

Living with a Sibling with Autism/PDD: Building the Bridge

A Thesis

Submitted in partial fulfillment
of the requirements for the degree of
Master of Arts in Special Education

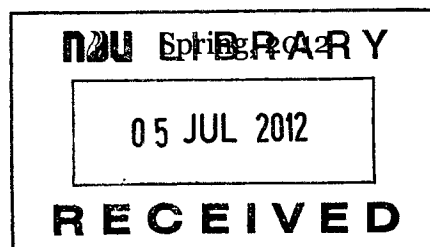
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Thesis Signature Page

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Living with a Sibling with Autism/PDD: Building the Bridge

Maria K. Margossian

Abstract

This research deals with the effects that living with a sibling with Autism has. The aim of the research was to investigate the effect of living with a sibling with Autism/PDD by using play therapy methods. In order to achieve this goal the researcher undertook a literature study to provide a better insight into the dimensions and complexities of defining autism and its related conditions, as in-depth look at the triad of impairments and the influence this has on the functioning of siblings of children with Autism/PDD.

The second objective was to undertake an empirical study with regards to the influence of Autism/PDD on the functioning of these siblings. The third objective was to make recommendations to parents and people working in families with children with Autism/PDD that will enable them to respond to the needs of these siblings.

The researcher made use of applied research. The data collection phase consisted of unstructured interviews, conducted in the form of play process. The research question was the following: What is the effect of living with a sibling with Autism/PDD?

Qualitative research was used in this study to enable the researcher to do a subjective exploration of reality and focused on the following aspects: helping, advocacy,

awareness and a need for information, positive and negative feelings that the respondents experienced about their siblings, the effect on the child in middle childhood as well as family stresses.

The researcher came to the conclusion that siblings of children with Autism/PDD experience both positive and negative feelings with regards to their brother/sister with Autism/PDD.

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Chapter 1: Introduction

“Autism is not a puzzle, nor a disease. Autism is a challenge, but certainly not a devastating one. Autism is about having a pure heart and being very sensitive. It is about finding a way to survive in an overwhelming, confusing world. It is about developing differently, in a different pace and with different leaps.

Autistic beings develop and bloom if their spirits, talents and self-esteem are not destroyed by bullies, prejudice and being forced to be ‘normal’”

- Trisha Van Berkel

—

Every family will respond to the challenge of autism in its own way. Most parents don't have much reason to know about autism until they become concerned that their child may have it. Most parents agree that caring for a child with autism requires tremendous energy, patience, resourcefulness and flexibility. Often, adaptations are necessary. Parenthood is demanding enough, but when a child has social, communication and behavior problems, getting through a typical day can be exhausting and frustrating. Many families face huge challenges caring for siblings who have a brother/sister with autism (SWA) (Lessenberry & Rehfeldt, 2004).

Autism Spectrum Disorder is a range of neurological disorders that most markedly involve some degree of difficulty with communication and interpersonal relationships, as well as obsessions and repetitive behaviors. It appears during the first three years of life (Duby & Johnson, 2009). As the term “spectrum” indicates, there can be a wide range of effects. Those at the lower-functioning end of the spectrum may be

profoundly unable to break out of their own world. Children typically have difficulties in verbal and non-verbal communication, leisure and play activities and social interactions (Janzen, 1996).

Many of these children have brothers and sisters. These siblings will share the same concerns that the parent of children with special needs experience. They will also experience issues that are uniquely theirs (Knott, Lewis & Williams, 2007). Parents are not the only family members whose lives revolve around the child with autism. These children also become the center of action in the lives of their brothers and sisters (Lessenberry & Rehfeldt, 2004). The whole family can therefore feel the impact.

When young people have questions about a sibling with autism clear answers are hard to find. Autism disrupts the typical relationship between siblings. It may be especially difficult for other children to understand why SWA gets so much of your attention. They may feel rejected or embarrassed by their sibling's communication and social difficulties. Some young siblings worry that they will "catch" autism and others wonder if they'll be responsible for their brother or sister's care.

Sibling relationship is the longest lasting relationship in the family, sibling issues are lifelong issues and change throughout the lifespan. Families report that it helps if each child feels special in the family and has a way to get his/her basic needs met. It also helps to explain autism to siblings in terms they are likely to understand (Cancro, 2008).

The siblings of the child with autism experience a wide range of feelings. Research indicates that siblings often do not understand or have misinformation

regarding the definition and cause of their brother or sister's disorder (Cancro, 2008). Throughout their lives, siblings share many of the concerns that parents of children with special needs experience, including isolation, a need for information, guilt, concerns about the future, and care giving demands. Brothers and sisters also face issues that are uniquely theirs including resentment, peer issues, embarrassment and pressure to achieve. In "My Brother is Different" (1997), Gorrod uses illustrations to describe some of the feelings that siblings of children with autism experience. One sibling comments: "If I'm playing on the floor, my brother tramples all over it. This is because he doesn't know how to play games, even if I try to explain them to him." And: "When I behave badly I get told off but my brother doesn't. This sometimes seems unfair" (Gorrod, 1997). It is to say that it may be difficult to cope with a lot of different emotions which change their experiences, from guilt, anger, anxiety to hope, sympathy, love and understanding.

Motivation for the choice of topic

The researcher has been working with family constellations that have a child with autism. The topic is told in the voice of someone who has occupied with children who require special attention for seven years now. Among the categories of special needs, dealing with students who have autism was considered one of the most important spectrum disorders during her career life.

The topic of interest is to investigate the effect of living with a sibling with autism by using play therapy method. The topic was formed taking into consideration the following questions:

- What are the feelings that young siblings express about their sibling with autism?
- What are the unique stresses and challenges that normal siblings encounter as a result of having a sibling that was diagnosed with autism?

The research in this study can assist important guiding information to the families which the researcher works with. Moreover, teachers and therapists can also benefit from the professional consultations to address the many issues they face.

Purpose

Do problems faced by families of a child with autism mean that the barriers between parents and children are too high for good communication about a sibling with autism? It simply requires extra effort from everyone in the family.

The purpose of the study is to interpret the effects of living with a sibling with autism. The research data will analyze the cooperation with the siblings by means of play therapy sessions in order to examine some of the specific things one can do to help children cope with the special needs of their sibling with autism.

This work will be of great interest to educators, parents and clinicians in their effort to facilitate the living with a sibling with autism. It attempts to ease the burden on families and particularly siblings that it is acceptable to have ambivalent feeling toward our sibling with autism.

Key Words and Terms

1. Biblio-therapy Bibliotherapy is an expressive therapy that uses an individual's relationship to the content of books and poetry and other written words as therapy. Bibliotherapy is often combined with writing therapy. It is an old concept in library science. The basic concept behind bibliotherapy is that reading is a healing experience. Bibliotherapy can consist solely of reading, or it can be complemented with discussion or play activity. A child might be asked to draw a scene from the book or asked whether commonality is felt with a particular character in the book. The book can be used to draw out a child on a subject he has been hesitant to discuss.

2. Middle Childhood Middle childhood brings many changes to a child's life. By this time, children can dress themselves, catch a ball more easily with only their hands, and tie their shoes. Developing independence from family becomes more important now. Events such as starting school bring children this age into regular contact with the larger world. Friendships become more and more important. Physical, social, and mental skills develop rapidly at this time. This is a critical time for children to develop confidence in all areas of life, such as through friends, schoolwork, and sports.

Here are some changes your child may go through during middle childhood:

Emotional/Social Changes

- More independence from parents and family.
- Stronger sense of right and wrong.
- Beginning awareness of the future.
- Growing understanding about one's place in the world.
- More attention to friendships and teamwork.
- Growing desire to be liked and accepted by friends.

Mental/Cognitive Changes

- Rapid development of mental skills.
- Greater ability to describe experiences and talk about thoughts and feelings.
- Less focus on one's self and more concern for others.

3. Play Therapy Play therapy is a technique whereby the child's natural means of expression, namely plays, is used as a therapeutic method to assist him/her in coping with emotional stress or trauma. It has been used effectively with children who have an understanding level of a normal three to eight year old, who are; distraught due to family problems (e.g., parental divorce, sibling rivalry), nail biters, bed wet, aggressive or cruel, social underdeveloped, or victims of child abuse. It has also been used with special education students whose disability is a source of anxiety or emotional turmoil. Practitioners of play therapy believe that this method allows the child to manipulate the world on a smaller scale, something that cannot be done in the child's everyday environment. By playing with specially selected materials, and with the guidance of a person who reacts in a designated manner, the child plays out his/her feelings, bringing these hidden emotions to the surface where s/he can face them and cope with them.

4. Siblings: Siblings are people who share at least one parent. A male sibling is called a brother; and a female sibling is called a sister. In most societies throughout the world, siblings usually grow up together and spend a good deal of their childhood with each other, like playing and having fun. This genetic and physical closeness may be marked by the development of strong emotional bond such as love or enmity. The emotional bond between siblings is often complicated and is influenced by factors such as parental treatment, birth order, personality, and personal experiences outside the family.

Chapter 2: Literature Review

“What would happen if the autism gene was eliminated from the gene pool?

You would have a bunch of people standing around in a cave, chatting and socializing and not getting anything done.”

- Temple Grandin -

In order to undertake scientific research on a specific problem, it is important for the researcher to have thorough background knowledge about the topic. The researcher orientates himself to the project, is to do a pilot study (Hubberman & Miles, 2002).

Boutelle (2008) is of the opinion that the goal of a literature study is aimed at contributing towards a clear understanding of the nature and meaning of the problem that has been identified. It provides a better insight into the dimensions and the complexities of the problem. In this study the focus will be on defining autism and its related conditions, an in depth look at the triad of impairments, the influence it has on the siblings of children with autism and builds on the different researches that have been made over the past decades.

Parents experience mixed emotions when they are told their child has autism. The effects of children with autism on families have been documented by parents and were recently made by clinicians and researchers. Usually the care and treatment of children with disabilities have been in the hands of institutions, professionals and schools. The process is being reversed and parents are slowly relinquishing the treatment, care and education of children with disabilities (Boutelle, 2008). The Son-Rise program, at the Option Institute in the United States of America, teaches parents,

volunteers and assisting professionals on how to design and implement parent-directed, child-centered, home-based programs for children with special needs (Kaufman, 1999). An autistic culture is being developed, with some individuals approaching support services and therapies and others believing autism should be tolerated as a different way of being, not a disorder to be cured.

Siblings also play an important role in the treatment of sibling with autism. Most children grow up with siblings and are raised by siblings in many cultures (Cancro, 2008). These siblings share the anticipation and excitement of a new baby but they also share the grief and pain that accompanies the birth of a disabled brother/sister (Harris & Glasberg, 2008). Therefore, it is very important to know and respond to the needs of these siblings.

The syndrome we know as autism has been a booming topic of interest on the part of researchers from the time of its description by Leo Kanner almost 70 years ago. In 1943, Leo Kanner coined the term "infantile autism". He described children who exhibited aloneness, delayed language development, repetitions of noises, limited range of spontaneous activities, poor eye contact and abnormal relationships with persons. Though the name autism is a recent concept, the disability has been known since 1799. The first description of autistic behavior was in 1799 but it only became a source of scientific research in 1943, after the publication of Kanner's article called "Autistic Disturbance of Affective Contact" (Iverson & Wozniak, 2007).

Most recent reviews tend to estimate a prevalence of 0.1 – 0.6 % of the general population. The number of reported cases of autism has increased dramatically during

the past decade. This increase is largely attributed to better diagnosis, referral patterns, availability of services and public awareness. As such, autism has commanded the attention of parents, practitioners, educators, researchers and policy makers who search for causes and solutions. The need for taking care of siblings of children with autism will increase as the number of children diagnosed with autism increase.

Another type of autism surfaced in the last decade. This new type autism also set a new challenge for families and siblings of children with autism. It was often referred to as “autistic syndrome”. Children generally appear normal in the first 15 to 18 months of life. They usually achieve normal motor milestones on schedule and appear to be affectionate and have above average intelligence, up until age of onset. They begin to develop speech, but they cease to progress or they begin to regress. They also become withdrawn and often self-stimulatory behavior like arm flapping, spinning, rocking or head banging appears. They are also quiet at times and hyper at other times (Janzen, 1996). A difficult time for families is the time between the age of recognition and the age of onset of disabilities. This is also the time when behavioral requirements for the non-handicapped siblings are formed (Seigel & Silverstein, 1999). This is also a stressful time for siblings because of the parents’ growing anxiety that there is something wrong with their child.

The triad of Impairments in Siblings with Autism

Diagnosis is based on behavior, not cause or mechanism. The defining characteristics of autism are qualitative occurring in three major areas: Activities and interests, verbal and non-verbal communication, impairment of imagination. Wing and

Gould (in Wing, 1998) studied the prevalence of autism in children under the age of fifteen. In this study the subjects were impaired in their capacity for reciprocal social interaction. The researcher found that this abnormality of social interaction was closely related to the impairment of imagination communication, which resulted in a narrow and repetitive pattern of activities. This cluster of problems is referred to as the triad of impairments.

Impairment of Social Interaction

Humans are social beings who are inclined to seek out the company of other people, offering each other the opportunity to share ideas, feelings, opinions and interests (Schoeman, 1996).

Socialization is the process by which children become aware of society and learn how they are expected to behave through observing and having contact with other people. Our social experiences influence how we conduct ourselves in public and how we develop as individuals. We all teach each other to be fitting and accepted members of society (Siegel & Silverstein, 1999). Children with autism do not learn socialization skills in the way that most of us do. Dysfunction in social behavior is a key defining feature of their disorder. They are very good at isolating themselves even in a room full of their family members. They may not understand how people behave and interact with one another. They may not be able to make sense of social experiences and may be unsure of how to behave in particular circumstances (Harris & Glasberg, 2005). By eighteen months of age most toddlers naturally pay attention to events and somehow want to get

into the act. A two-year-old with autism may be happy to sit by himself and repeatedly wave a piece of ribbon.

Since the thought processes of children with autism work differently than for most of other people, they may have considerable difficulty understanding and dealing with others. This dysfunction in social behavior can be classified into three categories: socially reclusive, socially indifferent, and socially awkward.

Social Avoidance: Children with autism may avoid nearly all forms of social interaction. They may have tantrums or run away when others try to speak with or come near them. It may seem as if they are fearful or do not like other people. It is more likely, however, that children with autism avoid other people because their voices hurt their ears, their smells are too strong, or their touch actually causes pain. They are strongly affected by sights, sounds, smells and touch (physical contact). Some infants with autism will even arch their backs or cry loudly to avoid contact with a parent or caregiver (Boutelle, 2008)

Social Indifference: Often children with autism do not seek out social interaction with others. This does not mean that they mind the company of other people, but they really do not mind being by themselves, either; many actually prefer it. It is possible that children with autism are socially indifferent because they receive no pleasure or joy from being around or interacting with others.

Social Awkwardness: Conversations usually require a mutual exchange or a give and take of information between two or more people. Children with autism do not have great skill when it comes to this type of social exchange and may talk only about them,

seeming self-centered to those around them. In addition, they may not have acquired the social skills to understand which types of language and behavior are considered socially acceptable (Duby & Johnson, 2009).

It has been suggested that the underlying problem of social impairment is the lack of the built-in ability to recognize that other people have thoughts and feelings (Duby & Johnson, 2009). The capacity to understand that another person thinks in the same way as the other is called theory of mind.

A theory of mind remains one of the quintessential abilities that make us human (Whiten, 1993). By theory of mind we mean being able to infer the full range of mental states (beliefs, desires, intentions, imagination, emotions, etc.) that cause action. In brief, having a theory of mind is to be able to reflect on the contents of one's own and other's minds. Difficulty in understanding other minds is a core cognitive feature of autism. The theory of mind difficulties seems to be universal among such individuals. This is also an adjustment for siblings. As one sibling comments: "He laughs when I am upset, because he doesn't always know what I am feeling (Gorrod, 1997).

Impairment of Social Communication

"The first time I had a major speech difficulty was when I joined a play school at the age of three and realized that the other children could join in and chat to one another. I guess that I did try to talk but I would get very frightened and hide inside myself, crying from the sheer agony of not being able to communicate freely"(Richard Attfield, an adult with autistic disorder and cerebral palsy, 1999).

By the age of two and a half, the average child can communicate quite well and may even be able to speak in short sentences. A child with autism, on the other hand, may use very few words at this age or may have lost the ability to use them. Instead of asking for something, a child with autism may lead by hand, gesture, cry, or scream for what he or she wants or needs. Some children with autism may not follow verbal directions or even imitate sounds or words. Others may speak very quickly, softly, or in some other stylized manner. Some who do not speak at all may be extremely skilled with letters or numbers, and those who do speak may repeat the same words over and over, apparently without much purpose (Lessenberry & Rehfeldt, 2004). When children with autism begin or fail to begin to use language, parents begin to detect how different their children are.

A lack of appreciation of the pleasure and social uses of language is always present in one form or another for children with autism. They tend to have a lack of understanding that language is a tool for conveying information to others. Even if they have a lot of speech, they talk at others and not with them. Some of the children are able to ask for their own needs but they have difficulty in talking about thoughts or feelings. Siblings also need to develop an understanding of this impairment. According to Gorrod (1997) a number of siblings find it difficult to understand why their brother/sister would keep on running in front of the television when he/she is watching or why they would scribble on their drawings. It is important for the siblings to have information about the practical ways in dealing with different situations. Gorrod suggests forced alternatives to language instead of open questions, for example: "Did you play soccer today?" instead of asking: "How was school today?"

Impairment of Behavior and Imagination

Children with autism have problems developing play skills because they often have a limited range of imagination. They do not understand how to pretend and can have a difficult time trying to play games with children their own age. This creates even more complications for them when relating to other people and forming friendships. More broadly, imagination is relevant to theory of mind since it involves an unreal world that exists purely in your mind, and being able to reflect on this virtual world. The virtual world is the content of one's mental state of imagining. One study of children with autism investigated the ability to draw pictures of unreal or impossible objects (such as two-headed people), and found that children with autism were either reluctant or less able to produce such drawings (Scott & Baron-Cohen, 1996).

Even though individuals diagnosed with autism are all very different in their own unique ways, this triad of impairments is what many of them have in common, affecting almost every aspect of their lives. This should be explained to siblings at a developmentally appropriate level. This can give them a better understanding of the reasons why siblings might, for example throw tantrums in shopping malls. In addition to the triad of impairments, additional features might be observed. This can include little or no eye contact, no real fear of dangers, bizarre eating patterns, laughing or crying for no apparent reason and abnormal sleep patterns and self-injurious behavior (Autism South Africa).

The Effect of Autism/PDD in Sibling Relationships

The nature of sibling relationship is a complex one. It is usually life- long. The feelings and the thoughts of siblings of children with autism vary considerably. Growing up with a sibling with disabilities make family relationships more complicated. It can have positive and negative effects and the issue of adaptation arises.

According to Knott, Lewis & Williams (2007) the unaffected sibling has an opportunity to have a profound and lasting effect on the child with a disability by being a model, supporter, teacher and care taker. The effects of the child with disabilities are not potentially negative but can also be potentially positive. According to Macks & Reeve (2007) adult siblings reported feeling deeply insecure about their identity and tried very hard to act or dress a certain way to be accepted. Having a sibling with a disability can bring additional difficulties to the challenge of fitting in.

As the sibling of a child with autism, he/she may have to cope with some of the behaviors and symptoms associated with the disorder, including hostility or abusiveness. They may also have to deal with unpredictable, embarrassing, or destructive behaviors. Trying to cope with these symptoms may cause stress and strained relationships among family members (Rosenberg, 2007). For many people, having a sibling with autism poses challenges and has a profound effect on their families. All of them report that they have felt the full range of emotional effects at one point or another.

Parents are often concerned about the long term effects that having a sibling with autism have on their children. According to Rosenberg, it would seem that siblings of

disabled children are not adversely affected. The negative and the positive feelings explained identify more about each specific feeling a sibling with autism might face in life

Negative Feelings

Feeling left out The child with autism naturally takes up a lot of their parents' time. Sometimes siblings may feel that they are left out and treated unfairly. Though these differences are inevitable it can leave siblings feeling less important than their brother or sister with autism (Rosenberg, 2007). The child might also feel angry at the parents for spending so much time and energy on the sibling with autism and not enough time with him making him feel left out.

Anger and guilt Since anger is a natural response in many sibling relationships, the child needs to know that it is acceptable to be angry sometimes especially when the sibling with autism somehow believes that he/she caused the autism for his brother/sister and feel guilty that he/she is perfectly healthy while the other is disabled. The healthy child may resent the amount of responsibility that has been placed on him/her in looking after the sibling with autism. He/she may also resent doing house chores which the brother or sister with autism is not required to do, even though he/she knows that sibling would have great difficulty doing them. They may also be angry at the family for allowing the sibling with autism to behave in ways that would normally be unacceptable (Rosenberg, 2007).

Praising the non-disabled siblings Parents should be mindful of praising the healthy sibling for small milestones as well (Bleach, 2005). It is crucial not to take the

accomplishments of the non-handicapped sibling for granted. This might result in a feeling that no matter how much they do, it is not enough to get their parent's praise. The children with the disability might receive tremendous feedback for simple accomplishments, such as using the potty for the first time or writing his or her name. The praise is definitely justified because the child with developmental delays finds it so hard to learn.

Inability to explain to friends The child may feel the need to keep the sibling's autism a secret because they believe that their problem is no one else's business. They feel scared that if their classmates know about the sibling's condition, they would make fun of him or stop being friends. They may feel embarrassed and unsupported by the reactions of their friends when they first meet their brother/sister. If the child is very disruptive it might be virtually impossible for children to invite their friends back home (Hames & McCaffrey, 2005).

Isolation The child might feel that they are not given the vital information about their sibling or that they are being left out of important decisions. They may also feel ignored by the professionals helping their siblings (Rosenberg, 2007:101)

Pressure The sibling might feel that he/she need to be an overachiever or perfectionist in school, sports activities, or in their behavior to make up for the abilities that his/her sibling lacks. They may also feel pressured to take care of their brother or sister with autism more than they would a normal sibling. Perhaps they are providing their parents with assistance and support that they might not otherwise have. If the sibling sees

his/her parents going through a lot of stress, they may try to act “grown-up” so that they don’t have to worry about them (Hames & McCaffrey, 2005).

Problem Behaviors The sibling might find him/her self fighting, yelling or arguing with family and friends, or even staying away from them. They may also feel the need to break things or stop doing the activities they once loved, such as sports or hobbies. Maybe they become home late and refuse to help with the chores. They may be depressed and “act out” by being rebellious, aggressive or irritable. They may spend most of their time with their friends and very little with their family. Perhaps the parents are too strict, too lenient or depressed (Bleach, 2005).

Positive Feelings

The effects of living with a sibling with autism are not only negative, but can also have a positive effect. These potential positive effects include maturity, responsibility, and tolerance, sense of closeness in the family and self-confidence and independence. Siblings of children with special needs observe the strengths and the struggles of their siblings. They also share in the achievements and celebrations of their accomplishments and their lives. By staying involved with their sibling’s services and special needs, their understanding of the need to celebrate their accomplishments, will be enhanced (Carlosn, 2002). Siblings of children with special needs often have greater tolerance, empathy and awareness of the consequences of prejudice and greater intolerance towards others.

The Factors Which Influence the Adjustment of Siblings

The nature of sibling relationship is a complex one but usually life- long and characterized by a great deal of care and affection. As siblings age, the relationship becomes more reciprocal and interact more equally. This is especially likely to happen in middle childhood when siblings begin to share social activities and interests. It is also in middle childhood that the awareness of sibling disabling condition starts taking the full picture.

Effects on the child in middle childhood

Children between the age of six and twelve start venturing out into the world and become acutely aware of the differences between people. They are able to understand an explanation of their sibling's special needs as long as it is explained to them in terms they can understand.

There is an important change in how siblings get along in middle childhood. Children start the process of separating from their family and focus more on their social and emotional role in the peer group. One of the developmental tasks of the child in middle childhood is socially move from the family to the peer group (Kaminsky & Dewey, 2002). This increased independency means that they will spend less time at home and they might have less interest in playing with their younger sibling with autism.

The child's growing confidence on their peer group can make them very susceptible to the reactions of other children concerning their sibling with autism (Kaminsky & Dewey, 2002). Some children may begin to turn away from their sibling

with autism in an effort to fit in with their peers. The child's behavior might be disconcerting to parents. By understanding that the changes in attitude reflects a developmental process can enable parents to be more patient, while still helping their daughter/son to understand that the rejection of their brother/sister is not acceptable.

The parents of high functioning children cited the following structural aspects as evidence for or against a normal family life. These are the areas parents find challenging and which influence their concept of normal family life. The areas, which rated the highest, are:

Social Outings and Activities

Many parents believe that family activities should always be shared as a family unit. When there is a child with autism, parents may feel especially strongly that this child should always be included in family events. They want to make it clear that the youngster is a full member of the family and the community, not someone to be left home with a baby sitter while the rest of the family has a good time (Lessenberry & Rehfeldt, 2004). Leisure activities, such as participation in clubs or sports and family activities such as visiting friends, attending family gatherings are often affected. One mother reported that they used to be able to go on outings but they stopped because their son would scream and run away and make life unbearable. This also affects the children because they stay at home more.

According to Miller (2001) it is important to continue to expose the child with autism to social situations, even if he/she finds it difficult. The child can develop a secondary handicap if he/she is too isolated from social situations. Examples of shared

family activities that can be performed very competently by many children with autism are jogging, bowling, or bike riding. Shopping at the mall, preparing a special meal, or going to a movie may also be shared events. It may take the child with autism longer to master the basic skills of an activity, but if you begin with modest goals and gradually build to broader objectives, it is reasonable to expect that many young persons with autism could go on family bike trip or go jogging with a sibling each morning.

Needs of Siblings

Each sibling of a child with autism is unique. Many of them share similar needs and concerns, though many of these needs and concerns change with age and circumstance. According to Sibling support project (2005) most siblings agree that they need during their childhood:

- Information on their sibling's condition, including how it is evaluated and treated
- Recognizing the sibling's own accomplishments and strengths.
- A need for quality times with their parents on an individual basis.
- Ways to cope with stressful event such as public and peer reaction, unexpected disruptions to family plans as well as extra home responsibilities.

Chapter 3: Using Play Therapy to Assess the Needs of Siblings with Autism

“The child is natural and spontaneous. When the child experiences a need or emotion, he reacts according to his real feelings. In this process he tells all about himself, his own functioning or his own way of handling things” (Schoeman & Van der Merwe, 1996 a: 61)

An exclusive body of literature has documented the effectiveness of play, as a counseling model in working with children and adolescents. Early pioneer Hug-Hellmuth is among the first who used play in an attempt to overcome the difficulties in the transition from therapy with adult to therapy with children. Anna Freud and Melanie Klein were the first to publish their ideas about play therapy with children in systematic way. Anna Freud considers that the child does not have the spontaneous ability to develop a transference reaction. She emphasized that the child in therapy does not form a transference neurosis like the adult. One of the reasons that she gives for this is that the child is still at an early stage of development, dependent on his parents, a situation which impedes the reconstruction of the original edition of his conflict (Hug-Hellmuth, 1921). In order to facilitate the development of transference the therapist uses different therapeutic aids. These include manipulation of an educational nature. Therefore, the educational role of the therapist is justified because the superego of the child is not sufficiently developed and he is still dependent on external objects. Anna Freud claims that negative transference must not be interpreted; she sees it essentially as an inconvenience which must be done away with, even through nonanalytical means. She assumes that fruitful work can be only accomplished through positive transference (Freud, 1927).

Klein saw the child's play in therapy as the equivalent of free association in adult and to making interpretations directly to the child's unconscious. Therapy provides a trouble clued a safe place from physical and psychological harm where he can let down his guards sufficiently to explore his thoughts and feelings. In assessing the needs of children, it is essential to reach out and meet them on a level they can understand. By using play therapy techniques and following an indirect approach, it is possible to break down the barriers that may prevent the therapist from reaching the child. The child in middle childhood has his/her own needs and concerns regarding his/her brother/sister with autism. This includes feelings around separating from their family or the reactions of their peers to their sibling with autism (Allen, Folger & Pehrsson, 2007). The researcher is of the opinion that it is important to help children explain to their friends what autism is in order to promote understanding.

The unique character of the child gives a special character to therapy with the child. Communication with children differs from communication with adults. This is an important element to consider especially during therapy. This influence makes the therapist speak less and observe more. For a child with autism, expressive language can be a challenge. Then the child's nonverbal communication is particularly prominent and is expressed through play therapy, gesture, facial expression and appropriate touching. The child's customs, dislikes, ideas and preferences influence his play to a large degree (Bratton & Ray, 2008).

A study by the psychologist Raymond Romanczyk (1999) identified common characteristics of play. He stated that play is intrinsically motivating because it is

pleasurable. During play, the child is more concerned with play itself than with the end result. Play has a make-believe quality and is therefore non-literal. Play is a natural way for children to express themselves, to act to sensitive material. Play is also flexible.

Reagon, Higbee & Endicott (2006) looked at how parents and siblings play with a child with autism. They found that parents tried harder to engage their child with autism in playing than their typically developing children. The more impaired the child was, the more effort parents made to encourage the child to play. It appeared that parents were doing their best to compensate for the child's limitations. By contrast, siblings made fewer efforts to help their brother or sister compensate for lack of play skills and often made little effort to engage their brother or sister in play.

A clinician observes thinks and interviews; these three activities define the work. This study suggests that if siblings had the necessary skills and interest, they might be able to engage their brother or sister with autism in some play activities and that the child with autism might show some reciprocal interest in the play. It reflects what literally practitioners have said – to make effective use of the facilities and resources in order to benefit children and to achieve the aim of this study, play therapy techniques will be used to assess the stresses and challenges siblings experience as a result of living with a brother/sister with autism.

Drawing

Drawing is a natural language for children and it offers a way to express feelings and thoughts. It was Donald Winnicott who noted the child's art could be used as a mean of

communication and in this way renders the young patients active participants in their treatment. Drawing helps:

- To enable the child to tell his/her story;
- To enable the child to express repressed or intense emotional feelings;
- To enable the child to gain a sense of mastery over events when he/she is experiencing or has experienced (Reagon, Higbee & Endicott, 2006).

A very effective technique in therapy is to have children draw their family as animals or symbols. They can use blobs of color, shapes, objects and things and animals and whatever else they can come up with.

The purpose of this activity is to elicit conversation from the children about themselves and their families. If the child's brother or sister with autism lives outside of the home, the therapist should indicate that the child should be included in the picture.

While drawings may say much about the child who creates them, what is important are the therapeutic benefits that the process of drawing provides. Sherratt (2002) uses a specific working model to elicit conversation from children around their creation. It is a modality that has a potent tool in debriefing, resolution and recovery.

- Have the child share the experience of drawing
- Let the child describe the picture in his/her own way
- Make the child elaborate on parts of the picture
- Select specific things in the picture for the child to identify with
- Ask the child questions to aid the process
- Exaggerate a part or parts of the picture to sharpen the child's awareness
- Have the child dialogue between two parts of the picture

- Have the child pay attention to colors
- Watch for the cues within the child's voice, tone, body posture, facial expression, body expression, breathing and silence
- Work on identification, helping the child to "own" what has been said about parts of the picture or the picture
- Work with the child's life situations and unfinished business
- Watch for missing parts or empty spaces in the picture and attend to that
- Stay with the problems on the child's foreground

It is important to give equal attention and emphasis to all family members, not just the child with disabilities. The therapist should also accept the children's descriptions as possible (Sherratt, 2002).

Sensory Play

Children use touch to get information about things around them. As they mature, they tend to rely on information from other senses, particularly visual, rather than touch. However, they still use touch when they cannot see something; for example, when trying to find a watch on the bedside table in the dark or getting a tissue out of a pocket. (Reagon, Higbee & Endicott, 2006).

The feeling bag is made of textured material and contains a range of "touch" objects, such as an orange, a small toy, glue, marble, wooden spoon and toy tree (Landreth, 2002). The child puts his hand into the bag and identifies the object. For the aim of this study, the researcher will use this activity as an ice breaker.

Incomplete Sentences

Incomplete sentences can address aspects as preferences and dislikes, friends, family, wishes and things that make the child happy or unhappy. It can also be a point of reference for further discussions and bring valuable information to the fore. This play

technique should help the child to relax and facilitate rapport between therapist and client (Meschiany & Krontal, 1998).

Books

Books can be used to enable the child to open the discussion on the child's feeling regarding a specific problem (Stahmer, 2004).

Stahmer (2004) raise the following advantages of biblio-play:

- Biblio-play is a good opener of conversations regarding problem situations.
- It is therapeutic in the sense that it corrects minister pretations, educates and generalizes.
- It spreads up the therapeutic pace
- It is a structured form of play and is therefore cost-effective as it directs the conversation towards the problem

Schoeman (1996) distinguishes between various phases in the therapeutic process regarding the use of children's stories:

Generalization:

The child might feel less alone and overwhelmed by his/her circumstances once he/she realizes that other people are experiencing similar situations to his own.

Identification:

The term projective identification as a mechanism in play therapy should be used here with caution. Through projective identification the child gets rid of unbearable feeling and transfers them to the object being identified with. But in this case, the object happens to be a toy. In its original definition, Melanie Klein described projective

identification as the child's omnipotent fantasy, that is, a fantasy and not a mechanism between two actual objects (Klein, 2006).

Projection:

Anna Freud also called it as displacement outward which is almost the complete opposite of turning against the self. It involves the tendency to see one's own unacceptable desires in other people. In other words, the desires are still there, but they're not one's desires anymore (Freud, 1927). The child unconsciously transfers certain feelings onto the character. She refers to three requirements necessary for the transformation to projection:

- The child must find a resemblance between his/her own situation and that of the character.
- The child must find resemblance between his emotions and that of the character.
- The child's unassimilated inner feelings must be intimidating and must make him anxious.

Modeling:

At this stage the child might begin to imitate the character's behavior.

Self-Insight:

During the last phase the child can come to the realization that there are resemblances between his circumstances and those of the character. He can also verbalize this realization. When the child recognizes the resemblances, this can signify that he is able to cope with his feelings.

The goal of this activity is to elicit conversations around similarities and differences between children. The researcher will show the child a collection of photographs of different flowers/cars and then ask them the following questions:

- Are these the same?
- How are these same?
- How are these objects different?

Once the child grasped the purpose of the questions, the researcher will then ask:

- Which one is better?
- Is one better than the other?

If the child answers yes, to this question ask them why. They would probably refer to a smell or a color by like. This means that they have a personal preference. The researcher should then discuss how different people can like different things but it does not make one better than the other.

The purpose of the techniques of identifying positive and negative feelings is:

- To assist the children in learning how to identify positive and negative emotion in themselves and other.
- To practice expressing verbally (Hess, 2006).

Once the children appear fluent in identifying emotions, it is time to practice identifying interpersonal situations that frequently result in positive and negative emotions. By focusing on the positive and negative emotions children experience, the therapist aims to focus on the polarities within the child self and his/her environment (Stahmer, 2004).

Landreth & Bratton (2002) state that when a person blocks an aspect of his/her personality, the denied side finds ways of expressing itself. This could be in a person's movements, voice gesture and posture. The therapist therefore does not only listen to the person's verbal level of communication but to the message behind the words on a non-verbal level.

The use of observation of non-verbal communication is especially important when dealing with these siblings of children with autism. Despite the outward behavior of the prettified sibling of a child with autism there may be internally felt ambivalence towards the disabled sibling. The negative feelings may be deeply buried and might be taboo to acknowledge out loud. Some of their prettified actions may occur in guilty compensation for "bad" thoughts about their brother or sister.

When a person has autism, the whole family is affected. Children normally realize at an early age that their brother/sister is different. They see it for themselves but they also observe their parents' reaction to their sibling's behavior.

Through thoughts and feelings of siblings are complex and vary considerably, the use of play therapy methods can identify thoughts and feelings. Play therapy could help siblings to project their feelings about their brother/sister with Autism/PDD.

Chapter 4: Research Design and Methodology

Purpose

In the previous two chapters the focus was twofold. The aim was to define autism and to discuss how autism might affect the siblings of these children. In chapter 3, the focus was on the use of play therapy methods to assess the needs to siblings. The empirical study and research findings are discussed in this chapter. The goal of this study was to investigate the effects of living with a sibling with autism by using play therapy methods. The research question was the following: “What are the effects of living with a sibling with autism?”

It is hypothesized that siblings of children with autism are not adversely affected. There might even be advantages. The results are expected to show that all children who have been interviewed will have deep feelings of love and affection for their siblings.

In this study, the researcher made use of the qualitative approach. Hubberman & Miles (2002) describe qualitative research as the multi-method in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials case study, personal experience, introspective, life story interview, observational, historical, interactional, and visual texts-that describe routine and problematic moments and meaning in individuals' lives. A qualitative researcher is concerned with:

- An exploratory and descriptive focus

- Emergent design
- Data collection in the natural setting
- Emphasis on 'human-as-instrument'
- Qualitative methods of data collection
- Early and on-going inductive analysis

The qualitative approach is used in this study. The researcher will use play therapy methods and techniques and observation. Using play therapy methods will also minimize the distance between the researcher and the participants.

For the purpose of this study the researcher made use of applied research. The purpose of applied research is to make qualitative research more relevant and more humanistic in the lives of people. Human beings are seen as capable to co-create their own reality. Therefore, data will be collected in cooperation with research participants or subjects. According to De Vos & Strydom (1998) applied research addresses immediate problems facing the professional in practice. The goal of applied research is the scientific planning of induced change in a troublesome situation.

Research Design

The research design is a plan or exposition of how the researcher decides to execute the formulated research problem. The objective is to plan and structure the project concerned in such a way that the validity of the findings are maximized.

Hubberman & Miles (2002) view a research design as a detailed plan for how research is conducted. The plan offers the framework according to which data will be collected to investigate the research question in the most economical way.

A descriptive research design was used in this study to describe the stresses and challenges experienced by the siblings of children with Autism/PDD. According to

Patton (2007) data collection procedures in qualitative research involves four basic types:

- Observations
- Interviews
- Documents
- Visual Images

In this study the data collection will consist of six individual sessions with each child, where unstructured interviews will be conducted in the form of play therapy sessions. One interview with the parents was conducted to obtain relevant information to the research. Patton (2007) indicates that unstructured interviews usually entails more than one interview and frequently involves series of interviews.

Unstructured interview is an interview without any set format. It allows questions based on the interviewee's responses. It is more like a conversation where the interviewee is relaxed. Unstructured interview permits full exploration of ideas and beliefs (Hubberman & Miles, 2002). The researcher does not participate in voicing her feelings, thoughts, experiences and beliefs with the interviewer.

In preparing for the interview it is important for the interviewer to define concepts, to assess data and to construct an interview guide. Observations of behavior are usually made in conjunction with an interview (Patton, 2007). The researcher will therefore also make use of observation in this study.

Procedure

Selection of Participants

The participants in this study were selected using a purpose sampling procedure. The selected participants consisted of children between the ages of six and twelve years age and are therefore in the middle childhood phase. The gender varied of one female and two males who have siblings with Autism/PDD. They were selected from English speaking schools in Dubai.

The researcher produced a letter of the informed consent (Appendix 2) which the researcher explained to the families who were asked to participate in the study. The researcher scheduled a meeting with each family, where only the parents of the participants were asked to attend. During the meetings, the families were briefed on the research being conducted and were also presented the informed consent form. After each parent of the participants in the study signed the informed consent sheet given to them by the researcher, the meetings started at the homes of the participants.

The participants attended six sessions, once a week, over a period of two months. Five of the sessions were conducted at the participants' houses in a room suited to do assessments with children. The fifths session were conducted at the houses (different rooms) of the participants, to enable the researcher to observe the interaction between the siblings. Four of the sessions lasted 50 minutes each. The fifth session lasted for a whole afternoon. The final session consisted of an activity as well as a party and lasted 90 minutes.

The researcher made use of applied research. This type of research makes qualitative research more relevant in the lives of people. A descriptive research design was used in this study to describe the challenges experiences by the siblings of children with autism.

Interviewing the parents:

During the preparation for the study, information was gathered about each participant. This information enabled the researcher to hypothesize about what might be happening to the child. In this study this phase involved an interview with the parents to discuss the child's suitability to the assessment methods.

Assessment by means of six play therapy sessions

Session 1

The researcher made use of sensory activities to start the first session. The researcher placed objects in a bag and asked the participants to guess what they are. During the first session the focus was on building relationship with the child. The aim was to find a connecting link between the child's world and that of the researcher. With the next activity, the researcher introduced the topic of same and different. The researcher showed each child pictures of different flowers and different cars. The discussion was centered on the differences between the flowers and the differences between the cars, but that they are the same. The researcher then showed the children pictures of their brothers and sisters and introduce the topic of being different from their brother and sister and that being different, is not necessarily bad.

Session 2

The purpose of the second session was to use a family drawing to enable the child to tell his/her story, as well as helping the child to express repressed or intense emotional feelings. By using the drawing the researcher helped the child to gain mastery over certain situations.

Session 3

In the third session the researcher made use of incomplete sentences to determine to what extent the research participant have unfinished business with regards to their brother/sister with autism.

Session 4

In the fourth session the researcher made use of biblio-play. A book (*My Brother is Different*, L. Gorrod, 1997) was used to enable participants to discuss autism. During this session the researcher determined the negative aspects that these children experience with regards to having a brother or sister with autism.

Session 5

During the fifth session, the researcher focused on the unique stresses and challenges that each of the children experience with regards to their brother/sister with autism. The researcher spent one afternoon with each child to observe the way in which the siblings interact.

Session 6

This will be the final session. The research participants made a collage about the positive aspects of their brother/sister with autism. Then we had a party.

Data Collection

Child 1

Biographical Information:

Child 1 is a seven year old girl in Grade 1. She attends a private British school in Dubai- UAE. Her teacher describes her as a very smart student. She is the eldest of two children. The participant has a younger sister (five years old) who is diagnosed with autism. This sister has been part of a very structured home based program for the past two years and has developed from being mute to having some speech. The parents requested that the word autism should not be used, but that the researcher should refer to her sister as someone who experience difficulty with speech.

Session 1

The goals of the session one were:

- To start establishing a relationship between the child and the researcher.
- To start the session with sensory activity to enable the child to come in contact with her senses.
- To introduce the research topic by doing the same and different activity.

Child 1's sessions took place at her house. The researcher explained to her that the research would consist of six sessions. We would meet each other in the house on Sundays at 4:00 pm. The sessions would last for fifty minutes.

The first activity was a sensory activity. The researcher put objects in a bag and we took turns to guess what they were. Child 1 was very quiet and shy at this point. By the end of this activity she seemed more relaxed, but was still very quiet.

The following activity was called "Objects can be the same and different". The researcher was aware that Child 1 loved cats and took out some pictures of different cats. The researcher then asked if the pictures were the same. She said no because they were of different types of cats. The researcher then asked her how the pictures were the same and then asked her how the pictures were different. She became very excited and enjoyed the activity. She told the researcher about her cat at home and about her favorite cat getting lost.

The researcher then took out a picture of Child 1 and a picture of her sister. The researcher asked her how they were the same and how they were different. Child 1 described differences like age and hair color. She did not say anything about her sister's disability.

The researcher then asked her whether her sister goes to school. She said no and that she goes to therapy each day and she has her own teacher who teaches her alone. She then said that her sister was unable to speak. The researcher asked her if she could think of any other differences. She said that she likes to play with leaves and little sticks and sand and that she herself likes playing with her dolls. The researcher asked her if she

knew why she was not able to speak. She said no, but that she would learn to speak and that she would be able to go to school with her sister. The researcher asked her whether she would like her sister to go to school with her. She said that she would like that because they would be able to play together at school as well.

After this discussion, the researcher terminated the session and discussed the arrangements for the following weeks.

Session 2

The goals of session two were:

- To use family drawing to enable Child 1 to tell her story.
- To use family drawing to enable the child to express repressed or intense emotional feelings.
- To determine the positive aspects of the relationship between the siblings speak.

Child 1 met the researcher after school. It was a warm day therefore we first had a drink together.

The researcher asked Child 1 to draw a picture of her family doing something together (See Appendix 4). The researcher assessed the picture with the use of Oaklander Model. Child 1 told the researcher that this was a mother and a father and two sisters who went away for the weekend. They went to stay in a wooden hut. They were able to swim in the beach. She said that they had fun, swimming and laughing. When the researcher asked

her if there was something she would change about the picture, she said that she wished that her sister could swim with her.

The researcher summarized the session by asking her to write down what she likes about her sister. She said that she likes playing with her. She likes swimming with her and laughing. She said that it was nice to go away to the hut and play with her sister. She also likes going to “Kidzania” to play with her.

Child 1 enjoyed the session because she loves drawing.

Session 3

The goal of session three was:

- To make use of incomplete sentences to determine whether Child 1 has unfinished business with regards to her sister with autism.

The researcher met Child 1 at her house after school. She was more talkative and told the researcher about her best friend. The session started off with an icebreaker. We used finger paint. It was very messy but great fun.

Then we did the incomplete sentences. Child 1 did not want to complete the sentence herself, so she asked the researcher to write them down. One of the sentences was “Something that would make life easier for my sister is...” Child 1 indicated that she didn’t know what to say. When the researcher asked her again she said that there was nothing that would make her sister’s life easier. She said that she is happy already.

The other sentence was “I love doing... with my sister.” She said that she loved playing on the trampoline with her sister. Child 1 said that she was teaching her sister to swim. She was holding her in such a manner that she was able to kick with her feet.

The researcher asked her what she would say if someone asked her why her sister does not speak. She thought about it for a while. She said that she would not say anything. The researcher asked her whether someone has ever asked her that specific question. She answered that nobody ever asked her that question.

When the researcher asked her whether there was something that she would change, she said that she would like it if her sister was able to speak. Then she would be able to go to the same school. She said that they could play together at school.

Session 4:

The goal of session four was:

- To use biblio-play to enable the researcher determine the unique stresses and challenges of having a sibling with autism.

At the beginning of the session the researcher explained the medium that would be used during the particular session. Child 1 became very excited about the activity because she loves books and stories. During this session the researcher brought some musical instruments and the researcher and Child 1 took turns to create different tunes on the instruments.

The researcher read “My brother is different” to Child 1. She seemed very interested and listened to it carefully. The researcher then asked her what she thought of the story. She

said that it was fun. The researcher then enquired whether she was able to identify with some of the situations that the character in the story experienced.

“When we play rough and tumble, my brother sometimes gets so excited that he bites or hits me” (Gorrod, 1997:4). Child 1 said that her sister sometimes gets too rough when they play. She does not always know how to play and she sometimes hurts her sister.

“When I behave badly I get told off, but my brother doesn’t”. This sometimes seems unfair (Gorrod, 1997:8). According to Child 1, her sister also gets told off if she is naughty. She does not think that her parents treat her fairly.

“At mealtimes my brother can’t sit still” (Gorrod, 1997:10). Child 1 identifies with this part of the story. She said that her sister jumps up and down at mealtimes. The researcher asked her what would happen if she should jump up and down during mealtimes. She said that she does not know.

“When we go shopping my brother screams and makes loud noises” (Gorrod, 1997:14). Child 1 says that her sister often screams when they go into shopping malls. She said that she didn’t like her sister screaming. When the researcher asked her whether people looked at them in a strange way when her sister screams, she said that she has never seen people who responded like that.

Session 5

The goal of session five was:

- To spend one afternoon with Child 1 and her sibling to enable the researcher to observe the interaction between the siblings.

The participant joined her mother as she was on her way to pick up Child 1's sister from her daily therapy sessions. The tutor was providing Child 1's mother with feedback on the day. Child 1 and her sister were playing on the stairs. Child 1 looked happy to see her sister and tried to engage her in a game. Her sister's concentration is limited and she has difficulty imitating play. Child 1 was very good in changing the game to include and involve her sister.

After picking her up, we went to a nursery with a playground. The girls' mother explained that her husband was staying at home because he wanted to rest. They run their own business from home. Since the youngest child was diagnosed with autism they found that their life has changed drastically. They spend a lot of time picking up and dropping her at therapy sessions. The participant's sister is unable to stay at home too long, and then she gets frustrated if she is not stimulated in a continuous basis. The parents have to take turns to involve the children in activities that will keep them busy. The children were playing on the swings and gym. Child 1's sister tried to involve her in playing on the swings. Child 1 seemed very protective. She was completely focused on her sister's needs but appeared happy to do so. When we arrived at their house both children went their own way. The younger sister then went into her sister's toy box and started playing with some of her sister's toys. Child 1 seemed concerned about her sister breaking them but did not want to take the toys from her because she was afraid that she would get upset and throw a tantrum. According to Autism South Africa (year unknown) tantrums may occur for no apparent reasons. The researcher showed Child 1 how to negotiate for a toy without causing her sister to get upset.

Session 6:

The goals of session six were:

- To make collage to focus on the positive aspects regarding her sister with autism.
- To terminate the series of assessments.
- To have an informal party and to evaluate the sessions.

The researcher explained to Child 1 how to make the collage. To help her, the researcher asked her the following questions: What is the one thing that your sister can do without any help from other peoples, name two things that you can do with your sister that almost nobody can get her to do. Child 1 loved making the collage about her sister. She is very creative and this was a very useful medium to express herself. She identified the following positive aspects:

- Loves going to “Kidzania” with her
- She likes swimming with her
- She learnt how to dress herself
- She can ask for a glass of juice by herself
- Child 1 can get her to put a DVD in the player by herself
- She is able to encourage her to say a part of “Humpty Dumpty”

The researcher and Child 1 had a party in the living room. We prepared microwave popcorn in the kitchen and had chips with soda drinks. An ice cream was eaten at the end. Child 1 enjoyed the party with the researcher only.

The researcher asked her which activity she enjoyed the most and she said that she enjoyed the session with the biblio therapy the most.

Child 2

Biographical Information:

Child 2 is a ten years old boy in Grade 3. He attends a private American school in Dubai – UAE. He is the third of four children. He has two older sisters, who are twenty one and nineteen years old. His younger sister (seven years old) was diagnosed with autism. She developed according to normal developmental milestones until two years of age when she started regressing. She also suffers from a metabolic disorder that results in her being on a very strict GFCF (Gluten Free-Casein Free), sugar and soy diet. She has been in a home based applied behavior analysis (ABA) therapy program for one year and eight months. The strict diet together with the strict ABA programs enables her to be less challenging to live with.

Child 2 himself suffers from a metabolic disorder and seems to be very sensitive to noise. If he sticks to his diet, he tends to be more happier and more flexible and willing to cooperate.

Session 1

The goals of session one were:

- To start establishing a relationship between the child and the researcher.
- To start the session with sensory activity to enable the child to come in contact with her senses.

- To introduce the research topic by doing the same and different activity.

The researcher interviewed Child 2 at his house for the first interview. The researcher explained her role to the Child 2. We discussed the length of each session (50 minutes) and that there will be six sessions in total. We would meet each other in the house on Tuesdays at 4:00 pm. Child 2 asked whether his sister would attend the sessions as well. The researcher clarified this by explaining that these six sessions will center in his needs and that it will not include his sister. This role clarification was important to Child 2 if the interview with the parents was taken into consideration. They stated that it was important to him to spend quality time with him alone and that he often resents the amount of attention that his sister requires. Child 2 appeared to be relaxed and very talkative.

The first activity involved the researcher and Child 2 taking turns in guessing the identity objects in a bag. He participated and enjoyed this activity. The next activity was called "things that are the same and different". The researcher was aware that Child 2 had an interest in motor cars and therefore chose the pictures for this activity accordingly. The researcher showed him pictures of different cars. He was very involved in explaining the differences between the cars.

The researcher showed Child 2 the pictures of himself and his sister and asked how they were similar. Child 2 seemed quiet and the researcher made some suggestions as to their family name and that they have the same parents and that both of them have eyes. He became involved again and enjoyed thinking of the differences. When the researcher asked him about one of the differences he mentioned that his sister is not allowed to eat

sweets the way he is. He told the researcher about an incident where he was having a piece of cake and that she became very upset and grabbed the piece of cake and stuffed it in her mouth. When her parents took the cake away she became very upset. They had to leave the restaurant because she became very disruptive. The researcher asked him about other differences. He said that she cries more than he does but that she is not able to say what troubles her because she is unable to speak.

Session 2

The goals of session two were:

- To use family drawing to enable Child 2 to tell her story.
- To use family drawing to enable the child to express repressed or intense emotional feelings.

Child 2 was very talkative when the researcher met him at his house. He was asking a lot of questions about the researcher's car and as they had a pool table at his house, we played pool for a short while. This served as an icebreaker.

The researcher then asked Child 2 to draw a picture of an animal family (See Appendix 5). He drew the first animal and started crying. He said that he could not draw and that the researcher was expecting too much from him. The researcher asked him to draw the animal in any way he wants. The researcher drew a picture herself and he stared laughing. Child 2 then drew the animals.

The researcher asked the child about the picture. He said that he drew his younger sister in the center of the page. He said that she is a nasty cat who hurts everyone. She cries

too much and breaks other people's things. He started crying again and said: "I hate this cat, I hate her. I am going to kill this cat." He said that he is the snake and that the snake is going away from the cat. He described his two older sisters as the other cat to the left of the big cat and the dolphin on the top of the page. He described his mother as the bird. When the researcher asked him about it, he said that the bird flies everywhere. The researcher asked him whether his mother is like a bird. He said yes and that she is always going somewhere. Child 2 drew his father as a human figure on the back of the page. When the researcher asked him about his father, he said that he takes care of everyone, even the bird.

The researcher then asked Child 2 if we could make his sister and himself out of clay. According to Van der Merwe (1996), playing with clay gives the child the opportunity to use primitive play material to work through his feelings. Clay can be used in combination with drawings of the child's environment. We made the figures. The researcher then enabled the child to express his intense emotional feelings by letting his clay figures destroy the clay figures which the researcher made. The researcher prompted him to tell the other animal (who represented his sister) how angry she made him. He threw her around and broke her into small pieces. The he seemed quiet for a while. He then said that he likes going to the gym where he can swim.

The session ended with a fun activity playing card game. We made arrangements for the following week's session.

Session 3

The goal of session three was:

- To make use of incomplete sentences to determine whether Child 1 has unfinished business with regards to her sister with autism.

We had to postpone and reschedule the third session because Child 2 had a dentist appointment. The researcher and Child 2 played a game of pool as an icebreaker.

When the researcher asked him what the nicest thing on earth was he said that it would be to have millions of dirhams to spend. He said that he could then buy anything he wants. The researcher asked him what he would buy. He said that he would buy a Jacuzzi for himself. He said that he wants to enjoy it by himself. The researcher asked him if he finds it hard to share with his sister. He confirmed that he found it difficult. He has to hide all his possessions from his sister because she destroys them. Children with autism are often destructive and break things that would be of value to other people.

When I asked him about himself and his mother, he said they like to go out to eat together. The researcher is aware of the fact that he hates going out for a meal with his family. He often asks his mother whether they could go out alone. He gets very anxious if they go out as a family and if they sit down in a restaurant. As a result of his sister's autism she herself gets very anxious in restaurants. It usually results in one of the parents having to leave the restaurant with her. The family tries their best to still go out as they could before, but it usually ends up being very stressful situation. That is also the reason why Child 2 would often become anxious about an outing even before they go. The researcher asked him whether it is hard to go on outings with his sister. He said that she cries very hard if they go out and that she does very funny stuff in public. He hates it when she gets so noisy.

Session 4

The goal of session four was:

- To use biblio-play to enable the researcher determine the unique stresses and challenges of having a sibling with autism.

“If I play a game on the floor my brother tramples all over it” (Gorrod, 1997:2). Child 2 told the researcher about a time when he was building a puzzle and his sister walked over his board game. He said that it made him very angry.

“When we play rough and tumble, my brother sometimes gets so excited that he bites or hits me” (Gorrod, 1997:4). Child 2 said that his sister was like that this morning, she got angry for no apparent reason and started to pinch and hit her brother. He said that she looked angry. He said that he gets angry with her because she took him by surprise. The one minute that he did not understand it and that he thinks that his sister is strange. The researcher asked him whether his sister often hurts him. He said no, she does not.

“Sometimes when I talk to my brother he ignores me” (Gorrod, 1997:12). Child 2 said that she sometimes ignores him. He said that it is not important and that he leaves her alone.

“When I behave badly I get told off, but my brother does. This sometimes seems unfair” (Gorrod, 1997:8). He said that his parents and eldest sister also tells her off if she is behaving badly. He said that his second eldest sister was unfair and that she tells him off even if he is innocent.

“At mealtimes my brother can’t sit still” (Gorrod, 1997:10). According to Child 2 his sister jumped up from the table on this particular morning. He said that she often jumps up and that she looks very angry. He also recalled an incident in a restaurant when she jumped up and ran into the kitchen.

“When we go shopping my brother screams and makes loud noises” (Gorrod, 1997:12). Child 2 said that his sister often screamed when they go into shopping malls. Child 2 responded by stating that her screaming bothers him a lot. It hurts his ears. He said that he was not aware of people looking at him.

Session 5

The goal of session five was:

- To spend one afternoon with Child 2 and his sibling to enable the researcher to observe the interaction between the siblings.

When Child 2 arrived home from school, his sister was having lunch with her special educator. The tutor left soon after lunch and the family’s helper took the responsibility of looking after her. Child 2’s sister appeared to have a difficult day and was crying and running around. It seemed difficult for her to focus on one activity and the helper had to leave her work to tend to the young girl’s needs.

Child 2 seemed to withdraw and sat down to watch television. He did not eat any lunch. When his mother arrived home, she asked him whether he had anything to eat. He refused to eat anything and his mother promised to sit with him while he ate. They just sat down when his sister started crying again. She seemed very upset and started

throwing things around in the house. Child 2's mother left to try and calm her down. He did not finish his lunch and went back to watching television.

The children's grandmother and aunt came around for a surprise visit. They did not stay long because Child 2's sister was really upset at that stage and all the attention seemed to focus on helping her, because she was so distressed.

After they left his sister appeared calmer and listened to music in her mother's room. The family was getting ready to go to a show at school that evening. Child 2 refused to get dressed to go to the show. At this point he was very emotional. He still did not eat lunch and his father was trying to encourage him to eat something before they left. They went to the show but Child 2's father came back earlier to help because the sister became very difficult at the show. Child 2 and his mother went home with another family after the show finished.

Session 6

The goals of session six were:

- To make collage to focus on the positive aspects regarding her sister with autism.
- To terminate the series of assessments.
- To have an informal party and to evaluate the sessions.

The researcher spent some party time with Child 2 at his house. Popcorn, chips and pretzels were prepared in the kitchen to eat and enjoy our time. We played pool table as well and Child 2 enjoyed his time. He was feeling so relaxed with his sister's absence

from the room. Afterwards we talked about the things he liked the most and the least. He did not enjoy the incomplete sentences, but he enjoyed the biblio-play.

Child 2 made a collage of his sister. He said that she loves her cat and that she would take her cat anywhere. She also likes French fries, it is her favorite food. He is able to get her to play on the back of his skateboard. They would go down the road in front of the house together.

Child 3

Biographical Information:

Child 3 is an eight year old in Grade 2. He is the youngest of three children aged thirteen and seventeen. His thirteen year old brother developed according to developmental milestones up to age of three years, when he started regressing. He lost his ability to speak and became increasingly hyperactive and aggressive.

Child 3's parents got divorced when he was one year and seven months old. His mother and brother with the delay, moved to another house to be closer to the facilities to support his brother. Child 3 and his older brother stayed behind with his father. Child 3 moved back with his mother when he started primary school.

Child 3's brother has been in and out of residential placements for the past four years. As a result of his aggression and hyperactivity, he has difficulty staying in a residential placement. Child 3's brother is staying with his family at the moment. He has experienced two violent outbursts since he has been back home. He has broken one of the big windows in their house and cut up most of his clothes.

Child 3's mother is experiencing a lot of hesitant feelings as to enter her son in an institution or keep him at home. She is also worried about the effect on Child 3. She feels very guilty about spending most of her time with her son with autism.

Session 1

The goals of session one were:

- To start establishing a relationship between the child and the researcher.
- To start the session with sensory activity to enable the child to come in contact with her senses.
- To introduce the research topic by doing the same and different activity.

The researcher met Child 3 at his house after school on Thursdays at 4:00 pm. He was alone, while his mother was working. His older brother was in a boarding house. The researcher asked him when last he saw his brother. He has not seen him for a few months. He will be coming home for his birthday. He is looking forward to seeing him because he misses his brother.

The researcher explained the rules of the session and the duration when they would meet each other.

The first activity is an icebreaker. We took turns in guessing what was in the bag. He is a very talkative and friendly young boy.

We then moved on to the same and different activity. He said that he and his brother were both boys and have brown eyes with brown hair. He had difficulty in thinking of

differences. The researcher prompted him and he eventually said that his brother was unable to speak and that he lives with his mother while his brother lives in a children's home. The researcher asked him why he thought that his brother was unable to speak. He said that his brother was autistic. The researcher asked him what autistic means. He said that it means that someone is unable to speak. The researcher asked him if he thought that he would ever speak. He said that his mother said that he would get better. Child 3 asked the researcher if the researcher thought that his brother would ever get better. The researcher said that she did not know.

The session ended and the researcher asked whether he enjoyed it and wanted to come for the next session. He seemed keen.

Session 2

The goals of session two were:

- To use family drawing to enable Child 3 to tell his story.
- To use family drawing to enable the child to express repressed or intense emotional feelings.

Child 3 spent a lot of time on his drawing (See Appendix 6). The researcher praised him for putting so much effort into his drawing. The researcher discussed the picture with Child 3. Child 3 drew a picture of their house. He and his mother are in the kitchen. He loves being with his mother early in the morning, before his brother gets up. They have a cup of tea together and then he gets dressed while his brother has breakfast.

He explained from the picture that his father was upstairs fixing a broken shelf. The researcher asked who broke the shelf, he said his brother broke it when he got angry. The researcher asked Child 3 about his father. He said that he wished that his father could live with them and fix things in the house. He misses his father. He said that they would move back with his father when his brother gets better. This really showed how important it was for him to have the right information about autism. It also showed that he needs more support to work through his feelings about his parent's separation.

Session 3

The goal of session three was:

- To make use of incomplete sentences to determine whether Child 1 has unfinished business with regards to her sister with autism.

The researcher explained the goal of the session. Child 3 asked the researcher to complete the sentences for him because he did not feel like writing it down himself.

* The thing I love most in the world... is to play with my play station. The researcher asked Child 3 whether there was anything he enjoyed doing with his brother. He said that he used to like it when they were all in the kitchen making a meal together. But lately his brother has been acting too "crazy". He said that he wants him to go back to the children's home because he is scaring him. The researcher asked him if he ever told his mother about his feelings. He said that she gets angry with him because she says that his brother should be with his family and not in a children's home. He said that it makes him unhappy.

* My mother... cooks a nice chicken meal. The researcher asked him when last they had chicken meal. He said that she has not done it in a while because she is so busy with his brother. He saw her crying in the kitchen the other day. He said that she always looks unhappy.

* My mother and I read... a story before I go to bed. He says that he really enjoys it.

* On my birthday... we went to McDonalds. The researcher asked him who went with him. He went with his big brother and his mother and three friends.

* My brother... used to be in children's home but lives at home now. It was for the first day and then he became difficult. He threw all the shampoo down the drains and started cutting up some of his clothes. Child 3 said that it scared him because his brother was bigger than he was.

* If---- breaks things.... I get scared. He broke my best toy. He said that he hates him.

* If I am naughty... I get a hiding. The researcher asked him if his brother gets told off. He said no and that his brother is much naughtier than he is.

* The things that makes me very sad... is when --- breaks my stuff. He should play with his own, I have to hide from him.

The session ended with a fun activity. We filled balloons with water and played with them. We arranged a time for the next session.

Session 4

The goal of session four was:

- To use biblio-play to enable the researcher determine the unique stresses and challenges of having a sibling with autism.

The researcher met Child 3 at his house. By the time the researcher arrived, Child 3's brother was still at home with his private tutor. It took a while to help him to get out of the house because he wanted to draw a picture with the researcher. The researcher had to sit down and draw a quick picture with him so that he could leave. Child 3 appeared quiet and reserved for a moment after his brother left. It was as if he needed a few minutes to sit down. For this reason the researcher started off with a relaxation and breathing exercise before starting the session.

The researcher explained the goal of the session. The researcher read the story to Child 3 and then asked him to identify parallels between his life and that of the boy in the book.

"If I am playing a game on the floor... My brother tramples all over it" (Gorrod, 1997:2). Child 3 explained when he is playing with something on the floor, his brother would often pick it up and put it on the table. He described an incident where he kept taking his game back on the floor. His brother became so frustrated that he picked up the game, put it on the table, picked his brother up, pulled out a chair and put him on the chair.

"When we play rough and tumble, my brother sometimes gets so excited, that he bites or hits me" (Gorrod, 1997:4). According to Child 3 he doesn't play physical games with his brother. He becomes too excited and scares Child 3.

“When I behave badly I get told off... but my brother doesn’t. This sometimes seems unfair” (Gorrod, 1997:6). When we go shopping my brother screams and makes loud noises. According to Child 3 his brother is very “strange”. He is unable to speak and makes all these loud, strange noise. He told the researcher about a time when he broke two of the windows in the house. He became disruptive that all the family members had to come and calm the situation. His mother then called the children’s home where he lived previously to help them stabilize him during the day. He said that he was very scared.

The researcher observed that he was getting very anxious at this point. He was quiet for a while. The researcher reflected that he looked upset. He started crying and said that his mother loves his brother more and that he always gets told off. The researcher talked to him for a while and he seemed calmer.

Session 5

The goal of session five was:

- To spend one afternoon with Child 3 and his sibling to enable the researcher to observe the interaction between the siblings.

The researcher accompanied the mother to pick up Child 3 from school and went home. After changing from school clothes to play clothes everyone had a cup of tea and a sandwich in the kitchen.

Child 3’s brother and his private tutor arrived within the half hour. The whole atmosphere changed in the house. Child 3 was very friendly and asked his brother about

school. His brother stood still and looked at him for a while. He walked to the fridge and showed in sign language that he wanted food. His mother made him a sandwich and they ate it together. He ate very quickly and then started being very hyperactive again. The private tutor took him to his room to draw some pictures. The researcher asked Child 3 to join them. We all went to the room. The activity lasted for a while and he jumped up again and started fidgeting with stuff in the room.

The researcher and Child 3 were in his room doing homework. His mother planned to take us all to the park when he finished his homework. He was very excited. We could hear Child 3's brother making loud noises. We rushed to his room and found that he is holding a big scissors and he was cutting his clothes. His mother was trying to convince him to give the scissors back. When she tried to approach him he became upset. She asked Child 3 and the researcher to go out of the room because she was afraid that he would get hurt. Child 3 appeared very anxious. His brother eventually finished cutting his clothes but cut his arm in the process. His mother took him to the hospital for stitches.

Child 3 started crying because he wanted to go to the park. His mother was trying to explain to him but he was very upset. He said that she never keeps her promises. Afterwards his mother told the researcher that she feels very guilty. She could have her day planned but one incident can change the whole day. She was really torn in her decision to stay together as a family or for her son to join an institution again.

Session 6

The goals of session six were:

- To make collage to focus on the positive aspects regarding her sister with autism.
- To terminate the series of assessments.
- To have an informal party and to evaluate the sessions.

The sixth session started off making a collage at his house. Child 3 identified the following positive aspects about his brother: that he likes chicken meals, that he is a good cook and that he is very strong. The researcher and participant then went to the kitchen and prepared microwave popcorn with chips. Child 3 didn't like soda drinks so we had juice. We went to the living room and listened to music.

Child 3 enjoyed the drawing and biblio play the most. He did not enjoy the first session and the session with the incomplete sentences, seeing that he thought it was boring. He enjoyed doing activities apart from his brother.

Data Analysis

Evaluation of session 1:

The aim of the first session was to establish a relationship with the participants and to introduce the topic. The researcher was able to establish a relationship with the children that enabled the researcher to gather information on the topic of the research.

Evaluation of session 2:

The goal of the second session was reached. Both Child 2 and 3 were able to express their emotion feelings. The researcher was also able to collect valuable information on the effects of living with a SWA has on the family. With the same and different activity

the researcher was able to determine the way in which the participants viewed their sibling's disability.

Evaluation of session 3:

The researcher was able to use incomplete sentences to gather information on the participants. This session was the least popular. Child 1 found it too difficult to write and draw pictures. Child 2 with his fear of failing found this activity stressful. This method was especially useful to Child 3 because it brought his unfinished business to the ground. He appeared very concerned about his brother's level of aggression.

Evaluation of session 4:

The children enjoyed the fourth session the most. The book, "My brother is different" was a useful tool. All three of the children were able to project their feelings and draw comparisons between the child in the book and their own situation. According to Schoeman (1996) the child makes use of projection to help himself to work through difficult parts in his life and to express feelings that he is not always allowed to express in the open. Biblio play was a very useful medium to gather information from all the three participants. Child 1 enjoyed this session the most. Child 3 was able to use this medium very well to express his feelings.

Evaluation of session 5:

The researcher was able to observe the interaction between the family members by spending one afternoon with them. The researcher was able to gather information on each child's specific stresses and challenges.

Evaluation of session 6:

The collage was a creative way in which the siblings could identify positive feelings towards their brother or sister with autism. It was very important to not only focus on the negative aspects but also focus on the positive feelings.

Results

Assessment for Child 1

- Helping:

Child 1 appears to play a strong helping role in her family. According to Siegel (1999) the child with autism is very good at isolating themselves even in a room full of family members or may be happy to sit with him/herself and wave a piece of ribbon. Child 1's sister is also able to isolate herself in such a way. She is continuously busy teaching her sister new things and tries to set a good example for her. It is mainly due to her efforts that her sibling with autism is able to have so many play skills. She also teaches her to swim. In her drawing she depicts her and her sister as being happy together. According to Stahmer (2004) one of the typical responses of children this age is to become overly helpful and well behaved in order to obtain their parents' affection. The researcher is of the opinion that her parents should be aware that she should not become overly responsible for her sister. She should be encouraged to be a child and to be spontaneous.

- Advocacy:

Child 1 stands up for her sister and is not ashamed to spend time with her. She appears to be unaware of children or adult making comment about her sister.

- Awareness:

Child 1's parents requested that the term autism should not be used. They do not use that term in their house but refer to their daughter as someone who is not able to speak. According to Landreth (2002) one of the needs of siblings is to learn ways to cope with stressful situations. Child 1 has a need to learn to negotiate with her sister to get her own needs met to avoid her sister throwing a tantrum.

Having fun:

Her picture depicts her and her sister as being happy together. She is often able to adjust the rules of games to accommodate her sibling to allow her to play with her.

Anger and guilt:

It appears that Child 1 has very little feelings of resentment towards her sister. Her parents make every effort to treat them equally. It is very important for Child 1 to have reaffirming words. Her sibling gets praised for every little achievement. If she gets praised Child 1 would ask to be affirmed too. She is asking for her needs to be met.

Isolation:

According to Rosenberg (2007) siblings often feel ignored by the professionals helping their sibling. Child 1 often also asks her sister's tutors to play games with her too. She also says that she wishes that she could have tutor to play with her all day.

Positive aspects:

The researcher also observed positive effects on Child 1. The researcher noticed tolerance and maturity shown by Child 1.

Need for information:

It appears that Child 1 is not in need of much information at this point. Her focus appears to be on the fact that her sister has difficulty with speech. As she grows older her need for information will increase.

It became evident through the assessment that Child 1 identified mostly positive aspects with regard to her sister with autism. Child 1's family went through major adjustments to their social life, family rituals and routine activities. Child 1 appears to make adjustments to be a vital part of her sister's progress.

She is concerned that her sister is unable to speak. Through Child 1 appears to be unaware of other people's comments about her sister, it is important for the parents to be aware that this might become a bigger issue as she grows up. One of the developmental tasks of middle childhood is to move away socially from the family to the peer group (Boutelle, 2008). The child's growing reliance on the peer group can make them vulnerable to the reactions of the peer group which can result in the sibling moving away from their sister/brother with autism in order to fit in the peer group. Her parents would be able to be more understanding if they view the possible changes in attitude as a developmental process (Boutelle, 2008).

Even though her parents have agreed not to use the word autism, Child 1 might need more information as she grows up. Between the ages of six and twelve, the child becomes acutely aware of the differences between people. The sibling is able to understand an explanation of the sibling's special need as long as it is explained to them in a way they can understand.

Assessment for Child 2

Helping:

Child 2 is not overly involved in the helping role. The support system in the house appears very helpful to ease the situation. They have a helper and two grown up daughters to help to support his sister. He tries to teach her things at time, but find her fluctuating moods and her difficulty to learn very hard.

Advocacy:

Though Child 2 seems to be very uninvolved with his sister, he stands up for her amongst his peers. He would defend her if another child makes an unkind remark about her.

Awareness:

Child 2 has not formally been informed about his sister's delay. His parents have open and lively discussions about her condition though. He does not ask many questions about her special needs.

Having fun:

They sometimes play together. When Child 2 plays outside with his friends, his sister sometimes joins them. He said that he likes going to the gym to swim with her.

Feelings:

Child 2 often feels left out. His sister can be very demanding at points and her vulnerable periods could sometimes last for days. His parent's attention will then naturally be focused on her. That is why he states that he would sometimes rather stay at home than go out with his sister. Harris and Glasberg (2008) state that children of any age may begin to doubt their importance and worth when their parents seem preoccupied with their sibling and appear to have no time to spend with them. After expressing his anger about his sister, Child 2 felt guilty about his feelings. It is important to reassure him constantly that it is acceptable to express his feelings.

Anger:

Child 2 experiences a lot of anger towards his sister. He resents her for being so aggressive and disruptive. He also resents her unpredictable behavior because it is so important to him to live a predictable life. He also gets angry because she takes his toys and sometimes breaks them. Anger is a natural response in many close relationships. The child needs to know that it is acceptable to be angry at times (Stelhi, 2004). It is important for Child 2's parents to become aware of his anger to enable him to express it in a healthy way.

Treating siblings equally:

Child 2 does not feel as if his parents treat him unfairly. He does not feel that he gets told off more than she does.

Family stresses:

Fun activities such as participation in sports and family activities such as friends visiting and attending family gatherings are often affected. Both parents and the two elder daughters were tennis players and used to spend a lot of time at the tennis club as a family. Friends tend to visit less and their family's social life changed considerably. Though the parents are very good at organizing activities that include the whole family, the outcome of these activities can never be predicted. Child 2 often avoids these activities.

Child 2 also mentioned that his mother is always on her way somewhere. As a result of her daughter's therapy and dietary needs she drives around a lot. She also has appointments with specialist and often has to cancel appointments with her son to see a specialist about her daughter. Her son gets very frustrated when she needs to rearrange plans continuously.

Assessment for Child 3

Helping:

The researcher observed that Child 3 has the desire to help his brother. He tries to connect with him on his level. His brother's unpredictable behavior makes it very

difficult to fulfill a helping role in the family. He appears to become more and more afraid of his brother's strength and size.

Feeling left out:

Rosenberg (2007) states that the child with autism naturally takes up a lot of their parents' time. Siblings may therefore feel that they are left out and that they are treated unfairly. Siblings can also feel less important. Child 3 is experiencing some of these feelings. His mother spends a lot of time with his brother because he is so demanding and because his behavior is so unpredictable. He feels left out of the activities that his mother and brother are involved in. He also has unfinished business about his mother and brother moving to another house without him. He has a desire to do fun things with his mother. He is feeling completely left out. Child 3 doubts his own importance when he says that his mother has forgotten him on the roof when they were playing hide and seek.

Anger and Guilt:

Child 3 is experiencing some ambivalent feelings towards his brother. One of his feelings is anger. He is also experiencing some guilt feelings about his anger. Anger is a natural response in close relationships and the child needs to be aware that it is acceptable to be angry. He starts crying because he is afraid he will get into trouble if he is honest about his feelings. Because the situation at home is so unstable and unpredictable, his mother is sometimes impatient with him.

Inability to explain to friends:

If the child with autism is very disruptive it might be virtually impossible for children to invite their friends back home (Rosenberg, 2007). Child 3 sometimes goes for a sleepover at a school friend's house. His friend has not been to Child 3's house for a sleepover yet. Child 3's mother mentioned that she does not feel comfortable inviting a child to the house who is not aware of the situation. She would like her son to be more settled before she invites Child 3's friends for a sleepover.

Awareness/ A need for information:

Though each sibling of a child is unique, many of them share similar needs and concerns. One of these needs is information on their sibling's condition and open communication within the family about the problems and sharing their experiences (Sibling Support Project, 2005). This is the reason why Child 3 asks whether his brother is crazy. He has needs for information on the condition and whether it will ever get better.

Social outings and activities:

Child 3 explains that they cannot go out as a family because his brother can display uncontrollable behavior in public. Social outings and activities are often influenced. They have to plan outings very carefully. This is also has effect on Child 3 because they have to stay at home more. He can also not invite friends for a sleepover at this point. He finds it very difficult.

Problems with changes in routine:

Individuals with autism seem to prefer consistency and maintaining the same routine. The slightest change in the routine can cause serious difficulties for their families. There also seems to be a tendency to be continuously afraid of harmless things, while they seem oblivious to real threats and dangers.

Child 3's brother needs a high level of consistency in daily routine. A change in routine can result in outbursts like when Child 3's brother cut up all his clothes. This resulted in Child 3's routine to be ruined since his mother changed his mind from going to the park with him. The unpredictability also results in an unpredictable life for Child 3. He has to adjust continuously.

Praising non-disabled siblings:

Child 3 appears to need a lot of verbal words of affirmation. During the fifth session the researcher observed that Child 3 tried to receive recognition in many different ways. His mother is very aware of this need and she reminds herself continuously because she is so focused on his brother.

Having fun:

As a result of the age gap between the two brothers, they do not play together. Child 3 is also afraid that his brother will break his toys. Child 3 appears to feel left out of all the fun in the house. He says that his mother does not play games with him anymore. In his drawing his mother and brother are cooking supper together. This is a very important ritual in their house, but Child 3 feels excluded from it.

Child 3 is experiencing ambivalent feelings towards his brother. According to Schubert (2001) children might experience conflicting feelings about their brothers/sisters throughout this age span. He loves him on the one hand but also holds a lot of resentment because of his brother. As a result of his brother's level of aggression Child 3 also appears to be afraid of him. He is able to see the positive aspects of his brother as well. He enjoys it when they are together as a family, cooking dinner.

Chapter 5: Conclusion and Recommendations

Conclusion

Growing up with a sibling with autism can be difficult and the needs of a child with autism are often overwhelming to his family, leaving normal children at times overshadowed. This study recognizes that siblings of autistic children need attention, love and care just as their sibling and have the right to share their experiences, good and bad.

The researcher had one interview with the parents of the research participants before the sessions with the children started. This served as a preparation for the research and enabled to obtain biographical information about the participants. In this study the researcher made use of play therapy methods to assess the needs of the research participants. The first part of each session started with a sensory activity to enable the child to come in contact with his/her senses. The reason for heightening their sensory experiences is because the children experience themselves and make contact through these modalities.

During the first session, the researcher made use of the same and different activity. This was a successful introduction to the research.

In the second session, the researcher made use of family drawing as an assessment tool. According to Miller (2001) drawing helps the child to tell his/her story, to express repressed or intense emotional feelings, as well as to enable the child to gain mastery over events which he/she is experiencing or experienced in the past. Child 2 was able to express his intense emotional feeling through this activity. He expressed a great deal of anger and frustration towards his sister. Child 1 was able to express positive feelings

through this exercise. She expressed her joy about being with her sister. Child 3 was able to express his feelings of not being treated equally to his brother with autism as well as a need to spend more quality time with his mother.

In the third session, the researcher made use of incomplete sentences to determine whether the research participants had unfinished business with regards to their sibling with autism. Through this activity the research participants were able to address aspects of like and dislikes, as well as stresses they experience in the family.

In the fourth session, biblio-play was also used as an assessment tool. According to Van der Merwe (1996) biblio-play is a good opener for conversations regarding problem situations. All the participants were able to identify with the character in the book and the researcher concluded that this was a very successful way of soliciting information.

Observations were used as an assessment tool in the fifth session to determine the unique stresses and challenges of each individual family. This was a valuable assessment tool seeing that the researcher was able to observe the interaction between the siblings first hand.

The final session included a collage of the positive and negative aspects of their sibling with autism/PDD. Through this activity the research participants were able to identify both positive and negative feelings.

- All three of the families had to make adjustments to the normality of family life. They were unable to engage in normal social outings like they used to. Though they all tried to include their children in activities it was difficult because they had to plan the activities

well and was never sure of the successful outcome. It was especially difficult to include Child 3's brother because he was so aggressive. According to Hess (2006) it is easy to see why the presence of aggression has a negative effect on a parent's definition of their family's normality.

Two of the research participants experienced anger toward their sibling. They were both angry about their sibling's aggression as well as their ability to disrupt any activity that was supposed to be enjoyable for them as a family.

The first research on the growth and development of siblings of children with disabilities appeared back in the late fifties and early sixties. This field began to be defined in the 1980s. Siblings with disabilities have a profound effect on the way they grow up and what they become when they are adults. Growing up with a sibling with autism can have positive and negative effects.

From this study the researcher concluded that siblings in middle childhood have the following needs:

- To have quality time with their parents which does not include their brother/sister with autism;
- To discuss ways in which they can cope with stressful situations where their sibling is concerned;
- To be included in teaching programs to enable them to feel as if they are helping their sibling as well;
- To be praised for small achievements as well;
- For the parents to understand why they get angry at their siblings and to be accepted for expressing these feelings.
- To still go on family outings and not stay at home because of their sibling with autism/PDD.

Recommendations

So as a professional, I am asked what do you recommend ? The bottom line is that the little scientific research that exists is not enough to tell for sure what to do – The picture of dealing with a sibling with autism is further complicated by the fact there are different perspectives.

My first goal of this thesis is to be practical. Theory could be great starting point but putting it into practice is what makes it valuable.

My second goal in writing this research was to make a conceptual contribution that would support families with autism. It is based on the principle that when we work with a child with autism, we need to work with the family and particularly siblings.

The best educators, the best interventions, the best assessments – still may not yield all the hoped for results. I often ask myself whether there may be more things to do than we may do.

Children as teachers

Siblings should be involved in the teaching programs of their siblings. In the collage activity all the participants shared something they taught their siblings which other people found impossible to do. They were all very proud of their achievement, both for themselves and their sibling.

The researcher is of the opinion that teaching siblings motivational techniques and improve the speech of the children will enable them to manage certain stressful situations with their siblings.

Sibling discussion groups

The researcher is of the opinion that sibling discussion groups and workshops could be an important forum for siblings to discuss their needs with regards of their brother/sister with autism/PDD. The importance of sibling support groups are the following:

- Through discussion groups, the multiple needs of more than one child and family can be met simultaneously;
- They provide an opportunity for emotional support and development;
- They provide an opportunity to meet with other children in similar situations. Children can learn that their families are not the only unique ones;
- They also allow children of the same age to describe different disabilities in ways which they understand it;
- Sibling groups can meet separately from parent support groups.

The researcher recommends that research should be done to design a program for siblings; for example, sibling support group. Workshops for parents and therapists should be conducted on the life-long issues concerning brothers/sisters with autism/PDD.

The use of play therapy methods was an effective way to investigate the effect of autism/PDD on siblings. The research question of this study was therefore answered. The researcher made conclusions and recommendations from the results of this study.

As a result of the increase of severe cases of autism in the past decade, as well as the shift to home based care, it became increasingly important to focus on the needs of the siblings. The researcher recommends more research into the undiagnosed cases of

autism/PDD. This will enable therapists/service providers to look after the needs of children with autism/PDD and the needs of the siblings of these children.

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Appendix 1

The Unstructured Interview with a Schedule

The play therapy sessions with the children were conducted with the use of a schedule. The schedule was used as a broad guideline for the researcher and contains themes and issues that are important to this research. The themes and issues that were explored were the following: helping, advocacy, awareness, feelings, middle childhood and family stresses.

1. Helping:

The researcher aimed to determine to which extent the research participants fulfilled a helper role within the family. This involved such as teaching their brother/sister new tasks and activities or setting an example of good behavior. The researcher also aimed to determine whether the research subjects were taking too much responsibility for their brother/sister or whether they were overly protective. It was also important to determine whether they felt any resentment in taking care of their brother/sister with Autism/PDD.

2. Advocacy:

It was important to determine whether the research subjects stood up for their brother/sister with Autism/PDD. Some children will be more comfortable than others in advocating for their brother/sister. It was important to know whether stares, comments or questions from the others and how they respond to it, intimidates the research participants. The researcher also explored whether the research participants explained their brother/sister's needs to others, how they responded to hurtful comments from others and whether they showed pride in what their brother/sister can do.

3. Awareness/Need of Information

A lifelong and ever changing need for information exists for the siblings of children with Autism/PDD. The researcher explored to which extent the research participants had

information about their brother/sister's developmental delay. This included understanding their brother/sister's delay and whether they asked their parents questions in this regards.

4. Feelings:

The researcher aimed to determine whether the research participants experienced the following feelings:

- Anger and guilt
- Anxiety about the views of others
- Feelings about parents only praising non-disabled siblings
- Frustration about the inability to explain to friends
- Feelings of isolation
- Feeling left out

5. Middle Childhood: Explaining in a way they can understand

There is an important change in the way siblings get along in middle childhood years. The researcher assessed whether developmentally appropriate information was given to them. On the middle childhood years it is also important to determine to which extent they are influenced by the reaction of their peers.

Appendix 2

Participant's name: -----

Date: -----

Researcher: -----

INFORMED CONSENT:

1. **Title of study:** Having a sibling with Autism / Pervasive Developmental Disorder.
2. **Purpose of the study:** The goal of the study is to investigate the use of play therapy methods to determine the effect that living with a sibling with Autism /PDD has on the child in middle childhood.
3. **Risks and discomforts:** There are no known risks or discomforts associated with this project.
4. **Benefits:** I understand there are no known direct medical benefits to my child for participating in this study. However, the results of the study may help the researcher gain a better understanding of how we learn and recall information about other people.
5. **Participant's rights:** My child may withdraw from participating in the study anytime.
6. **Confidentiality:** I understand that the results of testing will be kept confidential unless I ask that they be released. The results of this study maybe published during the official presentation of the thesis defense, but my child's records or identity will not be revealed unless required by law.

I understand my child's rights as a research subject, and I voluntarily consent to his/her participation in this study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

Parent's signature

Date

Appendix 3

SNIP

Sibling Need and Involvement Profile

SNIP helps parents and professionals understand the strengths and needs of siblings of children with disabilities or developmental delays. It is a guide to discover what siblings know and feel, highlighting areas that might be helpful to review and learn from. Use **SNIP** as a way to explore how siblings can be realistically and meaningfully involved in the lives of their brothers and sisters with delays. **SNIP** can also play an important role in the development of a comprehensive family support plan.

How it works: there are five sections, each addressing a different area of a siblings' relationship to his/her brother or sister: Awareness, Feelings, Having fun, Helping and Advocacy. Each section contains a description of key issues families often encounter, followed by a short questionnaire. Your answers help identify strengths (agreement=lower scores) and concerns (disagreement= higher scores). Each section also offers suggestions for building on these strengths or for dealing with these concerns. There are no right or wrong answers. Your responses should be based on what you know, feel or believe.

SNIP is probably most useful for siblings of age 4 or older. We suggest that a separate **SNIP** should be completed for each of your typically developing children age of 4 or older. Parents may want to complete **SNIPs** separately and then compare notes.

Finally, it may be helpful to set up some time to review your **SNIP** with key professionals to discuss the information and consider strategies tailored to your family.

Today's Date -----

Name of Sibling ----- **Age** -----

Parent(s) Name(s) -----

Name of child with special Needs----- **Age** -----

Having fun

Play is often called the “work” of children. It is how they learn the basics like counting and colors and numbers. Later, it is how they learn to make and keep rules, to work together toward a goal (“winning”) and to solve problems and manage adversity (“losing”).

Siblings are expected to play with each other. Often this is a practical necessity, because grown-ups are busy and the sibling is the only other child around to play with. But the play between siblings when one has disability or delay is often a little bit different. Some types of play may not be well suited to children with delays, especially when the play is very structured, as in a board game or somewhat complicated, as in a game of cards requiring certain math skills.

Games that rely on imagination and creativity, or games that allow either simplified or modified rules can be quite successful. Imaginative play and fantasy games like “dress-up” or acting out favorite TV or cartoon characters are usually accessible to all children. Arts and crafts, painting, clay work, block play, and other creative activities involve few rules and every child can participate at some level. And many games easily accommodate modified rules –hide and seek for instance, works well for a young wheelchair user if the goal or home is in a place that is easy to get to (say a pole in the parking lot instead of a tree in the middle of a field.)

One of the essential differences between the play of children and that of grown-ups is that children almost always have fun at it, even when they are losing. The goal is to encourage the positive interaction between siblings, helping them change or adjust the “rules” when needed.

	Strongly agree					Strongly Disagree
1. Enjoys playing with brother/sister	1	2	3	4		5
2. Chooses to spend time with brother/sister	1	2	3	4		5
3. Chooses to include brother/sister in activities with friends	1	2	3	4		5
4. Introduces brother/sister to others	1	2	3	4		5
5. Wants brother/sister included in family activities	1	2	3	4		5
6. Does not mind that brother/sister is unable to play certain games.	1	2	3	4		5

Building on strengths when responses suggest agreement:

- Allow or create opportunities for siblings to share what they especially enjoy about brother or sister with others.
- Encourage siblings to let their brother or sister do as much as possible for him/her and praise them for being patient if this takes a little to get.
- Praise or reward siblings for including their brother or sister in activities with their friends.
- Remind them (as needed) that they can have time alone with their friends too.
- Compliment your children on how well they play together or how well they complete a chore together on any other activity they engage in positively together. b

Dealing with concerns when responses suggest disagreement:

- Provide specific directions and suggestions or model how the children can play together, and be available to help guide them initially, your child's teachers may have ideas or advice on doing this successfully.
- Talk to siblings about their favorite games or things to do, and discuss how they might include their brother or sister in one or more of these activities.
- Look to other times when the child with the delay is having fun with someone else for clues on how your children can play successfully together.

Feelings

Children like adults have feelings about the people in their lives, the events and activities that make up their day and the good and bad things that happen to them. Some of these feelings pass quickly –often a child who says “I hate you” after being told to go to bed happily accepts a good night kiss and hug a few minutes later when he or she is locked in. Some children may talk about their feelings readily, and some may not, but most children let us know how they feel through actions if not their words. In either case, they are entitled to their feelings, whether pleasant or unpleasant, short-lived or long. Like adults, they need to have those feelings accepted not denied, ignored or criticized.

	Strongly agree				Strongly Disagree
1. Is seldom frustrated with behavior of brother/sister	1	2	3	4	5
2. Does not resent amount of time parents spend with brother/sister	1	2	3	4	5
3. Openly expresses feelings about brother/sister	1	2	3	4	5
4. Does not feel sorry for brother/sister	1	2	3	4	5
5. Does not resent special attention parents and others give to brother/sister	1	2	3	4	5
6. Is not embarrassed by the reactions of others to brother/sister.	1	2	3	4	5

Building on strengths when responses suggest agreement:

- Be respectful to all feelings that are expressed, acknowledge and praise siblings’ efforts to share their feelings with you, regardless whether these feelings are positive or negative.
- Keep in mind that siblings are likely to express their feelings differently as they pass through different developmental phases in their own lives.
- Encourage siblings to lend emotional support to other family members if this seems to be natural behavior on their part.

- Praise them when they use words or positive physical gestures (like hugging) to express themselves rather than hitting or other negative physical gestures.
- Encourage siblings to share their feelings with their brother or sister verbally or through play.
- Try to create a realistic role for the sibling to play in family discussions.

Dealing with concerns when responses suggest disagreement:

- Be open about your own feelings, provide a model for ways to talk about feelings.
- Listen carefully. Don't jump to conclusions or feel that you always have to have easy answers. Most importantly, avoid comments which close limits of communication like "you shouldn't say that" or "that's not a very nice thing to say"
- Reassure your child that everyone has times when things don't go well (a terrible, horrible, very bad day) and that such times seldom last very long.
- Don't just assume your child is upset or unhappy because of your other child's delay –it might be something else entirely. If you can, ask siblings directly what is upsetting them. If not, try to keep track of the times and situation where they become upset.
- If your child seems continually upset or seems to have nothing to say for several months, or just never seems happy about anything, it may be useful to get professional help –for you, for your child or for both of you.

Advocacy

Advocacy means speaking or standing up for someone else. Brothers and sisters often stand up for each other at home, at school, and on the playground. It may be all right for them to tease each other, but watch out if the kid next door tries.

As with most things, some children are going to be more comfortable than others in advocacy for their brother or sister with a delay. Some children are not intimidated by stares, questions, or comments from others, and easily respond to them. Some even anticipate such responses and take the first step themselves: "This is my sister Liz. She has cerebral palsy. So what game are we going to play?"

Advocating for their brother or sister may not come easily to other children. Perhaps it never occurs to them to speak up, or they do not realize how important it is or they simply do not know what to do or say. However, children will usually follow the lead of their parents. If they see their parents talking openly about their brother's or sister's delay with family and friends, they will not only learn the words to say, they will also learn that it is OK to speak out.

	Strongly agree				Strongly Disagree
1. Explains brother/sister's needs to others.	1	2	3	4	5
2. Willingly responds to questions from others	1	2	3	4	5
3. Comes up with ideas about how to help brother/sister	1	2	3	4	5
4. Responds to hurtful comments from others about brother/sister	1	2	3	4	5
5. Shows pride in what brother/sister can do and who he/she is as a person.	1	2	3	4	5

Building on strengths when responses suggest agreement:

- Encourage siblings to share their ideas or opinions on how best to advocate for their brother or sister. Role, play/ discuss real or imaginary situations where advocacy would be needed.
- Praise siblings for their efforts by citing examples of what they have done to advocate for their brother or sister.
- Include siblings in the process when considering a plan for your child with special needs, there can be strength in numbers.

Dealing with concerns when responses suggest disagreement:

- Point out things you have done to speak out or stand up for your child with special needs, explain what prompted you to do these things as well as the feelings you experienced to help siblings understand the reasons and motivations behind your own actions.
- Make sure siblings understand the difference between supporting their brother or sister and doing things for them that they could do for themselves.
- Have siblings observe the brother /sister in school or therapy to see how professionals advocate for him or her, look for examples of advocacy in books or movies and discuss them.
- Recognize that they may be too young to understand the need of advocacy or may lack the confidence and information they need to advocate for their brother or sister.

Awareness

“Awareness” is used here to describe whether a sibling does or does not have information about a brother or sister’s developmental delay. It also refers to how well the sibling understands that information. At this simplest awareness means that he or she has a name or at least a description, for the disability or delay.

Being aware also means the siblings can compare the similarities and differences between themselves and their brother or sister.” Sossie’s legs work differently than yours, so she needs her wheelchair to get around.” “Mike is very good at setting the table, but he needs your help to count out the plates and glasses.” This type of awareness can be called “internal”-siblings know how their brother or sister fits into their immediate world.

As children grow older, and their world gets larger with schoolmates, neighborhood friends, and other parents and siblings, their awareness of where and how their sibling “fits in” also changes. Over time, the sibling’s awareness enables them to share their own understanding with others. Sometimes, but not always, this can be difficult for children, as they come to know that everybody has someone like John in their family.

	Strongly agree				Strongly Disagree
1. Has been informed about brother/sister’s delay.	1	2	3	4	5
2. Understands brother/sister’s delay.	1	2	3	4	5
3. Asks parent(s) questions about brother/sister’s special needs.	1	2	3	4	5
4. Knows and understands brother/sister as well as anyone.	1	2	3	4	5
5. Shares what he/she knows about brother/sister with others.	1	2	3	4	5

Building on strengths when responses suggest agreement:

- Praise siblings for asking questions about their brother or sister.
- Encourage or create items to talk about what's going on in the family (family meetings, dinner conversations, etc.)
- Regularly shares information with siblings about their brother or sister—they will tell you if the “already know that” or ask questions for more details.
- Allow siblings to participate whenever possible in the formal process of reviewing reports or attending meetings with teachers, doctors, therapists and others.
- Read books or newsletters together about the disability or delay and discuss them.
- Ask siblings for their suggestions on how to tell other people, like neighbors, other family members or school friends, about their brother or sister's delay.

Dealing with concerns when responses suggest disagreement:

- Get books and videotapes about the developmental delay from the library or school to read or watch with the sibling, and use them to generate conversation and discussion.
- Avoid “quizzing” siblings about what they know or “lecturing” them on what they need to know—use (or make) natural situations for sharing this information.
- Ask your child's teacher, doctor, therapist, or other key professional for advice on increasing the sibling's awareness.
- Ask others who know your children how aware they think the sibling is about the delay.
- Take part in or arrange social activities with other families who have children with delays.
- Consider a support group to give the sibling opportunities to talk about his/her brother or sister.
- Keep in mind that children may be very aware of their brother or sister, but just not very talkative about what they know.

Helping

All children learn from each other. Brothers and sisters often teach each other how to tie their shoes, how to play hide and seek, and when (and for how long) it is safe to ignore calls to come home for dinner. It is more common for older children to take on this role with younger siblings, but it does happen the other way around. It is also more common for girls to take on this role because of cultural stereotypes about girls.

In families, where there is a child with a developmental delay, the natural instinct of children to “learn” can be pushed to either of two extremes. In some cases, there is a strong and explicit expectation that the older or more capable children are always responsible for helping the sibling with a delay. In others, the parents may not want to “burden” the other children and as a result children with delays may have little interaction with their own brothers or sisters.

The trick of course is to find a healthy balance between these extremes. The idea is to find ways for children to help, teach and learn from each other naturally in the normal course of their day.

	Strongly agree				Strongly Disagree
1. Teaches brother/sister new things	1	2	3	4	5
2. Sets a good example for brother/sister	1	2	3	4	5
3. Does not take on too much responsibility.	1	2	3	4	5
4. Is not overly protective of brother/sister.	1	2	3	4	5
5. Seldom resents being responsible for brother/sister.	1	2	3	4	5
6. Helps without being asked	1	2	3	4	5

Building on strengths when responses suggest agreement:

- Select one or more goals for the sibling to take responsibility for, such as helping their brother or sister clean the table, put laundry away, make his/her own lunch, or perhaps a “school” goal such as finishing homework or working on a program goal from the IEP.
- Praise/reward siblings for their efforts to help their brother or sister, be sure to say “thank you” occasionally, and set up times to do something special with them.

- If siblings are old enough, ask them what they think should be included in the IEP ,bring them to meetings whenever appropriate so they can hear other grown-ups talk about their brother or sister's strengths and areas that need attention.
- If possible, arrange for the sibling to spend a day or half-day in their brother or sister's classroom.
- If family, guests or a new baby-sitter is coming, allow the sibling to be one to explain the approaches or techniques your family uses with the brother or sister (of talking, helping to dress, etc.)

Dealing with concerns when responses suggest disagreement:

- Focus carefully on what appropriate teaching or helping roles for children to take on, versus those that are best left to parents or other grown-ups.
- Talk openly and honestly with siblings if you genuinely need their help with their brother or sister and explain why
- If possible, have siblings observe a therapy session ask them what they thought about how therapist worked with their brother or sister, if it gave them any new ideas for helping out .
- If siblings protest or complain about having to help, recognize that particular tasks maybe difficult, confusing or unpleasant for them, make sure you offer specific instructions, ask them if there are other tasks they would be more comfortable helping with.
- Pay close attention to how often you ask siblings to help as well as what you ask them to help with.
- Cultivate and use baby-sitter often, rather than expecting siblings to always fill this role. If the child with a delay requires special kinds of care train new sitters with short supervised baby-sitter sessions and gradually work up to longer independent sessions.

Closing Thoughts

Now that you've had a chance to think about how your children interact with each other, there are several ways to go from here. Hopefully, working through **SNIP** has given you a better idea about the dynamics of young brothers and sisters getting along with each other (or not). Just knowing what these factors are can sometimes help you be more observant with your children, so that you can head off problems before they become unmanageable as well as support and encourage positive interactions.

Most families will get some "good news" from the **SNIP** about their children and how they interact. It is true that children with a disability or delay often trigger circumstances that are different from, and more extreme, than those experienced by families without a child with a delay. But it is also easy to interpret even the most common difficulties as being "caused" by the child's delay, when more often than these are things that all families experience. We hope every parent who uses the **SNIP** will have several occasions to smile and say "how very ordinary"

For some families completing the **SNIP** will shed light on issues or problems that may need more direct attention. If this is the case, we suggest you discuss your concerns with someone who knows your children and whose advice you trust. This could certainly include your child's teachers, his or her physician, a close relative or friend, or someone involved with one of the many "advocacy" groups that serve children with delays and their families.

