93 (maximum/positive score). Items were scored as shown in Table 3.15 below. Some items were, however, reverse scored. These included: A4, A6, A10, A11, A12, B2, B5, C2, C7, C8, C9, C10.

Table 3.15: Scoring of the SAS

Positively worded items were scored as they stand:	Negatively worded items were scored in reverse:
3 = definitely, yes	1 = definitely, yes
2 = not sure	2 = not sure
1 = definitely, no	3 = definitely, no

Each participant's score was plotted according to the total range of scores, so as to determine whether the participant's score fell into the positive or negative end of the range. Subsequently these responses to individual items were evaluated. The means procedure was employed as a descriptive measure and the Friedman Two-Way Analysis of Variance (Steyn et al., 1998) was used to investigate the attitude components across the everyday life situations which were identified.

The Friedman Two-Way Analysis of Variance (Steyn, et al., 1998) is a non-parametric test. It was used in this study because of the small sample size. Therefore, it was not necessary to test for normality. The statistical package that was used to analyze the data from this study, BDMP (Statistical Solutions, 2011), compensated for the number of groups when the pairwise comparisons for the Friedman procedure was done and allowed the use of the 5% level of significance for each pair. Specific formula: $\alpha = 2\alpha/k(k-1)$, where k is the number of groups.

3.9 SUMMARY

This chapter described the method employed in this research project. The aim and sub-aims were specified, followed by a description of the research design and research phases. Details were provided regarding the design of the material and the subsequent pilot study. The criteria for participant selection were also presented. Descriptive information pertaining to the participants was discussed. Furthermore a detailed description of data collection procedures was provided. Finally, the procedures for the collection and analysis of data was outlined.

CHAPTER 4 : RESULTS

4.1 INTRODUCTION

In this chapter the attitudes of typically-developing children towards participation with their younger sibling with severe speech and language disabilities, as obtained from the Sibling Attitude Scale (SAS), are discussed. The reliability of the measuring instrument as well as that of the responses obtained from the participants is discussed first. This is followed by the presentation and analysis of data within the four everyday life situations specified in the sub-aims in Chapter 3. Subsequently, a comparison within each of the underlying components of attitude measurement across the four everyday life situations is provided. Figure 4.1 presents an outline of this chapter. It is important to note that the general ratings for most of the items ranged from 3=Highly positive to 1=Highly negative. The following items were, however, reverse scored: A4, A6, A10, A11, A12, B2, B5, C2, C7, C8, C9, C10.

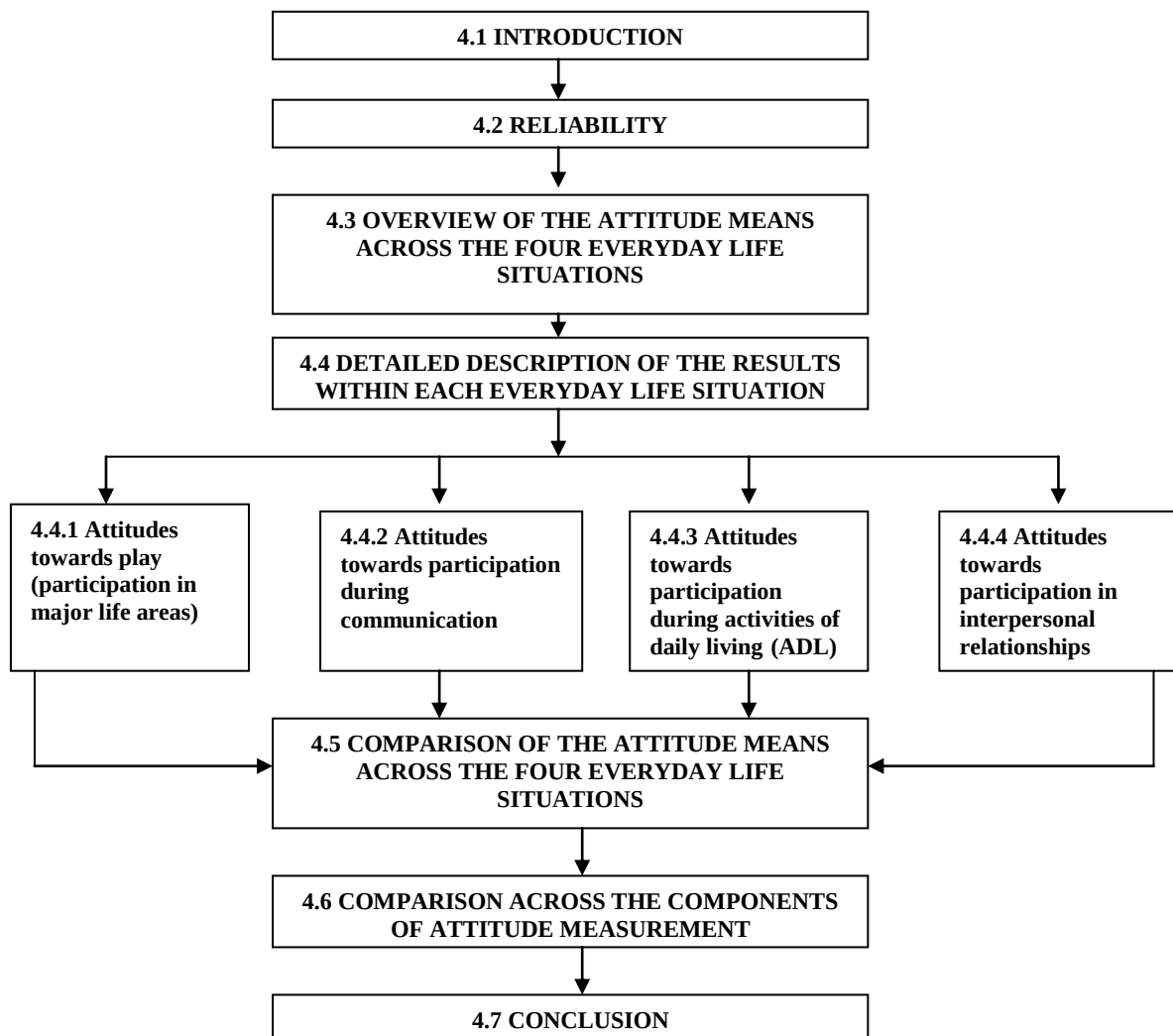


Figure 4.1: Chapter outline

4.2 RELIABILITY

A 3-point Likert-scale, with 31 response items, was used in this study to meet the needs of the target population (children 5-10 years) and to answer the research question. A more comprehensive 5-point Likert-scale was deemed too difficult for the young group of participants due to the cognitive and time-related demands it posed. A typical Chronbach Alpha Analysis (Owen, 1995) could not be performed to determine the reliability of the measuring instrument because of the 3-point Likert-scale, which resulted in too little variance in the responses obtained from the participants. Instead, descriptive statistics were used to analyze the response patterns of the typical participants (n=30) in the pilot study, obtaining percentages that allowed the researcher to identify expected patterns. The pilot study participants' responses were used in this analysis since they were all siblings of typically-developing children and were thought to give typically expected response patterns. The percentages obtained from this analysis indicated typical response patterns, because a high number of participants indicated expected responses. These percentages are reflected in Table 4.1.

Table 4.1: Percentages reflecting the pilot study participants' response patterns (n=30)

EVERYDAY LIFE SITUATION	EXPECTED RESPONSE	OTHER RESPONSE
PLAY (MAJOR LIFE AREAS):		
Affective items	70%	30%
Behavioural items	90%	10%
Cognitive items	70%	30%
COMMUNICATION:		
Affective items	53%	47%
Behavioural items	80%	20%
Cognitive items	70%	30%
ACTIVITIES OF DAILY LIVING (ADL) AS PART OF DOMESTIC LIFE:		
Affective items	70%	30%
Behavioural items	66%	34%
Cognitive items	66%	34%
INTERPERSONAL RELATIONSHIPS (TIME AND RESPONSIBILITY ISSUES):		
Affective items	65%	35%
Behavioural items	60%	40%
Cognitive items	82%	18%

Furthermore, the participants in the main study (n=27) were provided with opportunities to explain their choices and a review of their explanations reinforced the fact that they did not randomly select an option, but thought through the possible choices before assigning an item to a response category. Relevant and clear explanations were provided by all participants in the main study. The participants' responses were also distributed equally across the three rating options, i.e.

- *'Definitely, Yes!'*
- *'Not sure'* and
- *'Definitely, No!'*

These aspects indicate reliable responses on the measuring instrument.

4.3 OVERVIEW OF THE ATTITUDE MEANS ACROSS THE FOUR EVERYDAY LIFE SITUATIONS

As the main aim of this study was to determine the attitudes of typically-developing children towards participation with their younger siblings with severe speech and language disabilities, the measuring instrument was designed to tap into the three underlying components of attitude. According to Oppenheim (1998) attitudes are reinforced by beliefs (the cognitive component) and often attract strong feelings (affective component), which may lead to specific actions (behavioural component). The underlying components of attitude were used as the sub-sections in the SAS. Furthermore, as this study related to participation, four everyday life situations, which exemplify four domains of activity and participation, as outlined in the ICF-CY (WHO, 2007), were used to compile response items under each sub-section. These everyday life situations included:

- Play (participation in major life areas)
- Participation during communication
- Participation during activities of daily living (ADL) as part of domestic life
- Participation in interpersonal relationships (time and responsibility issues).

In order to obtain an overview of the attitudes of the participants (n=27) across the four everyday life situations, the means procedure was utilized during statistical analysis. The responses obtained from the participants could range from 1=Highly negative to 3=Highly positive, except for the reverse scored items specified in the introduction (4.1) to this chapter. The reverse scored items were rated 1=Highly positive to 3=Highly negative. Table 4.2 provides an outline of the grading scale used to describe the attitude means.

Table 4.2: Attitude means grading scale

RANGE	DESCRIPTION
2.5 – 3.0	Highly positive
2.1 – 2.4	Fairly positive
1.6 – 2.0	Fairly negative
1.0 – 1.5	Highly negative

As revealed by the results, the participants held highly positive attitudes towards participation in play (mean = 2.7, SD = 0.24). They also held highly positive attitudes towards participation during activities of daily living (mean = 2.5, SD = 0.21) and fairly positive attitudes towards participation during communication (mean = 2.4, SD = 0.22). The participants were least positive about participation in interpersonal relationships (time and responsibility issues) with a mean for this everyday life situation of 1.9 (SD = 0.29). Table 4.3 reflects the results as calculated using the means procedure (McMillan & Schumacher, 2006).

Table 4.3: Attitude means across the four everyday life situations

EVERYDAY LIFE SITUATIONS	MEAN (X)	STANDARD DEVIATION (SD)
Play (major life areas): (7 items)	2.72	0.24
ADL as part of domestic life: (11 items)	2.54	0.21
Communication: (7 items)	2.41	0.22
Interpersonal relationships (time and responsibility issues): (6 items)	1.96	0.29

In order to fully understand the attitudes across the four everyday life situations, the participants' responses for each response item as grouped under each everyday life situation were further analyzed. This allowed for more specific analysis of data.

4.4 DETAILED DESCRIPTION OF THE RESULTS WITHIN EACH EVERYDAY LIFE SITUATION

The responses obtained from the participants (n=27) for each response item were analyzed using descriptive statistics. This allowed for percentages to be determined for each response item (McMillan & Schumacher, 2006) that is represented in the form of bar charts to allow further discussion.

4.4.1 Sibling attitudes towards participation in play (major life areas)

The Sibling Attitude Scale (SAS) included seven response items pertaining to sibling participation in play (major life areas). The percentages for each response item were calculated and are presented in Figure 4.2.

4.4.1.1 Participant responses to individual response items

The two items scoring the highest positive rating by most of the participants both related to the enjoyment of play (A1 and C12). When the participants were asked if they enjoyed playing with their sibling with a disability (A1) 96% indicated '*Definitely, Yes!*'. Only 4% of the participants indicated '*Not sure*' to item A1, commenting 'Sometimes we fight'. No negative ratings were obtained for item A1. When asked if they thought their sibling with a disability enjoys playing with them (C12), all of the participants (100%) indicated '*Definitely, Yes!*' with some of them justifying their answer by saying 'I pick the best games', 'I always let him win' or 'I have the funnest toys'. Following this, item A5 asked whether the participants had fun when they played with their younger siblings. 89% indicated '*Definitely, Yes!*'.

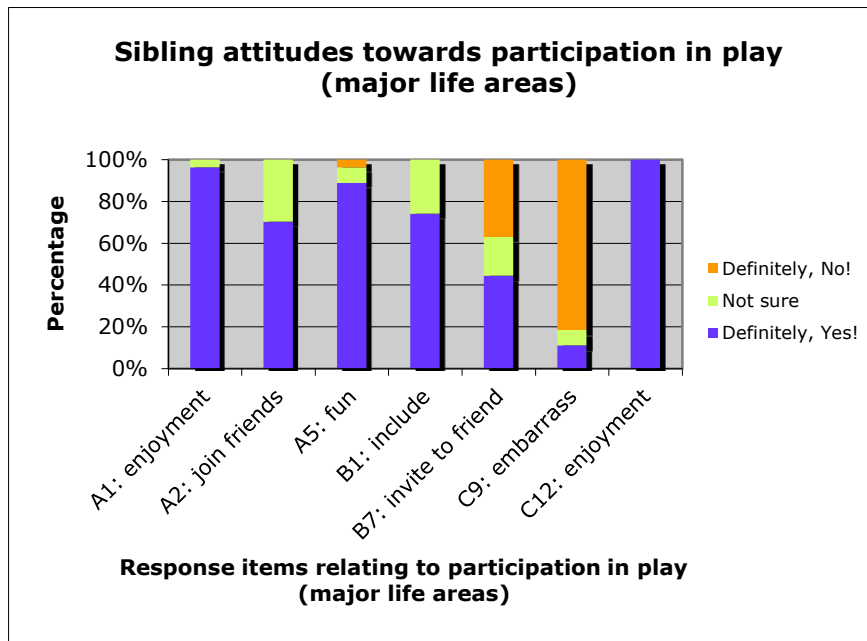


Figure 4.2: Sibling attitudes towards participation in play (major life areas) (n=27)

Item B1 was also rated highly positive as 74% of the participants indicated that they include their sibling with a disability in their games. The two response items that were rated the least positive by most of the participants pertained to sibling participation during play with the older sibling's friends (A2 and B7). In item A2, the older siblings were asked whether they liked it if their sibling with a disability joined in to play with their friends. Only 70% indicated '*Definitely, Yes!*' while 30% indicated '*Not sure*'. Comments and justifications for their answers to this response item included: 'Sometimes he bothers us', 'He annoys us when we play girl games', or 'Sometimes she doesn't understand our game'. When asked, in item B7, if they invite their sibling to a friend's house, the answers were more distributed across the response categories, with more participants indicating less positive responses such as '*Not sure*' (19%) and '*Definitely, No!*' (44%), commenting that the time they have with their friends is 'their time alone'. However, when asked if they thought their siblings wanted to embarrass them in front of their friends (C9), the participant responses indicated a positive rating of this item, as 82% indicated '*Definitely, No!*'

4.4.2 Sibling attitudes towards participation during communication

The Sibling Attitude Scale (SAS) included eleven items related to participation during communication. The percentages for each response item were calculated and are presented in Figure 4.3.

4.4.2.1 Participant responses to individual response items

As shown in Figure 4.3, the item with the highest positive rating, with 85% of the participants indicating *'Definitely, Yes!'*, was the item relating to participants knowing why their sibling with a disability cannot communicate as well as they do (C3). Each one of the participants was asked to explain their answer. Of the 27 participants, only three were familiar with their sibling's formal diagnosis and understood some of the characteristics and features of the disability, indicating 'My brother has Williams Syndrome', 'His brain didn't develop well', or 'His brain is different'. The remaining participants justified their answer by merely saying 'Because he is younger than me' or 'He is still learning to talk'.

Item A3 scored a high positive rating. This item related to the enjoyment of communication. 82% of the participants indicated that they enjoyed communicating with their sibling with a disability. Communication participation with the older sibling's friends (A4) was viewed positively, as only 19% of the participants indicated *'Definitely, Yes!'*, 7% selected *'Not sure'* and 74% of the participants indicated that they did not feel embarrassed when their sibling with a disability communicated with their friends. The participants who rated item A4 negatively (19%), commented: 'My friends don't understand him' or 'Sometimes he's not friendly with my friends'. The items specifically related to comprehension (receptive language) and the management of a communication breakdown (A6, A12, B2, C2), revealed that almost half of the participants (48%) indicated that they experience anger or frustration when they do not understand their younger sibling (A6). 44% of the participants placed the picture for this response item (A6) under *'Not sure'*, justifying their answer by saying 'Sometimes he tries very hard to talk' or 'I have to be patient. I'm not allowed to get angry'.

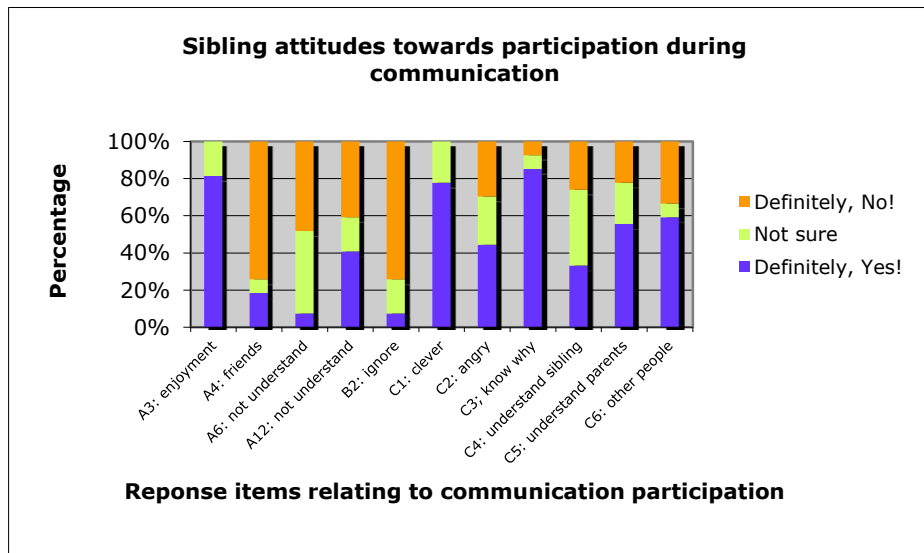


Figure 4.3: Sibling attitudes towards participation during communication (n=27)

When asked if they became angry when their sibling with a disability did not understand what they were saying (A12), 41% percent of the participants indicated a more negative attitude by selecting '*Definitely, Yes!*' and 41% of the participants indicated a more positive attitude by selecting '*Definitely, No!*'. When asked if they thought their siblings experienced anger when people did not understand him/her (C2), only 44% indicated '*Definitely, Yes!*'. Following the above, participants had to indicate whether they tended to ignore their siblings when a communication breakdown occurred (B2). Almost three quarters (74%) indicated that they do not ignore their sibling with a disability when they don't understand him/her. In answering the item pertaining to their opinion on how much of what is being said is actually understood by their younger siblings, just over half (56%) indicated that their siblings understand everything their parents say (C5) and only 33% of the participants indicated that their siblings understand everything they (the participants) say (C4).

In general, the majority of the typically-developing children (78%) felt that their sibling with a disability was clever (C1) and with item C6, 59% of the participants indicated that their siblings often engage with other people, even though their communication abilities are limited. The participants commented: 'He can do some maths', 'He can already count to ten', 'He likes talking to other people' or 'She is such a chatterbox'.

4.4.3 Sibling attitudes towards participation during activities of daily living (ADL) as part of domestic life

The Sibling Attitude Scale (SAS) consisted of seven items that measured sibling participation during ADL as part of domestic life. The percentages for each response item were calculated and are presented in Figure 4.4.

4.4.3.1 Participant responses to individual response items

The item scoring the highest positive rating (A8) asked the participants if they were proud to be their sibling's helper. All of the participants (100%) indicated '*Definitely, Yes!*' in response to this item. The results of items A7, B3, and B4 further expand on the results for item A8. When asked if they helped their siblings with disabilities to interact with unfamiliar people (B4) almost all (93%) of the participants indicated '*Definitely, Yes!*'. Furthermore, 85% of participants also indicated that they felt good (A7) about helping their sibling interact with unfamiliar people by indicating '*Definitely, Yes!*'. In response to item B3, 96% of the participants indicated that they definitely stood up for their sibling when they got teased, remarking that 'That's what big sisters are for'; 'I need to look out for my sister when Mom isn't there'.

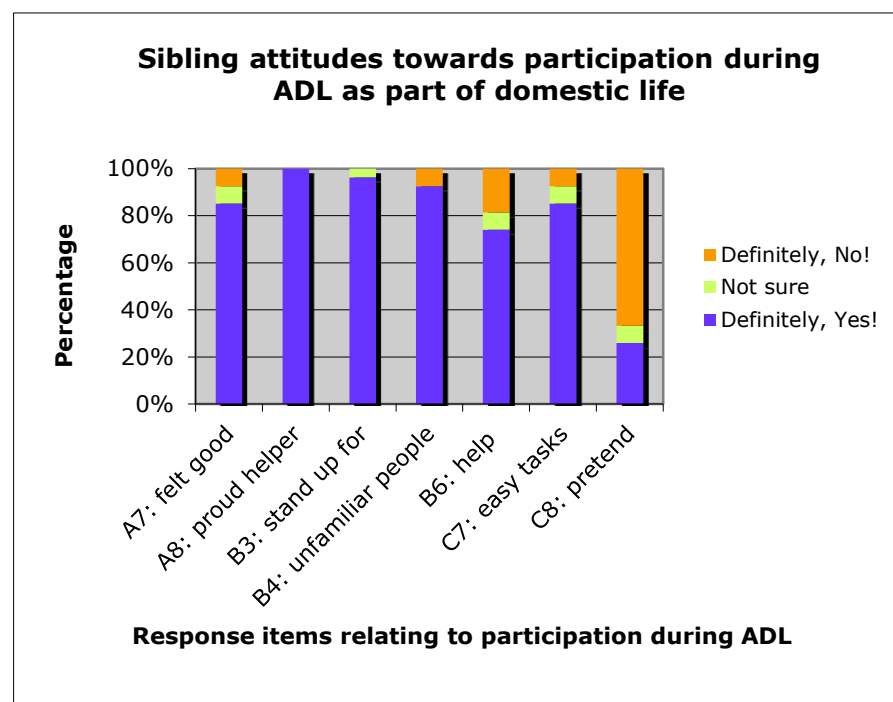


Figure 4.4: Sibling attitudes towards participation during ADL as part of domestic life (n=27)

74% of the participants indicated that they help their siblings perform some activities of daily living, e.g. '*jobs around the house*' (B6). Most of the participants were quite aware that their siblings with disabilities needed their help to perform easy tasks (C7) as 85% of the participants indicated '*Definitely, Yes!*'. They commented 'My brother needs help to clean his room' or 'My brother needs help picking up his clothes'. Item C8 expanded on the results in item C7, as most of the participants (67%) indicated that their siblings do not pretend to struggle with easy tasks, remarking 'She really does struggle', 'He really does need my help with his shoes', or 'Some things are really hard for him'. Only 26% of participants indicated that their sibling does pretend to struggle with easy tasks, commenting 'He is lazy over weekends', or 'He wants me to do everything'.

4.4.4 Sibling attitudes towards participation in interpersonal relationships (time and responsibility issues)

The Sibling Attitude Scale (SAS) consisted of six items that measured the attitudes of older, typically-developing children towards participation in interpersonal relationships (time and responsibility issues). The percentages for each response item were calculated and are presented in Figure 4.5.

4.4.4.1 Participant responses to individual response items

The item (A9) with the highest positive rating (93%) related to the enjoyment of spending time with their sibling with a disability; '*Definitely, Yes!*' was the most frequent choice. The remaining 7% of participants indicated '*Not sure*', justifying their answer by saying 'Sometimes we fight a lot' or 'Sometimes I want to be alone'. Next, participants were asked if they enjoyed spending time by themselves (A10) and 78% selected '*Definitely, Yes!*', commenting that 'Sometimes I like doing my own thing' or 'Sometimes my brother can't do the things I do'. 11% of the participants indicated '*Not sure*' and another 11% indicated '*Definitely, No!*', remarking 'I don't like being alone', or 'Games aren't fun when you play them alone'.

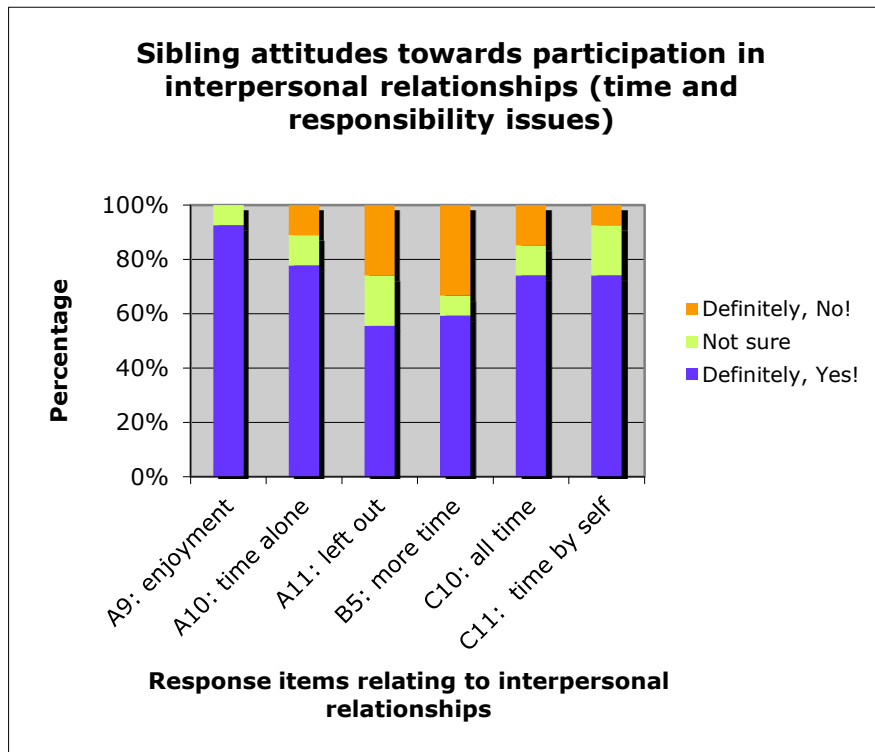


Figure 4.5: Sibling attitudes towards participation in interpersonal relationships (n=27)

The participants were asked if they felt left out when their parents spend more time with their sibling with a disability (A11). The responses to this item were distributed across the response categories, with 56% indicating '*Definitely, Yes!*', 19% '*Not sure*', and 26% '*Definitely, No!*'. These results were further confirmed by the participants' ratings for item B5, in which they had to indicate whether they wanted to spend more time alone with their parents. 59% placed their picture under '*Definitely, Yes!*' and 33% indicated '*Definitely, No!*' response, justifying it by saying 'My sister needs them more than I do', 'We do fun stuff when we are all together' or 'I don't need my parents a lot'.

Items C10 and C11 specifically related to spending time with their sibling with disabilities and having time to themselves. When asked if their parents expected them to spend all their time with their sibling (C10), 74% responded by selecting '*Definitely, Yes!*' and commenting 'My parents sometimes need my help' or 'My parents sometimes need me to look after my brother'. Only 15% selected the '*Definitely, No!*' response category. This response was contrasted by the participants' responses for item C11. This item asked if they were allowed to spend time by themselves. 74% indicated '*Definitely, Yes!*' and 19% of the participants indicated

'Not sure', commenting: 'I have to ask my parents first', 'I don't know if they will get cross if I do my own things'.

4.5 COMPARISON OF THE ATTITUDE MEANS ACROSS THE FOUR EVERYDAY LIFE SITUATIONS

In order to allow for a comprehensive discussion of results, further analyses was performed. Firstly, the means presented in Table 4.3, reflecting the means obtained for each individual everyday life situation, were analyzed using inferential statistics. The Friedman Two-Way Analysis of Variance (Steyn, et al., 1998) was used to analyze the data in order to allow for the comparison between the everyday life situations included in this study. The results are reflected in Table 4.4.

Table 4.4: Comparison of the attitude means obtained for the four everyday life situations (n=27)

EVERYDAY LIFE SITUATIONS								p-value
PLAY (MAJOR LIFE AREAS)		COMMUNICATION		ACTIVITIES OF DAILY LIVING AS PART OF DOMESTIC LIFE		INTERPERSONAL RELATIONSHIPS (TIME AND RESPONSIBILITY ISSUES)		
Mean	SD	Mean	SD	Mean	SD	Mean	SD	
2.72 ^a	0.24	2.41 ^b	0.21	2.54 ^{ab}	0.22	1.96 ^c	0.29	<0.0001*

* Significant difference at the 5% level

According to the results of this analysis, there was no statistically significant difference between participation in play (major life areas) and participation during activities of daily living as part of domestic life. There was also no significant difference between communication participation and participation during activities of daily living as part of domestic life.

The results did, however, reveal a statistically significant difference between participation in play (major life areas) and communication participation as well as between participation in play (major life areas) and participation in interpersonal relationships (time and responsibility issues) on the 5% level, with participation in play (major life areas) having the highest mean value (2.72, SD = 0.24) whilst participation in interpersonal relationships (time and responsibility issues) had the lowest means value (1.96, SD = 0.29). Furthermore, statistically significant differences were found between communication participation and participation in interpersonal relationships (time and responsibility issues) as well as between participation during activities of daily living as part of domestic life and interpersonal relationships (time and responsibility issues), on the 5% level.

Therefore, a statistically significant difference on the 5% level was found between participation in interpersonal relationships (time and responsibility issues) and all of the other everyday life situations included in this study, with interpersonal relationships (time and responsibility issues) having the lowest mean value (1.96, SD = 0.29).

4.6 COMPARISON ACROSS THE COMPONENTS OF ATTITUDE MEASUREMENT

Following the comparison across the everyday life situations, the Friedman Two-Way Analysis of Variance (Steyn et al., 1998) was further used to allow for the comparison across the affective, behavioural and cognitive components for each of the four everyday life situations included in this study, in order to allow for the identification of factors possibly contributing to the results shown in Table 4.4. The results are reflected in Table 4.5.

Table 4.5: Comparison between attitude components within the everyday life situations (n=27)

EVERYDAY LIFE SITUATIONS	ATTITUDE COMPONENTS						p-value
	AFFECTIVE		BEHAVIOURAL		COGNITIVE		
	Mean	SD	Mean	SD	Mean	SD	
Play (major life areas): Chapter d8	2.84 ^{ab}	0.25	2.41 ^a	0.59	2.85 ^b	0.33	0.0176*
Communication: Chapter d3	2.44 ^{ab}	0.36	2.67 ^a	0.62	2.35 ^b	0.31	0.0316*
Participation during activities of daily living (ADL) as part of domestic life: Chapter d6	2.89 ^a	0.29	2.79 ^a	0.32	1.81 ^b	0.57	0.0001*
Interpersonal relationships (time and responsibility issues): Chapter d7	1.99 ^a	0.33	1.74 ^a	0.94	2.04 ^a	0.55	0.2091

* Significant difference at the 5% level

With regard to the results obtained from the analysis of the items related to participation in play (major life areas) within each attitude component, these results indicated no significant difference between the affective and behavioural components and also no significant difference between the affective and cognitive component. A significant difference between the behavioural and cognitive component was evident

on the 5% level. The cognitive component had a higher mean value (2.85, SD = 0.33) than the behavioural component with a mean value of 2.41 (SD = 0.59).

In analyzing the items related to communication within each attitude component, the results indicated no significant difference between the affective and behavioural components and no significant difference between the affective and cognitive component. A significant difference between the behavioural and cognitive component was evident on the 5% level. In this case the behavioural component had a higher mean value (2.67, SD = 0.62) than the cognitive component (2.35, SD = 0.31).

The analysis of the items related to participation during activities of daily living as part of domestic life within each component of attitude measurement, indicated no significant difference between the affective and behavioural components. A significant difference between the behavioural and cognitive component was, once again, evident on the 5% level. The behavioural component had a higher mean value (2.79, SD = 0.32) than the cognitive component (1.81, SD = 0.57). This is indicative of a higher positive rating of the behavioural component as it relates to participation during activities of daily living. The mean value for the cognitive component (1.81, SD = 0.57) in this regard, had one of the most negative ratings of all of the attitude components across the four everyday life situations.

With regard to the items pertaining to interpersonal relationships (time and responsibility issues) no meaningful difference between the variables (attitude components) were found on the 5% level. Very similar ratings for all the attitude components in this everyday life situation were observed. The ratings for attitude components pertaining to interpersonal relationships (time and responsibility issues) had the lowest (most negative) ratings amongst all of the other components across the situations.

4.7 CONCLUSION

In view of the above findings, the following aspects must be highlighted:

Firstly, when the means across the four everyday life situations were calculated in order to obtain a broad overview of the participants' ratings, participation in play (major life areas) had the highest mean value (2.72, SD = 0.24), indicating the most positive rating of all four situations. Participation in interpersonal relationships (time and responsibility issues) had a mean value of 1.96 (SD = 0.29), indicating the least positive rating of all the everyday life situations. It is, however, important to note that even though the mean value for interpersonal relationships (time and responsibility issues) was calculated as the least positive in relation to the other everyday life situations included in this study, a mean value of 1.96 (SD = 0.29) is approaching the next category described as 'fairly positive', according to the grading scale in Table 4.2.

Secondly, in further analyzing the attitude means across the four everyday life situations the results indicated a statistically significant difference between participation in play (major life areas) and both communication participation and participation in interpersonal relationships (time and responsibility issues) on the 5% level. Interpersonal relationships (time and responsibility issues) also differed significantly, on the 5% level, from all the other everyday life situations included in this study.

Finally, in comparing the affective, behavioural and cognitive components for each of the four everyday life situations the cognitive component of participation in play (major life areas), the behavioural component of communication and the behavioural component of participation during ADL scored the highest positive ratings. No significant differences were found between the attitude components within the interpersonal relationships (time and responsibility issues) situation, but this everyday life situation scored the least positive rating.

4.8 SUMMARY

The results obtained from the 27 participants who completed the SAS using the Talking Mats procedure were presented and interpreted in terms of the sub-aims discussed in Chapter 3. The core results were summarized and will subsequently be explored further in Chapter 5.

CHAPTER 5 : DISCUSSION OF RESULTS

5.1 INTRODUCTION

In this chapter the results, as presented in Chapter 4, are critically discussed. The discussion includes a comparison of the results with previous research and existing theories and provides possible explanations for the findings reported in Chapter 4.

5.2 CRITICAL EVALUATION OF THE RELATIONSHIP BETWEEN PARTICIPATION IN PLAY (MAJOR LIFE AREAS) AND PARTICIPATION DURING INTERPERSONAL RELATIONSHIPS

The results in Chapter 4 indicated that when the means across the four everyday life situations were calculated in order to obtain a broad overview of the participants' ratings, participation in play (major life areas) had the highest mean value (2.72, SD = 0.24), indicating a high positive rating of this everyday life situation. In contrast, participation during interpersonal relationships (time and responsibility issues) had the lowest mean value (1.96, SD = 0.29), indicating the least positive rating of all the everyday life situations. The fact that the participants rated the items relating to interpersonal relationships (time and responsibility issues) negatively indicates that they hold the least positive attitudes towards participation in this everyday life situation as it relates to the items included in the measuring instrument.

5.2.1 Participation in play (major life areas)

Three possible explanations are given in the discussion that follows as to why the participants rated the items relating to participation in play (major life areas) so positively.

The first possible explanation for the positive rating of the items pertaining to play (major life areas) could be that play activities create increased opportunities for engagement and flow. According to Almqvist et al. (2007), engagement can be defined as 'the amount of time children spend interacting appropriately with the environment at different levels of competence'. Flow, on the other hand, is described by Csikszentmihaly (1997) as a child's complete absorption or engagement in a specific activity without external forces being able to distract that child.

In viewing play against the background of engagement and flow it is important to see it as a vehicle for learning and development of specific skills and roles (Admiraal, Huizenga, Akkerman & Ten Dam, 2011; Almqvist et al., 2007). Play participation, therefore, implies high levels of engagement in activities that are intrinsically motivating and within the child's initial competence, experience and interests. It also implies high levels of enjoyment because of the high level of autonomy or sense of control during these activities (Almqvist et al., 2007). This is evident from the responses obtained from the participants with regard to the items relating to the enjoyment of play (Figure 4.2). This increased sense of enjoyment and autonomy experienced by older, typically-developing siblings during participation in play (major life areas) due to the high levels of engagement and flow could, therefore, be a contributing factor to the high positive rating (mean = 2.7, SD = 0.24) of participation in play (major life areas).

Linking the concepts of engagement and flow with the eight bipolar dimensions of family life-cycle, as set out in Table 2.1 (Barnhill, 1979), further supports the explanation for this positive rating of participation in play (major life areas). Barnhill (1979) stipulates that when a child experiences a sense of autonomy, due to a shift towards individuation within the dimension of individuation-enmeshment, this experience will have a positive effect not only on the child's cognitive evaluation of family interactions, but also on that child's attitude towards participation in family activities, and subsequently sibling interaction. These positive attitudes of typically-developing siblings towards participation in play (major life areas) will therefore act as a positive environmental factor (Badley, 2008) impacting on both the quality and the quantity of sibling participation which in turn has a positive effect on the functional outcomes of the sibling with a disability.

A second possible explanation for the high positive rating of the items pertaining to participation in play (major life areas), could be the fact that play is an activity that is central to sibling relationships. Positive or negative experiences within the context of play will impact on the quality and quantity of sibling interactions. According to Powell and Gallagher (1993) play-orientated behaviours constitute the majority of sibling interactions, especially in the preschool years. In a study done by Caro and Derevensky (1997) the researchers attempted to investigate sibling interactions where

one sibling was typically-developing and the other sibling had a disability. They investigated the influence of disability on the sibling relationship, the behaviours of the sibling with and the sibling without a disability, as well as the roles assumed by the siblings. It was found that the sibling interactions during play were predominantly positive and that both siblings displayed mutual enjoyment during play. They also frequently observed positive affective behaviours, including spontaneous affection. The roles assumed by the typically-developing siblings consisted of directive behaviours as they often managed, taught or helped their sibling with a disability (Caro & Derevensky, 1997). These findings are supported by those of earlier researchers (Abramovitch, Corter, Pepler, & Stanhope, 1986; Minnett et al., 1983; Stoneman 2001) who also found that older typically-developing siblings tended to initiate more pro-social acts than their younger siblings; they also praised and taught their younger siblings more and younger siblings tended to imitate older siblings more. Integrating these research findings with Barnhill's eight bipolar dimensions of family life-cycle (Barnhill, 1979), one may more comprehensively explain the positive rating of items pertaining to participation in play (major life areas), as was found in this study. Not only is there a shift to the positive dimension (individuation) of individuation-enmeshment due to the leadership/teaching roles often assumed by the older typically developing siblings, but there is also a shift to the positive dimension of role reciprocity-role conflict; this results in the typically-developing sibling's experience of social success, since there are mutually agreed upon behaviour patterns in which he/she compliments the role of his/her sibling with a disability (Hakulinen & Paunonen, 1995). The social success experienced by the typically-developing siblings due to this shift will have a positive impact on their attitudes towards participation in play (major life areas) and will subsequently result in an increased quality and quantity of sibling interactions and participation.

A third possible explanation for the positive rating of the items pertaining to participation in play (major life areas), could be that the presence of a disability does not mask the fact that play in itself is an enjoyable sibling activity. This explanation is supported by the fact that the analyzed data of the pilot study, which included participants who have typically-developing siblings (Table 3.6 to 3.8), also indicated highly positive ratings (mean = 2.7, SD = 0.24) of the items under discussion. This explanation is also supported by the results obtained by Caro and Derevensky (1997)

who reported that play was equally enjoyed by both siblings irrespective of whether the younger sibling had a disability or not. These findings are positive in the sense that children with disabilities often do not have the same learning opportunities as their typically-developing peers due to various individual and environmental barriers (Johnson et al., 1996) preventing them from engaging in functional and meaningful activities, including play. If attitudes towards participation during play (major life areas) are highly positive, as seen from the findings of the current study and as reported in earlier studies (Caro & Derevensky, 1997; Stoneman, 2001), one could assume that positive attitudes will result in increased quality and quantity of sibling participation during play (major life areas). This will impact positively on the outcomes of the sibling with a disability, as play must be viewed as a vehicle for learning (Almqvist et al., 2007) and not only as an enjoyable sibling activity. Within the context of the sibling relationship positive sibling attitudes towards play participation could therefore be seen as a potential environmental facilitator of positive outcomes for the sibling with a disability.

5.2.2 Participation during interpersonal relationships (time and responsibility issues)

The fact that the participants rated the items relating to participation during interpersonal relationships (time and responsibility issues) as least positive may be explained in at least two ways. Firstly, the difference in the developmental ages of the typically-developing siblings and the siblings with disabilities may have impacted on their attitudes towards participation in this everyday life situation and, secondly, the presence of a severe speech and language disability impacted on the siblings' ability to share experiences on a deeper emotional level. Each of these two explanations is detailed below.

Firstly, in exploring the explanation relating to the developmental ages of the participants, it is crucial to consider the ages of the participants and their siblings with disabilities. The participants were between 5 and 10 years of age and their siblings with disabilities were always younger, with ages ranging from 3 to 7 years. According to Piaget's theory of cognitive development (Piaget, 1970; Piaget, 1971), the participants in this study can be placed in the concrete operational stage of development. This stage is characterized by an increased knowledge of their own

psyche as well as that of others and the influence of the psyche on behaviour, causing a rapid development of their self-concept, including the differentiation between their true self and their ideal self. Children in this stage of development are less egocentric and more sensitive to the needs of others, but tend to have high expectations of their parents and are easily disappointed with parental decisions and actions (Louw, van Ede & Louw, 1998). Children in the concrete operational stage also tend to engage in games that are more rule-bound and that require divergent thinking (Owens, 2000). In contrast, the siblings with disabilities can be placed in the pre-operational stage of cognitive development (Piaget, 1970; Piaget, 1971). Children in this stage are typically egocentric and therefore unable to understand the point of view of other people (Becvar & Becvar, 1996; Louw et al., 1998). This also implies that their actions and interactions mainly centre on their own needs and interests. They typically develop their categorical self during this stage; they evaluate and understand themselves and the people around them based on physical attributes, e.g. name, gender, age, skills and belongings (Louw et al., 1998). Their play is characterized as being premoral in the sense that the aim of the interaction is to have fun and take turns and not necessarily to abide by specific rules (Owens, 2000).

Taking the above into account, specifically the fact that older siblings are more aware of the feelings of others and are more developed in terms of their self concept but also have high expectations of their parents' actions and decisions, one could begin to gain insight into the fact that the participants indicated a need for more time spent by themselves as well as more time spent alone with their parents, subsequently rating participation during interpersonal relationships (time and responsibility issues) as least positive. This is supported by the fact that children are constantly in flux between the bipolar dimensions of mutuality-isolation (Barnhill, 1979), wherein they are attempting to define themselves as individuals but at the same time strive to feel part of the larger family system (Louw et al., 1998).

Secondly, one could argue that the presence of a severe speech and language disability impacts on the siblings' ability to share experiences on a deeper emotional level. A severe speech and/or language disability refers to a delay in the acquisition of pre-verbal as well as verbal communication skills during the reception and expression of thoughts, emotions and ideas (Owens, 2000). This delay impacts on an

individual's communicative competence (Light, 1997) and subsequently on their ability to function and participate in everyday life situations (WHO, 2007). In light of the above, one may deduce that social interaction on a deeper, more abstract level would be an immense challenge in sibling relationships where there is a severe speech and language disability.

Integrating both the explanations of developmental age and the impact of a disability on interpersonal relationships, the negative rating of the items pertaining to participation during interpersonal relationships (time and responsibility issues) becomes clear; it not only involves the impact of cognitive and social development but also that of language development and communicative competence which are both influenced by the presence of a disability.

Therefore, it appears that the presence of a disability in the context of a sibling relationship, does not impact negatively on the attitudes of typically-developing siblings towards participation in play (major life areas), but that its presence does seem to impact negatively on the typically-developing siblings' attitudes towards participation in interpersonal relationships (time and responsibility issues). These findings have relevance for intervention, because participation in play (major life areas) could be utilized as a potential environmental strength or opportunity in an attempt to minimize or cancel out the impact of the negative attitudes towards participation in interpersonal relationships (environmental barrier) on sibling participation (Badley, 2008), which will increase the probability of more functional and positive outcomes for the sibling with a disability (Granlund et al., 1996).

5.3 CRITICAL EVALUATION OF THE RELATIONSHIP BETWEEN PARTICIPATION IN PLAY (MAJOR LIFE AREAS) AND COMMUNICATION PARTICIPATION

The results in Chapter 4 indicated that the means across the four everyday life situations differed; for this reason the means were further analyzed using the Friedman Two-Way Analysis of Variance (Steyn et al., 1998) in order to explore the nature of these differences. The results indicated a statistically significant difference between participation in play (major life areas) and both communication participation ($p \leq 0.0001$) and participation in interpersonal relationships (time and responsibility

issues) ($p \leq 0.0001$) on the 5% level. Interpersonal relationships (time and responsibility issues) also differed significantly on the 5% level from all the other situations included in this study.

The fact that the means obtained from the items pertaining to participation in interpersonal relationships (time and responsibility issues) indicated a statistically significant difference from all three the means obtained for the other situations, allows the researcher to confirm the results as discussed above under 5.2. The fact that there was a statistically significant difference between participation in play (major life areas) and communication participation, and that participation in play (major life areas) obtained a higher mean value (mean = 2.7, SD = 0.24) than communication participation (mean = 2.4, SD = 0.22) will be discussed in the following section.

5.3.1 Participation in play (major life areas)

As stated above, play is one of the core activities in sibling interactions (Powell & Gallagher, 1993) and is typically characterized by high levels of engagement and flow (Almqvist et al., 2007). Play participation requires involvement in activities that are intrinsically motivating and on the level of the child's competence, experience and interests (Almqvist et al., 2007). Play participation also implies high levels of enjoyment, because the level of autonomy or sense of control during these activities is high. It is, however, important to note that different types of play exist and that each one of these types involves a different level of communication demand (Westby, 2000; Vig, 2007). Since the current study did not specify the nature of the play activities in the measuring instrument, it is difficult to draw conclusions about the level of language that was demanded during play.

However, the positive rating of participation in play (major life areas) in contrast to participation during communication might be explained by looking into the communication demands involved in certain types of play. Play during the preoperational stage of development, as probably exhibited by the siblings with disabilities in this study, primarily involves alone play, spectator play, parallel play, associative play, functional play, symbolic play and constructive play (Louw et al., 1998). These types of play are characterized by the fact that they are own-agenda motivated and very much related to the child's direct interests (Westby, 2000).

During these activities little to no formal communication is needed to participate in play activities. Given the fact that Caro and Derevensky (1997) found that older typically-developing siblings are sensitive to the needs of their sibling with a disability and the fact that they often adapt their activities, interaction styles and language use when interacting with their disabled siblings, one could hypothesize that the communication demand during play participation with their siblings with disabilities is low. Therefore, play between the typically-developing participants and their younger siblings with a disability might have been regarded as enjoyable and rewarding due to the fact that the level of activity and participation is on the level of competence of the sibling with a disability, and the communication demand is low. This may be presented as a possible explanation for the more positive rating of the items pertaining to participation in play (major life areas) than of the items relating to participation during communication, indicating that the impact of the sibling's disability does not impact severely on participation in play (major life areas).

5.3.2 Communication participation

Communication, as defined by Owens (2000), is the active process through which individuals exchange information and ideas, needs and desires. According to Alant, Bornman and Lloyd (2005), communication is context-based and implies the development of shared meaning between communication partners requiring active involvement, not only of the sibling with a disability, but also that of the typically-developing sibling (a more competent communicator) in the process of transaction (Renner, 2003). In view of the definition above one may argue that the required level of language as well as the overall communication demand during communication participation is high; since the siblings of the participants in this study had severe speech and language disabilities, this might have resulted in increased challenges during the communication process (Owens, 2000). This was evident in the participants' responses to the items pertaining to frustration and even anger experienced during a communication breakdown (Chapter 4). This could be a possible explanation for the less positive rating of communication participation in relation to participation in play (major life areas) and also for the statistically significant difference found upon further analysis of these everyday life situations. Furthermore, one may deduce that the impact of disability is more apparent for

communication participation than for participation in play (major life areas) due to the high level of demand posed by the activities involved in sibling communication as opposed to play.

The attitudes of communication partners set the scene within the communicative environment (Badley, 2008; Johnson et al., 1996), acting either as facilitators or barriers to functional and meaningful participation during interaction, and therefore holding important implications for intervention. The results of this study may allow clinicians and researchers to delineate barriers that are specifically related to communication participation, thereby attempting to minimize the effect of these barriers for children with disabilities by utilizing the facilitative everyday life situation of play within sibling participation.

5.4 CRITICAL EVALUATION OF THE ROLE OF THE THREE ATTITUDE COMPONENTS IN PARTICIPATION

Because the current study specifically focused on the attitudes of typically-developing siblings towards participation with their younger siblings with severe speech and language disabilities, the discussion of the results will be incomplete if the impact of the underlying components of attitude on participation were not further explored. In Chapter 4 the comparison of the affective, behavioural and cognitive components of each of the four everyday life situations revealed that the cognitive component of participation in play (major life areas), the behavioural component of communication and the behavioural component of participation during ADL scored the highest positive ratings. No significant differences were found between the attitude components within the interpersonal relationships (time and responsibility issues) situation, but this everyday life situation scored the least positive rating.

5.4.1 The affective component

The results in Chapter 4 showed that the rating of the affective component was high across all of the everyday life situations as it pertained to the items that were included in the measuring instrument. In a study done by Abramovitch et al. (1986) the researchers compared sibling relationships both in the presence and absence of disability. They reported that siblings of children with disabilities displayed

significantly more nurturing and affectionate behaviours than the siblings of children without disabilities. A study done by Gamble and McHale (1989) also found that children were kinder and more positive toward their siblings with disabilities than toward their typically-developing siblings. These findings are similar to the results of a study by Caro and Derevensky (1997), which reported frequent displays of spontaneous affectionate behaviour during sibling interactions. In comparing the pilot study results of the current study where siblings of typically-developing children were asked to complete the attitude scale, to the results of the main study, it was found that the affective ratings across all four of the situations were slightly lower for the pilot study participants than those of the participants in the main study. This could possibly indicate that the presence of a disability within a sibling relationship increases the impact of the affective component on the relationship, similar to the findings of the studies described earlier (Abramovitch et al. 1986; Caro & Derevensky, 1997; Gamble & McHale, 1989).

In contrast, some researchers found that siblings of children with disabilities often experience high levels of depression, anxiety and resentment (McHale & Pawletko, 1992) due to high levels of differential treatment by parents. Some siblings also reported a reduced sense of intimacy in their relationships with their siblings with disabilities (McHale & Harris, 1992). One could therefore argue that the presence of a disability within the sibling relationship can in some cases have a positive effect on the attitudes held by typically-developing children, impacting positively on their participation with siblings with disabilities. This broad generalization must, however, be approached with caution as the current study's findings are based on a small participant sample and the measuring instrument had a small amount of items. A study on a larger scale might enable further analysis of the merits of this argument.

5.4.2 The relationship between the behavioural component and the cognitive component

As shown from the results in Chapter 4, the statistical analysis of the attitude components across the everyday life situations indicated a statistically significant difference between the behavioural component and the cognitive component across three of the everyday life situations (play, communication and ADL). The

interpersonal relationship (time and responsibility issues) situation, however, indicated no such difference.

The fact that the pattern that seems to arise between the behavioural and cognitive components across the everyday life situations does not present itself in the interpersonal relationships situation (time and responsibility issues) may be attributed to the fact that the current study examined the attitudes of a small number of participants and that the measuring instrument consisted of a small number of items. The response items in the measuring instrument were also not distributed equally across the attitude components. These factors might have contributed to a reduced variability in the responses of the participants, thereby resulting in a reduced ability to establish statistically significant differences (Steyn et al., 1998). In future a similar study with a psychometrically validated instrument might be able to provide more insight in this regard.

Notwithstanding the above methodological issues and their impact on the results, one could attempt to explore a more theoretical explanation for the apparent relationship between the behavioural and cognitive components across the situations. The fact that the behavioural and cognitive components differ significantly across three of the four situations and the fact that the means for play (major life areas) and interpersonal relationships (time and responsibility issues) seem to reflect the same pattern, as do the means for communication participation and participation during ADL, could possibly be theoretically explained by the classification of these everyday life situations as either predominantly activity-based or participation-based situations.

Much debate has been documented in current literature regarding the distinction between the concepts of activity and participation within the ICF-CY (Coster & Khetani, 2007; Badley, 2008; Whiteneck & Dijkers, 2009). Researchers have been attempting to distinguish between the concepts of activity and participation, leading them to divide the nine domains as specified by the ICF-CY (WHO, 2007) into activity domains or participation domains. Clarifying this distinction would allow researchers to improve the measurement of activity or participation as well as the documentation of rehabilitation outcomes (Whiteneck & Dijkers, 2009). Coster and Khetani (2007) recommend using the characteristic of complexity in order to

distinguish between the dimensions of activity and participation. According to them, activities are units from which sequences are constructed and participation reflects the extent of engagement in a full range of activities in order to accomplish a larger goal. In order to distinguish between activity and participation Badley (2008) suggests the use of ten characteristics that fall into three major groups: the construct of the component, the individual effects and contextual influences. Whiteneck and Dijkers (2009), on the other hand, recommend that the distinction be made by labeling an activity as occurring on a person level while participation involves role performance at a social level.

Currently, researchers recommend grouping the first four activity and participation domains together as activity domains and the last five as participation domains (Coster & Khetani, 2007). Applying this theory to the everyday life situations targeted in the current study, participation in major life areas (play) would be viewed as a participation domain, as would participation during ADL and interpersonal relationships (time and responsibility issues). Communication, on the other hand, would be viewed as an activity domain. It is interesting to note that the current results show similarities between the patterns of the means obtained for play (major life areas) and interpersonal relationships (time and responsibility issues) as well as similarities in the patterns of the means for communication participation and participation during ADL.

Linking this data to data obtained from the attitude components may suggest that the involvement of the cognitive component plays a greater role in those everyday life situations that should rather be categorized as participation domains (major life areas and interpersonal relationships) due to a higher level of cognitive involvement (Badley, 2008), while a stronger behavioural component plays a greater role in the everyday life situations that could be classified as activity domains (communication and participation during ADL).

In considering this possible explanation it becomes necessary to once more incorporate the literature surrounding engagement and flow and also the literature on cognitive involvement. In evaluating play as an everyday life situation, one is able to establish that play participation requires high levels of engagement in activities that

are intrinsically motivating, and are within the child's initial competence, experience and interests (Almqvist et al., 2007). Furthermore, one should consider that play participation also requires a high level of cognitive involvement and voluntary control, since it is a sequence of planned activities within a functional context that result in the task of participating in the life situation of play as part of sibling relationships and recreational activities (Badley, 2008). The same holds true for participation in interpersonal relationships (time and responsibility issues), as interpersonal relationships focus on establishing and maintaining relationships within the context of an individual's social roles (Whiteneck & Dijkers, 2009), and also requires high levels of cognitive involvement (Badley, 2008).

In applying this same argument of engagement and flow as well as cognitive involvement to the everyday life situations of communication and participation during ADL, it becomes clear that both of these situations require lower levels of cognitive involvement because the activities that form part of these everyday life situations require more 'doing' (behavioural component) than 'thinking' (cognitive component). Closer investigation of the communication domain reveals that current literature published by Whiteneck and Dijkers (2009) explain the grouping of communication as an activity domain by stating that communication should be viewed in terms of specific individual skills such as introducing oneself or terminating a conversation. They further state that these are technically activities that may form part of a social role, but do not themselves constitute a social role (Whiteneck & Dijkers, 2009). In viewing participation during ADL as part of domestic life against the background of engagement and flow, it is important to note that these activities are often part of regular, repetitive daily routines and that they sometimes become automatic and habitual in nature, implying low levels of engagement and flow as well as reduced levels of cognitive involvement. According to Badley (2008) these characteristics are more descriptive of activities, which can be viewed as general things a child can do independent of context or purpose.

This data suggests that using a measure to indicate cognitive involvement as opposed to behavioural involvement may be helpful in an attempt to distinguish between the concept of activity and participation. Due to the small number of participants and response items and the related methodological issues in this study, generalization of

this argument must be approached with caution and should be further investigated in future research.

5.5 CONCLUSION

The following four main conclusions can be made:

Firstly, the presence of a severe speech and language disability in a sibling relationship does not mask the fact that play is an enjoyable sibling activity. Participant responses show that the attitudes of older typically-developing siblings towards participation during play (major life areas) are positive. Play can therefore be viewed as a potential everyday life situation (Badley, 2008) that could be utilized by clinicians in the facilitation of functional and sustainable positive outcomes for siblings with disabilities.

Secondly, the presence of a severe speech and language disability in a sibling relationship does influence siblings' ability to share experiences on a deeper social and emotional level, resulting in negative attitudes towards participation in interpersonal relationships (time and responsibility issues). The presence of a severe speech and language disability also impacts on the functional and meaningful participation of siblings during communication, especially when the communication demands are high, resulting in less positive attitudes held by older typically-developing siblings towards communication participation. This negative attitude may be viewed as a potential barrier to positive outcomes and clinicians should endeavour to utilize facilitative environmental factors in order to nullify or minimize the effects of this barrier on the outcomes of the sibling with a disability (Badley, 2008).

Thirdly, the response items included in this study showed that the presence of a severe speech and language disability in a sibling relationship does not impact negatively on the affective experience within the sibling relationship.

Fourthly and finally, the categorization of an everyday life situation as exemplifying either an activity or participation domain could be accomplished by reviewing the cognitive involvement (as indicated by levels of engagement and flow) required to participate in the activities specified for each everyday life situation.

5.6 SUMMARY

This chapter presented a critical discussion of possible theories in an attempt to explain the results of this study. These discussions and explanations were based on an integration of existing models of sibling interaction as well as on related theory. The following chapter comprises a critical evaluation of the study itself as well as recommendations for future research.

CHAPTER 6 : SUMMARY AND CONCLUSION

6.1 INTRODUCTION

This chapter provides a summary of the results obtained from the study as well as the conclusions reached following the integration of the results and current literature and theory. Following this, the study is critically evaluated and the clinical implications of the study are provided. Finally, recommendations for future research are made.

6.2 SUMMARY OF RESULTS

Children with disabilities often have limited opportunities to interact with other children (Johnson et al., 1996) and therefore, social interaction with their siblings takes on increased importance (Powell & Gallagher, 1993). According to Badley (2008), participation or involvement in a life situation, can be affected by environmental factors that either act as facilitators or barriers in any given situation. This is reiterated by the ICF-CY (WHO, 2007), as it is stipulated that the attitudes held by the people in the environment, in this case the attitude of the older, typically-developing sibling, will impact on not only the quality but also the quantity of interaction and participation of the child with a severe speech and language disability, in turn affecting the child's functional outcomes (Granlund et al., 1996).

In an effort to enable clinicians to facilitate increased functional and sustainable outcomes by increasing the quality and quantity of sibling interactions, this study endeavoured to explore the attitudes of older typically-developing children towards participation in four everyday life situations central to sibling interaction, specified in the ICF-CY (WHO, 2007), which included: participation in play (major life areas), communication participation, participation during ADL and participation in interpersonal relationships (time and responsibility issues). The data was obtained from 27 participants, who completed the measuring instrument (SAS) with the assistance of the researcher by means of the Talking Mats procedure.

The results indicated that the siblings held positive attitudes towards participation in play (major life areas) and that they were least positive about participation in interpersonal relationships (time and responsibility issues). One could therefore conclude that the presence of a severe speech and language disability within a sibling

relationships does not mask the fact that play is an enjoyable sibling activity, but that the presence of a severe speech and language disability, in a sibling relationship does, however, influence the siblings' ability to share experiences on a deeper emotional level (See Table 4.3). Play participation could, therefore, be viewed as a potential strength or facilitative factor (Badley, 2008) that might enable clinicians to utilize this everyday life situation (play) in order to facilitate functional outcomes for siblings with disabilities.

Furthermore the results of the current study indicated that the attitudes of typically-developing children towards communication participation with their younger siblings with severe speech and language disabilities were less positive in comparison to the attitudes they held towards participation in play (major life areas). It is possible, therefore, to conclude that the presence of a severe speech and language disability in a sibling relationship also impacts on functional and meaningful participation during communication. This might be due to the fact that the communication demands on the sibling with a disability for the activities within this everyday life situation are high and are directly affected by the sibling's disability. Therefore, sibling attitudes towards communication participation just like participation in interpersonal relationships (time and responsibility issues) pose possible environmental barriers to the attainment of positive outcomes for the sibling with a disability, but these potential barriers could be addressed and possibly minimized by utilizing the facilitative context of participation in play (major life areas).

In addition to the fact that the current study's results might indicate areas of strengths and needs within the sibling relationship that might aid clinicians in intervention planning for children with disabilities, the results additionally indicated possible grounds for the categorization of domains either as activity or participation domains. According to Whiteneck and Dijkers (2009), a more accurate understanding of the overlap and differentiation between activity and participation domains will allow researchers and clinicians to improve the actual measurement of activity and participation as well as the documentation of the rehabilitation outcomes. From the results it appears that the levels of engagement and flow (Almqvist et al., 2007) as well as the levels of cognitive involvement (Badley, 2008) for the activities included in this study, might be helpful in categorizing the domains as predominantly activity

or participation domains (See Table 4.5). Based on this hypothesis, the current study found that the everyday life situations of play (major life areas) and interpersonal relationships could possibly be categorized as participation domains due to their high levels of engagement, flow and cognitive involvement and that the everyday life situations of communication participation and participation during ADL be categorized as activity domains due to their lower levels of engagement, flow and cognitive involvement. As the participant sample as well as the number of response items used to represent each situation was small, the generalization of these results must be approached with caution. Further investigation of these findings could be attempted in future.

6.3 CRITICAL EVALUATION

In critically evaluating this study, the following four aspects need to be considered:

- It is widely accepted that siblings impact on the outcomes of children with disabilities. There however, exists a paucity of research regarding the influence of siblings on child outcomes and other areas of intervention, especially in the early developmental years. This could possibly be attributed to the fact that it is challenging to accurately capture the measurement of the thoughts, emotions and opinions of such a young population. This current study could therefore, be viewed as effective due to the fact that not only the measuring instrument (SAS) but also the data collection procedure was adapted (a Talking Mats procedure was used) in order to suit the needs of the participants.
- The comprehensive development process of the measuring instrument (SAS), including an in-depth pilot study comprising of the participation of three different groups, can be mentioned as a positive aspect in this study. This in-depth pilot study allowed the researcher to refine the language level as well as the length of the measuring instrument as to suit the needs of the target population in this study. These allowances included: the use of a three-point scale rather than a four point scale and the use of a limited number of response items under each sub-section which subsequently contributed to the unequal distribution of response items from the different everyday life situations. As a result of these allowances, less traditional methods of statistical analysis had to

be used in order to interpret the data and this could have affected the results. Even though an in-depth pilot study was done as part of the development of the SAS, the SAS was not psychometrically validated and this could also have impacted on the results.

- The use of the Talking Mats procedure in this study not only contributed to ensuring an age appropriate data collections procedure, but also contributed to the fact that the researchers obtained reliable participant responses. This procedure also allowed the researcher to obtain additional qualitative information in the form of participant justifications for responses, which were noted on each individual participant's SAS. Even though these additional comments were not formally analyzed, they were used to obtain a more comprehensive view of the results. This once more validates the use of the Talking Mats procedure when attempting to gain insight into the thoughts, ideas and emotions of populations for who traditional methods of data collection are challenging.
- Even though a small number of participants were selected from a limited geographical area, possibly impacting on the generalization of the results, the participants came from culturally, racially and socio-economically diverse backgrounds.
- The use of a descriptive survey design enabled the researcher to address the main aim and sub-aims of this study, yielding a large amount of data collected over a short period of time. The use of this design might, however, have resulted in the more in-depth issues not being investigated. One such example in this study pertains to the fact that the researcher cannot attribute the attitudes expressed by the participants, solely to the presence of a disability within the sibling relationship. Other contextual factors such as the age of the participants' siblings might also have resulted in similar attitudes being measured.

6.4 CLINICAL IMPLICATIONS

The results from the present study could have the following clinical implications:

- The attitudes of typically-developing siblings towards participation with their younger siblings with severe speech and language disabilities were generally positive, indicating that the sibling relationship could be utilized as a potential strength in the process of facilitating functional outcomes for siblings with disabilities.
- Participation during play (major life areas) can possibly be utilized as a context for the facilitation of functional and meaningful outcomes for children with disabilities.
- Clinicians could possibly aim to address the psychological, informational and emotional needs (behavioural and cognitive needs) of typically-developing siblings, either through direct intervention or in the form of support groups and training programmes, in order to facilitate more positive attitudes of typically-developing siblings towards communication participation as well as interpersonal relationships, in turn positively impacting on the outcomes of the sibling with a disability.
- To further attempt the categorization of the ICF-CY domains (WHO, 2007) into activity and participation domains, the principles of engagement and flow, along with cognitive involvement, may be explored as possible distinguishing factors. This may be used to further aid the accurate measurement of individual strengths and needs as well as rehabilitation outcomes.
- As the Talking Mats procedure (Murphy, Gray & Cox, 2007) proved to be a valid method of collecting data in this study, which targeted young children, future studies could attempt to use the Talking Mats procedure in order to obtain information regarding difficult to measure constructs from populations that typically struggle with traditional measuring instruments and techniques such as questionnaires.

6.5 RECOMMENDATIONS FOR FURTHER RESEARCH

Recommendations for further research based on the results obtained from this study, are as follows:

- To investigate the attitudes of typically-developing children towards participation, but with a sibling with more severe disabilities, as previous research (Buhrmester & Furman, 1990; Furman & Buhrmester, 1985; Karos et al., 2007; Klein et al., 2003; Minnett et al., 1983; Opperman & Alant, 2003) shows that various factors, including severity of a disability, impact on the attitudes held by people in the environment.
- To investigate the attitudes of typically-developing children towards participation, where the disability is characterized by instability and/or unpredictable behaviour/actions over time.
- To investigate the attitudes of typically-developing children towards participation with their sibling, using a comparative research design, in order to compare and contrast the effects of other contextual factors, such as the impact of the age of the sibling as well as the presence or absence of a disability. Therefore, aiming to establish whether the attitudes expressed can solely be attributed to the presence of a disability, or also to the difference in developmental age.
- To investigate the attitudes of typically-developing children towards participation in other everyday life situations, exemplifying activity and participation domains as specified in the ICF-CY (WHO, 2007) as well as the influence of engagement and flow factors on each activity and participation domain specified in the ICF-CY.
- To investigate the possibility of identifying specific everyday life situations and ICF-CY domains and activities that could be used as facilitative contexts, during intervention, in order to allow for more positive sibling interaction and subsequently more positive functional outcomes for children with disabilities.

6.6 SUMMARY

The conclusions of the research as well as a summary and integration of the results are presented at the beginning of this chapter. This was followed by a critical evaluation of the study as well as an indication of the clinical implications. Finally, recommendations for future research are discussed.

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APPENDIX A: TITLE REGISTRATION LETTER

Ons verw: Me P Woest / 23093537
Tel: 012 420 2736
Faks: 012 420 2698
E-pos: pwnu.woest@up.ac.za



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Fakulteit Geesteswetenskappe

15 April 2010

Me M Hansen
Doreenstraat 58
COLBYN
0083

Geagte me Hansen

TITEL/REGISTRASIE: STUDIERIGTING – MA IN AANVULLENDE EN ALTERNATIEWE KOMMUNIKASIE

Met genoeë deel ek u mee dat die volgende goedkeur is:

ONDERWERP: The attitudes of typically developing children towards participation with their siblings with severe speech- and language disabilities

LEIER: Prof J Borman

MEDELEIER:

U aandag word in besonder op die volgende gevestig:

1. **TERMYN VAN REGISTRASIE**
 - (a) U moet vir minstens een akademiese jaar as student vir die magistergraad geregistreer wees voordat die graad toegeken kan word.
 - (b) U registrasie moet jaarliks voor April hien toegeken word. Indien u nie al die vereistes vir die magistergraad voldoen het, geen herregistrasie sal na 31 Maart aanvaar word nie. U sal slegs geregtig wees op die toelating van u leier indien u jaarliks bewys van registrasie aan hom voorleë.
2. **GOEDKEURING VIR INDIENING**

Vir eksaminasie moet u voldoende eksemplare vir elke eksaminator indien, tesame met 'n skriftelike verduideliking van u leier dat hy/sy die indiening van die verhandeling goedkeur sowel as 'n verduideliking deur u, wat voor 'n Kommissaris van Ede geteken word, wat by Studenteadministrasie ingehandig word.
3. **KENNISGEWING VOOR INDIENING**

U moet my asseblief ten minste drie maande voordat u beplan om u verhandelingskripsie in te dien van u voorneme in kennis stel.
4. **VOORSKRIFTE IN VERBAND MET DIE VOORBEREIDING VAN DIE VERHANDELING/SKRIPSIE**

ASOOK DIE SAMEVATTING IS OP DIE KEERSY VAN HIERDIE BRIEF UITEENGESIT.

Die uwe



hms DEKAAN: FAKULTEIT GEESTESWETENSKAPPE

APPENDIX B: ETHICAL CLEARANCE LETTER



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Office of the Deputy Dean

9 April 2010

Dear Prof Bornman

Project: The attitudes of typically developing children towards participation with their siblings with severe speech-and language disabilities
Researcher: M Hansen
Supervisor: Prof J Bornman
Department: Centre for Augmentative and Alternative Communication
Reference number: 23093537

I am pleased to be able to tell you that the above application was **approved** by the **Postgraduate Committee** on 16 March 2010 and the **Research Ethics Committee** on 25 March 2010. Data collection may therefore commence.

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

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

We wish you success with the project.

Sincerely



Prof John Sharp
Chair: Postgraduate Committee & Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: john.sharp@up.ac.za

APPENDIX C: PILOT STUDY EVALUATION FORMS

The Sibling Attitude Scale

PILOT STUDY: EVALUATION FORM -- EXPERT PANEL

Participant number: _ _ _

To be completed by the pilot study participants.

Background Information:

1. The following attitude scale is intended to determine the attitudes of typically-developing children towards their younger siblings with disabilities.
2. The typically-developing children (participants) will be between 5 and 10 years of age.
3. The researcher will verbally present the items to the participants.
4. The participants will respond to the items by placing the desired picture symbol under a response category of their choice.
5. Participant responses will be noted in writing, by the researcher on each participant's attitude scale.

Instructions:

1. Please complete the following checklist after reviewing the questionnaire.
2. Please provide additional suggestions in the space provided. Thank you for your participation.

	More than adequate	Adequate	Less adequate	Inadequate
Instructions				
Response categories				
Order of categories				
Order of questions				
Wording of questions				
Sensitivity of questions				
Physical layout and visual impression				
Length of questionnaire				
Time needed to complete				

Comments and suggestions:

The Sibling Attitude Scale

PILOT STUDY: EVALUATION FORM -- CHILD PARTICIPANT

Participant number: _ _ _

To be completed by the the researcher with the pilot study participants.

Verbal Instructions prior to administering the scale:

1. This scale will be used to try and find out how big brothers/sisters feel about their small brother/sister that have problems with speaking and using good words and sentences.
2. The big brothers/sisters will be between 5 and 10 years old.
3. I will be using the same questions with the same pictures we did today.

After completing the scale:

1. Think about the questions I just asked and about the way I wanted you to answers them.
2. Please tell my what you thought of:

	I liked it a lot	It was okay	I didn't like it	I was terrible
The way I told you what to do				
The number of feeling pictures on the mat: too many/too few				
The pictures I used to show these feelings				
Did you understand the feelings the pictures tried to show				
The words I used in my questions				
The way the pictures and the mat looked				
The number of questions I asked you				
The time we had to finish the questions				

Comments and suggestions:

APPENDIX D: PARENTAL CONSENT LETTER AND SLIP

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Sentrum vir Aanvullende en Alternatiewe Kommunikasie
&
INTERFACE**

- 2006 Laureate Award, Education Innovation for the Fofa Project
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**Faculty of Humanities
Fakulteit Geesteswetenskappe**

May 2010

Parental Informed Consent Letter

THE ATTITUDES OF TYPICALLY-DEVELOPING CHILDREN TOWARDS PARTICIPATION WITH THEIR SIBLINGS WITH SEVERE SPEECH- AND LANGUAGE DISABILITIES.

Background

Communication interaction forms the foundation for early social-, emotional- as well as language development in children. Expectations and attitudes of communication partners greatly impact on the process of communication interaction. Negative attitudes toward people with disabilities might impact on the quality and quantity of communication interaction, in turn affecting further development of individual skills.

Sibling relationships have been described as emotional ties, existing in most children's lives that are commonly second in strength only to those between parents and children. Sibling relationships are a source of companionship, emotional support and it is during sibling interaction that children acquire many social and cognitive skills that are central to health and social development.

Very little information exists in the current body of knowledge as pertaining to the attitudes of typically-developing children towards their disabled siblings, especially with regard to interaction.

High-quality, comprehensive and meaningful service delivery and intervention involves the family, thus viewing them as key decision-makers in the intervention process. Literature does suggest that siblings have often felt excluded from the intervention process. This might have resulted in negative attitudes towards siblings with disabilities that in turn, could have affected the intervention outcomes negatively.

It is therefore, of great importance that interventionists have knowledge of attitudes as to enable them to structure efficient intervention programmes catering to individual and family needs.

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Fakulteit Geesteswetenskappe**

What are the objectives of this study?

The primary objective of this study is to determine and describe the attitudes of typically-developing children towards interaction with their siblings with severe speech- and language disabilities.

Why is my participation important?

Your participation in this research project will have no direct benefit to you. Your input will, however, contribute to the development of high-quality, comprehensive and meaningful service delivery and intervention for families of children with disabilities.

What is expected of me as a participant?

To enable your participation in this study, you and your child are requested to complete the *Parental Informed Consent Slip* and the *Sibling Assent* form. The child assent form will be completed together with the researcher, during the individual session with your child, on the day of the administration of the scale.

Furthermore you are requested to indicate the date you will be available to accompany your child to his individually allocated appointment in order to complete the attitude scale with the researcher. The administration of the attitude scale by the researcher should approximately take 30 minutes of your time.

Kindly e-mail the researcher or deliver by hand, both your Informed Consent form as well as the slip indicating your preferred date for the individual appointment. The researcher will then contact you to make a specific time on your selected date. Please retain this information pamphlet for your own use.

Will I experience any risk or discomfort during this study?

The only discomfort that you may experience whilst participating in this study is the sacrifice of your own free time so your child can complete the attitude scale.

As mentioned this should only take approximately 30 minutes of your time. All the information obtained from you and your child during the study will be handled confidentially as your child will be assigned a respondent number. You will not be subjected to any other risks.

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What are my rights as a participant in this study?

You may at any given time throughout this study decide to withdraw. Should you decide to withdraw, your decision to do so will in no way penalise you, or the services we offer to your child.

Will I have access to the research results?

The research results will be made available upon request following the completion of the project. The research data will be stored both as hard copy as well as in electronic format at the *Department of Library Services* at the University of Pretoria for 15 years.

Who can be contacted if I have any further questions?

Should you require any further information, you are welcome to contact me at 083 366 5666 or marykehansen@mac.com.

Thank you in advance for your time and co-operation!

Researcher: M Hansen

Supervisor: Prof J. Bornman

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Please complete this form and return it, together with your attendance slip to the researcher using the e-mail address provided or deliver it by hand to the researcher's office at The Talk Shop.

Office use
Participant Nr

--	--	--

Parental Informed Consent: Consent Reply Slip

Name of Participant: _____

Name of Parent: _____

Date: _____

I would not like to attend any of the sessions ☐

I would like to attend a session on: ☐ 8 May **OR** ☐ 15 May

Project title:

The attitudes of typically-developing children towards participation with siblings with severe speech- and language disabilities.

Researcher: Maryke Hansen
Master's Student
University of Pretoria

Supervisor: Prof. Juan Bornman

I understand my rights as well as my child's rights as a participant. I understand the scope of this study and the way in which it will be conducted. I understand that the sessions will be video-taped for data collection purposes and that all information used and obtained in this study will be treated as confidential. I hereby:

- ☐ voluntarily declare my consent for my child to participate in this study OR
☐ declare that my child may not participate in this study.

Parent of Participant

Date

Maryke Hansen
Researcher

Juan Bomman
Supervisor

I would like to get feedback about the results of this study.

☐

APPENDIX E: SIBLING ASSENT LETTER AND FORM

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**Faculty of Humanities
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Sibling Assent Letter

HOW OLDER BROTHERS AND SISTERS FEEL ABOUT PLAYING AND HELPING THEIR YOUNGER BROTHERS AND SISTERS THAT FIND IT HARD TO SPEAK.

Why is it important for me to do this?

When brothers and sisters play together they learn new things about the world and the people in it. Sometimes brothers and sisters don't like playing together because they don't always understand each other. This usually happens when a brother or a sister has a problem with speaking and using good words.

It is important for brothers and sisters to sometimes play together and to enjoy playing together. Brothers and sisters will always be your friends, even when you don't have other friends.

You are one of the very important people in your brother/sister's life, that can help them do better talking. It is important that the therapists that help your brother/sister know how you feel so they can help to make therapy fun for you and your Mommy and Daddy.

This might make it more fun for you and your brother or sister to play together, learn together and help each other when you need it.

What do I have to do?

If you want to help, you have to tell your Mommy or Daddy that you want to help. You can then stick a sticker on a special paper to show Mommy, Daddy and Maryke that you are keen on helping.

You will have a special day to come and visit your brother/sister's school. You will have to go with one of the therapists at your brother/sister's school. Her name is Maryke. She will ask you some questions about how you feel about helping and playing with your brother/sister. You will have to show Maryke how you feel by picking the picture you want. This will not be a test. All of your answers will be the right answers. No one will know what your answers are.

Mommy or Daddy will wait for you outside until you are finished.

You can also at any time choose to not help Maryke anymore. You can tell Maryke or Mommy and Daddy if you don't want to help. No one will be cross if you don't want to help.

Thank you for helping me!

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This form will be completed together with the researcher during the individual administration sessions.

Sibling Assent Form



Has someone read you the information letter and explained what today is all about?

YES

NO



Do you understand that it is your choice to help me today?

YES

NO



Do you understand that you can stop anytime you want to?

YES

NO

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Do you understand that I will be using a video camera today?

YES

NO



Do you have any questions?

YES

NO



Do you understand the answers I have given you?

YES

NO



Are you happy to help me today?

YES

NO

Participant name: Participant nr:

Date: Place:


Maryke Hansen
Researcher


Juan Bomman
Supervisor

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APPENDIX F: SCRIPTED INTERVIEW

SCRIPTED INTERVIEW

GREETING

1. Good Morning _____ (name of participant).
2. My name is Maryke.
3. You are here today because you can help me understand big brothers and sisters better.
4. Today I want to try and understand how **you** feel about playing, talking and helping your brother/sister.
5. I am going to show you some pictures about everyday things because I want to know what **you** think and feel about these things.

OBTAINING CHILD ASSENT

1. Before we start, you have to tell me if you want to talk to me and look at all the picture that I want to show you.
2. If you want to look at pictures with me, you can choose any colour crayon you like and draw circles on this paper around the pictures that show your answers. By drawing these circles around your answers, Mommy, Daddy and I will know that you are happy to look at the pictures with me.
3. If you don't want to look at pictures with me, you can tell me and I won't be angry.
4. You can also ask me to stop at any time.
5. I also want to look at the pictures and not write all the time AND I want to remember what we talked about, so I am going to use this video recorder to tape the session.
6. Do you have any questions?

COMPLETE THE CHILD ASSENT FORM

Thank you for doing such good drawing!

VIDEO RECORDING STARTS

MODEL ITEMS

1. Let's start!
2. We are going to talk about how you feel about different things. I am going to show you a picture of the thing we will be talking about.
3. Look, here I have a picture of an ice-cream. I want to know how you think and feel about ice-cream.
4. If you really like ice-cream, we'll put it here (show +). If you really don't like ice-cream, we'll put it here (show -). If you are not sure about how you feel about ice-cream, we'll put it here.
- (5. Do 3 and 4 with the exact same wording, for every model item, only replacing the "ice-cream" for the appropriate response item.)
6. There are no RIGHT or WRONG answers.
7. No one else will see your answers, except me and you.
8. Do you have any questions?

TRIAL ITEMS

1. Okay, now it is your turn to try.
2. Here I have a picture of a present. Do you like getting presents for your birthday?
3. If you really like getting presents for your birthday, you have to put the picture... (wait and check response)

4. IF POSITIVE: "Oh, I see that you like getting presents for your birthday". I also like getting presents for my birthday.
 5. IF NEGATIVE: "Oh, I see that you don't like getting presents for your birthday". Is this how you feel? Do you maybe want to change your answer.
 - (6. Continue with the rest of the practice items, using the exact same wording as in 2-5 as it applies to the individual response items.)
 7. Do you have any questions before we start with the rest of the pictures?
-

ADMINISTRATION OF THE SAS

1. Are you ready to start with rest of the pictures? Now, it is your turn to decide where you put the pictures. YOU choose where the pictures need to go.
2. Remember that you can ask me questions if there is something you don't understand.
3. You can stop me at any time if you don't want to answer look at the pictures any more.

**ADMINISTRATION OF THE SIBLING ATTITUDE SCALE:
ANY QUESTIONS, REPETITIONS OR EXPLANATIONS WILL BE RECORDED
ON THE SCALE.**

4. Thank you for looking at all of my pictures! You are a star! You deserve a sticker for all of your hard work. Choose the one you like!
5. Bye-bye, and thank you again for helping me!

**END OF SESSION
PHOTOGRAPH TAKEN OF TALKING MAT TO ALLOW FOR ACCURATE DATA
COLLECTION**

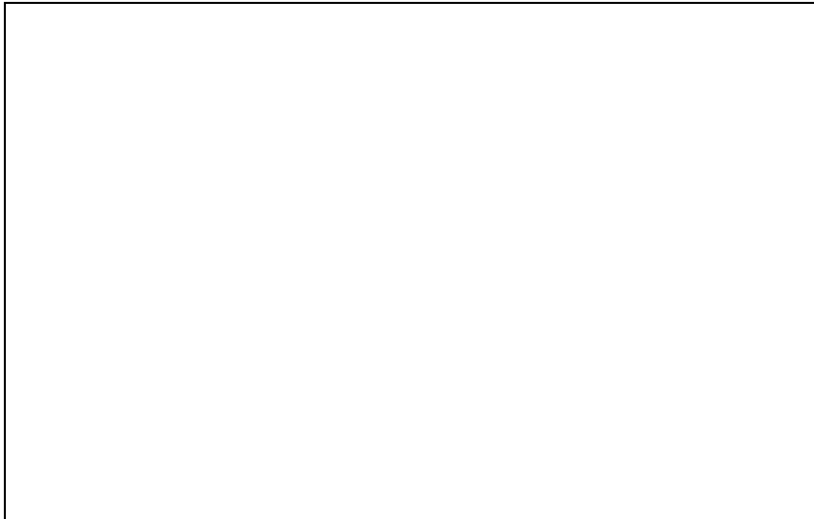
PHOTOGRAPH OF COMPLETED TALKING MAT FOR EACH SECTION

Participant number : __ __ __

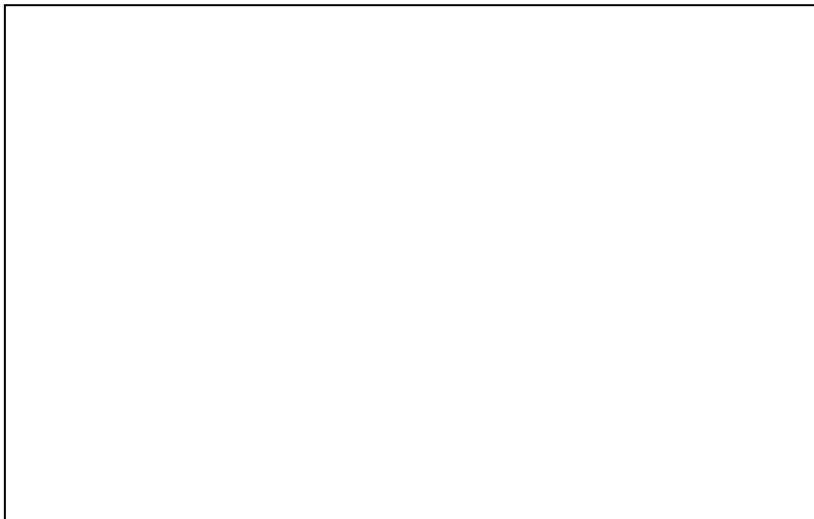
TALKING MAT FOR SECTION 1



TALKING MAT FOR SECTION 2



TALKING MAT FOR SECTION 3



APPENDIX G: SIBLING ATTITUDE SCALE

Sibling Attitude Scale

SECTION A: BIOGRAPHICAL INFORMATION FORM

Participant number: V1 1 to 3

General:

1. To be completed by the researcher prior to the administration session, using case history information.
2. To be attached to the completed SAS, after administration of the scale.

PARTICIPANT INFORMATION:

1. DATE OF BIRTH:

Y	Y	Y	Y	M	M
---	---	---	---	---	---

2. GENDER:

Male ☐ Female ☐

OFFICE USE:

V2 4 to 9

V3 10

SIBLING INFORMATION:

1. DATE OF BIRTH:

Y	Y	Y	Y	M	M
---	---	---	---	---	---

2. GENDER:

Male ☐ Female ☐

V4 11 to 16

V5 17

OTHER SIBLINGS:

OTHER #1

1. DATE OF BIRTH:

Y	Y	Y	Y	M	M
---	---	---	---	---	---

2. GENDER:

Male ☐ Female ☐

V6 18 to 23

V7 24

OTHER #2

1. DATE OF BIRTH:

Y	Y	Y	Y	M	M
---	---	---	---	---	---

2. GENDER:

Male ☐ Female ☐

V8 25 to 30

V9 31

OTHER #3

1. DATE OF BIRTH:

Y	Y	Y	Y	M	M
---	---	---	---	---	---

2. GENDER:

Male ☐ Female ☐

V10 32 to 37

V11 38

END

The Sibling Attitude Scale

SECTION B

To be completed in writing by the researcher, following the participant's response.

Participant number: ____

Verbal instructions as per SCRIPTED INTERVIEW FORMAT:

1. I am going to ask you a couple of questions about what you think and feel about your brother/sister.
2. You must answer my questions by putting each picture I give you under the picture that shows how you feel.
3. This is not a test. I just want to know what you think and feel.
4. There is no RIGHT or WRONG answer.
5. No one will see your answers, so you can tell me what you really think and feel.

RESPONSE	SYMBOL	NR
Definitely, yes	Thumbs up	
Maybe	Man shrugging shoulders	
Definitely, no	Thumbs down	

SECTION A: MODEL ITEMS	Definitely, YES!	not sure	Definitely, NO!
1. I like having ice-cream on a hot day.	3	2	1
2. I like it when a bee stings me.	1	2	3
3. I like swimming on a hot day in summer.	3	2	1

SECTION B: PRACTICE ITEMS	Definitely, YES!	not sure	Definitely, NO!
1. I like getting presents for my birthday.	3	2	1
2. I like getting lost in a shopping mall.	1	2	3
3. I like it when my friends tease me.	3	2	1

PARTICIPANT ELIGIBLE FOR STUDY:	
YES	NO

(Participants must complete 2 or more items successfully in order to take part in the study)

SECTION 1 : AFFECTIVE ITEMS	Definitely, YES! 	not sure 	Definitely, NO! 	
1. I like playing with my brother/sister.	3	2	1	A1
2. I like it when my brother/sister joins in to play with me and my friends.	3	2	1	A2
3. I enjoy talking with my brother/sister.	3	2	1	A3
4. I feel embarrassed when my brother/sister talks to my friends.	1	2	3	A4
5. My brother/sister and I have fun when we play together.	3	2	1	A5
6. I get angry when I don't understand my brother/sister.	1	2	3	A6
7. I feel good when I help my brother/sister talk to someone they don't know.	3	2	1	A7
8. I feel proud to be my brother/sister's helper.	3	2	1	A8
9. I enjoy spending time with my brother/sister.	3	2	1	A9
10. I like spending time by myself sometimes.	1	2	3	A10
11. I feel left out when Mom and Dad spend more time with my brother/sister.	1	2	3	A11
12. I get angry when my brother/sister does not understand me.	3	2	1	A12
TOTAL				A13

SECTION 2 : BEHAVIOURAL ITEMS	Definitely, YES! 	not sure 	Definitely, NO! 	
1. I always include my brother/sister in games I play.	3	2	1	B1
2. I ignore my brother/sister when I don't understand him/her.	1	2	3	B2
3. I stand up for my brother/sister when he/she gets teased.	3	2	1	B3
4. I speak for my brother/sister when people don't understand him/her.	3	2	1	B4
5. I want to spend more time alone with Mom and Dad.	1	2	3	B5
6. I help my brother/sister do jobs around the house.	3	2	1	B6
7. I invite my brother/sister to go with me to my friend's house.	3	2	1	B7
TOTAL				B8

SECTION 3 : COGNITIVE ITEMS	Definitely, YES! 	not sure 	Definitely, NO! 	
1. My brother/sister is clever.	3	2	1	C1
2. My brother/sister gets angry when people don't understand him/her.	1	2	3	C2
3. I know why my brother/sister can't talk as well as I do.	3	2	1	C3
4. My brother/sister understands everything I say.	3	2	1	C4
5. My brother/sister understands everything Mom and Dad says.	3	2	1	C5
6. My brother/sister talks a lot to other people.	3	2	1	C6
7. My brother/sister needs my help to do easy tasks.	1	2	3	C7
8. My brother/sister pretends to struggle with easy tasks.	1	2	3	C8
9. My brother/sister wants to embarrass me in front of my friends.	1	2	3	C9
10. Mom and Dad wants me to spend all of my time with my brother/sister.	1	2	3	C10
11. Mom and Dad let me spend time by myself.	3	2	1	C11
12. My brother/sister enjoys playing with me.	3	2	1	C12
TOTAL				C13

SCORING	
TOTAL SECTION 1	
TOTAL SECTION 2	
TOTAL SECTION 3	
SUM TOTAL	

TOTAL RANGE = 93

APPENDIX H: DECLARATION OF ORIGINALITY