

Living with a sibling with Autism/Pervasive Developmental  
Disorder: assessing the effects using play therapy methods

By

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Key words/Sleutelterme

Autism	Outisme
Assessment	Assessering
Siblings	Sibbe
Middle childhood	Middelkinderjare
Play therapy	Spel terapie
Incomplete sentences	Onvoltooide sinne
Projection	Projeksie
Biblio-therapy	Biblio-terapie
Observations	Waarnemings
Triad of impairments	Driehoek van beperkinge

## Opsomming

Die lewe saam met 'n broer/suster wat outisties is: 'n Assessering van die invloed op die kind in middelkinderjare deur die gebruik van speltherapie-metodes

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Die fokus van hierdie navorsing is op die sibbe van outistiese kinders. Die doelstelling van die navorsing was om te bepaal wat die invloed daarvan is om saam met 'n broer/suster te leef, wat outisties is. Die assessering het gefokus op die middelkinderjare-kind en is gedoen met behulp van speltherapietegnieke. Ten einde die doelstelling te bereik, is 'n literatuurstudie gedoen om insig te verkry in die kompleksiteit en dimensies van outisme en verwante kondisies, 'n indiepte fokus op die driehoek van beperkinge en die invloed wat dit op die funksionering van die broers/susters van kinders met outisme het, asook 'n beskrywing van speltherapiemetodes.

Die navorser het gebruik gemaak van toegepaste navorsing ten einde te bepaal wat die invloed is wat broers/susters van kinders wat outisties is, op hulle sibbe het. Inligting is ingesamel met behulp van ongestruktureerde onderhoude, in die vorm van speltherapie-sessies. Die volgende navorsingsvraag is gestel: Wat is die unieke probleme en uitdagings om met 'n broer of suster met Outisme/PDD te lewe?

Daar is van kwalitatiewe navorsing gebruik gemaak in die studie ten einde te fokus op 'n subjektiewe eksplorasië van realiteit eerder as 'n buitestaander se perspektief, soos dit gebruik word in kwantitatiewe navorsing. Die navorsing het onder andere gefokus

op die broers/susters se helperrol, bewustheid en 'n behoefte aan informasie, hulle vermoë om 'n advokaat te wees, beide positiewe en negatiewe gevoelens wat hulle

ervaar, die invloed hiervan op middelkinderjare asook die unieke gesinsprobleme van die gesin met 'n outistiese kind.

Die navorser het tot die gevolgtrekking gekom dat sibbe van kinders met outisme, beide positiewe en negatiewe gevoelens ervaar teenoor hulle sibbe met outisme.

## Summary

Living with a sibling with Autism/PDD: assessing the effects using play therapy methods

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This research deals with the effects that living with a sibling with Autism/PDD 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/PDD and its related conditions, an 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 a 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 as opposed to the outsider perspective of quantitative research.

This study 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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*If I could explain it*

*Brother  
Sister,  
Is who you are  
To one another*

*You eat waffles and macaroni  
Together,  
Put your pajamas on  
At the same time.  
And I scold you both,  
Although , for different reasons.  
Different universes.*

*I wish I could explain to you  
My 'pre-two' daughter  
Why your brother doesn't look at you  
Very often (or hug you back when you playfully hug him)  
Doesn't say as many words as you  
Doesn't say your name or (his).*

*The months have passed  
Of your innocent sister embrace  
And giving him little blocks, cars  
That may never be returned.*

*If you knew it was called autism  
Would it make a difference  
that too often I've told:  
"Your brother wants /o he left alone now"*

*Today, as you both .sit on the couch together  
Both separate and in the same room  
Playing different games,  
I see  
A toddler girl  
Who has learned to ignore  
What she cannot compete with*

Author unknown

# Chapter 1

## General Introduction

### 1.1 Introduction

When parents learn for the first time that their child has a severe disability, their lives change immediately. The family must cope with many stresses, such as readjusting their expectations for their child and dealing with financial situations they did not plan for. To be able to cope effectively, there may need to be significant changes in family roles, relationships and organization (Trachtenberg & Batshaw, 1999:743). One of the disabilities, which have a great impact on the whole family, is Autism/Pervasive Developmental Disorder (PDD).

The Autism Society of America (2001:1) describes autism as a complex developmental disability that typically appears during the first three years of life. Autism impacts on the normal development of the brain in the areas of communication skills and social interaction. Children typically have difficulties in verbal and non-verbal communication, leisure and play activities and social interaction.

Over 5.8 million children in the United States of America have disabilities. Many of these children have brothers and sisters. These siblings will share many, if not most, of the same concerns that the parent of children with special needs experience. They will also experience issues that are uniquely theirs (Meyer & Vadasy, 1994:16).

Each family goes through different stages as children arrive, grow up and move out and as parents grow older. Each stage brings new challenges as all families experience stresses, which demands new accommodations. What is particularly

different about families with a child with Autism/PDD is that the source of momentum for these families and the center around which family life revolves, is the individual with Autism/PDD. While some families fracture from the tension, some families grow closer. Parents are not the only family members whose lives revolve around the child with Autism/PDD. These children also become the center of action in the lives of their brothers and sisters (Cohen, 1998:67). The whole family can therefore feel the impact.

“...I have seen how sensitively and enthusiastically the brothers and sisters respond when they are given a clear and satisfying role. They play with their brothers and sisters. They coach them, encourage them, and give them attention and great caring. Very often, however, their needs are overlooked. While everyone else is paying close and constant attention to their brother and sister, while special programs and events seem to focus on that child, these generous and loving siblings often ask: “What about me?” (Shriver in Lobato, 1991:vii). This author indicated the dilemma which the siblings of children with Autism/PDD face. Their needs are often overlooked.

Siblings will likely spend more time with the child with special needs than any other person, with the exception of the mother of the child. The sibling relationship is generally the longest lasting relationship in the family and the brothers and sisters are likely to experience these concerns for a long period of time (Meyer & Vadasy, 1994:16).

The siblings of the child with Autism/PDD experience a wide array of feelings. This can range from feeling left out to anger and guilt feelings (Smeardon, 1998:14). In “My brother is different” (1997), Gorrod uses illustrations to describe some of the feelings that siblings of children with Autism/PDD 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 and explain them to him”. Another sibling expressed his feelings in the following way: “Sometimes when I talk to my brother, he ignores me. This is because he doesn’t always

understand what I am saying”. And: “When I behave badly I get told off but my brother doesn't. This sometimes seems unfair” (Gorrod, 1997:6-8).

From the side of the parents there is also guilt feelings. As one mother reports: “Craig takes up so much of our time and energy. I always feel like I'm shortchanging his brother and sister. It is hard not to feel that way.” According to Greenspan & Wieder (1998:374) the child with special needs demands more energy and time than their siblings. It is virtually impossible for parents not to feel concerned at times.

The researcher is of opinion that it is inevitable for parents to feel guilty at times about the amount of time and energy that is spent on the child with Autism/PDD. It is therefore important for the parent to become aware of the unique feelings of their non-affected child. This can help parents to take practical steps to connect with the feelings that the other children might experience.

## 1.2 Motivation for the choice of the topic

Prior to the birth of a new child, each family prepares themselves for the changes they know will affect the family. The effects of the child's presence become increasingly real as the delivery date approaches. Finances begin to change and the areas of parental responsibility starts to shift even before the birth. The family has no way of fully comprehending all of the changes a new baby will bring (Norton & Drew, 1994:67).

Various authors (compare Norton & Drew, 1994:7; Germishuys & Du Preez, 1993:32) are of the opinion that no family can be fully prepared for the birth of a child with disabilities. The birth of a child with disabilities presents significant difficulties to parents and other members of the family.

A child with a severe form of disability can therefore have a profound impact on his/her family. The influence can already start when the parents first realize that there is a problem and that it could continue indefinitely. Harris & Morgan (in Sanders & Morgan, 1997:16) are of the opinion that the effects on a family simply is not linear or unidimensional, but multifaceted and reciprocal, altering the total family system. The influence is therefore not only on the parents but also on the siblings and the relationship among the family members. Seligman (1991:27) indicates that a focus on children with disabilities ignores the other family members that might be affected. In addition, focusing only on the disabled child is short-sighted because it ignores the dynamics of family functioning. A disability in one family member affects the entire system and in turn affects the person with the disability.

As a result of the researcher's involvement with children with Autism/PDD and their families, a need was identified to do research on the factors that have an influence on the siblings of children with Autism/PDD. In a study by Grossman (in Lobato, 1991:16) it could be seen that the experience of the different siblings reflect opposite sides of the spectrum. One adult sibling reported feeling proud of their sibling's accomplishments while another sibling felt embarrassed by their sibling's inability. These adults reported that they were generally either harmed or they benefited from their unique family. They all reported that they felt the full range of emotional effects at one point in their lives. Knott, Lewis & Williams (in Trachtenberg & Batshaw, 1999:748) therefore concludes that children generally have mixed feelings about their siblings with disabilities. Though they are happy to be able bodied, they may also feel guilty that they do not have a disability. They naturally get angry from time to time about their brother or sister's behaviour or feel guilty because they can not do very much to help it (Smeardon, 1998:14).

Lobato (1991:17) therefore asks the following questions in terms of disability. This study will attempt to answer these questions in the context of Autism/PDD.

- “What are the feelings that young siblings express about their brothers and sisters?”
- “What are the unique stresses and challenges that siblings encounter as a result of having a sibling that was diagnosed with Autism/PDD ?”

The researcher is also of the opinion that the parents can benefit from being aware of the stresses as well as the feelings of these siblings about their brother or sister with Autism/PDD. The research in this study will enable the researcher to deliver a more effective service to the families she works with. Other professionals, as well as parents and teachers can also benefit from the conclusions and recommendations.

### 1.3 Problem formulation

Much of the literature on severe childhood disability and its effects on the family are, implicitly or explicitly, presented in the context of normality. When a severe disability is present, it is usually assumed to have serious effects on the family members, which can make normal family life difficult or impossible. Research on the impact of children with Autism/PDD on family life has also emphasized the difficulty of constructing a normal family life (Gray, 1997:1101). The researcher is of opinion that it is important to understand the difficulty of constructing a normal family life in a family where one or more of the children have Autism/PDD. Understanding the family’s view on family normality will also enable the practitioner to be able to determine each family’s unique stresses and challenges. Gray (1997:1101) did a study on the meaning of family normality. Parents cited the following evidence of a normal family life:

- Social outings and activities
- Emotional relationships among family members
- Family rituals and routine activities

- Intrusiveness of the child's symptoms
- Work and material goods.

Two themes are commonly found in parent's experiences of social outings and activities. The potential for disruption seems to influence the parent's experience of social outings. One mother explained her feelings about social outings in the following way: "We used to go out to dinner. We used to take a blanket and a pillow and he would lie on the floor and go to sleep. We would go on picnics and walks. We stopped going for picnics because...I felt pain to sit there and be embarrassed, and stuff food down your face quickly so you could get out of it as quick as you could. It was not my idea of fun. So we've gotten to a state where I don't want to go anywhere. We stay at home...therefore the children's interaction, which I believe is very important, is being impeded" (Gray, 1997:1101).

The second theme is the restrictions that the child with Autism/PDD places on the spontaneity of such activities. Several parents reported that their child would usually behave adequately in social situations only if they were given adequate warning about the event (Gray, 1997:1101). From the researcher's experience this will depend on the individual child. Warning the child too long before the event often leads to more anxiety.

The researcher is of the opinion that the potential of disruption, as well as the restrictions on the spontaneity of the events also have an influence on the siblings of children with Autism/PDD. Harris & Morgan (in Sanders & Morgan, 1997:16) who are of opinion that the effects on the family are multifaceted and reciprocal and therefore affects the whole family system, also confirm this.

The result of this is that the siblings might experience different feelings about their brother or sister with Autism/PDD. Young siblings might worry that they will also develop the disability or they might fantasize that they caused it by having bad thoughts about their siblings (Trachtenberg & Batshaw, 1999:748).

In middle childhood the sibling have a growing reliance on his/her peer group. This can make the sibling very vulnerable to the reactions of other children concerning their sibling with Autism/PDD (Harris, 1994:38).

The child with Autism/PDD might require extra time and care. The unaffected children might think that their parents love their disabled brother more than them (Trachtenberg & Batshaw, 1999:748). Feelings of resentment can also arise if the child with special needs becomes the focus of the family's attention or when the child is indulged, overprotected or permitted to engage in behavior that is unacceptable to other family members (Bendor & Podeanu-Czehotsky in Meyer & Vadasy, 1994:16). Smeardon (1998:13), who states that the siblings can be left feeling less important than their brother or sister with Autism/PDD, confirms this. They also get angry about their brother or sister's behaviour or feel guilty at times because they can not do much to help their brother or sister. (Compare Smeardon, 1998:15; Lobato, 1991:17.)

As the brother or sister of a child with Autism/PDD, a lifelong and ever changing need for information exists. (Compare Rosenberg, 2000:32; Meyer & Vadasy, 1994:16.) It is important to provide the siblings with developmentally appropriate information about Autism/PDD. This information should also be presented many times over the years and in increasingly mature and complex language as the child grows up (Harris, 1994:32). Children often ask the following questions:

- “Will he/she ever get better?”
- Why does he/she want to be on his own a lot?
- Why won't he/she play with me? Why won't he join in with our games?
- “Why doesn't he/she get told off like I do?”
- Why does he/she laugh when I get upset?
- Why does he ignore me sometimes?” (Davies, year unknown: 13).

Children, like adults, have feelings about the people in their lives, the events and activities that make up their day and the bad and good things that happen to them. While some children might talk about their feelings readily, some may not. In either case they are entitled to their feelings, whether it is pleasant or unpleasant, short-lived or long. Like adults, they need to have those feelings accepted, not denied, ignored or criticized (Fish; McCaffrey; Bush & Piskur, 1995:3). It is important for parents and professionals to accept their child's feelings and to answer his/her questions openly.

The researcher is therefore of the opinion that the feelings of the siblings of a child with Autism/PDD should be acknowledged. The child needs to know that it is acceptable to be angry at his/her sibling at times. They need to know that this is a natural response in many close relationships. (Compare Smeardon, 1998:14; Greenspan & Wieder, 1998:374.)The importance of this study is to do an assessment of the unique feelings that siblings experience to enable parents to take practical steps to help their unaffected children as well.

## 1. 4. Goal and objectives of the study

### 1.4.1 Goal

The goal of this study was to investigate the effect of living with a sibling with Autism/PDD by using play therapy methods.

### 1.4.2 Objectives

The objectives with regards to the goal were the following:

- To undertake a literature study to provide: a better insight into the dimensions and the complexities of defining Autism/PDD and its related conditions; an in-depth look at the triad of impairments and the influence this has on the

functioning of siblings of children with Autism/PDD; a description of play therapy methods.

- To undertake an empirical study with regards to the influence of Autism/PDD on the functioning of siblings in middle childhood.
- To make recommendations to parents and helpers who work in families with children with Autism/PDD that will enable them to respond to the needs of the sibling.

## 1.5 Research question

Research always commences with a research question or a hypothesis. While questions are posed about the nature of real situations, hypotheses are attempts about how things can be. When a researcher works qualitatively research questions are more relevant. Research questions may be concerned with a single variable or with the relationship between two variables (De Vos, 1998a:116).

This study will aim to answer the following question:

- What is the effect of living with a sibling with Autism/PDD?

## 1.6 Research approach

In this study the researcher made use of the qualitative approach. Mouton & Marais (1993:155) describe qualitative approaches as those in which the procedures are not as strictly formalized and where the scope is likely to be undefined. A more philosophical mode of operation is adopted.

For the qualitative researcher the only reality is the one constructed by the individuals involved in the research situation. Multiple realities exist in any given situation. This includes the researcher, those individuals being investigated and the

reader interpreting the study. The researcher also tries to minimize the distance between himself and those being researched, whether it is observing informants over a period of time, or actual collaboration (Cresswell in Schurink, 1998a:243).

The qualitative researcher is also concerned with:

- Understanding rather than explanation
- Naturalistic observation instead of controlled measurement
- A subjective exploration of reality as opposed to the outsider perspective that is used in the quantitative paradigm (Schurink, 1998a:243).

The qualitative approach was used in this study. The researcher used play therapy methods and techniques and observation. By utilizing play therapy techniques, the researcher did a subjective exploration of reality from the perspective of an insider. Using play therapy methods also minimized the distance between the researcher and the respondents.

## 1.7 Type of research

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. Data is therefore collected in cooperation with research participants or subjects (De Vos & Fouchè, 1998:80).

According to Arkava & Lane (in De Vos, Schurink & Strydom, 1998a:8), 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.

In this study the researcher collected data in cooperation with the respondents by means of play therapy sessions. Becoming aware of the effects which Autism/PDD has on the siblings, could lead to social change.

## 1.8 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 (Mouton & Marais, 1993:193).

The descriptive orientation is considered a necessary first step in the development of a research program because it establishes the foundation of any further undertaking. The goal of descriptive research is the careful mapping out of a situation or a set of events and therefore describes what is happening behaviorally. It tells us “how things are” (Rosnow & Rosenthal, 1999:15).

Thyer (Fouchè & De Vos, 1998a:123) views a research design as a blueprint or a detailed plan for how research is conducted. The blueprint offers the framework according to which data will be collected to investigate the research question in the most economical way (Huysamen in Fouchè & De Vos, 1998a:123).

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

## 1.9 Research procedure and strategy

According to De Vos (1998b:48), data collection procedures in qualitative research involves four basic types:

- Observations
- Interviews

- Documents
- Visual images

In this study the data collection phase consisted of six individual sessions with each child, where unstructured interviews were conducted in the form of play therapy sessions. One interview with the parents was conducted to obtain relevant information to the research. Schurink (1998b:303) indicates that unstructured interviews usually entails more than one interview and frequently involves a series of interviews.

The term unstructured interview is used to refer to the style of interviewing used by qualitative researchers. Berg (in Schurink, 1998b:298) describes unstructured interviewing as social interaction between equals to obtain research-relevant information. The researcher, however, does not participate in voicing his/her feelings, thoughts and observations. The interviewees share their feelings, experiences and beliefs with the interviewer (Schurink, 1998b:299).

For the purpose of this study, the researcher made use of unstructured interviews with a schedule (See appendix 1). The schedule was used as a guideline and contained themes that were important to research. The schedule ensured that all relevant topics were covered during play therapy sessions. The main advantage of this type of interviewing is that it provides for a relatively systematic collection of data, which also ensures that important data, is not forgotten (Shurink, 1998b:299-300).

In preparing for the interview it is important for the interviewer to do a careful literature study on the topic. This will enable the interviewer to define concepts, to assess data and to construct an interview guide (Schurink, 1998b:301). In this study the literature study consisted of two chapters, which enabled the researcher to construct an interview guide.

Observations of behaviour are usually made in conjunction with an interview (Sue; Sue & Sue, 1997:72). The researcher will therefore also make use of observation in this study.

The documentation phase consisted of the researcher writing reports on each individual session.

## 1.10 The pilot study

In order to undertake scientific research on a specific problem, it is important for the researcher to have thorough background knowledge about the topic. One way, in which the prospective researcher orientates himself to the project, is to do a pilot study (Strydom, 1998a:178).

### 1.10.1 Literature study

The aim of the literature study is to gain knowledge about the topic by working through previous research and to determine whether the topic is valid and researchable (Arkava & Lane in Fouchè & De Vos, 1998b:65). The literature study is not only important for the clear formulation of the problem. It is also important for the planning and implementation of the investigation (Cilliers in Strydom, 1998a:180).

Fouchè & De Vos (1998b:64) 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. The literature study provides a better insight into the dimensions and the complexities of the problem. In this study the focus was on the complexity of defining Autism/ PDD and its related conditions, an in-depth look at the triad of impairments and the influence this has on the siblings of children with Autism/PDD.

The prospective researcher can only undertake meaningful research if he/she is fully up to date with the existing knowledge on his prospective subject (Strydom,

1998a:179). This is of great importance in this study. There have been many misunderstandings about the term autism over the years, since the American Psychiatric Association created a new diagnostic category of Pervasive Developmental Disorder for Autism and its related conditions. Since then there has been a revision of the term in the Diagnostic and Statistical Manual of Mental Disorders in 1987 and 1994 (Author unknown, 1999:1). The researcher must thus be up to date with the existing knowledge on the subject to be able to undertake meaningful research.

### 1.10.2 The experience of experts

In spite of the wealth of literature which may exist in any field, it usually only represents a section of the knowledge of people involved in the field on a daily basis. The utilization of experts can help to delineate the problem more sharply and to gain information on the more technical and practical aspects of the prospective research (Cilliers in Strydom, 1998a:180). Consulting experts assisted the researcher with conceptualization of the problem formulation (Strydom, 1998a:181).

For this reason the researcher consulted the following experts:

- Jenny Buckle: Head of the Reach Program for the teaching of developmentally delayed children, Cape Town.
- Jan Holland: Program developer for persons with disabilities, using the Gentle Teaching Method; New Hampshire, USA.
- Fiona McDade: Working with people with disabilities in a homebased setting, Glasgow, United Kingdom.

The researcher consulted with these experts via e-mail and telephone conversations.

### 1.10.3 Feasibility of the study

This is a researchable topic for the following reasons:

- Given the emotional richness and the importance of sibling relationships it is reasonable to question whether children's psychological adjustment will be affected in significant ways when one of their siblings has a chronic illness or developmental disability (Lobato, 1991:30).
- Consent has been gained from the parents of the children who will be involved in the study (See Appendix 2).

### 1.11 Description of the research population delimitation/boundary of sample and sampling methods

It is important to firstly look at the meaning of the term population/universe before defining the term sample. The reason is that the term, sample, always implies the simultaneous existence of a population or universe of which the sample is a smaller section (Strydom, 1998a:190). Arkava & Lane (in Strydom, 1998a:190), defines a universe as all potential subjects that possess the attributes in which the researcher is interested. Population refers to the individuals in the universe who possess specific characteristics. Most researchers are interested in generalizing their results to a specified larger pool of individuals. The name for the larger pool is the population and the name of the fraction is the sample (Rosnow & Rosenthal, 1999:203).

In this study the population consisted of children in the middle childhood phase with brothers or sisters with Autism/PDD. A sample is the element of the population considered for actual inclusion in the study. It can be viewed as a subset of measurements drawn from a population in which the researcher is interested (Arkava & Lane in Strydom & De Vos, 1998:191).

The researcher made use of purposive sampling. This type of sample is based entirely on the judgement of the researcher. The sample is composed of elements

which contain the most representative and characteristic or typical attributes of the population (Singleton in Strydom & De Vos, 1998:198).

The respondents were between the ages of six and twelve years of age and were therefore in the middle childhood phase. The researcher made use of play therapy methods. By mapping out the relationship between the child with Autism/PDD and his or her sibling, the study described what happened behaviorally. The sample in this study consisted of the siblings of children with Autism /PDD in the researcher's practice. The researcher made use of three respondents, one female and two males between six and twelve years of age.

## 1.12 Ethical aspects

Since human beings are the object of study in social sciences, it brings its own unique ethical problems to the foreground (Strydom, 1998b:24). It was therefore important for the researcher to consider certain ethical principles.

The first ethical principle is **respect** for people and their autonomy. This refers to the subject's rights and ability to choose to participate in the study and to continue participating in the study (Rosnow & Rosenthal, 1999:59). Strydom (1998b:25) refers to this principle as **informed consent**. Obtaining informed consent implies that all adequate information on the goal of the investigation, the procedures, which will be followed during the investigation, the possibilities and advantages to which the respondents will be exposed, will be included.

In this study the researcher obtained informed consent from the parents of the respondents as well as consent from the respondents themselves on their willingness to be included in the study (See Appendix 2).

**Trust** is also an important ethical consideration in research. Trust in research refers to the establishment of a relationship of trust with the respondents (Rosnow & Rosenthal, 1999:29). The respondents in this study were children between the

ages of six and twelve years old. It was important to develop a relationship of trust between the researcher and the respondents. A relationship of trust is important because the child will be able to communicate on a deeper level with the researcher (Gardner in Van der Merwe, 1996a:22).

The release or **publication of the findings** is also an important ethical consideration, according to Strydom (1998b:32). The final written report must be objective, accurate, clear, and unambiguous and contain all essential information. For the purpose of this study the final written report is in the form of a dissertation.

The subjects will be informed about the findings without impairing the principle of **confidentiality**. This is seen as a form of recognition and gratitude to the participants (Strydom, 1998b:33). In this study the researcher will give feedback to the parents about their specific child's experience of having a sibling with Autism/PDD.

The **restoration of subjects** or respondents was also an important consideration. Strydom (1998b:33) suggests debriefing sessions during which respondents get the opportunity to work through their experiences after the study is done. If the researcher becomes aware that one of the respondents is in need of therapy, the researcher will refer them for therapy. This principle also connects with Rosnow & Rosenthal's (1999:59) principle of beneficence (doing well) and non-maleficent (do no harm). By referring the respondents for therapy, if necessary, the researcher will ensure that no harm is done.

## 1.13 Definition of concepts

### 1.13.1 Autism/ Pervasive developmental disorder (PDD)

Autism is often referred to as a spectrum disorder. This reflects the fact that the characteristics and symptoms of the disability comes in a variety of combinations and ranges from mild to severe (Rosenberg, 2000:31).

Leo Kanner defined infantile autism for the first time in 1943 (Piven, 1999:299). Siegel (1998:9) defines autism as a developmental disorder that affects many aspects of how the child sees the world and learns from his or her experiences. Autism is best recognized in a group of disorders collectively known as pervasive developmental disorder (PDD). The term pervasive developmental disorder is most accurately used to describe autism (autistic disorder as well as an array of non-autistic PDD's, such as PDD-nos, Asperger's syndrome, fragile-X syndrome, Rett's Syndrome and childhood disintegrative disorder). Autistic disorder is the technical term for autism in the DSM IV. The term autistic disorder is therefore used to encompass autism plus the non-autistic PDD's and is meant to correspond exactly to what the DSM IV refers to as PDD.

Many misunderstandings about the term autism have existed through the years. Parents, professionals and advocacy organizations have developed a practical approach for referring to the various PDD categories as 'the autism spectrum' and of using the terms autism and PDD interchangeably. This frame of reference persisted through various revisions of the Diagnostic and Statistical Manual of Mental Disorder (DSM). The Pennsylvania Department of Education recognized this common usage when it adopted the term Autism/PDD (Author unknown, 1999:1). For the aim of this study the researcher will make use of the term Autism/PDD because it encompasses autistic disorder and the non-autistic PDD's (Author unknown, 1999:1). The respondents in this study have brothers and sisters with Autism/PDD. The researcher is of the opinion that an understanding of Autism/PDD is not only important for the researcher but also for the siblings themselves because it can enable them to make better sense of their brother/sister's problem.

Autism impacts the normal development of the brain in the areas of communication skills and social interaction. Children with autism typically have difficulties in verbal and non-verbal communication, social interaction and leisure

and play activities. In some cases aggressive and self-injurious behaviour may be present. They may also exhibit repeated body movements, like hand flapping and rocking, and an unusual response to people or attachments as well as a resistance to changes in routines. They may also experience sensitivities in the five senses of sight, hearing, touch, smell and taste (The Autism Society of America, 2001:1).

### 1.13.2 Middle childhood

Middle childhood covers the ages from six to twelve years (Newman & Newman, 1999:264). This development phase can also be called late childhood. Late childhood starts at about six years, when the child enters school and extends to puberty (Van Rooyen & Ngwenya, 1997:44). In this study the respondents will be between the ages of six and twelve years and will therefore be in late/middle childhood.

### 1.13.3 Play Therapy

***“You can discover more about a person in one hour of play than in a year of conversation (Plato in Thompson & Rudolph, 2000:373).***

The child client gives a special character to therapy. The child’s style of communication is different from the adult’s style of communication. Non-verbal communication is especially prominent in the child. This non-verbal communication often surfaces through play (Van der Merwe , 1996a:6-7).

Violet Oaklander (in Geldard & Geldard, 1999:29) combines gestalt therapy principles and practice with the use of media when working with children. When working therapeutically, the therapist encourages the child to use fantasy. The belief is that the fantasy process will be the same as the life process of the child. Mediums like clay, storytelling, puppets and the imaginary journey can be used.

In the researcher's opinion, play therapy will enable the respondents to make contact with the feelings they experience as a result of living with a sibling with Autism/PDD.

#### 1.13.4 Sibling

According to the Reader's Digest Universal Dictionary (1988:14), a sib is a brother or sister; a sibling. A sibling is also defined as each of two or more children having one or both parents in common. A sibling is therefore a brother or sister that is connected by their parent(s).

#### 1.13.5 Assessment

The process of assessment is an attempt to comprehend the main elements of the problem situation and to understand the meaning of the problem for the client in their situation. It is also an attempt to use all the client's understanding and to direct all our professional knowledge in an active thinking process aimed at identifying what needs to be altered in the situation and to plan how these desired changes might be achieved (Compton & Galaway, 1989:443).

Assessment is the process of gathering information and drawing conclusions about skills, traits, abilities and the emotional functioning of the individual. Assessment tools are necessary to study and to practice mental health (Sue; Sue & Sue, 1997:72). Assessment will be used to gather information on the effect which a sibling with Autism/PDD has on the functioning of their brother or sister.

## 1.14. Outline of the research proposal

**Chapter 1** consists of the introduction to the research.

**Chapter 2** consists of a definition of Autism/PDD and an in-depth look at the triad of impairments in autism. This chapter will also consist of a description of the stresses and challenges experienced by the siblings of children with Autism/PDD.

**Chapter 3** consists of a theoretical description of play therapy methods.

**Chapter 4** consists of the empirical study. Specific attention is given to problem formulation, the goal of the study and the research method.

**Chapter 5** will consist of a summary of the research as well as conclusions and recommendations.

## Chapter 2

### The emotional effects of living with a sibling with Autism/Pervasive Developmental Disorder.

#### 2.1 Introduction

‘We need to unveil autism and educate people, but first we need to empower the parents’ (Jenny Buckle, a mother of triplet boys with Autism/PDD in Reach, year unknown: 2).

Traditionally 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 (Seligman, 1991:2). The researcher is of the opinion that this is being confirmed by the huge increase in home based programs for children with Autism/PDD. The Son-Rise Program, at the Option Institute in the United States of America, teaches parents, volunteers and assisting professionals how to design and implement parent-directed, child-centered, home-based programs for children with special needs (Kaufman, 1999:3). Within the South African context the organization Reach, aims to teach parents and tutors through intensive workshops. This therapy is based on the work of Dr Ivor Lovaas, who does Applied Behaviour Analysis (Reach, year unknown: 2)

Siblings also play an important role in the treatment of children with Autism /PDD. Most children grow up with siblings and are raised by siblings in many cultures (Lobato, 1991:2). 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 (Seligman, 1991:181). It is therefore very important to know and

respond to the needs of these siblings. Harris (1994:i) states that she is struck by the urgency of the needs of the young people in sibling support groups.

The purpose of this chapter is to explore Autism/PDD and the potential positive and negative effects this condition has on the siblings of children with Autism/PDD.

## 2.2 Defining Autism/PDD

‘Autism is going to be like an onion. There is not going to be a single cure, because there is not going to be a single cause. We will peel it away layer by layer’ (Bristol-Powers in Tan-Powers, 1999:1).

The term ‘infantile autism’ was created in 1943 by Dr Leo Kanner to describe a developmental disability that manifests itself early in life and is known for an abnormal self-centeredness (Theron, 1989:435). Though the name autism is a recent concept, the disability has been known since 1799. The first description of autistic behaviour 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’ (Theron in Louw, 1989:436).

Dr. Michael Goldberg (year unknown:1), from the Pediatrics & Young Adults ADHD/ADD-Learning Disabilities, Immune Dysfunction Autism Center, views classically defined autism as a devastating disorder. This disability used to be relatively rare and occurred in approximately one to two infants per 10 000 births. What used to be a relatively rare disorder is now twenty times more likely to occur. Statistics in 1997 suggest a frequency of 20 to 40 per 10 000 births.

According to the latest figures from the California Department of Developmental Services, California experienced a 31% a year increase in the number of children professionally diagnosed with the most severe cases of Autism entering its developmental services system. These figures do not include persons with Asperger’s, PDD, Nos or any other autistic spectrum disorders, just the children who

have received a professional diagnosis of level one, DSM IV autism. According to the department, there were 5108 cases of level one autism in 1994. At present there are 20377 cases in the system (Center for the study of autism, 2003:1). In the opinion of the researcher, the need for taking care of siblings of children with Autism/PDD will increase as the number of children diagnosed with Autism/PDD increase.

In this severe form of classic autism, there is an absence of speech and it could include symptoms of repetitive, unusual and/or self-injurious behaviour as well as extremely abnormal ways of relating to events, people and objects. Parents noticed that something was wrong within the first three to six months of the baby's life (Goldberg, year unknown: 1).

Another type of autism surfaced in the last decade. The researcher is of the opinion that this new type of autism also set a new challenge for families and siblings of children with Autism /PDD. 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 the 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 (Goldberg, year unknown: 1). 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 with respect to the handicapped siblings are formed (Siegel & Silverstein, 1994:64). In the researcher's opinion this is also a stressful time for siblings because of the parents' growing anxiety that there is something wrong with their child.

There is also an inconsistency with the belief that 70 to 80% of children with autism is mentally retarded. They do not present symptoms or signs that pediatricians or neurologists find atypical before the time of onset (Goldberg, year unknown:1).

## 2.3 The DSM-IV criteria for Autistic disorder and PDD, Nos.

For someone to determine whether a child is autistic or has another form of PDD, three aspects need to be considered:

- One needs to understand which kinds of behaviour patterns are not part of the syndrome;
- One needs to understand the function and form of behaviour and therefore understand why the child does the things he/she does;
- Thirdly, one needs to understand the formal diagnostic standards being used by the professional making a diagnosis (Siegel, 1998:18).

### 2.3.1 Autistic Disorder

To diagnose autistic disorder, a person must have positive signs on six out of the twelve criteria. At least two of the criteria must reflect difficulties in social development; at least two criteria in the area of atypical, interests and activities must also be met (Siegel, 1998:17).

*Table 1 : Autistic disorder*

(Siegel, 1998:17).

*To be diagnosed with autistic disorder there should be at least one sign each from parts A, B and C and at least six overall. The children meeting fewer criteria are diagnosed with PDD, Nos.*

A. **Qualitative impairments in reciprocal social interaction:**

1. A marked impairment in the use of multiple non-verbal behaviors such as eye- to-eye gaze, facial expression, body posture, and gestures to regulate social interaction.
2. A failure to develop peer relationships appropriate to the child's developmental level.
3. A lack of spontaneous seeking to share enjoyment, interests, or achievements

4. A lack of socio emotional reciprocity.

**B. Qualitative impairments in communication:**

1. A delay in or total lack of the development of spoken language. This is not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime.
2. A marked impairment in the ability to initiate or sustain a conversation with others despite of adequate speech.
3. The stereotyped and repetitive use of language or idiosyncratic language.
4. A lack of varied spontaneous make-believe play or social imitative play appropriate to the developmental level.

**C. Restricted, repetitive and stereotyped patterns of behaviour, interests or activity:**

1. An encompassing preoccupation with one or more stereotyped and restricted pattern of interest, abnormal either in focus or intensity.
2. An apparently compulsive adherence to specific nonfunctional rituals or routines.
3. Stereotyped and repetitive motor mannerisms for example hand or finger flapping, or twisting, or complex whole body movements).
4. A persistent preoccupation with parts of objects.

An abnormal or impaired development prior to age three manifested by delays or abnormal functioning in at least one of the following areas: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

### 2.3.2 Non-autistic Pervasive developmental disorders

When the child has a less severe form of behaviour, as described in Table 1, this might contribute to a diagnosis of PDD, NOS. If no criteria are met in the category of interests and atypical activities, but there are a variety of signs in the categories of communicative and social development, PDD, NOS can be diagnosed. PDD, NOS is sometimes used provisionally when the child is so young that many of the criteria are too difficult to see. Some clinician might give a diagnosis of PDD, NOS to a child who meets as few as two criteria for PDD, NOS (1 from part A and one from part B). This is not strictly incorrect, but clinically it matters a great deal which criteria the child meets. The reason for this is that some of the problems these children have, are also common in children with related problems such as developmental language disorders (Siegel, 1998:19).

#### □ Asperger's Syndrome

Children with Asperger's Syndrome (AS) were sometimes referred to as having schizoid personality, schizotypal personality and PDD, NOS. This changed however and is recognized as distinct from autism in a key number of ways:

- Children with AS may not be detected as early because only mild or no delays in language are present;
- Children with AS do not avoid others like autistic children do and are often described as “active, but odd”. They do relate in a more narrow way, usually centering activity on their own needs and particular interests (Siegel, 1998:21).

Randall & Parker (1999:96) confirm this by stating that the most obvious characteristic of AS is the person's particular, idiosyncratic areas of ‘special interest’. In contrast with autism, where interests are more likely to concern objects or parts of objects, the interests of the person with AS are most often concerned with specific

intellectual areas. According to Pansegrouw (2001) one of the main features of AS is pedantic, repetitive speech.

□ **Rett's Syndrome**

Rett's Syndrome is an autistic-like disorder (Tan-Powers, 1999:5). It is believed to have a genetic origin because it affects only females and is marked by a characteristic hand wringing movement.(Compare Siegel, 1998:22; Perry; Sarlo-McGarvey; Factor, 1992:235.) This statement is contradicted by Tan- Powers (1999:5), who states that boys can be born with the defective gene that is present in Rett's syndrome. They die of a severe brain disorder shortly after birth.

The hand wringing movement has to be present for a diagnosis of Rett's syndrome. Young girls with Rett's syndrome tend to begin life normally and then lose their acquired skills over time. Some girls develop a little language and then lose it. Language loss is common in Autism/PDD, so language loss alone does not indicate the presence of Rett's syndrome. The hand wringing movement has to be present for a diagnosis of Rett's syndrome to be made (Siegel, 1998:22).

During the girl's second year of life, the loss of abilities as well as the hand wringing movements become more prominent. This becomes so severe, that she has difficulty feeding herself and picking up objects. Most children eventually lose the ability to walk and develop mental retardation. Between the second and the sixth year, the child might meet the criteria for Autism/PDD (Siegel, 1998:22).

Rett's syndrome is classified as a non-autistic PDD. The reason is because the child can benefit from teaching approaches for children with Autism/PDD, for the period of time that the child shows signs of Autism/PDD (Siegel, 1998:22).

A girl with signs of Autism/PDD, who also shows any of the following characteristics, should be closely assessed for the possibility of Rett's Syndrome:

- Respiratory dysfunctions and EEG abnormalities;
- Social, language and motor regression and loss of previously acquired speech;
- Loss of purposeful hand skill;
- Severe psychomotor retardation;
- Gait apraxia and truncal ataxia (Rett Syndrome Diagnostic Criteria Work Group in Perry, *et al.*, 1992:236).

One of the factors, which have an influence on the family of children with Rett's syndrome, is the progressive nature of the disease. After the child is born and appears to be developing normally, parents build up a set of expectations about the child's future. The later the age of onset, the more difficult it becomes to relinquish the dreams and the expectations when it becomes more clear that the child will never attain them (Perry, *et al.*, 1992:245).

□ **Childhood disintegrative disorder (CDD)**

This is a fairly rare version of Autism/PDD. Children with CDD, have normal development in early life but starts to disintegrate in the first five years of life, until the child's behavioral difficulties is basically the same as a child diagnosed with Autism/PDD (Siegel, 1998:22).

This disintegration typically includes a loss of language, increasingly poor eye contact, a loss of desire for significant amounts of social contact and other forms of non-verbal communication. Children with CDD will typically speak easily in phrases and sentences before they loose their language (Siegel, 1998:22).

□ **Fragile X Syndrome**

Fragile X is identified through an examination of an individual's chromosomes. When Fragile X and autism occur together, the autism takes on a characteristic set of symptoms (Siegel, 1998:22):

- Frequent stereotyped motor movements;
- Pressured, often high pitched, rapid speech;
- A significant amount of echolalia;
- Very poor eye contact;
- Large, cupped, low-set ears;
- A prominent chin;
- Very flexible joints;
- Boys have large testicles.

More children with fragile X have PDD, NOS than autism. Many of the children with Fragile X and PDD, NOS can be described as having an odd way of relating to people, but are somewhat sociable and friendly in their own way (Siegel, 1998:23).

Rosenberg (2000:32) describes more non-autistic PDD's:

□ **Landau-Kleffner Syndrome**

Children with this syndrome are commonly male and lose their language abilities either gradually or suddenly between the ages of three and seven years. The typical autistic-like characteristic of this disorder is the failure to respond to sounds. Children with this disability do not seem to feel pain, can be aggressive and needs to follow a specific routine every day.

□ **Angelman syndrome**

In contrast to children with autistic disorder, people with this syndrome are often very affectionate and sociable and love laughing. They show other characteristics of autism like hand flapping, hyperactivity, little or no speech as well as sleeping and eating problems.

□ **Prader Willi syndrome**

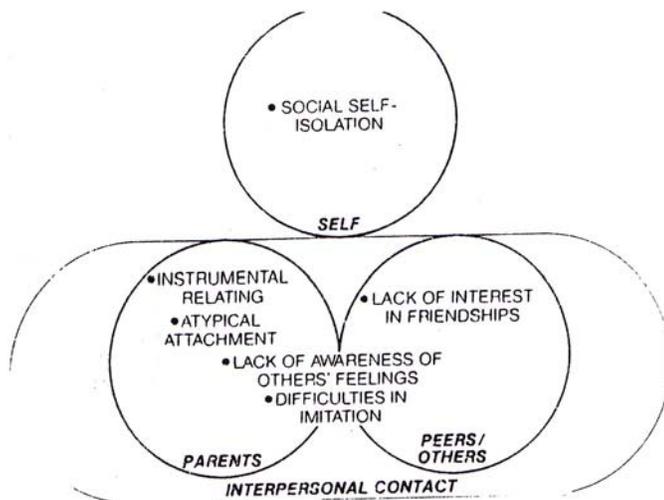
Individuals with Prader Willi syndrome usually exhibit delayed language development, learning disabilities, sleep disturbances, skin poking, temper tantrums, as well as a high tolerance for pain. This disorder is also caricaturized by an obsession with food.

## 2.4 The triad of impairments

The impairments found in this disorder occur in three major areas: Activities and interests, verbal and non-verbal communication, impairment of imagination (Sue; Sue & Sue, 1997:468). Wing and Gould (in Wing, 1998:15) studied the prevalence of autism in children under the age of fifteen in 1979. 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.

### 2.4.1 Impairment of social interaction

Figure 1: Impairment of social interaction



(Siegel, 1998:26).

“Anne-Marie was not shy: she was largely oblivious to people, and would sometimes actually avoid them, including, a lot of the time, her own mother. She drifted toward solitary spaces: the corners of a room, behind the curtains, behind the armchair. If I was somewhere else in the apartment, she never sought me out but could spend hours just manipulating a toy or poking at the rug. When visitors came, she gave them at most a fleeting glance, then turned away with a blank expression, despite their attempts to be friendly (Maurice, 1998:31).

Children with Autism/PDD tend to have little awareness of others and have poor or absent ability to make appropriate social contact (Autism South Africa, year unknown:3). This impairment of social interaction is outlined in Figure 1. They are very good at isolating themselves even in a room full of their family members. 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/PDD may be happy to sit by himself and repeatedly wave a piece of ribbon (Siegel, 1998:26). According to Wing (1998:15) the most severe form is the indifference and aloofness to other people. In less severe forms the child will passively accept social contact and show some pleasure in this. He/she might not make spontaneous approaches. (Compare Wing, 1998:15; Autism South Africa(ASA): 3.)

The child with Autism/PDD has difficulty forming relationships (ASA: 3). The quality of relating is also different in these children. According to Durand and Barlow (1997:454) behavioural clinicians have difficulty teaching people with Autism/PDD the more subtle social skills that are important for relating to peers. This also includes the ability to initiate and maintain social interactions that could lead to more meaningful relationships. Their relating tends to be instrumental rather than expressive. Most normally developed children display a great deal of social expressiveness. They constantly do something to provoke emotional reaction from someone or to show how they feel, for example bringing toys to show parents and looking toward the parent when the emotional state in someone in the room changes (Siegel, 1998:28).

The child with Autism/PDD mainly engages in instrumental relating. The child would for example use one or two powerful words like 'bye-bye' and use it whenever he does not like the situation. Parents often get the feeling that the child is more interested in getting what he wants than who gets it for him. The child also makes use of hand leading. The typical toddler would rather point than hand-lead. Pointing often emerges very late, if at all, in children with Autism/PDD (Siegel, 1998:28).

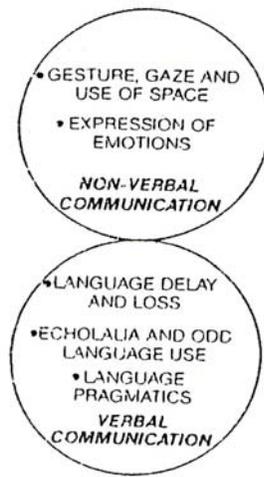
It has been suggested that the underlying problem of social impairment is the lack of the built-in ability to recognize that other people have thoughts and feelings (Wing, 1998:15). The capacity to understand that another person thinks in the same way you do is called theory of mind (Siegel, 1998:28). Baron-Cohen (1998:9) describes theory of mind as the ability to infer mental states, namely beliefs, desires, intentions, imaginations and emotions. Some of these children lack almost all signs of theory of mind. In such extreme cases one might view this as a form of mind blocking. They also experience problems discerning object from thought. They fail to understand metaphor and seem unable to deceive. They also tend to fail to recognize the eye-region as indication of what a person is thinking and feeling (Van der Gaag, 2001).

More commonly, people with Autism /PDD have some basic theory of mind. They have some difficulties in using it at a level that one would expect, given their intelligence in other areas (Baron-Cohen, 1998:9). 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, 1997:17).

## 2.4.2 Impairment of social communication

' The first time I realized 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, 1999:12).

**Figure 2: Development of communication skills in children with autistic spectrum disorders.**



(Siegel, 1998:44).

When children with Autism/PDD begin, or fail to begin to use language, parents begin to detect how different their children are. (Compare Siegel, 1998:43; Rosenberg, 2000:14.) Even though the absence of spoken language seems to be the first things for parents to detect, the early non-verbal communication of the child with Autism/PDD is usually absent or quite limited. They need to learn nonverbal communication (Siegel, 1998:44). About 50% of children with Autism /PDD do not develop speech. The children that develop speech, generally shows oddities such as echolalia (echoing of what has previously been said) (Sue; Sue & Sue, 1997:469). The development of social communication in children with Autistic Spectrum disorders can be seen in Figure 2.

Jim (in Sue; Sue & Sue , 1997:467) describes himself as feeling different from others and as unable to understand social signals. He is most comfortable when communication is concrete. He finds it difficult when different subjects or informal communication occurs. This leads to difficulty in forming relationships because of the communication problems. He reflects his inability to communicate in the following poem he wrote:

I built a bridge  
Out of nowhere, across nothingness  
And wondered if there would be something  
On the other side.  
I built a bridge out of fog, across darkness  
And hoped that there would be light on the other side.  
I built a bridge out of despair, across oblivion  
And knew that there would be hope on the other side.  
I built a bridge  
Out of helplessness, across chaos  
And trusted that there would be strength on the other side.  
I built a bridge  
Out of hell, across terror  
And it was a good bridge, a strong bridge,  
A beautiful bridge.  
It was a bridge I built myself  
With only my hands for tools, my obstinacy for supports,  
My faith for spans and my blood for rivets  
I built a bridge, and crossed it,  
But there was no one there to meet me on the other side.

A lack of appreciation of the pleasure and social uses of language is always present in one form or another for children with Autism/PDD. 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 (Wing, 1998:15).

Siblings also need to develop an understanding of this impairment. According to Gorrod (1997:16) 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.

The researcher is of the opinion that it is important for the siblings to have information about the child's difficulty in processing information and about practical ways in dealing with different situations. Pansegrouw (2001) suggests forced alternatives to language instead of open questions, for example: "Did you play tennis or soccer today?" instead of asking: "How was school today?"

Jordan (2001) also suggests the following in teaching communication:

- Musical support, for example: "This is the way we brush our teeth, brush our teeth, brush our teeth ..."
- Visual means, for example the TEACCH (Treatment & Education of Autistic and Related Communication Handicapped Children-Adults) program.
- Focus on one dimension at a time.
- Kiss things better instead of too much touch. If a child is hypersensitive to touch, hugging him when he got hurt might feel like an assault.
- Don't make a request when you want to make a command, for example: "Please sign the register" instead of "Would you mind signing the register?"
- Be clear in your commands, for example: "Take the empty glass to the kitchen and leave it there".

### 2.4.3 Impairment of behaviour and imagination

Jordan (2001) calls this triad of impairment a lack of flexibility in thinking and behaviour. One of the outward manifestations of this impairment is the inability to play imaginatively with objects or toys or with other children or adults. They also tend to focus on trivial aspects of things in their environment instead of an imaginative understanding of the meaning of the whole scene. The child will for example attend to one earring instead of the whole person (Wing, 1998:16).

According to Autism South Africa (year unknown: 4) the impairment of behaviour and imagination also includes the following:

- Children will pursue activities repetitively and cannot be influenced by suggestions of change;
- The children’s play may appear complex, but when closely observed, it shows rigidity and stereotypical patterns;
- The inappropriate use of toys in play;
- Holding onto objects, for example carrying a piece of wool for the whole day;
- Tantrums may occur for no apparent reasons;
- Changes in routine may cause distress;
- The children’s interests and range of activities may be limited;
- The children tend to have unusual habits such as spinning, rocking, finger-flicking, continual fiddling with objects, tapping and scratching of surfaces, or arranging objects in lines or patterns. This behaviour is called self-stimulating behaviour. It refers to repetitive body movements or a repetitive movement of objects. This behaviour is common in many individuals with developmental disabilities, but it appears to be more common in autism. This stereotypical behaviour can involve one or all five senses, for example:

Table 2: Self-stimulatory behaviour

<u>Sense</u>	<u>Action</u>
<i>VISUAL</i>	Staring at lights, moving fingers in front of eyes, hand flapping, repetitive blinking.
<i>AUDITORY</i>	Snapping fingers, making vocal sounds, tapping ears

<b><i>VESTIBULAR</i></b>	Rocking side-to-side, rocking front-to-back
<b><i>TASTE</i></b>	Licking objects, placing body parts or objects in one's mouth.
<b><i>SMELL</i></b>	Smelling objects, sniffing people

(Edelson, 1999a:12).

Various explanations have been given for the motivation as to why a person may engage in stereo-typical behaviours. One set of theories suggests that these behaviours present a person with sensory stimulation because the person is hyposensitive. Another theory states that the person finds the environment too stimulating and that he/she is in a state of sensory overload (hypersensitivity) (Edelson, 1999a:12).

Jim, a twenty-seven year old man with Autism/PDD, describes this difficulty with sensory processing. Jim reports that touching remains a difficult area for him. Jim describes touching as not necessarily painful but as an intense feeling which can sometimes be overwhelming. He finds it hard to describe his sensory processing, but explains it in the following way: "Sometimes the channels get confused, as when sounds come through as colour. Sometimes I know that something is coming somewhere, but I can't tell right away what sense it is coming through (Cesaroni & Garber, 1991:305).

Albert, a thirteen old boy with Autism/PDD reports premonitions of intense auditory stimuli. He is able to hear a train approximately five to ten minutes before it passes his home (Cesaroni & Garber, 1991:306). Georgie Stelhi (in Stelhi1991:169) describes a storm as something that sounds like a machine gun. These children are also bothered by peripheral noise, which makes it difficult for them to learn. This

hypersensitivity to sound is treatable by a series of auditory integration therapy (Edelson, 1999b:1).

The researcher is of the opinion that 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, senses being diminished or heightened, bizarre eating patterns, a high pain threshold, laughing or crying for no apparent reason, abnormal sleep patterns and self-injurious behavior (Autism South Africa, year unknown: 5).

## 2.5 The effect of Autism/PDD on sibling relationships

When children are hurt, ill or disabled, they need personal and physical attention, and this has consequences for the whole family (Davis, 1993:11). Each form of disability presents specific problems for the child and the family. Each condition has specific stresses and makes particular demands upon the resources of the family and the child. Common to them all is the need to adapt physically, socially and psychologically (Davis, 1993:11). The family's way of adapting will therefore also have an influence on the siblings of the children with Autism/PDD.

The feelings and the thoughts of siblings of children with Autism/PDD are complex and vary considerably (Smeardon, 1998:13). Growing up with a sibling with disabilities makes family relationships more complicated (Porterfield, 1997:9). It can have positive and negative effects. (Compare Lobato, 1991:17; Porterfield, 1997:9.) According to Porterfield (1997:9), 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 caretaker. Various authors (compare Lobato, 1991:17; Smeardon, 1998:13) are of the opinion that the effects of the child with disabilities are not

potentially negative but can also be potentially positive. The researcher is of the opinion that it is therefore important to look at the full range of feelings that the child in middle childhood can experience. According to Lobato (1991:16) adult siblings reported feeling that they were generally either harmed or they benefited by their family's uniqueness. All of them report that they felt the full range of emotional effects at one point or another.

### 2.5.1 Negative feelings

#### □ **Feeling left out**

The child with Autism/PDD 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/PDD (Smeardon, 1998:12). Greenspan & Wieder (1998:374) confirms this by stating that it is virtually impossible not to feel concerned and guilty at times because a child with special needs demands more time and energy. Harris (1994:13) states 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 for them.

#### □ **Anger and guilt**

From time to time children with siblings with Autism/PDD get angry at their brother and sister's behaviour. As one sister explains it: "If I'm playing a game on the floor, my brother tramples all over it. This is because he doesn't know how to play games (even if I explain them to him)". "When we play rough and tumble my brother sometimes gets so excited that he bites or hits me. This is because he can't control how he feels"(Gorrod, 1997:2-4). Because anger is a natural response in many close relationships, the child needs to know that it is acceptable to be angry sometimes (Smeardon, 1998:14). Especially younger siblings might feel that they somehow

caused their sibling's disability or may feel guilty about not being disabled themselves (Rosenberg, 2000:40).

□ **Views of others**

Several siblings have commented that the way the public reacts to their brother/sister is difficult to cope with (Smeardon, 1998:14). This is how one sibling described her experience: “ When we go shopping my brother screams and makes loud noises. People stare and talk about us...they do not know my brother can't talk like me” (Gorrod, 1997:14). Some siblings feel embarrassed in public while other siblings feel angry at the reactions of other people.

□ **Treating siblings equally**

“When I behave badly I get told off... But my brother doesn't. This sometimes seems unfair. Mum says this is because I know when I am being naughty but my brother doesn't” (Gorrod, 1997: 7). Children are very aware of differences in how they are treated (Harris, 1994:78). Though fights between siblings are a normal part of everyday life in all families, there might be a tendency for the parents to side with the disabled child. They might also expect the other child to compromise. Some parents might for example, expect the non-disabled child to always clean up after playing, while it is never expected from the disabled child. This favoritism can lead to feelings of resentment toward the parent and the sibling with the disability (Siegel & Silverstein, 1994:193).

□ **Praising the non- disabled siblings**

Parents should be mindful of praising the healthy siblings for small milestones as well (Siegel & Silverstein, 1994:194). “ I bring home a paper with a B grade my mother says: “Well you'll have to try harder next time. But she makes a big fuss

about anything Amy brings home, no matter how sloppy it is” (Meyer & Vadasy, 1994:4).

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 child 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**

Siblings 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 (Smeardon, 1998:15).

□ **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 sibling (Rosenberg, 2000:40)

## 2.5.2 Positive feelings

The effects of living with a sibling with Autism/PDD are not only negative, but can also have a positive effect. These potential positive effects include maturity, responsibility, altruism, tolerance, humanitarian concern and careers, sense of closeness in the family and self-confidence and independence (Lobato, 1991:17).

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 (Russell, 1997:6).

Siblings of children with special needs often have greater tolerance, empathy, and awareness of the consequences of prejudice and greater intolerance of intolerance towards others. Children are more open to celebrate diversity themselves. Such an optimistic outlook on life, is beneficial to these siblings (Russell, 1997: 6).

□ **Children as teachers**

The basic principles of behaviour management are valuable educational tools. Years of research have helped to refine behavioral procedures into sophisticated methods for creating an effective learning environment. Some of the tried and tested methods of teaching children with Autism/PDD are positive reinforcement, well-delivered instructions and prompts (physical and verbal guidance). Consistency of teaching methods for behaviour across settings and people are important for the child with Autism/PDD (Harris, 1994:102). According to Lovaas; Koegel; Simmons & Long (in Harris, 1994:102) it is important for families to be partners in their children's education to ensure consistency from school to home. Siblings can therefore become valuable teachers for their brother/sister with Autism/PDD. In 1987, Koegel, O'Dell and Koegel developed a program incorporating motivational techniques and functional language use. It was designed to be used in the natural environment and was therefore suited to home use. Laski, Charlop, and Screibman (1988) taught parents to use these techniques which significantly increase and improve the speech of the children (Koegel; Schreifmann; Good; Cerniglia; Murphy & Koegel, 2000:3). The researcher is of the opinion that teaching siblings these techniques will enable them to manage certain stressful situations with their siblings.

In order to teach the normally developing child to become an effective teacher/playmate for his brother/sister with Autism/PDD, it is important to follow a

series of three steps. It is important to go slow and do just a little each day. It is important to be liberal in praising the children. It is important to create a setting for teaching. Three basic steps need to be taught, namely:

- Giving effective/clear instructions
- Rewarding good behaviour
- Prompting new skills

## 2.6 Factors which influence the adjustment of siblings

### 2.6.1 Effect 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/ definition of their sibling's special needs as long as it is explained to them in terms they can understand. Children in middle childhood may worry that the disability is contagious or wonder if something is wrong with them too. This is true for the early part of middle childhood. Between the ages of nine to twelve, children can typically understand that it is a problem of the brain and that it is not contagious. Many of their misconceptions they had as younger children can be changed as they become increasingly more mature in their discussion of the disorder (Harris, 1994:37).

Children may also experience some guilt feelings for having negative thoughts or feelings about their sibling or guilt for being the non-disabled child (Timmons & Schubert, 2000:1). They might also feel that behavioral deficiencies on the part of their sibling is partly their fault and that they should keep their sibling from acting badly (Siegel & Silverstein, 1994:69). One of the typical responses of children this age is to become overly helpful and well behaved or to become non-compliant in order to obtain their parent's attention. Throughout this age span children might experience conflicting feelings about their sibling (Timmons & Schubert, 2000:1). Siegel & Silverstein (1994:69) confirm this by stating that latency-age children often

compartmentalize their feelings. It can therefore be difficult to know exactly what they think or feel about their sibling. It might also be hard to put into words just how their sibling is different even though they are aware of very real differences.

According to Dunn (in Harris, 1994:11) 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. The building blocks for greater independence in adolescence are being put in place (Harris, 1994:37). One of the developmental tasks of the child in middle childhood is to socially move from the family to the peer group (Bender, 2000:33). This increased independence means that they will spend less time at home and they might have less interest in playing with their younger sibling with Autism/PDD.

The child's growing reliance on their peer group can make them very vulnerable to the reactions of other children concerning their sibling with Autism/PDD. (Compare Harris, 1994:38; Smearon, 1998:15.) Some children may begin to turn away from their sibling with Autism/PDD in an effort to fit in with their peers. The child's behaviour 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 (Harris, 1994:38).

During this developmental phase the child also becomes increasingly aware of their parents as people who can make mistakes. This might result in children being critical of their parents, especially in the way they deal with the child with Autism/PDD. The child is provided with a realistic model of their parents, instead of a super hero whose achievements can never be equaled by the youngster growing up (Harris, 1994:38).

## 2.7 Potential family stresses

When viewing the family as a unit, it is suggested that most people would use structural aspects of their family's situation as for or against its normal character (Gray, 1997:1101). 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
- Emotional relationships among family members
- Family rituals and routine activities
- Intrusiveness of the child's symptoms

### □ **Social outings and activities**

Leisure activities, such as participation in clubs or sports and family activities such as having and visiting friends, attending family gatherings are often affected (Hornby, 1994:38). Parents felt that they are most restricted for the following reasons: One mother reported that they used to be able to go on outings but that 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 (Gray, 1997: 1101).

Some parents also feel that the spontaneity of social activities becomes restricted. Several parents reported that their child had to have adequate warning of outings and activities. Even then, the success of an activity is not guaranteed (Gray, 1997:1101). According to Jordan (2001) it is important to continue to expose the child with Autism/PDD to social situations, even if he finds it difficult. The child can develop a secondary handicap if he is too isolated from social situations.

□ **Quality of emotional relationship among family members**

Parents generally see their family as normal when they experience supportive and emotionally intimate interactions with other members of their family. They see their family as not normal when rejection and conflict characterize such interactions. The demands made by the child's symptoms often lead to conflict between family members. One mother stated the following: "There is so much bickering going on. There is always a lot of shouting and noise in the house. That is just depressing on its own...always conflict between the kids...there is so much conflict in the house, you can't live like in a normal house" (Gray, 1997:1102).

□ **Problems with changes in routine**

Individuals with Autism/PDD seem to prefer consistency and maintaining the same routine. The slightest alteration in routine can cause serious difficulties for their families. There also seems to be a tendency to be continuously frightened of harmless things, while they seem oblivious to real threat and dangers (Norton & Drew, 1994:70). This behaviour may make it difficult to take the family on outings. Moreno and Donnelan (in Norton & Drew, 1994:70) state that unpredictable behaviour in children who appear normal, causes people to react negatively by saying that the child is a brat instead of seeing his behaviour as part of the disability.

## **2.8 Needs of siblings**

Each sibling of a child with Autism/PDD is unique. Many of them share similar needs and concerns, though many of these needs and concerns change with age and circumstance. According to Lobato (1991:65) most siblings agree that they need the following during their childhood:

- Information on their sibling's condition, including how it is evaluated and treated (Sibling support project, 2001:1).

- Open communication within the family about the problem and sharing their experiences. Fish; McCaffrey; Bush; Piskur; Katz; Harrington; Betz & Scott (1995:1) designed a questionnaire called SNIP (The sibling need and involvement profile) to enable parents to determine the areas in which they can support their child in dealing with his/her brother/sister with Autism/PDD (See appendix 3).
- Recognizing the sibling's own accomplishments and strengths.
- A need for quality times with their parents on an individual basis. Greenspan & Wieder (1998:374) uses the floor time approach where the child with Autism/PDD plays one-on-one with the parents and the child is in control of the game. He suggests floor-time for the non-disabled sibling as well (See appendix 4). Knowing that they can have the parent all to themselves may compensate for limited attention at other times. Contact and support from other siblings and families. According to Meyer and Vadasi (1994:4) siblings should be provided with opportunities to meet other siblings of children with special needs. In their opinion, it is almost unthinkable for parents to cope with their child's special needs, without the help of other parents. Yet, this often happens to brothers and sisters. In the USA siblings of children with special needs go to 'sibshops' with other children with the same needs. At these sibshops brothers and sisters know that they are not alone with their unique joys and concerns.
- Ways to cope with stressful events such as public and peer reaction, unexpected disruptions to family plans as well as extra home responsibilities.

## 2.9 Summary

Parents are often concerned about the long-term effects that having a sibling with Autism/PDD have on their other children. According to Smeardon (1998:16) it would seem that siblings of disabled children are not adversely affected. There might even be advantages. Mates (in Smeardon, 1998:16) found evidence to suggest that having an autistic sibling is associated with interpersonal, care taking skills and positive self-concept. In the 1995 report of the NCH Action for Children the results were both positive and negative (Smeardon, 1998:16). Though a substantial amount of children

experienced difficulties, all the children who were interviewed had deep feelings of love and affection for their siblings. Many also had a positive attitude towards disability and found friends understanding and supportive.

## Chapter 3

# Using play therapy to assess the needs of siblings with Autism/PDD

### 3.1 Introduction

“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, 1996a: 61).

In assessing the needs of children, it is essential to reach out and meet them on a level they can understand. By using play techniques and following an indirect approach, it is possible to break down the barriers that may prevent the therapist from reaching the child (Schoeman, 1993:31). A ‘playing cure’ is therefore a more appropriate descriptor of therapy with children, than Freud’s ‘talking cure’ (Cangelosi and Schaefer in Thompson & Rudolph, 2000:393).

The child in middle childhood has his/her own needs and concerns regarding his/her brother/sister with Autism/PDD. This includes feelings around separating from their family or the reactions of their peers to their sibling with Autism/PDD (Harris, 1994:39). Smeardon (1998:15) is of the opinion that it is important to help children explain to their friends what Autism/PDD is in order to promote understanding.

The unique character of the child client gives a special character to therapy with the child (Van der Merwe, 1996a:6). Violet Oaklander (1988:53) demonstrates a unique way in working with children by using gestalt therapy practice and principles with the use of media, such as drawing, when working with children.

In this chapter the focus will be on ways to use play therapy in assessing the needs of siblings of children with Autism/PDD.

## 3.2 The child as client

### 3.2.1 Differences between the child and the adult as client

Communication with children differs from communication with adults. This is especially important during therapy. (Compare Geldard & Geldard , 1999:2; Van der Merwe, 1996a:6) The child's non-verbal communication is particularly prominent and is expressed through play, gesture, facial expression and appropriate touching (Van der Merwe, 1996a:16.) The child's customs, preconceived ideas, dislikes and preferences influence his play to a large degree. This might even serve to hinder his spontaneous reactions to what he really feels and experiences (Schoeman, 1993:1). The following differences between the child and the adult as client should be considered in assessing children's needs:

#### □ ***Differences due to developmental level***

- Children are in the process of development. Their conduct will therefore be immature;
- The child has a short attention span;
- The structuring of the therapy may be limited because there is an inability to conceptualise especially concerning time and space;
- Ambivalence is common. The child therefore shows no definite patterns in handling conflicts or problems (Van der Merwe, 1996a:8).

#### □ ***Differences in communication***

- The child's style of communication is different from that of adults. The child's non-verbal communication is especially prominent and surfaces through play;
- The child finds verbalization of feelings difficult, even on a conscious level because his/her feeling language is usually limited;
- The child does not usually respond well to questions (Van der Merwe, 1996a:8).

□ ***Differences in the handling of the client role***

- A formal atmosphere may be counterproductive because children are so spontaneous. A relaxed atmosphere might suit them better;
- The child is usually not involved in treatment by own choice but because an adult brought them;
- Significant people in the child's life must be involved in therapy. It is impossible to work with the child in isolation (Van der Merwe, 1996a:8).

### *3.3 The child-therapist relationship*

The child-therapist relationship is one of the most important factors in achieving a successful therapeutic outcome (Geldard & Geldard, 1999:6). Kadushin (1990:114) describes the therapeutic relationship as the communication bridge between the therapist and the client. The messages pass over the bridge with greater or lesser difficulty, depending on the nature of the emotional interaction. Several other factors need to be taken into account in the process of establishing a relationship with the child client:

#### 3.3.1 Attributes of the child therapist relationship

- **A connecting link between the child's world and the world of the therapist**

It is important for the therapist to join the child within the child's framework. The relationship is primarily about connecting with the child and staying with the child's perceptions. The child may see the environment in which he lives in a different way from which his parents view it (Geldard & Geldard, 1999:6). It is important for the therapist to be a friend to the child and to make himself emotionally available to the child. The therapist should be able to share authority in the relationship with the child to ease the child's discomfort (Schoeman, 1993:2). According to Oaklander (in Kottman & Schaefer, 1993:281) the therapist is not a better or more important person

than his/her client regardless of age or education. The therapist brings himself fully, genuinely and congruently into the session.

□ **The child therapist relationship should be exclusive**

The child should experience his relationship with the therapist as exclusive. It is important for the child to feel that he has an exclusive relationship with the therapist (Geldard & Geldard, 1999:6). This is an important fact to consider during the assessment of the siblings of the child with Autism/PDD because they often feel left out.

□ **The child-therapist relationship should be safe**

The therapist should create an environment in which the child feels free to gain mastery over his feelings and act out in a safe place. The child should feel safe that his/her disclosures will be treated confidentially (Geldard & Geldard, 1999:6).

□ **The child therapist relationship should be authentic**

The relationship between the child and the therapist should be genuine and honest. The relationship should be consistent with the person the therapist is and the way the child is. The authentic relationship gives the child the opportunity to expose his inner self and to find that he does not have to pretend (Geldard & Geldard, 1999:6).

□ **The child therapist relationship should be purposeful**

If the child clearly understands the reason for seeing the therapist, the relationship has the potential to be purposeful. It is important for the therapist to facilitate play or other activities to be purposeful and not aimless (Geldard & Geldard, 1999:10).

Hobbs (1997:24) is of the opinion that the relationship is devalued if the therapist is overprotective, detached, cold or authoritarian. The role of the therapist is to be a facilitator.

### 3.4 The use of projection in play therapy

The child makes use of projection to help him/her work through difficult parts of his/her life. He/she is often not allowed to express his/her feelings out in the open. Children are often forced to 'behave' themselves within their families. They often carry unexpected resentment, incomplete awareness and anger with them as a result. As a result of the child's unfinished business, he/she becomes unable to establish organismic self-regulation. The child desperately tries to maintain a balance at this stage. As a child strives towards closure all the unfinished business remains, needing this to be projected onto something else. Because of the child's lack of experience the child projects all of his unfinished business onto his/her own body. The unfinished business creates malfunctioning, which represents expressiveness of unresolved conflicts (Schoeman, 1996a:70).

Clark and Fraser (in Schoeman, 1996a:64) state that 'projection is imagining that our (unwanted) feelings belong to someone else'. According to Schoeman (1996a:64), healthy projection is an art. Pathological projection is the result of a person not being aware of and not accepting responsibility for what is being projected.

Projection therefore serves the following objectives in the life of the child:

- It gives the child the space to sort out the expectations with which the world confronts him;
- It is an attempt by the child to dispel what he cannot yet handle;
- It offers the child a means of maintaining his self-respect;
- It also offers an escape when the child is unready to accept rejection and criticism.

## 3.5 Play therapy methods and assessments

### 3.5.1 Forms of play

The following are forms of play

#### Dramatized Play

##### Medium

Role-plays

Puppets

Dance and movement

#### Creative Play

##### Medium

Clay

Sand tray

Drawings

Letters

#### Biblio-play

##### Medium

Life book

Dairy

Comic strips

Poems

Story. (Compare Thompson & Rudolph, 2000:386; Oaklander, 1988:97-85.)

Schaefer (in Thompson & Rudolph, 2000:373) 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.

For the purpose of this study the gestalt activities should be adapted for children. In this study the focus is on the child in middle childhood. Mullen (in Thompson and Rudolph, 2000:173) suggests that therapists familiarize themselves with the developmental level of their clients. By understanding developmental principles, the gestalt therapist will understand differences in how clients construct reality as they move and grow through various stages of development.

Geldard & Geldard (1999:90) use media as a way of engaging the child as well as enabling the child to tell his/her story. In choosing media/activity the therapist should be aware that each child is different. The activity/media should be matched with the individual child and with the child's abilities and needs.

The therapist should consider the following factors when choosing media/activities:

- The child's developmental age. Murphy; Paeschel; Duffy and Brady (in Seligman 1991:184) observed that the type of information requested appears to be related to age.
- Children between the ages of six and nine years old asked questions about speech and motor development and they were interested in the medical and biological information presented to them. Concerns about the future were more evident amongst the children between ten and twelve years old;
- Whether the child is being counseled in a group or individually;
- The current counseling goals (Geldard & Geldard, 1999:92).

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/PDD. Stuart (in Fourie, 1993:46) views assessment as the simultaneous collection and evaluation of data in order to move to the action phase.

### 3.5.2 Drawing

The goals when using drawing, are the following:

- 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 which he/she is experiencing or has experienced (Geldard & Geldard, 1999:90).

A very effective technique in therapy is to have children draw their family as animals or symbols. The therapist will lead the children in the following way: “Close your eyes and go into your space. Now think of each member of your family. If you were to draw them on a piece of paper as something they remind you of, rather than real people, what would that be? If someone in your family reminded you of a butterfly because they flit around a lot, is that what you would draw them as ... You can use blobs of colour, shapes, objects and things and animals and whatever else you can come up with” (Oaklander, 1988:26).

Lobato (1991:102) states that the purpose of this activity is to elicit conversation from the children about themselves and their families. If the child’s brother/sister with Autism/PDD lives outside of the home, the therapist should indicate that the child should be included in the picture.

Oaklander (1988:53) uses a specific working model to elicit conversation from children around their creation:

- Have the child share the experience of drawing. This is a sharing of self
- Let the child describe the picture in his/her own way
- Make the child elaborate on parts of the picture
- Ask the child to describe the picture as if it were the child
- 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 colours
- Watch for the cues within the child’s voice, tone, body posture, facial expression, body expression, breathing, 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 be as matter-of-fact and accepting of the children's descriptions as possible (Oaklander, 1988:26).

### 3.5.3 Sensory play

The feeling bag is made of textured material and contains a range of 'touch' objects, such as an orange, a small toy, glove, marble, wooden spoon, toy tree and nailbrush (Jennings, 1993:88). The child puts his hand into the bag and identify the object. For the aim of this study , the researcher will use this activity as an icebreaker.

### 3.5.4 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 (Van der Merwe, 1996b:126).

### 3.5.5 Books

Books can be used to enable the child to open the discussion on the child's feeling regarding a specific problem. Van der Merwe (1996b:110) 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 misinterpretations, educates and generalizes
- It speeds up the therapeutic pace
- It is a structured form of play and is therefore cost-effective as it directs the conversation towards the problem.

Smith and Porter ( in Van der Merwe, 1996a:14) distinguish 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**

Once the child identifies with the character projection and modeling comes into place. Crompton (in Van der Merwe, 1996a:14) prefers the term recognize, to identify. He believes that identification implies that the child should find a replica of himself in the character of the story. By using the term recognizing it suggests that although the reader sees similarities between his life and that of the character, he is also able to see important differences.

### **Projection**

The child unconsciously transfers certain feelings (often unacceptable ones) onto the characters. This is called projection. Smith (in Schoeman, 1996b:114) 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 behaviour.

### Catharsis

The child's feelings can be released during the processes of projection and modeling. Release on such an impersonal level affords the child the opportunity of examining the consequences from a safe distance.

### 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 verbalise this realization. When the child recognizes the resemblances, this can signify that he is able to cope with his feelings.

In this study the researcher made use of biblio-play. The researcher made use of a book called 'My brother is different' (Gorrod, 1997).

## 3.5.6 People can be the same and different

The goal of this activity is to elicit a conversations around the 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 the 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 they 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 (Lobato, 1991:107).

### 3.5.7 Techniques to identify positive and negative feelings

The purpose of identifying positive and negative feelings is:

- To assist the children in learning how to identify positive and negative emotions in themselves and others;
- To practice expressing them verbally (Lobato, 1991:125).

Once the children appear fluent in identifying emotions, it is time to practice identifying interpersonal situations that frequently result in positive and negative emotions (Lobato, 1991:125). By focussing on the positive and negative emotions children experience, the therapist aims to focus on the polarities within the child self and in his/her environment (Thompson & Rudolph, 2000:166).

## 3.6 The use of observation in play therapy

Fritz Perls (in Corey, 1995:308) states 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/PDD. Despite the outward behaviour of the parentified sibling of a child with Autism/PDD 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 parentified actions may occur in guilty compensation for 'bad' thoughts about their brother/sister.

### 3.7 Summary

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

Though 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

## Empirical study

### 4.1 Introduction

In the previous two chapters the focus was twofold. The aim was to define Autism/PDD and to discuss how Autism/PDD might affect the siblings of these children. In chapter 3 the focus was on the use of play therapy methods to assess the needs of the siblings. The empirical study and research findings are discussed in this chapter. Specific attention is given to problem formulation, the goal of the study and the research method that was used in this study.

The goal of this study was to investigate the effect of living with a sibling with Autism/PDD by using play therapy methods. The research question was the following: “What is the effect of living with a sibling with Autism/PDD?”

The respondents attended six sessions, once a week, over a period of two months. Five of the sessions were conducted in a room suited to do assessments with the children. The fifth sessions were conducted at the houses of the research 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 experienced by the siblings of children with Autism/PDD.

## 4.2 Assessment by means of six play therapy sessions

- Interviewing the parents

This was the time of preparation for the empirical study where information was gathered about each child. This information enabled the therapist to hypothesize about what might be happening to the child. By gathering information, suitable media could be selected to enable the therapist to interact with the child. This stage also involved contracting with the parents. (Compare Geldard & Geldard, 1999:35.) In this study this phase involved an interview with the parents to discuss the child's suitability to the assessment methods. This phase also included a discussion about and signing of the letter of consent.

- Session 1

The researcher made use of sensory activities to start the first session. The researcher placed objects in a bag and asked the respondents to guess what they were. During the first session the focus was on building a relationship with the child. The aim was to find a connecting link between the child's world and that of the researcher. This session also served as an introduction to the topic of the research. 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 centered on the differences between the flowers and the differences between the cars, but that they were the same. The researcher then showed the children pictures of their brothers and sisters and introduced the topic of being different from their brother and sister and that being different, was 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 also helped the child to gain mastery over certain situations. The researcher used Oaklander's model (Oaklander, 1988:53) to elicit conversation with children about their creation.

- **Session 3**

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

- **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 the respondents to discuss Autism/PDD. During this session the researcher determined the negative aspects that these children experience with regards to having a brother or sister with Autism/PDD.

- **Session 5**

The data collection phase in qualitative research involves observation. During the fifth session we focussed on the unique stresses and challenges that each of these children experience with regards to their brother/sister with Autism/PDD. The researcher spent one afternoon with each child to observe the way in which the siblings interacted.

- **Session 6**

This was the final session. The research participants made a collage about the positive aspects of their brother/sister with Autism/PDD. We had a party.

## 4.3 Child A

### 4.3.1 Biographical information

Child A is a seven-year-old girl in Grade 1. She attends a private Christian school. Her teacher describes her as a very intelligent and talented pupil. She is the eldest of two children. The respondent has a younger sister (five years old) who is diagnosed with Autism/PDD. 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/PDD 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 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 explain the aim of the research, the roles of the researcher and the child, to establish boundaries and limits.
- To introduce the research topic by doing the same and different activity.

Child A's first session took place at her school. The researcher explained to her that the research would consist of six sessions. We would meet each other in the same room on

Tuesdays at 14:00. The sessions would last for fifty minutes. We also established boundaries and limits around the sessions.

The first activity was a sensory activity. The researcher put objects in a bag and we took turns to guess what they were. Child A 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 A loved cats and took out some pictures of different cats. The researcher then asked her 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 cats at home and about her favorite cat getting lost. The researcher asked her whether the one cat was better than the other. She indicated that it was not the case.

The researcher then took out a picture of child A and a picture of her sister. The researcher asked her how they were the same and how they were different. Child A described differences like age and sex and hair colour. 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 that she has her own teacher who teaches her alone. She then said that 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 whether her sister flicks her fingers in front of her eyes or plays with her fingers. She said yes. She said that her sister does not care much for playing with

dolls and cars. 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:

Child A met the researcher after school. It was a warm day; therefore we first had a drink together. Then we did an icebreaker. The researcher had bottles, filled with different smelling liquids. We each took turns to smell the liquids and to say what the smell reminded us of. After being quiet initially, Child A started to participate in the game. Most of the smells were related to something at her house. One of the bottles contained bubble bath that smelt like pine forest. It reminded her of a school outing, which she went on a few weeks prior to this session.

- The researcher asked Child A to draw a picture of her family doing something together. (Appendix 5). The researcher assessed the picture with the use of Oaklander's model. Child A 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 river. 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 To use family drawing to enable Child A 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.

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 cabin and play with her sister. She also likes going to “Tumble Town” to play with her.

Child A 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 A has unfinished business with regards to her sister with Autism/PDD.

The researcher met Child A at the same place 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 A did not want to complete the sentences 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 A indicated that she did not 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 thinks that she is happy already.

One of the other sentences was ‘ I love doing ...with my sister’. She said that she loved playing on the trampoline with her sister. They also enjoyed playing ring-a-

roses. Child A 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 already liked playing together at home and that it would be fun if they could play together at school.

- **Session 4**

The goal of session four was:

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

At the beginning of the session the researcher explained the medium that would be used during the particular session. Child A 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 A took turns to create different tunes on the instruments.

The researcher read 'My brother is different' to Child A. 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 A 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 A, her sister also gets told off if she is naughty. She does not think that her parents treat her unfairly.

‘At mealtimes my brother can’t sit still’(Gorrod, 1997:10). Child A 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 A 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 A and her sibling to enable the researcher to observe the interaction between the siblings.

The researcher joined the family as their mother was on her way to fetch Child A’s sister from her daily therapy sessions. The tutor was providing Child A’s mother with feedback on the day. Child A and her sister were playing on the stairs. Child A looked happy to see her sister and tried to engage her sister in a game. Her sister’s

concentration is limited and she has difficulty imitating play. Child A was very good in changing the game continuously to include and involve her sister.

After picking her up we went to a nursery with a playground. The children's 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/PDD they found that their life changed drastically. They spend a lot of time picking up and dropping her at therapy sessions. The respondent's sister is unable to stay at home too long, and then she gets frustrated if she is not stimulated on 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 the jungle gym. Child A's sister tried to involve her in playing on the swings and the jungle gym. Child A 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 initially. The younger sister then went into her sister's toybox and started playing with some of her sister's toys. Child A 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. According to Autism South Africa (year unknown: 4) tantrums may occur for no apparent reasons. The researcher showed Child A how to negotiate for a toy without causing her sister to get upset.

- **Session 6**

The goals of session six were:

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

The researcher explained to Child A 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 people; name two things that you can do with your sister that almost nobody can get her to do. Child A 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 ‘Tumble Town’ with her
- She likes swimming with her
- She learnt how to dress herself
- She can ask for a glass of juice by herself
- Child A can get her to put a video in the machine by herself
- She is able to encourage her to say a part of ‘Humpty Dumpty’.

The researcher took Child A to the local shopping mall for a cold drink and an ice cream. She loved it. The researcher asked her which activity she enjoyed the most and she said that she enjoyed the session with the biblio-therapy the most.

## 4.4 Child B

### 4.4.1 Biographical information

Child B is a ten-year-old boy in Grade 3. He attends a private school in his hometown. He is the third of four children. He has two older sisters, who are twenty-one and nineteen years old respectively. His younger sister (seven-years-old) was diagnosed with Autism/PDD. 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 Gluten-,casein-, sugar- and soy free diet. She has been in a home-based applied behaviour analysis and pivotal training program for one year and eight months. The strict diet, together with the strict behavioral program enables her to be less challenging to live with.

Child B himself suffers from a metabolic disorder and seems to be very sensitive to noise. He recently completed a series of Auditory Integration Therapy to enable him to be less sensitive to noise. If he sticks to his diet, he tends to be happier, 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 a sensory activity to enable the child to come in contact with his senses.
- To explain the aim of the research, the roles of the researcher and the child, to establish boundaries and limits.
- To introduce the research topic by doing the same and different activity.

The researcher interviewed Child B at his house for the first interview. The researcher explained her role to Child B. They discussed the length of each session (50 minutes) and that there will be six sessions in total. Child B asked whether his sister would attend the sessions as well. The researcher clarified this by explaining that these six sessions will center on his needs and that it will not include his sister. This role clarification was important to Child B 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 B appeared to be relaxed and very talkative.

The first activity involved the researcher and Child B taking turns in guessing the identity of 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 B 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 B the pictures of himself and his sister and asked how they were similar. Child B seemed quiet and the researcher made some suggestions as to their surname 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 B to tell his story
- To use family drawing to enable the child to express repressed or intense emotional feelings.

Child B 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 while. This served as an ice breaker.

The researcher then asked Child B to draw a picture of an animal family (See appendix 6) 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 started laughing. He 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 B 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 B if we could make his sister and himself out of clay. According to Van der Merwe (1996c:197), 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 figurine destroy the clay figurine, 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. Then he seemed quiet for a while. He then said that he likes going to the gym where they can swim. Child B reached a catharsis in the process of projecting the relationship between himself and his sister with Autism/PDD.

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

- **Session 3**

The goal of the third session was:

- To make use of incomplete sentences to determine whether Child B has any unfinished business with regards to his sister with Autism/PDD.

We had to postpone and re-schedule the third session because Child B had a dentist appointment. The researcher and Child B 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 rands 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. The researcher asked him who would go with him into the jacuzzi. 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 prized possessions from his sister because she destroys them. Children with Autism/PDD are often destructive and break things that would be of value to other people. (Compare Gorrod, 1997:2; Jordan, 2001.)

When I asked him about himself and his mother, he said that 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/PDD 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 would before, but it usually ends up being a very stressful situation. That is also the reason why Child B 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 the fourth session was:

- To use biblio-play to enable the researcher to determine the unique stresses and challenges of a sibling with Autism/PDD.

‘If I play a game on the floor my brother tramples all over it’ (Gorrod, 1997:2). Child B 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 B said that his sister was like that this morning at the auditory integration therapy. 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 she was happy and the next minute she would be very unhappy and hurt him. He said 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 B 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 doesn’t. 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 B 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 B said that his sister often screamed when they go into shopping malls. Child B 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 B and his sibling to enable the researcher to observe the interaction between the siblings.

When Child B arrived home after school, his sister was having lunch with her one-to-one tutor. The tutor left soon after lunch and the family’s maid took the responsibility of looking after her. Child B’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 maid had to leave her work to tend to the young girl’s needs.

Child B 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 B’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 B'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 function at school that evening. Child B refused to get dressed to go to the function. 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 all left. They went to the function but Child B's father came back earlier to help because she (the sister) became very difficult at the function. Child B and his mother went home with another family after the function finished.

- **Session 6**

The goals of the sixth session were:

- To terminate the series of sessions of assessments.
- To evaluate the assessment together with the child.
- To make a collage to focus on the positive aspects regarding his sister with Autism/PDD.
- To have an informal party and to evaluate the sessions.

The researcher took Child B to a shopping mall to play games at the games arcade. 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 B 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 hill in front of the house together.

## 4.5 Child C

### 4.5.1 Biographical information

Child C is an eight-year old boy 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 the age of three years, when he started regressing. He lost his ability to speak and became increasingly hyperactive and aggressive.

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

Child C'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 C'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 apartment and cut up most of his clothes. The situation is very volatile. It varies from being reasonably calm to very disruptive.

Child C's mother is experiencing a lot of ambivalent feelings as to institutionalize her son or to keep him at home. She is also worried about the effect on Child C. She feels very guilty about spending most of her time with her son with Autism/PDD.

- *Session 1*

The goals of the first session 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 his senses.

- To explain the aim of the research, the roles of the researcher and the child, to establish boundaries and limits.
- To introduce the research topic by doing the ‘same and different’ activity.

The researcher met Child C at his house after school. He was alone, while his mother was working. His older brother was in a children’s home. 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 and 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 that they were both black. 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 C 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 the second session were:

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

Child C spent a lot of time on his drawing. (Appendix 7). The researcher praised him for putting so much effort into his drawing. The researcher discussed the picture with Child C. Child C 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 C 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/PDD. It also showed that he needs more support to work through his feelings about his parent's separation.

- **Session 3**

The goal of the third session was:

- To make use of incomplete sentences to determine whether Child C has any unfinished business with regards to his brother with Autism/PDD.

The third session started off with an ice breaker. The researcher used small bottles with different fragrances. We took turns to smell the contents of the bottles and say what it reminded us of.

The researcher then explained the goal of the session. Child C 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 C 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 curry.* The researcher asked him when last they had chicken curry. 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 a children's home but lives at home now.* It was nice for the first day and then he became difficult. He threw all the shampoo down the drain and started cutting up some of his clothes. Child C 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 thing that makes me very sad...is when \*\*\*\*\*breaks my stuff. He should play with his own; I have to hide it 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 the fourth session was:

- To use biblio-play to enable the researcher to determine the unique stresses and challenges of living with a sibling with Autism/PDD.

The researcher met Child C at his house. By the time the researcher arrived, Child C's brother was still at home with his carer. 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 C appeared quiet and reserved for a moment after his brother left. It was as if he needed a few minutes to wind down. For this reason the researcher started off with a relaxation and breathing exercise before starting with the session.

The researcher explained the goal of the session. The researcher read the story to Child C 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 C explained that 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 to 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 C he doesn’t play physical games with his brother. He becomes too excited and scares Child C.

‘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 C his bother is very ‘strange’. He is unable to speak and makes all these loud, strange noises. He told the researcher about a time when he broke two of the windows in their apartment. He became so disruptive that the police had to come to the house to calm the situation. His mother then called the children’s home where he lived previously to help them to stabilise him during the day. He said that he was very scared.

He also spoke about a time when his brother ran into the local corner shop and started unwrapping some of the sweets and throwing them on the floor. His mother struggled to get him out of the store while the owner of the store was furious. He would also at times throw all the shampoo in the bathroom down the drain. After the window- incident his mom sent him away to live with his aunt for a while. He said that his mother was very nasty to him at that point and that he did not anything wrong.

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.

The researcher noticed some tennis racquets in the house. The researcher suggested that they go outside and hit a tennisball against the wall. This also seemed to be an opportunity to unload some of his aggression.

- **Session 5**

The goal of session five was:

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

The researcher picked Child C up from his school and took him home. On our arrival, Child C's mother was at home already. After changing from school clothes to play clothes everyone had a cup of tea and a sandwich in the kitchen.

Child C's brother and his care-worker arrived within the half hour. The whole atmosphere changed in the house. Child C was very friendly and asked his brother about school. His brother stood still and looked at him for a while. He did not answer his questions just echoed what he asked. He walked to the fridge and showed in sign language that he wanted food. His mother made him a sandwich and they had a sandwich together. He ate very quickly and then stared being very hyperactive again. The carer took him to his room to draw some pictures. He asked Child C to join them. We all went to the room. This activity lasted for a while and he jumped up again and started fidgeting with stuff in the lounge.

The researcher and Child C 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. Then a commotion broke loose. We could hear Child C making loud noises. We went to his room. He had a big knife and he was cutting his clothes. His mother was trying to convince him to give the knife. When she tried to approach him he became upset. She asked Child C to go out of the room because she was afraid that he would get hurt.

Child C appeared very anxious. His brother eventually finished cutting his clothes but cut his arm in the process. His mother, being a nurse thought that it was serious and decided to take him to the hospital for stitches. She asked the researcher and the childcare worker to go with her because she was on her own and was afraid that he would be very unruly in the hospital.

We drove to the hospital. Child C started crying because he wanted to go to the park. His mother was trying to explain but he was very upset. He said that she never keeps her promises. Afterwards his mother said 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 be institutionalised.

- **Session 6**

The goals of the sixth session were:

- To terminate the series of assessments.
- To evaluate the assessment together with the child.
- To make a collage to focus on the positive aspects regarding his brother with Autism/PDD.
- To have an informal party and to evaluate the sessions.

The sixth session started off with making a collage at his house. Child C identified the following positive aspects about his brother: that he likes chicken curry, that he is a good cook, that he is able to plat hair, faster than any one he knows and that he is very strong. The researcher and research respondent then went to the park. Afterwards Child C had an ice cream in the park. Child C enjoyed the drawing and bibilio 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.

## 4.6 Evaluation of sessions

### Evaluation of session 1

The aim of the first session was to establish a relationship with the research respondents 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 B and C were able to express their intense emotional feelings. The researcher was also able to collect valuable information on the effect that living with a brother/sister with Autism/PDD has on the family. With the same and different activity the researcher was able to determine the way in which the respondents viewed their sibling's disability.

### Evaluation of session 3

The researcher was able to use incomplete sentences to gather information on the unfinished business of the research participants. This session was the least popular. Child A found it too difficult to write and drew pictures. Child B, with his fear of failing found this activity stressful as well. This method was especially useful to Child C because it brought his unfinished business to the foreground. He appeared very concerned about his brother's level of aggression.

### Evaluation of session 4

The children enjoyed session four the most. The book, 'My brother is different' was a very useful tool. All three of the children were able to project their feelings and drew comparisons between the child in the book and their own situation. According to Schoeman (1996a:70) 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 three participants. Child A enjoyed this session the most. Child C 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 first hand 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/PDD. It was very important to not only focus on the negative aspects but also focus on the positive feelings.

## 4.7 Assessment

### 4.7.1 Child A

- Helping

Child A appears to play a strong helping role in her family. According to Siegel (1998:26) the child with Autism/PDD 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 A'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 is able to have so many play skills. She also teaches her to swim. In all her drawings she depicts her and her sister as being happy together. According to Schubert (2001:2) 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 A stands up for her sister and is not ashamed to spend time with her. She appears to be unaware of children or adults making comment about her sister.

- Awareness

Child A's parents requested that the term autism/PDD 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 Lobato (1991:65) one of the needs of siblings is to learn ways to cope with stressful situations. Child A has a need to learn to negotiate with her sister to get her own needs met and to avoid her sister throwing a tantrum.

- Having fun

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

- Isolation

According to Rosenberg (2000:40) siblings often feel ignored by the professionals helping their sibling. Child A often asks her sister's tutors to play games with her too. She also says that she wishes that she could have a tutor to play with her all day.

- Positive aspects

The researcher also observed positive effects on Child A. The researcher noticed tolerance, maturity and altruism shown by Child A.

- Need for information

It appears that Child A is not in need of much more 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 A identified mostly positive aspects with regard to her sister with Autism/PDD. Child A's family went through major adjustments to their social life, family rituals and routine activities. Her sister's symptoms can also be considered intrusive. (Compare Gray, 1997:1101.) Child A appears to make adjustments and is positive. She enjoys playing with her sister and appears to be a vital part of her sister's progress.

She is concerned that her sister is unable to speak. Though Child A 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 (Bender, 2000:33). 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 brother/sister with Autism/PDD in order to fit in with the peer group. Her parents would be able to be more understanding if they view the possible changes in attitude as a developmental process. (Compare Smeardon, 1998:15; Harris, 1994:38.)

Even though her parents have agreed not to use the word Autism/PDD, Child A 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.

#### 4.7.2 Child B

- *Helping*

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

- Advocacy

Though child B 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 B 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 B plays outside with his friends his sister sometimes join them. This is more the exception than the rule. He said that he likes going to the gymnasium to swim with her.

- Feelings

Child B 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 (1994:13) states 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 B felt guilty about his feelings. It is important to reassure him constantly that it is acceptable to express his feelings.

- Anger

Child B 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 (Smeardon, 1998:14). It is important for Child B's parents to become aware of his anger to enable him to express it in a healthy way.

- Treating siblings equally

Child B 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

Leisure activities such as participation in sports and family activities such as friends visiting and attending family gatherings are often affected. Parents often feel more restricted, especially with regards to the spontaneity of leisure activities, and often choose to rather stay at home. (Compare Hornby, 1994:38; Gray 1997:1101.) Both parents and the two elder daughters were avid 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 B often avoids these activities.

Since their youngest daughter has been diagnosed with Autism /PDD life has become less predictable and activities have changed. Predictability is very important for Child B. Individuals with autism seem to prefer consistency and maintaining the

same routine. The slightest alteration in routine can cause serious difficulties for their families. There also seems to be a tendency to be continuously frightened of harmless things, while they seem oblivious to real threat and dangers (Norton & Drew, 1994:70). This behaviour may make it difficult to take the family on outings or to predict whether outings will in fact happen on the planned day.

Child B 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.

### 4.7.3 Child C

- Helping

The researcher observed that Child C has the desire to help his brother. He tries to connect with him on his level. His brother's unpredictable behaviour 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

Smearon (1998:12) states that the child with Autism/PDD 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 C 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 the city without him. He has a desire to do fun things with his mother. He is feeling completely left out. Harris (1994:13) states

that children of any age may doubt their importance if their parent seems preoccupied with their sibling. Child C 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 C 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 (and hating him at times). 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 volatile and unpredictable, his mother is sometimes impatient with him.

- Inability to explain to friends

If the child with Autism/PDD is very disruptive it might be virtually impossible for children to invite their friends back home (Smeardon, 1998:15). Child C sometimes goes for a sleepover at a school friend's house. His friend has not been to Child C's house for a sleepover yet. Child C'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 C's friends for a sleepover.

- Awareness/ A need for information

Though each sibling of a child with Autism/PDD 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. (Compare Lobato, 1991:65; Sibling support project, 2001:1.) This

is the reason why child C asks whether his brother is crazy. He has a need for information on the condition and whether it will ever get better.

- Social outings and activities

Child C explains that they can not go out as a family because his brother can display uncontrollable behaviour in public. Social outings and activities and the spontaneity of social activities are often influenced. They have to plan outings very carefully. This also has an effect on Child C 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/PDD seem to prefer consistency and maintaining the same routine. The slightest alteration 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 C's brother needs a high level of consistency in his daily routine. A change in routine can result in outbursts like when child C's brother cut up all his clothes. This resulted in Child C's routine being changed because he was late for school because his mother could not walk with him. The unpredictability also results in an unpredictable life for Child C. He has to adjust continuously.

- Praising non-disabled siblings

Child C appears to need a lot of verbal words of affirmation. During the fifth session the researcher observed that Child C 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 C is also afraid that his brother will break his toys. Child C appears to feel left out of all the fun in the house. He says that his mother does not play games with him any more. In his drawing his mother and brother are cooking supper together. This is a very important ritual in their house, but Child C feels excluded from it.

Child C is experiencing ambivalent feelings toward his brother. According to Schubert (2001:1) children might experience conflicting feelings about their brothers/sisters throughout this age span. He loves him on the one hand but also harbors a lot of resentment because of his brother. As a result of his brother's level of aggression Child C 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.

## 4.8 Summary

This chapter discussed the empirical study of the research. It included an in-depth look at the way play therapy was used to assess each siblings' stresses and challenges with regards to having a brother /sister with Autism/PDD.

Child A appeared to have the least problems with regards to coping with the stresses and challenges of living with a sibling with Autism/PDD. Her only wish was for her sister to be able to speak and to be able to go to school with her. Child B experienced a lot of anger towards his sister. He found her unpredictable behaviour very challenging. Her disability also impacted on the family as a whole. Their ability to go on social outings was also impaired. Child C often felt excluded from the activities that revolved around his brother with Autism/PDD. He also dealt with his brother's escalating aggressive behaviour.

The researcher made use of applied research. This type of research enabled the researcher to make qualitative research more humanistic and relevant in the lives of people. The research includes an evaluation of the stresses and challenges each child identified.

## Chapter 5

### Summary, conclusions and recommendations

#### 5.1 Introduction

The first research on the growth and the development of siblings of children with disabilities did not appear until the late fifties and early sixties. This field began to be defined in the 1980's. Since then it has been documented that brothers and sisters with disabilities have a profound effect on the way siblings grow up and what they become when they are adults. Growing up with a sibling with disabilities makes family relationships more complicated (Porterfield, 1997:9). Growing up with a sibling with disabilities can have positive and negative effects. (Compare Lobato, 1991:17; Porterfield, 1997:9.) According to Porterfield (1997:9), 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 caretaker.

#### 5.2 Aim and objectives of the study

The goal of this study was to investigate the effect of living with a sibling with Autism/PDD by using play therapy methods. The first objective with regards to the goal was to undertake a literature study to provide a better insight into the dimensions and the complexities of defining Autism/PDD and its related conditions; an in-depth look at the triad of impairments; the influence this has on the functioning of siblings of children with Autism/PDD.

Chapter 2 of this study consisted of a definition of Autism/PDD and an in-depth look at the triad of impairments in Autism/PDD, as well as a description of the stresses and challenges experienced by the siblings of children with Autism/PDD.

The third chapter of this study consisted of a theoretical description of play therapy methods that were used to assess the needs of the siblings with Autism/PDD. The child as client; the child-therapist relationship and the use of projection in play therapy was also discussed. This allowed the researcher to achieve the second objective, namely to undertake an empirical study with regards to the influence of Autism/PDD on the functioning of siblings in middle childhood. The researcher made use of the same and different activity, incomplete sentences, family drawings and a collage.

The empirical study consisted of one chapter and included a discussion on the way in which the researcher assessed the needs of the research participants.

The last objective was to make conclusions and recommendations to parents and people who work in families with children with Autism/PDD that will enable them to respond to the needs of the siblings. The researcher gave feedback to the parents of each research participant with regards to their child's individual needs and recommended that Child B and C go for therapy. This principle connected with Rosnow & Rosenthal's (1999:59) principle of beneficence (doing well) and non-maleficence (do no harm). By referring the respondents for therapy, the researcher ensured that no harm was done.

The aim and objectives of the research was reached in the following way: The researcher had six play therapy sessions each, with three respondents and one interview with the parents of the research participants. The researcher was able to determine the effects that being a sibling of a child with Autism/PDD had on each research participant. The researcher was also able to give feedback to the parents with regards to their individual child's needs. The researcher also included suggestions and activities for parents and caregivers to enable them to respond better regarding the needs of the research participants (See Appendix 4).

## 5.3 Research procedure

The research question of this study was the following: What is the effect of living with a sibling with Autism/PDD? This question will be answered in the conclusions and recommendations of this study.

A qualitative approach was used in this study. The researcher used play therapy methods, and techniques as well as observation. By utilizing play therapy techniques, the researcher did a subjective exploration of reality from the perspective of an insider. Using play therapy methods also minimized the distance between the researcher and the respondents.

In this study the data collection phase consisted of six individual sessions with each child, as well as one session with the family of the research participant and one interview with the parents.

The play therapy sessions were conducted with the use of a schedule. The schedule was used as a guideline for the researcher and contained themes that were important to the research. The schedule ensured that all relevant topics were covered during play therapy sessions. The main advantage of this schedule was that it provided for a relatively systematic collection of data, which also ensured that important data was not forgotten.

## 5.4 Summary and conclusions of the research

- 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. It enabled the researcher to obtain biographical information and also included the contracting phase with the parents.

- 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. According to Oaklander (1988:109) it is important to make use of sensory activities and experiments to help children to heighten their sensory functions. 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 Geldard & Geldard (1999:120) 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. The research participants enjoyed this activity. Child B was able to express his intense emotional feelings through this activity. He expressed a great deal of anger and frustration towards his sister. Child A was able to express positive feelings through this exercise. She expressed her joy about being with her sister. Child C was able to express his feelings of not being treated equally to his brother with Autism/PDD as well as a need to spend more quality time with his mother.
- The researcher made use of incomplete sentences to determine whether the research participants had unfinished business with regards to their brother/sister with Autism/PDD. Through this activity the research participants were able to address aspects of likes and dislikes, as well as stresses they experience in the family.
- Biblio-play was also used as an assessment tool. According to Van der Merwe (1996b:110) biblio-play is a good opener for conversations regarding problem

situations. All the respondents 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 brother or sister with Autism/PDD. Through this activity the research participants was able to identify both positive and negative feelings.
- With regards to the helping role the researcher aimed to determine whether the research participants were taking too much responsibility for their brother/sister with Autism/PDD. According to Siegel & Silverstein (1994:24) the use of observation of non-verbal communication is especially important when dealing with the parentified sibling of the child with Autism/PDD. Despite the outward behaviour of the parentified child there may be a lot of internally felt ambivalence toward the disabled siblings. These negative feelings may be deeply buried. The researcher was of the opinion the Child A had the biggest potential to become a parentified child. In giving the feedback to the parents the researcher stressed the importance of enabling Child A to be more spontaneous and playful at times and that she should not feel responsible for her sibling all the time.
- 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 all 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 C's brother because he was so aggressive. According to Gray (1997:104) 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 siblings. 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.
- 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/PDD;
  - ◆ 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 their 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 to stay at home because of their sibling with Autism/PDD.

## 5.5 Recommendations

- Children as teachers

Siblings should be involved in the teaching programs of their siblings. In the collage activity all the respondents shared something they taught their siblings which other people found impossible to do. They were all very proud of the achievement, both for themselves and their sibling. In 1987 Koegel; O'Dell and Koegel developed a

program incorporating motivational techniques and functional language use. It was designed to be used in the natural environment and was therefore suited to home use. Laski; Charlop and Screibman (1988) taught parents to use these techniques which significantly increase and improve the speech of the children (Koegel, *et al.*, 2000:3). The researcher is of the opinion that teaching siblings these techniques 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 to their bother/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 a rich 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, though parallel to parent support groups.
- The researcher recommends that research should be done to design a program for siblings; for example sibling support groups.
  - Sibling support projects should be created in the form of awareness materials for parents, service providers and bothers and sisters, for example, websites, newsletters and children's books. This is very important for siblings in the South

African context. The existing literature was written within the European and American context.

- Workshops for parents and service providers should be conducted on the life long issues concerning brothers/sisters with Autism/PDD.

## 5.6 Concluding remarks

The use of play therapy methods was an effective way to investigate the effect of Autism/PDD on siblings. The research question (What is the effect of living with a sibling with Autism/PDD?) of this study was therefore answered. The researcher made conclusions and recommendations from the results of the study. This study is to the benefit of social work as a profession because it includes specific techniques that could be used to assess the needs of siblings of children with Autism/PDD.

As a result of the increase of severe cases of Autism/PDD in the past decade, as well as the shift to home based care, it becomes increasingly important to focus on the needs of the siblings. Within the South African context the researcher recommends more research into the undiagnosed cases of Autism/PDD, especially in the rural areas. This will enable 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 is important to this research. The themes and issues that were explored were the following: helping, advocacy, awareness, feelings, middle childhood and family stresses.

#### 1.1 Helping

The researcher aimed to determine to which extent the research participants fulfilled a helper role within the family. This involved activities such as teaching their brother/sister new tasks and activities or setting an example of good behaviour. 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.

#### 1.2 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 others and how they responded to it, intimidated 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.

### 1.3 Awareness/ Need for 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 regard.

### 1.4 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,

### 1.5 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. In 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:** Living with a sibling with Autism/Pervasive Developmental Disorder: assessing the effects using play therapy methods.
2. **Purpose of the study:** The goal of this 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 researchers 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 at any time.
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 may be published in professional journals or presented at professional conferences, 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 sibling's 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 age 4 or older. We suggest that a separate **SNIP** should be completed for each of your typically developing children age 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 \_\_\_\_\_

Thomas Fish, Frances Dwyer McCaffrey, Katrina Bush, & Susie Piskur

## Having Fun

Play is often called the “work” of children. It is how they learn 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 a 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	2	3	4	5
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 or sports	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 their brother or sister with others.
- Encourage siblings to let their brother or sister do as much as possible for him/herself, and praise them for being patient if this takes a little longer.
- 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, or any other activity they engage in positively together.

### 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 tucked in. Some children may talk about their feelings readily, and some may not, but most children let us know how they feel through their 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	2	3	4	5
1. Is seldom frustrated with behavior of brother/sister					
2. Does not resent amount of time parents spend with brother/sister					
3. Openly expresses feelings about brother/sister					
4. Does not feel sorry for brother/sister					
5. Does not resent special attention parents and others give to brother/sister					
6. Is not embarrassed by the reactions of others to brother/sister					

### Building on strengths when responses suggest agreement:

- Be receptive to all feelings that are expressed; acknowledge and praise siblings' efforts to share their feelings with you, regardless of whether those 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 a 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 lines 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 advocating 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 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	2	3	4	5
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 <i>can</i> 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 and 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 their 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 for 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 its simplest, awareness means that he or she has a name, or at least a description, for the disability or delay.

Being aware also means that siblings can compare the similarities and differences between themselves and their brother or sister. “Susie’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 siblings’ 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 “not everybody has someone like John” in their family.

	Strongly Agree			Strongly Disagree	
	1	2	3	4	5
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 times to talk about what’s going on in the family (family meetings, dinner conversations, etc.).
- Regularly share information with siblings about their brother or sister—they will tell you if they “already know that” or ask questions for more detail.
- 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 “teach” 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 ideal is to find ways for the children to help, teach, and learn from each other naturally in the normal course of their day.

	Strongly Agree			Strongly Disagree	
	1	2	3	4	5
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 clear 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/IFSP.
- 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/IFSP; 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 the 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 are 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 the therapist worked with their brother or sister, or if it gave them any new ideas for helping out.
- If siblings protest or complain about having to help, recognize that particular tasks may be 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-sitters 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-sitting 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 the **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.*

We believe 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 not 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, your pastor or other church advisor, a close relative or friend, or someone involved with one of the many "advocacy" groups that serve children with delays and their families.

Finally, if this exercise has prompted you to want additional information, the following resources may be helpful. In any case, feel free to contact us at the Nisonger Center at the address below with your comments or suggestions. Our best wishes to you and your family.

APPENDIX 4

## Siblings: Helping your other children

### Floor time sessions

Floor time is not just for children with special needs. It is important to have at least one floor time session a day with the other children. One-on-one playtime when the child is in control is important for all children. Knowing that the child can have him all to himself could compensate for your limited attention at other times. This could create an avenue for expressing feelings and thoughts that they may not be able to put into words.

- Problem-solving discussions

If the children are verbal it could be positive if they are included in problem-solving discussions about their siblings with special needs. The parent should give them room to talk about how they feel about their brother/sister with special needs, without being criticized or judged. It is important not to feel as if you have to fix their feelings, but to listen carefully.

- Making it a family challenge

When discussing the child with special needs with your children, make sure to reiterate that it is a family challenge. Though the family members are not responsible for creating the problems, you can help the child together as a family. Each child can have a special role to play in helping the children.

- Involving your other children in floor time with their sibling

Siblings often feel a sense of loss and wish for a brother or sister that could talk or play. You as a parent can moderate this situation by using floor time as the time to teach the siblings to play with each other.

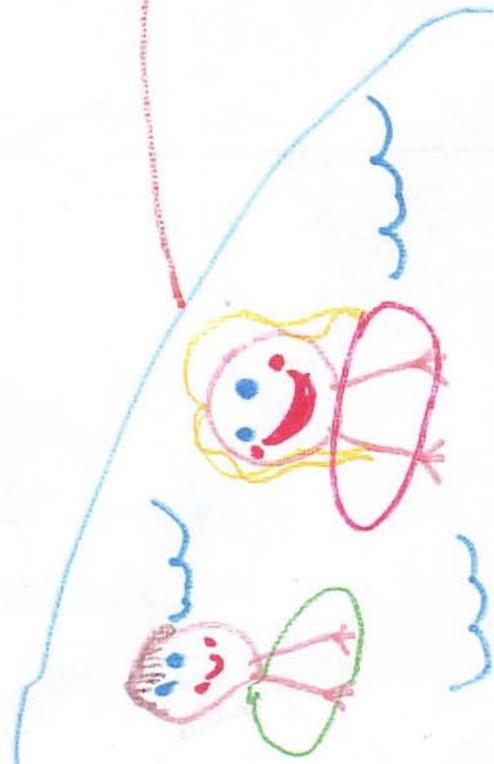
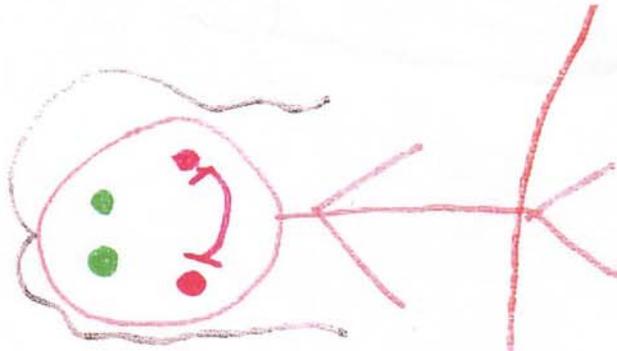
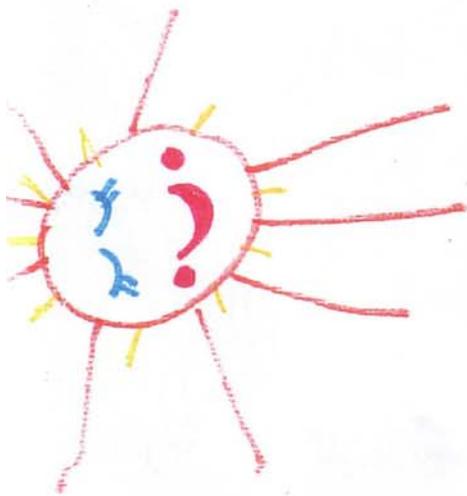
- Don't be afraid of feelings of hostility

Siblings sometimes feel anger towards the child with special needs. A parent shouldn't be hurt or angry or afraid when the child expresses these feelings. These feelings are natural. It is better than having these feelings bottled up. It should not be taken too seriously either. Their feelings are often a fluctuating mix, which can vary with their mood, the day and the behavior of their sibling.

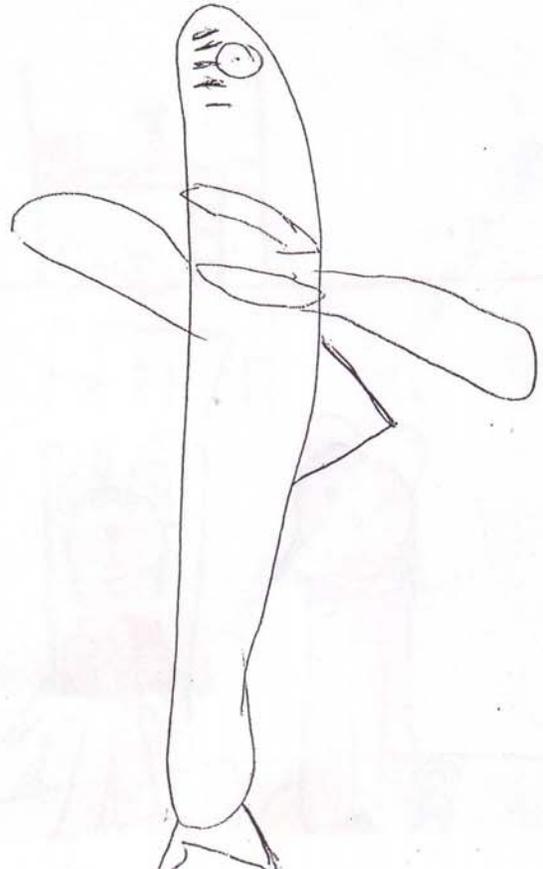
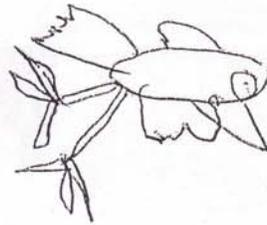
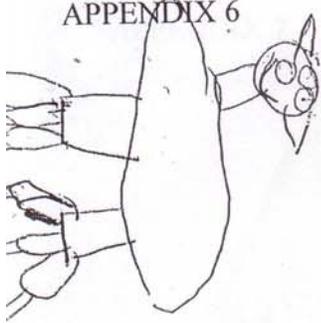
Greenspan & Wieder, 1998:37.2

APPENDIX 5

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APPENDIX 6



APPENDIX 7

