

Sibling Relationships in Families with a Child with Special Needs

*A case study of a Norwegian family with a child
with Down syndrome and her three siblings*

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IV

Abstract

This study aims at exploring sibling relationships in a family which has a child with special needs. Since most previous research studies undertaken on sibling relationships were based either on parental or professionals' opinions and perspectives, the sibling relationships were presented primarily from the point of view of outsiders and did not take into consideration the siblings' own voice. This study aims at investigating sibling relationships from both insiders' (i.e. the child with special needs and the siblings) and outsiders' (i.e. the parents) perspectives, hopefully giving a fuller understanding of the various aspects such relationships entail.

A multi-methodological research approach was used in this single embedded case study of a family with an 11 year old girl with Down syndrome and her 10, 7 and 5 year old siblings. Both systemic and psychodynamic theories were used in analyzing the research data. A 'Kinetic Family Drawing' projective method was conducted with the child with Down syndrome and her three siblings and in-depth phenomenological interviews were held with the mother and the father of the family. In addition, participant observations in the family's house gave a unique opportunity to capture the siblings' and parent-child interactions in an environment which is natural both for the children and for the parents.

All methods of research investigation indicated the presence of warm and supportive relationships between the child with Down syndrome and her siblings. The children's kinetic family drawings illustrated that the siblings perceived their sister with Down syndrome to be an active, happy and equal sibling. The data from the father's and mother's interview was consistent with, and supported the findings of K-F-D. The parents described having caring and close relationships between their children who were both with and without special needs.

Although the positive findings were dominant in this case study, several challenges became evident. These were mainly related to the social exclusion of the child with Down syndrome by her peers and challenges in balancing parental attention when the child with Down syndrome needed extensive care because of health problems. The parents had, however, developed strategies for solving these difficulties (such as organizing frequent play dates in their own house) that can be relevant for many families with a child with special needs as well. As such this research investigation can contribute to both the understanding of and parental management of sibling relationships where one child has special needs.

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1 Introduction

1.1 Research Problem and Background of the Study

Sibling relationships are often the longest relationships which individuals may have. Frequently, they last throughout a whole life span, starting either from birth or a very young age. They are longer than the relationships with parents, spouses or children. Most individuals grow up in families with at least one brother or sister and emotional ties between siblings are usually very strong (Senner & Fish, 2012). Although parents are a primary source of socialization, sibling interactions give children an opportunity to learn about their own and others' emotions, to share secrets, argue, and negotiate (Lam, Solmeyer and McHale, 2012).

Sibling relationships obtain additional significance in families with children with disabilities, due to the advocacy role that siblings take for their brother or sister with special needs (Barr, McLeod and Daniel, 2008; Skotko and Levine, 2006; Benderix and Sivberg, 2007). Furthermore, the birth of a child with special needs is a life-changing event for many families and influences the daily life of every member (Olsson and Roll-Pettersson, 2012). Many research articles and books (Roll-Pettersson, 2001; Mlodik, 2009) are published on the topic of parental reactions to having a child with a disability and have stated that giving birth to, and bringing up, a child with special needs typically causes shock, denial, grief, anger, guilt, sorrow and a feeling of helplessness.

However, despite the fact that sibling relationships are highly important in families with a child with special needs, little attention was given to these relationships until the early 1980s and most of the research was focused on parents, and particularly on mothers (Dyke, Mulroy, and Leonard, 2009, Barr et al., 2008; Stoneman, 2005). Only over the last two decades has a growing body of research been focused on siblings of children with disabilities. These siblings have been described as the "forgotten child" or the 'family member most neglected during serious childhood illnesses' (Nielsen et al., 2012).

1.2 The Need for the Study

Most of the previous research studies on sibling relationships in families with a child with special needs were based either on parental, or professionals' opinions and perspectives. Therefore, those studies did not identify how siblings themselves perceive their relationships with their brother or sister with special needs, and presented only the perspectives of the parents (Stalker and Connors, 2004; Guite, Lobato, Kao, & Plante, 2004; Senner & Fish, 2012). This study looks at sibling relationships in families with a child with special needs from both insiders' (siblings) and outsiders' (parents) perspectives. Systemic family theory (Minuchin, 1979), which is one of the theoretical approaches on which this study is based, developed the '*child-in-context*' paradigm to understand the development of the child and highlighted the importance of 'systems' in which the child is developed. This study followed the '*child-in-context*' paradigm and is intended not only to explore how siblings perceive their relationships with their brother or sister with special needs, but also how significant people in their 'context' (parents) understand those relationships from an outsider's point of view.

Furthermore, more research is needed to determine the effects of specific disabilities on sibling relationships (Nielsen, et al., 2012) as there is a certain level of inconsistency in sibling relationship findings, which might be explained in terms of the fact that sibling relationships are different depending on the type of special need which the child has (Pollard et al., 2013).

1.3 The Objectives of the Study

This study has three main objectives:

1. To explore the relationships between children with special needs and their siblings;
2. To identify the psychological support which siblings of children with special needs may need in their families and in society;
3. To provide information about the psychological characteristics of siblings of children with special needs to parents, as well as to different healthcare professionals.

1.4 Research Questions

The main research question and underlying research questions of the study are based on the analysis of previous research studies on sibling relationships in families with a child with special needs.

The main question of the study is:

How are the relationships between children with special needs and their siblings perceived by them and their parents?

Because the main question is broad, I have developed the following ***underlying questions***:

1. How do children with special needs perceive their relationships with their siblings?
2. How do siblings perceive their relationships with their brother or sister with special needs?
3. How do children with special needs and their siblings perceive their relationships with their parents?
4. How do parents perceive the relationships between their children with and without special needs?
5. How do parents perceive their relationships with their children with and without special needs?

As is apparent from the objectives of the study, as well as from the research questions, the focus of the study is on the siblings of a child with special needs, rather than on the child with special needs. The fourth and fifth underlying questions do not explore the relationships between siblings directly, but they go further in an attempt to understand how the presence of a child with special needs influences his or her sibling's relationships with parents and how parents perceive the relationships with their children with and without special needs.

1.5 Research Design and Methodology

This study is a single embedded case study and is based on Husserl's phenomenological approach with an intention to present the participants' reflections based on their 'lived

experiences' (Van Manen, 2007, p. 12). According to the theory of a phenomenological approach, we have a phenomenal reality, and, as such, it remains open to a multiplicity of interpretations (Spinelly, 2005, p. 8). Following the phenomenological approach, in-depth, phenomenological interviews with open-ended questions were conducted with parents in order to understand their perceptions of their children's relationships and the meanings which they make of their experience of being a parent of children both with and without special needs (Seidman, 2013, p. 16). Apart from conducting interviews with parents, the kinetic family drawing projective method was used with children in order to identify how children themselves perceive and interpret the relationships between family members (specifically their relationships with their parents and siblings). In addition, I was a participant observer in the family's house.

1.6 Outline of the Thesis

The thesis is divided into five chapters.

It begins with an Introductory Chapter, which briefly introduces the research problem and background of the study, the need for it, as well as the research design and research questions of the study.

It is followed by Chapter Two (Theoretical Foundations and Relevant Research) which sets out to:

a) Discuss the main psychological theories on the development of children and the importance of the family and sibling relationships in that process; and

b) Provide an overview of the previous empirical research studies conducted on the topic of sibling relationships in families with a child with a disability.

Chapter Three (Research Design and Methodology) describes the research design of the study, methodology and methods chosen to answer the research questions with an emphasis on the measures performed to ensure validity and reliability. Additionally, this chapter presents discussion of ethical considerations and approval, sampling procedure, as well as data analysis techniques.

Finally, Chapters Four (Data Analysis and Discussion) and Five (Conclusion) present and discuss the findings of the study and draw concluding remarks with an emphasis on the implication for future research and practice.

2. Chapter Two

Theoretical Foundations and Relevant Research

2.1. Introduction

It goes without saying that the family is one of the most significant aspects in the development of children and their personalities. Family relationships, which give children appropriate and healthy models for future relationship development, are the best assistance that children can have in learning to build relationships outside of the family (Henderson and Thompson, 2011).

Although different psychological schools and theories have viewed the influence of biological and social factors on the child's development differently, a commonly held view is that all of them emphasize the importance of parent-child relationships in the development of the personality of the child. The present study will use the theories of Alfred Adler (1924), John Bowlby (1969), and Salvador Minuchin (1979) for the analysis and discussion parts of the research data.

2.2 Personality development in Individual Psychology: Alfred Adler

Adler (1924) highlighted the significance of early childhood on personality development. According to his theory of individual psychology, individuals have an innate potential for relating to others. It is *social interest* rather than a *superego* (Freud, 1949) or *collective unconscious* (Jung, 1975) that establishes the guidelines for constructive personality development. Adler (1924) said that everyone begins life as a weak and helpless child, and everyone possesses the innate drive to overcome this inferiority. These feelings of inferiority may be also influenced by body or organ sickness (real or imaginary), by having older and more powerful siblings, or by parental neglect, rejection or pampering (Henderson and Thompson, 2011). He highlighted two pathogenic ways of children's upbringing that are

highly important in understanding the common mistakes made by parents of children with and without special needs (Ewen, 2010)

1. Pampering – giving the child excessive attention, protection and assistance. Such pampering or ‘spoiling’ takes away the children’s independence, initiative and self-confidence. Organ inferiority or illness may cause strong feelings of helplessness in the child. However, as discussed above, individuals may overcome and compensate for this unless they are pampered by their parents instead of being encouraged (Ewen, 2010, p. 89, 90).
2. Neglect – The opposite extreme of pampering is neglect, which creates the impression that the world is cold and unsympathetic.

Research studies on sibling relationships in families with a child with special needs (Senner & Fish, 2012; Waite-Jones and Madill, 2008; Packman et al., 2008) indicate that these pathogenic factors in personality development described by Adler occur many times in families with a child with special needs. First of all, many parents tend to focus their attention on the child with a disability, and sometimes, instead of encouraging the child to fulfill his or her potential, they overprotect the child with special needs thus preventing the child from creating a positive sense of self-esteem and self-confidence. Because of the excessive focus on the needs of the child with special needs, parents may unintentionally neglect important aspects in the development of their other children (Moyson and Roeyers, 2012; Waite-Jones and Madill, 2008). As Skotko and Levine (2006) reported, siblings have felt that parents needed to balance their attention between their children with and without a disability and they also need to feel encouraged to fulfill their potential.

Another concept of individual psychology which is significant for families of children with special needs is the significance of ‘*birth order*’. Adler believed that the position of the child in the family might have an impact on the development of the personality of the child. For instance, the eldest child is the center of parental attention and may be shocked when the younger sibling is born. Unless the parents carefully prepare the eldest child to cooperate with the newcomer, and continue to provide sufficient attention after the second child is born, this painful dethronement may well cause an inferiority complex. Second-born children tend to be competitive or even revolutionary and so on (Ewen, 2010, p. 91).

The research findings from previous studies suggest that Adler's idea of the birth order is relevant for families with a child with special needs. For instance, the study conducted by Dyke, Mulroy and Leonard (2009) showed that parents were less likely to report disadvantages for the siblings in families which had several children, as well as in cases of later birth order of the child with special needs. The authors suggest that this may be connected to the fact that the care of the child with a disability can be shared more easily within a larger family. Furthermore, children from large families might not expect much 'one to one' time and attention from their parents, and, therefore, it is easier for them to share their parents' attention and love with their sibling with special needs.

2.3 Attachment Theory: John Bowlby and Mary Ainsworth

Although most psychological theories focused on the importance of understanding of parent-child attachment, John Bowlby's attachment theory (1969) remains the most important theory to explain parent-child attachment processes (Lamb et al., 1999).

Bowlby (1969, p. 316) argued that there are two variables which have proved to be significantly related to development of attachment behavior: first of all, it is the sensitivity of the mother in responding to her baby's signals, and, secondly, the amount and nature of interaction between mother and baby. Quality, rather than amount of interaction, is important, as children can be attached to both parents, whereas they spend much less time with one of them.

Sibling as a principal attachment-figure: Bowlby and Ainsworth believed that siblings might also be the principal attachment-figure for the child. They stated that it was evident that whom a child selected as his or her principal attachment-figure, and how many other figures to whom he becomes attached, turn in large part on who cares for him and on the composition of the household in which he is living. As Ainsworth (1967 cited in Bowlby, 1969, p. 307) found many times father and older siblings were the subsidiary attachment figures for infants.

2.4 Systemic Theory: Salvador Minuchin

Psychiatrist Salvador Minuchin (1979) takes into consideration the ‘systems’ in which a child and a person lives and interacts. The structural family approach defines a family not as a collection of individuals, but as a system, an organized whole whose parts function in a way that transcend individual characteristics (Minuchin, Nichols, Lee, 2007, p. 1).

Minuchin (1979) used the concept of ‘*the child- in-context*’. This approach assumes an epistemology that conceptualizes a harmonious integration of the child’s inner and outer context. On the one hand, the child influences his/her context, as significant people will interact with the child according to his/her responses and behavior. On the other hand, the behavior of the child was stimulated by the social context and significant people (Minuchin and Fishman, 1979, p. 78).

Minuchin pays attention to the following three sub-systems:

The spouse subsystem: Even if this subsystem does not include children, it is the basic and crucial factor for children’s development because it is the first model of intimate relationships for the child (Montgomery, 1979, p. 1314).

The parent-child subsystem: Due to this subsystem, children learn how to communicate with people who have more power than they do and create a level of expectations from people who have more resources and are stronger than they are.

The sibling subsystem: Minuchin believes that the psychological theories were often focused more on parent-child relationships rather than on sibling relationships, whereas this subsystem is highly significant for the child’s development. Siblings form a child’s first peer group. Siblings generally take different positions in the constant give and take. The process continues, and these patterns become highly significant when children move to the extra-familial peer groups, such as the classroom system and later in the world of work. In large families, the siblings organize themselves in a variety of subsystems according to developmental stages (Minuchin and Fishman, 1981, p. 19).

Thus, the discussion of the findings of this study will be based on the three theories discussed above, which all emphasize the significance of parent-child and sibling relationships in the development of the personality.

2.5 Siblings of Children with Special Needs: Relevant Research Findings

2.5.1 Parental and Sibling Views about Sibling Relationships in Families with Children with Special Needs

Little attention was given to sibling relationships in families with a child with special needs until the early 1980s as most of the research was focused on parents, and particularly on mothers (Dyke, Mulroy, and Leonard, 2009, Barr et al., 2008; Stoneman, 2005) and siblings were often overlooked in pediatric family-centered services, in which parents were typically the focus (Senner & Fish, 2012). As Strohm (2002) states, many researchers explored parents, their relationships between each other and with the child, their emotional field, financial situation, and many times siblings were the ones who were forgotten. Kutner (2007) agrees that, only recently, have health-care and child development professionals looked closely at what it is like to be the sibling of a child who has an emotional, mental, or physical disability.

Early studies on siblings' views and experiences usually were based on either parental or professional perspectives, without counting the siblings' own views and often presented a depressive picture of the relationships (Stalker and Connors, 2004) and clinical services were developed based on parents' reports (Guite, Lobato, Kao, & Plante, 2004). However, studies which have parents as the primary source of information have generally been more negative than studies which use siblings as informants (Senner & Fish, 2012).

Senner and Fish (2012) claim that, when considering siblings' needs, it is important to have reports not only from parents, but also from siblings. The authors used the method of 'Sibling Need and Involvement Profile' designed for siblings of individuals with developmental disabilities for their research study. A comparison of children's self-report scores to the scores of their parents exhibited low correlations, proving that parents and the

siblings do not always have the same view about sibling's relationships with a brother or sister with a disability.

Guite, Lobato, Kao, & Plante (2004) conducted a study which compared sibling and parental reports of sibling adjustment to chronic illness or developmental disability. The findings of the study exhibit the fact that, sometimes, the perspectives of the siblings and parents may be different and parents can report more negative adjustment problems for siblings, than siblings do for themselves.

2.5.2 Feelings, Emotions and Experiences of Siblings of Children with Special Needs

The review of the literature revealed six central themes which were present in the majority of research articles. The following section presents findings of different research studies on *ambivalence of emotions and feelings, bullying, protecting the child with special needs, lack of parental attention, feeling sorry for parents and siblings with special needs and lack of information about the sibling's special needs*. Afterwards, the contrasting findings of different studies are discussed.

1. Ambivalence of emotions and feelings

Waite-Jones and Madill (2008) found out that siblings often have feelings of ambivalence towards their brother or sister who has a disability. For instance, siblings may feel sorry to see that their brother or sister with a disability feels pain, but also think that they are doing it in order to get parental attention. Furthermore, siblings may fight for parental attention, but still be concerned about their brother's or sister's well-being. They may also have negative feelings towards their brother or sister with a disability, but try not to show it to the family and at the same time feel guilty.

Another study conducted earlier by Connors and Stalker (2003) exhibited ambivalence of feelings as well. The authors stated that, on the one hand, siblings might hate their brother or sister with a disability, while, on the other hand, they feel a great deal of love and a desire to protect them.

Packman et al. (2008) conducted a research study on the siblings of children with cancer, which showed that siblings of children with health problems may have feelings

similar to those of siblings of children with disabilities. Their participants included 77 siblings of children with cancer and their parents. They used the projective methods 'Human Figure Drawing' (HFD) and 'Kinetic Family Drawing- revised'. The findings indicated that siblings often became jealous and angry because their brother or sister with cancer received more parental attention, as well as were feeling guilty towards the sibling who was suffering from cancer. Authors found that siblings' drawings often showed emotional distress and need for family support.

Overall, the siblings of children with disabilities may feel anger, guilt, and resentment (Senner & Fish, 2012). They can be angry that they can be punished for misbehavior, which will be forgiven in the case of the sibling with a disability. However, often they cannot express their feelings directly, as they realize or have been told many times that they are healthy whereas their brother or sister with a disability needs extra support. Therefore, having a sibling with a disability can put the natural rivalry between siblings on another level (Kutner, 2007).

2. Bullying

The studies of Benderix and Sivberg (2007) and Stalker and Connors (2004) revealed that siblings of children with disabilities were themselves a target for bullies. Several children reported that they had been taunted about having a sibling with a disability. There were cases, when the bullying did not appear constantly, but was nevertheless very hurtful, with children being told offending or rude words for their brother or sister.

However, many siblings did not tell their parents about the bullying as they did not want to add more worries to them (Stalker and Connors, 2004).

3. Protecting the sibling with special needs

Barr, McLeod and Daniel (2008) discovered that siblings can take the role of protectors for their sibling with a disability against outsiders. Protection may take the form of guarding the child from bullying and undesirable friends. However, as the researchers state, when a sibling takes a parent-like role, there is a risk of '*parentification*', when a child takes reversal role and sacrifices his or her own needs in order to support parents who are overburdened.

Skotko and Levine (2006) who had combined 33 years of experience of conducting workshops for more than 3,380 brothers and sisters of children with Down syndrome believe that, though siblings have both positive and negative feelings, they generally have more positive experiences. Through the context of workshops they found that most of the siblings took on an advocacy role for their brother or sister with a disability at some point in their lives. In the researchers' workshops, brothers and sisters took on caring responsibilities for their siblings, whether they were male or female and whether they were younger or older than the child with Down syndrome. However, siblings highlighted that the responsibility should be limited. The authors concluded that, though every member of the family supports the child with a disability, parents should first ask and not demand from a sibling to be always available for entertaining or babysitting.

4. Lack of parental attention

As Skotko and Levine (2006) found, siblings appreciated each of the accomplishments of their brother or sister with a disability as they understood that it might take the child who has a disability time and effort to accomplish the task which would seem easy for them. They also understood that their parents were happy and proud for each small achievement of their child with a disability. However, siblings felt that parents should balance their attention between their children with and without a disability. The authors highlighted that siblings need to feel encouraged to fulfill their potential too.

Barr, McLeod and Daniel (2008) also revealed that siblings experienced a lack of parental attention, because their parents were concentrated more on the needs of the child with a disability.

5. Feeling sorry for parents and siblings with a disability

Siblings may be upset when they see their brother or sister with a disability feeling pain or being bullied, as well as when seeing their father or mother upset. They try not to cause any additional troubles for their parents, as they think their parents already have too

many problems (Waite-Jones and Madill, 2008; Moyson and Roeyers, 2012; Benderix and Sivberg, 2007).

6. Lack of information

As Scelles, Boutheyre, Dayan and Picon (2012) highlight one of the most important topics for siblings of children with disabilities was the difficulty of speaking about the disability within family or with friends. In cases where they had questions regarding disability they felt both shame and guilt.

Therefore, Waite-Jones and Madill (2008) and Kutner (2007) suggest that parents and professionals need to give siblings satisfactory information about their brother's or sister's disability. This information has to be presented according to children's age and developmental needs. For instance, a preschooler might be told that he cannot catch the disability the way he can catch cold or that he did not cause the sibling's disability. Older school-age children, and especially adolescents, often have to explain their sibling's disability to friends and classmates. They need social skills to answer such questions. Furthermore, adolescents who are dreaming of independence need to know the family's long-term plans including their further expected participation in the sibling's life.

2.5.3 Positive and Negative Experiences

Positive findings

Mophosho, Widdows and Gomez (2010) conducted a pilot study in order to explore 9-18 year old children's interactions with and perceptions of their siblings with special needs. The data was combined from three research tools—interview, observation and kinetic family drawing. With the help of a thematic analysis of the data, they revealed the following themes: acceptance, wishing, helpfulness, responsibility friendship, and resilience (p. 81). The authors found that all participants expressed love for their sibling with special needs and tried to support them to finish the tasks which their siblings could not. Although they wished that their sibling could walk or do other things they could do, they accepted the fact that their sibling had special needs (84, 85). The researchers concluded that siblings should be included

in family intervention as often they are facilitative role models for their brother or sister with a disability (p. 81).

Graff et al. (2012) conducted qualitative descriptive study and interviewed twenty-three adolescent siblings of children with Down syndrome who also had additional health problems. The vast majority of participants (21/23) found that growing up with the child was a positive experience. They reported that they learned to be responsible and to have a higher level of acceptance. Children also reported that having a brother or sister with Down syndrome made them better people, that they sometimes were amazed at how their sibling could overcome all of their health issues and that they needed to learn from them as to how to have all these problems but still be positive.

Dyke, Mulroy and Leonard (2009) classified the effect which children with disabilities may have on their siblings' personality characteristics among positive aspects. This included an increased tolerance and awareness of difference, a caring nature, increased maturity compared to their peers and an appreciation of their own health and abilities.

Siblings' understanding of a disability: Stalker and Connors (2004) conducted a two-year study on siblings' understanding of a disability. 24 children aged from six to nineteen who had siblings with disabilities were interviewed. The authors examined siblings' perceptions of impairment, disability and difference. Two versions of an interview schedule were designed for siblings—a semi-structured one was used with six to ten-year-olds, a looser topic guide for those aged 11–15. The researchers found that although the siblings were aware of their brother' or sister's disability, the majority of them when asked to describe their brother or sister to someone who had never met them, made no mention of impairment and reported the similarities between themselves and their brother or sister with a disability. Younger ones tended to focus on physical appearance, for instance described the color of eyes, hair of their brother or sister. Several children saw their siblings as different, but most of them did not attach any negative value to the impairment and perceived the fact of being different as normal. However, several siblings described their brother or sister as different because their impairment restricted what the children with disabilities could do. For instance, they reported that they were unable to talk to their brother or sister about what was happening in their lives as they might have done if the sibling did not have a cognitive impairment.

As Stoneman (2005) highlights, although having a brother or sister with a disability does not cause pathology or maladaptation in many children, it is also true that a few children seem to be harmed by their experience. The challenge of sibling researchers is to find out more about what distinguishes these children and their families and to learn ways of better supporting them.

Negative findings

Waite-Jones and Madill (2008) interviewed four members of eight families with an adolescent diagnosed with juvenile idiopathic arthritis. Authors used the method of grounded theory in order to analyze the interviews with four members of the family including the sibling. Five themes were produced from the analysis of the siblings' interview transcripts: comparing with a norm, social contagion, emotional contagion, amplified ambivalence, and social and emotional adjustment (p.484). Siblings felt that their families were different as it took them more time to complete the activities than in other families. Siblings also felt that their time was sometimes restricted as they needed to take care of their brother or sister. Therefore they could not spend their free time as their peers.

Siblings may be upset at parents when they are asked to babysit with the sibling, as they have to miss several extracurricular activities. Children feel as if they are not given the right to be just a child (Kutner, 2007).

Dyke, Mulroy and Leonard (2009) state that, according to the reports of parents of children with disabilities, the siblings also experienced a sense of embarrassment and ostracism by their peers, an increased burden and sense of responsibility to support with care of the disabled sibling.

2.6 Summary

This chapter aimed at presenting relevant theories and research for the current study. As mentioned in the introduction, the study has been developed within the theoretical framework of three psychological theories: Adler's (1924) '*Individual Psychology*', '*Attachment Theory*' by Bowlby and Ainsworth (1969) and '*Systemic Family Theory*' by Minuchin (1979). In summary, the literature review has shown that, until the 1980s, most of the research on children with disabilities was focused on parents and children, whereas siblings were often

forgotten (Dyke, Mulroy, and Leonard, 2009, Barr et al., 2008; Stoneman, 2005). Furthermore, the majority of research studies examining siblings of children with disabilities and their relationships were based on parental reports (Senner & Fish, 2012; Guite, Lobato, Kao, & Plante, 2004; Stalker and Connors, 2004). Several studies revealed similar findings about sibling relationships and highlighted several themes, such as ambivalence of feelings and emotions, lack of parental attention, bullying by peers, protecting the child with a disability, lack of information about the siblings' special needs and feeling sorry for a brother or sister with a disability and parents (Barr, McLeod and Daniel, 2008; Waite-Jones and Madill, 2008; Benderix and Sivberg, 2007; Skotko and Levine, 2006; Connors and Stalker, 2003). However, there is still some inconsistency in the research findings about the influence of different kinds of disabilities on the sibling relationships (Pollard et al., 2013; Dyke, Mulroy and Leonard, 2009). Furthermore, there is a need to attain insight into the sibling relationships by not only having parental opinions, but also from the point of view of the siblings, as research showed that often they may have different views about their relationships (Senner & Fish, 2012).

3. Chapter Three

Research Design and Methodology

3.1 Introduction

This chapter presents the research design, approach, methodology and methods of the study, as well as measures performed to enhance validity and reliability of the study. Furthermore, this chapter discusses the sample and sampling process, data collection and analysis procedure, as well as ethical considerations and approval of the study.

3.2 Research Design: Qualitative Research Study

A qualitative research design was chosen in order to obtain an in-depth understanding of each participant's understanding and perception of the relationships. This design gives the researcher an opportunity to get a comprehensive and thorough understanding of the research topic, because it explores the social phenomenon from different perspectives. Furthermore, as the objective of the study is to explore the relationships of children with special needs with their siblings based on their own and their parents' *perception*, this study uses a phenomenological approach.

3.2.1 Phenomenological Approach

This study follows Husserl's (the founder of the phenomenology) concept of the 'life world' which means investigating the way things are actually *lived and experienced in the context* and the situation in which they occur. In other words, when an experience of a phenomenon is investigated, it is done via real life examples in which the phenomenon or experience is not isolated from the full context in which it was experienced (Giorgy, 2006, p. 74, 75). Following a phenomenological approach, this research study aims to go to the life world of families of children with special needs and to collect the raw data which consists of concrete descriptions of lived events by the children with special needs, their siblings and parents living through the experience.

A phenomenological approach denies the possibility of any final or completely 'correct' interpretation, since such would presuppose that we had direct knowledge of an ultimate reality. However, we do not and our interpretations are far from being certain, and remain open to alternatives in meaning. Regardless of how singular or generally shared our interpretations of the world may seem to be, they remain interpretations. Similarly, children with special needs, their siblings and parents, regardless of the fact that they share the same social context (the same family situation) may have different perceptions about sibling relationships in their families. However, it does not assume that one can judge their perceptions or interpretations as right or wrong, as there is no 'correct' answer how siblings relationships should be. What most of us accept is that a 'correct' interpretation is not based upon external, objective laws or 'truths' that have been universally ascertained. Rather, our judgment is influenced, to a great degree, by consensus view points agreed upon by a group of individuals or by a whole culture (Spinelly, 2005, p. 8). Sibling relationships and responsibilities towards each other may differ from culture to culture, which means that what is supposed to be considered ideal sibling relationships in one family, can be perceived as far from being perfect in another. Stoneman (2005, p. 339), who examined the existing research on sibling relationships until 2005, has questioned whether there is an ideal 'goal standard' to which researchers should compare sibling relationships in families with a child with a disability? He found that, at its most basic level, ideal sibling relationships involving a child with a disability frequently had been conceptualized by the researchers as relationships that did not harm the typically developing sibling. If researchers put the standard of sibling relationships as '*warm, supportive and without conflicts*', which has been another way of conceptualizing sibling relationships, they can actually form a different picture, as it is hard to find sibling relationships without conflicts or difficulties also in the families without a child with special needs, without any economic difficulties and so on. Not surprisingly, it would be hard to meet in the reality these ideal sibling relationships and often the failure to have ideal sibling relationships has been blamed on the child with a disability (Stoneman, 2005).

Thus, this study, in following the phenomenological approach, accepts that each of us can be described as *a being-in-the-world* and each of us *experiences being-in-the-world in a unique way* (Spinelly, 2005).

3.3. Research Methodology

3.3.1. Embedded Single-Case study

Case study design was chosen based on several significant criteria. First, as Yin (2009, p. 4) states, the more the research questions require an in-depth understanding of some social phenomenon and explanation of some present circumstance, the more the case study method will be relevant. Secondly, the case study investigates a contemporary phenomenon in depth and within its real-context, especially when the boundaries between phenomenon and context are not clearly evident (Yin, 2009, Robson, 2011).

The second criterion is highly significant for the current study, since the social phenomenon of the study (sibling relationships) inevitably is mirrored through the context (family, society) and, moreover, highly influenced by the context. As parents play an important role in developing the personalities of their children and the relationships between them (based on their own perceptions and desire how sibling relationships should be), sibling relationships between children with and without special needs may be different in each family.

The major unit of analysis for the current case study is the *relationships between children with special needs and their siblings*. It is an embedded case study as, besides having a main unit of analysis (the relationships between siblings), it also has three subunits of analysis concerning: *children with special needs, their siblings and parents*. As Yin (2009) highlights, the subunits of analysis can often give more comprehensive opportunities for extensive analysis. This study used subunits of analysis to enable comprehensive exploration of the studied phenomenon and to understand the major unit of analysis from insiders' (siblings) and outsiders' (parents) view.

This study used three methods of data collection: in-depth, phenomenological interviews with parents, kinetic family drawing projective test with children.

3.3.2. Phenomenological Interviews with Parents

The purpose of this study is not to test hypotheses, and not to evaluate the ideas of the research participants. Instead, it tries to understand *lived experiences* of the participants and to focus on the meanings the participants make of their experiences (Seidman, 2013).

Therefore, in-depth, phenomenological interviewing was conducted with parents of children with special needs and open-ended questions were used with the purpose to help participants to reconstruct their real life experience within the topic of the present study (see Appendix 6).

Within the phenomenological approach, the interviewer must be an approachable human being since more and better data is likely to be provided in a situation where there is a sense of connection and rapport with another person. The more psychologically sensitive the topic of the research is, the more difficult it is for the participant to talk about, and the more important the relationships between the participant and the interviewer become (Giorgy, B., 2006, p. 76).

3.3.3 Kinetic Family Drawing projective method (K-F-D) with children

This study used a K-F-D projective method with children in order to identify how children perceive and interpret the relationships between family members, how they understand their role in the family, and what kind of difficulties they may experience in a family or with certain members of it.

Burns and Kaufman (1971), the originators of the method, believe that young children usually express themselves more naturally and spontaneously through actions rather than through words. Furthermore, kinetic (action) drawings have been found to be more informative than drawings obtained by the traditional akinetic instructions. According to the authors, akinetic tests and instructions, such as ‘Draw-A- Person’ or ‘Draw- A-Family’ yield relatively inert figures. On the contrary, the addition of movement to the akinetic drawings in the K-F-D helps to understand child’s feelings not only as related to the self-concept, but also in interpersonal relationships.

The instructions of K-F-D are very simple, yet they give children an opportunity to depict family interactions in a dynamic way giving an insight into everyday relationships and communication between family members (Vertue, 2007).

The drawings are obtained from children individually, not in a group session. The child is asked the following '*Draw a picture of everyone in your family, including you, doing something. Try to draw whole people, not cartoons or stick people. Remember, make everyone doing something – some kind of action*'. The situation is terminated when the child indicates either verbally or by gesture that he/she has finished (Burns and Kaufman, 1971). The examiner may then ask the child questions about the drawing, such as what is happening and who is in the picture. In the current study the Kinetic Family Drawing will give an opportunity to the children with disabilities and their siblings when drawing a picture on a blank page, project their thoughts, concerns, conflicts and needs in an unconscious level which will remove the barrier of acting in a socially desirable way.

Studies using the K-F-D method for identifying sibling relationships in families with a child with special needs revealed that, many times, siblings of children with disabilities feel excluded from the family and mother's love (siblings encapsulated themselves in a box, chimney, and so on, whereas the child with a disability was usually drawn close to the mother). On the contrary, children with disabilities draw themselves with their mother, while isolating other family members (Stein, 2001, Siegel and Kornfeld, 1980).

3.3.4 Participant Observation

Participant observation was used to cover a mixture of observation, interviewing and the K-F-D method. Being a participant observer gave me an opportunity not only to share the life experiences of the parents and the children, but also to have a unique opportunity to observe parent-child and sibling interactions in everyday natural situation for the family members (Delamont, 2004).

3.4 Validity and Reliability

It is widely accepted that validity in phenomenological social science may be complicated by subjectivity (Mabry, 2008). Subjectivity refers not only to the interpretation

and analysis, but also to the fact that social phenomena are perceived differently not only by different researchers but also by different participants. However, as this study is phenomenological, it is significant that it reflects as much as possible the views and perceptions of the participants, and not the researcher's subjective interpretation. As I had been working with families of children with special needs previously, it was important not to give a sense of bias to the data collection and analysis processes with my previous experience, and not to have certain expectations concerning the results. As Seidman (2013, p. 17) states, the goal of the researchers using a phenomenological approach to interviewing would be to come as close as possible to understanding the true 'is' of the participants' experience from their subjective point of view (Seidman, 2013, p. 17).

To enhance validity in this study, two methods were used: **data and methodological triangulation**. Methodological triangulation is proved to be one of the most commonly used ways for establishing validity in a case study.

Data triangulation

During the data collection procedure, triangulation by data source involves collecting data from different persons in different ways (interviews with parents and K-F-D with children with special needs and their siblings). Comparing how much and in which way each participant confirms, elaborates and rejects information from other sources helps to ensure the completeness of the data (Mabry, 2008, King and Horrocks, 2010).

In the current research, I used the data triangulation technique involving both parents and siblings; therefore this study had different persons' reflections and interpretation on the same topic. As the previous research showed that parental views on sibling relationships may be different from siblings' opinions (Senner and Fish, 2012; Guite, Lobato, Kao and Plante, 2004), data triangulation appeared to be a significant aspect for enhancing validity.

Methodological triangulation

Another way of enhancing validity in case study is methodological triangulation, which involves using multiple methods to explore the social phenomenon (Guion, 2002). This study used triangulation of semi-structured interviews, the K-F-D projective method and participant observation

Generalisation/ Transferability: This study does not follow the purpose of generalizing the data, as it is evident from its design and methodology, but rather tries to receive thorough and in-depth understanding of the phenomena. King and Horrocks (2010, p. 160) suggest that qualitative research studies need to follow the principle of transferability in place of generalizability. Transferability is based on the ability of the researcher to provide sufficient rich details so that a reader can assess the extent to which the conclusions drawn in one setting can transfer to another. Or as Yin (2009, p. 15) asserts, the purpose of the case study is to expand and generalize theories (analytic generalization) and not to enumerate frequencies (statistical generalization). Following Yin's idea, this study aims to contribute to the previous findings and theories on sibling relationships in families with a child with special needs. Yin believes that theory development is an essential design phase in case study and using the theory in single case studies helps to establish the external validity, whereas using multiple sources of evidence enhances the construct validity.

Reliability: Reliability in qualitative research is complicated by the fact that the researcher's subjectivity shapes the research process. Therefore, one cannot be sure that the findings produced by one researcher will simply be replicated by a second researcher following the same methodology as the first (King and Horrocks, 2010). Maxwell (1992, p. 288) asserts that reliability refers not to an aspect of validity or to a separate issue from validity, but to a particular type of threat to validity. If different observers or methods produce descriptively different data of the same events or situations, the *descriptive validity* (and other types of validity as well) of the data is under question. He suggests a solution to the problem either with the help of data modification, so that different observers come to agree on their descriptive accuracy or by ascertaining that the differences were due to differences in the perspective and purposes of the observers and were both descriptively valid. Furthermore, Maxwell (1992, p. 281) believed that *understanding* is more fundamental concept for qualitative research than validity and discussed the following categories of understanding that are relevant to this case study.

Descriptive Validity: This research study used a high quality tape-recorder, which allowed determination as to whether the informant made a particular statement during the interview or not.

Interpretative Validity: To ensure interpretative validity, this study relies as much as possible on the words and concepts of the participants.

3.5 Sampling Procedure

Purposeful Sampling

This case study sought to find the participants based on the purposeful sampling. As Maxwell (1992) states, the issue of sampling plays a different role in qualitative research than it does in quantitative and experimental research, because qualitative studies are usually not designed to allow systematic generalizations to some wider population. Hence, this study also tried to identify the sample for its representativeness and informativeness.

Initially, the study aimed to involve two or three families which have both a child with cerebral palsy and a child without special needs. Several schools, as well as an organization working with persons with cerebral palsy were given information about the study and asked to mediate in gaining access to the sample. However, no reply was received from them throughout several months, which, because of the time pressure connected with the deadline of the master thesis, lead me to make the criteria of the sample more flexible. Thus, instead of trying to find families of children with cerebral palsy, the criteria of the sample included families which have a child with any kind of special needs and a child without special needs. Again several schools, a nursery and a rehabilitation organization were contacted, and, ultimately, access to the sample was received through a school leader of one of the inclusive schools in Oslo. The mother of the family was given information sheet from the school leader and expressed her willingness to participate in this study. She contacted me and we decided on a day when I could go to their house.

The family in this case study consists of 6 members: the mother, the father and their four children (11 year old girl with Down syndrome and her three siblings 10 and 7 year old brothers and 5 year old sister). The father of the family was Norwegian and the mother was from an English-speaking country. Both the parents and the children could speak English. Due to the fact that this family was large and all 6 members participated in the study thus providing rich data about their experiences, there was no more need to involve the second family because of limited space and opportunities to present the data even from one family.

3.6 Ethical Considerations

Due to the fact that qualitative research mostly intends to know the perceptions, feelings and beliefs of people, and the researcher establishes a rapport with participants, it demands a highly careful and responsible approach from the researcher (Hennink, 2011).

Both parents and children were informed that they could withdraw from the research at any time or not answer a question if they did not want to discuss that particular one. Furthermore, since the study covers sensitive topic all the means were kept in order to protect the identities of research participants, and ethical principles of confidentiality, privacy and anonymity of the research were followed (De Vaus, 2002). Any identifying information (including the children's names on the drawings) was replaced with other names.

As the study involves children, parents were given all the information about the method of K-F-D and, apart from signing informed consent form (see Appendix 7), they also signed a parental consent form for their children (see Appendix 8). However, parents were not given the drawings afterwards as children were assured that the ethical norms of anonymity and confidentiality would be kept, and no one except them and the researcher would know which drawing belonged to them. Furthermore, apart from parental consent as to their children participating, the children were also given an assent form and signed it (see Appendix 9). The assent form explained in simple terms what the study was about and children were asked if they were willing to participate.

Importantly, the following ethical principles for the research with children were also followed (Clark, 2013)

1. Ethics of engagement: The children were happy to take part in the drawing test and in the study.
2. Ethics of place: It is worth highlighting that it was very important that the research was carried in the family's home, for the natural atmosphere for the children (in the playing room of the house). That was one of the main reasons that they got involved in the research with easiness.
3. Ethics of representation: All the names of the children were replaced by other names.

The ethical approval was attained through the Data Protection Official for Research at the Norwegian Social Science Data Services (NSD) with interview guide, informed consent forms and description of the K-F-D test (see Appendix 1).

3.7 Data Analysis Procedure

3.7.1 Phenomenological Analysis

Van Manen (2007) stated that a phenomenological text is ultimately successful only to the extent that its readers feel addressed by it - in the totality or unity of their being. The text must reverberate with their ordinary experience of life as well as with their sense of life's meaning.

The study followed a descriptive phenomenological psychological research method founded by Amadeo Giorgi which was based on Husserl's philosophical method (Giorgi, 2006, p.68). Thus, the analysis of this study was based on the following four steps:

1. **Reading for a sense of the whole:** The entire description has to be read because the phenomenological perspective is a holistic one. One cannot begin with an analysis of description without first having understood the whole situation. I tried to 'get into the story' and to know the overall sense of the description before continuing on to the next step (Giorgi, p. 71).
2. **Dividing the description into parts:** This means establishing meaning units. Since clarifying the psychological meaning of experience is the goal of the analysis, the data is divided into parts based on psychological criterion and resulting parts are therefore called 'meaning units' (pp.71-72).
3. **Transforming the data:** The third step involved transforming the concrete expressions in each meaning unit into the psychological meaning of those expressions. Specifically, this meant taking what was described both explicitly and implicitly and asking, from a psychological perspective 'what does this mean'? The data gives a *lived account of an experience* rather than an analysis of the experience and my purpose was to identify the psychological meaning exemplified by this particular account.

4. **Synthesizing the transformed meaning units:** In the fourth step, I tried to see what is really essential about these transformed meaning units and connected meanings belonging to the participants' experience (p. 73).

3.7.2 KFD Analysis

The analysis of the KFD projective method focuses on the action or movement rather than the inert figures. The addition of movement mobilizes the children's feelings about himself and about his place in the family, thus exposing the quality and extent of interpersonal relationships in the family (Brunner, 2010).

This study used an interpretative manual for the K-F-D analysis published by the founders of the K-F-D method (Burns and Kaufman, 1972), which in its turn was structured in a developmental and partially Freudian framework.

The analysis of KFD was based on psychoanalytical interpretation. Certain characteristics of the drawing were noted upon analysis, such as the placement of family members; the absence of any members; whether the figures were relatively consistent with reality or altered by the child; the absence of particular body parts; erasures and so on. The analysis is based on the general four categories: 1. actions; 2. distances, barriers, and positions; 3. physical characteristics of the figures; and 4. styles (Vertue, 2007).

4. Chapter Four

Data Analysis and Discussion

4.1. Introduction

This chapter provides the presentation of the research data with the subsequent analysis and discussion. Since the study is based on a phenomenological approach, the research data is presented in the form of quotations illustrating the participants 'lived experiences'. The interpretation of the children's K-F-Ds is based on the interpretation manual (See Appendix 2, 3, 4 and 5) provided by the originators of the method Burns and Kaufman (1972) and on the traditional psychoanalytic symbols (Weiner and Greene, 2008; Hammer, 1975). Importantly, the analysis of the K-F-D takes into account each child's own description of the drawing, as well as the information attained during participant observation and interviews with the parents. Multiple research methodology was used in order to have the voices of both parents and their four children on sibling relationships with the child with Down syndrome. Participant observation gave me an opportunity to include my own voice while analyzing the KFDs of the children.

As diagram 1 illustrates, since the purpose of the study is to identify 'the relationships between siblings in a family with a child with Down syndrome', *each sibling's 'lived experience'* is presented individually and is based 1) on the analysis of each child's K-F-D, which combines the description of the K-F-D by the child and the subsequent analysis based on the interpretation manual, 2) parental interviews and 3) information attained during the participant observation. The main themes discussed in each child's case are the *support* provided from one sibling to another, the *conflicts* between the siblings, and their *relationships with their parents*. However, there are also specific themes for each sibling's case, such as 'being the oldest brother in the family', 'not being invited to birthday parties of classmates' and so on. Finally, the discussion of the findings will be provided in relation to the theoretical framework of the study.

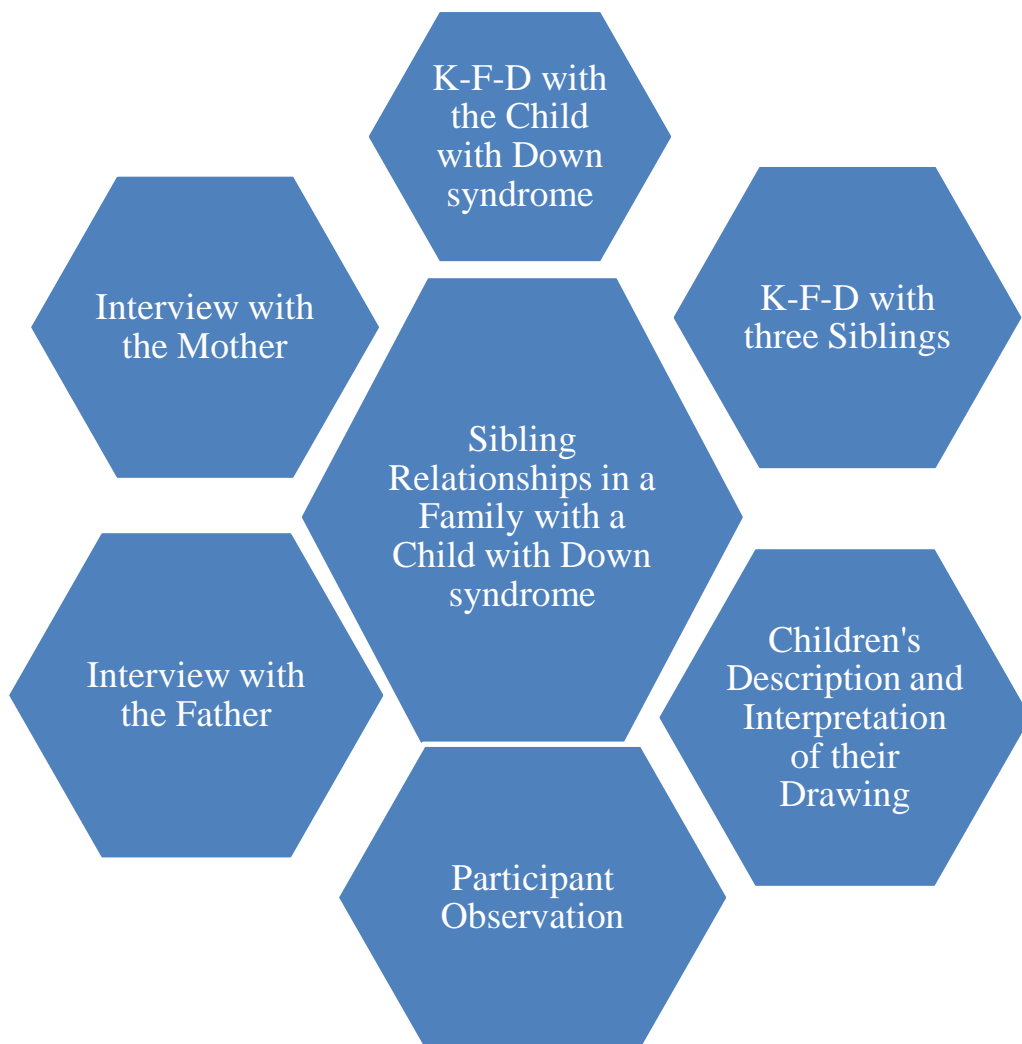


Diagram 1

4.2 Sibling relationships in a family with a child with Down syndrome: Case description

The Bernsen family is quite large consisting of six members: parents and their four children. The oldest child Ingrid is 11 years old and was born with Down syndrome. After 16 months of Ingrid's birth, Lukas (10 years old) was born. The younger children Henrik and Monica are 7 and 5 years old respectively.

4.3 Participant observation in the family's house

Apart from conducting interviews with parents and drawing test with the children, I had an opportunity to be a participant observer at the family's everyday life. I spent five hours in the family's home playing with the children and eating dinner with the family.

There are five major aspects that were present in the participant observation.

1. Warm and Loving Atmosphere

Throughout these hours, I sensed a warm and loving atmosphere. The openness and trust of both parents and children were highly significant aspects supporting the genuineness of the research data.

2. The emphasis on the play

The second aspect which I noticed was the emphasis on the important role of playing in the family's life. The basement was replaced with a big playroom with free space for children's games. Similar to many families which have both girls and boys, the family differentiated between girls' and boys' activities. For instance '*girl stuff*' and '*boy stuff*' were separated by boxes. This aspect of differentiation between girls and boys also became evident in the interviews of parents and kinetic family drawings of the children.

3. Spouse sub-system

Thirdly, I observed a highly respectful relationship between the husband and wife. It was evident that they were used to talking together and discussing the issues concerning their children's education and upbringing, and were able to follow the same rules and be consistent with their decisions. This aspect was evident also from their interviews, as even though I had individual interviews with them they gave similar answers to many question in relation to their children.

Since I had phenomenological interviews with parents, during the interview process and the whole day which was spent in their house, I shared findings from previous studies and particularly the findings highlighting the importance of providing siblings with information about special needs of their brothers and sisters. Before I would leave the family's house, the parents asked me to go to a separate room and share with them my knowledge about sibling relationships in families with a child with special needs. It was obvious that they started to think about providing information to the siblings after the interview. They told me that they

had not thought much about this before and would try to find a book explaining how to give the information.

4. Social approachability of the children

The children were socially approachable. They got involved in the conversation with me without any difficulty, and quite quickly were ready to play with me and to show affection. After finishing the drawing test and the interview with the father, the family invited me to have dinner with them before the interview with the mother started. I gave several drawing materials to the children in order to thank them for their participation (such as crayons, drawing paper, craft supplies and so on). The children accepted the drawing materials with great happiness and many hugs. I tried to choose drawing materials that would be relevant for their ages (5, 7, 10, and 11). The children had no conflicts or difficulties in dividing the materials between each other, and were very happy to share their work with me or their parents. One of the children (Lukas, 10 years old) even decided to give the result of his work to me as a present.

5. My 'inclusion' in the family

I felt included by the family. During the dinner the parents were telling me about their recent trip and I also had an opportunity to present myself. Ingrid was totally independent in eating, similar to the other siblings. After dinner again I had a chance to play with the children. We were working with the drawing materials. As I knew before that Ingrid was taking dance classes, I asked her to show me several dances after we did the drawing test. This she remembered and we went to the playroom after the dinner to dance. She has a dance video program, where one needed to repeat the movements which appear on the screen. A sensor equipment shows how exactly or active that person performs the movement. Ingrid was following the dance videos with great enjoyment.

After a while, the parents and two other siblings, Henrik (7 years old) and Monica (5 years old), joined and the siblings started to dance with Ingrid by repeating the movements appearing screen. It was a little difficult for the parents to stop the dancing process, so that I could have an interview with the mother, as the children still wanted to dance.

As I will discuss later in the interview and K-F-D analysis sections, Bernsen's family is a very happy and caring family. Play is the dominant topic in the family both for parents

and children. The atmosphere in their house, the pictures around, the happy faces and open hearts of the children demonstrated close and caring relationships between family members. Despite of all these aspects, the family still needs to overcome certain difficulties and stereotypes in the society.

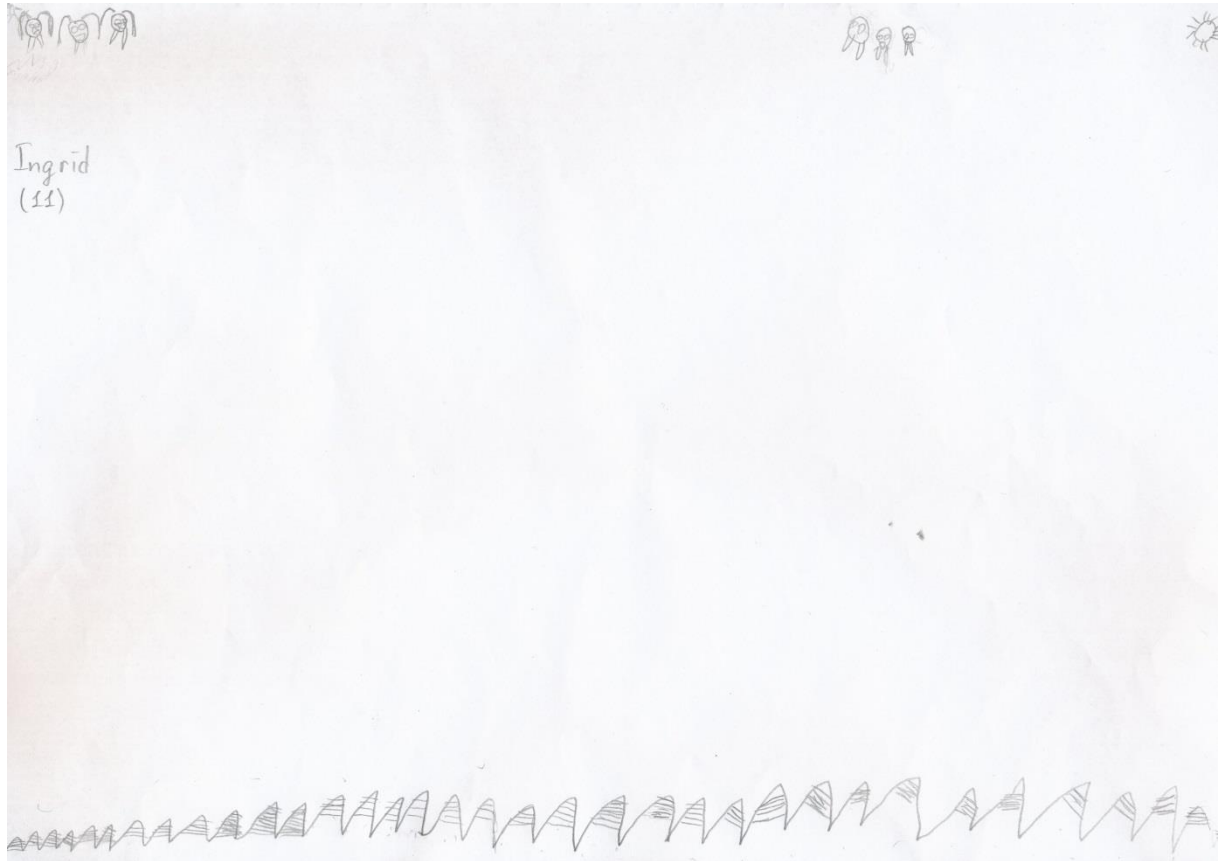
4.4 K-F-D and Interview Analysis

The following sections will illustrate Ingrid's and her siblings 'lived experiences' based on the K-F-D analysis, children's description of their drawing and parental interviews. As the children are at different stages of their development, and therefore have different 'experiences' of the relationships with Ingrid, each child's case will be presented individually.

First of all, Ingrid's 'lived experience' is provided. Ingrid is an eleven year old girl with Down syndrome.

4.4.1 Ingrid's 'lived experience'

1. Ingrid's picture of her family



- 2. Description of the K-F-D by Ingrid:** Ingrid described her picture and presented her family members in the following alternation ‘*Mum, Monica, Ingrid, Papa, Henrik, Lukas*’. Afterwards, she also drew my attention to the Sun.

When describing her drawing, Ingrid also showed the grass outside their window and it seems that for her, the family was associated with their house and their life in it.

3. The analysis of Ingrid’s K-F-D

Style: Ingrid drew a picture of her family ‘divided’ into ‘girl’ and ‘boy’ subgroups. As discussed above, in her family, the identification with the same-sex parent and gender expectable activities was common among the children, and we will see later in the thesis that this aspect was also evident in the drawings of other children.

Symbol (s): Two symbols used by Ingrid are *the sun* and *the grass*.

Sun: In Ingrid's drawing, we can see the Sun in the two upper corners of the paper, although it is bigger and more evident in the upper right corner. It seems that she tried to draw a cloud but erased it (in the left corner). Many well-adjusted children can illuminate the drawing of the human figures by adding the shining sun, typically in the upper corner of the sheet. It is unusual for children to add heavy clouds or sun shade which can mirror unhappiness. However, Ingrid erased the cloud. Erasures are considered as an expression of anxiety and frustration, and in Ingrid's case it can be explained with the fact that, as her mother told me, Ingrid is upset because her friend, who she is used to play with, is going to leave soon.

Grass: As it is obvious in the drawing, the grass covers the entire bottom of the page, but varies in size. The grass in this drawing can indicate perseverance, as Ingrid could not stop the drawing process until she has finished the line of the grass.

Location of Self: Ingrid identified herself with the female representatives of her family and drew herself near her younger sister Monica. It could be explained that she drew the younger siblings nearer the parents as they need more help. Monica is next to her mother and Henrik is drawn next to his father, whereas she and Lukas are next to their little sister and brother respectively. The hair of all girls is alike. They all have long pigtails while the boys and the father are represented without hair.

Thus, Ingrid's K-F-D revealed her identification with the female representatives of the family. The way of drawing the grass may indicate perseverance which can also lead or be connected with the stubbornness attributed to Ingrid by her parents. The sun illustrates the overall warm atmosphere in the family.

4. Ingrid's relationships with her siblings from parental perspectives: Interview Analysis

Warm relationships with the siblings

Both parents believed that Ingrid has warm relationships with her siblings and that they like to play with each other. They both highlighted that especially Ingrid and Monica play a lot together and as girls both like to play with the dolls.

As the father described:

'It's a very nice relationship; siblings think about her just like a regular sibling. They do of course recognize that she has special needs and considerations. They take care of each other just like normal siblings and we treat them the same or try to.'

The father also added that when they had friends Ingrid was integrated into the play most of the time. Sometimes she, however, wanted time alone and liked to watch TV or work on a computer.

Siblings' understanding and perception of Ingrid's special needs

The parents acknowledged that although they have never talked with the siblings about Ingrid's special needs, they are all aware of it. The mother said:

'They all know that Ingrid is special. She is working on lower Math, she was the last one to learn how to ride a bike. She just learned in May that was really great. On our trip we were able to rent six bicycles and we rode them down to the beach. She just learned in May and we did that in July. It was huge, because she watched everybody learn how to bicycle before herself and she finally got it, and she is so proud.'

The father adds: *'I think the siblings are more considerate for her needs. We don't talk that much about her being special, so for them she is just another sibling, but they see that she is different and act differently'*.

Both parents said that they have never heard the children being embarrassed about Ingrid. The following statements further illuminate this topic. The father said:

'I have never ever heard them saying anything negative about her having special needs. Of course, they sometimes feel jealous, they are just sibling for other reasons, but nothing abnormal I think, it's good relationships between the siblings and they do play a lot together'. I never hear them saying 'Oh, I don't like when Ingrid comes over in school. Ingrid loves to see them at school, but she does not really... when she is in school I think she is occupied with other things than her siblings. So that's good too, that they have their own things in school.'

The mother had a similar opinion. She explained:

'I cannot think of one time that they were embarrassed really by her. I don't know how they act at school.'

'Imaginary Mums and Dads'

According to the mother, Ingrid has an imaginary Mum and Dad. This aspect seems from time to time to upset the parents or the siblings. The mother explains:

'Last night I was upset with Ingrid. She gets into a make believe world, a lot of times she says she has two dads, before she had two mums. I was driving in the car and she has this make

believe telephone and she likes to talk on it, and she talks about stuff that her peer-age talk about. So she says 'Monica, do you have a PC? And then she will say 'I don't have a PC, or mine is destroyed', whatever. She just gets into these make believe things, and she was talking about... I said 'Ingrid, I don't want to believe any more, I have got a headache, it's loud in the car, and it was just too much, it was a long day. And I said put the telephone away, and she wouldn't. So Monica took over that role and said 'you don't have two dads'. She supported me; Monica did, and teaching her [Ingrid] that she needs to behave, follow rules'.

Ingrid's stubbornness and ability to protect herself

One of the characteristics which the mother described with Ingrid was her stubbornness. She said:

'Henrik and Ingrid are very strong willed, they are the ones who are going to timeout the most, especially when they were younger. They have longer consequences, because they don't learn from small consequences. Like we may take the computer away from Ingrid for three days, so that it actually sits, she does not learn it from half an hour or even an hour a day. Henrik is exactly the same way'.

However, having a strong will is also good for Ingrid and other children with special needs as it gives them an opportunity to protect themselves. The mother recalls a situation when someone in the neighborhood teased Ingrid, she was able to protect herself and Lukas did not even need to get involved.

'I remember a situation just here in neighborhood a little bit ago where one of the little girls said that, I hope I don't repeat it wrongly, but she said 'Oh, Ingrid is here too' and Ingrid understood that comment, and they were teasing her a little bit and she stood up for herself. And then they came back to the house and Lukas told me about the story, and he said 'wow she is really tough', [laughing]. Ingrid was not going to take those comments, I cannot really tell you what it was, Lukas would be able to tell you, but it was negative. So, she understands that there is a distance. The distance was growing from about the third grade for Ingrid. So there have been times when she was sad, definitely'.

Despite Ingrid's apparent *stubbornness* and *toughness* it is obvious that she feels unhappy when excluded. Her awareness of being different indicates an ability of self-reflection.

Ingrid's experience of social exclusion by the classmates' families

Both the mother and the father highlighted the fact that Ingrid was not being invited to her classmates' birthdays. However, the parents still continued to invite her classmates to their house and they noted that Ingrid's classmates like to come to their house.

The mother recalls:

'She had her first and last play date, when she went home with somebody after school in first grade, the third grade is the last time she got invited to a birthday party, and she is in sixth grade now. But, I continue to invite kids to her birthday parties, and I continue to invite kids home because it means a lot to her. And, in fact, we know these kids so well now that they ask to come to our house'.

Similar to the mother, the father of the family also spoke about the fact that Ingrid is not being invited to her classmates' houses. When he was asked where the siblings mostly spend time together, he answered:

'Most of the time here at home. She has not been invited to birthdays for three years. But she has friends over, so we invite them to our house, and then they do make cookies together, and play, I guess like normal. And her classmates like to come over here, they even ask to come over here, but they don't invite back, so...'

Parents have their own explanations in relation to this situation. Although, it is hard for them to realize the fact that their child is not being invited to her classmates' houses, they do not blame other parents and approach the situation with understanding. The mother believes that one of the reasons can be that *'Norway is an expensive country and frequently two parents need to work'*. She stipulates that, because she is at home, she has more time for organizing the play dates. Another reason mentioned by the mother was that *'maybe not everybody knows how to interact with Ingrid'*. However, despite all this understanding, it was still obvious that she still feels pain because of her daughter's being excluded from birthdays. She continues with the following example:

'I can't put my finger on, why she hasn't been invited. She is pretty high functioning, she can carry on a conversation, to me she is not that much different. She is so social, and she is high functioning. I think it would have been different if we had a lower functioning child, but she really creates that personal... you can see that tonight.... Now if I give a play date to Noah, she is the first one asking whether she can have a friend over tomorrow'.

Another difficulty for the mother is that she is a foreigner in Norway. She explains:

'I am not sure, what it would be like in my country, it might be the same. Sometimes, it's hard because I am a foreigner, so I am not sure how things work, but I don't know if it's specific to Norway or not...'

The mother was also very objective towards Ingrid. She understands that although sometimes the other children are not behaving nicely towards her daughter, Ingrid herself can sometimes be not polite. The mother describes:

'Ingrid, can be unreasonable [laughing], she can do things that are not so nice too. For example, there are two girls over there [in the neighborhood], and she always invites the one.'

And the other one is just two years older. I always say 'what about the other girl, Ingrid, that's not nice just to say to the one 'come with me', but the other girl is standing right there and you wouldn't like that either. So she has to learn from her own..., she might get the same kind of behavior from somebody else, but she is also guilty of doing the same thing. But the other girl is her favorite [laughing]'

Thus, we can assume, that, even though the school itself can be inclusive (from the learning perspectives), outside the school the classmates or their families still might be not ready to involve the child with special needs and in this way it might create social exclusion.

Ingrid's inclusion through her relationships with her siblings, play dates organized in her house, neighborhood friends and dance classes

Although Ingrid is no longer invited to birthdays and play dates, she managed to create a nice friendship with neighborhood children, and particularly one of them. At first sight, it may seem that maybe inclusion was not implemented fully in the classroom, but achieved in the neighborhood. However, the following description by the mother makes it clear, that unfortunately the children in the neighborhood are also excluded (either because of their religion or some other reason). The mother explains:

'She has a wonderful friend; this happened in the fourth grade. There is a family across the street; they don't go to birthday parties. I don't know if it's only their family or all people who follow their religion. I am not sure; they don't really have any play dates, so they come to our house even at play dates, because Ingrid wants them to come. Ingrid and this other girl have really become good buddies, especially really tight in the fourth grade, and most of the fifth grade. Now it's kind of disappearing, they are going to be moving out in December and Ingrid is really sad about that. But I never expected that to happen, that was a gift, cause it meant so much to Ingrid and to us, and they are here a lot, that was that little boy that rang four times [laughing]. They are almost seven siblings playing together, our four and their three, they just went over ...'

The mother's positive evaluation of this neighborhood interaction is evident. It was apparent that not only Ingrid, but also her three siblings are involved in the communication with the neighborhood children.

Siblings' support to Ingrid

Both parents pointed out that the siblings' support to Ingrid happens in everyday events and activities. The father remarks:

'When Ingrid comes home and we sit at the dinner table, if Ingrid does not remember everything, then her siblings would add on to it or tell more about it, so kind of trigger

Ingrid's mind, so that she remembers all the things. She has problems with short term memory and long-term memory, so they try to help her a little bit. Sometimes they take over and they tell the whole story. And we are sitting at the dining table and we are making sure that she has the time to explain what happened in a day, if there is anything...'

Other examples of the support between siblings will be described individually for each child (Lukas, Henrik and Monica) under the description of their 'lived experiences'.

Ingrid's conflicts with her siblings

The topics of conflicts between Ingrid and her siblings reported by her parents are similar to the conflicts happening in every family between siblings. The mother describes:

'TV channel, for example, just when we came in, Ingrid said 'I don't want to see a boy show, Mum'. Or if they want an i-Pad at the same time or a toy'.

According to the father, the only difference was that Ingrid would express her emotions in a more noticeable way.

'Nothing special really, just the same as in between the other siblings, she just gets more frustrated and perhaps shows more than the other siblings, she would cry loudly, even if it...pretend, being very verbal, but some other kids do the same way to, so ...'

Hence, the previous examples given by the parents, show that the conflicts between their child with Down syndrome and her siblings are similar to those appearing between typically developing siblings.

The role of the dance in Ingrid's and her siblings' lives

As was described earlier, Ingrid was taking dance classes and also she was organizing performances in which she was engaging her siblings and friends from the neighborhood. The mother stated *'Ingrid's entertainment heart influenced the whole family.* The following description by the mother illuminates Ingrid's passion for dance:

'She loves it... You know, she makes her own performance also. For her father's birthday we ate, opened presents and then they both danced, for the same song they both had their versions, so the girls danced the first and then the boys danced after. So, she does that a lot, and she gets a neighbor girl involved'.

The father also points out Ingrid's ability to involve the siblings and everyone in the family into her performances:

'She loves to dance. She just starts alone sometimes, and sometimes with Monica. Sometimes they set up a show, for the parents, for us, to see them, the girls and the boys will show after so that they have something in addition. Then I have the whole performance. Our two neighbor girls, they also participate and they are dancing as well'.

Furthermore, I observed and participated in a 'dance game' with Ingrid. She had the ability and talent of sharing her enthusiasm with people and was able to repeat the dance movements which she saw on the screen.

The impact of having a Down syndrome on Ingrid's relationships with her sibling

According to the father, there are certain activities that may be influenced by having Down syndrome. He explains:

'I think, she cannot participate in all activities at the same level. When they play soccer outside, Monica is a lot younger, and she can do more with that soccer. The same is with gymnastics, certain limits to what she can do, and also running around... In the beginning she struggled with her heart too, but now it has been improved, but there are some activities that are more difficult for her to follow up on'.

However, he also adds that there are activities that are not impacted on very much:

Computer games, watching TV and programs, pretty much the same. She has her favorite things that she watches over and over again usually'.

The mother noted that having Down syndrome influenced their family both positively and negatively:

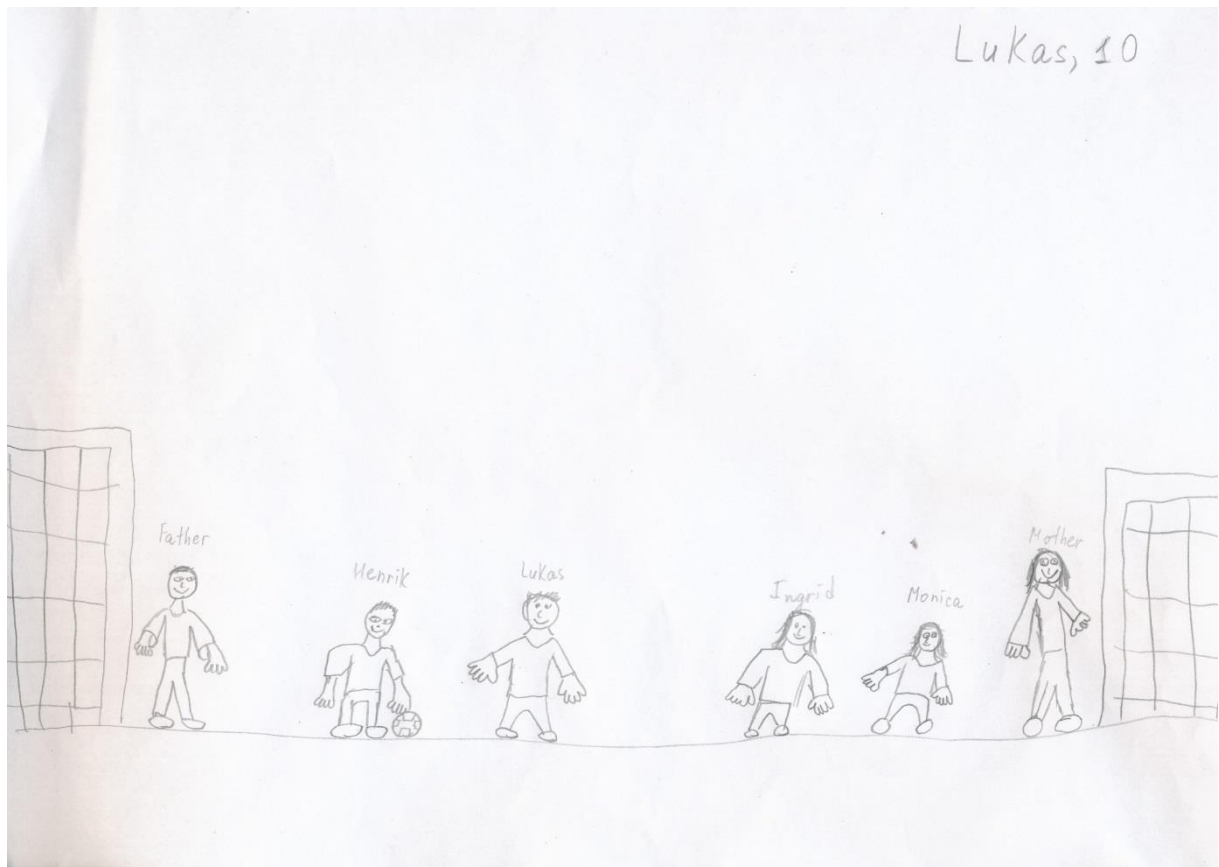
'I think my family is more outgoing because of Ingrid. She is just herself, she is really comfortable with who she is, she gets sad about friends sometimes, but she shakes it up very well. She is a positive influence in a way she is, the positivity she brings, and I cannot think of one huge example, but this performances, she likes, her entertainment heart has influenced all of us. That's big thing. The negative would be her...I know that strong will is really good, but I asked her for her phone 15 times last night, she won't give it to me. That's frustrating, and it can be frustrating for the kids too, to have the fight for things, her stubbornness is kind of not always a benefit [laughing].

Thus, the analysis of Ingrid's K-F-D and parental interviews revealed the overall positive and warm relationships of Ingrid with her siblings and her parents. Her ability to involve the siblings in her dance performances and to join the whole family around dance performance has a positive impact on the relationships of all family members. Ingrid's stubbornness was described by her mother as being one of her negative characteristics which time to time mediated her behavior and created difficulties for both her siblings and the parents.

4.4.2. The 'lived experience of Lukas'

This section will present the relationships of Lukas (Ingrid's 10 year old sibling) with Ingrid and with the other family members.

1. The K-F-D of Lukas



2. Description of the drawing by Lukas

Lukas drew the picture of his family as showing everyone playing football. According to his description, the father and the mother are the goalkeepers. There are two teams: a boy team and a girl team. He said that the family plays football also in the real life and both teams win. Lukas stated that he likes to spend time and play with his brother and sisters, and when asked with whom he likes to spend most time, he did not indicate a particular sibling and said that he is close to all of them. When I asked whether he is having some difficulties, problems or conflicts with his siblings, he replied: *'Sometimes, my brother and I get mad together, but it gets better, and we are still friends'*.

3. Analysis of the K-F-D of Lukas

Style: First of all, one can notice that Lukas drew all the family members in horizontal (equal) position. He did not use the styles of either compartmentalization or encapsulation described by Burns and Kaufman (1972) as indicators of isolating certain family members or themselves by the children. As discussed above in Bernsen's family, children tended to identify themselves with the same-sex parent. Similar to Ingrid, Lukas divided the 'football team of the family' into two teams: 'a girl team' and 'a boy team'.

Lining at the bottom: According to Burns and Kaufman (1972), the lining on the bottom of the paper is typical for children who feel instability in the home and are trying to maintain stability by creating a very solid foundation. However, the bottom line of Lukas is very thin and presents a part of the football field, thus it does not allow us to conclude that he experiences some kind of instability. Instead this may indicate that the family has a platform and is grounded.

Symbol (s)

Ball: The energy may be condensed or symbolized in objects such as ball. We can see in the K-F-D of Lukas, he gives the ball to his younger brother, Henrik. Thus, he gives the 'force' of the game to his younger brother.

Goalkeepers: Lukas drew his parents as goalkeepers of the game. This indicates the perception of the parents by Lukas as symbols of security and his trust toward them.

Location of Self: Although Lukas drew himself in the boy team, he is also somewhat in the middle of the picture indicating his closeness to everyone. As discussed afterwards, Lukas has been described as the older brother in the family by his parents, even though Ingrid is a year older than him. It is noteworthy that he was also defined to be a caring brother for Ingrid and it can be one of the reasons, that he drew Ingrid next to him (although in a 'girl' team) and himself slightly taller.

Characteristics of Individual K-F-D Figures

Open hands: Lukas drew himself and the family members with hands open to the sides as a sign of active interaction and sociability with the outside world. In the drawing of Lukas, the only person whose hands are not as open as the hands of other family members is Henrik. It

could be because Lukas drew him holding the ball, which made it impossible to draw him with open hands. However, it could be also because of the behavior or communication difficulties which Henrik has (according to his parents). Lukas, himself, mentioned fighting with Henrik.

Omission of Body Parts:

Ears: Lukas did not draw ears to the family members, and only he has one (right) ear. If this aspect is combined with other parts of the drawing, as well with the parental interviews, it can be asserted that Lukas perceives himself as a ‘listener of the family’.

Overall, it is evident from the K-F-D of Lukas that he drew every member of his family smiling, happy and engaged in the same activity (playing football). The parents are the goalkeepers (protectors) of the family, whereas the children are free to play. He drew his sister with Down syndrome in between him and her little sister, which means that Ingrid is not seen as close only to the parents or overly attached to them. Instead, she is perceived as an equal sibling who is participating in playing football with her siblings.

4. Parental perspectives of the relationships of Lukas with Ingrid and his other siblings

According to both parents, Lukas has become the oldest sibling in the family, although Ingrid is one year older than him. The father explains:

‘Lukas perhaps takes more care and becomes the big brother in the family, even if Ingrid is the oldest’.

When telling me how she tries to balance her attention between her children during daily life activities (like helping with homework), the mother said:

‘Lukas does everything himself, that’s how life has been for Lukas. He tolerates it. He does come to me and ask for questions, but he is basically the oldest sibling. That is our family too, that’s very typical. So he kind of superseded...’

The mother also points out that Lukas takes care of Ingrid and has always been the person that understands her. She asserts:

'Lukas has got a very soft-heart and he really gets her, what she needs, to understand something'.

However, both the father and the mother believe that the situation is more balanced now for Lukas. As the father stated:

'Lukas is more relaxed from the feeling that he is somehow the older brother. I think Ingrid is managing more on her own, she does not run away, her behavior is better. I think he is more relaxed now, and he is doing his own things more, and not thinking so much about her, which is a good thing. This is always something you as a parent are worried about, that they take too much about her, instead of just being a regular child'.

Hence, both parents agreed with the fact that Lukas has become the oldest sibling in the family, and therefore has taken caring responsibilities for the younger siblings. However, as the father remarked, because of Ingrid's more independence, Lukas is in a more relaxed position now.

Support given by Lukas to Ingrid

In the mother's opinion Lukas has the ability to explain Ingrid how to perform certain activities. She describes:

'Ingrid wants to write something on the paper, Lukas would be the first one to say let me help you, and then you can copy it. Lucas tells her how to get from A to B, he explains things, and he is very smart socially, so he explains it to her in terms that she can understand'.

However, Lukas was also rational when deciding to help Ingrid. For instance, he could understand whether Ingrid was able to protect herself in some situation or if she was at fault in the situation. When the mother recalled the story when someone in the neighborhood teased Ingrid, she noted that Lukas did not get involved. The mother explains:

'When they came back to the house and Lukas told me about the story, he said 'wow she [Ingrid] is really tough', [laughing]. He [Lukas] is careful too, and he knows Ingrid can be kind of unreasonable, [laughing], she can do things that are not so nice too'.

Hence, even if many times Lukas behaves as the oldest sibling of the family and cares for Ingrid, he also understands that there are situations when Ingrid does not have a nice behavior too or she is able to stand up for herself.

The impact of having a sister with Down syndrome on the social life of Lukas

According to the mother, Lukas is '*socially aware*'. She was able to remember only a small incident when the friends of Lukas commented on Ingrid's behavior:

'I remember, that the first play date that Lukas had, I had four little boys over, and one of the little boys saw Ingrid on the computer and said 'O, childish'. Something she was doing on her PC, but that was only the first grade. This little boy, he did not know Ingrid really. I think that was his first experience of seeing a child with Down syndrome. But they have kind of grown into; I cannot think of one time that they were embarrassed really by her.'

The mother's story may indicate the fact that, even if it could be unusual for the siblings' friends to see Ingrid for the first time, afterwards they got used to seeing her.

Conflicts between Lukas and Ingrid

The mother attributes to Ingrid's stubbornness the fact that Lukas sometimes refuses to do certain things for her. She explains:

'Lukas also feels kind of a weight on his shoulders in some ways. Ingrid is very stubborn and to get her from A to B sometimes can be very difficult and he does not want that stress, so that is kind of struggle, because he basically refuses. So, it's a huge weight on his shoulder to feel stuck, because when you are stuck with Ingrid, you are stuck. Several people said in my family that they have hit the wall with Ingrid, they cannot make her to do what they want her to do, it is such a helpless feeling [laughing].

From the mother's interview, we can conclude that the parents do not make the siblings take care of their sister with special needs. They asked, but the sibling (Lukas, in this case) had the right to refuse, if he did not want to help with that particular issue.

The relationships of Lukas with his parents

The mother's guilty feelings towards Lukas

Lukas was born soon after Ingrid's birth (16 months after). At this period Ingrid had health problems. The mother expressed having guilty feelings towards him, as Ingrid needed more attention because of her health problems. She acknowledges:

'Ingrid was really sick, the first two and a half years with pacemaker and pneumonia, and Lukas came in 16 month. I remember having some of these feelings when I felt bad, like I was not giving him enough. But those years are long time ago now, and she is 11, and she has been healthy since she was...two and a half'.

The mother highlighted the aspect that her husband was always telling her that Lukas received sufficient attention from him.

'My husband always says 'he is getting a lot from me, you don't have to worry. So, it's true he has really got special and a very nice bond with Lukas. They go running, and they are talking about soccer. Lukas gets that need met through my husband and my husband is a very caring person'.

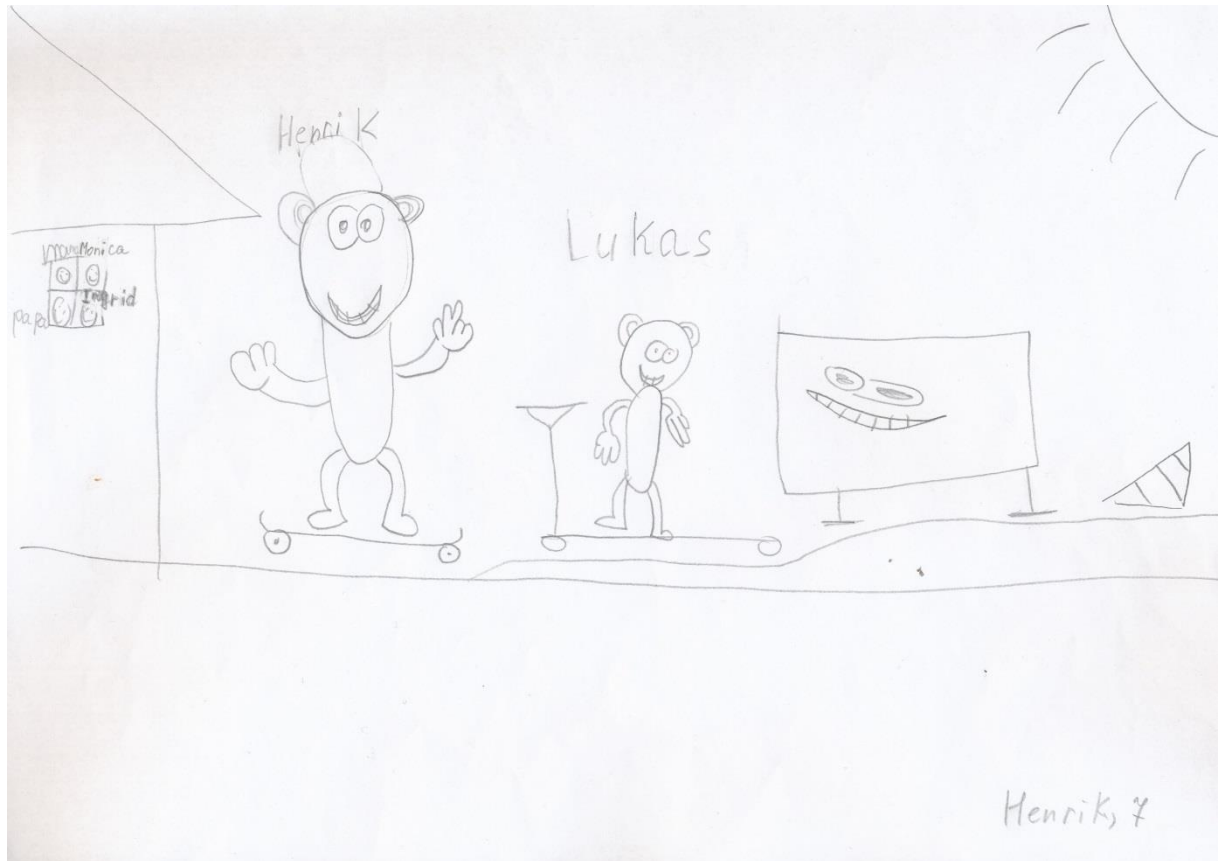
The above discussed topic illustrates the significance of the spouse relationship in the children's upbringing, particularly in the families where one of the children needs medical care or more attention because of health problems. The father's support and care for Lukas also supported his wife and made her believe that all her children receive parental love and attention.

The K-F-D of Lukas and the parental interviews portrayed the supportive and caring relationships between Lukas and Ingrid. However, the perception of Lukas as the oldest child in the family by the parents, siblings and by Lukas himself puts him in a rather sensitive position. For instance, he has additional responsibilities and experiences that stem from his position and are typical for the oldest children in the families (such as doing the homework alone). Furthermore, as it was apparent from his K-F-D, he considered himself as the listener of the family and described himself as being close to all family members.

4.4.3 Henrik's 'Lived Experience'

This section presents the 'lived experience' of Henrik (Ingrid's 7 year old sibling).

1. Henrik's picture of his family



2. Description of the drawing by Henrik

Henrik said that he liked to spend time with his brother and liked it when Lukas was with him. In the beginning he drew only a picture of Lukas and himself with the trampoline. After he started to describe his picture he drew the Sun. He did not draw other family members before I asked about them. After my question he drew them in the right corner looking out of the window. When I asked whether he likes to spend time with his sisters he answered ‘*No, because they are playing just like girl’s stuff*’ and he described the games which his brother and he liked to play which were considered to be ‘boy games’.

3. The Analysis of K-F-D of Henrik

Style: Encapsulation

As it is obvious from the picture, the most important persons in the family for Henrik are himself and his older brother Lukas. As mentioned, he even drew only Lukas and himself in the beginning. Afterwards, he encapsulated other family members in the house. The parents and the sisters are looking out of the window and all of them are smiling. They are in the background and distant from himself and his brother.

Self-perception

Size: In Henrik's picture he represents himself as bigger and taller than Lukas, although Lukas is three years older than him. The parents and sisters are very small. They are looking at, but are not in contact with him, and somehow give him freedom to enjoy his play with Lukas.

Smile and Teeth: Although Henrik drew himself and Lukas smiling, we can notice the teeth, which in projective drawings are considered to be a symbol of aggression or/and protection. Even the springboard is smiling, but it also has teeth. It seems that Henrik wants to be engaged in communication and games. At the same time his 'teeth', aggression or protection may indicate that there is a hindrance in making friends. As we can see he drew his older brother Lukas much smaller than himself and in a more relaxed way. As it was evident from the description of the picture by Henrik, he likes to spend time with Lukas, and perhaps he even tries to compensate with him for the lack of attention in school. Furthermore, he drew no barriers with Lukas and drew Lukas and himself with similar face features, which can indicate an identification process with his brother.

Symbols: Sun

A light (the Sun) is shining above and depicts a general warmth in the family and was discussed in the part of the analysis of Ingrid's K-F-D as well.

The omission of neck

The omission of a neck may indicate the free flow of basic body drives with a probable lack of adequate control. This aspect of Henrik's drawing corresponds also with his father's interview data that Henrik had difficulties in school with controlling his anger.

Gender expectable behavior and games: in a similar way to the other children in the family, Henrik tends to differentiate 'girl and boy activities'. According to his explanation, he does not like to play with the sisters as they like to play more the '*girl stuff*'.

Burns and Kaufman (1972) state that sometimes children who strive for dominance, use techniques such as placing their heads above the rest of the family figures. Large size figures seem to reflect weak internal controls and expansiveness. However, after having an opportunity to spend several hours in Henrik's family's house and having interviews with parents, Henrik's elevated figure seems to take a different interpretation. As Henrik's parents

described in the interview, Henrik had difficulties in school with controlling anger, and also had difficulties to participate in some social activities though he wanted much. Furthermore, the mother said only Ingrid and Henrik were not invited to birthday parties usually. And I was there when Henrik came and said that he wanted to be invited. Thus, by taking into consideration all these aspect, one can notice that the whole body of Henrik is open for relationships with the outside world. His arms are open, his ears are big, his eyes are widely open as if he wants to say ‘I am here, I want to play, I want to be considered’.

4. Henrik’s relationships with Ingrid and his other siblings from parental perspectives

The following section presents parental opinions in relation to Henrik’s relationships with Ingrid and other siblings. As mentioned, the interview data is consistent with Henrik’s K-F-D in several aspects.

Support provided to Ingrid by Henrik: according to the mother while Lukas would have enough patience ‘*to explain things and tell Ingrid how to get from A to B*’, Henrik would just *do it*’.

Hence, the mother’s comparison of the siblings’ support to Ingrid illustrates, that Henrik provides his help to Ingrid by doing some activity instead of her, rather than explaining her how to achieve it by herself. This aspect can be explained with the fact that Henrik is only 7 years old and has not still developed the necessary levels of patience and empathy to help Ingrid to develop her own skills.

Conflicts between Henrik and Ingrid

The mother remarks that, as both Ingrid and Henrik are stubborn, they often disagree with each other:

‘Henrik and Ingrid are very strong willed. They are the ones who are going to timeout the most, especially when they were younger, and they have longer consequences, because they don’t learn from small consequences’.

The mother adds, that Ingrid can also take the role of teaching Henrik how to behave:

‘If Henrik is not behaving, than Ingrid will pipe up and say ‘Henrik, you have to listen to mama, mama told you to do this, you have to do that. So she can also take that role on’.

The previous examples by the mother demonstrated that Ingrid and Henrik have similar characters that can from time to time cause conflicts between them.

Henrik's difficulties in school

Both the father and the mother pointed out Henrik's difficulties in school. The father says:

'Henrik had difficulties in school with the learning and behavior, and also with anger and controlling his anger'.

The parents explained that these difficulties were partially due to the fact that he was not ready for school, but there is a Norwegian regulation for beginning school. Secondly they consider that it might be that Henrik did not receive enough attention from them in certain periods of his life. The father explains:

'It's difficult to say what caused it, but it could be that he wasn't given perhaps enough attention from us as parents in certain times in his life. So he became a little bit more frustrated about the things ... it's hard to say. I think most of it was that he was immature; he was not ready for school. He was frustrated, he was just not ready, and we should have held him back one more year'.

Henrik's difficulties in school made his mother feel guilty towards him. She recalls:

'I am a speech therapist, and I spent lots of hours with Ingrid. Then when Henrik got in the first grade I realized he was really lacking some skills, but he was also a little boy that would not sit down with paperwork. We did a lot of memory games with him, but he was not ready for learning. He is a boy, he was born late, he is bilingual, and if I had my choice I would not take him to the first grade. But we had to, because that's was Norway's regulation. Anyway, I felt major guilt for probably about four months, as I felt I had not done enough for him and that my time had been spent with Ingrid'.

However, the mother also felt that everything started to be more in a balance and she tends to consider the needs of the younger children (Henrik and Monica) first now. She says:

'So he [Henrik] is coming around now. But I tend to take Henrik and Monica first before Ingrid now...Henrik is reading now, so it has come along, so it's more of a balance, that it has been in the past'.

Exclusion from play dates and birthdays with their peers concerned not only Ingrid, but also Henrik. According to his parents, he is also not invited to birthdays and has problems in being involved in some play activities with his peers although he tries a lot. Furthermore, I was present when he said that he wanted to be invited. However, it does not seem to be connected with the fact that he has a sister with Down syndrome, as his parents did not report any

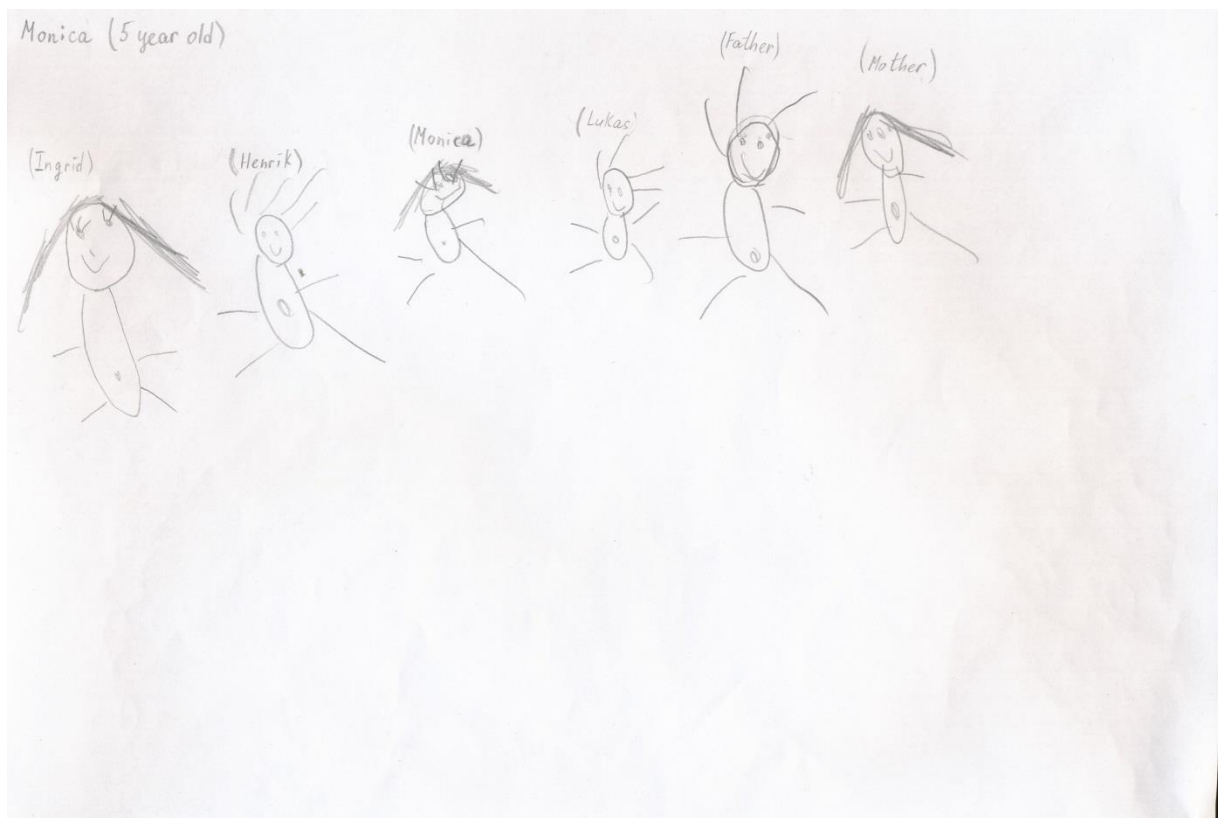
difficulties of socialization for the two other siblings (Lukas, 10 years old and Monica, 5 years old). Instead, it seems to be connected more with one of the aspects described by his parents.

Overall, Henrik's K-F-D analysis and his parents' interviews illustrate that the most important person in the family for Henrik is his older sibling Lukas. Henrik drew Lukas and himself playing together, while the other family members are encapsulated in the house. Both the K-F-D analysis and parental interviews illuminate Henrik's need for friends and social relationships.

4.4.4 The 'Lived Experience of Monica'

Monica is the youngest child of the family (5 years old) and this section presents her 'life experience'.

1. Monica's picture of her family



2. Description of the drawing by Monica

Monica started the description of her drawing first of all by showing herself in the picture (which is quite typical for 5 year old girl). Afterwards, she showed the pictures of every

member with everyone's name: *'This is Ingrid, this is Henrik, this is me, this is Lukas, this is papa and this is mama'*. She said that everyone is playing and that she likes to play with everyone. To my question about who she likes to play with most, she answered Lukas. Afterwards, she also said that Lukas plays football best in her family.

3. K-F-D Analysis

Style: Monica, similar to Lukas and Ingrid has put no barriers between family members. However, if the other siblings divided the family or family activities into 'boy' and 'girl' sub-groups, Monica drew the family members as a whole and playing all together.

Position of Monica in the family

It is natural, that Monica, as the youngest child in the family, drew her picture in the middle and surrounded by all family members, as usually the youngest children receive attention not only from parents, but also from older siblings. As one can see from the drawing and from the description of the drawing by Monica, Lukas has a status of playing the best and an older member of the family, as Monica even drew a picture of Lukas next to the parents. Furthermore, as she said, she likes to play with him most of all, and she drew herself next to Lukas and her eyes looking at the direction of Lukas (and/or parents).

Self-perception and perception of other family members

Except Lukas, other family members are drawn bigger than Monica, which, of course, corresponds to the reality. Perhaps, she tried to identify herself with Lukas by giving both of them the same size. She drew the female representatives with long hair and Ingrid and herself with long eyelashes, thus highlighting their feminine characteristics.

Symbol: Belly Button

In Monica's picture, everyone has a belly button, which symbolizes attachment and dependency and is considered to be quite typical for the children aged up to 7 years old.

Overall, we can see that Monica, similar to her siblings, drew a picture of a happy family playing all together. There are no barriers between family members and none of them is isolated. It is also apparent that everyone in the family is smiling and 'flying freely' in the drawing. They are free, their arms are open for communication and interaction with each other and with the outside world.

4. Monica's relationships with Ingrid and her other siblings from a parental perspective

Playing together

According to both parents, the relationships between Monica and Ingrid are similar to typical relationships between sisters, as they both like to play with dolls. The father explains:

'Ingrid and Monica play a lot together. Maybe because they are girls both of them, just pretending being a family, with the Mum and babies'.

The mother adds that:

'Ingrid can be bossy, she tells everybody what to do basically in the house [laughing], and she is a big sister to Monica'.

As discussed throughout the thesis, the siblings like to make dance performances for the parents, and often Monica and Ingrid can start with the dancing (girls' part) and boys will join or show their part afterwards.

The mother also noted that Monica was starting to notice that Ingrid needed help in certain things. However, this aspect did not seem to hinder their playing process or relationships.

Support given by Monica to Ingrid

Monica is only 5 years old and, therefore, sometimes she may react in a spontaneous way at Ingrid's behavior. This aspect may be helpful both for Ingrid and for other family members. As it was presented under the section ***Ingrid's lived experience (4.4.1)***, Monica could support Ingrid in a situation with imaginary Mums and Dads and to teach Ingrid how to follow rules and behave in certain situations.

Conflicts between Monica and Ingrid

As the parents stated, the topics for conflicts between the siblings were typical, such as TV channel, i-Pad, and a toy. The mother recalls another reason for conflict between Ingrid and Monica:

'There was couple of nights in a row last week when Ingrid wouldn't stop talking, and Monica wanted her to be quiet so that she could go to sleep. So she came out several times saying that Ingrid wouldn't stop talking and I can't sleep, and that kind of thing. Ingrid complained about Monica, they are definitely sisters equal [laughing]'.

Thus, although Monica does not explicitly comment about Ingrid's special needs, she corrects her and her comments can be of support to Ingrid and her behavior.

Overall, both parental interviews and K-F-D analysis identified Monica's positive relationships with her siblings and parents. As the youngest child of the family, she depicted herself in the middle of the drawing surrounded by her siblings and parents. Furthermore, parental interviews illustrated that Ingrid and Monica have created relationships typical for the sisters, such as playing with dolls or role-games.

4.5 Parental Strategies for the Siblings 'Social Development'

This section will draw upon the main strategies used by the parents for their children's inclusion in the society, as well as balancing their time among their children, solving the conflicts between the siblings and regulating their behavior.

4.5.1 Strategies promoting Ingrid's and her siblings' inclusion

Play dates

As described previously two of the children (Ingrid and Henrik) are not being invited to birthdays and play dates. However, the parents organize many play dates for each of their children and invite the siblings' classmates and neighborhood friends. The mother also pointed out that her children like different kinds of organization of play dates:

'Henrik wants to have his own play date by himself, and not to have many kids around his play date, because he feels he gets left out. So every child is different, and everyone likes different things. He likes that one. Ingrid loves one to one too, but she also likes to have the group'.

Hence, the described statement by the mother revealed her ability to reflect on her children's individual characteristics and to take them into consideration while organizing play dates for them.

4.5.2 Parental strategies used for balancing attention between the child with Down syndrome and their other children in daily life and in extreme situations

It goes without saying, that every family may experience periods when a certain member needs more attention than the others. Similarly, Bernsen's family had periods when parents needed to spend more time with Ingrid because of her health issues connected to her heart.

The mother recalls:

'We had different situations ... Like last year, around Christmas time, I had to leave the other three children, I was sick myself with flue, but I had to go through surgery with Ingrid. So, there have been times when I had to be away from other kids and the attention had to be on her because of her health problems. But it does not happen often anymore, it used to happen a lot when she was younger.'

Hence, the mother's explanation showed that there are situations, when she has to do be with Ingrid more than with the other children. However, when asked about strategies for balancing the time in everyday life, both parents highlighted the aspect of having an opportunity to be at home as very important. Besides, the mother also said that she does homework with the children individually, except with Lukas who is perceived as being the oldest and the most independent child. The mother acknowledges:

'I am at home that helps. Just an example, on Mondays and Tuesdays we do homework. With Henrik I do it every day, because that's the way his classroom works, but I know that I have to sit down with Ingrid, Henrik and Monica, all individually. Lukas does everything himself, that's kind of what has been for Lukas; he is basically the oldest sibling.'

The mother also highlights that she tries to be fair with organizing play dates for every child equally. She says:

'If I give a play date to Henrik, Ingrid is the first one asking whether she can have a friend over tomorrow. So I have to be fair with them. I am not going to do four play dates every week, it tires me out. They have to take turns, like I might do boys one week, girls the next week, and sometimes not at all, so it depends.'

The father remarks that achieving the balance is difficult:

'That is a hard balance. And I think at times for homework Ingrid has taken more time, with reading. We try to balance it as good as we can. We are at home both of us in the evenings and at weekends. So, it's a challenge. Luckily, she was the first child, so when she was sick a lot in the hospital than it was only her.'

The parental statements showed that although maintaining the balance between their children can be often challenging, they have developed several strategies in order to keep the balance

the best way they can. One of the most important strategies remarked by the parents is the fairness with the children. However, in extreme situations (such as sickness, hospitalization) the mother's attention needed to be more concentrated on Ingrid.

4.5.3 Strategies for solving the conflicts between the siblings and regulating their behavior

As it is obvious from the parents' reports, they try to be fair to their children in solving their conflicts and do not overprotect or justify Ingrid's behavior every time. The mother asserts:

'I am trying to make Ingrid listen in all situations when she is really out of line, I don't know, we try to be fair with things, I guess we use consequences and time out, especially when they were smaller, just regular discipline things.'

And the father says:

'We try to find out what happened, first of all, and then, if someone did something bad to Ingrid, then we tell them to apologize to the other.'

In their children's upbringing the parents explained their use of consequences and timeout in the following manner.

[Father]: *'Sometimes we have consequences, when they have to go to their room for a time out, before we had sitting them in a corner if they did not behave for a certain appropriateness, usually, if they are three year old, three minutes, five year, five minutes'.*

The mother adds:

'We take away things that they like, for example TV time or iPad time. Like we may take the computer away from Ingrid for three days, so that it actually sits, she does not learn it from half an hour or even an hour a day, and Henrik is exactly the same way'.

Furthermore, the father pointed out they also reward the children for their good behavior and try to encourage them to show it:

'Usually we give them awarding too. They have duties around the house, so Ingrid, Monica, Lukas, Henrik, they all do chores around the house. They do dishwashing, taking the garbage out, so different things and then they get money for that when they do their chores, our reward [laughing].'

The statements by the parents showed that they implement the strategies regulating their children's development equally for all the siblings. Ingrid follows the same rules as her siblings do.

4.6 Information given to the siblings about Down syndrome

Both the mother and the father never talked with the siblings about Ingrid's special needs.

However, the parents were sure that the siblings were aware that Ingrid has special needs. The mother explains:

'We have never...It's kind of funny we have never really sat down and told them, we did not feel a need to, I guess. I don't know whether other families do, you are just kind of used to the idea...'

The father expressed a similar point of view:

'Honestly, we have not really talked about it. They see it, I think they know about it, perhaps my wife, explains more about it than I do, and my wife is also the one who does most of the homework with them... I have not really thought about it that much. I think they learn about in school too that there are people with special needs, special behaviors and being inclusive and those kinds of things. It's probably an advisable thing to do, to talk more about it'

Although the parents have never talked about Ingrid's special needs with her siblings, after the interview they started to reflect more on this topic. As discussed earlier, after individual interviews, three of us had a joint discussion in which I shared the previous research findings about the importance of the information given to the siblings.

4.7 Sharing their 'lived experience': advice given by the parents to other families

At the end of the interview, the parents shared their ideas about sibling relationships with other families. The mother recalls:

'When you have a child with Down syndrome you think that they are going to be left behind, that they are the ones that are not going to get the attention. I remember us having a huge...I was okay with Ingrid having Down syndrome, we found 18 weeks, that we would have a special child and that she had heart effect, we knew all that, we have to teach her all these things, and I am a speech therapist, but I remember having an overwhelming feeling for her loneliness. I thought she was going to be such a lonely child...And her physical therapist told me 'it's actually the opposite, it's usually the siblings who don't receive as much attention'. So, I had that voice in my head really. I guess, that, just to be aware, to treat them all the same way and they say that you are supposed to discipline them all the same way. I am not a perfect discipliner and I had to read a few books, especially on strong willed kids. I

remember, I read the book that was the first night I made her stay in her room, she came out of her bed, but she stayed in her room, but when you are disciplining you need to have your rewards... it's not easy, my husband is much better than I am, but I have learned...'

The mother's story exhibited that, sometimes, the professionals working with families with children with special needs can influence parental understanding about the difficulties the siblings might have. As it was clear from her statement, she kept the advice given to her by Ingrid's physical therapist.

The father gave the following advice:

'I think being fair and having predictability in the daily life, so they know what happens in the morning, what happens in the afternoon. I think that's actually good for the other siblings as well, that they know that there is a certain structure in a day perhaps taking away frustration, from everyone, parents and siblings. I think if they can motivate and reward, that's perfect if you have systems for that, you have fair rewards for everyone at their level. But also not everyone is perfect and us too. Sometimes we tend to leave to consequences for negative behaviors. It is also important that there are consequences because kids with Down syndrome will push the limits and they are very stubborn. If you don't have rules and consequences they will use it for what is worse and you will have trouble then in daily life. And with the siblings too, because they see that she is perhaps treated differently because of her special needs. Treating them the same but making sure that you do it on the right level for the kids.'

Thus, apart from highlighting the importance of predictability in the daily life, the father also noted about the importance of both rewarding good behavior and the consequences for the negative ones which will be adequate for each child's developmental stage.

Overall, the data of the children's K-F-D, parental interviews and participant observation illustrated a good family atmosphere, and the parents' attentiveness to every child's individual needs. They are able to create a good interactive platform for the family, which was apparent from the children's drawings. They depicted their parents as being there for them, playing with them, and smiling. The children's individual stories all indicate family togetherness and warm relationships. The sibling conflicts which parents described are indeed normal sibling conflicts, and the siblings' warm and supportive relationships were also evident in their own pictures and their descriptions.

4.8 Discussion

The purpose of this study has been to identify and analyze sibling relationships in families with a child with special needs in relation to the following main research question:

How are the relationships between children with special needs and their siblings perceived by them and their parents?

As discussed in chapter one, underlying questions have been developed because of the broadness of the main research question. Hence, this section aims to answer the research questions based on the findings and the theoretical framework of the study.

1. How do children with special needs perceive their relationships with their siblings?

Ingrid's K-F-D analysis and her description of it revealed her identification with the female representatives of the family. She drew herself next to her younger sister Monica. This aspect is remarkable as it shows that she is not overly attached to her mother, as it may happen with children with special needs and perceives herself as close to her younger sister. She drew her brother's next to her father. As presented earlier, in Bernsen's family the identification with the same-sex parent and gender expectable activities were common among the children, and this aspect of differentiating the boys and girls was seen in other children's drawings as well. Overall, Ingrid's picture illustrated warm atmosphere in the family, with the sun shining above all the family members.

2. How do the siblings perceive their relationships with their brother or sister with special needs?

The children's K-F-D description by them and the analysis of it based on the interpretation manual (Burns and Kaufman, 1972) illuminated that the siblings perceived Ingrid as equal sibling to them. Importantly, none of them drew Ingrid next to her mother or her father indicating that she was perceived similar to the other siblings. She was depicted next to her siblings (mostly Monica) playing and participating in the same activity as

everyone else in the family. It is worth noting that the siblings drew Ingrid smiling, happy, active and playing with all of them. They described that they like to play with her. The exception was Henrik, who wanted to play mostly with his older brother Lukas, and did not like to play with either Ingrid or Monica, because they like to play girl games. Thus, even if he said, he does not like to play with her; it was not because of her special needs, but because of different preferred activities.

3. How do the children with special needs and their siblings perceive their relationships with their parents?

As highlighted previously, none of the siblings, and not even Ingrid herself, drew her just next to the mother or the father, pointing out the equality between the siblings in receiving parental love and care. Perhaps, the only explanation of children's decision of locating themselves and the siblings in the drawing was again the identification with the same-sex parent (girl's and boy's football teams in the case of Lukas, separation of the girls' and boys' corners by Ingrid, or identification with the older brother in Henrik's case).

Overall, K-F-D analysis showed that the children perceived their parents as being equally engaged with them in the playing process, smiling and protecting them. As the K-F-D of Lukas illustrated, they are the goalkeepers of the game, indicating the parents' ability to create a secure platform for their children's interactions.

4. How do parents perceive the relationships between their children with and without special needs?

The interview analysis exhibited that both parents believed that Ingrid has good relationships with her siblings and that they like to play with each other. The father believed that though siblings understand that Ingrid has special needs, they still treat her as the other siblings without special needs. The parents did not remember a situation when the siblings were embarrassed by Ingrid's special needs. The topics of the conflicts between Ingrid and her siblings reported by her parents were similar to the conflicts happening in every family between siblings, such as TV channel, iPad and so on.

According to parental interviews, siblings' relationships with Ingrid could be different depending on the siblings' ages and sex. For instance, both of them emphasized that relationships between Monica and Ingrid are similar to typical relationships between sisters,

as they both like to play with dolls. Lukas was described by the parents as the oldest sibling who mostly takes care of Ingrid and is the person that understood her best. The mother attributes to Ingrid's stubbornness the fact that Lukas sometimes refuses to do certain things for her. This is accepted by the parents with an understanding. Moreover, both parents highlighted that they are happy with the fact that Lukas is in a more relaxed position from the feeling that he is the oldest sibling in the family due to Ingrid's independence.

Thus, Adler's concept about '*birth order*' seemed to have a great impact on the development of Lukas. Even though he was the second child in the family, the parents and other siblings accepted him as the oldest child. The parents described him to be very supportive towards Ingrid. Moreover, both Henrik and Monica chose him as their favorite companion for playing. As Bowlby and Ainsworth (1969) believed siblings can also be a principal attachment figure for the child. For instance, Henrik's K-F-D illustrated that he seemed to be particularly attached to his big brother and in his drawing placed them together as the central family sub-system for himself.

Furthermore, the father expressed an idea that Ingrid's being the first child made it more possible to give her the attention she needed in the beginning. The mother also felt it was essential to use a lot of time in teaching Ingrid daily life skills, and now she could take into account the needs of the younger children (Henrik and Monica) more. This finding contradicts with the finding by Dyke, Mulroy and Leonard (2009), which showed that parents were less likely to report disadvantages in cases of later birth order of the child with special needs. The contradiction can be explained by several reasons. As Skotko and Levine (2006) found, sibling relationships in families with a child with special needs can be different depending on family size, birth order, age difference and gender association.

The findings of this case study are consistent with the findings of Mophosho, Widdows and Gomez (2010), who also used interviews, observation and K-F-D and found that the siblings expressed love toward their sibling with special needs and were trying to help their sibling to accomplish the tasks that was hard for them. As the parents in the present study mentioned, the siblings could support Ingrid in everyday simple activities based on her needs. For instance, as Ingrid had problems with short-term and long-term memory, the siblings could try to help her to remember what happened during the day and tell about it at the dinner table.

One of the most remarkable findings of this case study is that the parents do not make the siblings take care of their sister with special needs. They just ask about it, but the sibling (Lukas, in this case) had the right to refuse, if he did not want to help with a certain particular issue. This is a very important point, as the previous research showed that siblings of children with special needs were obliged to take care of their brother or sister with special needs, and many researchers (Kutner, 2007; Skotko and Levine, 2006) concluded that parents needed to give the siblings the right to have their own childhood.

This study supports the finding from previous research (Scelles, Bouteyre, Dayan and Picon, 2012; Waite-Jones and Madill, 2008; Kutner, 2007) that the siblings are not given information about their sibling's special needs. Neither the mother nor the father has ever talked with the siblings about Ingrid's special needs. However, the parents were sure that the siblings were aware that Ingrid had special needs based on their indirect information, for instance because she works on a lower mathematics, she was the last one to learn to ride a bicycle and so on. As Scelles, Bouteyre, Dayan and Picon (2012) highlight one of the most important topics for siblings of children with disabilities was the difficulty of speaking about the disability within family or with friends. In cases when they were faced with a question regarding disability, they were feeling both shame and guilt.

Hence, the parental interviews presented sibling relationships with the child with Down syndrome as being supportive and warm. However, the parents also did not tend to idealize the siblings' relationships, overprotect Ingrid or make the siblings' babysit for her. Both parents were aware that the children with Down syndrome can be very stubborn sometimes, and it can be very stressful for the siblings to take the responsibility for her. Therefore, they approached with understanding the children's refusal to help Ingrid.

5. How do parents perceive their relationships with their children with and without special needs?

As many psychological theories (Freud, 1949; Adler, 1924; Erikson, 1950; Bowlby, 1969) have suggested, early experiences are crucial for the child's personality development. The findings of the study show that parents realized their essential role in their children's development. For instance, both parents agreed that the difficulties in the school for Henrik could be connected with not receiving enough parental attention in certain periods of his life.

The findings of the study suggest that neither the father nor the mother used pathogenic ways of children's upbringing highlighted in individual psychology by Adler (Ewen, 2010). Both the K-F-Ds of the children and the interviews of the parents revealed that none of four children were *pampered* or *neglected*. Even if in certain periods of the family's life parents needed to give more attention to Ingrid, because of her hospitalization or heart problems, they tried to divide their attention to all the children by following certain strategies. One of them was that the father could try to compensate the mother's attention, as in the case of Lukas, where the father developed closer relationships with him. Another strategy for balancing their attention was that the parents tried to identify the needs of the individual child for that particular period. This was evident with the recent follow-up of Henrik's behavior. However, both parents pointed out that balancing their time was challenging. As the mother said, she used to feel guilty towards other children because she needed to devote a lot of time to Ingrid during the first stages of her development, even though she knew that the father tries to fill the gap. However, the family has overcome those stages and both of them mentioned that the situation was more balanced now. The previous empirical research also demonstrates that siblings might experience lack of parental attention in certain periods of their life (Barr, McLeod and Daniel, 2008, Skotko and Levine, 2006).

As Minuchin's systemic theory states, the family moves in stages and *follows a progression of increasing complexity*. Similar to every family, Bernsen's family needed to go through changes and become more complex with each child's birth. On the one hand, the values of the spouse sub-system, the overall context of the family influenced the development of Ingrid, Lukas, Henrik and Monica. On the other hand, each of the siblings, with their own temperaments, characteristics made changes in the family. With every new born child the parents needed to develop a new pattern of parent-child subsystem, as, for instance Lukas, or Ingrid, might require the formulation of a different parent-child sub-subsystem and that of Henrik or Monica in a totally different way. The spouse sub-system in this family seemed to be very harmonious which also expanded to their children's upbringing. It was also noticeable from the children's drawings that the children saw their parents as happy and mostly engaged in the playing process with them. For instance, in the K-F-D of Lukas the parents are the goalkeepers of the family, meaning that the children are somehow the players, and the parents are the protectors. Furthermore, according to systemic theory, the family also changes depending on each member's activity in the other systems in which they are involved. For instance, when one of the children goes to a nursery or to a school, the whole family needs

also to adapt to a nursery system or a school system as well, because it may impact their family life. In Bernsen's case, the family was impacted on by the fact that Ingrid was not being invited to birthdays of her classmates. This was hurtful for the parents. However, they have somehow found an alternative solution by organizing play dates in their own house and thus encouraging and developing their children's peer relationships.

Overall, the parents were highly reflective and self-critical towards their experience of having children both with Down syndrome and without special needs. The mother was aware that there were periods when she needed to spend much more time with Ingrid because of her health problems or daily life skills training, but she also realized her significant role in her other children's lives. That is why, now that Ingrid has already become more independent, she is able to give her attention more to the needs of the younger children. Furthermore, another significant aspect is that the father of the family has always supported her in taking care of the children and also developed close and warm relationships with the children, that was also depicted by the children in their K-F-Ds where he was portrayed as playing and interacting with the children.

Chapter Five

Conclusion

This chapter presents the conclusions emanating from the study and draws the final lines between the research topic, findings and their implications.

5.1 Concluding remarks on the research process and findings

As highlighted in chapters one and two, sibling relationships in families with a child with special needs have been given little attention in the research and most of the studies tended to focus either on parental feelings of having a child with special needs or parent-child relationships (Dyke, Mulroy, and Leonard, 2009, Barr et al., 2008; Stoneman, 2005). Furthermore, the existing studies on sibling relationships mostly presented only parental perspectives of their children's relationships without taking into consideration the children's own views of their relationships with their brother or sister with special needs (Guite, Lobato, Kao, & Plante, 2004; Stalker and Connors, 2004).

Hence, the present case study aimed to fill this gap in the research and to explore sibling relationships in a family with a child with special needs based not only on parental, but also on siblings' views, in this way having all voices of the family members on sibling relationships. As persons of different age groups demand different relevant methods, phenomenological in-depth interviews have been used with the parents and 'K-F-D' projective method with the children. In addition, participant observation gave an opportunity to see the interaction between family members in the family's house. Apart from having an opportunity to have the voices of all the family members, methodological and data triangulation also helped to enhance the validity of the research study. The research process showed that the K-F-D method was relevant for this case study, as it provided unique insights into the 'lived experiences' of all four children regardless of their age differences (5, 7, 10 and 11). The children enjoyed the process, while at the same time depicted rich information about their perceptions of the relationships in their family. In addition to interviews and K-F-D,

participant observation has given me an opportunity to observe parent-child and sibling interactions in the family's home. The openness and trust of both parents and children gave an opportunity to attain deeper knowledge of their lived experiences, yet also highlighted the significance of the researcher's responsibility to be committed to the ethical guidelines, respect the parents' and children's rights of confidentiality and anonymity. Furthermore, the ethics of beneficence presented a significant value for the study, as I had an opportunity to share with the family key findings from the previous research, which seemed to be applicable in their family as well (such as need to talk to children about their sister's Down syndrome).

The findings based on the analysis of all three methods revealed warm and supportive relationships between the child with Down syndrome and her siblings.

First, the participant observation gave an opportunity to see close relationships of the family members in daily life. The atmosphere in Bernsen's house, the pictures around, the happy faces and open hearts of the children and parents all demonstrated close and caring relationships between family members.

Secondly, the children's K-F-Ds illustrated that both Ingrid and her siblings perceived her as an equal and active member of the family. She was depicted by the siblings as smiling and playing with all of them. It is noteworthy, that she was perceived to be closer to the siblings rather than to her parents, and she as well depicted herself next to her sister Monica. Furthermore, common symbols and themes in the children's K-F-Ds were the sun, playing, smiling, open hands and so on. Remarkably, the parents were also perceived by the children as engaged in the playing process, which according to the children's descriptions also happens in the real life.

Finally and importantly, the parental interviews also illuminated supportive and caring sibling relationships. Both parents believed that Ingrid has good relationships with her siblings and that they liked to play a lot together. The parents have never heard the children being embarrassed of Ingrid and reported that the siblings were supportive towards Ingrid in daily life. The reasons for sibling conflicts mentioned by the parents were typical conflicts occurring in every sibling relationships (iPad, toy, TV channel). However, the parents also stated that everything used to be more difficult when Ingrid was younger and needed to gain skills for the daily life and felt that everything started to be more in a balance now. Essentially, they have developed the same rules of regulating their children's behavior and

rewarding them for every child, and, therefore, did not try to overprotect Ingrid, if she was guilty. This finding contradicts with the findings of Kutner (2007) who found that the siblings felt angry that they could be punished for the misbehavior that would be forgiven to their sibling with special needs.

Another remarkable findings of this case study contrasting with the previous research (Skotko and Levine, 2006) is that the parents in this case study do not make the siblings take care of their sister with special needs. They sometimes may ask for support, but the sibling (Lukas, in this case) had the right to refuse. The parents understood that the siblings had the right to have their own childhood and were worried that they could think much of their sister with Down syndrome instead of just being a regular child. Notably, they also were objective towards Ingrid and knew that the children with Down syndrome can be very stubborn sometimes, which can cause stress for the siblings in trying to help her and, therefore, the parents approached the situation with an understanding.

Furthermore, several other common findings in the literature did not occur in this study. Among them were that none of the methods used in the present study showed that the children have *ambivalent or negative feelings* (as found by Waite-Jones and Madill, 2008; Packman et al., 2008, Connors and Stalker, 2003), that the siblings experienced *bullying* (Benderix and Sivberg, 2007; Stalker and Connors, 2004), have the experience of *protecting the sibling with a disability or 'parentification'* (Barr, McLeod and Daniel, 2008, Skotko and Levine, 2006) or *feel sorry for the sibling with special needs and parents* (Waite-Jones and Madill, 2008; Moyson and Roeyers, 2012; Benderix and Sivberg, 2007).

Overall, as it was obvious from the findings, this study provided a positive example of sibling relationships in the family with a child with special needs. Parental abilities to provide love and care to all the children resulted that none of the siblings felt jealous or angry with their sister with Down syndrome for taking from them the parental love and attention. Instead, they all perceived Ingrid as an equal and active member of the family, smiling and playing with all of them. The findings of the study suggest that sibling relationships can be particularly significant in cases when the child experiences some kind of exclusion in the school or outside (for instance Ingrid's exclusion from birthdays and play dates). As, unfortunately, nowadays society still does not seem to be ready to provide full inclusion of the children with special needs, sibling relationships, as well as parental strategies to involve their child with special needs in peer relationships become highly significant.

5.2 Limitations of the study

Generalization: This study provides a rich description of only one family with a child with Down syndrome by presenting the voices of all family members, yet it does not allow concluding that similar findings will be found in other families with a child with Down syndrome and especially with another kind of special needs. Families differ substantially from each other. The family in this case study illustrated a positive example of sibling relationships. However, the case of this family was unique first of all because of the fact the mother was a speech therapist. The person seeing Ingrid for the first time and talking to her would understand how much effort, attention and time has been given to the formulation of Ingrid's independence, skills and the current level of development. Furthermore, the same results could be different in single-parent families, as the parents in the present study were very supportive towards each other and highly consistent with the upbringing of their children. For instance, as the mother highlighted, when she used to feel guilty towards Lukas for not spending much time with him, his husband was always telling her that Lukas received enough attention from him. This aspect would require another kind of solution in a single-parent family, as well as in the family, where one of the parents is able to spend only a little amount of time at home because of economic situation or job demands.

Researcher's bias: As I was a participant observer in the family's house and spend several hours with them by playing with the children, having dinner with family and communicating with them, I have become more emotional towards the children and the parents. Therefore, my subjectivity towards the family members can be considered to be a limitation, as I attained the insider's view towards the situation in the family. This aspect could have had somehow influenced also data analysis process, as even though I tried to increase the reliability of the research by following accepted analysis procedure for K-F-D projective method (based on the interpretation manual), there was still a room for my own subjective understanding and perception of several symbols depicted by the children. This aspect is also relevant for consideration within the analysis of parental interviews. Furthermore, since the child with Down syndrome was more fluent in expressing herself in Norwegian, important information

could have been lost when she was trying to express herself in English as she had to repeat herself in order to be understood.

Difficulties in finding the family: One of the major difficulties in the research process was the difficulty of finding a family. This aspect influenced the amount of time left for the data analysis.

The first limitation discussed above gives ideas for future research which are presented in the section which follows.

5.3. Implications for the future research

1. The need to explore and to identify how different kinds of special needs impact sibling relationships.

As discussed, this case study had an objective to fill the gap of researching siblings own views and understanding on their relationships with their siblings with special needs. However, the study provides only lived experiences of siblings of children with Down syndrome in one Norwegian family. There is a need to identify sibling perspectives also in families with different kinds of special needs. As siblings of children with severe intellectual disability may have totally different lived experiences from those of the siblings of Ingrid, who, regardless of her stubbornness, is a happy child who loves to dance and make performances with the siblings for their parents.

2. The need to investigate sibling relationships during adolescence or adulthood

The present study presented only views of children aged below the adolescence period, when playing is still the dominant significant aspect of the family's life. However, the sibling relationships may attain another direction with starting the adolescent period, when playing goes to the background, and peer relationships and group belonging becomes the most important value. The review of adolescent theories affirms (King, 2004) that this period is often a transitional and challenging period for many individuals who often have conflicting emotions and confusions. Therefore, it could be assumed that the sibling relationships during the adolescent period can be different from the experiences of the children in early childhood.

Furthermore, another significant research area would be sibling relationships which may also take another dimension in adulthood, when the siblings create their lives outside of the parental house.

Thus, future research on siblings' experiences in families of children with different kinds of special needs, as well as with different sibling age groups may give an opportunity to create a more holistic understanding on the discussed topic, as the literature review showed that there is still an absence of such a consistency.

5.4 Implications for practice

1. The key role of the practitioners in providing the necessary information about possible sibling difficulties to the families

First, as the mother's statement made it clear, professionals working with families with a child with special needs can have a great impact on the parental understanding of the possible sibling difficulties. As was evidenced, the mother kept in her mind the words of Ingrid's physical therapist, who told her that siblings of children with special needs might not receive sufficient attention from the parents. Hence, there is a need for professionals to be aware of their roles in the lives of the families and take the responsibility to pass the knowledge to the families they are working with in form of seminars, support groups or in any other way.

2. The importance of encouraging the parents to speak about the child's special needs with the siblings

Secondly, this study supports the finding from previous research (Scelles, Bouteyre, Dayan and Picon, 2012; Waite-Jones and Madill, 2008; Kutner, 2007) that the siblings are not given information about their sibling's special needs. Neither the mother nor the father has ever talked with the siblings about Ingrid's special needs, whereas all the mentioned researchers found the significance of providing the siblings with satisfactory information about their brother's or sister's special needs. In the present study, the parents started to reflect on this topic after the interview question about this topic, meaning that again the practitioners need to direct the parents' attention towards this significant point.

3. Develop programs encouraging the parents of typically developing children to learn to interact and include their children's classmates with special needs into the play dates or birthdays

Finally, although the finding that the child with Down syndrome was not being invited to birthdays did not have an impact on the siblings' lives in the present case study, it is still noteworthy to highlight, that, unfortunately, even the families with such a positive experience and atmosphere need to overcome the hurtful feelings of their child's exclusion from the play dates and peer relationships outside of the school walls. One of the explanations given by the parents for their child's exclusion was the fact that families did not know how to interact and include the child with special needs. Thus, it seems to be highly important that the school psychologist or any other professional helps other families to be aware of their children's classmate's special needs and encourage them to include them in the play dates or birthdays organized in their house.

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7 Appendices

7.1 Appendix 1: Letter confirming Ethical Approval from Norwegian Social Science Data Services

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES



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Vår dato: 19.08.2013 Vår ref:34997 / 3 / AMS Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 15.07.2013. Meldingen gjelder prosjektet:

34997	<i>The relationships between children with cerebral palsy and their siblings</i>
Behandlingsansvarlig	Universitetet i Oslo, ved institusjonens øverste leder
Daglig ansvarlig	Liv Margarete Lassen
Student	Avgustina Martirosyan

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

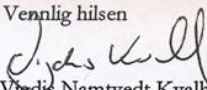
Personvernombudets tilrådning forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

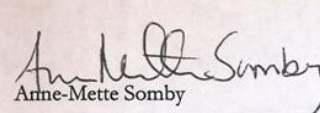
Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, <http://www.nsd.uib.no/personvern/meldeplikt/skjema.html>. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://pvo.nsd.no/prosjekt>.

Personvernombudet vil ved prosjektets avslutning, 05.12.2013, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen


Vigdis Namtvedt Kvalheim


Anne-Mette Somby

Kontaktperson: Anne-Mette Somby tlf: 55 58 24 10
Vedlegg: Prosjektvurdering
Kopi: Avgustina Martirosyan, Olav M. Troviks vei 26, Ho. 115, 0864 OSLO

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7.2 Appendix 2: The K-F-D Analysis Sheet of Lukas (Burns and Kaufman, 1972)

Name: Lukas Age: 10 Sex: Male

I. Style (s)

- Compartmentalization
- Edging
- Encapsulation
- Folded Compartmentalization
- **Lining on the Bottom**
- Lining on the Top
- Underlining Individual Figures

II. Symbol (s)

- A. **Ball**
- B. **Parents as Goalkeepers/Security**
- C.
- D.

III.A: Actions of Individual Figures

Figure	Action
Self	Playing football
Mother	Playing football
Father	Playing football
Younger Brother	Playing football
Younger Sister	Playing football
Older Brother	Playing football
Older Sister	Playing football

III.B: Actions between Individual Figures

Figure	Action	Recipient
Self (Lukas)	Playing football	In a 'boy team'
Mother	Playing football	In a 'girl' team'

Father	Playing football	In a 'boy team'
Younger brother	Playing football	In a 'boy team'
Younger sister	Playing football	In a 'girl team'
Older sister	Playing football	In a 'girl team'

IV.Characteristics of Individual K-F-D Figures

- **Arm Extensions**
 - Self
 - Mother
 - Father
 - Younger brother
 - Younger sister
 - Older sister
 - *Other ... Hands are open to the sides*
- **Elevated Figures**
 - Self
 - Mother
 - Father
 - Younger brother
 - Younger sister
 - Older sister
- **Erasures**
 - Self
 - Mother
 - Father
 - Younger brother
 - Younger sister
 - Older sister
- **Figures on Back**
 - Self
 - Mother
 - Father
 - Younger brother
 - Younger sister
 - Older sister
- **Hanging**

- Self
 - Mother
 - Father
 - Younger brother
 - Younger sister
 - Older sister
-
- **Omission of Body Parts**
 - Self
 - Mother
 - Father
 - Younger brother
 - Younger sister
 - Older sister
-
- **Omission of Figures**
 - Self
 - Mother
 - Father
 - Younger brother
 - Younger sister
 - Older sister
-
- **Picasso Eye**
 - Self
 - Mother
 - Father
 - Younger brother
 - Younger sister
 - Older sister
-
- **Rotated Figures**
 - Self
 - Mother
 - Father
 - Younger brother
 - Younger sister

- Older sister

V. K-F-D Grid

A. Height

- Self (Lukas), 3.5cm
- Mother – 4.4cm
- Father-3.8cm
- Younger brother (Henrik)-3.2cm
- Younger sister (Monica) -2.6 cm
- Older sister (Ingrid)-2.9cm

B. Location of Self –in the ‘boy team’ playing football, between Henrik and Ingrid

C. Distance of Self from

Mother –9.8cm

Father -5.7cm

7.3 Appendix 3: Henrik’s K-F-D Analysis Sheet

K-F-D Analysis Sheet: Henrik

Name: Henrik **Age:** 7 **Sex:** Male

III. Style (s)

- Compartmentalization
- Edging
- **Encapsulation**
- Folded Compartmentalization
- **Lining on the Bottom**
- Lining on the Top
- Underlining Individual Figures

IV. Symbol (s)

- E. Sun
- F. Teeth
- G. Trampoline (with teeth)
- H.
- I.
- J.

III.A: Actions of Individual Figures

Figure	Action
Self	Playing with Lukas
Mother	Looking out the window
Father	Looking out the window
Younger Sister (Monica)	Looking out the window
Older Brother (Lukas)	Playing with Henrik
Older Sister (Ingrid)	Looking out the window

III.B: Actions between Individual Figures

Figure	Action	Recipient
Self	Playing with Lukas	Lukas
Mother	-	
Father	-	
Younger sister	-	
Older brother	Playing with him	Henrik
Older sister	-	

IV.Characteristics of Individual K-F-D Figures

A. Arm Extensions

- *Self*
- Mother
- Father
- Younger sister
- Older brother
- Older sister

B. Elevated Figures

- *Self*

- Mother
- Father
- Younger sister
- Older brother
- Older sister

C. Erasures

- Self
- Mother
- Father
- Younger sister
- Older brother
- Older sister

D. Figures on Back

- Self
- Mother
- Father
- Younger sister
- Older brother
- Older sister

E. Hanging

- Self
- Mother
- Father
- Younger sister
- Older brother
- Older sister

F. Omission of Body Parts

- Self
- Mother
- Father
- Younger sister
- Older brother
- Older sister

G. Omission of Figures

- Self
- Mother
- Father
- Younger sister
- Older brother
- Older sister

H. Picasso Eye

- Self
- Mother
- Father
- Younger sister
- Older brother
- Older sister

I. Rotated Figures

- Self
- Mother
- Father
- Younger sister
- Older brother
- Older sister

V. K-F-D Grid

A. Height

- Self -11cm
- Mother -3mm
- Father-7mm
- Younger sister (Monica) 4mm
- Older brother (Lukas) – 5.6cm
- Older sister – 5cm

B. Location of Self –with the older brother Lukas

C. Distance of Self from

Mother –approximately, 4 cm

Father - approximately, 4 cm

7.4 Appendix 4: Ingrid's K-F-D Analysis Sheet

Name: Ingrid Age:11 Sex: Female

I. Style (s)

- Compartmentalization
- Edging
- Encapsulation
- Folded Compartmentalization
- Lining on the Bottom
- Lining on the Top
- Underlining Individual Figures
- None

II. Symbol (s)

- *Sun*
- *Grass (with finished details)*
-
-
-
-

III.A: Actions of Individual Figures

Figure	Action
Self	-
Mother	-
Father	-
Younger Brother	-
Younger Sister	-
Older Brother	-
Older Sister	-

III.B: Actions between Individual Figures

Figure	Action	Recipient
Self		
Mother		
Father		
Younger brother Younger sister		
Older sister		
Younger sister		

IV.Characteristics of Individual K-F-D Figures

- **Arm Extensions**
 - Self
 - Mother
 - Father
 - Younger brother
 - Younger sister
 - Older brother
- **Elevated Figures**
 - Self
 - Mother
 - Father
 - Younger brother
 - Younger sister
 - Older brother
- **Erasures**
 - Self
 - Mother
 - Father
 - Younger brother
 - Younger sister
 - Older brother
 - **Other ... Clouds**
- **Figures on Back**
 - Self
 - Mother
 - Father

- Younger brother
- Younger sister
- Older brother

- **Hanging**
 - Self
 - Mother
 - Father
 - Younger brother
 - Younger sister
 - Older brother

- **Omission of Body Parts**
 - Self (Ingrid)
 - Mother
 - Father
 - Younger brother
 - Younger sister
 - Older brother

- **Omission of Figures**
 - Self
 - Mother
 - Father
 - Younger brother
 - Younger sister
 - Older brother

- **Picasso Eye**
 - Self
 - Mother
 - Father
 - Younger brother
 - Younger sister
 - Older brother

- **Rotated Figures**

- Self
- Mother
- Father
- Younger brother
- Younger sister
- Older brother

V. K-F-D Grid

A. Height

- Self – (Ingrid) 9mm
- Mother -9mm
- Father -1cm
- Younger sister (Monica)9mm
- Brother (Lukas)- 7mm
- Brother (Henrik) -7mm

B. Location of Self –identified with the other female representatives of the family (the mother and Monica) on the left upper part of the paper

C. Distance of Self from

Mother –1.1cm

Father -16.8 cm

7.5 Appendix 5: Monica's K-F-D Analysis Sheet

K-F-D Analysis Sheet: Monica

Name: Monica Age: 5 Sex: Female

- **Style (s)**

- III. Compartmentalization
- IV. Edging
- V. Encapsulation
- VI. Folded Compartmentalization
- VII. Lining on the Bottom
- VIII. Lining on the Top
- IX. Underlining Individual Figures

- **Symbol (s)**

- **Belly Button**

-
-
-
-
-
-

III.A: Actions of Individual Figures

Figure	Action
Self (Monica)	playing
Mother	Playing
Father	Playing
Older Brother (Henrik)	Playing
Older Brother (Lukas)	Playing
Older Sister	Playing

III.B: Actions between Individual Figures

Figure	Action	Recipient
Self	Playing	
Mother	Playing	

Father	Playing	
Older brother (Henrik)	Playing	
Older brother (Lukas)	Playing	
Older sister	Playing	

IV.Characteristics of Individual K-F-D Figures

- **Arm Extensions**
 - Self
 - Mother
 - Father
 - Younger brother
 - Older brother
 - Older sister
- **Elevated Figures**
 - Self
 - Mother
 - Father
 - Younger brother
 - Older brother
 - Older sister
- **Erasures**
 - Self
 - Mother
 - Father
 - Younger brother
 - Older brother
 - Older sister
- **Figures on Back**
 - Self
 - Mother
 - Father
 - Younger brother
 - Older brother
 - Older sister
- **Hanging**
 - Self

- Mother
 - Father
 - Younger brother
 - Older brother
 - Older sister
-
- **Omission of Body Parts**
 - Self
 - Mother
 - Father
 - Younger brother
 - Older brother
 - Older sister
-
- **Omission of Figures**
 - Self
 - Mother
 - Father
 - Younger brother
 - Older brother
 - Older sister
-
- **Picasso Eye**
 - Self
 - Mother
 - Father
 - Younger brother
 - Older brother
 - Older sister
-
- **Rotated Figures**
 - Self
 - Mother
 - Father
 - Younger brother
 - Older brother
 - Older sister

V. K-F-D Grid

A. Height

- Self (Monica) – 5.5cm
- Mother – 3.7cm
- Father -6 cm
- Older brother (Henrik) – 5cm
- Older brother (Lukas) – 3.6cm
- Older sister (Ingrid) – 5.5cm

B. Location of Self: in the middle of the drawing Ingrid and Henrik from one side and Lukas, Father and Mother from another

C. Distance of Self from

Mother –7,7cm

Father -3.7 cm

7.6 Appendix 6: Interview Guide

1. How would you describe the relationships between your child with special needs and your child or children without special needs?
2. Do your children spend time together?
 - If yes, how do they like to spend time together? How often? Where?
 - If no, how do you think, what are the reasons that they do not...?
3. Do your children support each other? If yes, can you give some examples of the support they give to each other?
4. Usually, it is normal for all siblings to have conflicts. Do your children have conflicts as well? If yes, what kind of conflicts do they have?
5. How do you try to solve these conflicts?
6. Do you think having special needs influences your child's relationships with his/her brother or sister without special needs? If yes, how?

7. How do you think, your child without special needs perceives the fact that his/her brother or sister has special needs? Has his/her understanding been changed over time? (if yes, how?)
8. Do you think that the experience of having a brother/sister with special needs influences the life of your child without special needs? If yes, how?
9. Many parents feel that it is difficult for them to balance their time and attention between the child with special needs and their other children. What are your feelings about this topic? How do you balance your time and attention between all your children?
10. Is there anything you think parents should take especially into account in bringing up their children with and without special needs?
11. Is there anything else you would like to add?

7.7 Appendix 7: Informed Consent form for Parents



UNIVERSITY OF OSLO

DEPARTMENT OF SPECIAL NEEDS EDUCATION

INFORMED CONSENT FORM

My name is Avgustina Martirosyan. I am a master student at the University of Oslo. I am conducting a research study with my supervisor Liv M. Lassen **about the relationships of children with special needs with their brothers and sisters.**

This informed consent form is for parents of children who have both children with and without special needs.

The project has been reported to the Data Protection Official for Research at the Norwegian Social Science Data Services.

The Informed Consent has two parts.

- 1. Information sheet, in order to share information with you about the purpose and procedure of the study.**
- 2. Certificate of Consent (For signatures, if you choose to participate)**

Information Sheet

Purpose

The purpose of this study is to understand how children with special needs and their brothers or sisters perceive and support each other, how they like to spend time together, what kind of conflicts they may have. This will give an opportunity to understand the difficulties children with special needs and their siblings may have in their relationships with each other and in the family, as well as to develop a program which can support the families with a child with special needs.

Type of Research Intervention

You will be asked to answer several questions about your children's relationships with each other. The questions will be in the form of an interview and will be about your own reflections and perceptions of the support your children give to each other, conflicts or competition they may have, activities they like to be engaged in and so on. You are free to refuse to answer any of the questions, as well as to withdraw from the interview at any time. You are being invited to participate in the research because I believe that your experience as a parent of a child with special needs and of a child without special needs will contribute a lot to the understanding of relationships between children with and without special needs.

Duration

The interview may last from 30 to 40 minutes.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not.

Possible Risks

I am asking you to share with me personal and family information, and you may feel unpleasant to talk about some of the questions. However, you do not have to answer all of the questions and have the right to withdraw from the interview at any time. You do not have to give a reason for refusing to answer any of the questions or refusing to take part in the research.

Benefits

Probably there will be no direct benefit for you from your participation, but the information given by you may help to understand better the relationships of children with special needs with their brothers and sisters, the difficulties children with special needs, as well as their brothers and sisters without special needs may have. This will help to develop support programs for families and for children who may be in a similar situation.

Confidentiality

The information given by you will be kept private. Any information about you will have a number on it instead of your name and only the researcher will know what your number is. Furthermore, if you choose, that I can use audio recorder, the recordings will be kept in a safe place and no one, except the researcher will have an access to it. After writing the dissertation, all recordings will be destroyed.

CERTIFICATE OF CONSENT

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Name of Participant _____

Signature of Participant _____

Date _____

Day/month/year

Statement by the researcher/person taking consent

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this paper has been provided to the participant.

Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent_____

Date _____

Day/month/year

7.8 Appendix 8: Parental Consent Form for the Children's Participation



UNIVERSITY OF OSLO

DEPARTMENT OF SPECIAL NEEDS EDUCATION

INFORMED PARENTAL CONSENT FOR RESEARCH INVOLVING CHILDREN

My name is Avgustina Martirosyan. I am a master student at the University of Oslo. I am conducting a research study with my supervisor Liv M. Lassen **about the relationships of children with special needs with their brothers and sisters.**

Whenever researchers involve children in their research study they ask for permission from their parents. After you read more about study, and, if you agree, the next thing I will do, is that I will ask your children for their agreement as well. Apart from conducting an interview with parents, who have children both with and without special needs, I also want to involve the children in this research study, as I feel that it is important to attain knowledge how children themselves perceive their relationships.

The project has been reported to the Data Protection Official for Research at the Norwegian Social Science Data Services.

The Informed Consent has two parts.

1. Information sheet, in order to share information with you about the purpose and procedure of the study.
2. Certificate of Consent (For signatures, if you choose that you want your children to participate in the study)

Information Sheet

Procedure

Psychological projective method will be used with children, which will include the following. Children will be asked to draw on the A4 paper their family members 'doing some activity'. They do not need to have special drawing skills for it, as they are free to draw however they want or feel. This will give an opportunity to understand how children perceive themselves, their brothers and sisters, and other family members in the family. Afterwards, they will be asked to describe the picture and to explain why they decided to draw a family in that particular way and family members doing that particular activity. This will also give an opportunity to understand how children perceive their relationships with their brothers or sisters.

Voluntary Participation

You do not have to agree that your children take part in the study. I understand that the decision can be difficult when it involves your children, and you are free to say no. You can ask any question you may have and then come to the final decision.

Duration

The duration of the research will depend on how long it will take from the child to draw the picture, but I expect that it may take approximately one hour including the description of the picture and follow up questions by the researcher.

Risks and Discomforts

I believe that there are not any potential risks for your children's participation, but if they feel discomfort they are free to refuse to continue their participation at any time. They are also free not to answer any question or not to talk about any part of the drawing if they feel

uncomfortable. If the follow up questions are too personal, children may refuse to answer to any of them either. The follow up questions will be about the drawing of the child, why he or she has decided to draw him/her and the brother or sister doing that particular activity, what do they like to do in general with their brother and sister and so on.

Benefits

There may be no direct benefit for you from your children's participation, but the information given by them may help to understand better the relationships of children with special needs with their brothers and sisters, the difficulties children with special needs, as well as their brothers and sisters without special needs may have. This will help to develop support programs for families and for children who may be in a similar situation.

Confidentiality

The information given by your children will be kept private. Any information about them will have a number on it instead of their name and only the researcher will know what their number is. Your daughter/son may choose to tell you about his/her participation and drawings or answers, but she/he does not have to do this. The researcher will not be sharing with you the answers given to us by your child as well, as I will promise the children that the information given by them will be kept private.

Certificate of Consent

I have been asked to give consent for my daughter/son to participate in this research study where she/he will be asked to draw family members doing some activity and describe the picture with follow up questions by the researcher. I have read the information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily for my child to participate as a participant in this study.

Name of the Parent or Guardian _____

Name of the Child _____

Signature of the Parent of Guardian_____

Date _____

Day/month/year

Statement by the researcher/person taking consent

I confirm that the parent was given an opportunity to ask questions about the study, and all the questions asked by him/her have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving parental consent, and the consent has been given freely and voluntarily.

A copy of this Informed Consent Form has been provided to the parent or guardian of the participant _____

Name of Researcher/person taking the consent _____

An Informed Assent Form will be completed by the children as well.

7.9 Appendix 9: Assent Form for Children



UNIVERSITY OF OSLO

ASSENT TO PARTICIPATE IN RESEARCH

This Informed Assent Form has two parts:

- Information Sheet (gives you information about the study)
- Certificate of Assent (this is where you sign if you agree to participate)

Information Sheet

My name is Avgustina. I am from the University of Oslo. I am asking you to take part in a research study as I want to know more how children like to spend time with their brothers or sisters, how they support each other or what kind of conflicts and difficulties they may have in communication with each other and with the family members.

Procedure

If you agree to be in this study you will be asked to draw a picture of your family members doing some activity. You do not need to have special drawing skills for it, as you are free to draw however you want or can. There is no right or wrong, and you may draw as you want and feel. Then, you will be asked to describe your picture and several questions about your drawing.

Duration

You are free to take your time and to draw a picture as long as you want to. After that you will be asked questions about your drawing and will be asked to describe your picture.

Voluntary Participation

You are free to refuse to participate in the research at any time, as it is only up to you to decide whether you want to participate or not. We have also asked your parents' permission for your participation. But, even they said yes, you are still free to decide not to participate in the research now or at any time.

Risks

I believe that this study will not hurt you in any way, but in case you feel it does, you are free to refuse to take part in it at any time or you can refuse to answer any question or not to describe any part of your picture if you do not want to do it.

Benefits

Probably this study will not have a direct benefit for you, but it will help us and other people to understand how children like to spend time with their brothers and sisters, what kind of conflicts and difficulties they may have, and to try to find ways of supporting children to overcome those difficulties.

Confidentiality

Signing your name at the bottom means that you agree to be in the study, however your name will not be mentioned anywhere in the study, and will be replaced with a number, so no one except the researchers will know which answers have been given by you or which picture has been drawn by you.

Certificate of Assent

I have read this information (or had the information read to me). I have had my questions answered and know that I can ask questions later if I have them.

Name of the child _____

Signature of the child: _____

Date: _____

day/month/year

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving assent, and the assent has been given freely and voluntarily.

Name of Researcher/person taking the assent _____

Signature of Researcher /person taking the assent _____

Date _____

Day/month/year

Parent/Guardian has signed an informed consent ___Yes ___No ____ (initialed by
researcher/assistant