THE EXPERIENCES OF A TUTOR DURING THE IMPLEMENTATION OF AN APPLIED BEHAVIOUR ANALYSIS PROGRAMME: A CASE STUDY

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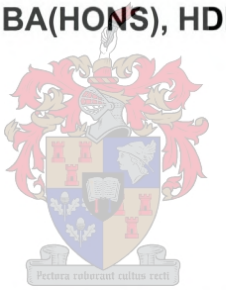

Assignment submitted in partial fulfillment of the requirements for the degree of Master of Education in Educational Psychology at the University of Stellenbosch

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DECLARATION

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

SUMMARY

This study was undertaken with the view to explore the experiences of tutors of children with the dual diagnosis of Autism and Down syndrome during the implementation of an Applied Behaviour Analysis support programme

The parents of the children willingly participated in a research project of the Department of Educational Psychology and Specialized Education at the University of Stellenbosch. A private individual funded the project. The aim of the project was to evaluate the effectiveness of an Applied Behavior Analysis support programme over a period of 26 weeks on an individual that has Autism. The programme impacted the daily lives of the tutors. The question soon arose as to how the intensive contact between tutor and the child would be experienced by the tutor.

A literature review was conducted to obtain a perspective of research done in this field. I fulfilled the dual role of researcher and trainee educational psychologist. The social contructivist framework was chosen as the preferred educational psychological framework from which to approach the study, while the participatory action research paradigm lent itself to describe the individual experiences of the tutors. The experiences were gathered from interviews, observations, video material, journals and reflections.

The research report describes a variety of possible experiences the tutor underwent and the repercussions thereof. Suggestions were made as to how adaptations to the programme could serve to expand the training of educational psychologists and tutors.

OPSOMMING

Hierdie studie is onderneem om die belewenisse van tutors van kinders met die dubbel diagnose van Outisme en Down sindroom tydens 'n Toegepaste Gedragsmodifikasie Analise program te ondersoek.

Die ouers van die kinders het vrywilliglik deelgeneem aan 'n navorsingsprojek van die Departement Opvoedkunde en Spesialiseringsonderwys van die Universiteit van Stellenbosch. Fondse vir die projek is van 'n privaat persoon ontvang. Die doel van die projek was om die effektiwiteit van die program oor 'n tydperk van 26 weke te evalueer. Die tutors se daaglikse lewe is deur die program beïnvloed en die vraag het ontstaan hoe die intensiewe kontak tussen kind en tutor deur die tutor beleef sou word.

'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 sosiaal konstruktiwistiese raamwerk is bespreek as 'n sinvolle opvoedkundige sielkundige raamwerk, terwyl die deelnemende aktiewe navorsingsparadigma homself daartoe leen om die belewenisse van die tutors te beskryf. Die belewenisse is ingesamel deur middel van onderhoude, observasie en video materiaal, 'n joernaal en refleksies.

Hierdie navorsingsprojek beskryf 'n verskeidenheid van die moontlike belewenisse van die tutors sowel as die moontlike nagevolge daarvan. Voorstelle oor moontlike aanpassings in die program word gemaak om sodoende die opleiding van tutors sowel as opvoedkundige sielkundiges in opleiding te verbeter.

This study is dedicated to the Lord God who made this opportunity possible.

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CHAPTER ONE

INTRODUCTION AND PROBLEM STATEMENT

1.1 INTRODUCTION

The Department of Educational Psychology and Specialized Education at the University of Stellenbosch initiated a research project on Autistic Spectrum Disorder and Down syndrome during September 2000. Various support programmes are available to assist children with Autistic Spectrum Disorder. The University of Stellenbosch became interested in the use of Applied Behaviour Analysis (ABA) as a therapy method for individuals with Autistic Spectrum Disorder after their experiences with a mother who has triplet boys with Autistic Spectrum Disorder.

The discipline of ABA therapy is based on more than 50 years of scientific research and continues to evolve as new research develops. According to Green (1996:30), support for children with Autistic Spectrum Disorder should be an ongoing process with competent professional analysis of research findings. Green (1996:34) is also of the view that the most prominent person in the study of Autistic Spectrum Disorder is Ivar Lovaas. Ivar Lovaas and his colleagues at the University of California-Los Angeles (UCLA) conducted a thorough investigation into a home-based behavioural support programme for young children with Autistic Spectrum Disorder in 1987. They discovered that 47% of the group who received intensive behavioural support for 40 hours a week achieved normal intellectual functioning, against only 2% of the control group (Lovaas & Smith, 1988).

These findings, together with the results of studies conducted by other behavioural researchers such as Anderson and the behavioural analysts at Murdoch University in Western Australia (Birnbrauer & Leach, 1993) strengthen the perception that behavioural analysis therapy is effective in improving the functional level of children with Autistic Spectrum Disorder. The research done by Lovaas and Smith (1987) was repeated by others such as Anderson *et al.* (1987); Birnbrauer and Leach (1993) and

the PDD Clinic, Langley Porter Psychiatric Institute, University of California at San Fransisco (Sheinkopf & Siegel in Green, 1996). According to Green (1996:36), the results of these studies add to the evidence that ABA therapy appears to be more effective in treating Autistic Spectrum Disorder than other support methods.

My involvement in the research started in December 2000 when the University of Stellenbosch approached me to join the research project on Autistic Spectrum Disorder and Down syndrome as trainee psychologist. I would become trained in the principles of the ABA therapy and be one of the two tutors responsible for supporting a learner who has Autistic Spectrum Disorder as well as Down syndrome. I agreed to participate in the research for the full period of six months.

For the purposes of this study I intend to come to an understanding of the experiences of the tutors, and as such will discuss the process of the tutors' involvement with the learner. Becoming intimately involved in the daily lives of the learners might result in the tutors' experiencing changes in their own lives. I will document my findings in this respect.

In this chapter I intend to orientate the reader as to the purpose of this study. I would also like to bring the dual role of tutor and trainee educational psychologist to the attention of the reader. In order to understand the research process, I also intend to describe the research approach and its usefulness and applicability to this specific study.

1.2 PROBLEM STATEMENT AND AIM

According to Weingarten (1992:45), therapy is a conversation between the participants which allows each member a contribution – an art of contact and change through conversation. In the case of this study, one could understand this to mean that the interaction between the child and myself as tutor was an opportunity to construct meaning and add value to each other's worlds. As the therapist, I possibly influenced the support programme by the meaning I constructed out of our interaction. At the same time I could be influenced by the way the boy constructed meaning out of his day-to-day experiences.

The problem statement of this study is formulated as: What are the experiences of a tutor of a learner with the dual diagnosis of Autism and Down syndrome during the implementation of an Applied Behaviour Analysis support programme?

I aim to come to some understanding of the lived experiences of the tutors and to determine whether any additions should be made to the support programme in order to enhance the tutoring process. I was one of four tutors who were trained in the principles of Applied Behaviour Analysis therapy. Two children, who had previously been diagnosed as having Down syndrome as well as Autistic Spectrum Disorder, would participate in the project initiated by the University of Stellenbosch. The purpose of the project would be to further evaluate the effectiveness of a home-based Applied Behaviour Analysis support programme running for a period of six months for a child with Autistic Spectrum Disorder and Down syndrome.

The principles of ABA include many elements and dimensions which constitute assessment and behaviour changing procedures; this emphasizes skills training designed to change behaviour in a systematic and measurable way. According to Anderson, Tara and Cannon (1996:181), the decision to use ABA is not an easy one since it impacts on the whole family unit and is strongly behavioristic. However, it does give hope. It is also important that the parents realize the need to work closely with the tutor to develop the best approach for their child and their specific situation. Romanczyk (1996:198) strengthens my perception of the influence of tutor and child on each other when he states:

> ... interactions have powerful influences on behaviour.

In chapter two the Applied Behaviour Analysis therapy programme will be discussed in more detail.

Mash and Wolfe (2002:257-259) use the word 'autism' to describe the characteristics of an individual with Autistic Spectrum Disorder. For the purpose of this study, I will continue to use the word autism within the same context. I will also use the term 'ABA therapy' in the place of 'Applied Behaviour Analysis therapy' for practical reasons.

1.3 MOTIVATION FOR AND BACKGROUND TO THE STUDY

In 2001 I was the tutor of a boy with the dual diagnosis of Autistic Spectrum Disorder and Down syndrome. In the past medical and educational professionals were doubtful whether Autistic Spectrum Disorder and Down syndrome could exist together. Wakabayashi (1979:31) reported a case in 1979, but since then very few cases have been noted. However, studies over the past few years by researchers such as Capone (1999) and Ghaziuddin, Tsai and Ghaziuddin (1992) report that although rare, it is indeed possible. The most important discovery for me in tutoring this child was that the presence of a multi-disability has much more implications and greater impact for the individual and his/her world than would be the case for an individual with a single disability. To understand the possible impact of these disabilities it is important to discuss their characteristics.

Down syndrome

According to Grobler (1973:1) the diagnosis of Down syndrome is fairly well researched and the community has knowledge about it. I am of the opinion that there is still very little expected from individuals with Down syndrome and that the community prefers to maintain a distant relationship.

Researchers have still not yet established the real cause of Down syndrome. According to Grobler (1973:1), Langdon Down used the term 'mongolism' for the first time and also gave the physical descriptions of such an individual in 1866. The features he mentioned included a small skull, a large tongue protruding from a small mouth, almond-shaped eyes, a flat nasal bridge, a short bent fifth finger, broad square hands and a coarse dry skin. Newton (1997:4) states that it was only in 1959 that studies by Lejeune showed that Down syndrome was due to an abnormality of the 21st chromosome. He termed this abnormality – where there are three of the 21st chromosome instead of the normal two, trisomy 21. Newton further explains that the term mongolism used by Langdon Down has been replaced by Down syndrome in the scientific literature.

Various researchers, such as Penrose and Smith (1966), Van den Berg (1966) and Vedder (1962), state that children with Down syndrome have special educational and emotional needs due to a degree of mental retardation.

The criteria (DSM-IV, 1994:46) for mental retardation are:

A. Significantly sub average intellectual functioning: an IQ of approximately 70 or below on an individually administered IQ test.

B. Concurrent deficits or impairments in present adaptive functioning in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety.

C. The onset is before age 18.

Autism

According to Maurice (1996:4), the diagnosis of Autism still leaves parents with a feeling of hopelessness and confusion, which is mainly due to ignorance about the condition.

When faced with the diagnosis of Autism in their child, a parent could very well demand a list of scientific criteria proving the diagnosis. Autistic Spectrum Disorder is included in the DSM-IV (APA, 1994:70-71) as one of the Pervasive Developmental Disorders. The criteria are:

A) A total of six (or more) items from (1), (2) and (3) with at least two from (1) and one each from (2) and (3):

1) qualitative impairment in social interaction as manifested by at least two of the following:

   a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expressions, body postures and gestures to regulate social interaction
   b) failure to develop peer relationships appropriate to developmental level
   c) a lack of spontaneous seeking to share enjoyment, interest or

achievements with other people

d) lack of social or emotional reciprocity.

2) qualitative impairments in communication as manifested by at least one of the following:

a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through mime or alternative modes of communication)

b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

c) stereotyped and repetitive use of language or idiosyncratic language

d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

b) apparently inflexible adherence to specific, nonfunctional routines or rituals

c) stereotyped and repetitive motor mannerisms, (e.g. hand or finger flapping)

d) persistent preoccupation with parts of objects.

B) Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: 1) social interaction; 2) language as used in social communication, or 3) symbolic or imaginative play.

C) The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Aarons and Gittens (1999:x) warn parents that even though learners with Autistic Spectrum Disorder share the same underlying impairment, each family and individual is different.

According to Smith (1996:48), children with Autism have difficulty processing input from the environment and/or translating input into effective action. Mash and Wolfe (2002:258) describe these children as obsessive and anxiously insistent on the sameness of daily routines. The authors also remind us of Raymond, the individual with an encyclopaedic memory portrayed in the film *Rainman*. From the portrayal of Raymond it could seem that some individuals with Autism may possess special talents. Mash and Wolfe (2002:260) state that some learners with Autism may indeed possess special talents, but all have special needs. Educators have the challenge of meeting the special needs of these learners and of assisting them in making meaning of their world.

Barlow and Durandt (1999:439) feel that clinicians are becoming more interested in understanding diverse childhood problems. Mash and Wolfe (2002:244) indicate that children with Down syndrome may also have other developmental delays, which could include Autism. Hassold and Patterson (1999:46) report an increasing number of cases of children with the dual diagnosis of Autism and Down syndrome.

Reports by Ghaziuddin *et al.* (1992) and Howlin (1995) describe seven individual children with the dual diagnosis of Autistic Spectrum Disorder and Down syndrome. The behaviours of these children include cognitive delays, communication delays and unusual responses to stimuli, as well as medical disorders such as hypoxic cardiac diseases. These reports strengthen my perception that a multi-disability is of greater impact than a single disability.

A diagnosis of both Autistic Spectrum Disorder and Down syndrome is fairly new to the field of psychology, with only a few cases identified (Ghaziuddin *et al.*, 1992). Several studies such as those of Anderson, Avery, Dipietro, Edwards and Christian (1987), Birnbrauer & Leach (1993), Maurice (1993) and Smith and Lovaas (1993), have shown that ABA can result in dramatic changes for children with Autism. Ivar Lovaas' (1987:3-9) use of the ABA technique has shown substantial results in treatment of children with Autism in America. Research on this topic seems to be

lacking in South Africa. I find no documented research published in South Africa during the period of this study.

The possibility of growth and learning must never be left uncovered. Gardner in Goleman (1996:37), as cited by Lomofsky (1999:70), states:

> Cultivating a variety of natural abilities will help learners to identify their natural competencies and gifts ...

The individual needs of these children must therefore also be attended to in order for them to develop and add value to their world. Mash and Wolfe (1999:406) state that a variety of programmes have been developed for children with Autism, but according to the studies of Lovaas (1987:3), the behavioural approach is the best in teaching new skills to such children since treatment includes all significant persons in all significant environments. Olney (2000:54) emphasizes the individual needs of children with Autism:

> When interacting with an individual with Autism, it is important that the counselor understand the person first as an unique individual.

In this regard both the community and the parents could easily discard a child with a disability, especially if the child has a multi-disability. Studies by various researchers such as Aarons and Gittens (1999), Cuskelly and Jobling (2002) and Newton (1997) have indicated that parents receive very little support and guidance from hospital personnel after the birth of their child. Newton (1997:36) suggests that a multidisciplinary team might be useful in providing necessary support to the parents. Newton (1997) continues by indicating that parents who received good support were more positive towards their child's future.

Ligthart (2002:4) states that the effect of a child with a disability on the whole family unit is multifaceted and can easily alter the relationships in the unit. One could understand this to mean that families with a child with a disability can also be seen as a 'disabled family'. According to Aarons and Gittens (1996:92) these families are often isolated because of the rejection they experience from the community. Cuskelly (2002:6) stresses the value of social interaction since it strengthens the growth potential of both child and parents.

According to Green (1996:29), ABA methods are used to develop socially acceptable behaviour and to decrease socially unacceptable behaviour. This could require the commitment of tutor and parents in order to facilitate effective change. Green (1996:31) further argues:

> ... if behaviour-change procedures are not carried out consistently across settings, people and time, any gains the child makes are likely to be lost.

My experiences as a tutor as well as a trainee psychologist left me with a number of unanswered questions. As trainee psychologist, my lecturers encourage me to be a reflective practitioner. I understand this to mean that I must continuously be actively involved in my own learning process, while at the same time being conscious of the learning experiences around me. Swart (1994:17) cites Hills and Gibson as confirmation:

> As you go about doing your work, responding to phenomena, identifying problems, diagnosing problems, making normative judgments, 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 ...

1.4 RESEARCH PROCESS

In order to understand the process of learning and the resulting changes, one has to address the educational development of the learner against a theoretical framework. According to Donald *et al.* (2000:32), a theoretical framework is the background against which the challenges of development may be understood and interpreted. Durrheim and Terre Blanche (1999:36) state that the theoretical framework:

> Provides the rationale for the research and commits the researcher to particular methods of data collection, observation and interpretations.

Babbie and Mouton (2001:53) state that it is important that the term 'methodological approach' is made clear, because the words 'approach' and 'paradigm' are used interchangeably. The authors continue to clarify the meaning by stating that the selection of methods and techniques used are dependent on the aims and objectives of the research. One could thus understand that the term paradigm could be used to include method and technique, as well as the underlying assumptions and principles regarding their use. On the other hand, the term approach could be used to describe the observational methods such as interviews, observations and personal documents (Babbie & Mouton, 2001:53).

I used a qualitative, non-experimental approach as my point of departure for this study. Mertens (1998:34) states that a qualitative approach is commonly used to provide thick descriptions of the field of study. The author describes "thick" as meaning detailed and comprehensive descriptions. For the purpose of this study "thick" descriptions will entail the day-to-day experiences of the tutors. A qualitative approach is at the same time flexible enough so that variables can be considered before the final conclusions of the research are reached.

The theoretical perspective of social constructivism assists me to understand my experiences. I am aware that there are two uses of social constructivism, namely as social theory and as learning theory. Social theory is based on the belief that social reality is socially constructed. According to Donald, Lazarus and Lolwana (2000:40) learning theory means that the learner takes part in activities which are directly relevant to the application of learning. For the purposes of this study the focus will be

on the perspective of social constructivism and the three principal assumptions of Vygotsky (Donald *et al.*, 2000:41), namely: a) the community is central in constructing meaning. The people around the child greatly affect the way he or she sees the world; b) the type and quality of tools used for development determine the pattern and the rate of development; and c) problem-solving skills and tasks are seen within the zone of development. Engelbrecht and Green (2001:7) confirm the assumptions of Vygotsky by stating that human beings cannot help but be engaged in the construction of meaning within their social communities.

From my understanding of the constructive perspective of Vygotsky (Donald *et al.*, 2000:40) I developed an interest in the study of my experience as tutor of the autistic/Down syndrome child. Throughout my role as tutor I experienced growth in knowledge as each day built upon the experiences of the previous day. My active participation in the study influenced my thoughts, actions and dialogue. At the same time I saw changes in the child as well. I relate this to Terre Blanche and Durrheim's (1999:52) statement that "research is an immensely creative activity". These authors further indicate that probably the most common sources of data production in constructivism are interviews and observations (Terre Blanche & Durrheim, 1999:52).

In view of the above I developed an interest in participatory action research. My own participation in the research developed on a daily basis. For the purposes of this report I will use the abbreviation PAR for participatory action research. My deepening interest in PAR strengthened my initial perspective of meaning being built out of experiences. For the research design of this study I chose PAR as the methodological framework from which to conduct my research. According to Terre Blanche and Durrheim (1999:228) the relationship between researcher and participant results in the active process of production of knowledge. PAR is possible within social constructivism since similarly to social constructivism, PAR seeks to develop knowledge as well as gain insight into the research process.

PAR developed out of the acceptance of participant observation as a methodology. Babbie and Mouton (2001:56) highlight the work of Mead (1949) and Redfield (1953), wherein the influence of the researcher in the research process is recognized. Researchers were viewed as becoming more actively involved with their subjects and this forced qualitative researchers to become more critical of their research methods.

The result of this development was that PAR could now be seen as a cyclical process involving diagnosing a problem, planning action steps and implementing and evaluating the outcomes in conjunction with all the participants involved.

Fals-Borda (1988:85) used the term PAR to distinguish it from research methods whose aims were to maintain the status quo. He saw PAR rather as seeking change by redressing inequity and sharing power. This could mean that the researcher faces the challenges of establishing a sense of collaboration with the community involved and of creating meaning by working together with other players through all phases of the research.

1.5 STRUCTURE

In **chapter one,** I orientate the reader by providing the motivation for the study. I explained my dual role as tutor 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 appeared in the title. I described the research approach I would use and its usefulness and applicability to this specific study.

In c**hapter two,** I provide an overview of literature relevant to this study. I first discuss Down syndrome and Autism as two different disabilities before giving an overview of the concomitant disorder. In this chapter I also outline the effects of Applied Behaviour Analysis (ABA) on children with Autism and how early intervention benefits the final prognosis. Since the intervention does not only affect the child, I also indicate the effect of the programme on the tutor.

In **chapter three** the method of enquiry is discussed in detail. I indicate how Participatory Action Research (PAR) formed the basis from which the experiences of the tutors were investigated. I also describe the different techniques used to produce the data and the steps taken to analyze these. Lastly, I outline the ethical issues of research which were considered for this study.

In **chapter four** the findings of the study are discussed. I provide the relevant background information in order to contextualize the case under discussion. I interpret the data produced and discuss the themes as they emerge from the various sources. A summary of the main themes is provided as a conclusion to the chapter.

In **chapter five** I provide the reader with a brief summary of the content of all of the chapters. I indicate the factors seen as limiting the study. I conclude by discussing recommendations for further 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 of this study will be on the following: a) constructivism as a method of making meaning and building knowledge through the contact between the tutor and the child; b) the concomitance of Down syndrome and Autistic Spectrum Disorder; c) the Applied Behaviour Analysis programme; and d) the lived experiences of tutors during the tutoring process.

2.2 AUTISTIC SPECTRUM DISORDER AND DOWN SYNDROME

I found very little literature available on the dual diagnosis of Autistic Spectrum Disorder and Down syndrome. However, I found ample literature on the two disabilities as *separate* disorders, which served to assist me in understanding the complexity of the dual diagnosis. I will therefore first discuss the two disabilities separately before discussing the concomitance of the disorder.

The diagnostic criteria for Down syndrome and Autism according to the DSM-IV (APA, 1994:46, 70-71) were discussed in Chapter One.

2.2.1 AUTISTIC SPECTRUM DISORDER

2.2.1.1 Historical background

Autism was first described in 1943 by psychiatrist Leo Kanner, and again in 1944 by Austrian paediatrician Hans Asperger (Aarons, 1996:5). The use of the term 'autism' caused confusion right from the start since it had previously been used in connection

with aspects of schizophrenia. Kanner (1943) used it to describe the social impairments, abnormal language development and unusual interests of the individuals he studied. Asperger applied the term to children who were socially maladroit, had bizarre obsessions and yet were verbal and quite bright.

Morton (1989:44) mentions the work of Dr Lorna Wing, who revived interest in the work of Asperger. She distinguished between the work of Kanner and Asperger by noting that the commonalities were as important as the differences. The result was that scientists recognized Autism to be more complex than previously assumed (Barlow & Durandt, 1999:454).

2.2.1.2 Clinical features of Autism

People with Autism may suffer from a bewildering array of problems. According to Maurice (1996:45-55) these problems include food allergies, sensory disturbances, gastro-intestinal problems, obsessive compulsiveness, epilepsy and attention deficit hyperactivity disorder. When Kanner first described the condition in 1943 he listed a number of features which in theory would identify the disorder. Aarons (1996:5-6) lists these points as they could still be relevant today:

1. An inability to develop relationships: The child with Autism has difficulty interacting with people and is likely to show more interest in objects than in humans.
2. Delay in the acquisition of language: Some children do not develop meaningful speech but some do acquire language. Invariably the development is later than in other children.
3. Non-communicative use of language after it develops: The child does not use the words at their disposal in meaningful communication.
4. Delayed echolalia: The child repeats snatches of videos, songs, jingles and phrases.
5. Pronominal reversal: The child substitutes 'you' for 'I'.
6. Repetitive and stereotyped play: The play patterns are very limited with no imaginative play.
7. Maintenance of sameness: The child shows insistence that the surroundings in their daily lives must not change.

8. Good rote memory: Many children with Autism show remarkable feats of memory and rote learning.
9. Normal physical appearance: This feature encouraged Kanner to believe that these children had normal intelligence. This led parents and professionals to have unrealistic expectations of children with Autism.

Looking at the above, it is evident that the consequences to the development of the child are serious. If viewed from a constructivist perspective, the lack of interaction could mean a lack of building meaning. Donald *et al.* (2000:40) state that it is in a relationship where development of learning takes place. Mash and Wolfe (2002:341) state that the early years of childhood development are the most powerful for learning, which is mostly done through imitation. It is through imitation that children learn language and non-verbal communication. Heather (heatherm@cruzio.com) says that for children with Autism this ability only comes after a long struggle, and even then these individuals find it difficult to detect the subtle signals that other individuals pick up easily.

2.2.1.3 Prevalence and course

According to Mash and Wolfe (2002:272) Autism is thought to affect at least 4-5 children per 10 000, and is on the rise. The increase could be attributed to a broadening of the criteria as well as to greater recognition of the differing forms of Autism. Aarons (1996:16) states that Autism is also approximately 3-4 times more common in boys than in girls.

Aarons (1996:33) also states that young children with Autism not only look normal, but are positively attractive in appearance. However, the attractiveness diminishes as eye contact becomes vague and is avoided and body language becomes distant.

Mash and Wolfe (2002:273) state that the pattern of symptoms of these children does change over time and some improvement is evident with age. The improvement is, however, very gradual and the individual will continue to experience social problems. Maurice (1996:31) is of the opinion that this is the reason why support should be from as early an age as possible in order to maximize its effectiveness.

In studying the literature surrounding Autism, much controversy surrounding prognosis was revealed. I quote the Autism South Africa Foundation:

> To date Autism is not curable but it is treatable. Intensive team intervention and an individualized specific educational plan must be implemented as early as possible to ensure the children reach their full potential in life. The earlier the correct and appropriate intervention, the better the prognosis. (http://www.bccs.co.za/autism-sa)

I believe that there is hope for families as well as individuals that have Autism. The important aspect to consider at this stage is not whether the individual will eventually be cured, but how the individual can be assisted to maintain a happy life.

According to the *Concise Oxford Dictionary* (1964:689) learning can be defined as, among others: Get knowledge of, or skill in; by study, experience of being taught; and to commit to memory. McMahon (1997:3) argues that constructivism takes learning beyond a passive position to a place where the learner would be the active agent in his/her own learning process.

For the purpose of this study I wanted to determine whether learning through an ABA support programme would be part of the interaction process between the learner and myself.

2.2.1.4 Causes of Autism

Barlow and Durandt (1999:451) state that there are many theories as to the reason for development of Autism. The idea that there might be a biological reason for Autism has especially intrigued many researchers. The authors continue to speculate about the helpfulness of both past and present theories in order to gain understanding of Autism.

Aarons (1996:15) reports that Kanner in 1943 suggested that a 'cold and unresponding' mother caused Autism. Clinical experience and research done by Koegel, Schreibman, O'Neill and Burke (1983) and McAdoo and De Myer (1978) discredited this view.

Olney (2000:51) is of the opinion that Autism is a low-incidence developmental disability resulting in impairments in socializing, communication and imagination. The nature and severity of Autism would impact on the individual because of the mental disability status. Insight into the relevance of social interaction is critical in

order to understand how interaction will influence the construction of knowledge for both tutor and learner.

Studies by Wing and Gould in 1979 (Morton, 1989:44) suggested that Autism is a syndrome and not just a collection of symptoms. Mash and Wolfe (2002:275) state that studies have found that brain abnormalities may underlie the problems that children with Autism have in shifting their attention from stimuli to stimuli. Goldberg (file://F:\REACH CLINIC\Studies & Research\Basic Info 1.html) advised parents to study the effect of diet as well. He is of the opinion that all possible options should be investigated in order to provide the child with maximum growth and developmental potential.

2.2.1.5 Support for children with Autism

Shortly after a child is diagnosed with Autism, parents start hunting for help and encounter a vast number of available treatments. These include education, various drugs, music therapy, special diets, ABA, and more. According to Green (1996:15), these suggested treatments could benefit most if not all people with Autism. However, it is not that simple. Autism is still a disorder where breakthroughs are ardently wished for by virtually everyone who works with affected people. Green (1996:16) is eloquent in criticizing the reports of quick fixes and miracle cures when she states:

> ... some of these therapies appear to work: the child might seem to be better while in therapy...often the family feel good...its continued use likely even when objective evidence shows that other treatments are more effective.

Green (1996:17) states that parents must feel confident about the treatment procedure they will be subjecting their child to. She continues to caution parents against accepting support programmes that are recommended without the necessary insight into the specific needs of the individual child.

2.2.2 DOWN SYNDROME

2.2.2.1 Historical background

According to Mash and Wolfe (2002:231) the evolutionary degeneracy theory of the 19th century described mental retardation as the 'missing link' between humans and

lower species. Langdon Down also described the people with the anomalies he studied as an evolutionary throwback to the Mongol race, and subsequently termed these people as having 'mongolism'. Fortunately in 1959 Lejeune in France discovered that the features that made Down syndrome so distinctive were genetic in origin. Newton (1997:3) states that the findings of Lejeune's research started a process of understanding that gave people with Down syndrome the opportunity to show what can be achieved despite their disability. Mash and Wolfe (2002:247) state that chromosome abnormalities are the single most common cause of mental retardation, and that Down syndrome is the most common disorder resulting from such an abnormality.

2.2.2.2 Clinical features

According to Barlow and Durand (1999:460) people with Down syndrome have characteristic facial features. These include folds in the corners of their eyes, a small mouth with a protruding tongue and a flat nasal bridge. They also tend to have congenital heart malformations. The authors also state that all people with Down syndrome past the age of 40 years show signs of Alzheimer's disease, a degenerative brain disorder that causes impairments in memory and cognition.

Newton (1997:19) states that the most consistent features in Down syndrome are facial appearance, skeletal structure leading to short stature, and anomalies of the heart.

According to Hassold (1999:39), the most defining factor is the existence of the additional 23rd chromosome. However, Hassold states that the appearance of this extra chromosome is not due to any fault of the parents and that parents would benefit by receiving additional comfort and understanding in this regard.

2.2.2.3 Prevalence and course

Grobler (1973:6) reports that Down syndrome is the single most recognizable group with disabilities. Statistics point towards prevalence figures of 5 per 100. This is based on studies carried out during the 1960s. Mash and Wolfe (2002:247) state that a rate of 1,5 per 1000 births is more realistic. However, for most individuals with Down syndrome the extra chromosome results from non-disjunction, the failure of the 21st

pair of the mother's chromosome to separate during meioses. The incidence of Down syndrome in mothers older than 45 years increases dramatically to 38 per 1000 births.

Cuskelly (2002:18) states that children with Down syndrome struggle to learn at the same rate as other children. Many of these learning disabilities are biologically determined. Other influences also affect the developmental process. It is evident that a supportive learning environment is critical for children with Down syndrome. Hassold (1999:133) is of the opinion that the question is not *if* education should be offered to persons with Down syndrome, but *when and how* it should be. The Down Syndrome Association of South Africa is also of the opinion that learners with Down syndrome should be given the opportunity to develop their maximum potential (x:26).

Cuskelly (2002:21) describes how in the past, very little was expected from individuals with Down syndrome. At the same time, the life expectancy of individuals with Down syndrome was relatively short. Mash and Wolfe (2002:252) warn that this is changing and that children with Down syndrome now have a greater life expectancy than ever before. The importance of this for the study is that the learner is more able to participate in activities which are directly relevant to the application of learning.

2.2.2.4 Causes

According to the Down Syndrome Association of South Africa (x:8):

> Downsindroom kan nie genees word nie aangesien dit deur n fout in die chromosome veroorsaak word. Hierdie fout kan ook nie by n persoon met die toestand herstel word nie.

This confirms the studies of Lejeune in 1959 which indicated that a chromosomal abnormality was possibly the cause of Down syndrome. Further studies by Le Roux (1968) and Thorne (1965) confirmed that the chromosome abnormality was found mainly on the 21st chromosome. The reason for the production of this extra chromosome has still not been revealed. However, according to Grobler (1973:21) studies have shown that chromosomal abnormalities are found in greater numbers in mothers older than 35 years than in mothers younger than this age.

2.2.2.5 Treatment

Barlow and Durand (1999:462) state that biological treatment of individuals with an intellectual disability is not a viable option. The authors are of the opinion that these people could benefit by teaching them the skills they need to become productive and independent. The skills could be viewed as the same type of skills that people with Autism would benefit from. Barlow and Durand (1999:464) state that when teaching skills to learners with Down syndrome, the tutor also needs to focus on the task of including them in the community.

2.2.3 DOWN SYNDROME AND AUTISTIC SPECTRUM DISORDER

2.2.3.1 Historical background

According to Capone (1999:8) there is very little commentary about Down syndrome and Autistic Spectrum Disorder. He mentions that it was commonly believed that the two conditions could not exist together and that the child with Down syndrome just had a severe intellectual disability. Mash and Wolfe (2002:283-290) state that children with Autism could very well display other symptoms, but few diagnosed cases of Down syndrome together with Autistic Spectrum Disorder are recorded. More cases are however being recorded; Patterson (1999:16) states that since 1979 36 reports of Down syndrome together with Autistic Spectrum Disorder have been revealed. Vatter (1998:1) is of the opinion that as many as 10% of Down syndrome children may also have Autism. It is possible that many cases go undiagnosed because of the complexity of Autism.

2.2.3.2 Signs and symptoms

The official term for Autism as defined in the DSM-IV (1999:65-70) is Pervasive Developmental Disorder (PDD). PDD is a class of five diagnosable disorders, which includes Autism. Autism is diagnosed by evaluating the behaviour of the patient. (See the figure below.)

Difficulty in mixing with other children		Insistence on sameness; resists changes in routine	
Inappropriate laughing and giggling		No real fear of dangers	
Little or no eye contact		Sustained odd play	
Apparent insensitivity to pain		Echolalia (repeating words or phrases in place of normal language)	
Prefers to be alone; aloof manner		May not want cuddling or act cuddly	
Spins objects		Not responsive to verbal cues; acts as deaf	
Inappropriate attachment to objects		Difficulty in expressing needs; uses gestures or pointing instead of words	
Noticeable physical overactivity or extreme underactivity		Tantrums - displays extreme distress for no apparent reason	
Unresponsive to normal teaching methods		Uneven gross/fine motor skills. (May not want to kick ball but can stack blocks.)	

Adapted from the original by Professor Rendle-Short, Brisbane Children's Hospital, University of Queensland, Australia (Vatter, 1998:5).

This diagnosis is quite complex and should only be done by qualified professionals.

Children who have Down syndrome are diagnosed at birth. Children who have Autism are often diagnosed much later. Children who have Down syndrome and Autism are often overlooked because professionals attend more to the medical complications and *expect* developmental delays. Capone (1999:8) acknowledges the concern of parents about their child's developmental delays and encourages them to share their concerns with the professionals assisting them, since this could benefit the eventual support programme for the child.

Vatter (1998:5) states that 'atypical' behavior such as repetitive motor behaviour, fascination with and staring at lights, extreme food refusal, repetitive language problems and absent language should be brought to the attention of professionals. The author is of the opinion that although studies of Down syndrome and Autistic Spectrum Disorder are limited, studies by Ghaziuddin (1992), Wing and Gould (1979), Turk (1992), Bregman (1988) and Wakabayashi (1979) indicate that about 10% of people with Down syndrome also display autistic features.

2.2.3.3 Causes

Capone (1999:9) states that Autism is in itself a mystifying disorder and when combined with Down syndrome is even more difficult to understand. The author states that there are some medical conditions where Autism is more likely to occur, such as Fragile X syndrome, chromosomal anomalies and seizures. Gilberg and Coleman (2000:141) are of the opinion that the medical condition Down syndrome is probably a critical factor in the developing brain of a child and in the emergence of Autism.

Morton (1989:45) states that the once popular view of the 'refrigeration mother' has fortunately lost its effect. This viewpoint attributed loss of interaction to the failure of bonding between mother and child. Capone (1999:10) states that nowadays parents display concern about their child and he encourages parents to get involved with professionals in finding the most effective support programme for their child.

2.2.3.4 Support for learners with down syndrome and autistic spectrum disorder

Herbert (1996:2) states that the vast majority of children's behaviours are learned. Children have to be taught socially acceptable manners. Olney (2000:52-54) discusses

a number of possible intervention programmes for people with Autism, such as the neurobiological model, clinical-behavioral model and social model. The common thread through all is that skills have to be taught. For children who have Autism as well as for children who have Down syndrome, the basic needs of the individual have to be addressed. It is therefore of paramount importance that the same criteria should be applied for an individual who has Down syndrome and Autistic Spectrum Disorder. Capone (1999:8-15) reminds us that the earlier the support is started, the better the prognosis will be.

2.3 APPLIED BEHAVIOUR ANALYSIS

When confronted with a child with learning difficulties, it is not uncommon for professionals to feel that these influence the whole existence of the child. However, Jordan (2001:10) states that it is not just a matter of recognizing the educational needs of these children, but also the individual and other relevant needs. The author continues to elaborate on the significant differences between children and how no single approach will suit all individuals. The challenge is to find the most effective approach that will benefit the child. Therefore, in order to decide on whether to use a specific support programme, clear knowledge about the programme is essential. Siegel (1996:159) states that the decision to use a specific support programme is one that is difficult for every combination of child and family. Parents need to consider their family needs since any support programme could impact on the whole family unit.

2.3.1 THE USE OF APPLIED BEHAVIOUR ANALYSIS

As mentioned above, a support programme has significant impact on the family unit. Harris and Weiss (1998:5) state that early support is effective, but also very specific. By deciding to use ABA as an early support programme, the parent must understand the features of this support method.

Harris and Weiss (1998:5) explain the features of ABA therapy as follows:

- intensive treatment – at least 30-40 hours per week with the teaching done on a one-to-one basis

- highly structured approach – carefully designed and predictable pattern of instruction

- minimal leisure time during which the child is not actively learning – breaks are followed by brief lessons at a rapid pace

- teaching is done in a space specially provided and arranged for this purpose.

According to Cooper, Heron and Heward (1989) as cited by Green (1996:29), ABA employs methods based on scientific principles of behaviour. These principles build socially acceptable behaviour and reduce unacceptable behaviour. The research done by Lovaas and Smith in 1989 showed that learners with Autism do not learn the same way as other learners. The authors described the method of ABA as teaching children basic skills in small measurable units. Appropriate responses are rewarded and consequently reinforced. According to the principles of behaviour modification, this would result in changing the unacceptable behaviour of the individual. Green (1996:32) states that the work of Lovaas was ground-breaking but also thoroughly researched, and as such could be recommended as having proved its success.

Powers (2000:193) states that parents who choose this support programme need to work closely with tutors to ensure that consistent teaching happens at home and at school, and that the goals are thus abided by. Harris and Weiss (1998:35) reiterate the view of Powers when they encourage parents to check on the progress of the support and whether the individual needs of their child are attended to.

2.4 EXPERIENCES OF TUTORS

Literature on the experiences of tutors of children with Autism was limited. However, Spectrum (file://A:\4.htm) encouraged tutors to continue reading about ABA therapy and become aware that ABA is a different method of teaching. Spectrum (file://A:\4.htm) states:

> A new method for teaching children with Autism looks for their greatest interest ... and uses it to lever more learning, and more appropriate behaviour.

The most important feature for the tutors to consider was that the behaviour of the child would be targeted. As a result the tutors could expect quick results and much

evidence of success. Spectrum (file://A:\4.htm) comments on the speed of results in an ABA programme, and how both parents and child are rewarded when breakthroughs occur. The tutors would then also achieve satisfaction in the knowledge that they were instrumental in a small way.

According to the Son-Rise Programme (file://A\exp 1.htm) in America, tutors have a significant influence on the process. Molly Burke from Son Rise described her experiences as "magic". She explains how she has changed by having the opportunity to interact with a child who has Autism. Larkey (file://A:\exp 2.htm) states that the role of the tutor would be to meet and understand the specific needs of the child. Furthermore, tutors also need to be encouraged since they themselves may be unsure of themselves.

Larkey (file://A:\exp 2.htm) found that most tutors commented on their own lack of knowledge about the learning disability of the child with Autism. This lack influenced the tutor's response to the learner. According to Anderson, Tara and Cannon (1996:187-193), it is important to remind the tutors that the successes of ABA therapy are found in strictly abiding to the principles of ABA therapy. The role of the tutor is to tutor the child according to the ABA principles and not to allow their own personality as a changing element in the therapy process.

2.5 CHAPTER SUMMARY

Through a review of relevant literature I 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 tried to clarify them. I also discussed the constructivist framework as an approach from which the experiences of the tutors will be explored. The literature overview will ensure that I can link the research findings to existing theories and results that are relevant to the problem statement.

CHAPTER THREE

METHOD OF ENQUIRY

3.1 INTRODUCTION

In this chapter I discuss the research methodology of this study. As mentioned in Chapter One, Babbie and Mouton (2001:53) stated that it is important that the term 'methodological approach' is made clear because the words 'approach' and 'paradigm' are used interchangeably. The authors continued to clarify the meaning by stating that the selection of methods and techniques used are dependent on the aims and objectives of the research. The term 'paradigm' could be used to include method and technique, while 'approach could be used to describe the observational methods, such as interviews, observations and personal documents. For the purposes of this study I will use the term approach.

3.2 THEORETICAL FRAMEWORK

In this study I work from a social constructivist framework. Social constructivism according to Donald *et al.* (2000:40) is "understanding complex systems and relationships [that] cannot be reduced to understanding their elements only".

From a constructivist perspective, this could then mean that the learner and the tutor are active agents in their development. In other words, both are together building knowledge as well as being influenced by this knowledge.

From the above, the deduction could be made that the constructivist perspective influenced my approach to the study. For a clear understanding of the constructivist approach, it is necessary to clarify the role of:

- learning,
- social interaction, and
- social interaction and learning.

a) According to the *Concise Oxford Dictionary* (1964:689) learning can be defined as: Get knowledge of, or skill in; by study, experience of being taught; and to commit to memory.

b) According to Donald *et al.* (2000:41), psychological theorists like Vygotsky (1978) emphasize that knowledge is a social construction, which is learned through social interaction. The authors continue that at the centre of Vygotsky's theory is the notion that development takes place through social relationships. McMahon (1997:4) is of the opinion that social constructivism offers hope for educators since it views the context in which learning occurs as part of the learning process. At the same time the learning takes place in the context in which the learner functions.

c) It would be convenient to view social constructivism as a simple solution to making meaning out of the learning process. According to Donald *et al.* (2000:41), humans cannot be understood as objects that are passively influenced by forces around them. Vygotsky's theory of social constructivism has room for active and involved participants. McMahon (1997:5) argues that collaboration between participants is important and that learners could with help from adults master concepts otherwise unattainable by them.

According to file://A:\social construct 2.htm, Vygotsky followed three principal assumptions, namely:

1. Making meaning:
   - the community plays a central role,
   - the people around the child affect the way he/she sees the world.
2. Tools for cognitive development:
   - the type and quality of these tools determine the pattern and rate of development,
   - the tools include culture, language and adults involved.
3. Zone of proximal development:

- Problem-solving skills can be placed into three categories: a) those performed by the student, b) those that cannot be performed even with help, and c) those that can be performed with help.

According to Donald *et al.* (2000:40), people are shaped by and are active shapers of their social context. The authors view constructivism as an active process wherein humans are the active participants in their learning process. Engelbrecht and Green (2001:7) confirm Donald et *al.*'s view by stating that human beings cannot help but be engaged in the construction of meaning within their social communities.

Constructivism can thus be viewed as of great importance to psychology since it challenges the reductionistic thinking of positivism. Reductionism assumes that reality needs to be broken into small bits before the whole can be understood. According to Donald *et al.* (2000:41), constructivism shifts the emphasis to the active role of humans in shaping their development.

In this study an approach of learning in interaction will be undertaken. I will continually and actively explore the influence of learner and tutor on each other. Note should be taken, however, that my perception and experiences might shape my selection and eventual interpretation of the data since I will be an active participant in the research process.

Out of my understanding of the above constructive perspective, I developed an interest in the study of my experience as tutor of the boy with Down syndrome and Autism, and the simultaneous influence on both of us. Throughout my role as tutor I experienced continuous growth in knowledge as each day built upon the experiences of the previous day. One could relate this to Terre Blanche and Durrheim's (1999:52) statement that: "research is an immensely creative activity …". These authors further indicate that probably the most commonly used sources of data production in constructivism are interviews, where different patterns can come to the fore while at the same time the interviewee is exerting influence. Participant observation is also used in data production, and was used extensively in my research.

3.3 METHODOLOGY

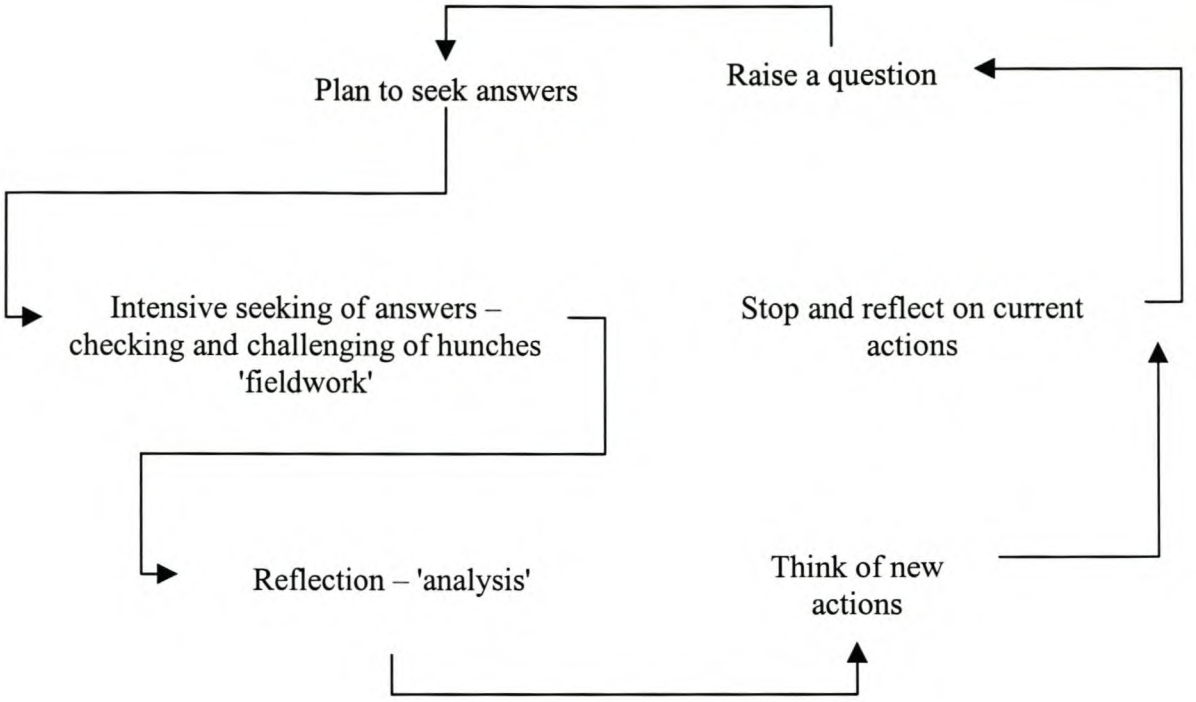
As an active participant in the research process I developed an interest in participatory action research (PAR). According to Terre Blanche and Durrheim (1999:228), the relationship between researcher and participant results in an active process where knowledge is produced. In this study I would attempt to involve all relevant participants in the production of knowledge, with social constructivism as my research approach and PAR as the methodology.

PAR developed out of the acceptance of participant observation as a methodology. Babbie and Mouton (2001:56) highlight the work of et Mead (*The Mountain of Arapesh*, 1949) and Redfield (*The primitive world and its transformations*, 1953) wherein the influence of the researcher in the research process is recognized. According to Nash and Wintrob (1972:527), as cited by Babbie and Mouton (2001:56), the acceptance of participant observation resulted in qualitative researchers becoming more critical of their research methods.

PAR is therefore a research approach with its own developmental history. Reason and Rowan (1981:489), cited by Babbie and Mouton (2001:58), state:

> New paradigm research involves a much closer relationship than that which is usual between the researcher and the researched: significant knowledge of persons is generated primarily through reciprocal encounters between subject and researcher, for whom research is a mutual activity involving co-ownership and shared power with respect both to the process and to the product of the research.

The exact origin of PAR is open to dispute, but according to Babbie and Mouton (2001:63) the propositions of Levin (1946) can be credited as the start of action research. PAR is seen as a cyclical process involving diagnosing a problem, planning action steps and implementing and evaluating the outcomes:



Adapted from Wadsworth http://www.scuedu.au/schools/sawd/ari/ari-wadsworth.html

According to the writings of Seymour-Rolls and Hughes (1995:1), PAR is a method of research where positive social change is the driving force for the research. PAR grew out of the need to include all participants in the process. Babbie and Mouton (2001:64) are of the same opinion when they state:

> In PAR, participants are truly co-researchers whose 'insider knowledge' is as valid for scientific science-making, as is the outside researcher's technical expertise and abstract general knowledge.

Furthermore, Fals-Borda (1988:85) used the term PAR to distinguish it from research methods whose aims were to maintain the status quo; PAR rather seeks change by redressing inequity and sharing power.

Babbie and Mouton (2001:64) cites Whyte (1995) who stated that PAR is a research method where the individuals involved in the research project all actively participate in the gathering of data. One could understand this to mean that the researcher faces the challenge of establishing a sense of collaboration among the community involved, and creating meaning by working together through all phases of the research.

3.3.1 KEY PRINCIPLES OF PAR

I adopted the seven steps as set out by Babbie and Mouton (2001:315-331), namely:

1. The role of the researcher as change agent
2. The importance of participation in PAR
3. The democratic nature of the research relationship
4. How local knowledge is incorporated into the research
5. Knowledge is generated for action
6. The role of empowerment
7. Methodological issues.

3.3.1.1 The role of the researcher as change agent

The beginning of a PAR project may be difficult to pinpoint. Babbie and Mouton (2001:316) state that:

> ... the professional researcher as specialist, comes from outside the community to initiate PAR to investigate certain problems.

This assumption about the identity of the researcher is not acceptable to all. For instance, Huizer (1984:17) is of the opinion that the research should be carried out by all interested parties directly involved in the community. This could include researcher, parents, teachers and other interested parties as well as the child involved. Terre Blanche and Durrheim (1999:230) consider PAR as an attempt to mediate between individuals with collective needs. This could imply that the researcher is an independent person in the research process with the main focus of equality of humanity in mind.

In this study I adopted the role of change agent by focusing specifically on the needs of the learner I was tutoring. I intended to allow him the opportunity to develop according to his own pace, but also to motivate further learning in him. I also foresaw

the need to educate the domestic assistant at home to allow him to do things for himself so that he would not just wait passively for her to attend to his needs.

3.3.1.2 The importance of participation

Kemmis and McTaggart (1988:5) state that:

> PAR can be defined as collective, self-reflective enquiry undertaken by participants in social situations in order to improve the rationality and justice of their social practices.

Babbie and Mouton (2001:315) make a distinction by involving the participants in all the stages of the research and also taking note of the degree and nature of their participation. This implies that the participants could be involved from: a) designing and planning the study; b) implementing the plan; c) evaluating the plan; and d) writing up the results. Babbie and Mouton (2001:315) believe that the participants would thus be included to the extent that there would be combined sharing of decision-making during the research process and in terms of the manner in which the research is conducted.

Babbie and Mouton (2001:317):

> ... no change agent is ever free of the obligation to do whatever is necessary to enhance participation.

This implies that the researcher has several responsibilities, of which Wadsworth (1995:4) specifies the following. The researcher should be:

- more conscious of 'problematising' an existing action and more conscious of who is problematising it and why,
- more explicit about 'naming' the problem and more self-conscious about raising an unanswered question and focusing an effort to answer it,
- more systematic and rigorous in efforts to get answers,
- more carefully documenting and recording action and what people think about it and in more detail and in ways which are accessible to other relevant parties,

- more intensive and comprehensive in our study, waiting before we jump to conclusions,

- changing actions as part of the research process, and then further researching these changed actions.

These are but a few of the possible responsibilities of a researcher. Many more could be added. In this study I immersed myself in my role as researcher since I had to involve all other participants such as the parents, the domestic help and the teacher from the boy's school in the process as well. The parents and the teacher were skeptical about the research process, and I would have to provide regular feedback in order to maintain their support. (See Addendum, Appendix F.)

3.3.1.3 Democratizing the research relationship

PAR as research method seeks to decrease the distance between the researcher and the subject. Terre Blanche and Durrheim (1999:230) cite Brown and Tandon (1983): "PAR insists on communal participation in the process of knowledge creation, so that knowledge can never become the property of individuals." PAR thus insists on equal power sharing in the project and all participants in the research project should learn and teach on equal footing. The participants in this study should become more eager to share in the process as the research developed by encouraging the boy to communicate. I intended to learn from the teacher about the learner's previous performances. The domestic help and the parents would assist me in implementing the process at home.

3.3.1.4 The incorporation of local knowledge

According to Babbie and Mouton (2001:321) local knowledge - i.e. the perspectives and values of the participants - are relied upon and incorporated into the research process. This is of value as it acknowledges the differences of experience between individuals in the same situation. Guerrero (1995:30) continues this thought when she states:

> PAR draws on the own experience as well as on the experience of others ... The framework is dynamic ...Designs for research are changed as we utilize the process of constituency input.

One could therefore interpret Guerrero's statement to mean that the input every individual brings to the research bears equal value. In this study the information that the other participants bring to the research will impact on my expectations of the research. My expectations were to see changes in the performance of the learner according to the stipulations of the ABA programme.

3.3.1.5 Knowledge for action

According to Babbie and Mouton (2001:333), PAR is concerned with action that induces positive and corrective social change. This implies that the efforts of the researcher are not merely curiosity-driven and that entering into the community means entering the real lives of real people. Change can therefore not be brought about just for the sake of change. Change must be to the benefit of those affected. This ties in with the statement of Chitere and Mutiso (1991:3), who indicate that:

> This improves the participants' overall quality of life, making PAR desirable for 'balanced development' to occur.

Babbie and Mouton (2001:320) are of the opinion that PAR scholars must encourage participants to stimulate and assist other into action. In this study I intended to encourage the parents to engage with other parents who had children with disabilities. Mash and Wolfe (2002:99) state that:

> Rash and disorganized behaviours of children are a constant source of stress for parents, siblings and teachers ...

The above statement could imply that parents themselves can be of assistance to each other. This study could encourage such interaction.

3.3.1.6 The role of empowerment

Participating in knowledge creation sets the groundwork for empowerment, which is a key principle of PAR. According to Babbie and Mouton (2001:323), empowerment is the means of acquiring knowledge which will lead to the advancement of society. Terre Blanche and Durrheim (1999:237) confirm this:

> ... the researcher needs to enter the community in a respectful way , with the desire to learn as much as to teach.

The question can then be posed of how can this be achieved through PAR. As researcher, I attempted to address the question by implementing the steps outlined in the following paragraphs.

3.3.1.6.1 Conscientization

The *Concise Oxford Dictionary* (1964) describes the words 1) conscience as: moral sense of right and wrong; and 2) consciousness as: state of being, totality of a person's thoughts.

According to Babbie and Mouton (2001:233) the term 'conscientization' is generally used to refer to raising participants' 'self-awareness'. More specifically, self-awareness is raised through collective enquiry. This may be linked to the view of Reason (1994:328):

> ... to see through the ways in which the establishment monopolizes the production and use of knowledge for the benefit of its members.

In this study I will attempt to draw from the knowledge of the parents as well as the teachers in order to gain insight into the needs of the learner.

3.3.1.6.2 Learning

Education is also viewed as an point of emphasis of PAR. According to Engelbrecht (1999:8), learning is an ongoing process and it could therefore be viewed as part of empowering the participants. Babbie and Mouton (2001:233) distinguish the following learning processes:

- Basic learning: This refers to the fundamental learning process which could range from literacy to intricate skills.

- Learning to discover new knowledge: participants gain new insight into their world.

- Learning to articulate and systematize knowledge: participants distinguish between different knowledge levels.

- Learning to be assertive: participants are empowered and confident about their own knowledge.

Learning insights such as these mentioned above allow for more realistic interpretations of the gathered data. Through PAR, researcher and participant thus truly can become co-responsible. In this study I attempted to stimulate the desire to learn in the child.

3.3.1.7 General methodological issues

PAR methodology uses various data production methods, for example interviews and observations. However, because of the problem-solving nature of PAR, it is important that the method used can be adapted to the specific situation. According to Babbie and Mouton (2001:325), PAR must be structured differently in different settings. This could be the reason for the use of a wide array of methods. McTaggart (1991:177) is also of the opinion that PAR is an open-minded research method. One could understand this to mean that the data produced are more important that the method used.

Babbie and Mouton (2001:328) state that the researcher should however consult all available data, even stories and historical accounts, in order to validate his/her interpretations. For the purposes of this study I produced an historical account of the learner's development as well as past medical and observational documentation. I also kept written communication with the parents, which would serve as a journal.

3.3.2 RESEARCH CONTEXT

As discussed in Chapter One, the University of Stellenbosch received the opportunity to investigate the effectiveness of an Applied Behaviour Analysis support programme for children with the concomitance of Down syndrome and Autism due to funds being allocated for specialized research in this field. A lecturer had contact with two families whose children had been diagnosed with Down syndrome and showed Autistic Spectrum Disorder features. Both these families indicated their willingness to participate in the research. The University of Stellenbosch contacted four trainee educational psychologists to become trained in the principles of ABA therapy since their training does not include this skill. The trainee educational psychologists would receive their training from Mrs. Jenny Buckle and become tutors to the learners.

Three years ago Jenny Buckle, a mother of identical triplet boys, was given the news that all three of her sons have Autism. She was referred to a school that would assess her children, but the school had a waiting list and could only assist the family after 18 months. This was not acceptable to Jenny and she started her own in-depth research on the Internet. She came across various support programmes that are used overseas.

On the basis of the results published about the work of Ivar Lovaas, she decided to implement ABA for her children. She trained tutors to assist her and started the support programme on her children, with much success. The success that was achieved and the publication of the story of her success in a local magazine (*Sarie*, August 2000) resulted in many phone calls from other parents. Jenny realized the desperate need of other parents, and subsequently initiated REACH as a support network as well as a training opportunity for tutors. Jenny choose the name REACH as it symbolizes the potential of humans to 'reach' out towards their own growth (Jenny Buckle, Training session, January 2001).

The REACH support network is run according to the following principles:

- child-specific behavioural support
- information and advanced workshops
- parent training and support

- setting up and maintaining home programmes
- continued research and training
- natural environment therapies
- trained therapists.

REACH thus provides hope and motivation for early support programmes. With all of this in mind, the University of Stellenbosch approached REACH to assist them in the training and monitoring of the tutors that would be part of the research project. Jenny Buckle agreed to participate in the research process.

The parents of the child volunteered their participation as they were desperately trying to get help for the education of their son. The boy was diagnosed with Down syndrome as a baby and also displayed sufficient signs of Autism. An agreement was reached between the university and the parents, and tutoring of the boy started in February 2001 and ended in September 2001.

3.3.2.6 Identifying information of the tutors

NAME	**Anne***	**Beth***	**Cathy***	**Delia***
QUALIFICATIONS	B.A, B.A. Hons	B.Prim.Ed. B.Ed., M.Ed.	B.Prim.Ed., B.Ed.	B.A., HDE, B.A. Hons
SEX	Female	Female	Female	Female
LANGUAGE OF INSTRUCTION	Afrikaans	Afrikaans	English	English

*Not their real names. Pseudonyms were used for ethical reasons.

The tutors would have to devote three and a half hours to the tutoring process on a daily basis. The research project was scheduled for a period of six months. However, the ABA support programme may be continued for as long as the learner would benefit from it. The tutors would thus have the opportunity to continue as tutor, even after the research project had ended.

3.3.3 SAMPLING

According to Reason (1994), the preferred way of explaining the practice of PAR would be through case descriptions where the sampling would entail various case discussions. In this study, however, sampling was done through convenience sampling methods. According to Mertens (1996:265), convenience sampling is undertaken when the participants volunteer participation in a study, which was the case in this study. Since volunteers participated in this study, this research cannot be generalized to be representative of all people with Autistic Spectrum Disorder and Down syndrome. Nor can the experiences of the tutors be generalized to represent the experiences of all tutors working with children who have Autistic Spectrum Disorder and Down syndrome.

3.3.4 DATA PRODUCTION

According to Terre Blanche and Durrheim (1999:381), research is a circular activity moving from the general to the specific, where the outcome will then represent a particular experience. Gough (1999:264) mentions that "we produce data by our own acts of will and intent, that data are fashioned by human purpose and action". One could interpret this to mean that data are not collected, but produced through the activities of humans.

Many data production techniques are available to the qualitative researcher, but Mertens (1998:317) focuses on three: observations, interviews and documents and record reviews or field notes. All provide information about the field of research.

As PAR focuses on participation in the research process, I identify with Adler and Adler (1994) who distinguish between 'pure' observation and participant observation. Mertens (1998:319) cites Adler and Adler in this regard:

> ... the research field has shifted to value more the insider perspective and thus researchers have tended to take on more of a membership role...

Observation allows the researcher to collect data by direct contact with the participants, which was what I did by tutoring the boy. In this study I also used video recordings to enhance the observation technique since I could review the experience again and thereby relive and confirm my interpretation. As Neuman (2000:361) states:

> The researcher becomes an instrument that absorbs all sources of information. In addition to physical surroundings, a researcher observes the people and their actions.

Following from this, I decided to make field notes to validate my findings and compare my experiences with those of other tutors during the final interpretations. Babbie and Mouton (2001:275) state that:

> ... field notes are important to enhance the validity and reliability of research done ...

Neuman (2000:363) reinforces this, stating that good notes are of great value to the substance of the research.

In this study it was not possible to write extensive notes while tutoring since the support programme requires constant attention from the tutor. Jotted notes had to suffice. Detailed notes were written up at night after the tutoring by making use of the jotted notes and also drawing from memory.

In order to enhance the validity and reliability of my personal observations, I also made use of interviews. Ary, Jacobs and Razavieh (2002:434) state that:

> Interviews are the most widely used method for obtaining qualitative data ... on subjects' opinions, beliefs and feelings about the situation in their own words.

According to Mertens (1999:321), an open-ended and unstructured interview allows the interviewee to determine the flow of the process. She describes the benefit of this as the opportunity to gain additional insight from the interaction between the participants, since their responses are more free and relaxed.

I interviewed the other tutors by using pre-arranged questions and allowing free flow of their answers. The interviews were tape-recorded and the responses transcribed (see Addendum, Appendix A).

In this study I used interviews to elaborate on my own experiences since I was concerned that my experiences should be confirmable. Babbie and Mouton (2001:278) cite Lincoln and Guba (1985) in this regard:

> ... an adequate trail should be left to enable the auditor to determine if the conclusions, interpretations and recommendations can be traced to their source and if they are supported by the inquiry.

According to Terre Blanche and Durrheim (1999:387), a PAR study is a study that leads to action, but during the research process itself change may also occur. This implies that the interviewer should be sensitive to the experiences of the participants. The participants in this study were made aware of the nature of the study and the implications of their participation, which included their being willing to participate in interviews as well.

3.3.5 VALIDATION AND VERIFICATION

Wadsworth (1995:13) states that:

> ... the strength of the values we hold will determine the power of our research efforts
> ... [it] comprises the long hours of talking, thinking and sharing ...

One of the key principles of a PAR study would be to validate the findings with and by the participants. Babbie and Mouton (2001:328) point out that "facts are checked with firsthand knowledge" and "alternative explanations are recognized."

The authors continue by stating that validation is thus a process where the experiences and interpretations of experiences of all participants have equal value. Terre Blanche and Durrheim (1999:235) point out that data are of immediate value, while Babbie and Mouton (2001:329) confirm this by stating that the data can be processed immediately and therefore immediately corrected and verified by the participant. This should be sufficient to enable participants to defend evidence and also convince others. In this study the data would be confirmed on a daily basis with the parents as well as the supervisor at REACH.

3.4 DATA ANALYSIS

According to Merriam (1998:187) several levels of data analysis are possible in a research study. Data analysis can be seen as the process of constructing meaning out of data, which in the end constitutes the findings of the study. She regards the object of data analysis as to convey understanding, and cites Stake (1995:78):

> We are trying to understand behavior, issues and contexts ...We try to find the pattern or the significance through direct interpretation, asking ourselves 'What did that mean?'

The analysis is continued by a systematic search using the techniques of interviews, observations and field notes to provide the data. This data is then searched and categories or themes identified which would contribute to understanding.

In devising the themes, I planned to investigate the experiences of the tutors. However, as Dey (1993:30) states:

> Our intuitions have place in analyzing the data, but we can definitely benefit from a more rigorous and logical procedure of analysis.

Guba and Lincoln (1994:114) state that knowledge is accumulated through dialect. This means that identifying themes would involve looking for units of data with corresponding meanings. Merriam (1998:179) refers to Guba and Lincoln (1985) to explain what a unit of data is. Guba and Lincoln believe that it should reveal information relevant to the study and that it should have 'individual' meaning. 'Individual' in this context I understand to mean that it should be able to stand as relevant information, without any other explanation being given or needed.

According to Terre Blanche and Durrheim (1999:139), the purpose of analysis is to provide 'thick' descriptions, which place the real-life events of the study into perspective. Clifford Geerz (1973) describes thick descriptions as:

> ... a thorough description of the characteristics, processes, transactions and contexts that constitute the study, as well as the researchers' role in constructing this description.

According to Dey (1993:30), description lays the basis for starting analysis, but I could find no fixed pattern for data analysis. Tesch (1990:78) affirms this by stating that the more informal the studies are, the more difficult the data analysis is. I eventually turned to the step-by-step presentations of Terre Blanche and Kelly (1999:141-149) to explain the process that I followed.

Step One: Familiarization and Immersion

The authors suggest that while the researcher is still producing data, the process of interpreting and describing is already under way. During the first step I reviewed the field notes, documents and interviews thoroughly again to refamiliarize myself with the data. I made new notes of my thoughts and brainstormed with the other tutors in

order to reimmerse myself in the data. At this stage I already had ideas about the emerging themes and started making notes about possible changes to the themes as well.

Step Two: Inducing Themes

Terre Blanche and Kelly (1999:141) state that:

> Themes should ideally arise naturally from the data, but at the same time have a bearing on the research question.

In this step the researcher has to consider all the available data to find the underlying principles. Wiersma (1995) suggests that by organizing the data it becomes easier to define the different themes. Lincoln and Guba (1985:347) state that these themes provide a reasonable reconstruction of the collected data, while Bogdan and Bilken (1998) argue that the themes can only be coded according to the researchers' own individual styles after the reconstruction of the data.

In this study I made notes as the data were collected. The themes developed as all the data were reviewed and put together. While I was reviewing the data I naturally also started coding them. This means that the process of inducing themes and coding happened simultaneously as the body of the data was broken down into small pieces, labelled and grouped together. I selected codes according to the themes that I planned and allocated my own abbreviations to the themes. The themes that I initially devised and the set of codes that I used was as follows:

Frustration	Fr
Anxiety	Ax
Irritation	Ir
Excitement	Ex
Change	Ch
Lack of Knowledge	Lk
Parents' Expectations	Pe
Tutors' Expectations	Te

Step Three: Elaborating

Terre Blanche and Kelly (1999:144) state that when one immerses oneself in the data, the material is viewed in a linear sequence. However, by coding the data this sequence is broken and units are grouped together so that finer nuances are exposed. During this study the coding of the data would reveal to me that even if the tutors experienced the same training and tutoring processes, each one would attach their own meaning to these experiences.

Step Four: Interpretation and Checking

According to the authors the final step is interpreting the data and giving a written account of the themes. Terre Blanche and Kelly (1999:145) are firm in their suggestion that this is also the stage where the researcher should check for weak points in the research. This would also entail reflecting on the researcher's own involvement in giving meaning to the themes. This stage would be the stage where my own personal involvement in the research would be highlighted the most. I would have to reflect at depth on my own interpretations of the themes and whether I could substantiate my own experiences and meaning making.

3.5 ETHICAL CONSIDERATIONS

Ethical considerations arise where there is interaction between people. Babbie and Mouton (2001:520) specify that ethics are of special relevance where there is the potential for a conflict of interest, and the right thing to do is not always self-evident. While conducting this research I felt that certain ethical issues needed to be considered, namely voluntary participation, anonymity and confidentiality and reporting, which I will discuss in more detail. Ary, Jacobs and Razavieh (2002:503) confirm my concern by pointing out that it is important to adhere to ethical standards in conducting research since the validity and reliability of the research is determined by your professional conduct.

3.5.1 VOLUNTARY PARTICIPATION

According to Ary, Jacobs and Razavieh (2002:438) the data production methods could provide the researcher with sensitive information about the participants. The

participants should therefore be aware that they might be required to reveal personal information. It is also possible that due to the research procedures, certain information will be made known to strangers. The participants should therefore have the choice of whether they want to participate in the research. This study was done with a specific learner who was not able to volunteer participation. The parents of the learner thus had to give their consent. Babbie and Mouton (2001:521) highlight the following:

> It is important to emphasize that the issue of not harming people is of particular concern when we investigate more 'vulnerable' groups (like children) in society.

Neuman (2000:97) also confirms the above by suggesting that participants sign a statement giving consent to their participation after being adequately informed about the research procedures. In this study I complied with this and got verbal and written consent from the parents of the learner before the research process started (see Addendum, Appendix C).

3.5.2 ANONYMITY AND CONFIDENTIALITY

According to Neuman (2000:91), the relationship between the researcher and other participants in the research is based on trust. This implies that the responsibility is on the researcher to protect and oversee the interests of the people being studied. Ary, Jacobs and Razavieh (2002:437) confirm this statement, but include issues of confidentiality and anonymity in the relationship when they state that participants should remain nameless and other information should be treated as confidential. In this study this meant that in the write-up of the research the names of the participants would be substituted with others and other personal information was not made public. Neuman (2000:99) concludes this paragraph on this issue by stating:

> Anonymity means the subjects remain anonymous or nameless ... confidentiality means that the researcher holds it in confidence or keeps it secret from the public.

3.6 REPORTING

Babbie and Mouton (2001:526) state that:

> In any rigorous study the researcher should be more familiar that anyone else with the technical shortcomings and failures of the study.

This could imply that the researcher should adhere to the rules about reporting on the research. Out of this is would be obvious that the researcher must be honest about the findings of the research and admit to failures as well as successes. Babbie and Mouton (2001:527) state that the researcher is accountable to society and should therefore be very aware of the professional conduct required. This includes the obligation to be responsible about the availability of the research. Since this study is part of a research project of the University of Stellenbosch, the findings will be made available at the University in the form of a bound thesis.

3.7 CHAPTER SUMMARY

The theoretical foundation of the methodology has been discussed in this chapter. Through a constructivist framework and an active involvement in the case study, I tried to understand the experiences of the tutors. The methods of data production, analysis and interpretation were discussed. I tried to demonstrate how the criteria of voluntary participation, anonymity, confidentiality and reporting contributed to the trustworthiness of the data. The interpretation and presentation of the data follow in the next chapter.

CHAPTER FOUR

THE CASE STUDY

4.1 INTRODUCTION

I will attempt to come to an understanding of the experiences of the tutors during the tutoring process of a child that has Down syndrome and Autism (DS/ASD). The broader context of the child as well as the tutors involved will be outlined. The implementation of the tutoring programme will also be placed in context. Thereafter, the themes that emerged from the sources of data will be interpreted.

The methods applied to verify the data and to ensure that the findings were valid accounts of the tutors' experiences were discussed in chapter three. I would like to draw the reader's attention to the fact that the tutors were from different backgrounds and approached the project with different aspirations. It might therefore be difficult to reach consensus about aspects concerning the tutoring process. I would also like to remind the reader that convenience sampling was done where the child's parents volunteered participation. Generalization of findings is therefore not possible.

4.2 CONTEXTUALISATION

4.2.1 IDENTIFYING INFORMATION OF CHILD 1

NAME:	Chris*
GRADE:	No formal grade
SCHOOL:	Seal College
DATE OF BIRTH:	01/08/1989
SEX:	Male
HOME LANGUAGE:	English

LANGUAGE OF EDUCATION: English

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

4.2.1.1 Context of family

Chris is the elder of two children. His younger sister attends a local school and is currently in grade 5. Chris lives with his mother, father and sister in a suburban area with an average socio-economic status. His mother works full-time at a large company in Cape Town. She arrives home at approximately 6 o'clock every day. His father is self-employed and runs his business from their home. His sister arrives home from school every day at approximately 2 o'clock. The children have a nanny that has been with the family since Chris's birth. The nanny attends to the personal needs of both children during the afternoon.

Chris attends a privately owned special school where children with severe impairments are provided with support and education. He did not respond well to the implementation of the support programme at home, exhibiting resentment and becoming visibly upset. I initially attempted to continue with the ABA therapy process but after spending a day with Chris at his school, I realized that he was used to a specific routine.

I discussed my thoughts with my supervisor and it was decided to subject Chris to the support programme at school during the mornings. He responded well to this. The tutors speculated that this could be because he was used to the routine of attending school. After school hours a second tutor tutored Chris at home. He responded very well to this.

According to the principles of PAR as stated by Terre Blanche and Durrheim (1999:230), the research relationship should have a democratic nature whereby the distance between the researcher and the subject is decreased. By allowing Chris to maintain his routine I attempted to adhere to the principles of PAR.

4.2.1.2 Developmental details

4.2.1.2.1 Physical

In the first trimester of pregnancy a placenta malfunction occurred and Chris's mother experienced spot bleeding. The birth was difficult due to low muscle tone and the baby was a forceps delivery. Chris had to have a haemoglobin injection since his mother was Rh negative. Two weeks after birth he was diagnosed with Down syndrome. Chris was on Epilim for petit mal seizures between the ages of 3 and 7. Chris was tested for hearing loss but his hearing was found to be normal. He does have a history of ear infection. Chris sat at 9 months, crawled at 12 months and walked at 2 years. He was toilet trained at age 4 and started dressing and undressing himself at age 7. He still struggles to button clothing and he has low muscle tone.

4.2.1.2.2 Language and speech development

Chris's speech is frequently incoherent. He tries to talk, but his language is not always appropriate. He is more willing to point to what he wants than to verbalize his request. Chris often reverts to echolalia when enticed into conversation. His parents report that his speech development has improved since the implementation of the support programme. He is more able to follow basic instructions and is more able to communicate his needs.

4.2.1.2.3 Emotional and social development

At the beginning of the support programme Chris demonstrated mostly parallel play. He did not interact with any peers and spent his time climbing on the jungle gym or sitting on the grass. He did not make appropriate eye contact and did not respond when called. Persistent attempts were necessary to get his attention. He was able to greet people appropriately, but needed prompting. His play was not age appropriate and he engaged in inappropriate use of toys.

Chris presented as a generally happy child. After implementation of the support programme at the school, he did not appear unduly upset by further changes to his routine. However, he could be stubborn when he wanted to continue an activity. I experienced this as positive growth in the construction of his knowledge. His

enjoyment of the activity could be interpreted that he was building new meaning out of his interaction with the tutor. Chris enjoyed a good laugh and responded with delight when he noticed that the tutor was happy with his responses. Although Chris did not engage in peer play, he responded well to play initiated by the tutor. He was eager to please and time proved that Chris enjoyed the social contact. He developed his own unique style of greeting the tutor and displayed a degree of jealousy when the tutor paid attention to the other children.

4.2.2 IDENTIFYING INFORMATION OF CHILD 2

NAME:	Andre*
GRADE:	No formal grade
SCHOOL:	Not attending school currently
DATE OF BIRTH:	24/04/1992
SEX:	Male
HOME LANGUAGE:	Afrikaans
LANGUAGE OF EDUCATION:	Afrikaans

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

4.2.2.1 Context of family

Andre is the elder of two children. His younger sister attends a pre- school and spends the afternoons with a day mother. Andre lives with his father, mother and sister in a suburban area with an average socio-economic status. His 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. Andre'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. Andre used to attend a special school for children with Down syndrome, but since the start of the research projects follows a home-based support programme. His one tutor arrives at 07h30 in the morning and the second tutor takes over at 11h00. At 14h00 Andre goes to a daycare centre, from which he is collected at the same time as his sister from her after-care.

4.2.2.2 Developmental details

4.2.2.2.1 Physical

In the first trimester of pregnancy Andre's mother experienced a threatened miscarriage. The pregnancy was difficult and an emergency caesarian section had to be performed at 31 weeks. The baby received oxygen and spent 3 days in an

incubator. Andre was diagnosed 3 days after birth with Down syndrome. He was a sickly baby and often in hospital. Andre walked at age 2 years and 4 months. His favourite toys are puzzles, books and balls.

4.2.2.2.2 Language and speech development

Andre's speech is incoherent. He has few verbal skills and prefers to point to what he wants. He experiences problems with certain sounds and cannot formulate a sentence. He can obey simple tasks and responds to praise and reprimand.

4.2.2.2.3 Emotional and social development

At the beginning of the support programme Andre demonstrated stubbornness and did not participate in group activities. He needed close supervision at all times, tending to wander away from the group. He did not respond to instructions and only reacted to activities of interest to him.

4.3 TRAINING PROGRAMME

The training of tutors was based on the principles of Applied Behaviour Analysis (ABA). The training programme for the tutors was scheduled as 2 weeks of intensive training at the beginning of January 2001. The tutors subsequently received training on the background of ABA, the skills needed and the drills that would be implemented. The tutors were also given a practical demonstration of the application of the drills in order to see the speed at which the drills should be administered. As the tutors had already met the children they would be tutoring on previous occasions, they were ready to start work by February 2001. The tutoring process commenced in February 2001 with fortnightly meetings. These meetings gave the tutors the opportunity to check their skills and also to update the support programme.

4.4 EMERGENCE OF THEMES

4.4.1 INTERVIEWS

According to Babbie and Mouton (2001:233) a typical interview will reveal many statements and questions. I did not make use of a questionnaire but rather one-to-one

interviews, which included open-ended and closed-ended questions as well as statements. Babbie and Mouton (2001:237) state that a one-to-one interview is a popular method of collecting data since it provides the interviewer with the opportunity for interaction.

For the purpose of this study I used statements and questions from my own personal experience as a tutor to determine whether the other tutors agreed with me. I also used open-ended questions in order to evoke discussion. Babbie and Mouton (2001:253) mention that open-ended questions can evoke many responses, which could lead to much more questions. According to the principles of PAR as set out by Babbie and Mouton (2001:321), participation by all the role players is important. Donald *et al.* (2000:41) state that in social constructivism the community is central to constructing meaning. These statements could be interpreted to mean that the information shared by myself and the other role players caused us to rethink the expectations we had of the learners.

As mentioned in Chapter Three, face-to-face interviews are convenient and widely used by researchers. The respondents were all participants in the research project and were therefore willing to respond. The questions which were previously arranged resulted in the structure of the discussion being different to that of a normal conversation. The interview attempted to gain insight into and understanding of the emotions and experiences of the tutors. The same questions were asked of all the tutors, but evoked different responses (see Addendum, Appendix B).

The questions I intended to pose to the tutors were as follows:

1. What motivated you to join the programme?
2. Did you ever think of withdrawing from the programme? What motivated you to continue/withdraw?
3. Did you need any kind of support?
4. What type of things that happened during the course of the day caused you to reflect upon them at home?
5. Do you experience some emotion when you talk about the programme – how do you explain these emotions?

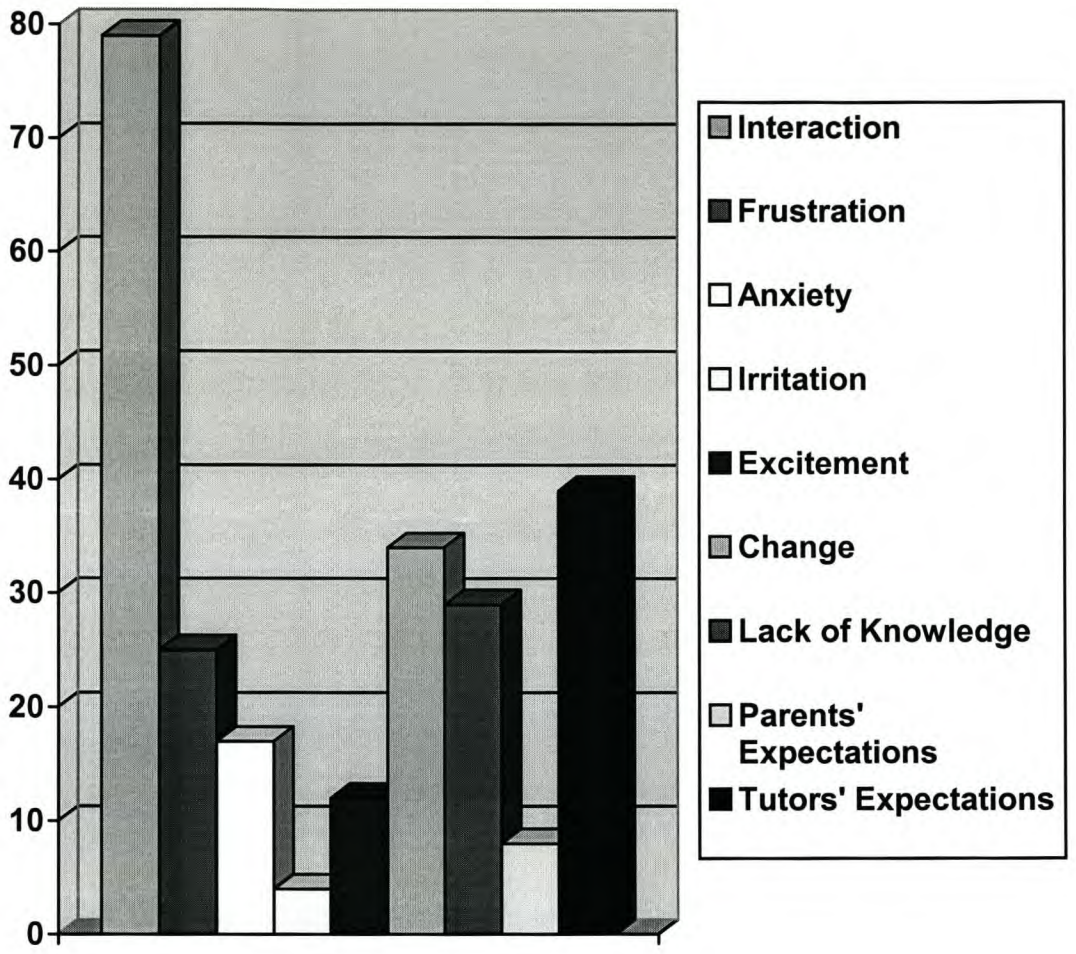
6. I found some things lacking in the programme. Are there things that you found lacking in the programme? What would these things be?
7. Having had the experience of working with this child, any specific thoughts concerning your work as Educational Psychologist?
8. What thoughts would you share with others new to the ABA experience?
9. Would you recommend that all Educational Psychologists share the ABA training that you had? Why?

In coding the responses I discovered that my initial set of themes and codes was not complete. The tutors were unanimous in describing the value of interaction between themselves and the learners. I added Interaction with the code of In to the set of themes. This was the theme that was indicated by the tutors to be of the highest value in the tutoring process. The final set of themes and the codes I used were as follows:

Interaction	In
Frustration	Fr
Anxiety	Ax
Irritation	Ir
Excitement	Ex
Change	Ch
Lack of Knowledge	Lk
Parents' Expectations	Pe
Tutors' Expectations	Te

The tutors were relaxed and eager to discuss their experiences as tutors. The opportunity to discuss the experience led to quiet reflection and some degree of emotion, since the children had had a definite impact on the tutors.

I coded the interviews and plotted the number of responses on a graph to indicate the values that the tutors attached to each individual theme (see graph below).



Graph of responses

The tutors were all in agreement that the programme was recommendable. They also agreed that the principles of ABA are valuable and the results of the studies of Lovaas (1987) were accepted as possible. However, the tutors were of the opinion that the concomitant disorder of Autistic Spectrum Disorder and Down syndrome influences the application of the support programme. The tutors constructed different meaning out of their interaction with the learners as the strict and rigid method of ABA was not entirely accepted by them as the best method for a learner with Autistic Spectrum Disorder and Down syndrome.

The personality of the child needs to be recognized. At the same time, the personality of the tutor also needs to be considered since the child with Down syndrome is by nature more susceptible to attention and love. A child with Down syndrome responds more readily to touch and socializing than a child with Autism. The tutors were of the

opinion that in the concomitant disorder of Autistic Spectrum Disorder and Down syndrome the Down syndrome characteristics override the behaviourisms of Autism.

The tutors were all trainee Educational Psychologists. As such they were of the opinion that better knowledge about support options for children with Autism would be a valuable addition to their training programme as psychologists. They do realize that the practical training on the principles of ABA would be impossible to include in the training programme of all Educational Psychologists, since it is a specialized field of support. It could, however, benefit future psychologists to be more aware of the successes of ABA. Babbie and Mouton (2001:320) state that PAR scholars aim to encourage participants to interact and motivate others to action. In this study I constantly encouraged the parents of the learner to inform other parents of the ABA programme and the available help.

According Babbie and Mouton (2001:328), one of the key principles of PAR is to validate findings with participants. One could understand this to mean that the researcher would 'check the facts' with the participants. For the purpose of this study, I 'checked the facts' with the other tutors by discussing my findings with them, as well as giving them the drafts of my interpretations to read. Any disagreements were discussed until consensus was reached and then rectified before the final report was written.

4.4.2 OBSERVATIONS AND VIDEOS

Most of the observations of Chris were made during the tutoring sessions and the free play opportunities during the course of the day. The tutoring sessions were videotaped to allow the founder of REACH to monitor progress. The videos also gave the tutor the opportunity to observe the development of trust and interaction between tutor and child.

My observations of Chris indicated that he is a learner with the concomitant disorders of Autism and Down syndrome. I was unsure whether the initial training I received in the principles of ABA would be sufficient to provide adequate support for this specific child. I found that I needed to supplement my training in the principles of ABA by gaining insight into the difficulties that a learner with Down syndrome has.

The principles of PAR, according to Babbie and Mouton (2001:321) stipulate that the incorporation of local knowledge adds to the value of the research process. I asked Chris's teacher for her opinion of his abilities and skills. She was happy to share information and suggested that I make adaptations to the speed of the drills and the time of expected response since Chris had low muscle tone. I agreed to her suggestion. This resulted in almost immediate success for Chris since his own level of ability was taken into consideration. (See Addendum, Appendix F.)

Chris showed the same loving nature usually portrayed by individuals with Down syndrome. He enjoyed a good laugh and was delighted when he realized my satisfaction with his responses to the drills. He was clearly motivated to continue working with me. At the same time, I could see that he received personal satisfaction by achieving the desired results. To me as his tutor, this was a breakthrough of significance. He continued to show the same desire to please towards the tutor that tutored him at home. This was also a breakthrough of significance since we could then safely assume that there was transference of success from one place to another and one person to another. One could thus conclude that Chris had learnt from one experience and by learning was able to gain new insight into his world. According to the principles of PAR (Babbie & Mouton (2001:233)), Chris became confident about his own abilities.

4.4.3 JOURNAL

Chris received his tutoring during school hours at Seal College. He arrived every morning at 08h30 and was met by me at the school. As the contact between his parents and myself was minimal due to a lift service to and from the school, we decided to use a journal to keep us informed of all developments. This proved to be a great success. We recorded the events of the day and could also share our emotions and hopes in this journal. The journal also gave us the opportunity to document the successes of the day. This gave the parents something to hold onto. Chris's mother used the journal as a method of regularly informing the tutors of events at home that would have an impact on the tutoring process.

I had noticed that Chris was picking up weight. This concerned me as Chris already had poor body stature due to low muscle tone. I mentioned my concern to his mother

telephonically. She agreed to use the journal as a method of keeping me informed about his diet as well. Children who have Autistic Spectrum Disorder could have food preferences. Chris preferred bread and chips. By means of the journal I could encourage his mother to slowly introduce other food sources as well. This was difficult for his mother since Chris did not easily take to new tastes and food sources. She accepted the encouragement eagerly and gave as much co-operation as possible. The parents returned the encouragement by giving regular feedback on their experiences with their child. This encouraged me as tutor to continue the hard work and not to focus on the occasional failure. (See Addendum, Appendix G.)

4.4.4 REFLECTIONS

The opportunity to receive training in the principles of ABA was of immense value to myself as well as to my colleagues. It was an opportunity to receive training in a therapy skill we would not otherwise have acquired. We were also excited about the opportunity to work with a child and his parents on an intimate level and hopefully to add value to their lives.

The physical work of tutoring is tiring. As mentioned in Chapter Two, tutoring is given for 30-40 hours per week with no acknowledgement of your own emotions. Tutors should be aware that ABA support programmes could be monotonous and emotionally draining. All your energy and focus is on the child with little regard to anything else. The tutor will have to be prepared to continue tutoring with no acknowledgement of their personality and abilities.

The realization that the *therapy* is the process and not the therapist support is a difficult adjustment to make. Engelbrecht and Green (2001:7) stated that human beings are actively involved in the construction of meaning, but with ABA therapy the tutors had to adjust to the realization that the successes were due to the programme and not their abilities. The most difficult realization for the tutors was that failures, such as an inability to pronounce words correctly, should not be taken personally but rather be seen as an opportunity to review the drills and the skills with which they are applied.

I do not think the tutors were fully aware of the impact the ABA programme would have on their personal lives. The tutoring process requires a full day of intense

concentration since the learner is stimulated continuously with very short breaks between the drills. The tutors became tired and even irritable with the parents, who needed encouragement to continue the process after the tutors had left for the day. Nevertheless, the tutors gained experience and insight into the real lives of people with disabilities. The depth of understanding and empathy that was fostered in the tutors could not easily be replicated. (See Addendum, Appendix B.)

4.5 SUMMARY OF THEMES

In this section I will highlight the dominant themes which emerged through the data analysis. In Chapter Three I explained that I conducted interviews with the other tutors involved in the project. These interviews were coded to determine whether there were any similarities in the responses (see Addendum, Appendix A). I also reviewed the field notes and videos to confirm my own personal notes and observations. I need to emphasize the fact that the interpretations of the tutors' experiences are my personal perceptions. I stated in Chapter One that a qualitative framework provides the opportunity to remain flexible enough so that variables can be considered before final conclusions are reached (Mertens, 1998:34). At the same time a qualitative framework allows for the personal interpretations that this study lends itself to.

It seems that the tutors were all excited about the opportunity to participate in research relatively new to the field of psychology. The principles of ABA therapy are not included in the general training of Educational Psychologists. The opportunity to gain this training was viewed by the tutors as opening up possibilities for their future careers.

The opportunity of working with a special child with special needs touched the hearts of each tutor in unique ways. The programme demanded specified application skills, which according to Lovaas (1987:7) would determine the success of the support programme. The tutors participated in the programme with good training and sound ability to apply these skills, but soon found themselves influenced by the person they had to tutor. The tutors discovered a special 'love' from and for the child they tutored.

As mentioned in Chapter Two, the principles of ABA therapy determine that the tutor adhere to a strict and rigid pattern. This pattern requires the tutor to work through a specific drill and to continuously increase the pace. Correct responses are rewarded immediately and incorrect responses corrected immediately. The resistance the learners might exhibit is ignored and the drill is administered until the learner responds in the correct manner.

The tutors found these principles to be too rigid for the concomitant disorder of Down syndrome and Autism. The personality of the Down syndrome individual influenced the interaction between tutor and child. It was only after adaptations and allowances were made for the uniqueness of the Down syndrome personality that breakthroughs were achieved.

The tutors realized that a learner with Down syndrome enjoys personal interaction and has a natural tendency to please. In comparison to the learner who has Autism, the learner with Down syndrome is more susceptible to body contact. The learner with Down syndrome has an intellectual disability, which the learner with Autism does not necessarily have. At the same time, the learner with Down syndrome could have low muscle tone, which would influence the manner and speed with which they can react to instructions. The tutors realized that they would have to allow more time for the learner to respond as the characteristics of Down syndrome override the features of Autism.

4.6 CHAPTER SUMMARY

In this chapter I interpreted and discussed the experiences of the tutors while tutoring a child with Down syndrome and Autism. I carefully reviewed the available data in order to come to an understanding of their experiences. I attempted to link my interpretations to the PAR methodology as discussed in Chapter Three. My interpretations are therefore subjective since I was myself an active participant in the research process. I interpreted the data from my own personal frame of reference of working with a child that has Down syndrome and Autism. My interpretations may therefore not be generalized to the broader population as already indicated in Chapter Three.

CHAPTER FIVE

SUMMARY AND POSSIBILITIES FOR FURTHER RESEARCH

5.1 INTRODUCTION

This study focused on the experiences of tutors who worked with a child with concomitant Autistic Spectrum Disorder and Down syndrome. The learner with Autistic Spectrum Disorder and Down syndrome syndrome was involved in a research project initiated by the Department of Educational Psychology of the University of Stellenbosch. The project intended to evaluate the effect of an Applied Behaviour Analysis intervention on a child with Autistic Spectrum Disorder and Down syndrome. The project proved to have extensive effects on all the participants, and the question soon arose as to what impact the programme had on the tutors.

The specific aim of this study was to gain insight into the experiences of the tutors of the child undergoing an Applied Behaviour Analysis support programme.

In this chapter the implications of the research findings will be provided. I will attempt to pay attention to the limitations of the study and also to provide recommendations for further research. Each chapter is also briefly discussed.

5.2 SUMMARY

Chapter One provided a brief overview of the motivation for the study. I was contacted by the University to become involved with the study as a tutor to a child with Down syndrome and Autism. As trainee psychologist I viewed this opportunity as an extension of my training, since not many people are trained in the principles of Applied Behaviour Analysis. The opportunity to work closely with a boy for an extended period of time would give me an opportunity to gain valuable insight into a child who has Down syndrome and Autism. I outlined my involvement with the

programme and the subsequent development of my interest in the experiences of the tutors.

I formulated the development of the research by clarifying some key concepts. This provides the reader with insight into the establishment of REACH, the support network, as well as gaining some understanding of the relevant research. I continued to provide information regarding the research framework from which I conducted my study. I discussed the theoretical perspective of social constructivism as a means of understanding the experiences of the tutors. Social constructivism as explained by Vygotsky (Donald *et al.*, 1999:40) states that human beings are engaged in the construction of meaning within their social communities. It was also indicated that it was out of this interest that I chose PAR as the framework from which to conduct my research. PAR is seen by Mertens (1998:34) as one of the frameworks that dominate in social research. The appropriateness of this choice was highlighted by my focus on attempting to understand the insider perspective of the tutors' experiences.

In Chapter Two I briefly discussed literature about the theoretical perspective of social constructivism. According to Donald *et al.* (2000:40), the learning process of humans is an active process. In this chapter I indicated that the support programme will therefore have an effect on all the participants and not solely on the learner.

Reviewing literature on the concomitant disorder of Autistic Spectrum Disorder and Down syndrome continued the chapter. Very little literature was available on the concomitance, so the two disorders were first discussed separately. Attention was given to historical development, prevalence, causes and treatment.

Research on the concomitant disorder was then discussed, also referring to aspects of diagnosis, causes and treatment. It was stressed that diagnosis of the concomitance is difficult and should be done by a professional. Treatment programmes and prognosis were also discussed and mention made that professionals agree that early support is crucial (Capone, 1999:8-15).

In this chapter I also discussed the principles of ABA, which has shown positive research results with children who have Autism (Lovaas, 1987:7).

In conclusion, I highlighted the experience of the tutors. I mentioned how the tutors were affected by interacting with children who have Autism. I made specific mention of the Son-Rise Programme (file://A\exp 1.htm), where tutors described their interaction with the children as 'magic'.

Chapter Three focused on the methodological approach used in the research. I attempted to clarify the role of the researcher within the social constructivist framework and how my active involvement in the research shaped my research method. A variety of techniques of data production such as observation, interviews and documentation were discussed. I also indicated how the data produced were verified in order to meet the criteria of validity and verification. Lastly, the ethical issues concerning anonymity, confidentiality and reporting were discussed.

Chapter Four focused on the findings of the study. The cases involved were placed in context in order to provide the background against which the data were interpreted. A variety of themes emerged while analyzing the interviews and reflections, the main ones being Interaction, Tutors' expectations, Change, Lack of Knowledge, Excitement, Anxiety, Frustration, Irritation and Parents' expectations. I indicated how these themes should be interpreted against the active involvement of the tutors in the programme.

5.3 DISCUSSION OF FINDINGS

In this study the principles of the Applied Behaviour Analysis intervention programme were analyzed and viewed as effective. According to Green (2001:42) an ABA programme should be delivered by individuals with extensive training in the method, ideally under the ongoing supervision of a professional who has advanced training and experience of the ABA principles and methods.

The tutors were in constant contact with the supervisor, who attempted to reinforce the rigid principles of ABA therapy in them. The tutors were, however, affected by the personality of the child they tutored. The tutors made specific mention of the love they experienced. The interaction between child and tutor resulted in a bonding which is not mentioned in the ABA programme as described by Lovaas. The social constructivist perspective of Vygotsky (Donald *et al.*, 2000:41) as described in

Chapter Three mentions that gaining knowledge is a process that is enhanced by social interaction.

The tutors were also of the opinion that it is important to consider the diagnosis in determining the support programme. This study focused on children who have Autism and Down syndrome. When determining the support programme, it would be beneficial to consider the characteristics of both disabilities and not to focus solely on Autism. The overriding disability would determine much of the support to be given, but both disabilities would have an influence on determining the application of the specific skill training.

The tutors experienced much change in the individual child. The initial frustrations of the resistance exhibited by a child with Autism was soon overcome, and the tutors' interactions with the learners increased proportionally as the learners responded to the positive rewards. The continued interaction between the tutor and child lessened the initial anxiety of performance of the tutors, which was replaced by excitement about the growth processes in the child. The tutors focused on the needs of the individual child and attempted to foster continued interest in the learning process. According to Maurice (2001:8) ABA therapy has a curriculum that the tutors follow and this teaches the child with Autism how to learn. The tutors differed in their opinion - they found that the learners had specific needs that had to be attended to.

The following could be viewed as limitations of this study:

- With a qualitative study, generalizations to the whole population are not possible. Furthermore, the study was approached from a participatory framework, where the researcher was intimately involved with the study. However, this study provided valuable information with regard to the daily experiences of tutors of a support programme as intensive as Applied Behaviour Analysis.

- The ABA programme has strict application patterns, which are researched in depth in children with Autism. The application of this programme in children with additional disabilities has not yet been sufficiently researched. As a result, the tutors had to make adjustments to the applications for maximum benefit for the child with Down syndrome and Autism.

- A child with Down syndrome has debilitating factors unique to Down syndrome. The strict application patterns of ABA does not allow for these factors, with the result that the child struggles to comply with some of the expectations. I found at certain stages of the support programme that adaptations had to be made to allow for the Down syndrome characteristics of the child. I was of the opinion that the Down syndrome characteristics overrode the behaviourisms of Autism. The natural tendency of lovingness of the individual with Down syndrome seemed to surface. I am aware that this characteristic might have influenced my experience of the child.

- Very little literature was available on the concomitance of Down syndrome and Autistic Spectrum Disorder. I found it difficult to decide which disability was of primary influence in my tutoring process, since the disabilities intermingled with each other. I could not find literature that could guide my uncertainties.

- Very little literature was available on the tutoring experience in children with Autism, and none on the tutoring of learners with concomitant Down syndrome and Autistic Spectrum Disorder. Having been able to study some literature would have provided me with some confidence, but I am also proud of the contribution that we as tutors have made to the application of an ABA support programme.

5.4 IMPLICATIONS AND RECOMMENDATIONS

The findings of this study relate to the results of the studies done by Lovaas in 1987. The children responded favourably to some of the principles of Applied Behaviour Analysis. They experienced positive growth in a large number of areas, such as eye contact when called, responding verbally when called, performing tasks on command, sitting still when requested, and identifying colours as well as their written name.

The experience of the tutors could also be related to previous research. The reflections of tutors involved in the Son-Rise Programme could be viewed as confirmation of the emotions experienced by the tutors involved in this study.

From the perspective of researcher as well as trainee psychologist, it became increasingly clear to me that the interaction between tutor and child could not be

ignored. The strict principles of the ABA support programme require little emotion from the tutor. However, the possibility exists that interaction between a tutor and a child with Down syndrome and Autism differs from the interaction between a tutor and a child with Autism alone. It became clear that the tutors needed additional information about the disorder of Down syndrome in order to fully understand the child they were tutoring.

I view this study and its findings as an illustration of the impact that a programme such as ABA would have on the community in which the individual exists. The individual does not build meaning by living in isolation, but draws on the actions and reactions of individuals living in close contact with him/her. As such, both tutor and child were influenced, but the influence also extended to the programme as well as others involved.

5.5 CHAPTER SUMMARY

This study demonstrated that the Applied Behaviour Analysis support programme impacted on the lives of the tutors and the children. The tutors could not 'distance' themselves from the intense daily contact with the child. They became influenced by the personality of the child. The result was that they examined the principles of the programme more critically. Their conclusion was that the principles of ABA are effective, but the characteristics of the concomitant disorder need to be considered in the final support programme.

The tutors had to extend their training to include knowledge about Down syndrome. The skills training of the children had to be adapted in order to acknowledge the abilities of a person with Down syndrome. In this process it became difficult to adhere to the strict patterns of ABA. The overriding decision, however, was that the individual needs of the children had to be met.

As trainee educational psychologist and researcher involved in this process, I too needed to reframe my experiences in order to view them objectively. The long distances I travelled and the long hours spent with the child caused me to reflect on my personal strengths and motivations. At times I needed to review my professional

skills in dealing with the needs of the child. This provided me with the opportunity to develop my professional skills. This will benefit me in my future practice.

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

REFERENCE LIST

Aarons, M. & Gittens, T. (1999) *The handbook of Autism. A guide for parents and professionals (2nd edition).* London: Routledge.

Adler, P.A. & Adler, P. (1994) Observational techniques. In: N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research.* Thousand Oaks, California: Sage.

Anderson, S.R., Avery, D.L., Dipietro, E.K., Edwards, G.L. & Christian, W.P. (1987) Intensive home-based early intervention with autistic children. *Education and Treatment of Children,* 10:352-366.

Anderson, S., Taras, M. & Cannon, B. (1996) Teaching new skills to children with Autism. In: C. Maurice (1996) *Behavioral intervention for young children with Autism: A manual for parents and professionals.* USA: Pro-ed Publishers.

Ary, D., Jacobs, L.C. & Razavieh, A. (2002) *Introduction to Research in Education (6th edition).* USA: Wadsworth.

Autism South Africa: http://www.bccs.co.za/autism-sa.

Babbie, E. & Mouton, J. (2001) *The practice of social research.* Cape Town: Oxford University Press.

Barlow, D. & Durand, V. (1999) *Abnormal Psychology: An integrative approach (2nd edition).* USA: Brooks/Cole Publishing Company.

Birnbrauer, J.S. & Leach, D.J. (1993) The Murdoch early intervention program after 2 years. *Behavior change,* 10:63-74.

Bogdan, R.C. & Bilken, S.K. (1992) *Qualitative Research for Education: An Introduction to theory and Methods (2nd edition).* Needham Heights, Massachusetts: Allyn & Bacon.

Bregman, J. & Volkmar, F. (1988) Case study: Autistic Social Dysfunction and Down Syndrome. *Journal of American Academy of Child and Adolescent Psychiatry,* 27:440-441.

Brown, L.D. & Tandon, R. (1983). Ideology and political economy in inquiry: Action research and participatory research. *The Journal of Applied Behavioral Science,* 19(3):277-294.

Capone, G. (1999) Down Syndrome and Autistic Spectrum Disorder: A look at what we know. *Disability Solutions,* 3(5,6):8-15.

Chitere, O. & Mutiso, R. (Eds.) (1991) *Working with rural communities: A participatory action research in Kenya.* Nairobi: Nairobi University Press.

Cooper, J.D., Heron, T. & Heward, W. (1989) *Applied Behavior Analysis.* Columbus, OH: Merrill.

Cuskelly, M., Jobling, A. & Buckley, S. (2002) *Down syndrome across the life span.* London: Whurr Publishers.

Denzin, N.K. & Lincoln, Y.S. (Eds.) (1994) *Handbook of Qualitative Research.* Thousand Oaks. California: Sage.

Dey, I. (1993) *Qualitative data analysis.* New York. Routledge.

DSM-IV: *Diagnostic and Statistical Manual of Mental Disorders* (1994) Washington DC: American Psychiatric Association.

Donald, D., Lazarus, S. & Lolwana, P. (1999) *Educational Psychology in Social Context: Challenges of developmental social issues and special needs in South Africa.* Cape Town: Oxford University Press.

Engelbrechts, P & Green, L. (2001) *Promoting learner development: Preventing and working with barriers to learning.* Pretoria: Van Schaik Publishers.

Fals-Borda, O. (1984) Participatory Action Research Development. *Seeds of Change,* 2:18-20.

Fowler, H.W. & Fowler, F.G. (Eds.) (1964) *The Concise Oxford Dictionary of Current English (5th edition).* Oxford: Clarendon Press.

Geerz, C. (1973) *The interpretation of cultures.* New York: Basic Books.

Ghaziuddin, M., Tsai, L. & Ghaziuddin, N. (1992) Autism in Down's syndrome: Presentation and diagnosis. *Journal of Intellectual Disability Research,* 36:449-456.

Gilberg, C & Coleman, M. (2000) *The biology of Autistic Syndromes.* London: Cambridge University Press.

Goldberg, M.J. (1997) A new definition of Autism. File://F:\REACH CLINIC\Studies & Research\Basic Info 1.html.

Gough, N. (1999) Book review of David W. Jardine (1998) To dwell with a boundless heart: Essays in curriculum theory, hermeneutics, and the ecological imagination. *Journal of environmental education,* 4:262-265.

Green, G. (1996) Early Behavioral intervention for Autism. What does research tell us. In: Maurice, C. (1996) *Behavioral Intervention for young children with Autism. A manual for parents and professionals.* USA: Pro-ed Publishers.

Grobler, S.A. (1973) *Die Downsindroom kind.* Pretoria: J.L. van Schaik Bpk.

Guba, E.G. & Lincoln, Y.S. (1994) Competing Paradigms in Qualitative Research. In: N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of Qualitative Research.* Thousand Oaks, California: Sage, 1994.

Harris, S.L. & Weiss, M.J. (1998) *Topics in Autism. Right from the start. Behavioral intervention for young children with Autism. A guide for parents and professionals.* U.S.A.: Woodbine House Inc.

Hassold, T.J. & Patterson, D. (1999) Down syndrome: A promising future together. Wiley Liss Publications.

Heatherm@cruzio.com

Herbert, M. (1996) ABC of Behavioral Methods. Great Britian: Stanley L. Hunt Printers Ltd.

Huizer, G. (1984) Harmony vs confrontation. *Development: Seeds of Change,* 2:14-17.

Jordan, R. (2001) *Autism with severe learning difficulties.* Human Horizon series. London: Guernsey Press.

Larkey (file://A:\exp 2.htm)

Lighthart, R. (2002) The lived experiences of a sibling during the implementation of an Applied Behaviour Analysis intervention program: A case study. Stellenbosch: University of Stellenbosch. (Masters thesis)

Lincoln, Y.S. & Guba, E.G. (1985) *Naturalistic inquiry.* Thousand Oaks, California. Sage.

Lovaas, O.I. & Smith, T. (1987) Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology,* 55:3-9.

Mash, E.J. & Wolfe, D.A. (2002) *Abnormal Child Psychology (2nd edition)* U.S.A.: Wadsworth.

Maurice, C., Green, G. & Luce, S.C. (1996) *Behavioral Intervention for Young Children with Autism. A Manual for Parents and Professionals.* Texas: Pro-Ed Publishers.

McTaggart, R. (1991) Principles for participatory action research. *Adult Education Quarterly,* 41(3):168-187.

Merriam, S.B. (1998) *Qualitative research and case study application in education. Revised and expanded from case study research in education.* San Francisco: Jossey-Bass.

Mertens, D. (1998) *Research Methods in Education and Psychology: Integrating diversity with quantitative and qualitative approaches.* California: Sage Publishers.

Morton, J. (1989) The origins of Autism. *New Scientists,* 124(1694):44-47.

Neuman, W.L. (2000) *Social Research Methods. Qualitative and Quantitative Approaches (4th edition).* Boston: Allyn & Bacon.

Newton, R. (1997) *The Down's syndrome handbook. A practical guide for parents and carers.* London: Vermilion.

Olney, M.F. (2000) Working with Autism and Other Social-Communication Disorders. *Journal of Rehabilitation,* 66:51-56.

Powers, M.D. (2000) *Children with Autism. A parents' guide.* U.S.A.: Woodbine House Inc.

Reason, P. (1994) Three approaches to participatory inquiry. In: N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research.* Thousand Oaks: Sage.

Romanczyk, R. (1996) Behavioral Analysis and Assessment: The cornerstone of effectiveness. In: C. Maurice (1996) *Behavioral intervention for young children with Autism: A manual for parents and professionals.* USA: Pro-Ed Publishers.

Schwandt, T.A. (1994) Constructivist, Interpretivist Approaches to Human Inquiry. In: N. Denzin & Y. Lincoln (1994) *Handbook of Qualitative Research.* California: Sage Publishers.

Siegel, B. (1996) *The world of the autistic child. Understanding and treating Autistic Spectrum Disorders.* Oxford: Oxford University Press.

Son-Rise Program (file://A\exp 1.htm)

Spectrum (file://A:\4.htm)

Stake, R.E. (1995) *The Art of Case Study Research.* Thousand Oaks, California: Sage.

Swart, R. (1994) Die Opleiding van die Opvoedkundige Sielkundige as Reflektiewe Praktisyn. Auckland Park: Randse Afrikaanse Universiteit. (Doktorale Proefskrif)

Terre Blanche, M. & Durrheim, K. (Ed.) (1999) *Research in Practice: Applied Methods for the Social Sciences.* Cape Town: University of Cape Town Press.

Terre Blanche, M & Kelly, K (1999) Interpretive Methods. In: M. Terre Blanche & K. Durrheim (Eds.), *Research in Practice: Applied Methods for the Social Sciences.* Cape Town: University of Cape Town Press.

Tesch, R. (1991) Software for Qualitative Research: Analysis Needs and Programme Capabilities. In: Fielding, Nigel G. & Lee, Raymond M. (Eds.), *Using computers in Qualitative Research*. London: Sage.

Valentine, G.H. (1966) *The Chromosome Disorder.* London: William Heinemann Medical Books Ltd.

Van den Berg, J.H. (1966) *Kleine Psychiatrie.* N.V. Nijkerk: Uitgeverij G.F. Callenbach.

Vatter, G. (1998) Diagnosis of Autism in Children with Down syndrome. File://A:\Diagnosis of Autism in Children with Down syndrome.htm.

Vedder, R. (1962) *Mongolisme.* Groningen: J.B. Wolters.

Wakabayashi, S. (1979) A case of infantile Autism associated with Down's Syndrome. *Journal for Autism and other Developmental Disorders,* 9(1):31-35.

Wiersma, W. (1995) *Research methods in education: An introduction.* Boston. Allyn & Bacon.

Weingarten, K. (1992) A consideration of Intimate and Non-intimate interactions in therapy. *Family Process,* 31:45-59.

Whyte, W.F. (Ed.) (1991) *Participatory Action Research.* Newbury Park: Sage.

APPENDIX A

QUESTIONS FOR INTERVIEWS

1. What motivated you to start/join the program?
2. Did you ever think of withdrawing from the program? What motivated you to continue?
3. Did you need any kind of support?
4. What type of things that happened during the course of the day caused you to reflect upon it at home?
5. Do you experience some emotion when you talk about the programme - how do you explain these emotions?
6. I found some things lacking in the programme. Are there things that you found lacking in the programme? What would these things be?
7. Having had the experience of working with this specific child, any specific thoughts concerning your work as an Educational Psychologist?
8. What thoughts would you share with others new to the ABA experience?
9. Would you recommend that all Educational Psychologists share the ABA training that you had? Why?

Tutor: Cathy*

1. I just thought it would be a challenge – something new. I had worked with learners with needs – special learners. A unique opportunity. I had background already. An opportunity to develop new skills I think.

2. Yes, - especially when we reached a platform. Why did I stay - umm, there was no development in B* I was frustrated. Nothing happened. That with the long hours was demotivating. But the hope and to see if ABA really works. They said it did and I wanted to see for myself and of course the boy. I think more the personality, mote than the therapy itself.

3. Initially no, I did not have enough training. I started in January not really knowing and that was demotivating. Planning was not good either. The distance I had to travel every day – I had to work through that. In general – I got support from J* and from B* himself – a lot- the interaction. Also friends and family always asking. I didn't get formal support.

   The interaction between the tutors also – I needed to communicate about the day's process. Especially where we became stuck – I needed the other's input. Maybe if we could plan together or do debriefing at the end of the week.

4. There are some points I would change in the process – like the time frames between the instruction and the response. The 30 second rule does not apply with DS. It will break them and demotivate them. Also to allow more social time. Early on, if you take the children back to 0 months, with ABA social skills comes much later. With ASD/DS you must incorporate these right from the start.

5. I had a lot of emotions during the process. Frustration. I think of B* a lot. The humor, love, affection. His photo is still next to my bed. I think of the child, my personal opinion in this therapy it can never just be the therapy. Umm, there was definitely a change of energy

between us. Definitely not just the therapy – something else.

6. The DS forced you to take the process slower. There is more communication and touch taking place. You had to accommodate these. You'll break the child if you don't. I think it is not just a therapy you force onto somebody, because it is behaviourism you know. With the DS personality the child is a consideration.

7. I think – a couple of things are important. Be careful to judge at face value. You see DS and you expect love, kindness, sociability and then you get Autism. You get the anger, the resistance. That is difficult to deal with and you must be aware of that. Working with a child – you as the psychologist needs to work with the interaction of both disorders. You can't just focus on one aspect. You must allow for all the disorders. You must know things like low muscle tone. With this child it was – weird – umm where the DS is for example sociable, the Autism took that away. But with ASD/DS, once I broke through, there was a lot of contact.

8. Short term yes- it works – the question is if it will be sustained – I don't know. It needs to be worked at. Some skills stayed, we saw that after the break, but eventually the family needs to make it a way of life. Autism could make the child withdraw again. The parents need continual support. The frustration must be facilitated

9. I think ABA has definite value for many reasons. The basic principles of ABA can be adapted to suit any type of therapy. The knowledge of the milestones that ABA taught me. ABA also showed me how to break down a skill, a bit of occupational therapy included into my training. I liked that. The awareness of the programme is good. I think educational psychologists need to know that. We also work with the parents and must be able to guide them when they choose. The parents must be commited though.

*substituted for ethical reasons

Tutor: Beth*

1. I think initially I decided to join because it was a good research topic. I decided to get more information because of that. Really only initially. I always had an interest in children with special needs. I learnt more about Down syndrome and autism and I would work with only one specific child for a long time. Initially it was the research only.

   I thought about what it would mean in future. I might go overseas again and work there. Not many people are trained in ABA and I would be able to include it in my practice. It would have benefit in my professional live in future

2. I never considered to stop. My husband often considered it. For me – what I was getting personally in the relationship with the child was motivation. Finances was a worry. I could never just stop and leave the child. Many days I got tired and was not in the mood for the drive, but when you come through the gate and the child gives hugs – that personal interaction between myself and the child! I think it part of being a psychologist – that building of a relationship between you and the child.

3. Support came from the other tutors and from my husband. If I couldn't see other tutor or had my husband, it would have been more difficult – even though the relationship with the child was good. The times at J*'s house was good – to talk about the programme and the drills. I think support from other tutors are necessary for others that are trained. Contact with others that are in a similar boat so to speak.

4. I would reflect on me as a person, not necessarily on the programme. I thought how I needed to interact with the parents. They viewed me as a friend. It was difficult to know where the boundaries were. I was part student, part professional, part researcher with their daughter. To maintain boundaries of person coming into their house when they discussed personal issues about the programme. I would say things and then wondered if I

said things I shouldn't have. I would reflect on role of psychologist – where did that end and where did role as friend start? Is it possible?

Ax Lk
Lk Ax

5. Ek wil sommer huil. Without it sounding "dweperig" I think children especially special children with special needs are placed on earth to teach us something. When I think of S* I experience a different type of "love" or "compassion". It makes me happy to be with him. He touches something another child wouldn't have. It is the first time I missed somebody I worked with for a long time like I miss him.

Ax
Te
In
Ex Te
In
In Ch

6. Apart from the general disorganized approach? I think it would have been better if someone specifically was appointed for the parents. J* tried her best and R* was available. Parents needed more than they got. They looked for it from the tutors – this caused the boundaries issues. Someone maybe not linked to the programme/tutors. Someone to support – continued after the project. The adaptation of new tutors. The university is not part anymore. Lives were changed and then left again, it's not right. The parents struggle. The programme continues for them, but nobody helps them.

Te
Te
Pe
Pe In
Fr Ax
In Ch
Ch
In Ch Ax Ir
Pe
Ax Fr Ir

7. My thoughts concerning ABA. I think ABA is good and I could see it worked with S* in many ways. Also at the same time, without a relationship with this child – the child must want to please you. The child must want to show their good behaviour. If you don't have that – with all the techniques and rewards – if the child is not comfortable with you as a person it won't work.

Ch In
Ch
In
Ex In
Te
In

New starters with ABA are at the beginning so worried about doing it right – this is not as important as just being with the child. It is important to use initiative.

Lk
In
Ch

A child that just has autism it is maybe different

Lk

Every child is unique, but with S* the Down syndrome overrides the autism. The structure of ABA is good, but you must consider the child. With Down syndrome the

In Ch
Lk Ch In
In

lovingness must be considered. The essence with autism is that you can't make contact. With Down syndrome it is exactly the opposite. S* has the behavioral things of autism, like the stimming, but he wants to be loved.

8. I think it is not necessary to have the practical training to be an ABA tutor. It would be helpful and good to be part of the Educational Psychologists background to be familiar with the techniques. Especially to be aware of the theories of autism. There are different ways of treating autism. Would also be good to be aware of other conditions going with autism.

* substituted for ethical reasons.

ANSWERS
Tutor: Anne*

1. Wat gebeur het – ja voor dit het ek met 'n outjie gewerk met outisme. Ek het toe ook in die Bronnesentrum gewerk en R* en W* het geweet ek werk met die kind en toe een dag vra hulle vir my of ek sou wou deel hê in die projek. Ek het ja gesê. Veral omdat ek al klaar dit doen. Ek wou meer uitvind. En ja, ook omdat ons by 'n huisgesin betrokke sou wees, nie iets wat enigiemand sommer sou doen nie.

In
In
Te Ex
Te Ex

2. Ja en nee – ek het moeg geraak. Dit vat heeltyd van jou. Jy gee soveel van jouself. Ek wou nooit net ophou nie. Ek het soveel van S* gekry en daar was soveel volrdering. Nee, ek kon nie net los nie. Ja, ek het moeg geraak, maar ek wou nie net ophou nie.

Fr In
In Ch
Ch Te
Fr

3. Ondersteuning. Ons het baie ondersteuning gekry, veral van die ouers of. Ek het gevoel ek beteken iets, dit was lekker. Ons het genoeg gesien. En ek en B* het mekaar elke dag gesien en ons het mekaar baie ondersteun. En dit was ook lekker om met die ander tutors te praat. Van die ander tutors het ek ook ondersteuning gekry. In 'n ABA program is ondersteuning kritiek, Kontak met jou mede tutors. Vat baie uit 'n mens. Het kontak met ander nodig.

In
In Te
In
In Ex
In
Ax In
Ax In

4. Ek het by die huis gedink oor goeters soos – baie goed. Tegniek self. Op die video gekyk. 'n Mens raak baie krities oor jouself. Ek wonder oor hoe ek dinge doen en ander maniere om dinge te doen om dit interessant te hou. Op ander vlak – dit wat S* uitstraal het my geraak en dit was lekker. Daardie vreugde, daardie lief wees, vry wees, ja.

Ch Ax
Te
Ch Te Ax
In
Ex In

5. Ja emosies is wakker gemaak. Ja, die feit dat jy soveel van jouself gee. Maar hy was ontvanklik daarvoor. Met die ander kind was dit anders. Hulle gee nie terug nie, S* het teruggegee. Die lieftalligheid of karakter van die Down sindroom was definief daar. Ek self is nie 'n

Ex In
In Ch
In
In

vashou en druk tipe mens, maar S* het dit net gevat en afgebreek. Die interaksie met S* en die betrokkenheid by die gesin – die gesin het jou ingetrek. Die grense was DUN, maar ek en S* het gedans en klomp dinge gedoen. Daardie menswees en saamwees. Daar is 'n ongelooflike verskil tussen ASD/DS en en ASD. ASD is heeltemal anders as ASD/DS. ASD is heeltemal – deur jou kyk en geen kontak – met S* was daar definitef kontak. S* was definitief meer sosiaal.

6. ABA was effektief maar nie nodig om so streng te wees hier soos met ASD nie. Rewards werk goed, maar baie meer interaksie is moontlik. Die storie van net die tegniek en nie die persoon is nonsense hier. S* het definitef gereageer op my as mens. In program alreeds uitgekom dat aanpassing vir Down sindroom nodig is. Die menswees kan jy nie skei nie.

7. Die persoon van die tutor het tog 'n invloed en ook die kind. Met 'n sensitiewe kind byv. Gaan 'n meer sensitiewe tutor beter werk. Maar by suiwer ASD is die tegniek baie belangriker as by Down sindroom, want hulle manipuleer. "Persoon" van die kind is tog ook belangrik. Ons is nie robotte nie.

8. ABA aanbeveel? Beginsels werk definitief ja. Maar wie dit doen en hoe. Die kwessie van gedrag en beloning – dit werk. Ek is tog versigtig. Ouers moet hulle huiswerk doen. Kyk ook na die kind se omstandighede, skool ens. Die menswees agter alles bly vir my belangriker as die tegniek.

9. Dit hang af van of die persoon belangstel in outisme en ABA. Dit help nie jy leer vir iemand van dit en hulle gaan dit nooit gebruik nie. Ek is bly ek het die geleentheid gehad. Mense daar buite het nie vertroue in die professionele mense nie, want hulle weet nie waaroor dit gaan nie. Dis 'n spesialis gebied. As Opvoedkundige Sielkundige gaan ons met kinders werk en moet tog dan weet van outisme en Down sindroom en dan ook ASD/DS. Daar is soveel tegnieke. Tog dink ek dis waardevol, kyk na die voorkoms, dit vermeerder. Om dit deel te maak van die kursus – miskien meer inligting oor

die tipes intervensies, maar elkeen moet ook maar self ondersoek instel, daar is te veel inligting. Daar is ook nie resepte nie. Lk

10. Ek dink dat jy nie weet waaroor dit gaan voordat jy nie self die praktiese ervaringe opgedoen het nie. In Lk

*substituted for ethical reasons

APPENDIX B

As deel van die projek was ek 'n tutor vir . van Januarie tot Desember. Dit was nogal 'n ondervinding om elke weeksoggend 7:30 by die op te daag en op 'n manier deel van hul daaglikse oggendprogram te word. Dit was soms moeilik om nie die grense oor te steek van "ek is net se tutor". Die ouers het so 'n behoefte om hul gevoelens en gebeure te deel dat 'n mens dikwels daarby betrek is as ondersteuning vir hulle.

Ek het die opleiding baie interessant gevind veral aangesien ek reeds die vorige jaar 'n tutor was vir 'n leerder met outisme. Alles het vir my duidelik geword, en ek het uitgesien om met te begin werk. Ek moet sê, ek was nogal op my senuwees die eerste dag. Ek het nie geweet wat om te verwag nie, en almal het soveel verwagtings gehad. Ek het gewonder hoeveel sukses sou ons behaal, maar dit was 'n lekker uitdaging. Een van die onderliggende beginsels van ABA-terapie is dat die tutor nie so 'n groot invloed het op die proses nie, maar dat dit eerder die program/proses is. Ek wonder nogal hieroor? Ek dink die tutor se persoonlikheid speel tog 'n groot rol.

Ek het so baie by geleer oor om lief te hê. Hy sou sommer hardloop en op my skoot spring, en was opgewonde oor die kleinste beloning (soos om buite die bal te gaan skop/om die blok te stap/video kyk/musiek luister) kan sekere dinge so terdeë geniet! Hy het vir my hierdie lewenslus en ware omgee gedemonstreer in 'n tyd wat dit vir my baie beteken het.

Om tutor te wees vir drie en 'n half ure was parytkeer uitputtend, want 'n mens gebruik alle energie en fokus op die kind sonder om jou eie gevoelens te erken. Daar was 'n keer wat hy my met 'n *clipboard* 'n blou-oog gegee het, en dan moes ek maar net voortgaan met *tutoring* en dieselfde beginsels toepas asof niks gebeur het nie. Dit was ook moeilik die kere wat hy nie lekker voel, en wanneer hy goed begin rondgooi of begin huil/skree. Dit vat aan 'n mens en dit was soms moeilik om dit nie persoonlik op te neem nie.

Dit het my bewus gemaak van die uitdagings waarmee die gesin lewenslank te doen het - emosioneel, finansieel, sosiaal,ens.

Hy het my geleer van dankbaarheid vir wat ek het, en om van myself te gee - hy het soveel vir my gegee.

My belewenis van ABA terapie met _____

Die storie mag dalk 'n bietjie deurmekaar voorkom, want ek dink sommer soos ek skryf. Eintlik dink ek al vandat jy my verlede week weer gevra het om my belewenis neer te skryf aan hoe dit regtig gevoel het.

Om my storie te begin moet ek eers die gevoel beskryf wat ek gehad het toe ek hom die eerste keer ontmoet het. Al was ek goed voorberei op wat om te verwag, was dit nogsteeds vir my 'n moeilike ervaring. Daardie eerste dag toe hy niks met ons te doen wou hê nie, was nogal erg! Hy het buite op sy maag gelê en 'n wurm intens bestudeer. Die arme wurmpie was van tak na tak rondbeweeg en het later maar half dooierig voorgekom. Deur die hele proses was se aandag toegespits op die wurmpie en wou hy aanvanklik maar net mooi niks van ons weet nie. Woordeskat was beperk tot "no!" of "go!" wat hy in sy kenmerklike hees stemmetjie met heelwat emosie na ons kant gebulder het. Ek onthou hoe ek by die huis gekom het en oortuig was daarvan dat die fout by my lê. Die outisme se aandeel was glad nie ter sprake nie, net my eie gevoel van mislukking omdat ek nie kon deurdring tot hom nie.

Alhoewel Jenny genoem het dat die terapie niks met die terapeut te make het nie, kon ek nie help om te voel dat ek eers op 'n persoonlike vlak tot hom moes deurdring voordat die terapie kon begin nie. Die eerste glimlag en oogkontak van sy kant af het soos 'n oorwinning gevoel. Aanvanklik was die begin van die terapie vir my 'n uitdaging. Elke suksesvolle poging van sy kant af het my van voor af moed gegee om voort te gaan daarmee. Toe bereik ons die "groot stilstand". Niks gebeur nie - nuwe take word nie bemeester nie en die ure word frustrerend en lank. Ek besef nou dat die gebrek aan voldoende opleiding voordat die proses begin is, baie hiermee te make gehad het. Dinge sou miskien anders gewees het as ek voor die tyd meer opleiding ontvang het. Dit maak egter nie 'n verskil aan die belewing van die situasie nie. ABA terapie kan nogal sielsdodend wees. Om dag in en dag uit vir 4 ure aaneen dieselfde opdragte keer op keer te herhaal en entoesiasties te beloon is nie maklik nie. Die weerstand van sy kant af en sy frustrasie en moedeloosheid het definitief 'n uitwerking op my gehad. Ek moet erken dat daar tye was waar ek die terapie onderbreek het om net weer by die mens, te wees. Om hom te leer ken sonder herhalende opdragte wat met weerstand begroet is.

9/6/02

Ek dink dit was vir ons albei 'n moeilike tyd. Om en by dieselfde tyd het ons verdere opleiding by . ontvang. Wat 'n "eye opener"! Eweskielik het ek besef waaroor die terapie werklik gaan en het ek besef waar ons in ons onkunde foute gemaak het. Die opleiding het my egter ook nie ongeraak gelaat nie. , die seuntjie wat tydens die opleidingsproses terapie ondergaan het, se gille het my baie ontstel. Meer ontstellend nog, was die feit dat sy ma die hele proses moes aanskou. Dit was vir my asof 'n perd ingebreek geword het. Sy moedelose gesnik aan die einde - volgens die terapie 'n deurbraak - het my oorweldig. En toe - die glimlag! Hy kry die take reg, verstaan wat van hom verwag word en reageer op die belonings. Wat 'n kontras! Ek kon nie help om te dink wat binne hom gebeur het nie. Het hy oorgegee? Waarom die glimlag? Was dit 'n respons op almal om hom se blydskap toe hy take bemeester? Wat het hy werklik ervaar?

In Ax
Lk
Ax In
Ax In
Lk
In Ex
In Ex Ch

se terapie het na die "stilstand" en ons daarop volgende opleiding weer 'n opflikkering getoon. Ewe skielik kon hy take bemeester wat voorheen "onmoontlik" geblyk het. Sy prestasies het my met trots gevul. Ek was bly vir die aandeel wat ek daarin kon hê. Nee, ek dink steeds nie dat dit slegs die terapie is wat 'n verskil gemaak het nie, maar wel 'n kombinasie van terapie en menslikheid. Uitreiking na hom toe en om hom die spasie en tyd te gee om te leer. Ons het ons terapie in 'n sekere mate by aangepas en dus kon dit nie meer net die terapie wees nie. Sy verwagte responstye is verleng, terapie is afgewissel met tye vir interaksie met ander en vir sommer net saam wees tye.

Ax Tr. Lk
Ch Te
In Ch
In
Ch Te

Vir my persoonlik was die grootste deurbraak die haarsny proses. Die wete dat dit altyd 'n groot kopseer besorg het en dat hy nou toelaat dat sy hare gesny word is wonderlik. Ek sou graag wou weet of dit nogsteeds die geval is. Dit was regtig lekker om deel te word van . se lewe. Ek het ongelooflik baie by hom geleer en nee, dit is nie weens die terapie nie.

Ex In
TE
Lk Ex
In

het my geleer om weereens die geluk in die eenvoudige dinge in die lewe te vind. Hy het my geleer van uitreiking na ander. As hy, vir wie dit so moeilik is, kan uitreik na ander - hoeveel meer kan ek nie? Hy het my geleer van vergewe, maak nie saak wat nie! Hy was hoeveel keer deur van die ander kinders afgeknou of hardhandig behandel, maar na 'n rukkie het ... maar weer sy arm om hulle gegooi of gelag uit sy maag uit. in samewerking met die ander kinders by sy skool, het my ook geleer om nie so maklik te gril vir loopneuse, kwyl, boude afvee en ander (voorheen ondenkbare) grillerige dinge nie. het my ook geleer om verby die "gestremdheid" te kyk en die mens raak te sien. My vorige ervaringe met leerders met "barriers" het my wel goed hierop voorberei (en dit was maklik), maar omdat . se "barrier" so opsigtelik was en die terapie so meganies het dit langer geneem om werklik die mens te ontdek.

In
In Ch Ex
In Ch.
Ch
Ch
Lk In Te

Alhoewel ABA terapie dalk nie my verkose vorm van terapie sal wees nie, twyfel ek geensins daarin dat dit werk nie. Ek het gesien hoe dit werk. Wat wel nou na afloop van die proses vir my hartseer is, is dat ons "wakker" gemaak het, bewus daarvan dat hy take suksesvol kan bemeester en gewoond aan individuele aandag - en nou is die proses gestaak. Wat doen dit

Ex Ch
Ch
Te Ax Tr.

9/6/02

ERVARINGE AS TUTOR GEDURENDE DIE DS/ASD PROJEK:

Rona het ons klasgroep min of meer in Augustus 2000 gevra of enige iemand sou belangstel om deel te hê in die projek. Ek was dadelik geïnteresseerd, maar het gewonder oor die finansiële implikasies wat dit sal inhou. Na 'n gesprek met het ek besluit om dit aan my man te noem en te kyk wat gebeur. Hy het ingestem, aangesien hy gesien het hoe graag ek dit wil doen, hoe baie dit in die toekoms kan beteken en op grond van die feit dat die US ook sou help met die petrolgeld.

In September het ons begin met die eerste opleiding en aanvanklik was dit ek, en . .. Ons was almal baie opgewonde. Namate die projek ontvou het, het ons egter meer en meer bewus geword dat die tyd en geld daaraan verbonde baie meer gaan wees as aanvanklik voorgestel. het besluit om te onttrek en ek het ook onseker begin voel. My onsekerhede is egter oordonder deur my eerste ontmoeting met Ek kon nie dink dat ek nié met hom moes werk nie! Ek was ook oortuig dat ek met sy ouers oor die weg sal kom. Dit was egter vir 'n tyd daarna duister wie saam met my sou werk en ek het op stadiums begin benoud voel dat ek dalk die enigste sou wees. het eers in Januarie besluit om die groep te join. Deur al hierdie onsekerhede heen het geweet dat ek met moet werk en ek kon dit nie oor my hart kry om anders te dink of te besluit nie.

Teen Januarie toe die werk moet begin, was ek uitgerus en lus vir die ding. Ek was oortuig daarvan dat die tyd met vrugte gaan afwerp. Na die eerste maand het die prentjie egter bietjie anders daaruit begin sien. Ek het begin twyfel oor my vermoëns as tutor, die akademiese druk het begin oplaai, ek kon nie borge kry vir petrolgeld nie en die US het ook nie vorendag gekom met hulle bydrae nie. Boonop

het baie moeg geraak van die 108 km se ryery elke dag. Ek en het gereeld hieroor gepraat (wat gehelp het), maar sommige dae was dit baie moeilik om aan te hou en positief te bly! Al die verskillende vergaderings en eise deur die ouers gestel het natuurlik nie gehelp om die las ligter te maak nie. Deurentyd egter, was dit die gedagte aan en sy liefdevolle geaardheid wat my kon opkikker op dae wat ek regtig min energie gehad het.

Die hoogtepunte van die projek was eindeloos. Al die nuwe vaardighede wat aangeleer het, sy ouers se tevredenheid, die besondere band wat ek met hom opgebou het, my tesis, my werk met sy sussie … te veel om te noem en te onthou. Daar was laagtepunte. Die geld en gesukkel om dit uitgesorteer te kry het my soms laat voel dat die universiteit nie besef watter groot opoffering dit vir my is en hoeveel energie daarin gaan nie. Ek moet ook sê dat die bestuur van die projek my soms koud gelaat het. Die moeilikste deel vir my was egter om objektief te bly en verskillende rolle wat ek vervul het van mekaar te skei. Tutor, terapeut, vriendin, student. Die grense was by tye baie minder duidelik as ander en dit het my forseer om gedurigdeur te reflekteer oor wat met my aan die gebeur is. Verseker nie 'n maklike proses nie, maar ek is baie dankbaar dat dit gebeur het aangesien ek soveel oefening in die handhawing van professionele grense kon kry: wanneer raak jy betrokke en wanneer gee jy liewers net jou oor; wanneer praat jy saam en wanneer bly jy stil; hoe reageer jy as die regte kanale jou in die steek laat; wat bespreek jy met ouers en wat nie, ens..

Die jaar het my ervaring gegee wat ek vir niks sal verrruil nie. Nou, byna 'n jaar later, dink ek steeds gereeld aan en het ek gereeld kontak met sy ouers. Die lekkerste is dat ek vir hulle as 'n vriendin kan ondersteun. Die slegste? Dat hy tans byna geen vordering maak nie. Ek voel dat die US miskien 'n groter rol in die

nasorg ook moes speel. 'n Mens kan nie net ingaan en mense se lewens verander en dan weer onttrek nie. Dis nie regverdig nie en ook nie verantwoordelike praktyk nie.

APPENDIX C

UNIVERSITEIT VAN STELLENBOSCH
UNIVERSITY OF STELLENBOSCH

LETTER OF AUTHORITY

Undersigned _____ father/mother/guardian/client (underline the applicable) gives permission to the UNIT FOR EDUCATIONAL PSYCHOLOGY of the UNIVERSITY OF STELLENBOSCH to:

1. obtain information about myself/my son/my daughter from relevant persons/sources, and to give information to such appropriately skilled persons/sources;

_____
SIGNATURE

2. make and/or observe, if necessary, video and sound recordings of the examination/aid programme. Such recordings/observations will be handled anonymously and in strict confidence;

_____
SIGNATURE

3. use information obtained for research and training purposes (once again anonymously and in strict confidence).

_____
SIGNATURE

04 / 10 / 2000
DATE

_____
WITNESS

Eenheid vir Opvoedkundige Sielkunde
G G Cillié-gebou, Ryneveldstraat, 7600 Stellenbosch
Privaatsak X1, 7602 Matieland, Suid-Afrika
Tel: (021) 808 2229 Faks: (021) 808 4336

Unit for Educational Psychology
G G Cillié Building, Ryneveld Street, 7600 Stellenbosch
Private Bag X1, 7602 Matieland, South Africa
Tel: (021) 808 2229 Fax: (021) 808 4336

APPENDIX D

DS-ASD Research Project

1. PERSONAL DETAILS OF CLIENTS	
CHILD	
Christian name(s)	
Surname	
Date of birth	01-08-1989
Position of child in family	1ST
Number of children in family	2
FATHER/GUARDIAN	
Full name	
Qualification	electronics diploma
Occupation	manager
Age	46
Working hours	8am - 5pm
Work telephone number	557 3750
MOTHER/GUARDIAN	
Full name	
Qualification	travel consultant
Occupation	"
Age	39
Working hours	8am - 4-30pm
Work telephone number	419 2603
HOME ADDRESS	**POSTAL ADDRESS**

2. SCHOOL DETAILS

Name of current school	SEM COLLEGE
Grade	been there 3 years (not grade)
Teacher's name	CHARNEL VAN HEERDEN
Past schools attended Rivelands	Chere Botha Centre (2–7) – started early classes Glendale (1 yr) – reason – DISTANCE children leave at 6am – get home 4 pm
How did your child adjust to school when she/he went for the first time?	Started at age of 2 – he didn't protest adjusted well Some mornings protest like any normal child
Has your child ever refused to go to school? If yes, why?	No – since at Sem College grade has been ok! Jacob picks him up – combi – 7.45 am
What is your child's attitude to school?	Now happy – used to be a loner (Chere Botha) Since Sem more involved – built up confidence
What is your child's attitude to his/her teachers?	Loves his teacher
What is your child's attitude to homework?	Book will pictures point to them Bit of protesting – if make it a game OK.
Has your child ever changed his/her attitude? If yes, how (positive or negative) and why?	GLENDALE – protest – main reasons start they here. Got happier now CB – long – more dep – more a loner Glendale – children bigger – think there was a bit of bullying at playtime
Does your child achieve above or below his/her ability? Why?	Below average – don't want him removed from his current environment. If out of this environment doesn't achieve GLENDALE stimulated – upgraded him – teaching method
Does your child have problems with any specific subject?	Hate fine motor Loves sport, physical exercise

3. FAMILY STATUS

Married: child(ren) live(s) with both parents	Living together: child(ren) live(s) with both parents	Divorced: child(ren) live(s) with father	Divorced: child(ren) live(s) with mother	Separated: child(ren) live(s) with father	Separated: child(ren) live(s) with mother	Widowed: child(ren) live(s) with surviving parent	Legal guardian with whom child(ren) live(s)
~~X~~							

Home language	ENGLISH
Citizenship	SA

functioning at about 4–5 yr level – pre-school
children walk here more or less at same level
PRESCHOOL WORK self-help skills etc
unobserved
VERY GOOD AT SCHOOL
ROUTINE – good at it – structure / limits
expected him to get him up – this age – progress not acceptable STOP – instead of carry on + then repeating

4. FAMILY RELATIONSHIPS AND PARENTING STYLE

Do the parents agree on the approach to discipline?	Yes
How are the children disciplined?	Jane cut - bathroom Jane was corporal punishment - smack on bottom
How does the client respond to discipline?	It does work - especially the bathroom Performs, carries on - knows put there for a reason - doesn't go back
How would you describe your child's relationships with:	
Mother	Very good, close close knit more at Jane
Father	Very good like - do go out as a family
Siblings MEGAN	Very good
Does the child have a special bond with any family member?	Hard with her grandfather passed away Gets on with everybody > Debbie's dad
Does the child feel uncomfortable with any family member?	No
Are the child's grandparents alive?	grandmother (Debbie's side) Both Richard's parents passed away before born
If so, do the child's grandparents play an important role in his/her life?	Not really Jane in CT
Was mother/father separated from the child at any stage of his/her life?	Maximum a week / 10 days - not months Mum - commitments
If applicable, how did the child adapt to the birth of sibling(s)?	Just over a year - Bradley (13 months) OK Not likely very DS mentally behind Megan
How does the child spend his/her free time?	Plays through books, plays in garden, Watch videos, listen to music, go for walks with myself, Debbie, Megan / mum
Does the child speak freely to mother/father about problems?	No

Knows done wrong - don't do it again
↓ after a few warnings

1995 - dad's busy reps if sells a similar car

When she was born mentally same as hers & not jealously

strongly cat

5. PREGNANCY

Was this pregnancy planned?	Tried for 7 years - IVF procedure didn't work - finally preg at Sydney - spontaneous pregnancy while on waiting list -
Were there any medical, emotional or other problems during pregnancy? If yes, describe.	1st trimester - spot bled
What was the duration of the pregnancy?	2 weeks early
What was the age of mother at birth?	28

6. BIRTH

- Dr on first suspected something else.

	Yes	No	Describe
Was the birth normal?		✓	
Did you have a Caesarean section		✓	
Were you anaethetized?		✓	EPIDURAL
Was labour induced?		✓	
Were instruments used (forceps/suction)?	✓		FORCEPS - by mainly ahead
Was it an easy birth?		✓	Difficult: had to cut - to muscle tear
Was the baby born head first?	✓		
Did the baby cry immediately?		✓	
Was the baby's colour normal?	✓		Blueish + the - pink
Was oxygen administered after birth?		✓	
What was the birth weight?	3 kg - normal		
What was the APGAR score?	FAILED - paediatrician knew DS		

7. POST NATAL HISTORY

	Yes	No	Describe
Was the baby placed in an incubator?		✓	
Did the baby have jaundice?		✓	
Did the baby have sucking or swallowing problems?	✓		Problems sucking + swallowing
Was she/he breast fed? (How long)		✓	Formula milks

Covered underlying antibiotics -

Slept - never woke for feeds

drops fed him
paediatr.

	Yes	No	Describe
Did she/he have colic?		✓	
Did she/he have any allergies?		✓	
Did she/he have high/low muscle tone?	✓		LOW
Did she/he cry a lot?		✓	very quiet / understandably / met basic needs
Was she/he easily soothed?			

8. MEDICAL HISTORY

Did your child have	Yes	No	Describe
Prescribed immunizations	✓		→ ✓ Oral Polio prescheol MMR
Childhood illnesses (name)	✓		Chicken pox.
Meningitis		✓	
Encephalitis		✓	
High fever		✓	
Epilepsy	✓		petit mal seizures (3-4 months) - TEST regularly Ea twilight - various drugs - EPILIM - (7yo) look him off now
Gastroenteritis✓ Dehydration	✓		NOT BOTH
Allergies		✓	
Middle-ear infection	✓		yes, one set of grommets
Tonsilitis	✓		tonsils removed
Sinusitis	✓		adenoids removed
Asthma		✓	
Eczema		✓	
Head injury/concussion		✓	
Other injuries/sicknesses	✓		post nasal drop, phlegm - Less muscle tone.
Hospitalization	✓		appx respiratory (old - pneumonia (2x)
Operations	✓		tonsillectomy / grommets / adenoids
Physical abnormalities		✓	FLAT FEET (podiatrist
Visual problems		✓	not eyes tested - never suspected
Hearing problems		✓	(old 100% hearing loss in right ear (NOT TRUE)
Does your child currently use medication? If yes, what?		✓	
Is your child's health currently satisfactory?	✓		But overweight; diet not good Quite active.

Hmo physio suction pt for chest

Sleep we dental health wise.

Can't go to dentist
Trusts GP
Never had thyroid tested - draw blood.

IF IN PAIN CANT GET NEAR HIM

	Yes	No	Describe
Are there any family illnesses (eg heart disease, diabetes, psychiatric conditions)		✓	

9. DEVELOPMENTAL HISTORY

9.1 MOTOR

9.1.1 At what age did your child	Months	Describe
• Lift his/her head	± 6	OS- heavy heads
• Smile	± 2	smiled early
• Roll over	± 11	hard to help /track
• Sit without support	± 13-14	
• Crawl	± 16+18	
• Pull him/herself up against objects	~~12~~ 16	
• Stand	± 18	
• Walk	± 36-24	
9.1.2 At what age was your child		
• Toilet trained during the day	4yo	
• Toilet trained at night	4yo	
9.1.3 Describe your child's control over big movements?		more willing to do gross moto-
9.1.4 Describe your child's control over small movements (eg. stringing beads)?		fine motor -poor doesn't have the interest does it because he has to -

9.2 LANGUAGE AND SPEECH

9.2.1 At what age did your child say his/her first words?	21/2 13 - papa - GRANDPA
9.2.2 How would you describe your child's vocabulary? (good, average, poor)	fairly verbal- starting to string 3 words together more unless frustrated
9.2.3 Can your child sequence his/her thoughts to tell you something?	starting to do so
9.2.4 Does your child speak fluently?	no
9.2.5 Does your child follow instructions? (How many at a time)	3 basic instructions - simply phrased

— always receptive
— not using it functionally
can express needs single words

9.3.16	Is the child (underline if applicable): Moody / rebellious / shy / independent / solitary / inclined to jealousy / careless / obedient / easy to manage / attention seeking / exceptionally tidy / untidy / day-dreamer selfish / domineering / active / quiet / enthusiastic / easily distracted / pays attention / appreciates aesthetics / loving / can take the lead / cheerful / humorous / reponsible / spontaneous / self controlled / sympathetic / dishonest / honest Any other traits? STUBBORN, great manipulator, very determined doesn't like to battle (low persistence) lazy, spontaneous non-aggressive - now standing up for himself - TAUGHT
9.4 SOCIAL DEVELOPMENT	
9.4.1	How does your child get on with friends? Doesn't play with them
9.4.2	Does she/he prefer to play alone or with friends? Yes
9.4.3	How would you describe your child's play? DRAWING, throwing chalk cloths, tickles with brushes, likes sharp
9.4.4	Is your child a leader or follower? neither
9.4.5	Is your child domineering/aggressive? No
9.4.6	How does your child fit in at school? Very popular at school funny - sense of humour enjoy talk due to co. - well liked
9.5 COGNITIVE DEVELOPMENT	
9.5.1	Is your child curious? No
9.5.2	How do you rate your child's long-term memory? (good, average, poor) Good
9.5.3	How do you rate your child's short-term memory? (good, average, poor) Poor
9.5.4	How do you rate your child's concept of time? (good, average, poor) Poor - starting to do - knew weekend (cross for Mc Donalds) - knows of late.
9.5.5	How do you rate your child's language concepts? (good, average, poor) Poor

Sense of direction - now + of where home is (developing) - COMING SO LATE

Dorothy Mackay
no development

9.5.6	How would you rate your child's concept of number? (good, average, poor)	Poor - can't to 10 - doesn't mean anything
9.5.7	Does your child participate in the school program?	Yes
9.5.8	Does your child take an interest in school activities?	Yes

9.6 PHYSICAL DEVELOPMENT

		Yes	No
9.6.1	Does your child avoid:		
	• physical contact (with no fear - doesn't mind)		✓
	• sand play		✓
	• finger painting (wouldn't at first)		✓
	• other (specify) DRAWING - prefers using all fine motor - loves books		
9.6.2	Is your child sensitive to		
	• heat/cold - prefers cold (swimming)	✓	
rough -	• clothing - no labels / scratchy things	✓	
	• water in the face/hair - if wash face but shower into pool	✓	> but loves swimming
	• rough foods LOVES		✓
	• other (specify) SCUMS (hyp pitched - shrills etc (arrowen)	✓	
9.6.3	Does your child get car sick?		✓
9.6.4	Is your child afraid of heights? no sense of danger		✓
9.6.5	Is your child clumsy?		✓
9.6.6	Can your child:		
	• Jump (I feel - not both off jump off things)	✓	DO TOO much for him because he's taken so long - never interested
	• Stand on one leg (5 seconds) - not good at it yet		✓
	• Walk in a straight line (loses balance)		✓
	• Hold a pencil firmly (fine motor)		✓
	• Draw a simple picture (very clumsy / no force / doesn't enjoy)		✓
	• cut with a pair of scissors	✓ with help	
	• sit upright at a table + eats with fork spoon	✓	
	• catch a ball (a big ball / short distance)	✓	doesn't try too big
	• ride a bicycle (scooter)		✓

Client monkey bars
swing
strong grip
unscrew tops / pour

make own sandwiches at school - not at home (gets it done for him)

9.2.6	Describe your child's interest in stories? (good, average, poor). What kind of stories?	Concentrates - loves stories Have story time - enjoy. Not at home.
9.2.7	Can your child retell a story she/he has attended to?	No - will recite nursery rhymes one after the other - actions / sings
9.2.8	Does your child have any speech problems?	

routine
at home not relaxed.

STRONG NEED TO COMMUNICATE

- MOVIES - need to be animated

imitates mimics speech

9.3 EMOTIONAL DEVELOPMENT

9.3.1	How confident is your child?	Lack of fear but not confident
9.3.2	What is his/her general mood or emotional state?	Cheerful / happy
9.3.3	Where does she/he sleep?	Own room
9.3.4	Describe the sleep pattern	Good. 8.30 PM - 6.30 AM
9.3.5	Does she/he sleep well?	Good / yes
9.3.6	Does she/he eat well?	Yes
9.3.7	How dependent/independent is your child?	Very dependent on us but can be on his own (doesn't stay)
9.3.8	Can she/he play alone?	Yes
9.3.9	Describe his/her concentration ability?	Short
9.3.10	Does she/he enjoy school?	Yes
9.3.11	Does she/he complete tasks?	Yes, at school - not at home. - have to keep reminding him - step by step reminder
9.3.12	Does she/he confuse fantasy and reality?	No
9.3.13	Does she/he have frequent angry outbursts? - CAN'T TELL YOU WHAT HE WANTS	Yes if cannot communicate Mimic - argument / lash out at you → other age
9.3.14	Does she/he wet the bed (enuresis)?	No

gentle firm through

9.3.15 Indicate by underlining if any of the following are present:

Sleeplessness/ nightmares / sleep talking / sleep walking / restless sleep / fearful / anxious / nailbiting / temper tantrums / fear of the dark / other phobias (state)

→ hospital → doctor → needles → medical.

APPENDIX E

UNIVERSITEIT VAN STELLENBOSCH
UNIVERSITY OF STELLENBOSCH

❶ PERSOONLIKE GEGEWENS VAN KLIENT

KIND	
VOLLE NAAM VAN KIND	
Noemnaam	
Van	
Geboortedatum	24 · 04 · 92
Plek van kind in gesin	oudste
Aantal kinders in gesin	2
Tel. No. Tuis ☎	
Huis adres _	Pos adres ✉
Kerkverband NG · Kerk	
NAAM VAN VADER / VOOG	
Titel van vader/voog (prof/dr/mnr)	mnr
Beroep	onderwyser
Ouderdom	43
Werk tel. Nr. ☎	

./ REF.:

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Departement Opvoedkundige Sielkunde en Spesialiseringsonderwys
Privaatsak X1, Matieland 7602, Suid-Afrika
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Faculty of Education
Department of Educational Psychology and Specialised Education
Private Bag X1, Matieland 7602, South Africa
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❶ PERSOONLIKE GEGEWENS

NAAM VAN MOEDER / VOOG	
Titel van moeder / voog (prof/dr/mev)	mev.
Beroep	Lektrise
Onderdom	38
Werk tel. Nr. ☎	
Bure, familie of vriende se tel. Nr. ☎	

Vorige evaluasies deur professionele persone? arbeidsterapeut / spraakterapent	
Ontvang u kind tans terapie/behandeling	Nee
NAAM VAN SKOOL	Alta du Toit
Adres van skool Kuilsrivier	Tel van skool ☎
Naam van onderwyseres /departementshoof	Heloise
Vakke	?
Hoe verloop sosialisering by die skool?	Skool X Dagmoeder ✓
Deelname aanbuitemuurse aktiwiteite? Beskryf	swem, atletiek
	swemlesse

VERSLAE MAG GESTUUR WORD AAN
(VOLTOOI SLEGS INDIEN NODIG)

NAAM	ADRES

Hiermee verklaar ek _____ dat verslae aangaande

_____aan die bogemelde persone gestuur mag word

_____ _____

HANDTEKENING **DATUM**

❷ STATUS VAN GESIN

1	=	Beide ouers	2	=	Stiefpa	3	=	Stiefma
4	=	Wewenaar	5	=	Weduwee	6	=	Voogde
7	=	Geskei, bly by pa	8	=	Geskei, bly by ma	11	=	Ander
9	=	Vervreem, bly by pa	10	=	Vervreem, bly by ma			

Status	1
Moedertaal	Afrikaans
Burgerskap	SA
Het die kind 'n besondere band met een van die gesinslede?	Al 3 dieselfde
Voel die kind ongemaklik by enige van die gesinslede?	/
Leef die kind se grootouers nog?	1 oupa oorlede
Indien wel, het hulle 'n sterk invloed op sy/haar opvoeding?	Ja, stephan en oupa
Was die moeder/vader op 'n stadium geskei van die kind?	Verlede jr. 3 weke, by ouma & juf
Indien van toepassing, hoe het die kind gereageer op die koms van 'n nuwe baba?	3mnde oud, afknou, byt, by ouer slaap
Hoe bring die kind sy vrye tyd deur?	TV; puzzles, buite met water
Praat die kind maklik met die moeder/vader oor hul probleme?	tantrum
Werk die moeder vandat sy kinders het? Beskryf asseblief.	Lang kraamverlof, 6mnde (11 weke in hospitaal), 5 uur gaan haal

❸ SWANGERSKAPGESKIEDENIS

Het die moeder enige van die volgende gehad?		JA	NEE	BESKRYF
3.1	Bloedarmoede		X	
3.2	Hoë bloeddruk		X	
3.3	Dreigende miskraam	✓		17 weke
3.4	Toksemie / Toksoplasmose			?
3.5	Nierprobleme		X	
3.6	Hartprobleme		X	
3.7	Vroeë kontraksies		X	
3.8	Duitse masels		X	
3.9	Virus infeksies		X	

3.10 Braking		X	
3.11 Beserings		X	
3.12 Medikasie		X	
3.13 Emosionele probleme		X	
3.14 Ander	✓		Plasenta disintegreer ± 28 weke. brugbabas, min beweging noodkeiser (31 wke)
3.15 Beplande swangerskap?	✓		
3.16 Het moeder gerook?	~~was~~	X	
3.17 Was die swangerskap voltermyn?		X	31 weke:
3.18 Ouderdom van moeder met die geboorte van die kind?			30 jaar (29:10)

❹ GEBOORTEGESKIEDENIS

	JA	NEE	BESKRYF
4.1 Was die geboorte normaal?		X	
4.2 Het u 'n keisersnee/nood-keisersnee gehad?	✓		noodkeiser
4.3 Het u 'n epiduraal gehad?		X	narkose
4.4 Het u narkose gehad?	✓		
4.5 Het u 'n induksie gehad?		X	
4.6 Was daar instrumente gebruik?		X	
4.7 Was dit 'n maklike geboorte?	✓		traumaties (6 min) nie so ervaar
4.8 Is die baba kop eerste gebore?		X	brugbaba
4.9 Het die baba dadelik gehuil?	✓		
4.10 Was die naelstring om die nek?		X	
4.11 Het die baba suurstof ontvang?	✓		ventilator, 3 dae
4.12 Was die baba se kleur normaal?			nie seker
4.13 Wat was die geboortegewig?	1, 29kg		
4.14 Wat was die Apgartelling?	4, 7, 8		28cm kop lengte 32cm
4.15 Watter slaapposisie het die baba verkies?	Op sy		

Vry. gebore 24

Ma. gehoor Downs-sindroom (Geneticus) 28

6 weke later gehoor

Gnetjie de Jongh

❺ POST NATALE GESKIEDENIS

		JA	NEE	
5.1	Was die baba in 'n broeikas?	✓		5 weke : 3dae ventilator, 1 week buite
5.2	Het die baba suig- of slukprobleme gehad?	✓		10ml melk elke voeding; na 3 mnde 75 ml
5.3	Is u baba geborsvoed? (Hoe lank)		✓	borsmelk gedrink
5.4	Het die baba geelsug gehad?	✓		4dae oud → 3dae lank
5.5	Enige allergieë	✓		Hooikoors
5.6	Was dit 'n koliekbaba?		✓	
5.7	Het u spierstyfheid of - slapheid opgemerk?	✓		Lae spiertonus
5.8	Het die baba baie gehuil? Maklik getroos?		X	Glad nie

❻ MEDIESE GESKIEDENIS

Het u kind die volgende gehad?	JA	NEE	OUDERDOM / BESKRYF
Kindersiektes (noem asb)	✓		Babamasels ± 2jr / Waterpokkies 7jr
Meningitis		X	
Enkefalitis		X	
Hoë koors / koorsstuipe		X	Nooit koors gehad, meer toe ouer
Epilepsie		X	
Gastro-enteritis / dehidrasie	✓		In hospitaal ± 6jr
Allergieë: bv suiwel, graan, sitrus, preserveer- kleur- en geurmiddels		X	
Otitis media (middeloorontsteking)	✓		Baie; 11 keer pypies; adenoids Januarie 2000
Tonsilitis (mangelontsteking)	✓		Kortisone; ± 2jr
Sinusitis	✓		met hooikoors, haal bril af babatyd
Asma	✓		~~Met hooikoors~~, kroep, 6mnde oud longontsteking (3 virusse) 5weke
Ekseem		X	
Hoofbesering / Harsingskudding		X	
Ander beserings / siektes			~~Tek~~ Testikels nie afgesak 5jaar oud
Hospitalisasie			Eerste 2jr 17 weke 6 wke 6mnde 5 weke 6weke aan/af
Operasies?			ore, testikels, mangels

Skarlakenkoors 5jr (5dae in hospitaal).
└ gesondheid drasties verbeter

Kortisoon van 6mnde – 5jr (8keer/dag; 3keer)

longontsteking a.g.v. reflux, vog in longe

Fisiese abnormaliteite		✓	Gaatjie in hart gehad
Visieprobleme	✓		± 05 albei oë
Gebruik u kind tans medikasie?		✓	Somtyds hooikoors Rinex, Zyrtec.
Is u kind se gesondheid op die oomblik bevredigend?	✓		Besonder
Is daar enige familiële siektes (bv: Diabetes, Mellitus, Harttoestande, Asma, Genetiese Afwykings, Epilepsie, Longtoestande, Allergieë, Psigiatriese Toestande	✓		Ma → Angina (Ina se ma) Halfbroer → epilepsie Ouma – depressie omstandighede: Ina – universiteit verlede jaar medikasie (Sirzone) angstigheid, anti-depressante nie lank

❼ ONTWIKKELINGSGESKIEDENIS

	Maande	
7.1 Op watter ouderdom het u kind:	6	
☐ Kop opgelig:	6mnde	In hospitaal
☐ Geglimlag:		
☐ Omgerol:		
☐ Gesit sonder ondersteuning:		
☐ Gestaan		
☐ Gekruip (hoe?):		
☐ Teen voorwerpe opgetrek:		
☐ Geloop	28mnde	2jr 4mde: Fisio 6mde – 3jr 1/week
7.2 Beskryf u kind se handvaardigheid:		links, skryf op sie manier goed
7.3 Watter tipe speelgoed verkies u kind:		Puzzles, boeke, bal
7.4 Beheer oor groot bewegings bv. hardloop (lomp/ gemiddeld/goed?)		Goed
7.5 Beheer oor klein bewegings bv. krale ryg (lomp/gemiddeld/goed?)		Goed
7.6 Toilet beheer: Bedags Snags		✓ Niks snags; begin potty train

❽ PERSOONSBEELD

8.1 **Affektiewe Gesteldheid**	
☐ Selfvertroue?	Goed; Kies mense; ignoreer sommige
☐ Algemene gevoelsaard	saggeaard, afgelope 6mde
☐ Selfstandigheid tuis: bad, aantrek, eet:	Toesig hou bad; Trek self aan; soklies sukkel: mes en vurk
☐ Hoe verloop die slaap roetine?	4, ½ 5, 5 uur elke nag
☐ Waar slaap hy/sy?	eers eie bed; dan by ouers
☐ Kan hy/sy alleen speel?	Ja – nie karretjies
☐ Eet en slaap hy/sy goed?	Slaap goed; reguleer homself
☐ Konsentrasievermoë	Afhangende v. aktiwiteit
☐ Distansïering van ouers	Oupa ✓✓✓ Plek tevrede ✓
☐ Verwar hy/sy fantasie met werklikheid	Nee / Nie beantwoord
☐ Voltooi hy/sy take?	Ja
☐ Geniet hy/sy die skool?	Seker, manipuleer, Alta du Toit Chenie Botha
☐ Kry hy/sy gereeld woede uitbarstings?	Tot jr terug, uitsondering, frustrasie
☐ Ly die kind aan enurese (bednatting)? Indien wel is die kind reeds deur 'n medikus ondersoek?	
☐ Dui aan of enige van die volgende teenwoordig is: slaaploosheid/somnambulisme/nagmerries/ praat in die slaap/ slaap onrustig/ skrik maklik/ byt naels/ woedebuie/bang vir donker/ander fobies	af en toe: praat onrustig (baie) hoogtevrees
☐ Is die kind? (onderstreep in dien van toepassing) humeuring/opstandig/skaam/selfstandig/alleenloper/geneig om jaloers te wees/agtelosig/gehoorsaam/maklik hanteerbaar/aandagsoekerig/besondernetjies/slordig/dagdromer/selfsugtig/baaspelerig/woelig/stil geaardheid/entoesiasities/ maklik afleibaar/kan goed aandag gee/waardeer mooi dinge/liefdevol/kan leiding neem/opgewek/kan humor insien/verantwoordelikheidsbesef/spontaan/ kan met selfbeheersing optree/kan simpatie hê/hulpvaardig/oneerlik/eerlik Enige ander? mededeelsaam	hardkoppig normale grense; relatief gehoorsaam wie altyd maklik hanteerbaar
8.2 **Sosiaal**	
☐ Inskakeling by skool	
☐ Leier/volger	
☐ Dominerend/Aggressief	

❒ Buitemuurse aktiwiteite/ /sport?	
❒ Verkies hy/sy alleenspel?	
8.3 **Kognitief**	
❒ Is hy/sy nuuskierig?	Ja, soek, maak kaste oop
❒ Hoe meen u is die kind se langtermyngeheue?	Goed
❒ Hoe meen u is die kind se korttermyngeheue?	Moeilik; OK; onthou wel
❒ Spraak?	swak
❒ Tydsbegrippe	nee, begrip v. roetine
❒ Spelbelange	
❒ Deelname aan skoolprogram	konsert, swem, atletiek, geniet dit
❒ Doen hy/sy selfstandig huiswerk?	nee
❒ Skep hy die indruk dat hy dagdroom	nee
❒ Peuter hy voortdurend met voorwerpe?	ja, stimming
❒ Belangstelling in skoolse aktiwiteite	nee
8.4 **Liggaamlikheid**	
❒ Rats/lomp	rats
❒ Bal vang/gooi	ja
❒ Klim- en klouteraktiwiteite	ja
❒ Toon hy/sy moontlik enige van die volgende:	
○ hoogtevrees ○ rysiekte	hoogtevrees
○ gevoelig vir:	
a. hitte/koue	nee
b. klere	ja, soms
c. water in sy/haar gesig	geniet dit baie
d. growwe kosse	
○ vermy hy/sy:	
a. fisiese kontak	soms
b. sandspel	nee, geniet dit
c. vingerverf	nee, " "
e. ander?	water spele
○ kan hy/sy spring?	ja
○ kan hy/sy op een been staan (5-	

sekondes)	ja
O kan hy/sy op 'n reguit lyn loop	nee
O hou hy/sy 'n potlood toereikend vas?	nee
O kan hy/sy 'n eenvoudige prentjie teken?	nee
O kan hy/sy knip?	ja met 'n links skêr
O sit hy/sy regop by 'n tafel?	ja
O toon hy/sy 'n gesonde eetlus	ja
O kan hy/sy goed hoor?	ja
O weet hy/sy hoe oud hy is?	ja - kan wys
O kan hy/sy fiets ry?	ja
8.5 **Normatief**	
☐ Aanvaar hy/sy gesag geredelik?	nee
☐ Kan hy/sy die genot van die oomblik uitstel indien nodig?	nee
☐ Toon hy/sy deursetting?	nee
☐ Speel hy/sy ouers af teenoor mekaar?	nee
☐ Hoe straf u, u kind en wat is sy/haar reaksie?	"time-out" in badkamer Verstaan dit goed - goeie reaksie
8.6 **Spraak en Taal**	
☐ Voer hy/sy opdragte uit? (Hoeveel na mekaar?)	Soms - 2 "gaan haal lap - vee skoon"
☐ Kan hy/sy gedagtes orden as hy iets vertel?	nee
☐ Kan hy/sy gedigte en rympies memoriseer?	nee
☐ Ondervind hy/sy probleme met bepaalde klanke?	ja
☐ Praat hy/sy vloeiend?	nee
☐ Kan hy/sy aandag aan 'n storie gee en enkeke feite herroep?	nee
☐ Toon hy/sy belangstelling in boeke?	ja
Enige ander inligting of probleme wat u as belangrik ag?	

❾ OPVOEDINGSTYL en GESINSVERHOUDINGE	
Is die ouers eenstemmig oor gesag?	Ja
Konsekwent?	Ja
Toegeeflik?	Ja
Outokraties?	Nee
Beskryf sy/haar verhouding met:	
Moeder	Baie goed
Vader	" "
Broer(s)/Suster(s)	Knaa soms sussie af, andersins baie gehoeg aan mekaa
Watter eienskap hou u die meeste van?	liefdevol
Watter eienskap hou u die minste van?	koppigheid

Baie Dankie

--ooOoo--

APPENDIX F

61

Program Body Parts (Receptive and Expressive)

- Program Procedure:
  (1) *Identifies Body Parts*—Sit in a chair facing the child. Establish attending and state the instruction "Touch ___ (body part)." Prompt the child to touch correct body part on him/herself and reinforce responses. Fade prompts over subsequent trials and differentially reinforce responses demonstrated with the lowest level of prompting. Eventually, only reinforce correct, unprompted responses.
  (2) *Labels Body Parts*—Sit in a chair facing the child and establish attending. Point to a body part on yourself and say "What is this?" Prompt the child to name the body part and reinforce the response. Fade prompts over subsequent trials. Differentially reinforce responses demonstrated with the lowest level of prompting. Eventually, only reinforce correct, unprompted responses.
- Suggested Prerequisites:
  (1) Follows five one-step instructions.
  (2) Identifies the body part and labels familiar objects.
- Prompting Suggestions:
  (1) Model the response or physically guide child to perform response.
  (2) Model the correct response.

Instruction	Response		
(1) "Touch ___." (2) "What is this?"	(1) Touches the correct body part (2) Labels body part	Date Introduced	Date Mastered
1. Head	✓ ✓ ✓	2/15	2/25/4
2. Feet	✓ ✓ ✓	2/15	
3. Stomach	✓ ✓ ✓	2/15	
4. Nose	✓ ✓ ✓	2/15	
5. Mouth	✓ ✓ ✓	2/15	
6. Legs	✓ ✓ ✓	2/15	
7. Eyes	✓ ✓ ✓	2/15	
8. Ears	✓ ✓ ✓	2/15	
9. Hair	✓ ✓ ✓	2/15	
10. Cheeks			
11. Shoulders	✓ ✓ ✓	2/15	
12. Hand	✓ ✓ ✓	2/15	
13. Face	✓ ✓ ✓	2/15	
14. Arm	✓ ✓ ✓	2/15	
15. Fingers	✓ ✓ ✓	2/15	
16. Elbow	✓ ✓ ✓	2/15	
17. Chin			
18. Toes	✓ ✓ ✓	2/15	
19. Thumb	✓ ✓ ✓	2/15	

► *Helpful Hint:* Initially choose body parts that are not located within close proximity to one another (e.g., initially, teach discrimination of head and feet rather than nose and eyes).

Program Matches

- Program Procedure: Place item(s) on the table in front of the child. Present an item that corresponds to one of the items to the child and state the instruction "Match." Prompt the child to place the item on top or in front of the corresponding item and reinforce the correct response. Fade prompts over subsequent trials. Differentially reinforce responses demonstrated with the lowest level of prompting. Eventually, only reinforce correct, unprompted responses. Initially, begin with one item present on the table; gradually introduce additional items.
- Materials: Identical objects and pictures, letter cards, colored objects, number cards, and shapes.
- Suggested Prerequisites: Sits in a chair.
- Prompting Suggestions:
  1) Physically guide the child to perform the response.
  2) Use a positional prompt by placing the item on the table closer to the child.

Instruction: "Match."	Response: Places item top or in front of the corresponding item	Date Introduced	Date Mastered
1. Identical objects		28/01	23/02
2. Identical pictures		28/01	23/02
3. Pictures to objects	50 100; 90 100; 100; 100	13/3	20/3
4. Objects to pictures	50 50; 100 100; 100	13/3	20/3.
5. Colors		28/01	23/02
6. Shapes		28/01	23/02
7. Letters 100 100	100 20 50; 100; 100 100	26/02	6/3
8. Numbers (non id. pictures)	50; 100; 80; 90; 50; 100; 100	26/02	9/3
9. Nonidentical objects	100; 100; 80 100 100; 100	26/02	7/3
10. Associative objects (e.g., pencil to paper)	80, 80, 80 · 90; 100; 100; 60, 100; 100, 100	13/3.	30/3

► *Helpful Hint:* Initially, choose objects that will nest or lie on ... other (e.g., cup, spoon, or plate). You may ... to start with at least three items on the table and vary ... sions of the items to enhance discrimination.

Numbers 100; 100; 100 19/3 20/3.

Program: Objects (Receptive and Expressive)

- Program Procedure:
  (1) *Identifies Objects*—Place object(s) on the table in front of the child. Establish attending and state the instruction "Give me ___ (name of object)." Prompt child to hand you the object and reinforce the response. Fade prompts over subsequent trials. Differentially reinforce responses demonstrated with the lowest level of prompting. Eventually, only reinforce correct, unprompted responses.
  (2) *Labels Objects*—Sit in a chair facing the child. Establish attending and present an object. Say "What is this?" Prompt child to label object and reinforce the response. Fade prompts over subsequent trials. Differentially reinforce responses demonstrated with the lowest level of prompting. Eventually, only reinforce correct, unprompted responses.
- Materials: Objects.
- Suggested Prerequisites:
  (1) Matches identical objects.
  (2) Follows 15 one-step instructions.
  (3) Imitates sounds and simple words.
- Prompting Suggestions:
  (1) Physically guide child to hand the object to you.
  (2) Model the label.

	Instruction (1) "Give me ___." (2) "What is this?"	Response (1) Gives correct object (2) Labels object	Date Introduced	Date Mastered
1.	Banana	100, 100, 100	2/3/4	2/6
2.	Picture	100, 100, 100	2/3/4	2/6
3.	Sock	100, 100, 100	2/3/4	2/6
4.	Shoe	100	2/3/4	2/6
5.	Ball	100	2/3/4	2/6
6.	Phone	100, 100	2/3/4	2/6/4
7.	Book	100, 100	2/3/4	2/6/4
8.	Block	100, 100	2/3/4	2/6/4
9.	Tissue	100, 100, 100	2/5	4/5
10.	Cracker	90, 100, 100, 100	2/5	4/5
11.	Juice	100, 100, 100	2/5	4/5
12.				
13.				
14.				

Helpful Hint: Choose objects that are relevant to your child. For example, if your child prefers certain toys (e.g., Big Bird or Elmo), use these as the first few objects to teach. The first several objects should sound different (e.g., do not teach "shoe" and "juice" as your first two objects because they sound so similar). If your child has trouble learning receptive labels, try teaching object-related commands (e.g., "Get a tissue" and "Throw the ball"). Gradually move objects closer together and change the instruction to "Give me a tissue" and "Give me the ball."

Program: Imitates Oral Motor Movements

- Program Procedure: Sit in a chair facing the child and establish attending. Present the instruction "Do this". while simultaneously modeling an oral motor movement. Prompt child to perform the movement and reinforce the response. Fade prompts over subsequent trials. Differentially reinforce responses demonstrated with the lowest level of prompting. Eventually, only reinforce correct, unprompted responses.
- Suggested Prerequisites: Sits in a chair; makes eye contact; imitates gross and fine motor movements.
- Prompting Suggestions: Physically place the child's mouth in the correct position. Use materials that may facilitate responding (e.g., horn or bubbles for blowing, lollipop for sticking tongue out).

Instruction: "Do this."	Response	Date Introduced	Date Mastered
1. Open mouth	100; 100; ~~90~~ 100	20/3	30/3
2. Stick out tongue	100; 100; 100	20/3	24/3
3. Put lips together	100; 90; 100, 50	20/3	30/3
4. Tap teeth together	100; 100; 100, 100	20/3	24/3
5. Blow	100; 100; 100, 100	30/3	3/4
6. Smile	100; 100; 100, 100	30/3	3/4
7. Pucker	100; 100; 100, 100	30/3	3/4
8. Kiss	90; 100; 100, 100	30/3	2/4
9. Place tongue to top teeth	100; 100; 100, 100	30/3	3/4
10. Place top teeth over lower lip	0, 0; 0, 0 100; 100; 70, 100	30/3	

► *Helpful Hint:* Assess the goal of this program. If you are introducing it as a prerequisite for verbal imitation, it may be best to pair a sound with the movement from the start. If you're having trouble prompting a movement, try using a mirror. Have the child look at both of your reflections in the mirror when you present the model and then fade the use of the mirror.

Mastered 24/4/2021

Program: Imitates Actions with Objects

Modelling

- Program Procedure: Place two identical objects on the table. Sit across the table facing the child. Establish attending. Present the instruction "Do this" while simultaneously modeling an action with one of the objects. Prompt child to perform the action with the other object and reinforce the response. Fade prompts over subsequent trials. Differentially reinforce responses demonstrated with the lowest level of prompting. Eventually, only reinforce correct, unprompted responses.
- Materials: Objects for the actions.
- Suggested Prerequisites: Sits in a chair.
- Prompting Suggestions: Physically guide the child to perform the response.

Instruction: "Do this."	Response	Date Introduced	Date Mastered
1. Place block in bucket		28/01	23/02
2. Ring bell	70; 90; 100; 100; 100	28/01	~~23/02~~ 27/3
3. Push toy car		28/01	23/02
4. Wave flag	100; 0; 100; 20; 100	20/02	12/3
5. Hit drum	100; 100; 100; 100	20/02	6/3
6. Put on hat	100; 100; 100;	20/02	6/3
7. Scribble	50; 100; 100; 100	7/3	9/3
8. Wipe mouth	100; 100; 100; 100	7/3	9/3
9. Bang toy hammer	100; 100; 100	12/3	16/3
10. Shake maraca	100; 100; 100; 100	13/3	16/3
11. Feed doll	~~12~~ 0; 100; 100; 100	13/3	20/3
12. Hold phone to ear	~~13~~ 100; 100; 100	13/3	19/3
13. Drink from cup	100; 100; 100	12/3	15/3
14. Blow horn	~~100~~ 70; 100; 100; 100	12/3	26/3
15. Brush hair	20; 50; 100; 100; 100	13/3	20/3
16. Make actions with a doll	100; 50; 100; 100	20/3	27/3
17. Roll Playdoh	50; 100; 100; 100; 100	13/3	20/3
18. Place coin in bank			
19. Kiss doll	0; 100; 100; 100	20/3	27/3
20. Stamp paper			

► *Helpful Hint:* Teach play-related imitations that your child might enjoy.

Program: Imitates Gross Motor Movements

- Program Procedure: Sit in a chair facing the child and establish attending. Present the instruction "Do this" while simultaneously modeling a gross motor movement. Prompt the child to perform the action and reinforce the response. Fade prompts over subsequent trials. Differentially reinforce responses demonstrated with the lowest level of prompting. Eventually, only reinforce correct, unprompted responses.
- Suggested Prerequisites: Sits in a chair.
- Prompting Suggestions: Physically guide the child to perform the response.

Instruction: "Do this."	Response	Date Introduced	Date Mastered
1. Tap table		28/01	23/02
2. Clap hands		23/01	23/02
3. Wave	80, 100, 100, 100	20/02	7/3
4. Place arms up	90, 100, 100, 100	20/02	7/3
5. Stomp feet	100, 100, 100	20/02	6/3
6. Tap legs	100, 100, 100	23/03	7/3
7. Shake head	100, 100, 90, 100	7/3	12/3
8. Nod head	80, 100, 60, 70, 90, 80	7/3	27/3
9. Turn around	50, 100, 100, 100, 100	/3	20/3
10. Cover face with hands	100, 100, 80, 100	7/3	21/3
11. Tap shoulders	80, 100, 100, 100	/3	20/3
12. Jump	80, 100, 100, 100	/3	20/3
13. Circle arms	100, 70, 70, 100, 100, 100	20/3	3/4
14. Tap stomach	100, 100, 100, 100	5/03	6/3
15. March	100, 100, 100	20/3	26/3
16. Put arms out	100, 100, 100	20/3	26/3
17. Knock	20, 90, 100, 100, 100	7/3	26/3
18. Put hands on waist	70, 100, 100, 100	20/3	27/3
19. Rub hands together	100, 100, 100, 100	20/3	24/3
20. Tap head	70, 100, 100, 100	/3	20/3

► *Helpful Hint:* Some children may learn object-mediated imitation (e.g., ringing a bell, placing a block in a bucket) faster than gross motor movements. After teaching five imitative responses, probe novel ones; the skill may have generalized!

Wave.
Arms up
Stomp feet

	1	2	3	4	5	6	7	8	9	10	%		%	%
6.13	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Circle Arms		
19.3											80	Come here		
4											100	Put hands d		
8.1	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Clap hands		
2	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Point close		
3	X	X	✓	✓	✓	✓	✓	✓	✓	✓	80	Make index f		
4	X	X	X	✓	✓	✓	✓	X	X	✓	50	Hide thumb		
5	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Wiggle fingers		
TIES → 7	X	X	X	X	✓	X	✓	✓	✓	✓	50	Hand behind to t		
8	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Point to body		
10	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Pretend under		
9.5	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Blow		
6	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Smile		
7	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Pucker		
8	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Kiss		
9	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Place tongue		
10	✓	X	X	X	X	✓	✓	✓	✓	✓	100	Place tip teeth over lower lip		
10.1	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Stamp upper		
2	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Turn around		
3	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Put arms out		
4	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	March		
12	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Point it		
13	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Touch toes		
20.1	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Head		
2	✓	✓	✓	✓	X	✓	X	✓	✓	✓	80	Feet		
3	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	90	Stomach		
4	✓	X	X	✓	✓	✓	✓	✓	✓	✓	80	Nose		
5	X	✓	X	✓	✓	X	✓	✓	✓	✓	70	Mouth		
6	✓	X	✓	✓	✓	✓	✓	✓	✓	✓	90	Legs		
7	X	X	✓	✓	✓	✓	✓	✓	✓	✓	80	Eyes		
8	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Ears		
9	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Hair		
65.1	✓	✓	✓	✓	✓	✓	X	X	X	X	60	Ma		
2	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Pa		
3	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	Put		
4	✓	✓	✓	✓	✓	✓	X	X	X	✓	70	Bat		

02/03

		1	2	3	4	5	6	7	8	9	10	%	%	%	Comments
2	5														Eyes 5s & Look at m
3				emy good											Hands. quiet
6	4	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	80	100		Arms up.
6	3	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	100		Wave
6	5	✓	✓	✓	✓	X	✓	✓	✓	X	✓	60	100		Stomp feet
6	6	X	X	X	X	X	X	X	X	X	X	20	50		Tap legs.
7	2	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	100		Ring bell
	4	P	P	P	P	P	P	P	P	P	P	20	20		Wave flag.
	5	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	100		Hit drum
	6	✓		spot on.											Put on hat.
19	3	X	X	X	X	X	X	X	X	X	X	0	0		Come here
	4	X	X	✓	✓	✓	✓	P	P	✓	✓	60	50		Put hands down
	5	X	X	X	X	X	X	X	X	X	✓	80	80		Wave bye
	6	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	100		Give me hug.
63	3	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	100		One pref it. & one not
141	7	X	✓	✓	✓	✓	X	✓	X	✓	✓	90	100		Letters.
	9	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100	90		Non id. obj.
		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	80	100		Non id pic.

In betweens

puzzle

reading

Threading

play dough.

Scribbling

Body parts

go for walk

6/3

		1	2	3	4	5	6	7	8	9	10	%	%	. %	Comments
2	5		good												Look at me.
3			good												Hands quiet.
6	3	✓	✓	✓	✓	✓	✓	X	✓	✓	✓	100			Wave
	4	X	X	X	X	X	X	P	X	P	✓	100			Arms up
	5	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100			Stomp feet
	6	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100			Tap legs
	14	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100			Tap tummy
7	2	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100			Ring bell
	4	X	X	X	X	X	X	X	✓	✓	✓				Wave flag
	5	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓				Hit drum
19	4	✓	✓	✓	✓	X	✓	P	✓	✓	✓	80			Put hands down
	5	✓	✓	X	✓	✓	✓	X	✓	✓	✓				Wave bye
	6	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓				Give me hug.
63	3	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100			Pref item + not
141	7	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓				Letters
	8	X	X	X	X	X	X	X	X	X	X	O	100		Non id. Pic.
	9	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	100			Non id obj.

In betweens

Threading
playpark
reading
bubbles
Scribbling.

Lunch

with other pics

APPENDIX G

He is being so FUNNY lately, I find myself laughing to myself a lot because of the things he is saying. He chats away to himself a lot & sings all the time — He's favourite is at the moment is

" Michael rowed the boat ashore "Alleluia "

So funny. Had a good meeting with Jenny last night. She is stunned at the progress. Thanks ladies —

4/

I had the priveledge of hearing Alleluia as well!! He enjoyed singing it.

is progressing so well for me. He is so relaxed & happy just to be himself.

has a problem with h mum. Don't know if she'll be in tomorrow either. Mum is really ill.

2/8 Thanks so much Ladies for spoiling him so much yesterday And the best is that he KNEW he was being spoiled and that it was his special day. The attention went on all day, the afternoon Granny came around and he got the Tigger Movie Video. His auntie Renee a little later and we took him to the Spur for supper. His party is on the Saturday from 5 - 7pm same venue

Ido there!
Ide really tried today. Did well with his vocab + attended very well.
A teapot is now officially known as a peepot! Lets not ask him to make tea for guests, they won't know what they're getting!
Have a nice day!
♡

I'm going for an ear op tomorrow, wish me luck, overnight in hospital + off for about 10 days.

9/5 Hi
Best of luck for your op x.
I'm sure everything will be 100%. Trust & be confident.

We had a fantastic day today. was very responsive & we had lots of laughs. A wonderful breakthrough with writing skills. I'm sending you a sample. Everything is done by himself with no help! Still need to work on

Luv

10/5 I had to post-pone my op until next thursday, too busy @ work. I can't believe the writing skills, you say he did this without any help? Great!

1/3.
He was fine this afternoon, but got tired later on.
After lunch he tends to be very vocal, almost as if he is "high". He sees things against the walls and makes funny sounds. This normally lasts for ± ½ an hour. I think that we must try to not allow him to scream and shout. He is waiting for us to give in! At school he does not try this anymore, because he knows that it won't work.
I am going to try to get him to say goodbye every afternoon. (even if this leads to huge arguments) He must learn to generalize what we learn in class.

2/3. We also find that on some days he is very loud, shouts a lot + is generally very difficult - I haven't established a pattern yet but maybe I should chart the behaviour as well as what he has eaten that day. The screaming is terrible I know, we stop him verbally and if that does not work he gets sent to the bathroom — but it still continues anyway. I'm ~~not~~ never know why he is screaming, your first reaction is to ask see what he wants, but although he understands you when you ask "what do you want" or "whats wrong" - he still insists of screaming. Some days WHY is it when he knows to say hello or

We are having a problem getting him to sleep, he goes to bed and lies awake for ages - As though his brain is still active.

PS Jenny has arranged that we meet @ my house Monday 26/2 @ 19:00.

22/2

Hi there! He was fine today! We picked up the pace and therefore he got lower scores than before. After an hour however, he started doing his drills faster and correctly!

Started 4 new drills today: give a hug; ring bell; point to body parts and put on a hat.

(Did [illegible] phone you last night? She told us that the meeting will be at her house, because [illegible] (from 1/8) must also come to the meeting.

Have a good day!

Hi guys!

must think we are nuts driving him like this! We (J) are really pushing him & he is responding. New skills are coming in, so expect a bit of behaviours

Love

Brush
Dried Beans / Seeds / Lentils etc
Bubbles - Big
Blowing thingy
Pegs
Sticky things
Jelly powder.

12/2 Welcome back ladies,
Hope you have a good week.
Live sent in beans & Jelly.
Will send the brush tomorrow.
Please let me know if you need anything else.
Thanks.

12/2 - What an amazing day I've had with . I am very thankful for our training, it helped to make things clearer for me!! I'm pos. that will now take off seeing we have a better grounding now. I worked with your boy from 9 — 12!! The ballet lady came & we ever worked while she was here. last huge reward was to join in all the fun & he was so brilliant. He stood on command he even pointed for me on occasion & when he decided that he likes (again) what we're doing he was so willing to please that I just loved him to pieces!! Thanks for your beautiful boy!

the video didn't save last time. As you'll see on today — he was a pleasure!!!
I have lots of fun together. I feel we can move on to the next stages. It's only battle at this stage is to match identical objects. His matching of pictures are spot-on though.
One step instructions are still not mastered yet either & pointing still with whole hand though he can point when he wants to.

Ps. - I had a wonderful evening with & has seen him again

Bye

2/2
Wonderful! Excellent! I am so proud of your boy! He got his matching sorted out! 100%
Matching of objects also improved! 9
Pointing to objects was great → 90%
Eye contact was excellent!
We're on the right track!
→ 9-10 o'clock
Afternoon → protested a little, then settled down nicely.
Worked for 2¼ hour 'non-stop'!
Have a great weekend!

What else can I say - said it all! Watch the video & you'll see just how fast you are improving!
Nice weekend

30/01

was very chatty yesterday afternoon. He woke in the middle of the night and wanted to watch a video at 3.AM.
Hope he has a good day today.

1/2

He there! Yesterday was brilliant!
He was tired today. Did not want to do much. I decided not to push him to much.
We also [illegible] [illegible] [illegible] to see video. [illegible]
[illegible]

What a [illegible] [illegible]
[illegible]