THE LIVED EXPERIENCES OF A SIBLING DURING THE IMPLEMENTATION OF AN APPLIED BEHAVIOUR ANALYSIS INTERVENTION PROGRAM: A CASE STUDY

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B.Prim.Ed   B.Ed   M.Ed

Assignment submitted in partial fulfilment of the requirements for the degree

Master of Education

(Educational Psychology)

at the

University of Stellenbosch

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March 2002

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I, the undersigned, hereby declare that this assignment is my own original work, and that I have not previously in its entirety or in part submitted it at any university for a degree.

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SUMMARY

THE LIVED EXPERIENCES OF A SIBLING DURING THE IMPLEMENTATION OF AN APPLIED BEHAVIOUR ANALYSIS INTERVENTION PROGRAM: A CASE STUDY

This study was undertaken with the view to explore the lived experiences of a non-disabled sibling while an Applied Behaviour Analysis intervention program was followed with her brother. Her brother has a dual diagnosis of Down syndrome and Autistic Spectrum Disorder.

The parents of these children volunteered to take part in a research program funded by a private individual. The purpose of the project, coordinated by the Department of Educational Psychology and Specialised Education of the University of Stellenbosch, was to evaluate the effectiveness of the intervention program over a period of 26 weeks. The question soon arose as to how the non-disabled sibling in the family will experience this intensive intervention in which the family's usual activities would be altered in many ways.

A literature review was conducted in order to obtain a perspective of research done in this field. I fulfilled the dual role of researcher and trainee educational psychologist. The ecosystemic framework was chosen as the preferential educational psychological framework with which to approach the study, while the interpretive research paradigm lent itself to interpreting the lived experiences of the sibling. The lived experiences were gathered from questionnaires, interviews, observation and video material.

This research report describes a variety of possible experiences the sibling underwent, and the repercussions thereof within the family system. Suggestions were made as to how appropriate support for parents, as well as for non-disabled siblings, could serve to help them reframe these experiences.

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OPSOMMING

DIE PERSOONLIKE BELEWENIS VAN 'N SIB GEDURENDE DIE IMPLEMENTERING VAN 'N TOEGEPASTE GEDRAGSANALISE PROGRAM: 'N GEVALLESTUDIE

Hierdie studie is onderneem om die ervaring van 'n nie-gestremde sib tydens die implementering van 'n toegepaste gedragsanalise intervensieprogram met haar broer te ondersoek. Haar broer is gediagnoseer met beide Down-sindroom en Outistiese Spektrum Versteuring.

Hierdie kinders se ouers het vrywilliglik aan 'n navorsingsprojek van die Departement Opvoedkundige Sielkunde en Spesialiseringsonderwys aan die Universiteit van Stellenbosch, deelgeneem. Fondse vir die projek is van 'n privaat persoon ontvang. Die doel van die projek was om die effektiwiteit van die intervensieprogram oor 'n tydperk van 26 weke te evalueer. Die familie se daaglikse aktiwiteite is in 'n groot mate deur die program beïnvloed, en die vraag rondom hoe die nie-gestremde sib die intervensieprogram sal beleef, het ontstaan.

'n Literatuurstudie is onderneem om inligting oor bestaande navorsing in te win. Ek het tydens die projek die rol van beide navorser en opvoedkundige sielkundige in opleiding vervul. Die ekosistemiese raamwerk is bespreek as 'n sinvolle opvoedkundige sielkundige raamwerk, terwyl die interpreterende navorsingsparadigma homself daartoe leen om die persoonlike belewenis van die sib te interpreteer. Die belewenis is ingesamel deur middel van vraelyste, onderhoude, observasie en video materiaal.

Hierdie navorsingsverslag beskryf 'n verskeidenheid van die sib se belewenis en wys op die uitwerking hiervan binne die gesinsopset. Voorstelle oor wyses waarop voldoende ondersteuning aan ouers sowel as nie-gestremde sibbe die belewenis positief kon herinterpreteer, word gemaak.

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This study is dedicated to Johann Ligthart

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ACKNOWLEDGEMENTS

At presenting this study, I would like to sincerely thank the following people who each contributed in an unique way:

- Rona Newmark: supervisor.

- Janneke Vermaak: for reviewing and support in interpreting the data.

- Sanet Swanepoel: for technical editing.

- Sarah Oosthuizen: for language editing.

- My husband, Johann, for continuous support and motivation.

- Petru, Ina, Stephan and Elizna Rossouw.

<div align="right">Riana Ligthart</div>

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CHAPTER ONE

INTRODUCTION AND PROBLEM STATEMENT

1.1 INTRODUCTION

The Department of Educational Psychology and Specialised Education, Faculty of Education of the University of Stellenbosch, initiated a research project on Autistic Spectrum Disorder (ASD) and Down syndrome (DS) during September 2000. This research was initiated as a result of funding received from a parent of a disabled child, and was to be allocated specifically for research on ASD. The purpose of the project was to evaluate the success of Applied Behaviour Analysis (ABA) therapy on learners having a dual diagnosis of DS and ASD.

The project co-ordinator, a lecturer at the University of Stellenbosch, attended the international conference of the Down syndrome Association in Australia in March 2000. It was at this conference that she met a South African woman whose son has Down syndrome. This mother was exploring the possibility that her child might have Autistic Spectrum Disorder, in addition to Down syndrome. She was desperately seeking answers about her child's condition. At the conference, information about the concomitance of the two disorders was readily available, and the assumptions about her child's condition were strengthened.

On returning to South Africa, the co-ordinator was informed that there was a possibility of funding for research. She drew up a research proposal, which the funder approved, and the funds were allocated towards the project. She then invited the family she'd made contact with via the conference to take part. This first family met up with another family associated with the Down Syndrome Association, who's

son with Down syndrome had already been diagnosed as having Autistic Spectrum Disorder. They too established contact with the university, and both families volunteered to take part in the project.

Jenny Buckle, an expert in the practical application of ABA, was approached to play a leading role in the project. Jenny is a mother with triplet boys with Autistic Spectrum Disorder. After investigating all possible interventions for them, Jenny made the decision to subject her boys to intensive behaviour therapy (ABA). She trained three tutors who started working with them for seven hours per day, and has since seen remarkable progress. She also started a consulting service named REACH. This organisation trains tutors in the principles of ABA therapy, in order to provide intensive one-to-one support for children in South Africa with Autistic Spectrum Disorder and other Pervasive Developmental Disorders. After meeting with the first family, Jenny Buckle noted that their son did indeed seem to show most of the symptoms of ASD.

The use of ABA therapy with learners with ASD is based on the research of Lovaas (1987:7). ABA uses the behavioural principles of operant conditioning to teach a child new skills. In his research, Lovaas (1987:7) reported that 47% of the learners with ASD in the experimental group receiving ABA therapy for 40 hours per week, achieved normal intellectual and educational functioning as against only 2% in the control group. According to Lovaas and Smith (1989:17), behavioural treatment is the only intervention which has consistently been found to improve ASD diagnosed children's functioning.

My involvement in the research started when I was approached by the university to join the project, and to become trained in the principles of ABA therapy. My role would be to support one of the identified learners with DS/ASD as a tutor. Four different tutors were to be trained to work with the two boys daily. The research project would extend over a period of six months.

As a trainee educational psychologist doing ABA therapy, I conducted the study from an ecosystemic framework. An ecosystemic framework involves an awareness of the interrelationships between individuals, groups and contexts, and according to Keeney (1979:118), emphasizes ecology and whole systems. Not only did I find the progress of the children receiving the therapy exciting, but I was also intrigued by the changes that take place in the entire family system during the implementation of this intervention program. A field of interest I found most fascinating was the influence which this program might have on the non-disabled sibling in one specific family. As a researcher I intended to interpret the non-disabled sibling's experiences, but at the same time as a tutor of one of the disabled learners, I was also part of the non-disabled sibling's stories and lived experiences. I explored the relationships within the family system, and particularly how these relationships might have affected and added to the sibling's experiences during the intervention program. In exploring the sibling's lived experiences, the personal meanings which she attached to these experiences became the focus of my study. I needed to consider how she interpreted her experiences and in which way they were put together in order to construct her personal reality.

1.2 MOTIVATION FOR THE STUDY

In the past, medical and educational professionals were doubtful as to whether Down syndrome (DS) could exist in concomitance with Autistic Spectrum Disorder (ASD). According to Bregman and Volkmar (1988:441), professionals believed that the behaviour displayed by these children was secondary to their limited intellectual ability. Since the first documentation by Wakabayashi (1979:31), reports of ASD in children with Down syndrome have been quite rare. However, over the past few years various researchers (Capone, 1999; Kent, Evans, Paul & Sharp, 1999; Howlin, Wing & Gould, 1995; Ghaziuddin, Tsai & Ghaziuddin, 1992), reported that, although rare, such a dual diagnosis can indeed be made.

According to Gillberg and Coleman (2000:140), the presence of autistic features in children with Down syndrome means that the child needs special educational programs of the type designed for children with autism. If these learner's individual needs are not met, the learner is unlikely to reach his or her educational potential. Mash and Wolfe (1999:406) state that a variety of educational and intervention programs have been developed for children with ASD. All of these focus mainly on teaching children appropriate communication skills and social behaviour. Hultgren (2001:1) states that Applied Behaviour Analysis (ABA) is an approach which specifically addresses the many challenges found in learning encountered by children with ASD. According to Swiezy (1999:25) and Patterson (1999:16), this approach has been extremely successful with children with ASD, and has also proven to be effective with children having Down syndrome.

Various authors (Sanders & Morgan, 1997; Donelly, 1991; Turk, 1991) have indicated that a child with a disability has an impact on each family member, as well as upon the family as an unit. The effects are both multifaceted and reciprocal and can alter the whole family system. Not only parents and siblings are affected, but relationships among family members may also be altered. Furthermore, it has also been reported that siblings of these children appear to bear a triple burden of stress, increased responsibility for their disabled brother or sister, and decreased parental support for themselves (McHale & Gamble, 1989; Hannah & Midlarsky, 1985; Simeonsson & McHale, 1981; Trevino, 1979). By looking at the lived experiences of a sibling during an intervention program, this study will attempt to describe the world of the sibling as she experiences it. McHale and Gamble (1989:421) argue in this regard: "*Studying the daily lives of children with disabled siblings, therefore, may provide insight into issues facing other children and families in contemporary society.*"

The relevance of this study pertains to the fact that the diagnosis of DS/ASD as a concomitant disorder is fairly new to the field of psychology and that only a few cases have been identified (Ghaziuddin *et al.*, 1992; Kent *et al.*, 1999). The use of

ABA as an intervention technique with these children further adds to the relevance of this study. Lovaas and Smith (1989:17) contend that ABA has been successfully used with learners with ASD, but in South Africa it has yet to be tested with children having the concomitant disorder of DS/ASD.

An intervention program based on the principles of ABA is extremely time consuming and involves commitment and sacrifices from the whole family. In the case of this project, the parents were involved in analysing data, parent training courses, regular meetings, as well as being responsible for altering the diet of the learner with DS/ASD. Due to the amount of time and energy spent by the parents in organising and implementing this program, it was possible that the sibling of the child with the disability, could be affected.

1.3 PROBLEM STATEMENT

The problem statement of this study is: What are the lived experiences of a sibling when an Applied Behaviour Analysis intervention program is followed with her brother who has Down syndrome and Autistic Spectrum Disorder?

According to Donelly (1991:110) it is possible that the presence of a handicapped child can influence a non-disabled sibling's emotional and psychosocial development. When exploring the lived experiences of the sibling during an intervention program, I thus assume that the level of her emotional and psychosocial development will influence the way she constructs meaning from her day-to-day experiences.

Romanczyk (1996:405) notes that Applied Behaviour Analysis, also known as behaviour modification or behaviour therapy, is an approach which has its roots firmly within a research/academic framework of behaviourism. Based on Skinner's classical studies, ABA takes a functional approach to behaviour and explores the

relationships between behaviour and its antecedents and consequences. Mash and Wolfe (1999:49) explain that positive and negative reinforcement are seen as consequences which increase the target response, while extinction and punishment, in contrast, have the effect of decreasing a response.

Bird and Buckley (1994:5) state that Down syndrome is a chromosomal abnormality in which there are three 21st chromosomes rather than the normal two. Children with Down syndrome typically function at a moderate level of mental retardation, have an increased likelihood of medical problems, and have unusual physical features. Mash and Wolfe (1999:G-5) state that this syndrome is also called trisomy 21. According to Mash and Wolfe (1999:359), some distinguishing physical features include a small skull; a large tongue protruding from a small mouth; almond-shaped eyes with sloping eyebrows; a flat nasal bridge; a short, crooked fifth finger; and broad, square hands.

The criteria (DSM-IV, 1994:46) for mental retardation consists of three core features which are considered to accurately describe some of the characteristics of learners with Down syndrome. Firstly, the person must have "*significantly sub-average intellectual functioning*", determined on the basis of formal intelligence testing or clinical judgement. Secondly, diagnosing requires "*concurrent deficits or impairments in adaptive functioning*", which refers to the ability to perform daily activities. Thirdly, the abovementioned two characteristics must be evident prior to the age 18 years.

According to Smith, Polloway, Patton and Dowdy (1998:224), the characteristics of ASD overlap with those of many other disabilities such as speech and language disorders, however there are distinct features of this syndrome which distinguish it from others. ASD is included in the DSM-IV (APA, 1994:70) as one of several pervasive developmental disorders. The following definition of Autistic Spectrum Disorder is stated in Scott, Clark and Brady (2000:6), and is provided by the Autism Society of America:

> *Autism interferes with the normal development of the brain in the areas of reasoning, social interaction and communication skills. Children and adults with autism typically have deficiencies in verbal and non-verbal communication, social interaction, and leisure activities. The disorder makes it hard for them to communicate with others and relate to the outside world. They may exhibit repeated body movements, unusual responses to people or attachments to objects and resist any changes in routines. In some cases, aggressive behaviour may be present.*

Even within ASD there are extreme differences and manifestations of the disorder which may differ depending on the developmental level and the chronological age of the individual (APA, 1994:66). Janzen (1996:7) states that there is no single behaviour which is indicative of Autistic Spectrum Disorder, but rather that the significant factor is a pattern of behaviour from the four areas of communication, relating to people and the environment, responses to sensory stimuli and developmental discrepancies.

The modern medical profession recognises that people with Down syndrome may also have a psychiatric-related diagnosis such as Autistic Spectrum Disorder (Capone, 1999:8). Capone (1999:8) and Ghaziuddin *et al.* (1992:453) further state that this diagnosis of ASD in the presence of mental retardation (DS/ASD) is possible on the basis of the characteristic pattern of social and communication impairment. It is further strengthened by the presence of certain "atypical" behaviours. Janzen (1996:7) mentions that the combined effects of ASD and other conditions are greater than if any of the conditions occur independently.

1.4 RESEARCH PARADIGM

I conducted my study from an interpretive approach. This research approach has ideas from different traditions embedded in it. Schwandt (1994:118) states that it seems to have been influenced by the intellectual tradition of hermeneutics, the *Verstehen* tradition in sociology as well as the phenomenology of Alfred Schultz. Húsen (in Keeves,1998:18) supports the idea that interpretive research grew from the phenomenological philosophy developed by Husserl (1859-1938). Phenomenology emphasised the importance of a widened perspective when trying to gain insight and understanding into human beliefs and activities.

> *Through empathy, by widening the perspective and trying to understand human beings as individuals in their entirety and in their proper context, it [phenomenology] tries to avoid the fragmentation caused by the positivistic and experimental approach that takes a small slice which it subject to closer scrutiny (Húsen, 1998:18).*

Van Manen (1990:9) adds to the above description, and describes phenomenology as the study of the lifeworld which aims to reach an understanding of the nature or meaning of everyday experiences. The question phenomenology asks is "What is this or that kind of experience like?". Researching the lived experiences of a sibling is most suited to this philosophy.

Qualitative research is an umbrella concept covering several forms of inquiry that help us to understand and explain the meaning of social phenomena with as little disruption of the natural setting as possible. Other terms often used interchangeably are *naturalistic inquiry, interpretive research, field study, participant observation, inductive research, case study,* and *ethnography* (Merriam, 1998:5).

Even though these terms all encompass a number of diverse methodologies, Gough and Mousley (2000:28) state that *interpretation* is the key concept which links them, and that one should use the term 'qualitative' when referring to data instead of using it to describe a methodology. In this study I will use the term 'interpretive' and 'qualitative' interchangeably when referring to the type of research or the methodology.

According to Merriam (1998:6), qualitative researchers are interested in understanding the meanings, or impressions, which people have constructed in order to make sense of their worlds. Merriam (1998:6) argues that qualitative research "*implies a direct concern with experience as it is 'lived' or 'felt' or 'undergone'*." Qualitative research is therefore based on the view that reality is constructed by individuals interacting with their social worlds. Through an interpretive approach, an attempt to understand the complex world of lived experience - from the point of view of the sibling who live them - will be made. Therefore, the key concern or goal then is an understanding of experiences from the sibling's perspectives. Schwandt (1994:118) refers to this understanding as a concern for the life world, the "emic point of view" or "insider's perspective". The interpretive researcher believes that in order to understand this inner world of meaning, one needs to interpret it. When conducting interpretive research, the aim is to capture internal realities which people have constructed, and meanings are therefore the essence of the research findings. According to Gough and Mousley (2000:31), human behaviour and actions cannot be fully understood through description only. There is a crucial difference between merely describing, and interpreting, the intention of an action or behaviour. Characteristic to the interpretive research approach is that, in order to fully comprehend human behaviour, it should be viewed as intentional. The motivation behind behaviour, as viewed by the person performing the action, should be considered as part of the research. The term interpretive is used when a researcher is trying to understand people's behaviour through interpreting the meaning which those people themselves attach to their behaviour (Gough & Mousley, 2000:31).

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The experiences of the sibling as the focus of this study, will be described as she herself interprets her own actions. However as a researcher, I also bring my own influences to the process and give a subjective account of what the sibling experiences. Gough and Mousley (2000:31) explain that in comparison to the positivist view of the importance of objectivity and neutrality in research, the interpretive approach allows for the researcher to describe phenomena from a subjective and participant position. The data analysis, findings and production is not free of my frames of reference and personal judgements. These authors further point out that, based on these frameworks for understanding information, the data can be analysed in many different ways.

As a trainee educational psychologist, I am continually encouraged to be a reflective practitioner. According to Swart (1994:14), a reflective practitioner can be viewed as an active, life-long learner, who purposefully and continuously reflect on their own practice. Swart (1994:17) states in this regard:

> As you go about doing your work responding to phenomena, identifying problems, diagnosing problems, making normative judgements, developing strategies, etc., think about your responses to situations and about what it is in the situation, and in yourself, that leads you to respond that way...

Being in this role implies that I therefore will be aware of my personal, as well as my professional, development during the course of the project. It further requires that I reflect on how my culture, norms, values, perceptions and previous experiences influence my interaction with the disabled learner, the non-disabled sibling, as well as the family as a whole, and how this impact on my interpretation of the sibling's experiences.

1.5 STRUCTURE OF PRESENTATION

In **Chapter One**, I sought to orientate the reader through providing the actuality and motivation for the study. I explained my dual role as both researcher and trainee educational psychologist and indicated the implications of these different roles for the study. I described the problem, and clarified key concepts as they appear in the title. In outlining the interpretive research paradigm, I indicated its particular usefulness and applicability as a research approach in this study.

Chapter Two provides an overview of literature relevant for this study. I discuss the concomitance of Down syndrome (DS) and Autistic Spectrum Disorder (ASD), and also indicate how Applied Behaviour Analysis (ABA) therapy can be used with children with this dual disorder. In this chapter I outline the effects which interventions with disabled children could have on their non-disabled siblings, and also give an overview of general childhood psychosocial and emotional development.

I attempt to give a detailed description of the method of inquiry in **Chapter Three**. I indicate how a qualitative case study approach is followed to investigate the lived experiences of a sibling, and also describe the different techniques used to produce the data. Furthermore, I explain the steps in the data analysis procedure and elaborate on how the produced data is verified. Lastly in this chapter, I indicate how the ethical issues of research were adhered to.

In **Chapter Four** the findings of the study are discussed. I provide relevant background information in order to contextualise the case under discussion. I interpret the data and provide themes as they emerge from all the different sources. A summary of the main themes concludes the chapter.

Chapter Five provides the reader with a brief summary of the content of all the previous chapters. I indicate which factors are seen as limiting the study, and discuss the implications and recommendations stemming from this research.

CHAPTER TWO

LITERATURE REVIEW

2.1   INTRODUCTION

In this chapter I will review literature relevant to the research topic and problem statement of the study.

The focus will be on the following concepts: The ecosystemic approach; the concomitance of Down syndrome and Autistic Spectrum Disorder; Applied Behaviour Analysis; the impact which a disabled child has on family life and on non-disabled siblings; and general childhood development.

2.2   THE STUDY OF A NON-DISABLED SIBLING

As I explained in Chapter One, the Applied Behaviour Analysis intervention with the learner with DS/ASD involved in this study, was approached from an ecosystemic perspective.

Freedman and Combs (1996:5) cite Auerswald (1987) who states that the ecological systems paradigm defined a family as "... *a coevolutionary ecosystem located in evolutionary timespace*".   Donald, Lazarus and Lolwana (1997:34) explain that the systems perspective's "... *main concern is to show how individual people and groups at different levels of the social context are linked in dynamic, interdependent and interacting relationships*."

For a clear understanding of the ecosystemic approach, it is necessary to explore the role of: (a) ecological thinking; (b) systems theory; and (c) cybernetic epistemology. The focus is the functioning of human beings in systems where ecological and cybernetic principles are operational.

a)   According to Keeney and Sprenkle (1982:9), ecological thinking speaks of the interdependence and interrelationships between an organism and its environment. Ecology thus refers to the linkages among systems and how systems affect one another. Change in one system will affect and bring about change in another system linked to that. In this study there are several individual systems which affect each other (i.e. the disabled boy, the non-disabled sibling, the father and the mother). All of these individual systems are arranged into a bigger family system, which is part of a social context. In terms of ecological thinking therefore, the intervention with the disabled learner will have an affect on the non-disabled sibling.

b)   Systems theory was developed as a movement away from the reductionistic tradition towards a holistic approach. According to O'Connor and Ammen (1997:xiv), systems theory is fundamentally based on the principles of wholeness, organisation, and relationships. Van der Hoorn (1995:17) stresses that, although systems thinking closely resembles holistic thinking, it is in fact more than holistic thinking. While holistic thinking considers the whole to simply be a sum of its parts, systems thinking simultaneously consider and investigate the relationship between the whole and its parts. In order to summarise systems theory, O'Connor *et al.* (1997:xiv) quotes Steinglass (1978) as characterising systems theory as:

> *...attention to organisation, to the relationship between parts, to the concentration on the patterned rather than on linear relationships, to a consideration of events in the context in which they are occurring rather than an isolation of events from their environmental context.*

Systems thinking involves a perception of social contexts as systems, where the function of the whole is dependent upon the function of, and interaction between, all the parts. In order to understand the whole, the relationship between the parts needs to be examined.

O'Conner *et al.* (1997:5) refers to Maturana (1980) who indicated that even though there is a powerful relationship between an individual and the system of which it is a part, the individual still maintains autonomy. This implies that an individual interacts with its world and creates internal meaning and reality from the interaction. In order to understand an individual's functioning within a system, one needs to understand the individual's perception of how needs get met within the system. The importance of this for the current study is that the non-disabled sibling can be seen as an individual who will demonstrate certain behaviours in order to get her needs met in the larger family system. During the intervention however, she might experience a change in her needs which may, in turn, lead to a change in her observable behaviour. These actions or behaviours can have an effect on all the other individual systems who then, in turn, react from their subject-dependent perspective, influencing the functioning of the entire family system. To understand the non-disabled sibling, it is important to take note of how her needs get met within the family system.

Various authors (Barker, 1998:27; Zigler in Schopler & Mesibov, 1984:22) indicate that systems theory has been at the heart of family therapy theory for several decades. Freedman *et al.* (1996:2) are of the opinion that looking at families as systems provides one with very useful ways in which processes and patterns of interconnection can be described.

c) Cybernetics is a term that is used in systems theory to refer to and describe the circuits of communication and interaction patterns within systems. Freedman *et al.* (1996:3) gives the following definition of the word "cybernetics", as described by Norbert Wiener in 1950: *"Cybernetics refers to an emerging body of knowledge about structure and flow of information-processing systems."*

Keeney (1979:119) states that Bateson (1972) believes the basic rule of systems theory to be that in order to understand a phenomenon, one needs to consider the context and communication patterns relevant to the phenomenon. According to Freedman *et al.* (1996:3), the implication of this is that therapists could view families as machines who could be controlled from the outside. Therapists could make decisions about how families should and should not be functioning. This opinion very much links up to what Becvar and Becvar (1996:62-75) call "*simple cybernetics (also known as first-order cybernetics)*". This involves an observer external to the system objectively observing the interactions within those systems. Through making these observations, the observer would form an opinion about dysfunction in the system and elicit goals in order to eliminate the problems (Freedman *et al.*, 1996:3-5). It would therefore be necessary to have a clear conception of the family's functioning before the intervention, in order to effectively interpret the sibling's experiences during the intervention.

In comparison to this, Becvar and Becvar (1996:75-83) also refer to "cybernetics of cybernetics" (or second-order cybernetics) when describing any observer as part of the system being observed. Any description of the system would be a reflection of the observer and the observer could not be capable of detached objectivity. Freedman *et al.* (1996:7-9) states that this move away from "first-order" to "second-order" cybernetics made family therapists aware of different ways to view the family. Instead of looking for patterns of behaviour in families, they rather focussed on patterns of meaning. Through asking circular questions, therapists made family members aware of their interconnectedness; on how any single member's feelings and actions influenced the feelings and actions of others. While therapists reflected on feelings and answers to these questions, they became more involved in the family system (Freedman *et al.*, 1996:9).

Smith *et al.* (1998:466) indicates that the success of intervention with a disabled child depends upon the involvement of the entire family to a great extent. When implementing a complex intervention program, it is therefore not

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only the child that is affected. Zigler (1984:22) argues that those who are concerned with, and work with, disabled children are working within a multifaceted complexity of situations. These situations involve systems within systems - all interacting and affecting the others. From an ecosystemic perspective, it can be assumed that the intervention in a disabled child's life will affect the whole family system. The relationships between members of the system as well as communication patterns within such a system may be altered. Attention should be given to the experiences of everyone in the family whose lives may be affected through the intervention with the disabled child. The focus of this study will, however, only be on the experience of the non-disabled sibling.

In order to study lived experiences of the sibling, both a "simple cybernetics" (Becvar & Becvar, 1996:62) and a "cybernetics of cybernetics" (Becvar & Becvar, 1996:75) perspective will be taken. I will explore the reciprocal interdependent relationships within the family and between the individual systems. Note should be taken, however, of how my perceptions and previous experiences might shape my selection and interpretation of data.

2.3 AUTISTIC SPECTRUM DISORDER and DOWN SYNDROME

2.3.1 INTRODUCTION

In the search for literature on the dual diagnosis of Autistic Spectrum Disorder and Down syndrome, I found that very little information was available. Seeing that these two disabilities can be diagnosed as separate disorders, I have therefore decided to discuss them as such. Available information on the concomitant disorder will be discussed thereafter.

2.3.2 AUTISTIC SPECTRUM DISORDER

2.3.2.1   Historical background

According to Mash and Wolfe (1999:372) the term *autism* was first used in 1911 by the Swiss psychiatrist Eugen Bleuler. Bleuler used the term in an attempt to describe individuals with schizophrenia. In the early 1940s two other psychiatrists, Kanner and Asperger (Mash & Wolfe, 1999:373), independently studied children who displayed social impairments, abnormal language, and restricted and repetitive interests. These children were thought to experience a loss of contact with reality, without having schizophrenia. Scott *et al.* (2000:2) states that Kanner (1943) published a landmark paper in which he described the case histories of these children. Their conditions differed remarkably and uniquely from anything reported up until that time. Kanner (1943) identified a number of characteristics which all of these children exhibited, and noted that this particular group of behaviours was different from that of childhood schizophrenia and mental retardation. Kanner (1943) called this disorder early infantile autism, and the characteristics which he observed and recorded are the same as those used to diagnose ASD today. According to Jordan (2000:8), Kanner (1943) saw the defining principles of the syndrome as being:

- profound withdrawal;
- obsessive desire for the preservation of sameness;
- good rote memory;
- intelligent and pensive expression;
- language without real communicative intent;
- over-sensitivity to stimuli; and
- a skilful relationship to objects.

Mash and Wolfe (1999:373) indicate that since Kanner's original report more than half a century ago, ASD has increasingly come to be recognised as a biologically based, lifelong, developmental disability.

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2.3.2.2 *Prevalence and Course*

Mash and Wolfe's (1999:394) account on recent research suggests that ASD may affect as many as 15 to 20 children per 10 000, much more than the 4 to 5 per 10 000 that has previously been reported. They further point out that ASD is found in all social classes and has been identified in every country in which it has been sought. It is 3 to 4 times more commonly found in boys than in girls. According to Gillberg and Coleman (2000:85), Wing (1996) proposed that Aautism Spectrum Disorders might be as prevalent as 1 in 100 children. Janzen (1996:6) states that ASD can occur with or without other disabilities and the symptoms and effects thereof can range from mild to severe. Those affected with ASD can have intellectual abilities ranging from gifted to severely intellectually impaired.

Mash and Wolfe (1999:395) indicate that the symptom profiles in children with ASD can change over time. Most children show gradual improvement of their symptoms with age, even though they continue to experience many problems. However, they will continue to display impairments that make them different from others throughout their lives. Gillberg and Coleman (2000:70) report that unspecific symptoms are often present in the first few years, whereas the typical syndrome crystallises in later preschool years. Adolescence may bring improvement, but also in some cases, deterioration. As Janzen (1996:12) states: "*... it is just as difficult to predict the potential of a child with ASD as it is to predict the potential of a normally developing child.*"

In studying the existing literature, controversy surrounding the possible recovery from ASD was revealed. Several reports (Williams, 1994; Maurice, 1993), including personal and mother-child accounts of people being completely "cured" from the disability, became evident.

I believe that an early diagnosis and extensive intervention program is of the utmost importance. Instead of debating the curability issue, the focus should rather be on early implementation of the most applicable intervention program, so as to optimise the individual's potential.

2.3.2.3   Causes

Barlow and Durand (1999:451) are of the opinion that, because ASD is such a puzzling condition, one should not be surprised to find numerous theories of why it develops.   They state that one such generalisation of why it develops is that it probably does not have a single cause.   Rather, they say, that there may be a number of biological contributions that combine with psychosocial influences to result in the unusual behaviours of people with the disability.   Smith *et al.* (1998:246) indicate that there indeed is no single specific cause for ASD.   Organic factors such as brain damage, genetic links and complications during pregnancy may cause the condition, although in most cases no cause can be confirmed.   Janzen (1996:6) states that anything which causes the central nervous system to develop abnormally can cause ASD.   The event that initially triggers the abnormal development, could occur during fetal development, during birth or after birth.   Goldberg (1998:3) suggests that ASD is a state of dysfunction induced in the brain by a disregulated immune system.   As Goldberg (1998:4) suggests, "*a leaky gut, which represents a hyperpermeable intestinal lining*", allows bacteria, toxins and food leaks, all of which can have an effect on body and brain functioning.   Edelson (1999:1) indicates that there is also a great deal of evidence that a form of yeast called candida albicans, may cause autism.   Smith *et al.* (1998:249) and Janzen (1996:6) contend that knowledge and understanding about the causes of ASD in each individual case can contribute to planning an intervention program.   The importance of making an early diagnosis, and implementing a comprehensive form of intervention when the child is still very young, remains a more important issue than knowing the exact cause of the disability (Janzen, 1996:7).

2.3.2.4   Treatment

As Mash and Wolfe (1999:404) state, most treatments of ASD are directed at maximising the disabled child's potential and helping the child and family to cope with the disability more effectively.   Smith *et al.* (1998:249) indicate that, regardless of the specific intervention used, the following general principles should be considered when teaching new skills to children with ASD:

- Make instructions clear and simple.
- Prompt as needed. Prompts can be environmental, gestural, verbal, or physical.
- Provide corrective feedback.
- Reinforce appropriate behaviour.

Mash and Wolfe (1999:404) as well as Smith *et al.* (1998:249), report that treatment programs for children with ASD should target the specific social, communication, cognitive and behavioural deficits commonly seen in these children. Anderson *et al.* (1996:183) add that skills which focus on the areas of learning readiness, language and cognitive development, fine and gross motor development, play and self-help should be included in an intervention program. As children with ASD have great difficulty making changes and generalising previously acquired skills to new environments, Anderson *et al.* (1996:191) indicated that these areas should also be directly addressed in treatment programs.

Although Barlow and Durand (1999:455) state that behavioural approaches have been most clearly documented as benefiting children with ASD, it is critical that any treatment approach be tailored to meet the needs of an individual child and family. Williams (1996:49) supports this and states: "*Ideally, whatever is used to tackle 'autism' should be appropriate to the particular problems of the person they are dealing with.*"

2.3.3 DOWN SYNDROME

2.3.3.1   Historical background

Burns and Gunn (1993:1) report that the first evidence of this syndrome can be traced back to the artefacts of the Olmecs in ancient Mexico. However, the first detailed description thereof came much later in 1866. According to Cunningham (1996:60), Langdon Down - the doctor who first identified people as having Down syndrome - thought that their appearance resembled that of the oriental Mongolians.

Thus, the condition first became known as "mongolism". As both Cunningham (1996:60) and Burns *et al.* (1993:2) state, it was almost a hundred years after that in 1959, with the discovery of the extra chromosome, that the syndrome could be positively diagnosed. Until then the diagnosis of the syndrome was based purely on the presence of specific physical features as reported by Down.

2.3.3.2   *Prevalence and Course*

Cunningham (1996:81) reports that the prevalence figure for Down syndrome is about 1.1 to 1.2 per 1000 of the population. However, this prevalence figure was based on studies carried out in the 1960s and Mash and Wolfe (1999:359) state that the changes in lifespan and survival have altered this figure to 1.5 per 1000.

According to Mash and Wolfe (1999:352), the mental ability of children with Down syndrome may plateau during the middle childhood years, and then decrease over time. Bird and Buckley (1994:7), however, believe this to be a myth, and state that the diagnosis of Down syndrome neither predicts development nor place a ceiling on progress. They state that the mental development may alternate between periods of gain and functioning, as well as periods of little or no advance. Although people with DS continue to develop in intelligence, they do so at slower rates throughout their childhood years. Bird and Buckley (1994:6) also indicate that even though it was assumed that most children with DS would become dependent adults, reports of them living and working independently increase every year. The same authors (1994:9) warn that there is no significant evidence to support the view that children with DS experience decline in progress with age, or that their development reaches as ceiling during adolescence.

Cunningham (1996:82) states that, in the past, people used to think children with Down syndrome would never survive adolescence. This, however, is changing all the time, and children and adults with Down syndrome now have a greater life expectancy than ever before (Mash & Wolfe, 1999:352).

2.3.3.3   Causes

Various authors (Barlow & Durand, 1999:460; Cunningham, 1996:83; Mash & Wolfe, 1999:359) indicate that Down syndrome is caused by the presence of an extra 21st chromosome, and is therefore sometimes referred to as trisomy 21.   During cell division, two of the 21st pair of the mother's chromosomes fail to separate.   When these two then join with the single 21st chromosome of the father, the result is three number 21 chromosomes instead of the normal two.   The special physical and mental characteristics associated with Down syndrome arise from an imbalance in genetic material, which then disrupts the normal program of development.   Bird and Buckley (1994:5) report that the chances of a woman having a child with DS increases from about 1 in 2000 at the age of 20, to 1 in 18 at the age of 45. Cunningham (1996:84) states that the vast majority of cases of Down syndrome are not associated with a family's genetic predisposition towards having children with this condition.

2.3.3.4   Treatment

Barlow and Durand (1999:465) record that biological treatment for people with mental retardation and Down syndrome is not a viable option.   Generally, the treatment for individuals with these disabilities parallel those used for people with ASD.   Treatment focus mainly on teaching them skills which they will need in order to become more productive and independent.   Mash and Wolfe (1999:370) are of the opinion that intervention efforts are most successful when offered as early as possible.

2.3.4 DOWN SYNDROME AND AUTISTIC SPECTRUM DISORDER

2.3.4.1   Incidence and Diagnosis

According to Capone (1999:10), it is very difficult to estimate the prevalence of ASD among children and adults with Down syndrome. This is due to the disagreement over diagnostic criteria and incomplete documentation of cases over the years.

However, there is an increasing number of reports about the two conditions co-existing. Patterson (1999:16) states that a review of literature on this subject since 1979 reveals 36 reports of DS/ASD. Nevertheless, even when autistic symptoms are evident in a child with Down syndrome, these tend to be attributed to the associated learning difficulties, rather than being adequately assessed in their own right. Howlin, Wing and Gould (1995:412) indicate that the diagnosis of autism in other children is usually made well before they reach school age, but diagnosis of ASD in children with Down syndrome tends to be much later. The reason this combination is underdiagnosed, seems to stem from the belief in the "Down syndrome personality". Persons with Down syndrome are said to be affectionate and easy in temperament, which is in direct contrast to the typical "autistic personality" (Howlin *et al.*, 1995:412).

On the question of which would be the primary disability, it is generally considered to be ASD. Guthrie Medlen (1999:7) argues in this regard that: *"Even though a child may have Down syndrome 'written all over him', it is the autism that gets in the way of learning and reacting in a way that would be expected of a child with Down syndrome."*

It can therefore be assumed that early recognition of this association is critical because of the impact it has on educational and therapeutic interventions, and in some cases the need for further medical assessments and treatments. Gillberg and Coleman (2000:140) state that such a dual diagnosis needs to be based on a consistent pattern of behaviour over a period of time and only after other etiologies of the symptoms have been ruled out. According to Vatter (2001:1), the main areas to watch for in a child with Down syndrome suspected of having a complicating disorder such as ASD, is in the social and emotional areas. Capone (1999:6) reports on research findings which compared behaviour exhibited by children with DS only and children with DS/ASD. The most general findings indicated that children with DS/ASD were more likely to have:

–   a history of developmental regression;
–   poor communication skills;
–   self-injurious and disruptive behaviours;

–   repetitive motor behaviours;

–   unusual vocalizations;

–   unusual sensory responsiveness;

–   feeding problems; and

–   increased anxiety, irritability, difficulty with transitions, hyperactivity, attention problems and significant sleep disturbances.

Further research is still necessary in order to gain greater understanding of Down syndrome and Autistic Spectrum Disorder. Patterson (1999:17) and Ghaziuddin, Tsai and Ghaziuddin (1992:454) state that only through research, will barriers in diagnosis, as well as access to appropriate medical and educational interventions, be reduced.

2.3.4.2   Causes

Capone (1999:11) states that the causes of ASD is generally poorly understood, whether or not it is associated with Down syndrome. There are some medical conditions in which ASD is more common, such as fragile-X syndrome, seizure disorders and chromosome anomalies. Down syndrome should be included in this list. Gillberg and Coleman (2000:141) indicate that the impact of a pre-existing medical condition such as Down syndrome on the developing brain is probably a critical factor in the emergence of ASD in a child. Children with Down syndrome are more prone to develop infantile spasms and thyroid problems, both of which can, according to Gillberg and Coleman (2000:142), lead to the development of autistic features. Kent, Evans, Paul and Sharp (1999:157), suggest that obstetric complications may have an etiological role in autism. The same authors argue further in this regard that different organic problems and congenital or early acquired brain deficits may be responsible for the development of autistic disorders in some individuals. This may be either as the result of a chromosome abnormality or indirectly because of an increased vulnerability to harmful effects during the neonatal period. It seems, however, that in the present state of knowledge of the causes of autistic conditions, it is possible only to speculate on the etiological implications of the association of autism and Down syndrome (Howlin *et al.*, 1995:410).

2.3.4.3   Treatment

Williams (1994:49-87) discusses a number of educational and therapeutic programs that have been developed specifically for children with autism. These include behaviour modification, developmental social programs, sensory integration therapy, facilitated communication, holding therapy and biochemical treatments. According to Patterson (1999:16), these will probably be overlooked for a child with Down syndrome, unless a diagnosis for Autistic Spectrum Disorder is made. However, it is equally important for a child with a dual diagnosis of Down syndrome and Autistic Spectrum Disorder to access this intervention.

2.4 APPLIED BEHAVIOUR ANALYSIS (ABA) and AUTISTIC SPECTRUM DISORDER (ASD)

According to Scott *et al.* (2000:55), the history of ASD and behaviour analysis goes as far back as the 1950s, when Lovaas (1987) began working with people with autism. Being a behaviour analyst, he focussed primarily on observed behaviour in order to teach more productive behaviours. He addressed severe behaviour problems as well as language development. In spite of this intensive research, Lovaas (1987) achieved limited long-term results with older children treated in hospital settings. Gresham, Beebe-Frankenberger and MacMillan (1999:561) report on the UCLA Young Autism Project (YAP) which was initiated in 1970, and whose goal it was to maximise behavioural treatment gains made by children with autism. The original article describing the YAP was reported by Lovaas (1987), and a follow-up study of the same children was reported by McEachin, Smith and Lovaas (1993). Scott *et al.* (2000:57) state that because of limited long term results in earlier research, Lovaas (1987) redirected the YAP in three different ways:

–   It focussed on children aged 2-5 years, believing that younger children might be more capable of overcoming the biologically induced impact of autism.

–   Treatment was transferred away from institutional settings, moving to the homes of children, with parents playing an important support role.

–   Program intensity was increased to 40 hours of training per week.

According to Gresham *et al.* (1999:562), the YAP has proven ABA to be highly successful with children with ASD. Even though various authors (Gresham & MacMillan, 1997; Mundy, 1993; Schopler, Short & Mesibov, 1989), have criticised the research by Lovaas (1987) on many counts, Scott *et al.* (2000:141) report that as of 1998, well over 6 000 families in the United States have established successful home-based behavioural intervention programs for their children with ASD.

According to Romanzcyk (1996:105), ABA takes into account, at a precise and moment-to-moment level, how individuals learn in the context of their unique physical and social environments, taking into account their biological and learning histories. According to Anderson, Taras and Cannon (1996:181), ABA emphasises the "*employment of instructional technology in order to change behaviour in systematic and measurable ways*". These authors report that the key words of this definition are "technology", "systematic" and "measurable".   It is important that all the strategies used during the intervention can be described in detail for others to use, that they are introduced in a systematic manner and that they can be accurately measured for effectiveness. Hultgren (2001:4) states that a behaviourist looks at each of the behaviours exhibited by a child with ASD and does a functional analysis of each one.   The behaviourist then looks at which behaviours and skills the child needs, and break them down into simple pieces. Each skill is then taught in small, brief units called "trials" (Anderson *et al.*, 1996:182).   Every trial consists of an instruction, a prompt, a response and feedback. According to Mash and Wolfe (1999:34), these skills are all taught through the use of positive and negative reinforcement, and feedback on each trial is given immediately. The skills taught are consistently measured before new and more difficult patterns of behaviour are attempted. As Hultgren (2001:5) mentions, evaluation (analysis) of the effectiveness of trials is a critical part of the therapy. If the learner is not making progress, the therapist can conclude that the therapy is misguided, rather than that the learner is not responding very well.

Lovaas and Smith (1989:17) state that a behavioural theory derived from traditional work with children with ASD is at the core of behavioural intervention. This theory has four tenets: (a) autistic children's behaviours are consistent with laws of learning derived from the behaviour of other organisms; (b) autistic children have many separate behavioural difficulties best described as a developmental delay; (c) despite their difficulties, autistic children can, in specific environments, learn as much as other human beings; (d) their difficulties can be viewed as a mismatch between a deviant nervous system and average or typical environments, rather than as a disease. However, a number of practical and theoretical problems remain, which requires further research.

2.5 CHILDREN WITH DISABILITIES: EFFECT ON FAMILY LIFE AND SIBLINGS

As mentioned in Chapter One (see 1.1), the ABA intervention was approached from an ecosystemic framework. The implication of intervening from this framework, is that the possible effects of intervention on the other members of the family could not be underestimated and ignored. Therefore, through this study, it is the effect of the disabled child's intervention program on the non-disabled sibling, which is explored. However, I found literature on this topic to be very limited. There are, however, quite a number of publications on the effect that the disabled children themselves have on general family functioning as well as on non-disabled siblings. The following overview will discuss literature regarding this matter.

Various authors (Porterfield, 1997; Sanders & Morgan, 1997; Ghallagher, Beckman & Cross, 1983) argue that brothers and sisters have a profound effect on a child's psychosocial and emotional development, as well as on who they become as adults. Simeonsson and McHale (1981:153) report that when a sibling has a disability, family relationships become more complicated. Brothers and sisters of children with disabilities experience many emotions about having a family member with a special

need. Feelings of resentment towards the child with a disability is common among siblings of children with special needs. According to Russel (1997:4), these feelings may result from the loss of attention from their parents, feelings of unequal treatment and excessive demands placed on them as siblings. Donelly (1991:5) and Turk (1991:22) state that the siblings might further experience negative emotions resulting from the whole family's involvement with the child with disability.

Ghallagher, Beckman and Cross (1983:10) state that families of children who have disabling conditions are often faced with a unique set of problems as they attempt to adapt to the presence of the child with a disability in the family. Furthermore, families of children with disabilities appear to be particularly vulnerable to the experience of stress. There are many factors which may indeed add to the experience of stress. Such factors may exist within the disabled child, the parents, the siblings, the extended family, and even the institutions intended to help the child (Ghallagher *et al.*, 1983:11).

According to Russel (1997:3), siblings of children with disabilities experience both positive and negative feelings about having a sibling with special needs. Basically, siblings of these children experience many of the same emotions and concerns that the parents of children with disabilities feel. However, because the relationship between siblings and their parents, as well as between each other, is different from a parental relationship, they also have experiences and concerns that others may not be aware of. Russel (1997:7) discusses the "unusual concerns" and "unusual opportunities" which siblings of disabled children experience throughout their lives. The following are highlighted:

a)   *unusual concerns* such as over-identification and need for information, embarrassment, isolation, loneliness, loss, resentment, increased responsibilities, pressure to achieve;

b)   *unusual opportunities* such as maturity and insight, tolerance and diversity, pride, vocational opportunities, advocacy.

McHale and Gamble (1989:421) support Russel's view. They argue that the extra responsibilities which a disabled child assumes, the demands set on parents' availability for the non-disabled sibling, as well as additional stresses that the non-disabled sibling may face "*can give rise to emotional problems in children or problems for family relationships*". Alternatively, however, they state that this may also "*foster maturity and competence in the non-disabled sibling*". Various other authors such as Nixon and Cummings (1999), Hannah and Midlarsky (1985), Simeonsson and McHale (1981) also argue that a disabled child has a profound effect on non-disabled siblings and the family environment, be it negative or positive.

Hannah and Midlarsky (1985:511-515) give a review of literature that was designed to "*... explore the effects of sibship with a disabled child over a variety of conditions...*" (1985:510). There are several influences which disabled children might have on their non-disabled siblings, which seem common in research (Simeonsson & McHale, 1981; McHale & Gamble, 1989; Siegel & Silverstein, 1994; Hannah & Midlarsky, 1985). The most common psychological effects that were pointed out, were: anxiety, withdrawal or depression, aggression and/or poor peer relationships. Distress often takes the form of enuresis, encopresis, worries about own health, school failure, reduced cognitive efficiency or school refusal and phobia. Simeonsson *et al.* (1981:156) as well as McHale, Simeonsson and Sloan (1984:330) add to these effects of a negative nature, and state that problems with establishing self-identity are frequently seen in siblings of disabled children. Young siblings know that they are, in some sense, similar to their disabled brother or sister. The sibling often struggles with the question of how many characteristics of the disabled sibling they actually share. That is, these children may come to think of themselves as somehow "defective" (McHale *et al.*, 1994:331). As the sibling matures, these doubts may become redefined as a fear of having a disabled child, because of the genetic makeup that is shared with the disabled sibling (Simeonsson *et al.*, 1981:159).

Simeonsson *et al.* (1981:156) indicate that the effects exerted by a disabled child may frequently be expressed in terms of resentment towards the disabled child. This resentment experienced by siblings is a function of actual or perceived

demands imposed by parents. These demands may involve caretaking for the disabled child, household chores, or other tasks which the sibling must perform because of the additional time that a disabled child requires. McHale *et al.* (1984:331) state that role tension frequently develops when non-disabled siblings are expected to take care of a younger disabled child, and often subordinate their needs to those of the disabled child. In such families, the disabled child becomes the youngest child socially, regardless of birth order. As Simeonsson *et al.* (1981:157) point out, parental demands may also influence siblings of disabled children in an indirect manner. Siblings may assume responsibilities for inferred psychological needs of parents - that is, often assuming a responsibility to over-achieve and to 'make up for' the limitations of the disabled sibling.

Despite the negative impact that the presence of a disabled child may have on siblings, Hannah and Midlarsky (1985:512) indicate that there are several positive consequences or psychological benefits to having a disabled sibling. Non-disabled siblings may have greater tolerance, understanding of people and compassion. They may also display more idealism and humanitarian concern in their life goals and have enhanced self-esteems. A further benefit may be greater maturity and sense of responsibility than their age group (Hannah & Midlarsky, 1985:513). In conclusion, it became apparent from available resources that the presence of a disabled sibling may directly influence non-disabled sibling's development, but as Siegel and Silverstein (1994:28) indicate, more often these effects are mediated by the way the family as a whole operates. Simeonsson and McHale (1981:161-165) have reviewed research on family and child characteristics which are related to adjustment. An adapted summary of their analysis, as taken from McHale *et al.* (1984:334), is provided here.

TABLE 2.1 Correlates of adjustment in children with disabled siblings

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Family characteristics

1.	*Size*	Children from large families are better adjusted, provided their families have sufficient financial resources.
2.	*Socioeconomic status*	Families of low socioeconomic status have the problem of limited financial resources. Families of middle and upper socioeconomic status must adjust their high expectations for the disabled child's accomplishments.
3.	*Parental acceptance*	When parents are more accepting of the disabled child's condition their other children are better adjusted.
4.	*Marital relationship*	With a positive marital relationship, both parents and children adjust better to having a disabled child in the family.

Sibling's characteristics

1.	*Birth order*	Older siblings tend to be better adjusted, particularly when there is a span of 10 years or bigger between the non-disabled and disabled siblings.
2.	*Gender*	Oldest girls in the family are most adversely affected.

Disabled child's characteristics

1.	*Age*	As the disabled child grows older, the siblings in the family experience more problems.

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2.	*Gender*	Children the same gender as the disabled child experience more problems, except for the oldest female, who usually experiences the most difficulties.
3.	*Type of disability*	When the child's disability is ambiguous or undefined, siblings tend to be more poorly adjusted, especially in higher SES families.
4.	*Severity of disability*	When the child's condition is severe, and the child requires a lot of care, siblings experience more problems, especially in low SES families.

McHale *et al.* (1984:334)

2.6 CHILDHOOD DEVELOPMENT

2.6.1 DEFINITION OF CHILDHOOD DEVELOPMENT

In order to make sense of the impact that intervention with a learner with disabilities might have on his sibling's experiences, it is necessary to explore the context of childhood development.

While there are several models of development, I consider the specific model discussed by Brems (1993:46) to be quite comprehensive in its perspective on the interaction between the individual and the environment. This dialectic model stresses that development is not only guided by physical or biological factors within the individual, but is also impacted by psychological, cultural, and external factors. Given this, according to Brems (1993:46), development is viewed as "*...a never-ending, continual process that is shaped by the individual's experiences in his or her environment.*"

2.6.2 *FACTORS INFLUENCING DEVELOPMENT*

Brems (1993:47) and Louw (1990:17) indicate that when attempting to come to a better understanding of childhood development, it is necessary to consider all the factors that might play a role in determining its course. Apart from looking at the child's age, one needs to consider other factors, such as psychological, biological, environmental and metaphysical events. Considering all of these influences on development, as well as when and how they occur, may help one to understand the child more fully. This will also help to place the child's actions, needs and feelings in a developmental context unique to the child. According to Brems (1993:45), one needs to consider the above mentioned influences, as well as have an appreciation of age-normed expectations in order to make sense of an individual child's development. These age-normed factors should, however, be explored within the context of the child's experience in entirety.

Throughout the current study it will be necessary to consider as many factors as possible which may influence the sibling's experiences, as well as to look at age-normed development. Knowledge about age-appropriate psychosocial development will serve as a guide from which these experiences can be interpreted. As a basis from which psychosocial development will be viewed, the theory established by Erik Erikson (1950) will be outlined. Erikson's model provides guidelines for psychosocial development during different phases of a human being's life. As the sibling who is the focus of this study turned six during the time which the study was conducted, the development from birth to age 12 (according to Erikson's model), will be discussed.

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TABLE 2.2 Psychosocial development across the lifespan

Age	Conflict	Characteristics of success	Outcome
Birth to 1	Basic trust vs. Mistrust	learning to trust others; becoming trustworthy oneself	Hope
2 to 3	Autonomy vs. Shame and Doubt	learning self-assertion and rudimentary independence, taking pride in own actions and exercising judgement	Will
4 to 5	Initiative vs. Guilt	becoming curious and participating in environment; exploring and asking questions	Purpose
6 to 12	Industry vs. Inferiority	learning how to do and complete tasks; trying out new skills and discovering interests	Competence

Table adapted from Brems (1993:51)

When exploring the experiences of the sibling, I considered it necessary to explore these against the background of age-appropriate emotional development. In this process it may become clear as to whether it is possible to establish certain links between the sibling's experiences and the intervention program. It may also be that the experiences should rather be considered as appropriate according to the developmental age of the sibling. In addition to Erikson's model on psychosocial development, attention will also be given to theories regarding the emotional development of children. For this purpose Lane and Swartz's model, as used by Brems (1993:50), will follow.

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TABLE 2.3 Emotional development as outlined by Lane and Schwartz

Period	Experience of affect	Expression of affect	Differentiation of affect
Early Sensorimotor (0 to 1)	bodily sensation only, no cognitive experience or understanding	inability to express affect either for self or other	undifferentiated arousal
Late Sensorimotor (1 to 2)	global arousal and tendency to act upon it	specific actions are now associated with specific emotions	global perception specific actions associated with specific emotions recognisable by others
Pre-operational Thought (2 to 7)	limited range of experience	stereotypic and undimensional expression of limited repertoire	can identify only one affect at a time; can only tie one affect to one situation
Concrete Operations (7 to 11)	awareness of blends of feelings	complex, modulated and well-differentiated expression	recognition of concurring as well as opposing emotions
Formal Operations (11 to 15)	peak differentiation and blending experience of nuances	rich expression of quality and intensity	simultaneous recognition of blends in self and others

Brems (1993:50)

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2.7 CHAPTER SUMMARY

Through a review of relevant literature, I endeavoured to set the background against which the research data and findings will eventually be interpreted. I referred to the concepts in the title of the study and attempted to clarify them. I also discussed the ecosystemic framework as an approach from which the sibling's experiences will be explored. In addition to this, I pointed to specific models of general childhood development which could serve as a guide to distinguish between experiences which are age-normed, and those which can be linked specifically to the intervention program. The literature overview will ensure that I can link the research findings to existing theories and results relevant to the problem statement.

CHAPTER THREE

METHOD OF INQUIRY

3.1 INTRODUCTION

In this chapter I discuss the theoretical framework for the research. Attention will be given to the research approach, techniques used in the production of the data, as well as the data analysis. Criteria for verifying the trustworthiness of the study will be outlined and ethical considerations will also be discussed.

As explained in Chapter One (see 1.4), the lived experiences of siblings were explored from an interpretive paradigm. Terre Blanche and Kelly (1999:123) point to the characteristic ontology, epistemology and methodology of the interpretive research approach. These principles will serve as a background of the method of enquiry for this study, and are described by them as follows:

> *Researchers working in this tradition assume that people's subjective experiences are real and should be taken seriously (ontology), that we can understand other's experiences by interacting with them and listening to what they tell us (epistemology), and that qualitative research techniques are best suited to this task (methodology) (Terre Blanche & Kelly, 1999:123).*

Prior to the case study, I reviewed relevant literature. Through studying the most recent literature on the topic, the field of research was approached in an orderly and systematic manner. Huysamen (1992:198) states that investigating literature promotes understanding of the topic involved, as well as revealing gaps in existing knowledge that may require possible further research. This overview of literature

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contributes to identifying and establishing a theoretical framework according to Mertens (1998:34), which sets the disciplinary orientation on which this particular study was drawn. Merriam (1998:47) cites Schultz who states that the choice of a theoretical model guides the research process:

> *... in terms of the identification of the relevant concepts/constructs, definition of the key variables, specific questions to be investigated, selection of a research design, choice of a sample and sampling procedures, data collection strategies... data analysis techniques, and interpretation of findings.*

The theoretical framework for this study provided a basis for interpreting the experiences of a sibling during the implementation of an intervention program with her disabled brother.

3.2 RESEARCH APPROACH

A qualitative case study was chosen as the most effective means to investigate the field of study. It was used because of my interest in the specific case. The research will, therefore, not be approached with a hypothesis that should be tested, but it will rather attempt to make sense of day-to-day individual experiences, which cannot be predicted in advance.

Merriam (1988:21) provides the following definition of a case study: "*A qualitative case study is an intensive, holistic description and analysis of a single instance, phenomenon, or social unit.*"

Different researchers report different purposes for conducting a case study. In this regard, Stake (1994:236) states that, on the basis of such differences, there are three different types of case studies: intrinsic, instrumental and collective case

studies. Stenhouse (1988:49) further elaborates on these purposes, and states that case studies can, on the one hand be used because of interest in generalization, and on the other hand because the case itself is regarded as of sufficient interest to merit investigation. The purpose of conducting this particular case study was not because it represented other cases, or because it illustrated a particular trait or problem. Rather, I conducted it because of interest in the particular case itself, therefore, according to the aforementioned description it can be called an intrinsic case study (Stake, 1994:236).

Merriam (1998:29-32) adds that the case study can be further defined by its features. It can be characterized as being "particularistic", "descriptive", and "heuristic". This study was "particularistic", since it focussed on one particular sibling and her experiences during the time that her brother was involved in a specific project. The case itself was therefore important for "*what it revealed about the specific situation*" (Merriam, 1998:29). The study contained elements of description because the end product will be a "*qualitative description, instead of a report of numerical data*" (Merriam, 1998:29). The case was also "heuristic" since it provided a "*new understanding of the phenomenon under study*" (the sibling) (Merriam, 1998:31) and supported much of what is known about siblings of disabled children.

3.3   TECHNIQUES USED IN DATA PRODUCTION

3.3.1 INTRODUCTION

Van Manen (1990:52) states that within the human science perspective, the notion of data is ambiguous. When discussing the various approaches followed to produce lived-experience material, it is in some respects quite misleading to talk about data, especially since the concept of "data" is originally associated with more positivist social science approaches. However, the same author (1990:53) argues that it is not entirely wrong to say that qualitative methods use the term data. In research, whenever an important experience is related, it can be viewed as something gained.

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The entity gained, therefore, need not be quantifiable. Van Manen (1990:54) further reminds us that one needs to realise that lived experience descriptions are never identical to lived experience itself. All recollections of experiences are already transformations of those experiences. As he writes:

> ... the upshot is that we need to find access to life's living dimensions while realizing that the meanings we bring to the surface from the depths of life's oceans have already lost the natural quiver of their undisturbed existence (Van Manen, 1990:54).

The data for this study was produced over a period of 26 weeks. A variety of techniques were used in producing the data base, all of which will be discussed below.

3.3.2 CLINICAL EVALUATION

3.3.2.1 Intellectual functioning (see Appendix H)

The Junior South African Individual Scales (JSAIS) was administered. The JSAIS is an intelligence test which consists of both verbal and non-verbal subtests. According to Madge (1981:3), the content of the scale was designed to stimulate the child's interest, and the aim of the test is threefold in nature. The aims can be summarised as follow:

a) to establish the general intellectual level of children between the ages of 3 years 0 months and 7 years 11 months,

b) to evaluate a child's relatively strong and weak points in some significant facets of intelligence, and

c) to evaluate certain non-cognitive behaviour (Madge, 1981:4-5).

In this study, I did not apply the test specifically with the aim to record numeric results and to determine an intelligence quotient (IQ). Rather, while also taking note of the cognitive abilities, I used the test qualitatively in order to gain information regarding cognitive and non-cognitive patterns of behaviour. According to Coetsee (1978:4), qualitative analysis of responses in the JSAIS relies on the assumption that factors such as cognitive structure, cultural background and a child's field of experience underlie their responses. It is important that the test administrator takes note of specific aspects which might provide insight, as well as guide the tester into a better understanding of the child's total functioning. Coetsee (1978:5) gives examples of a few of these factors which should be considered. The child's approach to the situation can become evident through looking at interest, motivation, cooperation and initiative. It is also necessary to attend to the child's emotional state by reviewing factors like self-confidence, acceptance of and reaction to praise, anxiety, and pleasing behaviour. Other factors which should be noted are: motor problems; speech; speed of functioning; possible sensory deficits; vocabulary and use of language.

3.3.2.2 Projective Techniques

According to Kaplan and Sacuzzo (1997:437), the primary rationale underlying all projective tests is the "projective hypothesis". Peterson and Hardin (1997:20) refer to this as a qualitative hypothesis, which assumes that people's interpretation of a vague stimulus will reflect their needs, feelings, experiences, prior conditioning and thought processes. Kaplan and Sacuzzo (1997:438) warn, however, that conclusions drawn from a single response should never be absolute and definite. In this study all the projective techniques discussed below were used qualitatively. The interpretation of drawings are, therefore, based on the analogy that the "self" (Peterson *et al.*, 1997:21) of the sibling is projected into the stimuli which I provided.

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i)   ***Rorschach Inkblot Test*** (see Appendix D)

According to Brems (1993:170), the Rorschach test (Rorschach, 1942) is a personality assessment technique. The test consists of ten inkblots each printed onto one cardboard card. Kaplan and Sacuzzo (1997:439) state that the cards should be presented, one at a time, together with asking a very unstructured question such as "What might this be?". No restriction should be placed on the type of response, and no clues should be given concerning what is expected. The questions are related to actions and feelings seen on the different cards. Brems (1993:170) is of the opinion that the Rorschach is useful in personality description, identification of type and severity of pathology, evaluation of coping ability, as well as general interpersonal and intrapsychic style.

In this study, the Rorschach was used qualitatively by looking at the content of the sibling's response to each card. Brems (1993:171) refers to this as a form of content analysis. The analysis of the response is based on the content that has been found to occur most frequently in the ten cards. According to Klopfer, Ainsworth, Klopfer and Holt (1954:388-399), the cards can be divided as representative of the following:

Card I and Card V: reality testing or reaction to new situation.
Card II: self-image, person in relation to reality and sexual identity problems
Card III: relation to people in general, integration of feelings about people.
Card IV: relation towards father or male authority.
Card VI: sexuality.
Card VII: relation towards mother or femininity.
Card VIII, IX, X: affect and emotion.

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ii)   ***Draw-A-Person Test*** (see Appendix A)

Blau (1992:6) states that Machover's (1949) Draw-A-Person Test (DAP), as a standardised personality evaluation, is more than three-quarters of a century old. The same author (1992:7) suggests that drawing analysis is most fruitful when used with other standardised tests as part of a diagnostic battery. As the title implies, the DAP involves asking the child to draw a person. According to Brems (1993:174), it is believed that the artwork created through this process would reflect not only the child's overt approach and style, but also unconscious material such as intrapsychic conflict, psychological defence, interpersonal adjustment, and similar personality features. These characteristics can be assessed through exploration and interpretation of various components of the child's completed drawing. Blau (1992:7) states that the following are factors which may emerge from a DAP drawing:

- Severity of the person's emotional distress.
- Anxiety level.
- The person's concept of him or herself.
- Elements of the person's environment which are threatening or reassuring.
- The person's characteristic reaction or defence of stress.
- Level of psychosexual development.
- Amenability or availability of the person for treatment.
- The quality and nature of the person's parental figures.

iii)   ***Kinetic Family Drawing*** (see Appendix B)

As a third projective technique, the Kinetic Family Drawing Test (KFD) (Burns & Kaufman, 1970), was used. In administrating this test, the child is usually asked to draw their family, while introducing some activity into the drawing. According to Brems (1993:175), the artwork derived from these instructions lends itself to similar kind of interpretations as that of the DAP. Further interpretations such as those that have to do with the story line depicted in the picture, the type of action that is suggested, the placement of all objects on the page, and the relative distances of the objects from one another can be made. Also, spontaneously introduced objects can be of symbolic and interactive value (Peterson & Hardin, 1997:59).

According to Wakefield and Underwager (1998:176), image-based techniques can be extremely valuable in assisting children to communicate their feelings to adults. A crucial factor, however, is how these techniques are used by the interviewer. The same authors (1998:178) argue that if image-based techniques are used, it must be in a non-suggestive way that encourages children to provide details about their experiences and feelings. This implies that the interviewer should refrain from making any suggestions or asking questions which may project their own ideas about the child's emotions or family into the drawings. The specific instructions I used in administering the DAP, KFD and Rorschach are discussed in Chapter Four of this study (see 4.3.1.2).

iv)   ***Rotter Incomplete Sentences*** (see Appendix C)

As with the other projective techniques, it is believed that the incomplete sentences will reflect conflicts, values and needs. According to Kaplan and Sacuzzo (1997:459), the incomplete sentences may also give a person the opportunity to provide information that may have been too embarrassed to present verbally.

In this study, the junior version of the Rotter Incomplete Sentence Blank (Rotter & Rafferty, 1950) was used. The sibling was presented with twelve different incomplete sentences and asked to complete them. The specific instruction used is provided in Chapter Four (4.3.1.2).

3.3.3 QUESTIONNAIRES

3.3.3.1   *Teacher's questionnaire* (see Appendix E)

A structured questionnaire (Merriam, 1998:72) was sent to the sibling's teacher. I explained in Chapter One (see 1.1) that, as a trainee educational psychologist, I approached the project from an ecosystemic framework. As suggested by this framework, it may have been possible that the effect of intervention with the disabled learner could also manifest in the non-disabled sibling's school environment. The purpose of the questionnaire to the teacher was, therefore, to gain information from

this dominant system of which she is a part. Information gained through this questionnaire added to a more holistic view about the effect of the intervention on all the aspects of her life. I used this information together with that from the other techniques in an attempt to interpret the meanings she attached to her experiences. The questionnaire contained a number of close-ended questions (Huysamen, 1993:132) on the sibling's emotional functioning. The teacher was asked to select answers from a list provided. Space was provided for the teacher to write any comments she wished to.

3.3.3.2 *Questionnaire to parents* (see Appendix I)

The anamnesis, as used by the Unit for Educational Psychology at the University of Stellenbosch, was completed. This questionnaire provided a mixture of open-ended and structured questions on general development, emotional, social and personality functioning, discipline, family background and cognitive functioning. The purpose of this questionnaire was to formulate a general idea about the sibling's current and past functioning.

3.3.4 *INTERVIEW WITH PARENTS* (see Appendix F)

The interview with the parents was primarily semi-structured and the questions asked were open-ended. According to Merriam (1998:74), less structured formats assume that the individual respondents define the world in unique ways. The parents were requested to answer specific questions regarding their perceptions of their child's emotional functioning. These questions were chosen to guide me in exploring the sibling's general emotional functioning and development, as well as to further elaborate on information collected in the anamnesis discussed earlier (see 3.3.3.2) In addition to these semi-structured questions, however, two structured questions directly related to the sibling's experiences of the project were asked. The answers to all the questions were recorded in written form.

In relation to the interview, there was a deviation from the original plan. The details are discussed in 4.3.2.2.

3.3.5 OBSERVATIONS AND VIDEO MATERIAL

During the course of the intervention with the disabled child, I started with weekly play sessions with the sibling. Landreth (1991:7) is of the opinion that a child's world is one of concrete realities, and that their experiences are often communicated through play. Brems (1993:259) states in this regard that expression in play is not merely expression of interests, but expression of affect. Children work out their feelings through play and can express themselves freely, without having to fear any negative consequences. The purpose of these sessions, therefore, was to provide the sibling with the opportunity to express her feelings in a structured and safe environment. All these play activities were recorded on video tape. For the purpose of the play therapy sessions, a combination of different directive techniques were used.

Clinical observations were made throughout my contact with the sibling in the play sessions, as well as on the specific day that the questionnaires for the intellectual functioning and projective techniques were administered. In addition to all of these observations, informal day-to-day observations in my capacity as therapist of the disabled boy, were also made.

3.4 DATA ANALYSIS

> *The world of research is not tidy enough to provide us with a neat one-to-one correspondence between research interests and analysis procedures. For some approaches with a long tradition ... the analysis process has become quite well defined. In more recent ones ... researchers are still exploring and inventing individually. In some cases, scholars have adopted analysis procedures of related approaches, and in still others researchers use their own terminology... (Tesch, 1990:77).*

It seems though, that researchers who have the same interests do treat their data in somewhat similar ways. Tesch (1990:78) further points out that the more unstructured and informal the studies are, the more difficult it is to describe data analysis procedures. Terre Blanche and Kelly (1999:139) contend that it is difficult in interpretive research to have a clear separation between the point where data collection stops and the analysis process begins. According to the same authors (1999:140), interpretive analysis hardly ever proceeds in a very orderly manner. They do, however, suggest a step-by-step process, of which certain parts were particularly helpful and applicable for the purpose of analysing the data produced in this study. I will now discuss Terre Blanche and Kelly's (1999:141-144) steps and indicate how they apply to this study.

Step one: Familiarisation and immersion

The authors (1999:141) state that data analysis and production actually happen simultaneously. The researcher should have a preliminary understanding of the data by the time that the actual analysis starts. During this first step, the researcher has to once again study the data, focussing on the available texts instead of exploring the reality.

During the process of data production, I was continually reflecting on what the specific aspects might mean. After meeting with the sibling for the clinical evaluation (see 4.2.5), I went home to watch the video recording of the session. As I was watching it, I became aware of certain aspects of her behaviour which I thought could be meaningful and relevant in terms of the problem statement. I also reviewed the information from the projective techniques and started to hypothesise about what it could mean. Throughout all the play therapy sessions, I reflected on the video material in order to plan for further sessions. By doing this I engaged in analysing parts of the data. By the time that I had to start looking for themes, I had an understanding of the types of interpretations that could be made.

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Step two: Inducing themes

In this step, the researcher has to consider all the material in order to work out which principles underlie the data. It is necessary, therefore, to make use of a bottom-up approach and to consider all the data in order to find themes and categories. Terre Blanche and Kelly (1999:141) suggest that the themes should arise naturally from the data, while at the same time have meaning in terms of the research question. Van Manen (1990:77) suggests that in order to come to grips with the meaning of the data, it might be helpful to think of the phenomenon in terms of meaning units or themes. He states that making something of a lived experience by interpreting its meaning is not a rule-bound process, but a free act of seeing meaning.

> *Ultimately the concept of theme is rather irrelevant and may be considered as a means to get at the notion we are addressing. Theme gives control and order to our research and writing. ... Phenomenological themes may be understood as the structures of experience. So when we analyze a phenomenon, we are trying to determine what the themes are, the experiential structures that make up the experience. It would be simplistic, however, to think of themes as conceptual formulations or categorial statements. After all, lived experience cannot be captured in conceptual abstractions (Van Manen, 1990:79).*

When extracting themes from all the data I had available, I looked at the questionnaires (intellectual evaluation, projective techniques, anamnesis, teacher's questionnaire), written record of interview, video material and observations separately. From each of these sources, I sought to establish the main themes. In the case of the questionnaires, I wrote down the dominant themes and also made use of literature in order to establish what certain parts of the data could mean generally. I then applied these meanings in order to hypothesise about their applicability to the

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sibling's experiences. Because the interview questions were more structured, I consulted them as to ascertain whether any concurred with the themes derived from the questionnaires. I also reviewed all the videos and made written recordings of the development of each session, again looking for themes which matched with previously recorded ones. I compared these themes with the observations made, in order to add, elaborate and confirm existing themes.

Step three: Coding
Step four: Elaboration
Step five: Interpretation and checking

As already mentioned, the interpretive analysis process is, in reality, not a step-by-step one. I found it difficult to distinguish between steps three, four and five in the analysis process of this study, and will, therefore, discuss them together.

The process of coding is one of marking different sections of the data as relevant to specific themes. Elaborating, then, means that one should explore the themes more closely in order to look for possible sub-themes, as well as and subtle differences in bits of data originally organised together. Terre Blanche and Kelly (1999:144) suggest that one way of elaborating is to discuss your interpretation results with others. The final step, interpreting and checking, entails drawing up a written account of the phenomenon under study, as well as reflecting on the level of subjectivity involved in the production and analysis phases.

After establishing the themes in the different sources of data, I immediately began with a written account, in order to organise my ideas. The way in which I coded the data, was to mark the themes by putting them in bold font. I then started to elaborate on the themes by re-reading through the data so as to search for meanings I might have overlooked. In this part of the analysis process, I again discussed the data with a registered educational psychologist, who provided useful insight. Throughout the interpretation phase I attempted to link the findings with existing theories.

Tesch (1990:67) explains that in naturalistic inquiry, such as case study research, the researcher seeks to understand the nature of the phenomenon in front of her/him. In this type of inquiry, the researcher becomes the major research instrument, for reasons such as greater insightfulness, flexibility and responsiveness (Guba & Lincoln, 1988:81). According to Tesch (1990:93), the characteristic mode of analysis for case studies is "dialoguing with the data" and calls for "interpretation'". Case studies become the written accounts of the story of the case and the analysis is, therefore, usually concerned with pieces of data and what it means (Tesch, 1990:94).

3.5 DATA VERIFICATION

According to Miles and Huberman (1994:227), quantitative studies are evaluated using the criteria of internal validity, external validity, reliability and objectivity. In order to establish trustworthiness in a qualitative study, there should also be some form of accounting for reliability and validity. Ensuring the validity and reliability involves conducting the research in an ethical manner (Merriam, 1998:198). According to Mertens (1998:181), there are a variety of criteria against which data can be verified. These criteria of credibility, transferability, dependability and confirmability were found to be appropriate constructs for testing the trustworthiness of this qualitative study, and will be discussed below.

3.5.1 CREDIBILITY

According to Mertens (1981:63), the use of the criterion of credibility is useful in determining the truth value of a study. The credibility test, therefore, sought to determine whether there was any correspondence between the way the sibling actually perceived her experiences, and the way that I portrayed her viewpoints. Durrheim and Wassenaar (1999:62) state that research is credible when it produces findings which are convincing and believable.

The credibility of the research findings was improved by **prolonged and substantial engagement** (Mertens, 1998:181). My involvement with the case, and study thereof, was for the duration of January to August 2001.

Mertens (1998:182) states that **member checks** can be formal or informal and done continuously through the study. During the play activities I reflected on what I observed, and the sibling had the opportunity to correct my interpretations of what her actions were symbolising. Checking the data with her parents was more difficult because of the issue of confidentiality. Informal discussions as to how they interpreted their child's behaviour guided my interpretations.

The data base of the case study was scrutinised by an **independent researcher**. Fourie (1997:40) argues that, through this process, the data base can then be the subject of separate, secondary analysis of any reports by the original investigator. The data were analysed by an educational psychologist working in private practice. She posed critical questions, provided useful insights and guided me in the process of data analysis. Mertens (1998:182) refers to this as **peer debriefing**.

The credibility of the study was further enhanced by **triangulation,** or as Babbie (1992:109) explains it, the use of multiple sources of data in order to conclude findings. Sources of data used to form the data base included interviews, observations, videos and questionnaires. By means of analysing the data and looking for recurrent themes, the themes from the different sources were cross-checked for consistency of interpretations (Mertens, 1998:183).

3.5.2 TRANSFERABILITY

The second criterion for trustworthiness refers to the degree to which the research findings can be generalised to other contexts and settings. Merriam (1998:211) suggests that through a **"rich, thick description"** this criterion can be met. Therefore, "*extensive description of the time, place, culture and context*" (Merriam, 1998:212) of the family and sibling was provided in order to permit adequate comparisons with other cases. According to Mertens (1998:183), the responsibility of transferability in qualitative research is not so much that of the original researcher as that of the reader who wishes to apply the findings to another context.

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3.5.3 DEPENDABILITY

The third criterion of trustworthiness refers to the extent to which research findings can be replicated. In quantitative research this refers to reliability, or the degree to which the same results would be obtained if the study was to be repeated. Merriam (1998:205) states that reliability is problematic in social sciences, because human behaviour is never static. Therefore, in qualitative research the focus should rather be on dependability, or consistency of results, obtained from the data. According to Mertens (1998:184), a dependability audit, or case study protocol, should be maintained in order to provide the detail of the research process.

Merriam (1998:207) cites Dey (1993) who argues that: "*If we cannot expect others to replicate our account, the best we can do is explain how we arrived at our results.*"

In order to improve the dependability of this study, I leave an **audit trial** (Mertens, 1998:184), or a detailed description of the way data was produced, analysed and interpreted (see 3.3 and 3.4). I also attach a case record (Appendix A-I) as an addendum to this study, where examples of data are provided.

3.5.4 CONFIRMABILITY

Mertens (1998:184) states that confirmability is identified as the "qualitative parallel" to objectivity and means that the influence of the researcher's judgement is minimised. Qualitative data and interpretations thereof can be tracked to their source and are not figments of the researcher's imagination. The study's methods and procedures are described in detail, providing the process leading to the conclusions.

3.6 ETHICAL CONSIDERATIONS

According to Babbie (1992:464), social research almost always represents an intrusion into people's lives, and participation should, therefore, always be voluntary. The same author (1992:466) contends that social researchers should be aware not to harm the participants in any way, regardless of whether they volunteer for the study. It is possible in a social study to harm the participants psychologically, because they may be forced to face aspects of themselves and their families that they do not normally consider. Merriam (1998:219) is of the opinion that the burden of producing a study that has been conducted in an ethical manner, lies with the individual researcher. As this author (1998:218) explains:

> *While policies, guidelines and recommendations for dealing with the ethical dimensions of qualitative research are available to researchers, actual ethical practice comes down to the individual researcher's own values and ethics.*

The two families who were taking part in this research project (refer to 1.2) were voluntary participants. The sibling whose experiences were explored for the purpose of this study, was volunteered by her parents. Written consent was, nonetheless, obtained from her parents. The parents were fully informed of the consequences and boundaries of the research. The sibling was verbally informed about the project. She willingly participated and seemed to have enjoyed the sessions.

3.7 CHAPTER SUMMARY

The theoretical foundation of the methodology has been discussed in this chapter. Through an interpretive research design and a case study format, I sought to understand and interpret lived experience. The methods of data production, analysis and interpretation were discussed. I further demonstrated how the criteria of credibility, transferability, dependability and confirmability attributed to verifying the trustworthiness of the data. The interpretation and presentation of the data will follow in the next chapter.

CHAPTER FOUR

THE CASE STUDY AND FINDINGS

4.1 INTRODUCTION

As discussed in the previous chapter, I will attempt to come to an understanding of a sibling's lived experiences during the implementation of an intervention program with her brother. The broader context of the sibling involved will be outlined. Thereafter, the themes, as they emerged from the sources of data, will be interpreted. The methods applied to verify the data as well as to ensure that findings were valid accounts of the sibling's experiences, were discussed in Chapter Three (see 3.5). I would like to focus the reader's attention on the fact that the sibling might have experienced some emotional distress before the onset of the intervention. This distress is mainly due to the fact that her parents were very involved with her disabled brother. Her brother was a very sickly child when younger and her parents spent much of their time searching for answers surrounding his condition. It may, therefore, be difficult to distinguish between feelings which are relevant or irrelevant to the problem statement.

4.2 CASE CONTEXTUALISATION

4.2.1 IDENTIFYING INFORMATION

Name:	Marli*
Grade:	Grade R (reception)
Date of birth:	29 May 1995
Sex:	Female
Home Language:	Afrikaans
Language of Education:	Afrikaans and English

* Not her real name. A pseudonym has been used for ethical reasons.

4.2.2 CONTEXT OF FAMILY

Marli is the second born of two children. Her older brother (9 years) has Down syndrome and Autistic Spectrum Disorder. Marli lives with her mother, father and brother. Her mother is a lecturer at a local college and works full time. She has also taken on extra duties for financial purposes, spending two evenings a week working at the college. Marli's father teaches at a local high school. He has also taken on extra duties and lectures at the local college for one evening during the week. Marli, herself, attends a pre-school for five days of the week and stays at the school's after-care centre in the afternoons. Her brother used to attend a special school for children with Down syndrome, but since the start of the research project follows a home-based intervention program. His one tutor arrives at 07:30 in the mornings when Marli is still at home, and I, as second tutor, take over at 11:00. At 14:30 her brother goes to a daycare centre where he is collected at the same time as Marli when she leaves from after-care. The family lives in a suburban area and has an average socio-economic status.

4.2.3 DEVELOPMENTAL DETAILS

4.2.3.1   Physical

Marli was a planned child and was born when her mother was 33 years old. Her mother experienced some difficulties during the pregnancy, as bleeding occurred after an amniosinthesis. The placenta also started to disintegrate. Due to the fact that the firstborn was delivered by means of a caesarian section, the same procedure was followed with Marli's birth. After birth, Marli was placed in an incubator for about one hour. As reported by her father, her birth weight was normal. No feeding problems were reported and she was bottle-fed from birth up to the age of 24 months. Marli sat, crawled and stood up earlier than what is normally expected. She started walking at the normal age of 12 to 14 months. Marli was toilet trained during the day before she was two years old, and at nights between the ages of 2 to 3 years. Her farther reported her general health to be good.

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4.2.3.2   Language and Speech

Marli's general language development was reported to be good. She used her first words at the age of seven months and used three-word sentences before age 2 years. She has a great interest in stories, but her ability to retell a story was reported to be poor.

4.2.3.3   Emotional and Social

According to the categories of the anamnesis (see Appendix I) recorded by her father, Marli has an exceptional need for pampering, but is reasonably independent. She has a considerable amount of self confidence. Marli plays imaginatively and has a good ability to play with her friends, as well as on her own.

4.2.3.4   Personality

Through underlining the applicable words on the anamnesis form (Appendix I), Marli's personality was described by her father through the following words: independent, easy to manage, attention seeking, untidy, selfish, domineering, enthusiastic, easily distracted, appreciative, loving, can take the lead, cheerful, humoristic, has sense of responsibility, spontaneous, acts with self control, has sympathy and is honest.

4.2.4   DISCIPLINE

According to her father, Marli generally accepts discipline well, but sometimes has difficulties understanding why her brother with Down syndrome does not get punished for the same things that she does. Her father says Marli accepts his discipline more easily than her mother's.

4.2.5 CONTACT WITH RESEARCHER

I met Marli for the first time during October 2000 when I went to the family's house to observe Marli's brother. Another tutor, as well as Jenny Buckle, were also present at this occasion. On this particular day, Marli was initially very excited about the fact that we were there. The reason for her excitement might have been attributed to several factors. In my mind, however, she was excited that there were unfamiliar visitors to the house. However, her mood soon started to change. She wanted to know why we were only interested in her brother, and why we were only asking questions about him. She engaged in behaviour which deliberately focussed the attention on her, for example dressing up in different clothes, modelling her outfits to us, asking us to brush her hair and asking us to stroke her back. Her mother commented that this "attention-seeking" was a frequent occurrence, and that they found it extremely difficult to handle. We (the visitors) were at the house for about 2½ hours before I, together with another tutor, left. Jenny Buckle stayed for a while longer. As we were leaving, Marli disappeared into her room. Her mother later stated that after we had left she came out of the room with a dummy in her mouth, crawling and acting like a baby. She asked to be picked up, and eventually fell asleep on her mother's lap.

The next time I saw Marli was in January 2001, when the intervention with her brother had already started. The first time, however, that we interacted and I had the opportunity to observe her behaviour, was the day on which I did the clinical evaluation (1 February 2001).

As part of the original agreement with the parents, they received feedback on the findings of the evaluation. The purpose of this was to give them the opportunity to make a decision on possible emotional support for Marli. On the day of feedback, the parents indicated that they continually found it difficult to cope with Marli's "attention-seeking" behaviour. They accepted the suggestion that one of the tutors working with her brother, would come to work with her once a week. The information gathered from these sessions could then be used as part of the data for the research. Because of several practical difficulties however, this intervention only started in June 2001.

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4.3 EMERGENCE OF THEMES

4.3.1 CLINICAL EVALUATION

Marli's age at the time of the evaluation was 5 years 8 months. On this specific day, I administered the JSAIS, DAP, KFD, Rotter Incomplete Sentences and Rorschach test. It should be noted that the interpretations which are recorded here, are time and event specific. I am therefore giving an interpretation of observations made on 1 February 2001.

4.3.1.1 Intellectual evaluation

Throughout the evaluation it seemed that Marli was very aware of the camera and the fact that a recording was made. It seemed that she **wanted to behave in the correct way**, but at the same time liked the idea of being filmed. She asked me whether her parents would be watching the tape and be able to hear what she said. She also seemed a little **anxious,** which was evident by the constant wringing of her hands and touching of her hair. It was also very difficult to keep Marli's **attention focussed.** We had to take frequent breaks and she stated that she felt a little tired. The fact that the evaluation took place on a Friday afternoon as well as the number of subtests that were administered, could well have had an influence on her performance. She communicated well and it was easy to make contact with her.

One possibility is that Marli's anxiety causes her to feel as if she is not in control of her environment. Her pleasing behaviour during this incident may indicate that she tries to regain this control.

Evaluating Marli's performance on this day, I determined that she functioned at an average cognitive level (see Appendix H). Quantitative analysis indicated a significant difference (15 marks) between her performance on the Verbal (high average) and the Non-Verbal (average) scales. On the Verbal scale, the subtest Story Memory

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was significantly below her own performance average, as well as the universal average. Word Association was higher than her own average and the universal average. On the Non-verbal scale, the subtest Form Board was higher than her own average and the universal average, while the subtest Block Designs was lower than her own average, as well as the universal average.

Qualitative observations indicated that she probably struggles with paying attention (Block Designs, Story Memory), and that her auditive memory may be better developed than her visual memory. From the Vocabulary subtest it can be deduced that Marli may have slight language confusion, as she continually asked for the English version of a word before being able to indicate the meaning (even though she is Afrikaans speaking). Her good performance in the Form Board subtest could be an indication of a well developed visual organisational ability, and comprehension of part-whole relationships (Madge, 1981:19). Her performance in the Word Association subtest might indicate that her ability to think rationally in terms of visual stimuli is well developed for her age (Madge, 1981:29).

4.3.1.2 *Projective techniques*

i) *Draw-A-Person Test* (Appendix A)

I told Marli that she had to draw a person on the paper provided. I said to her that it can be any person and that she could turn the paper which ever way she liked to. Marli responded by drawing a girl. When prompted, she stated that it was a picture of herself and that she was five years old. I asked her to indicate three wishes that she might have. She responded with the following: to play in the dollhouse, to swing on ropes and to read books.

The figure which Marli drew was quite big and tall, with extended legs. According to Klepsch and Logie (1982:43), this could be an indication of **aggression** whereas Peterson and Hardin (1997:140) state that it can indicate a person seeing themselves as either **powerful** or **wanting more power.** She also shaded the baseline of the page which could suggest feelings of **insecurity** (Schoeman & Van

der Merwe, 1996:142). A possible indication of **anxiety, sadness or depression** came from the clouds drawn at the top of the page (Peterson & Hardin, 1997:138). It is further hypothesised that the spontaneous addition of clouds to a drawing indicates that she **might feel threatened** by the adult world (Koppitz, 1968). A further indication of possible feelings of anxiety, is the transparency of the arms and the colouring of the body. There is however a very small sun drawn into the picture which indicates that Marli might also experience **love and support**.

ii)   ***Kinetic Family Drawing*** (Appendix B)

Marli was asked to draw a picture of her family while they were engaging in an activity. She described herself as handing the food to her dad, while he was doing grocery shopping. Her mother was looking after her brother because he was trying to run away. In this picture there were not only clouds, but it was also raining. This, again, was a possible indicator of **anxiety and threat** from the adult world, or possible feelings of **sadness**. It was interesting for me that her brother was the only one who was not standing under the clouds and rain, almost as if he was standing outside the threat, or was not affected by it. A further point of interest was that the father was drawn so differently to the other members of the family, and that he was wearing what looks like a skirt. In my opinion this could suggest **uncertainties about the father's role in the family and her experience of him**. The fact that both Marli and her father were busy with food, made me wonder if that was connected to the idea of **nurturence**, and that the two of them might have taken on the role of being the members in the family who nurtured the others. The fact that her mother was looking after her brother who wanted to run away could suggest that she might have experienced her **mother as worried** about her brother, and also very **involved** in him and his doings. In this picture Marli's father was the only person who was drawn with hands and feet. Peterson and Hardin (1997:137) indicate that the omission of hands can indicate a **lack of control** and possible feelings of **helplessness**.

From the above two projective techniques, I view the most dominant themes to be that of anxiety, a need for control and sadness.

iii)   ***Rotter Incomplete Sentences*** (Appendix C)

Marli was given 12 incomplete sentences and asked to complete them by telling me what comes to her mind. Because she has not learned to write as yet, I read the sentences out and recorded her responses in written form. Not all the answers she gave revealed information about her emotional experiences and functioning, but I will point out those which were, in my opinion, significant for this study. Seeing that Marli is Afrikaans speaking, the sentence completion was conducted in Afrikaans.

Niemand weet dat ... "ek mag my privaat sien nie".
(Nobody knows that ... I may see my privates.)

Die ergste ding wat ooit met my gebeur het was ..."dat ek seerkry; dat ek nie my privaat mag wys nie".
(The worst thing that ever happened to me was... that I hurt; that I may not show my privates.)

From this information it seemed that Marli might have been **worried about or experienced problems surrounding her sexuality**. Her parents mentioned that Marli learned about sexual molestation at school shortly before this evaluation. Her mother was also discussing these issues with her.

iv)   ***Rorschach Inkblot Test*** (Appendix D)

For the purpose of this test, I showed her ten cards each with a different inkblot picture (Kaplan & Sacuzzo, 1997:439), and asked the following questions while showing each of them:

a)   What does the picture depict?
b)   What is it doing?
c)   How does it make you feel?

From this technique I gained information about her experience of authority, sexuality, reality, interpersonality, self-concept, her mother, affect and emotions (see 3.3.2.2). Again, I will only refer to those which, in my opinion, revealed significant information for the purpose of this study.

When looking at card (III), Marli said that it was 'grillerig' (creepy). Her first reaction was to refer to the picture as humans washing clothes. However, she then changed her mind and said that it was pictures hanging from the wall. According to Klopfer *et al.* (1954:392), being unable to perceive the human figures in this card, lead to the hypothesis that they are unable to accept or identify with others. In my opinion, in the case of Marli it could be that she does **not feel very comfortable with, or that she's unable to assert herself in,** certain interpersonal relations. From a developmental perspective it could be explained that she has not, as yet, mastered the task of autonomy vs. shame and doubt (see table 2.2), possibly, leading to feelings of insecurity.

In reaction to card (IV), Marli at first indicated that it was a butterfly and then referred to it as a giant. She changed her mind again, however, and said that it was a girl giant who is stamping her feet. Klopfer *et al.* (1954:393) states that this card indicates characteristics usually associated with the concept of father or authority. In my opinion Marli's response supports earlier assumptions (see KFD) and points to uncertainties regarding her experience of her father or the authority figures in her life. In referring to it as a girl giant, I wonder whether she might see herself, to some extent, as being an authority figure in the family, which could make her feel **insecure and anxious**. It could also be linked to her **possible need to assert herself** (as indicated in card III). It is possible that this assertiveness has become a tool she uses, especially in relating to her father.

Card (VI) is particularly characterised by the frequency with which sexual associations are made to it (Klopfer *et al.*, 1954:395). Marli indicated that this was a giraffe who was hurt because someone has stepped on his foot. This giraffe allows people to play with him. This supported the assumption that Marli might feel **worried or experience insecurities and possible hurt** surrounding **sexual issues** (see Rotter Incomplete Sentences).

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The mother affect card (VII) (Klopfer *et al.*, 1954:396) made Marli experience a feeling which is "nie lekker nie" (not nice). She referred to the picture as "Pappa en Mamma wil soen" (Mum and Dad want to kiss). "Mum has a baby in her tummy, they decide to part and then decide to stay." This card possibly suggested that Marli might have experienced **uncertainties,** and may have felt that there were ambiguous feelings in the household regarding the **idea of having children or having a specific child**. Through my interaction, observation of the family it was indicated on several occasions, and also stated by Marli's mother, that neither of the pregnancies were easy. In Marli's case in particular, her mother experienced feelings of anxiety and stress attributed to the first born's disability, premature birth and repeated illnesses and hospitalisation throughout his early developmental stages. She was also worried that she might loose her second baby due to bleeding and the disintegration of the placenta during the early stages of the pregnancy. Viewing this from an ecosystemic perspective, it could be possible that her mother's feelings were experienced by Marli as an unborn baby, as well as a young child (Louw, 1990:144-145). The feelings experienced within the individual system of the mother could affect the way that Marli experiences herself in relation to her mother, as well effect the meaning she creates from these experiences. This could then lead to Marli experiencing similar feelings to her mother.

4.3.2 QUESTIONNAIRES

4.3.2.1 *Questionnaire to teacher* (Appendix E)

This questionnaire was sent to Marli's class teacher with a cover letter explaining its purpose. It was completed in March 2001, approximately two months into the project. The questionnaire completed by the teacher did not reveal much information regarding Marli's experiences of the intervention with her brother. The teacher did, however, indicate that Marli sometimes engages in **attention-seeking** behaviour (no specific behaviours were indicated), but that this was not problematic in the school context. She also indicated that Marli was somewhat **sensitive to criticism** from her peers. Marli also tends to disturb others when seeking their attention and is **easily distracted** in the classroom.

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From an ecosystemic perspective, a child will behave in a way in which they perceive their needs to be met within the system. This may or may not coincide with how the other members in the system perceive their needs to be met (O'Connor & Ammen, 1997:5). Therefore, in order to understand a child's behaviour within a system, these authors point out that it should be seen from the child's perspective within his or her ecosystemic system. What the teacher terms "attention-seeking behaviour", can thus be interpreted as Marli's way of trying to fulfil a need. Marli's being sensitive to criticism of her peers can support the earlier assumption that she has a need to assert herself to a greater extent in interpersonal relationships (see 4.3.1.2).

4.3.2.2   Questionnaire to parents

Information from this questionnaire was used mainly to gain insight in Marli's general development and the details were integrated into the case contextualisation.

4.3.3 INTERVIEW WITH PARENTS (Appendix F)

The interview with the parents was semi-structured. They were asked to comment on specific aspects of Marli's general emotional and behavioural functioning. This interview was conducted in April 2001, when the project was already running for three months. The answers were recorded in written form. On the day of the interview, Marli's mother was not present so I conducted the interview with her father and left her mother a structured questionnaire (Appendix G) with similar headings used for the questioning in the interview. It should be kept in mind that the father's responses were spontaneous whereas Marli's mother might have had more time to reflect on her answers, and may also have discussed it with her husband. (The interview and questionnaire was in Afrikaans, but will be directly translated here.)

The question for all the items was: <u>Could you please describe/discuss the following regarding Marli, as completely as possible</u>?

Outbursts of anger

Father's response: With a reason or usually out of frustration. She refuses to talk when she does not get her way or when she is not the centre of attention. She is very particular about the equal treatment of her and her brother, and since the start of the project, her brother has increasingly become a threat and someone to compete with for attention. She sometimes acts like a baby in order to get attention.

Mother's response: She nags a lot.

Acceptance of authority

Father's response: She sometimes has difficulty with accepting authority and has to be given time-out in the bathroom.

Mother's response: Sometimes difficult.

During my personal engagement with the family, it seemed that there may be a general problem with discipline, structure and routine in the household. Both children are continually testing their boundaries and the parents seem to be finding it problematic treating the children equally in these circumstances.

Manipulation of authority

Father's response: She more regularly manipulates her mother's authority.

Mother's response: Not often.

Marli's father has, during a conversation on these issues, indicated to me that Marli regularly engages in unacceptable behaviour, which is then not regulated by her mother. He indicated that this was happening because Marli was manipulating her mother's emotions.

Perseverence

Father's response: Impatient
Mother's response: Good /Average

The following questions were also asked:

–   Has Marli's behaviour changed in any way since the start of the intervention with her brother?

Father's response: At school she continues as usual. At home it is more or less the same, she does seek more attention, though. She and her mother misunderstand each other, but that is not necessarily because of her brother. One way of seeking attention is by asking people to talk about her as well.
Mother's response: She does seek more attention. She is especially demanding when we have visitors, or when we go to visit friends and her brother is also present.

-      Are there any aspects of Marli's behaviour which, at this stage, worries you?

Father's response: No.
Mother's response: No. I think that the behaviour she exhibits is quite normal for her circumstances and age!

To me this answer came as quite a surprise because it was so contradictory to indications during general conversations with the parents. They had said that they find it continually difficult to consistently cope with Marli's attention-seeking behaviour. I was in doubt as to whether they really felt that it was "normal".

Information gained from the techniques discussed thus far, indicate possible feelings of anxiety, attention-seeking behaviour, sadness and insecurity. It can be assumed that her behaviour has worsened since the start of the intervention program, especially when studied in the light of her parents' comments. This might have been due to the fact that her brother receives special attention from his tutors, as

well as from her parents' involvement in the project. Because of this involvement, as well as her brother's progress and newly acquired skills, most of her parents' conversations with friends and relatives are dominated by this topic. She might experience his improved abilities to socialise and communicate as a threat, as well as a competition for her parents' and relatives' attention. If this was not the case, she would not have had the need to seek more attention. One way in which Marli seemingly seeks her parents' attention is to ask why they don't talk about her more often. She has also found different ways in which she tries to focus the attention on herself.

4.3.4 OBSERVATION AND VIDEO MATERIAL

Many of the observations of Marli were made during informal day-to-day interaction in my position as one of her brother's tutors. The more significant, formal observations were recorded during play therapy sessions with her. These sessions were conducted weekly or fortnightly during June, July and August 2001 and each contact session lasted about 45 (forty-five) minutes.

It was clear from my contact with Marli that she is a girl who loves her older brother dearly. She understands that he has Down syndrome and that he needs special intervention, but this causes ambivalent feelings. On one occasion she said that she wanted the Down syndrome to disappear. She indicated that she sometimes feels **angry** because people talk about her brother, look at his progress all the time and she feels that she does not get the chance to show people what she can do as well. She particularly experiences these feelings when people come to visit their house. Marli indicated that when she feels like this, she usually goes to her room and waits for the anger to go away. It helps, however, if her mum or dad comes to get her from her room or give her a little present. She indicated that the anger passes more quickly when she gets something nice to eat. This is probably because she experiences the treat as exclusive attention to her and her needs. Marli further indicated that she sometimes slams her bedroom door when she feels angry. Together with the anger, she also experiences a great amount of **sadness**. She indicated that she cries in her room and that she feels very sad in her heart.

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She stated that this happens every single day. The anger that Marli experiences can be directly related to the fact that her parents' attention has, in many ways, been taken away from her and redirected towards her brother. Through acting out, going to her room and slamming the door, she might be trying to regain this attention. This corresponds with other findings (see 4.3.2.1; 4.3.3).

I introduced Marli to a further activity in which she had the opportunity to express her emotions. We first identified possible emotions and she selected a colour to represent each of those feelings. After a process of elimination, Marli indicated that the two primary emotions she experienced were **anger** and **sadness**. Anger was associated with the colour pink, and sadness with the colour purple. I was curious as to which of the emotions was dominant and I asked her to show me. In response to this, she coloured an A4 piece of paper. She coloured about one eighth of the page with anger and all the rest she coloured with sadness. However, halfway through the colouring of the sadness, Marli mentioned that she made a mistake and that it should rather have been happiness. When I asked her to tell me more, she responded by asking me whether I am going to tell her mother about the sadness. I assured her that I would not. At this, she said that in that case the sadness should stay. I prompted Marli to tell me what her mother would say if she knew about the sadness. She said that her mother would be angry with her. This made me wonder whether Marli is possibly **trying to protect her mother's feelings**. One possible explanation could also be that her mother is not sure how to manage her daughter's emotions, and it is out of this inability that she reacts with anger. In turn, Marli **seeks recognition** and acts with inappropriate behaviour. A possible assumption is that her mother might feel sorry for her and this encourages Marli to respond with manipulative behaviour.

During another session, Marli was asked to make clay models of herself and her family. She made all the figures with arms stretched out, no hands and also no feet, apart from her dad. When asked about this, she said that she forgot to put shoes on her feet and then added this. Her mother and brother, however, she left without feet or shoes. According to Klepsch and Logie (1982:43-44), the omission of feet may suggest feelings of **helplessness** and **lack of security**. The omission

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of hands might also suggest lack of security and be a further possible indication of an **inability to handle the demands of the environment.** It is possible that Marli **perceives her mother and brother as** the people in family who are **helpless,** and that the family as a whole finds it difficult to cope with their circumstances. These indications were also found in the DAP (see 4.3.1.2). She further indicated that there was an invisible wall with herself and her father standing on the one side, while her mother is 'teaming up' with her brother on the other side. This might indicate that she experiences **her mother to be more involved with her brother.** This corroborates with an earlier indication (see 4.3.1.2:(ii)) that she may experience the family dynamics as that of herself and her father as the nurturers, and her mother and brother as the helpless ones.

On more than one occasion, Marli talked about her mother crying and how she (Marli) needs to then tell her father to **comfort her mother,** or in his absence, has to do it herself. She indicated that when her mother cries, it feels like her **own heart is breaking.** At the question of whether this happened often, she indicated that it does. These experiences might lead Marli to feel that she needs to look after her mother, and may unconsciously makes her **feel responsible for her mother's emotional well-being.** This might further reinforce the feelings of insecurity as she experiences her mother's emotional stress and helplessness, and added to this she does not have the available emotional skills to support her mother.

I have on occasions observed Marli taking advantage of these circumstances. It is possible that Marli knows that when she acts inappropriately or says something like "julle praat nooit oor my nie" (you never talk about me), her mother is going to feel guilty and immediately respond to her behaviour. Through this it she might deduce that **she can manipulate her mother's behaviour.**

Marli also told a story about a family. In the story the mother and father very much wanted a child and decided to go and look for one. As they were looking, they decided against it because if they were on their own, they could do things on their own like going out to dinner. She also told another story about a mother and father who decided to leave their children while they were sleeping. As they were leaving,

the mum and dad died. When the children woke up, the parents were gone and they remembered that their parents were dead. All of a sudden the children died as well and Marli said that someone shot them every time.

Viewing this ecosystemically, it could be said that Marli can sense the tremendous impact that the presence of her disabled brother has on her mother and father as individual systems, but also on the bigger family system. These feelings could also be interpreted from a developmental perspective. At the time when Marli had to learn to trust other people (basic trust vs. mistrust), her mother might have been overwhelmed by her disabled boy being very sick and in and out of the hospital. The basic task which Marli had to learn at this stage, was that of hope (see table 2.2). If she didn't master this, a possible consequence could be that she develops feelings of despair and hopelessness. The two aforementioned stories can be interpreted as such that Marli might feel that her parents' life would have been easier if they had not had this disabled child, and could consequently also wonder about how welcome her arrival in the family was. It may be that the possible homelessness makes her wonder about the meaning of life, and she could therefore come to the conclusion that it would be **better if they were all dead.**

Yet another story which she related was about how she went on holiday. Because I knew that the family and grandparents went together, I asked her about this. She responded by saying that no one went on this holiday with her, she was all by herself. She loved going on this holiday, because she could do whatever she wanted to. I wondered whether Marli might sometimes feel that she needs to "just get away" - that she **needs to be alone**, away from the family and the problems. This may also be the reason why she sometimes escapes into her room.

I have observed Marli in one situation where she was deliberately hitting, and hurting, her brother. The moment that she did this, she actually ran up to her mother and started complaining that he was hurting her. Her mother responded by scolding her brother. I could sense that he was upset and he started throwing around his mother's collection of miniature perfume bottles. Doing this, his mother gave him a hiding and reprimanded him and said that he should not be naughty.

He ran and hid behind his father's bedside table. Marli ran after him and started teasing and scolding him by repeating her mother's words of "jy's stout" (you are naughty). Her brother started crying and only after I went to him, did she stop her teasing.

This incident took place on a morning when I arrived to work with Marli's brother. It could be possible that, in my capacity as trainee educational psychologist, I was representing (in Marli's eyes) the reason why attention gets taken away from her. It could be that in this situation, where her mother was already angry with her brother, that Marli felt safe to express her feelings. She in a sense manipulated her mother's power in order to create a space to ventilate her possible feelings of **resentment**, **aggression** and **jealousy** towards her brother.

4.4 SUMMARY OF THEMES

In this section I will highlight those themes which were, in my opinion, dominant. In Chapter Two (see 2.2) I referred to how I took both a "simple cybernetics" (Becvar *et al.*, 1996:62) and "cybernetics of cybernetics" (Becvar *et al.*, 1996:75) approach in exploring the experiences of the sibling. I would like to again focus the reader's attention on the fact that the interpretations of the sibling's experience is my personal perception thereof. I also stated in Chapter One (see 1.4) how the interpretive research paradigm allows for this type of subjectivity when discussing certain phenomena.

It seems that Marli is part of a loving and supportive family who value her as an individual. She appears to be aware of this and to return this love. However, there are several indications in the discussed data of possible feelings of **anxiety** and **insecurity**. From an ecosystemic perspective this is demonstrative of the interrelations and interdependence of systems within systems, particularly in the dyadic relationship between Marli and her mother. I interpret her anxiety and insecurity in the family system as a manifestation of a possible problem in the

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mother-daughter relationship. As indicated earlier, Marli might observe her mother to at times be somewhat dependent on her for nurturence and comfort. This happens especially when her mother cries in her presence when her father is not at home. According to Lane and Swartz's (Brems, 1993:50) (see table 2.3) model of emotional development, Marli is currently in the stage of pre-operational thought. This means that she has a limited experience of emotion and can link only one affect to one specific situation. Marli might not be mature enough to manage her mother's feelings, because she does not understand, in all probability, the wide range thereof.

As an individual system, Marli knows which actions are necessary in order to get her needs met. Some of the ways in which she tries to regain power and control, is by **attention-seeking** behaviours and manipulating her mother's authority. However, this just serves to lead to increased feelings of insecurity.

It seems that Marli loves her brother dearly. At this stage of development, however, she might not be able to understand the importance of the intervention, or why the topic of conversation in the house mostly concentrates on him. This makes her feel **angry and sad,** and serves to support her perception that her needs are not fulfilled. It is possible that the only way through which she can ventilate these feelings, and get her needs met, is by being **aggressive** and **resentful** towards him. Through these behaviours she quickly becomes the centre of attention, which reduces her possible anxiety.

4.5   CHAPTER SUMMARY

In this chapter I attempted to interpret and discuss the lived experiences of a sibling. I carefully reviewed all the available data in order to discuss the themes which emerged. While interpreting the data, I attempted to link my interpretations with the ecosystemic framework, as well as the developmental models outlined in Chapter Two. My interpretations of the data were subjective, and based on my perceptions of how the family system functions. I interpreted the sibling's actions by building on my previous experience in working with children and families where I have seen similar behaviour.   My personal frame of reference therefore shaped the interpretations. The methods I used in order to verify the data, were discussed in Chapter Three.

CHAPTER FIVE

SUMMARY AND OPENING POSSIBILITIES FOR FURTHER RESEARCH

5.1 INTRODUCTION

This study focussed on the lived experiences of the sibling (sister) of a boy with Down syndrome and Autistic Spectrum Disorder (DS/ASD). The disabled boy was involved in a research project initiated and coordinated by the Department of Educational Psychology of the University of Stellenbosch. During this project the effect of an Applied Behaviour Analysis intervention program on the functioning of children with DS/ASD, was evaluated. Because of the extensive effect of the project on the functioning and activities of the families involved, the issue arose as to how this intervention will effect the non-disabled sibling in one of these families.

The specific aim of this study was, therefore, to gain insight into the lived experiences of a sibling while an Applied Behaviour Analysis program was followed with her brother who has been diagnosed with DS/ASD.

In this chapter, the implications of the research findings will be provided. I will attempt to systematise the findings, and will also pay attention to the limitations and recommendations which arise.

5.2   SUMMARY

As an introduction, **Chapter One** provided a brief overview of the motivation for undertaking this study.   My involvement was as trainee educational psychologist implementing an intervention program, and it was in this capacity that I worked from an ecosystemic framework.   I outlined my interest and concern for siblings, which had developed from this involvement, as well as my dual role as both researcher and therapist in a particular context.   I formulated the problem statement of the study in conjunction with focussing on clarifying some key concepts.   A further focus of this chapter was to provide information regarding the research paradigm.   I discussed interpretivism as it developed from phenomenology in an attempt to move away from a traditional positivist research approach.   It was also indicated that, because of this approach's concern with the lifeworld and everyday lived experiences, it was a suitable framework from which this particular study could be conducted.   The interpretivist research paradigm also allowed for subjective interpretations of data and the influence of the researcher's own experiences and world views on these interpretations, further indicating the appropriateness of this approach to the current study.

Chapter Two focussed on elaborating and further exploring the terminology and concepts which were at the basis of this study.   I discussed the ecosystemic approach and its operationalisation in this particular study through paying attention to the concepts of ecological thinking (Keeney & Sprenkle, 1982:9), systems theory (O'Conner & Ammen, 1997:ix) and cybernetics (Freedman *et al.*, 1996:3).   I pointed out that the intervention with children with DS/ASD will not only affect the particular individuals involved, but also has an influence on the whole family system.

This chapter was continued by looking at the disorders of Autism and Down syndrome.   Because of the fact that little research on the concomitance of these two disorders was available, they were initially discussed separately.   Attention was given to historical development, prevalence, possible causes and treatment programs.

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Research available on the concomitance of these two disorders was then discussed, while also referring to aspects of incidence and diagnosis, causes and treatment. It was stressed that diagnosis of the concomitance was difficult, due to the contradiction between the typical Down syndrome and Autistic Spectrum Disorder personalities. However, once the diagnosis was made, ASD was generally seen as the primary disorder. Even though the exact cause of the concomitance was not known, speculations about possibilities such as neurobiological factors and obstetric complications were generally found in research documents (Gillberg & Coleman, 2000:141). Regarding treatment programs, professionals agreed that knowledge about the exact cause was less important than early intervention. Increased knowledge about the concomitance of these disorders will enhance the possibility of early diagnosis as well as determining the best possible intervention. I then discussed the specific intervention strategy of Applied Behaviour Analysis, which has shown positive research results with children who have ASD (Lovaas, 1987:7).

I highlighted the effect that the presence of a child with a disability has on the family, as well as the non-disabled sibling. I indicated that a child with a disability might influence the family and siblings positively and/or negatively, therefore creating concerns as well as opportunities (Russel, 1997:3). The individual characteristics of the family, siblings, as well as of the disabled child, will generally influence the severity of the impact. Finally, in order to interpret the sibling's experiences, I provided a general childhood psychosocial and emotional developmental framework.

Chapter Three focussed on providing information regarding the method of inquiry. I pointed to the qualitative case study approach as a successful means for exploring this study. A variety of techniques used in the production of the data, such as questionnaires, interviews, video material and observation were discussed. I also indicated how the produced data was verified in order to meet the criteria of credibility, transferability, dependability and confirmability. Lastly, the ethical issues of the study were discussed.

In **Chapter Four** the data produced from the qualitative case study was analysed and interpreted. The context of the case involved was provided in order to sketch the developmental, social and emotional background against which the data was interpreted. The data was then analysed and interpreted through focussing on the general themes which emerged. A variety of themes and emotions became evident when analysing the data. In an attempt to interpret and attach meaning to these emotions, the most common themes which emerged could be reduced to: **anxiety, insecurity, anger, sadness, resentment and attention seeking.** I indicated how these themes should be interpreted against the background of the ecosystemic ans developmental models discussed in Chapter Two.

5.3 LIMITATIONS OF STUDY

The following could be viewed as limitations of this study:

–   With a qualitative study, and in particular a case study, the findings cannot be generalised to the population. This study, however, provided useful insight into the possible lived experiences of a non-disabled sibling during a specific intervention program.

–   Several factors in the sibling's family environment influenced her experiences during the intervention program. The most probable of these were embedded in the quality of the mother-child relationship and the mother's emotional well-being. Even though all of these factors were interrelated and may have lead to specific experiences, from an ecosystemic approach the interactions should be viewed circularly rather than linearly (Barker, 1998:28). The behaviour and experiences of the sibling could be seen as part of a circular process occurring within the family system, rather than being caused linearly by a single event, such as the intervention program with her brother. According to the information gathered from the sibling at the initial clinical evaluation, it could be assumed that a certain amount of emotional distress was present at

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the onset of the intervention with her brother. Some of the feelings experienced could therefore have been "carried in" from previous situations and events. Because all the feelings were essentially related, I did at some points find it difficult to make a clear distinction between them. The feelings and experiences reported in this study are, thus, not necessarily due to the ABA intervention program.

5.4 IMPLICATIONS AND RECOMMENDATIONS

The findings of this study relates to results from previous research (Russel, 1997; Donelly, 1991; Turk, 1991) regarding the effects that the presence of a child with a disability has on family life, as well as on the emotions of the non-disabled siblings. A variety of negative emotions were reported, such as: resentment, anxiety, anger, sadness, responsibility for inferred psychological needs of parents, aggression, insecurity, helplessness and threat. Through the experiences of the sibling, it was clear in many ways that the emotional well-being of the parents (more specifically the mother) seemed to play an important role in the types of feelings experienced by the non-disabled sibling.

Both from the perspective of researcher and trainee educational psychologist, it became increasingly clear to me that more attention should be paid to meeting the needs of parents of children with disabilities. During an intensive intervention program such as ABA, extreme pressures are placed on the whole family system. However, if the mother had been specifically supported to cope with personal stressors and, more importantly, to handle the ambivalent feelings her non-disabled child was possibly experiencing, the child's needs might have been met in a way that does not interfere with the needs of the other people in the family (O'Conner *et al.*, 1997:10). The unpleasant experiences during this intervention program could have been decreased or reframed.

In my view, it is extremely important that parents should be equipped with the skills necessary to handle their childrens' behaviour and to be supported emotionally even before such an intervention program is initiated. In conjunction with this, continued professional support to the non-disabled sibling, so as to process negative feelings, should also form part of an intervention program. In the case where an intervention program such as Applied Behaviour Analysis is implemented, the importance of parental emotional support should be prioritised, so as to provide a safe and stable environment in which siblings can express their feelings.

I view this study, and its findings, as an illustration of how the feelings and behaviours of every member of a system impacts on the family system as a whole (Barker, 1998:29; O' Connor *et al.*, 1997:11). When ensuring that the needs of the parents are met, it could be assumed that this will provide an environment in which children can have their needs fulfilled, in concordance with the developmental stages suggested.

5.5 CONCLUSION

This study has demonstrated that being a sibling of a child with a disability could provide challenging childhood experiences. These experiences could be viewed as opportunities and be reframed toward enhancing the psychosocial development of the learner.

During specific, intensive intervention with the disabled child in the family, the possible unpleasant experiences of the non-disabled sibling seemed to be further enhanced. Parents may need to be supported in understanding their non-disabled child's behaviour. When they understand what the behaviour is really about, and have the skills needed to manage the behaviour appropriately, they may help to enhance holistic development. However, in order to be able to support their child, the parents' emotional well-being is crucial. If this is not the case, the different

systems within the family seem to compete to get their needs met. When this happens, the family seems to get trapped in negative cycles, in which needs are inadequately communicated. In this process, it becomes difficult to cope with, and to positively reframe the non-disabled sibling's feelings and experiences.

As a trainee psychologist and researcher involved in this project, I too needed to reframe many experiences in order to view them positively. I travelled a long distance every day in order to support the learner with DS/ASD. Also, doing the ABA intervention program required intensive work and much motivation. In this process, I had the opportunity to reflect on my personal strengths and weaknesses. My dual role in the family at times made it difficult to know how to react to parents' comments and questions. In this regard, the research provided me with an incredible opportunity to develop my professional skills.

I am grateful for the privilege I had to be a part of this research project.

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CASE RECORD
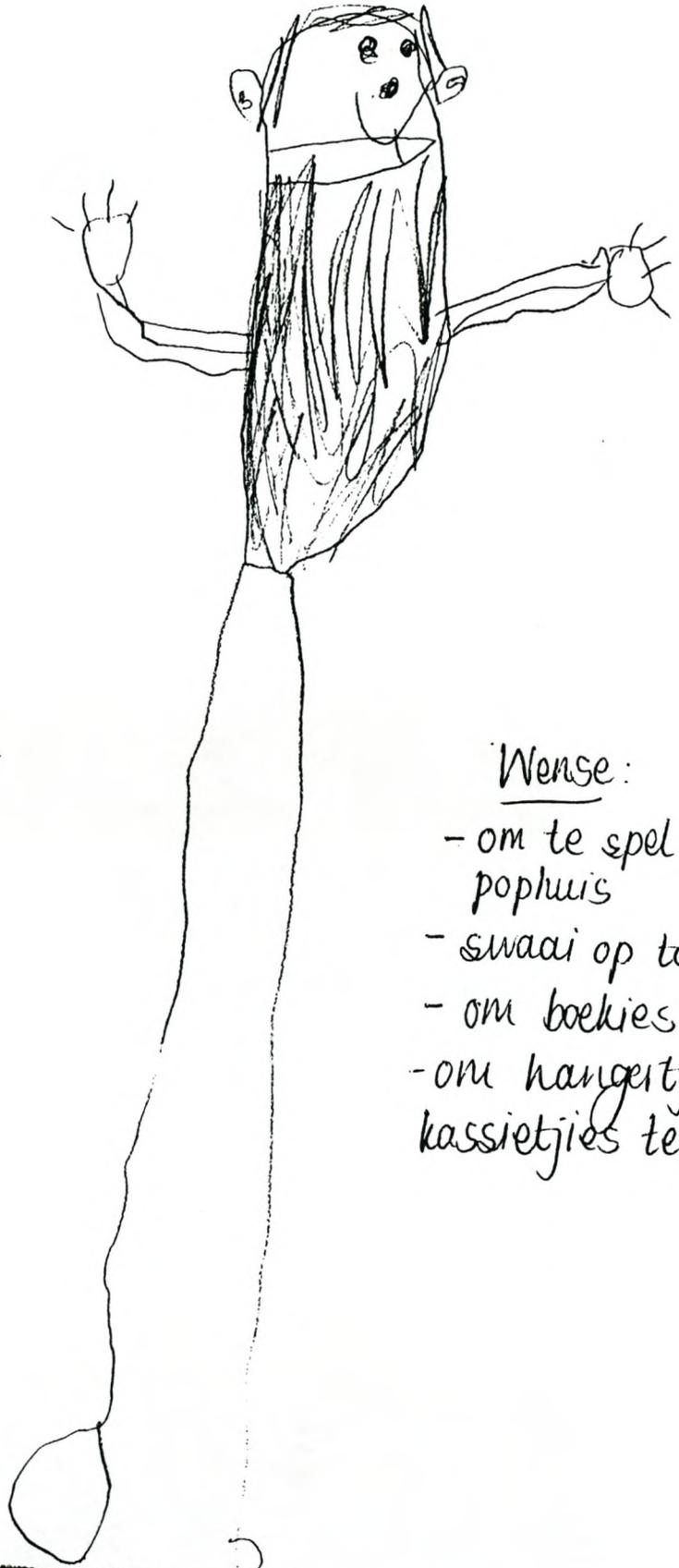
Wie het jy geteken?
Dit is ek.

Hoe oud is jy hier?
5 jaar

Wense:
- om te spel met pophuis
- swaai op toue
- om boekies te lees
- om hangertjies en kassietjies te hê

Pappa koop kos
Mamma pas boetie op
Ek gee kos aan
boetie wil weghardloop

Pappa

Mamma

Ek
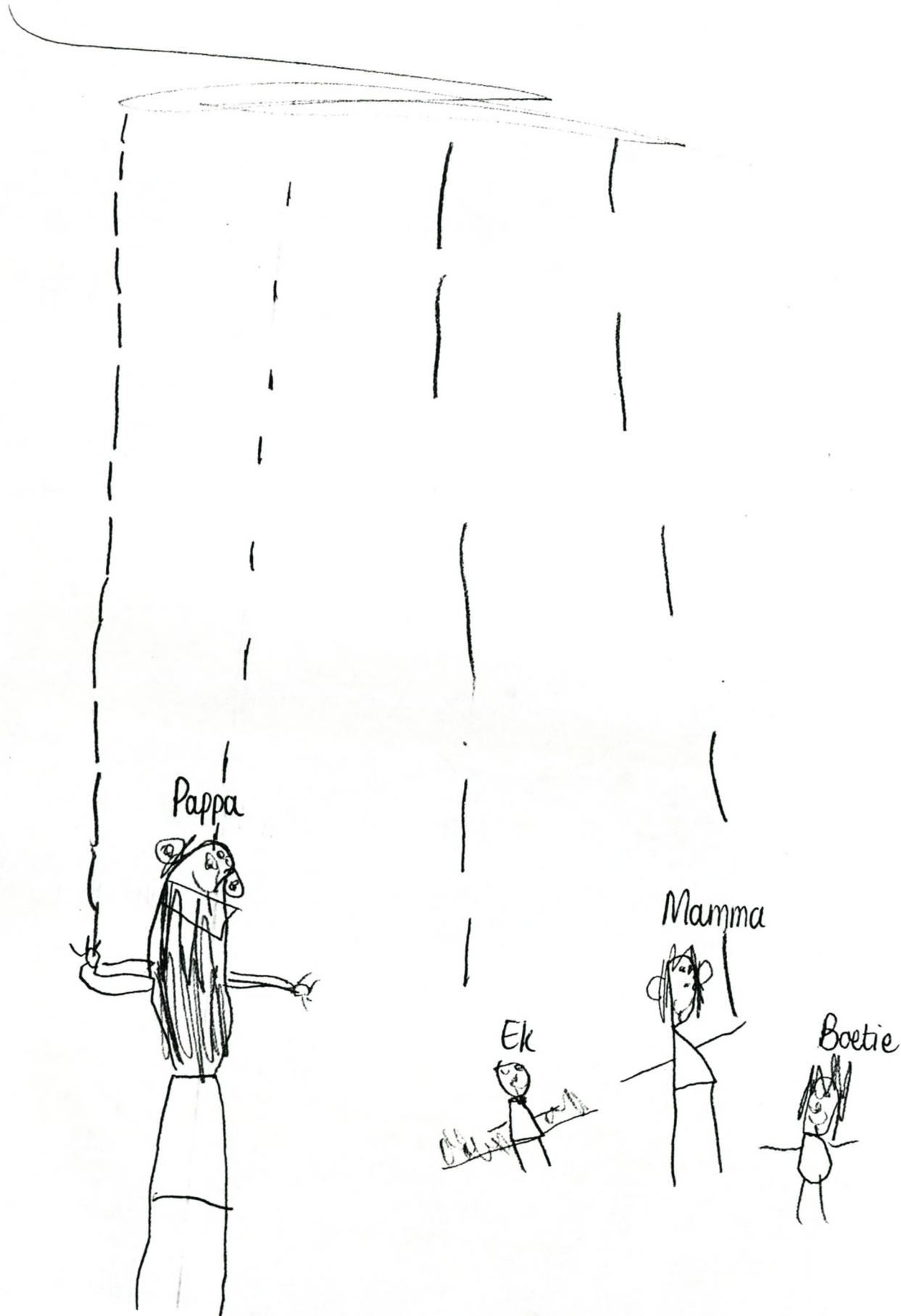
Boetie

JUNIOR ROTTER

Ek hou van _my pophuis en boeke._

Ek is bekommerd oor _boetie was amper dood. Dit was sad._

My ma _moet altyd vir my troos as ek huil. Ek huil oor boetie amper dood en ek op die hondjie trap._

By die huis _ek speel met die computer._

Niemand weet dat _ek mag my privaat sien nie._

My pa _werk vir ons as ek gespeel het ruim hy op._

Die ergste ding wat ooit met my gebeur het was _dat ek seerkry dat ek nie my privaat mag wys nie._

Ek word baie kwaad as _iets met my gebeur as ek huil of as mense nie wil hê ek moet TV kyk nie_

Dit maak my bly as _niemand met my raas nie ek my_

dinge kan doen.

My vriende _hulle speel met my; raas nie met my_

nie. Hulle speel as ek so sê.

Dit maak my hartseer as _hulle met my raas. As iets met_

my gebeur. Ek mag nie speel of inkleur nie.

Die gelukkigste tyd is _dat ek speel met iemand en_

alles kan doen saam met hulle.

NAAM _Marli_   DATUM _01·02·2001_   TOETSAFNEMER _R. Ligthart_

|	
	butterfly – lyk soos een hy vlieg weg van ons ; hy kan nie spee, nie lekker
	dis nog 'n butterfly hy sit Ons wil met hom speel, hy sal "ja" sê
	dit lyk soos 'n man met 'n strikkie en potte ; nee dis prentjies wat hang hulle was klere dis grilleng
	dis 'n skoenlapper ; nee 'n reus stamp voete ; nee dis 'n dogtertjie – reu. wat sit voel bangeng
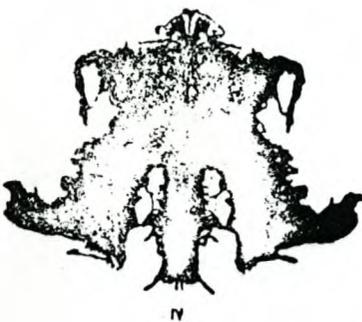
'n skoenlapper met bumpers op hom; dis
'n seuntjie skoenlapper

hy vlieg

hy's mooi ; ons wil met hom speel
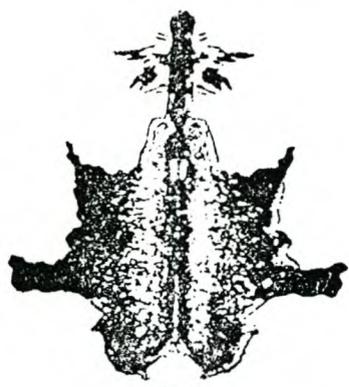
'n groot giraffe

hy skree dat hy seergekry het ; iemand
het op sy voet getrap

laat toe dat ons met hom speel

---

pappa en mamma wil soen; het baba
in haar maag; hulle loop weg van
mekaar en besluit om te bly

dis nie lekker nie
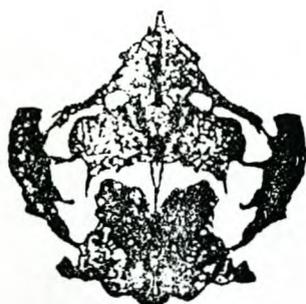
'n skoenlapper ; 'n boom wat molle
opklim — hulle is onder die grond

dis nie speleng nie
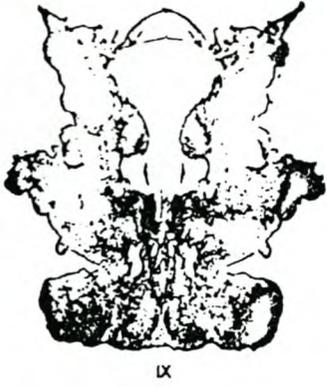
'n boom

niks klim op nie; of dis iets wat sit op
'n stoel; leeue wat speel met mekaar.

ons wil hulle uitlos anders gaan hulle
ons doodmaak.
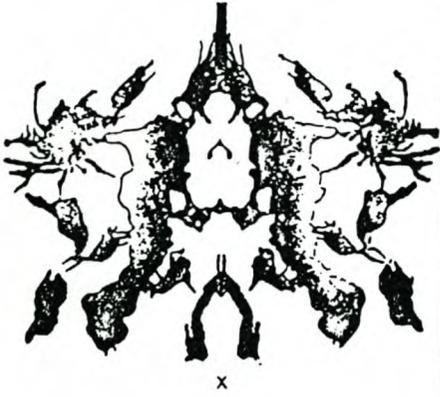
ek weet wat dit is; Pappa het 'n necklac
hy is 'n king; nee dis 'n dogtertjie, sy
'n bra aan, ons kan dit sien
sy's kaal, sy wil gaan swem; dis 'n
dogtertjie niuis
ons wil mamma kwaad maak, maar ons
wil ook nie.

OPSOMMING

mooiste kaart X
lelikste kaart IV

hou meeste van kaart VII
hou minste van kaart VIII

QUESTIONNAIRE FOR TEACHERS
(TO BE COMPLETED BY THE CLASS TEACHER)

Student name: _____

Grade: _____ Gr. R. _____

Date: _____ 15 Maart 2001 _____

Please answer the questions that follow by circling the appropriate

number: eg. 0   1   (2)

SCORING KEY	
0 - Not a problem	2 - Frequently a problem
1 - Sometimes a problem	

In addition to structured items, you are kindly requested to also complete the sections "other" and make specific comments regarding chosen items

A. PHYSICAL AREAS

	Not	Sometimes	Frequently
1. Physical complaints eg. headache, nausea	0	(1)	2
2. Fatigue or loss of energy	(0)	1	2

Other physical problems:

_____

_____

Specific comments on any of the above:

_____ is 'n lewendige, energieke

dogtertjie. Sy het al van hoofpyn

gekla & was dan net 'n bietjie

lê. Sy is baie energiek & vit

nie lank stil nie.

B. ACTING OUT

	Not	Sometimes	Frequently
1. Cheating	(0)	1	2
2. Seeks attention	0	(1)	2
3. Aggression	(0)	1	2
4. Disturbs others	0	(1)	2
5. Tantrums	(0)	1	2
6. Sudden outbursts	(0)	1	2

Other acting out behaviour:

_____

_____

Specific comments on any of the above:

Sy is lief vir gesels è dan kan
sy soms haar maats se dandag
aflei. Sy is 'n liefdevolle dogtertjie
è hou daarvan om aandag
te kry. Wat aggressie betref; sy
sal haarself verdedig as iemand
haar seermaak, maar ek sal nie
sê sy is aggressief nie.

C. DEFENSIVE / WITHDRAWN BEHAVIOUR

		Not	*Sometimes*	*Frequently*
1	Leaves group or class (walks out)	(0)	1	2
2	Cannot work alone	(0)	1	2
3	Distorts the truth (lies, exaggeration)	(0)	1	2
4	Draws into a shell	(0)	1	2
5	Needs constant approval	(0)	1	2
6	Sensitive to criticism	0	(1)	2
7.	Difficulty with expressive language	(0)	1	2

Other defensive / withdrawn behaviour:

_____

_____

Specific comments on any of the above:

Sy hou niks daarvan as iemand

vir haar lag as sy bv. geval

ε seergekry het nie.

_____

_____

_____

D. SOCIAL SKILLS

	Not	Sometimes	Frequently
1. Blames others	(0)	1	2
2. Prefers adult association to peers	(0)	1	2
3. Changes in friendship patterns	0	(1)	2
4. Appears depressed	(0)	1	2
5. Appears anxious or fearful	(0)	1	2
6. Poor self-concept	(0)	1	2
7. Frequent mood swings	(0)	1	2
8. Prefers to be alone	(0)	1	2
9. Prefers younger companions	(0)	1	2

Other problems with social skills:

—_____

_____

Specific comments on any of the above:

Sy is 'n baie gewilde dogtertjie

so die een dag speel sy met

'n groep maatjies ε die volgende

met 'n ander. Sy het nie 'n

probleem om met enige maats

te skakel nie.

E.   ACADEMIC PERFORMANCE

	Not	Sometimes	Frequently
1. Completing assignments in class	(0)	1	2
2. Completing homework	(0)	1	2
3. Requires additional time for assignments	(0)	1	2
4. Difficult to motivate	(0)	1	2
5. Rushes through work	(0)	1	2
6. Overreacts to corrections	(0)	1	2
✳ 7. Easily distracted	0	1	2
8. Requires constant reminders	(0)	1	2

Other problems with academic performance:

_____

_____

Specific comments on any of the above:

* Sy is lief vir gesels, so sy sal
maklik dit ё gesels op die mat
of terwyl sy werk. Dan het sy
elts weer aanmoediging nodig om
haar by haar werk of by my
te fokus.

F. PERSONALITY

Please underline <u>all</u> appropriate personality traits as they are
demonstrated by ` ` in the classroom / at school.

1.   *Is* ` ` : moody / rebellious / shy / independent / solitary /
inclined to jealously / careless / obedient / <u>easy to manage</u> /
exceptionally <u>tidy</u> / untidy / daydreamer / selfish / domineering *to some*
<u>active</u> / quiet / <u>enthusiastic</u> /<u>loving</u> / <u>can take the lead</u> / <u>cheerful</u> /
humoristic / sense of responsibility / spontaneous / sympathetic /
<u>honest</u> / acts with self-control / manipulative

2.   *Any other outstanding personality traits*

_____

_____

_____

_____

_____

_____

VRAE AAN OUERS

Naam van kind: Marli
Geboortedatum: 29·05·1995
Vandag se datum: 23·04·2001

Kan u asseblief die volgende aspekte rakende   se emosionele funksionering so volledig as moontlik aan my beskryf/ verduidelik?

1. Selfvertroue – Baie in sekere gevalle, min in ander. Tussen maats en in bekende situasies is sy OK. Onseker in onbekende situasies. Oor die algemeen 'goed'.

2. Algemene gevoelsaard
Opgewek, tevrede. Sy's soms selfsugtig. Kan leiding gee, ook by die huis.

3. Selfstandigheid
Onafhanklik

4. Slaaproetine
Nie eintlik problematies nie. Haar ma is soms meer toegeeflik.

5. Eetgewoontes
Sy eet goed en gesond. Sy's mal oor vrugte en groente.

6. Spel
Verbeeldingryk. Sy kan ook saam met ander speel.

7. Konsentrasie
Kan goed aandag gee.

8. Woedeuitbarstings

Met rede, gewoonlik frustrasie. Sy kry stilstuipes as sy nie haar sin kry nie of die "centre of attention" is nie. Sy gest op gelyke behandeling. Sien boetie as kompetisie/bedreiging.

9. Spanningsgewoontes

Nie regtig nie.
Bietjie bang vir donker.

10. Uitdrukking van emosies

Was nog altyd moeilik.

11. Vrese

Niks

12. Ervaring van traumatiese gebeure

Haar boetie het weggeraak en sy was baie angstig

13. Verhouding met portuurgroep

Baie goed. Sy's baie gewild.

14. Verhouding met volwassenes

Baie goed met mense wat sy goed ken

15. Gesagsaanvaarding

Soms moeilik. Sy word dan in die badkamer gesit.

16. Manipulasie van gesag

Manipuleer haar ma meer gereeld.

17. Deursetting

Ongeduldig

18. Reaksies tot nuwe situasies

Goed.

19. Liggaamlikheid

Sy kan alles doen wat volgens ouderdom verwag word. Sy's besonder rats.

20. Het u kind se gedrag op enige manier verander sedert die aanvang van die projek? Wees asseblief baie spesifiek.

In die skool gaan sy aan soos gewoonlik. By die huis, redelik dieselfde. Sy soek wel meer aandag. Haar ma en sy vryf mekaar verkeerd op.

21. Is daar enige aspekte van u kind se gedrag waaroor u op hierdie stadium bekommerd voel?

Die manier waarop sy aandag soek. Sy vra gereeld "wanneer praat julle oor my".

VRAELYS AAN OUERS

Beskryf asseblief die volgende aangaande u kind so akkuraat as moontlik deur gepaste woord(e) te onderstreep.

1. Selfvertroue: heelwat /min /gemiddeld /kan leiding neem
   Kommentaar:

2. Algemene gevoelsaard: liefdevol /opgewek /teneergedruk /teruggetrokke
   spontaan /stil geaardheid /selfsugtig/ woelig/
   entoesiasties /maklik hanteerbaar /eerlik/
   oneerlik /hulpvaardig

   Kommentaar:

3. Selfstandigheid t.o.v. bad, aantrek, eet: onafhanklik /min of meer
   onafhanklik /baie afhanklik van ouers
   Kommentaar: As S   gebad word + hulle is saam i.d. bad
   wil sy ook gebad word; soms met ete ook; soms met aa   ool

4. Slaaproetine: kan alleen slaap /gaan slaap sonder enige probleme / —
   slaaploosheid /praat in slaap /slaap onrustig /nagmerries
   Kommentaar: Wil gonglig aanhê; moet stories lees + bietjie gesels, a
       S   nog wakker is, sal sy kom kyk of hy m ons
           kamer is en da

5. Eetgewoontes: goed /gemiddeld/ swak
   Kommentaar: kla.

6. Spel: verbeeldingryk /gemiddeld /het leiding nodig /verkies om alleen te
   speel /verkies om saam met maats te speel
   Kommentaar: Speel net so lekker op haar eie as saam met ma

7. Konsentrasie: agterlosig /maklik afleibaar /kan goed aandag gee /
   dagdromer ?
   Kommentaar: As sy iets doen waarvor sy baie hou of geniet dan is
   haar konsentrasie baie goed. Bv. as sy in die poppe klas
   gee + verbeeldingryke spektjies spe

8. Woedeuitbarstings: gereeld /soms /nooit
   Kommentaar: Kan baie "nag"

9. Spanningsgewoontes: byt naels/ suig duim/ skrik maklik/ lyk gespanne
   Kommentaar: mê + var bogenoemde mê. Verkies om mê alleen te
   wees mê. Wil versekering hê dat ons in die aanbrek is.

10. Uitdrukking van emosies: geneig om jaloers te wees /kan met selfbeheersing optree /kan simpatie hê / opstandig /baasspelerig /waardeer mooi dinge /aandagsoekerig /wisselende emosies / besondere behoefte aan vertroeteling
Kommentaar:

11. Vrese: donker /om alleen te wees/ dat iets met ouers of self sal gebeur
Kommentaar:

12. Ervaring van traumatiese gebeure: fisies /emosioneel /seksueel
Kommentaar: ∫   *wat weggeraak het.*

13. Verhouding met portuurgroep: goed /gemiddeld /swak
Kommentaar:

14. Verhouding met volwassenes: goed /gemiddeld /swak
Kommentaar:

15. Gesagsaanvaarding: goed /swak /soms moelik
Kommentaar:

16. Afspeling van gesag: gereeld /min /nooit
Kommentaar:

17. Deursetting: goed /gemiddeld /swak
Kommentaar:

18. Reaksies tot nuwe situasies: goed /gemiddeld /swak
Kommentaar:

19. Liggaamlikheid: rats /lomp /kan bal gooi en vang /hoogtevrees/ rysiekte /gevoelig vir hitte, koue, klere, water in gesig, growwe kosse /vermy fisiese kontak, sandspel, vingerverf / kan op een been staan / kan op reguit lyn loop / hou potlood toereikend vas /kan knip /ken liggamsdele / sit regop by tafel /ken ouderdom /kan fiets ry
Kommentaar:

20. Het u kind se gedrag op enige manier verander sedert die aanvang van die projek? Wees asseblief baie spesifiek.

Soek baie meer aandag + is baie meer veeleisend as ons kuiergaste het of by mense gaan kuier. — Veral as A.   by is.

21. Is daar enige aspekte van u kind se gedrag waaroor u op hiedie stadium bekommerd voel?

Nee. Ek dink die gedag wat sy openbaar is baie normaal vir haar omstandighede + ouderdom!.

Skaalpunt
Scaled score

	Vormbord / Form Board	15
	Woordeskat / Vocabulary	8
	Parate Kennis / Ready Knowledge	11
	Getal- & Kwant.begr. / Number & Quant.Cncpts.	8
	Syfergeheue / Memory for Digits	11
	Blokpatrone / Block Designs	8
	Storiegeheue / Story memory	6
	Prentraaisels / Picture Riddles	11
	Woordassosiasie / Word Association	12
	Absurditeite A / Absurdities A	11
	Absurditeite B / Absurdities B	14
	Vormdiskriminasie / Form Discrimination	13

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Appendix H

INLIGTINGSVRAELYS 2

KLEUTERSKOOL

1. Indien kind 'n kleuterskool bywoon/bygewoon het:

SKOOL	PIKKIEPARK	Ice Simon Réprimer
TYDPERK	1997-2000	2001
SKOOLHOOF	ESTELLE + BEULAH.	JOAN LESCH
ONDERWYSERES	VERSKEIE	LOUISE

2. Het die onderwyseres enige probleme geïdentifiseer? | JA | NEE (X) |
   Indien wel, beskryf kortliks:

   _____

   _____

   _____

3. Oordeel u dat u kind skoolgereed is/~~was~~? | JA (X) | NEE | WEET NIE |

ONTWIKKELINGSBESONDERHEDE

A. Fisiek

1. Swangerskap

1.1 Was die swangerskap deurgaans normaal/onbekend/met probleme?
    Indien met probleme, omskryf kortliks <u>BLOEDING NA AMNIOSINTESE; PLASENTA</u>
    <u>WAT DISINTEGREER</u>

1.2 Was infertiliteit met hierdie swangerskap op die spel? | JA | NEE (X) |

1.3 Was dit 'n beplande swangerskap? | JA (X) | NEE |

1.4 Duur van die swangerskap? normaal/vroeggebore/na die bepaalde tyd gebore

1.5 Ouderdom met geboorte: moeder __33__

2. Geboorte

2.1 Was die geboorte normaal/onbekend/met probleme/keisersnee/induksie?
    Indien met probleme, omskryf: _____

    _____

    Indien keisersnee, waarom: _____ IS GEBORE MBV NOOD-KEISERSNEE DUS
    WEER 'N KEISERSNIT

    Indien induksie, waarom: _____

2.2 Duur van die normale geboorte: normaal/lank: _____ uur/kort: _____ uur

2.3 Voorkoms van baba na geboorte: blou/pienk/geel/merke aan hoof/ander

·2.4 Is suurstof toegedien na geboorte? | JA | NEE | (NEE crossed out)

Indien wel, waarom? _____

2.5 Is die baba in 'n broeikas geplaas? | JA | NEE | (JA crossed out)

Indien wel, waarom? SOOS NORMAALWEG NA KEISERSNIT

Vir hoe lank? ± 60 MINUTE

2.6 Geboortegewig   normaal (2,7) - 4 kg)/ligter: _____ /swaarder: _____

3. Voeding

3.1 Aard van voeding na geboorte: bors tot _____ mnde.: bottel tot 24 mnde.

·3.2 Enige voedingsprobleme as baba? | JA | NEE | (NEE crossed out)
Indien wel, beskryf: _____

3.3. Enige eetprobleme as kleuter of tans? | JA | NEE | (NEE crossed out)

Indien wel, beskryf: _____

4. Motoriek

4.1 Sit : normale tyd (6 - 8 mnde)/vroeër/later

4.2 Kruip : normale tyd (8 - 10 mnde)/vroeër/later

4.3 Staan : normale tyd (9 - 11 mnde)/vroeër/later

4.4 Loop : normale tyd (12 - 14 mnde)/vroeër/later

4.5 Beheer oor groot bewegings, bv. hardloop: lomp/gemiddeld/rats

4.6 Beheer oor klein bewegings, bv. krale ryg: lomp/gemiddeld/goed

4.7 Toiletbeheer bedags: onder 2 jr/2 - 3 jr/later as 3 jr
                    snags: onder 2 jr/2 - 3 jr/later as 3 jr

5. Algemene gesondheid

5.1 Het die kind al die voorgeskrewe immunisasies gehad? | JA | NEE | (JA crossed out)

5.2 Spesifiseer alle siektes, ouderdomme waarop die kind dit gehad het, of
     hoë temperatuur daarmee gepaard gegaan het en of die kind gehospitaliseer is:

MANGELS - 3JR   ~~AUTISMACUATERAPIIES~~ - 5JR PYPIES IN OOR ½

5.3 Spesifiseer alle beserings en operasies met betrokke ouderdomme waarop dit plaasgevind het:

PYPIES - 4JR   MANGELS - 5JR

5.4 Het die kind enige liggaamlike gebreke? | JA | N~~EE~~ |

Indien wel, beskryf: _____

5.5 Het die kind stuipe/kontakverlies/"black outs" gehad? | JA | N~~EE~~ |

Indien wel, beskryf (met betrokke ouderdomme aangedui)

5.6 Het die kind enige allergieë? | JA | N~~EE~~ |

Indien wel, spesifiseer: _____

5.7 Is die kind se algemene gesondheid volgens u mening: <u>goed</u>/gemiddeld/swak?

6. <u>Sensories</u>

6.1 Gesig : <u>goed</u>/probleme/weet nie

6.2 Gehoor : <u>goed</u>/probleme/weet nie

8. <u>Taal en spraak</u>

1. <u>Eerste</u> Woorde: ___7___ mnde.   Drie-woord sinne: <u>voor 2jr</u>/2 - 3 jr/Na 3 jr.

2. Belangstelling in stories: <u>groot</u>/gemiddeld/giad nie

3. Vermoë om 'n storie oor te vertel: <u>goed</u>/gemiddeld/swak

4. Probleme met woordkonstruksie? | JA | N~~EE~~ |

5. Is die kind se algemene taalontwikkeling volgens u mening <u>goed</u>/gemiddeld/swak!

6. Enige spraakprobleme? | JA | N~~EE~~ |

Indien wel, spesifiseer en dui aan of die kind ondersoek is in dié verband:

_____

INLIGTINGSVRAELYS 3

C. EMOSIONEEL

1. Ly die kind aan enurese (bedbenatting) of het hy daaraan gely? Wanneer?

JA	NEE

Indien wel, is die kind al deur 'n medikus ondersoek?

JA	NEE

Bevinding _____ NYT _____

2. Ly die kind aan **enkoprese** of het hy daaraan gely? (bevuiling) Wanneer?

JA	NEE

Indien wel, is die kind al deur 'n medikus ondersoek?

JA	NEE

Bevinding _____ NVT _____

3. Dui aan t.o.v. die kind: slaaploosheid/somnambulisme/nagmerries/praat in slaap/
slaap onrustig/skrik maklik/byt naels/woedebuie/bang vir donker/ander fobies:
_____/senutrekkings('tics')/besondere behoefte aan
vertroeteling/heelwat selfvertroue/min selfvertroue/gemiddelde selfvertroue/
onafhanklik/min of meer onafhanklik/baie afhanklik van ouers/wisselende emosies/
suig duim/gespanne.

D. SOSIAAL

1. Hoe kom die kind oor die weg met maats? goed/gemiddeld/swak.

2. Verkies die kind om alleen te speel/saam met maats te speel.

3. Kind se spel: verbeeldingryk/gemiddeld/het leiding nodig.

E. PERSOONLIKHEID

1. Is die kind: humeurig/opstandig/skaam/selfstandig/alleenloper/geneig om jaloers
te wees/agtelosig/gehoorsaam/maklik hanteerbaar/aandagsoekerig/besonder netjies/
slordig/dagdromer/selfsugtig/baasspelerig/woelig/stil geaardheid/entoesiasties/
maklik afleibaar/kan goed aandag gee/waardeer mooi dinge/liefdevol/kan leiding
neem/opgewek/kan humor insien/verantwoordelikheidsbesef/spontaan/kan met self-
beheersing optree/kan simpatie hê/hulpvaardig/oneerlik/eerlik.

2. Enige ander uitstaande persoonlikheidskenmerke: <u>BESONDER LIEF VIR</u>

      <u>- HAAR DS BOETIE .</u>

F. **DISSIPLINE**

. Hoe aanvaar die kind dissipline tuis? <u>Goed</u>/swak/<u>soms moeilik</u>.

Indien swak/soms moeilik, beskryf <u>VERSTAAN NIE ALTYD WAAROM HAAR BROER WAT</u>

<u>DS IS, NIE DIESELFDE AS SY GESTRAF WORD NIE - OMDAT HY NIE ALTYD VERSTAAN N</u>

.. Hoe aanvaar die kind dissipline van ander? <u>Goed</u>/swak/soms moeilik.

. Wie se gesag aanvaar die kind die maklikste? <u>Vader</u>/moeder/beide/ander persone:

     _____

. Watter vorm van straf het die beste uitwerking op die kind?

praat/lyfstraf/<u>ontneem van</u> voorregte/ander: _____

. Voel u dat u die kind en u ander kinders doeltreffend kan dissiplineer?

                                 | JA | NEE |

. **VERDERE GESINSAGTERGROND**

. Hoe kom die kind klaar met ander lede van die gesin? Goed/<u>met sommige goed</u>/swak.

. Het die kind 'n besondere band met een van die gesinslede? | JA | NEE |

In JA, met wie? <u>BROER -</u>

. Is die kind enige van die gesinslede besonder vyandiggesind? | JA | NEE |

Indien JA, wie? <u>Soms - BROER .</u>

. Het u enige soortgelyke probleme met enige van u ander kinders? | JA | NEE |

Indien JA, wie en beskryf <u>Soms ~~VOEL~~ RAND</u>   HAAR AAN -

     <u>BYT OF SLAAN HAAR .</u>

. Leef die kind se grootouers nog? | JA | NEE |

.1 Indien wel, het hulle 'n sterk invloed op sy/haar opvoeding? | JA | NEE |

Indien wel, omskryf: <u>VERAL SY OUPA "TOER" MET HOM EN HY</u>

<u>KUIER/SLAAP TEN MINSTE EEN KEER PER WEEK BY HOM. BEIDE</u>

<u>OUMAS HET OOK 'N GOEIE VERHOUDING MET HOM .</u>