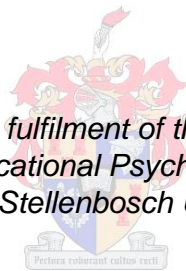


Children with Autism Disorder receiving Applied Behaviour Analysis Therapy: Parents' experiences

by
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Thesis presented in partial fulfilment of the requirements for the degree of Masters in Educational Psychology in the Faculty of Education at Stellenbosch University



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DECLARATION

By submitting my thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof, that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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ABSTRACT

The purpose of this study was to explore the experiences of parents who have a child previously diagnosed with autistic disorder who is following or has in the past followed an intensive Applied Behaviour Analysis programme.

Parents willingly participated in this research study. The aim of this study was to explore parents' experiences and the various challenges they face. This study also focuses on support and coping strategies experienced by parents. Parents were also asked to provide ideas for support strategies, coping strategies and advice to other parents who may be embarking on a similar journey.

A literature review was conducted in order to obtain perspective on research conducted in this field. I fulfilled the dual role of researcher and trainee educational psychologist. The interpretive paradigm was chosen as the framework for this study and the data was gathered by means of semi-structured interviews and written reflections.

This research report describes a variety of experiences that parents underwent and the repercussions thereof. Suggestions were made and parents shared advice and support strategies to help other parents who have a child with autism who may decide to embark on an intensive ABA programme.

OPSOMMING

Die doelwit van hierdie studie was om die ondervindinge van ouers met 'n kind wat voorheen met outistiese versteuring gediagnoseer is en wat tans of in die verlede 'n intensiewe Toegepaste Gedrags Analise program voltooi het, te verken.

Ouers het vrywillig aan hierdie navorsingsprojek deelgeneem. Die mikpunt van die projek was om die ouers se ervarings en die verskeie uitdagings wat hulle in die gesig staar, te ondersoek. Hierdie studie fokus ook op ondersteuning en hanteringstrategieë wat deur ouers ervaar word. Ouers is ook gevra om ondersteuningstrategieë, hanteringstrategieë en advies te bied aan ander ouers wat dalk 'n soortgelyke reis sal deurmaak.

'n Literatuuroorsig is gedoen ten einde die perspektief van navorsing wat op hierdie gebied gedoen is, te verkry. Ek het die dubbele rol van navorser en leerling opvoedkundige sielkundige gevul. Die interpretatiewe paradigma is gekies as die raamwerk vir hierdie studie. Die ervarings is vanuit semi-gestruktureerde onderhoude en geskrewe refleksies versamel.

Hierdie navorsingsverslag beskryf 'n verskeidenheid ervarings wat die ouers deurgemaak het, asook die gevolge daarvan. Voorstelle is gemaak en advies en ondersteuningstrategieë is deur ouers gedeel om hulp te verleen aan ander ouers van 'n kind met outisme wat 'n intensiewe ABA program gaan begin.

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- All my friends and family for their continuous support, patience and understanding.

ACRONYMS

ASD	Autism Spectrum Disorder
PDD	Pervasive Developmental Disorder
PDD NOS	Pervasive Developmental Disorder Not Otherwise Specified
ABA	Applied Behaviour Analysis

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CHAPTER 1

CONTEXTUALISATION AND RELEVANCE OF THE RESEARCH

1.1 INTRODUCTION

Parents who have children with pervasive developmental disorders face many difficult decisions and experiences regarding their child's treatment and support. Having a young child with autism impacts family and personal life extensively (Meirsschaut, Roeyers & Warreyn, 2010, p. 668).

Pervasive Developmental Disorder (PDD) is an umbrella term used to describe a broad spectrum of disorders which are characterised by similar patterns of behaviour; these disorders include Autistic Disorder, Asperger's Syndrome, Rett's Disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder not otherwise Specified (APA, 2000, p. 69). In 2001, a study of the primary school population in Cambridge reported that one in every one hundred and sixty-six children had an Autistic Spectrum Disorder (Baron-Cohen, 2008, p. 23). Children of all the participants in the current study had been diagnosed with Autistic disorder, which is henceforth described as autism.

Parents who have young children with autism are burdened with choice and responsibility when presented with copious amounts of information, as well as having to make difficult decisions regarding the treatment that best suits their child. These parents also have many different experiences over time regarding the treatment of their child (Valentine, 2010, p. 951).

Romanczyk, Gillis, White and Digennaro (2008) mention important considerations when implementing a treatment programme for children with autism (pp. 372-373). These include the identification of existing treatments available and the categorisation of these treatments in order to assist in the decision-making process. It is necessary to specifically look at the impact the family context may have on the treatment programme; family context meaning the family's level of involvement in the process of treatment. These factors are influenced by socioeconomic status, family stress level, siblings'

needs, services available, social support and parents' perceptions of treatment. All of these factors may have an impact on parents' experiences of treatment (Romanczyk et al., 2008, p. 373).

This study attempts to gain understanding of parents' experiences regarding their child with autism who is or has in the past been involved in an intensive therapy programme, with one of the main focuses being that of Applied Behaviour Analysis (ABA) therapy.

All the parents who participated in this research have children who attend or have in the past attended a school in Cape Town that focuses on therapeutic treatment; this school is referred to in this study as 'the therapy school'. Children in the therapy school attend one-on-one intense therapy sessions as well as group social therapy. The programmes are based on ABA therapy as well as other approaches best suited to the individual child. These approaches include Treatment and Education of Autistic and Related Communication Handicapped Children (TEACHH), Floortime, Relationship and development intervention (RDI), Picture Exchange Communication System (PECS) and many other internationally proven methods. The therapy school has a Grade R, a Grade 1 and a Grade 2 class, all of which follow the same structure as the mainstream curriculum.

1.2 BACKGROUND TO AND MOTIVATION FOR STUDY

According to various authors (Pottie & Ingram, 2008, p. 861; Kuhn & Carter, 2006, p. 565) the diagnosis of autism leaves parents feeling overwhelmed, confused and helpless. This is mainly due to the lack of knowledge regarding the condition. Parents who have children with autism experience higher levels of stress and psychological distress than parents with neurotypical children (Lopez-Wagner, Hoffman, Sweeney, Hodge & Gillian, 2008, pp. 245-259; Grindle, Kovshoff, Hastings & Remington, 2008, p. 52).

Applied behaviour analysis (ABA) is a form of therapy based on the theory that behaviour rewarded is more likely to be repeated than ignored behaviour. It is usually the most effective therapy for education and behaviour in children with autism. ABA interventions have been documented in research studies for over 30 years (Turkington & Anan, 2007, p. 7; Baron-Cohen, 2008, p. 110).

ABA is derived from the principles of behaviourism. The behaviour paradigm occurred in the twentieth century when psychologists studied the behaviour of organisms. B.F. Skinner was the leading exponent of behaviourism (Corey, 2009, p. 233). He found inspiration from the contributions of early behaviour theorists such as Ivan Pavlov, John Watson and Edward Thorndike (Naour, 2009, p. 6).

Early theorists of behaviour focused on what happens to an organism before a certain behaviour occurs, whereas Skinner focused on what happened after behaviour occurs. According to Skinner, behaviour is more likely to occur again if a person likes the response following on the behaviour that occurred. A word he used for this response/consequence is reinforcement. Reinforcement can be positive or negative (Wilkins & Matson, 2009, pp. 7-8). For example: if a child receives a toy after doing a puzzle, the toy would be a positive reinforcement. If a child received a hiding after he broke a toy, the hiding would be a negative reinforcement. Skinner named his conceptual framework operant conditioning (Naour, 2009, p. 6).

The intensity of Applied Behaviour Analysis therapy paired with other interventions may have an impact on parents' experiences in the home, with family and socially.

1.3 RESEARCH PROBLEM

The research project was undertaken firstly to attempt to understand parents' experiences and identify the challenges they may face whilst their child is doing Applied Behaviour Analysis (ABA) therapy. Secondly, it was attempted to identify support needs and strategies that may help parents and others to cope with the demands of ABA therapy. Previous studies on the experiences, stresses and support of families who have children with autism have been undertaken in various countries (Meadan, Halle & Ebata, 2010; Grindle et al., 2009; Pottie & Ingram, 2008; Hillman, 2006; Kuhn & Carter, 2006; Moes & Frea, 2002; Nevas & Farber, 2001). Various studies have focused on the experiences of parents who have a child with autism: these studies have mainly been done abroad (Woodgate, Ateah & Secco, 2008; Hurlbutt, 2011; Pottie & Ingram, 2008; Grindle et al., 2009). There seems to be a lack of knowledge on autism and little support is provided for parents in South Africa.

This study was therefore aimed at exploring the experiences of parents and possibly provide more avenues for the support needed for these parents in South Africa.

1.4 RESEARCH QUESTION

This study was guided by the following research question and sub-questions:

- What are parents' experiences of a child with autism doing Applied Behaviour Analysis therapy?
 - How do they experience their child's behaviour before and after ABA?
 - What are parents' experiences of their relationship with others (friends, family, husband, other children and the public) and what role does autism and/or ABA therapy play in these experiences?
 - What coping strategies and support do parents experience?
 - What support and advice do parents have for others who have a child with autism?

1.5 RESEARCH PARADIGM

A research paradigm is "a set of assumptions or beliefs about fundamental aspects of reality which gives rise to a particular world-view" (Maree & Van der Westhuizen, 2010, p. 47). The researcher believes that the reality of the experiences parents have lived through during their child's therapeutic process is a reflection of their internal and external worlds.

The study was situated within the interpretive paradigm. The interpretive paradigm is defined by a specific ontology, epistemology and methodology. It focuses on the question of the nature of reality (ontology), the relationship between the researcher and the participant (epistemology), and the techniques used to understand the research question (methodology) (Adams, Collair, Oswald & Perold, 2004, p. 356).

The researcher made use of qualitative inquiry, by which the reality of parents' experiences were explored by means of spoken and written text. Qualitative research is

in-depth research which focuses on the feelings and thoughts of the research participants (Henning, Van Rensburg & Smith, 2010, p. 3). The researcher's main interest was in understanding how people have constructed meaning in order to make sense of their world. Their world or reality is not fixed or measurable; instead there are numerous interpretations of reality that change over time (Merriam, 1998, p. 2). Researchers therefore study people's interpretations of and interactions with their world in a particular context at a specific point in time. This is done by means of interviews, observations and written documents. The process of qualitative research is inductive; the researcher gathers information to build theories, hypotheses or concepts (Merriam, 1998, p. 14).

Qualitative research is richly descriptive as words are used, opposed to numbers. The main focus is on society and culture and the beliefs, values and attitudes that influence people's behaviour (Maree & Van der Westhuizen, 2010, p. 22).

An interpretive paradigm is appropriate for researching parents' experiences as it focuses on their "lived experience" where their "multiple realities are socially constructed" (Merriam, 1998, p. 4). Therefore understanding their experiences is essential to understanding their meaning making, which, in the case of this study was the attribution to their child's ABA therapy. The methodological considerations are discussed in the following section.

1.6 RESEARCH DESIGN AND METHODOLOGY

The research design is the blueprint of the study; it establishes the methods that are used to conduct a study. The purpose is to find suitable answers to research questions. Research design is informed by a mode of inquiry, which is a collection of research procedures. As mentioned above, the mode of inquiry adopted in this research study is qualitative (Nieuwenhuis, 2010, p. 70).

The research methodology consists of the procedures or individual steps that need to take place to accurately execute the research design (Mouton, 2008, p. 55). The design and methods used in the research study are discussed below.

1.6.1 Design

The study that has been undertaken is a basic interpretive study that focuses on the personal and social challenges experienced by parents who have a child with autism, as well as the possible support strategies they have to adopt in order to maintain their wellness.

1.6.2 Literature study

The literature study guided the research process by providing a theoretical framework for the research. A number of research studies have been undertaken on the experiences of mothers, yet fathers' experiences have been neglected in the past. In South Africa, little research about both parents' experiences in the therapy process has been undertaken.

1.6.3 Research population and sample

The sample for this study was drawn from a list of parents from a school in Cape Town, referred to in this study as "the therapy school", where Applied Behaviour Analysis is used along with a variety of other treatment methods that are adapted to the needs of the individual child with autism.

Therefore the sample included parents (which could be a male and female, a male and male, a female and female, a male or a female), who have a child with autism (biological or adopted) who is currently or has been in an ABA therapy programme in the school. Individual interviews have been done with each parent. Six parents were interviewed and 5 parents wrote reflections on their experiences.

1.6.4 Research instrument

The main research instrument in this study was the researcher. According to Henning et al. (2010) "the researcher is unequivocally the main instrument of research and makes meaning from her engagement in the project" (p. 7). There are biases and shortcomings to having a human research instrument, which may impact the study. The researcher identified possible shortcomings and monitored them during the research process (Henning et al., 2010, p. 7).

1.6.5 Data collection methods

The methods of research used in this study consisted of individual semi-structured interviews and a brief written narrative/self-reflection from each participant. "The aim of qualitative interviews is to see the world through the eyes of the participant" and "to obtain rich descriptive data" in order to understand the participants' "construction of knowledge and social reality" (Nieuwenhuis, 2010, p. 87). As the researcher wanted to understand parents' meaning making of their experiences with their child with autism who was undergoing or had undergone intensive ABA therapy, as well as parents' views of their role in the therapy process. The data obtained from the interviews were recorded on a digital voice recorder and were fully transcribed afterwards. Before the researcher began conducting the research, a pilot study was conducted to validate and fine-tune the research instrument (Strydom & Delpont, 2011, p. 237). The pilot study was conducted with someone who was not part of the final research study, yet had reached all the research criteria indicated for the participants in the study.

1.6.5.1 Narrative

Parents wrote a brief narrative and reflection (minimum one page) on their experiences of having a child with autism doing Applied Behaviour Analysis Therapy. This was done in their-own time before the semi-structured interviews took place.

1.6.5.2 Semi-structured interviews

Individual qualitative semi-structured interviews took place. A pre-determined interview guide was used with open-ended questions in order to ensure that the same questions are covered in all the interviews and to allow flexibility and probes (Greeff, 2011, pp. 351-353). The semi-structured interview guide consisting of fourteen open-ended questions, which was used to guide the interviews, is provided in Addendum D.

The data obtained during the interviews were recorded on a digital voice recorder and were fully transcribed afterwards. The same questions were asked in each interview. The time period for interviews was approximately 30 to 45 minutes each.

It was important to establish a trusting relationship with research participants and abide by the ethical considerations discussed below.

1.6.5.3 Ethical considerations

Before interviewing the participating parents, the following ethical issues indicated in the Ethical Code of Professional Conduct (The Professional Board for Psychology, Health Professions Council of South Africa 18/5/B) 26/3/2000, and suggested by Babbie and Mouton (2009, pp. 528-531) were attended to: competent planning of research; responsibility for ethical conduct of research; compliance with provincial law and regulations on research; obtaining approval from institution supervising research; providing participants with information on the study; entering into an agreement with participants prior to conducting research ensuring that the rights of participants are being protected, acknowledging their privacy, addressing participants with sensitivity, indicating that participation is voluntary and information is confidential. Ethically, it was important to get a written and signed consent form with an explanation of the reason, aims and purpose of the research study (Babbie & Mouton, 2001). The ethical clearance letter for this study is provided in Addendum A; the clearance number was 312/2010. Permission was also needed to record the interviews on the digital voice recorder.

1.6.6 Data analysis

The data in this study was analysed using qualitative content analysis; the researcher began with the set of data such as the transcribed interviews. Significant themes were observed while reading the individual interview transcripts to get a global impression (Henning et al., 2010, p. 104).

Following this, the researcher began to identify units of meaning and each transcript was coded (raw data); the broad categories were indicated and from these the main themes were identified. These themes were organised in table format with each main theme forming a category in which common views were identified. Reflections were written down after each interview in order to help the researcher become aware of possible biases that could be introduced into the research process (Henning et al., 2010, p. 104).

1.7 DEFINITION OF TERMS

Terms used in this research report are defined as follows:

1.7.1 Pervasive developmental disorders

Pervasive Development Disorders (PDDs) comprise a group of disorders characterised by impairments in several areas of development, such as communication skills, reciprocal social interaction skills and restrictive, repetitive and stereotyped behaviour patterns. According to the *Diagnostic and Statistical Manual of Mental Disorders*, there are five different types of Pervasive Development Disorders. These include: Rett's Disorder, Childhood Disintegrative Disorder, Autistic Disorder, Asperger's Disorder, and Pervasive Development Disorder Not Otherwise Specified (APA, 2000, p. 69). In this study, the affected children of all the participants had been diagnosed with Autistic Disorder, which is described below.

1.7.2 Autistic disorder

The *Penguin Dictionary of Psychology* describes children with autism as:

characterised by a withdrawn state, a lack of social responsiveness or interest in others, serious communicative and linguistic impairments, and a failure to develop normal attachments, all frequently accompanied by a variety of bizarre ways of responding to the environment, usually including a fascination of inanimate objects and an insistence on routine, order and sameness (Reber & Reber, 2001, p. 68).

Autistic Disorder is extremely complex as no child with autism has the same level of functioning as another, therefore treatment is different for every child with autism.

1.7.3 Behaviourism

The *Oxford Dictionary of Psychology* (2009) states that:

According to behaviourism, virtually all behaviour can be explained as the product of *learning (1), and all learning consists of *conditioning (1). The contemporary work on *classical conditioning of the Russian physiologist Ivan Petrovich Pavlov (1849-1936), of which Watson was apparently unaware, added further impetus to the behaviourist movement as it became known in the US (Colman, 2009, p. 85).

Behaviourism is the school of psychology on which behaviour therapy was largely based. Early contemporary behaviour psychologist and the father of behaviourism, John Watson, believed that psychology should be about understanding what happens to people and how they respond (Spiegler & Guevremont, 2010, p. 18).

1.7.4 Applied behaviour analysis (ABA)

Applied behaviour analysis (ABA) is a form of therapy based on the theory that behaviour rewarded is more likely to be repeated than ignored behaviour. It is the most well-researched behavioural treatment for autistic children. Ivar Lovaas, who was an autism expert at the University of California at Los Angeles, developed ABA therapy (Turkington & Anan, 2007, p. 6). ABA therapy is explained in greater detail in the next chapter, as it is important to understand the components of ABA therapy for this research study.

1.7.5 Parents

In this research study, a parent is defined as one person (single parent) or two people who are the guardians of a child; parents could be a female or a male, a female and a male, a male and a male or a female and a female. A parent could be a biological or an adoptive parent in the case of this study.

1.8 STRUCTURE OF PRESENTATION

Chapter 1 provides the reader with a brief overview of the purpose of the study, the research problem and research design. The key concepts are defined and an outline of the research is provided.

Chapter 2 provides a detailed theoretical framework of past research studies related to the topic. A definition and detailed outline of Applied Behaviour Analysis Therapy is given. Autistic Spectrum Disorder (ASD) is discussed in detail, as it is important for the reader to understand the features of ASD in order to understand how parents may experience their child's different behaviours.

Chapter 3 provides a detailed discussion of the method of inquiry.

Chapter 4 consists of the presentation and discussion of the findings of the study.

Chapter 5 presents a discussion the implications and recommendations stemming from this study.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter contains a review of literature relevant to the research topic and problem statement of the current study. Behavioural therapy and ABA therapy is explained and a detailed description of Autistic Disorder is presented. Studies on the experiences of parents, mothers and fathers with a child receiving applied behaviour analysis therapy have also been included. The studies that are reported have been conducted in South Africa and abroad in order to get a more detailed overall perspective.

2.2 BEHAVIOUR THERAPY

Behaviour therapy is a broad term used to refer to an entire field of therapy. Behaviour therapy is used to help clients with a wide range of psychological problems including anxiety, depression, interpersonal difficulties and bizarre behaviours. These psychological problems are often distressing and maladaptive to clients as they can violate social norms and disturb other people, for example parents who may be troubled by their child's extreme socially awkward behaviour (Spiegler & Guevremont, 2010, p. 5; Corey, 2009, pp. 233-271).

In this section, the meaning of behaviour therapy and a brief history of behaviour therapy is given, and the behaviour model as well as the process of behaviour therapy is explained. The primary focus of this study is on parents' experiences with their child doing ABA therapy; this section focuses on the terms that are relevant to this specific type of behaviour therapy.

2.2.1 What is behaviour therapy?

As mentioned above, behaviour therapy is a broad term, which does not have one single definition. Many diverse types of behaviour therapy are used to treat a wide array of problems. These include: Desensitization Technique, Cognitive Behaviour Therapy,

Implosion Therapy and Applied Behaviour Analysis (Reber & Reber, 2001, p. 85; Spiegler & Guevremont, 2010, pp. 5-6).

Spiegler and Guevremont propose features of behaviour therapy which, according to them, are the core themes of behaviour therapy (2010, p. 6). These themes are discussed below.

- **Scientific**

Behaviour therapy in essence is a scientific approach that involves empirical evaluation and precision. All aspects in behaviour therapy have a precise definition, including those behaviours targeted for change, the goals for treatment and the procedures for assessment and therapy. Behaviour therapies are often preferred treatments as they are empirically supported and have upheld a high standard (Spiegler & Guevremont, 2010, p. 6; Corey, 2010, p. 237).

- **Active**

Behaviour therapy is an action therapy in which clients engage in specific actions to alleviate their problems. Many of the therapy procedures are used in the client's natural environment. For example, an anti-social client may begin to practise social skills in a therapy session and will have to practice these skills at home or school as part of therapy. When a client takes the therapy home it is more likely that changes will become a part of the client's life after the therapy has ended (Spiegler & Guevremont, 2010, p. 7; Corey, 2010, p. 238).

- **Present focus**

Behaviour therapy focuses on the present, as the assumption is that the client's problems are influenced by current conditions. Therefore procedures are used to change factors that are influencing a client's current behaviour (Spiegler & Guevremont, 2010, p. 7).

- **Learning focus**

Behaviour therapy places a strong emphasis on learning. According to the behaviour model, most problem behaviours develop, are maintained and change through learning.

In behaviour therapy, clients are provided with learning experiences where more adaptive behaviours replace maladaptive behaviours. The developments of many behaviour therapies were based on principles and theories of learning, which explain why the procedures work (Spiegler & Guevremont, 2010, p. 7; Corey, 2010, p. 238).

2.2.1.1 Common characteristics of behaviour therapy

Behaviour therapy is individualised in that therapy and assessment procedures are adapted to each individual client's personal characteristics and unique problem, as well as the circumstances in which the problem occurs (Corey, 2010, p. 238; Spiegler & Guevremont, 2010, p. 9).

Behaviour therapy occurs in a stepwise progression, with a client beginning from simple and progressing to complex or from easier to harder. This step-by-step process makes it easier for a client to slowly change behaviours. Different behaviour therapy procedures are often combined to increase the effectiveness of the therapy. These treatment packages are used to meet the client's individual needs (Spiegler & Guevremont, 2010, p. 9).

2.2.2 History of behaviour therapy

Behavioural principles have been used for thousands of years, yet the formal application of these principles is said to be around 60 years old. It was in the 1950s that contemporary behaviour therapy formally began to be practised in Canada, Great Britain, South Africa and the United States simultaneously (Spiegler & Guevremont, 2010, p. 17).

Jean-Marc-Gaspard Itard applied contemporary behaviour therapy as early as the 18th century to socialise a boy who grew up without human contact. The therapies that were used to teach this boy language and social behaviour, were the same as those used today to treat children with autistic disorder. These include modelling, prompting, shaping, time out and positive reinforcement. At that time no formal research was done on these different principles (Spiegler & Guevremont, 2010, p. 17).

In the beginning of the 20th century, experimental research on learning was conducted by Russian Psychologist Ivan Pavlov. In his research, a neutral stimulus was paired with a stimulus that elicited a particular response. After conditioning, the results showed that

the neutral stimulus alone elicited the response. This came to be known as classical conditioning (Reber & Reber, 2001, p. 122; Corey, 2010, p. 235). During the same period Edward Thorndike was investigating the strength and weakening of behaviours by applying different levels of consequences (reinforcement and punishment). Thorndike's use of positive reinforcement to get a desired behaviour is called operant conditioning (Spiegler & Guevremont, 2010, p.19). In the beginning of the 1930s, B.F. Skinner began investigating operant conditioning with pigeons and rats. In the 1950s Skinner and Ogden Lindsley undertook research studies to demonstrate that patients in psychiatric hospitals would perform meaningful tasks when given meaningful reinforcement (Spiegler & Guevremont, 2010, p. 22; Wilkins & Matson, 2009, p. 8).

In the 1950s, South African psychiatrist Joseph Wolpe developed several keystone behavioural methods, specifically systematic desensitisation (Wilkins & Matson, 2009, p. 11). Wolpe had two prominent students in South Africa: Arnold Lazarus, who later moved to United States, advocated extending the boundaries of behavioural therapy and Stanley Rachman, who moved to Britain, introduced desensitisation to British behavioural therapists. The above behavioural methods were developed as alternatives to traditional psychoanalytic therapy (Spiegler & Guevremont, 2010, p.23).

In 1966, the Association for Advancement of Behaviour Therapy was established in the United States to advocate for behavioural therapy. In the 1970s, behaviour therapy emerged as a major force in psychology and impacted psychiatry, social work and education. By 1990, behaviour therapy societies had been developed worldwide and behaviour therapy nowadays is practiced in many diverse countries (Spiegler & Guevremont, 2010, p.29).

2.2.3 The behavioural model

It is necessary to understand the model on which behavioural therapy is based to appreciate the nature of behaviour therapy. First, two different types of behaviour, namely covert and overt behaviour are explained and this is followed by a discussion of the ABC model.

2.2.3.1 Overt and covert behaviour

Overt and covert behaviours represent two broad categories of behaviour. Overt behaviours refer to the actions or public behaviours that people can see or hear directly. These include talking, eating, laughing and walking. Covert behaviours are those behaviours that cannot be seen directly. These behaviours are cognitions (thinking or imagining), emotions (feeling) and physiological responses (respiratory rate or muscle tension). These four modes of behaviour (overt behaviours, cognitions, emotions and physiological responses) are assessed and treated in behaviour therapy (Spiegler & Guevremont, 2010, p. 32).

2.2.3.2 The ABC model

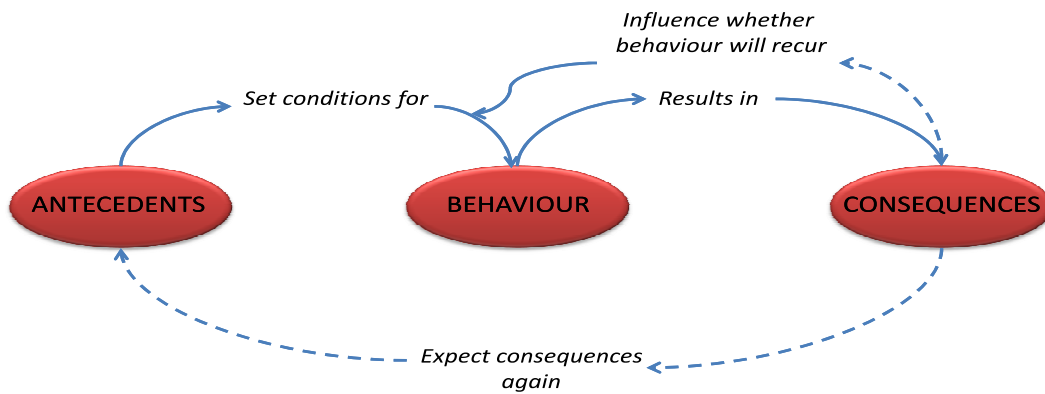
Different theories and models have been developed by psychologists to explain human behaviours. "According to the behavioural model, a person's behaviours are caused by present events that occur before and after the behaviours have been performed" (Spiegler & Guevremont, 2010, p. 36).

The ABC model (illustrated in Figure 2.1) consists of a sequence of antecedents, behaviour and consequences (Turkington & Anan, 2007, p 66; Spiegler & Guevremont, 2010, p. 37).

Antecedents are events that occur or are present before the person performs the behaviour. Consequences are events that occur after and as a result of the behaviour. For example, feeling tired is an antecedent for sleeping, and feeling rested the next day is a consequence of sleeping. (Spiegler & Guevremont, 2010, p. 36)

The ABC model is of great importance and is used directly in ABA therapy. Behaviour is maintained (caused or influenced) by a small number of antecedents and consequences. These are called maintaining antecedents or maintaining consequences.

There are two categories of maintaining antecedents, namely prerequisites and stimulus control. Prerequisites consist of the knowledge, skills and resources that are needed to set up for a specific behaviour to take place (requisite knowledge). The stimulus controls are conditions needed to 'set the stage' for behaviours to occur. The two types of stimulus control are prompts and setting events. Prompts are cues for someone to perform a behaviour, for example telling them verbally to perform the behaviour.

Figure 2.1: The ABC Model

(Spiegler & Gueremont, 2010, p.37)

Figure 2.1: The ABC Model

Source: Spiegler and Guevremont (2010, p.37)

Setting the event is more complex as specific environmental conditions are needed to elicit behaviour. The environmental conditions, for example, concern what time of day it is, who is in the room and what they are doing. Behaviour therapists use prompts and setting events in therapy to change a client's problem behaviours (Spiegler & Guevremont, 2010, p. 38).

If consequences are favourable, behaviour is more likely to be repeated, whereas behaviour is less likely to be repeated if they are unfavourable. Maintaining consequences therefore determine whether behaviour will occur again (Turkington & Anan, 2007, p. 6). How the ABC model is applied in behaviour therapy is discussed below.

2.2.4 The process of behaviour therapy

The process of behaviour therapy develops through a series of steps, which are provided and discussed below and shown in Figure 2.2.

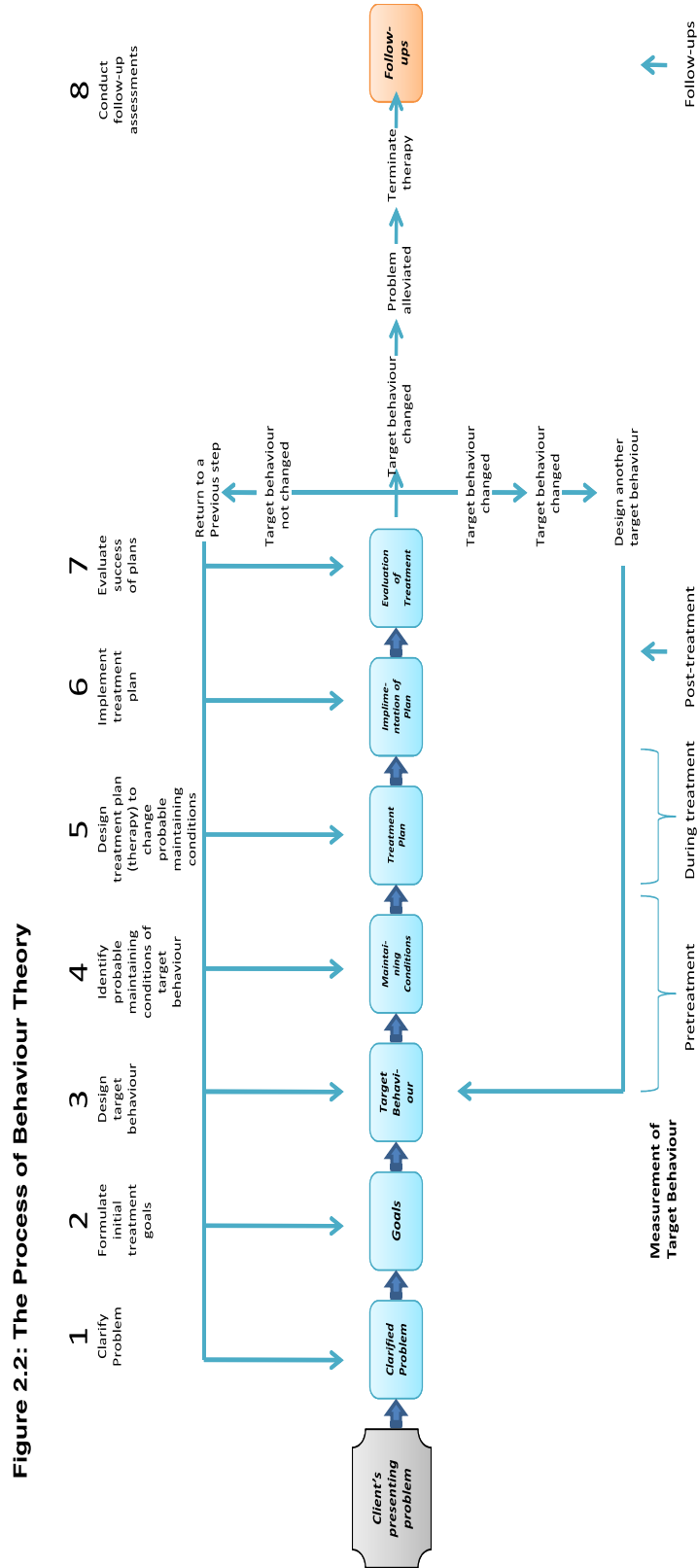
1. Clarifying the client's problem
2. Formulating initial goals for therapy
3. Designing target behaviour (the specific behaviour that will be changed)
4. Identifying the maintaining conditions of the target behaviour
5. Designing a treatment plan (specific therapy procedures) to change the maintaining conditions
6. Implementing the treatment plan
7. Evaluating the success of the treatment plan
8. Conducting follow-up assessments (Spiegler & Guevremont, 2010, p. 50).

Once the target behaviour has been designed, the measurement of it begins and continues throughout the evaluation of therapy. Once the target behaviour has been successfully changed, therapy can be terminated or the process can begin with another desired target behaviour.

In the first step, the therapist must help the client to narrow down his/her problems, as it is more efficient to treat one problem at a time. Once the client's problem is clearly identified, measurable goals must be formulated. These goals can be re-evaluated during the course of therapy and changed if necessary.

Once a goal has been established, the target behaviour needs to be designed. "A target behaviour is a narrow, discrete aspect of the problem that can be clearly defined and easily measured" (Spiegler & Guevremont, 2010, p. 53). It is best to begin with the least anxiety provoking and easiest behaviour.

There are two types of target behaviours. Acceleration target behaviours are those behaviours that a client would like to increase and deceleration target behaviours are



Source: (Spiegler & Guevremont 2010,p.51)

those a client needs to decrease. Acceleration target behaviours are simple and straightforward to deal with and behaviour therapy procedures are used directly to increase acceleration. Deceleration target behaviours are more complicated to deal with. The best way to deal with deceleration target behaviour is to replace it with acceleration target behaviour (Spiegler & Guevremont, 2010, p. 59).

The maintaining conditions of the target behaviour need to be identified in the fourth step. When the target behaviour occurs, a record can be kept and the antecedents and consequences can be noted. For example, in the case of Applied Behaviour Analysis, parents can be instructed to observe and record the circumstances that have led a child to reach a target behaviour. Therapists can then simulate the situation by introducing and removing the effects of the target behaviour (Spiegler & Guevremont, 2010, p. 59).

In steps 5 and 6, a treatment plan needs to be designed and implemented. The therapy procedures that will be used to change the maintaining conditions of the target behaviour are specified in the treatment plan. This plan is individualised for the specific client. In step 7, it is important to determine whether the target behaviour has significantly changed from the behaviour before the therapy was implemented. If the behaviour has not changed, one has to return to one of the previous steps. Therapy may be terminated if the treatment goals have been met successfully. Follow-up assessments can be done subsequently to ascertain whether the target behaviour has been maintained (Spiegler & Guevremont, 2010, p. 61).

2.3 APPLIED BEHAVIOUR ANALYSIS (ABA)

Turkington and Anan (2007, p. 284) have defined the term applied behaviour analysis as:

A style of treatment that uses a series of trials to shape a desired behaviour. Skills are broken down to their simplest components and taught through a system of reinforcement; prompts are given as needed when the child is learning a skill. As a skill is mastered the prompts are faded until the child can perform the task independently.

Of all the behavioural treatment methods for autistic disorder, Applied Behaviour Analysis is the best researched. Dr Ivar Lovaas and his colleagues at the University of

California at Los Angeles (UCLA) were the developers of the ABA approach (Turkington & Anan, 2007, p. 38).

In order to change behaviours, ABA therapists have applied principles of reinforcement. Reinforcement occurs when a consequence increases the likelihood that the target behaviour will reoccur; this reinforcing consequence is called a reinforcer (Corey, 2010, p. 236; Spiegler & Guevremont, 2010, p. 120). For example, if a child's target behaviour is to cross his/her legs and he/she receives a sweet when this is done (reinforcer/consequence), the child is more likely to repeat the behaviour (crossing of the legs) if the reinforcer is desired. There are two types of reinforcement, positive and negative, but behaviour therapists rarely use negative reinforcement. Types of positive reinforcers are tangible reinforcers (material objects such as food, clothes and books), social reinforcers (administered verbally such as praise, approval and attention), token reinforcers (symbolic items of value which can be exchanged for something desired), and reinforcing activities (shopping, sleeping late or going out for a meal) (Spiegler & Guevremont, 2010, pp. 121-123).

In ABA therapy, therapists do intense one-on-one therapy with a child for 20 to 40 hours in a week. Children are taught skills in a basic step-by-step manner, such as teaching colours one by one. These skills include reading, academics, social skills, communication and adaptive living skills. The beginning sessions start with formal structured drills, such as learning to point at an object when its name is given. As therapy continues, a shift is made towards generalising skills to other environments and situations. The main goal of these sessions is to reinforce desirable and reduce undesirable behaviour (Turkington & Anan, 2007, p.7).

ABA methods are used to support persons with autism to:

- increase behaviours
- teach new skills
- teach self control and self-monitoring procedures
- generalize or to transfer behaviour from one situation or response to another
- restrict or narrow conditions under which interfering behaviours occur
- reduce self injury or unnecessary repetition of movements (Turkington & Anan, 2007, p. 7).

Therapy is more effective when it has begun before the age of five and is extremely effective when teaching non-verbal children how to talk. It is helpful for parents to attend workshops or do courses in order to learn ABA techniques and use them at home (Turkington & Anan, 2007, p. 38).

An important principle in ABA training is discrete trial training (DTT); multiple studies have shown that DTT significantly improves symptoms among children with autistic disorder. This type of teaching breaks learning tasks into small components and uses positive reinforcement to teach each isolated part, the child therefore acquires the sub skill by rehearsal and repetition. For example: Tutor gives an instruction (SD) – Child responds (R) – Tutor gives a consequence (SR) (Brams, 2008; Turkington & Anan, 2007, p. 65).

The DTT method is used to control the mass of information that normally confronts a child with ASD by presenting the information in a slow manner. Learning tasks are arranged from simple to complex. The two main goals of DTT are teaching learning readiness skills (for example sitting in a chair and paying attention) and decreasing behaviours that interfere with learning such as aggression and tantrums (Turkington & Anan, 2007, p. 66).

In one of his many studies, Dr Lovaas's trained graduate students spent two years doing intense one-on-one therapy for 40 hours a week. His students worked with 19 young children with autism ranging from three to three and a half years. Almost 50% of the children drastically improved in that they became indistinguishable from typical children of that age and afterwards led fairly normal lives. The remaining 50% of children improved significantly; few did not improve much (Turkington & Anan, 2007, p. 38; Lovaas, 1987, pp. 3-7).

In 2006, Eldevik, Eikeseth, Jahr and Smith conducted a study published as *Effects of Low-Intensity Behavioural Treatment for Children with Autism and Mental Retardation*. In their study 13 children received 10 to 20 hours of one-to-one ABA therapy a week for two years compared to 15 children who received the same amount of eclectic therapy (a combination of three other therapies). The results showed that the behaviour therapy group showed a significantly bigger change in intellectual functioning, behaviour pathology, language comprehension and expressive language than the eclectic group.

The IQ results post-treatment in the behavioural group were reduced for 38% of the children. If, compared to other studies on ABA therapy, the gains were not as significant, this could be due to the lower intensity of treatment (Eldevik et al., 2006, pp. 213-222). Intensive behavioural treatment in young children with autism has resulted in better performance compared to those who have received a range of different treatments (Howard, Sparkman, Cohen, Green & Stanislaw, 2005, p. 376).

2.4 BEHAVIOURAL PARENT TRAINING

In Behavioural parent training (also called *parent management training* or *Behavioural child management training*) parents are taught behaviour therapy skills to manage their children's behavioural problems effectively (Spiegler & Guevremont, 2010, p. 200).

In this training, parents are given three important goals. These are to:

- (1) ensure that clear instructions are used that are direct and age appropriate;
- (2) be consistent when reinforcing a desirable behaviour; and
- (3) to give reasonable punishment if children's behaviour is disruptive.

Other therapy procedures taught to parents are scheduling of planned activities, the use of reinforcement and the use of time-out from positive reinforcement. Behavioural parent training is conducted in groups consisting of four to ten sets of parents, or with a single family. Procedures are rehearsed in the training sessions, with the therapist giving feedback. Homework is used as an important part of behavioural parent training. A study that was conducted on children whose parents received behavioural parent training revealed that these children's problem behaviours were reduced by 63% (Spiegler & Guevremont, 2010, pp. 200-202).

In a study undertaken by Doug Moes and William Frea (2002) to investigate contextualized behaviour support in early intervention for children with autism and their families, the researchers mention the benefits of parents' involvement in therapy. The aim of the study was to investigate how different variables of family context could be used to support families and individualise the treatment of communication training within specific family routines. They discuss the use of parent education in order to help

families manage challenging behaviour, to enhance social skills and to teach language. They mention the importance of social support to help families to cope with the stress associated with raising a child with autism. "One of the primary goals of behavioural parent training is to promote successful family interactions" (Moes & Frea, 2002, p. 521).

2.5 PERVASIVE DEVELOPMENTAL DISORDERS – AUTISTIC SPECTRUM DISORDER

Pervasive Developmental Disorders (PDDs) are distinguished by impairments in areas of development such as social interaction, communication, and the presence of stereotyped activities and behaviour.

According to the revised fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM – IV – TR), the different types of pervasive developmental disorders are Autistic disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (APA, 2000, p. 69).

The current study was focused on the experience of parents who have children who are receiving or have in the past received Applied Behaviour Analysis Therapy. All these children have at some stage been diagnosed with Autistic Disorder. I have therefore included this section on Pervasive Developmental Disorders where the main focus is on Autistic Disorder. The researcher believes that it is relevant for the reader to understand the characteristics of these children in order to have an idea of some of the experiences their parents may have. A list of the scientific criteria for the diagnosis of Autistic disorder is provided in Table 2.1.

Table 2.1: Diagnostic criteria for Autistic Disorder

- 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 behaviours such as eye to eye gaze, facial expression, 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, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - (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 alternative modes of communication such as gesture or mime.
 - (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 behaviour, 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 or twisting, or complex whole-body movements)
- 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 (APA, 2000, p.633).

Source: APA, 2000, p. 633

Autistic disorder (also called "early infantile autism, childhood autism or Kanner's autism") is a pervasive development disorder (PDD), which is characterised by varying degrees of problems with communication skills, social interactions and restricted, repetitive and stereotypical behaviours (Sadock & Sadock, 2007, p. 1191).

2.5.1 History and prevalence

Autistic disorder became prevalent in 1943 when psychiatrist Leo Kanner described 11 children who showed the following symptoms identified with the disorder during their first years of life: Withdrawn, disregard of people and objects; lack of eye contact; lack of social awareness; limited or no language; and stereotypical motor activities. Kanner called this disorder "early infantile autism", autism literally meaning "within oneself". The core features in children with autism were viewed as an "inability to relate themselves in the ordinary way to people and situations from the beginning of life". For decades it was thought to be a rare disorder, affecting around four children per 10,000 (Mash & Wolfe, 2005, p. 284). Recent findings however indicate a much higher prevalence of as high as one in every one hundred and fifty children with autistic disorder. This perceived rise in prevalence of autism may be due to increased awareness among professionals in distinguishing autism from mental retardation (Barlow & Durand, 2009, p. 513).

Children with autism are found in all social classes and are identified all over the world. Autistic disorder is more prevalent in the male population, being around three to four times more common in boys; this ratio has been fairly constant over the years. Although girls are affected by autism less often, they tend to have more severe intellectual impairments (Mash & Wolfe, 2005, p. 299).

2.5.2 Diagnostic features

During the onset of the disorder, parents usually notice unusual behaviours in their children. In some cases a baby will seem unresponsive to people from birth. In other cases, a child may develop normally without any symptoms until one or two years of age. The problem with communication and social skills in these children becomes more evident when they lag behind other children of the same age (Turkington & Anan, 2007, p. 29).

The following characteristics may be evident in a child with ASD: no meaningful gestures by the age of one year, such as babbling or pointing; no speaking by 16 months; not combining two words by the age of two; not responding to name; loss of language or social skills; lack of ability to play with toys appropriately: excessive ordering of objects or toys: no smiling as a response to others smiling; distinguished hearing problems; and attachment to one object or toy (Turkington & Anan, 2007, p. 21).

Infants with autism do not respond to affection or touching; they do not cuddle or maintain eye contact. Children with autism do not seem to form loving relationships with their parents; they often fail to communicate with anyone. When they speak, it is done in unusual ways, for example by parroting or blurting out meaningless phrases (this is called echolalia) (Mash & Wolfe, 2005, p. 291).

Children with autism tend not to use facial expressions or gestures to communicate their needs or feelings. They become isolated and caught up in their own world of rituals and interests; when this world is interrupted they tend to become extremely upset. Many children with autism show extreme fear of noisy or moving objects such as running water, vacuum cleaners, wind or battery-operated toys. At the same time they may show preoccupation or fascination with objects such as a rotating fan or flickering lights and they may develop attachments to strange objects such as a rubber band or a string (Mash & Wolfe, 2005, p. 290-294).

Children with autism are known to lash out at others if something (such as a chair) is moved out of their room, often screaming and kicking. They can spend hours playing in a corner, engaging in repetitive motor activities such as lining up objects, flapping their hands repeatedly or rocking. They often fixate on an object such as a tiny spot on their clothing (Mash & Wolfe, 2005, p. 292).

2.5.3 Autistic disorder across the spectrum

Autistic Disorder is a spectrum disorder, which means that its characteristics and symptoms are expressed in different degrees of severity and in different combinations. Children with autism vary widely in their cognitive, language and social abilities; they often are known to display features that are not specific to autism, such as mental retardation and epilepsy. This means that children who are diagnosed with autism can

be vastly different from one another. Mash and Wolfe (2005, p. 288) discuss three critical factors that show how children with autism can be different from one another:

- "*Level of intellectual ability*: from profound retardation to above-average intelligence" (Mash & Wolfe, 2005, p. 288). Some children have average intelligence and show normal development in some areas whereas others have severe mental retardation and develop very slowly in all areas.
- "*Severity of their language problems*", some children talk a lot and others are mute. Mash and Wolfe indicate that "[c]hildren with autism can fall anywhere between these two extremes" (Mash & Wolfe, 2005, p. 288).
- "*Behaviour changes with age*: some children make little progress, whereas others develop speech or become more outgoing" (Mash & Wolfe, 2005, p. 288).

Because autism is a spectrum disorder, children with autism are all unique in their particular ways and show vastly different symptoms, therefore treatment will be different for all children according to where they lie on the spectrum.

2.5.4 Course of the disorder

The onset of Autistic Disorder mostly occurs prior to three years old. In a few cases parents will report concern about their child since birth, often due to lack of interest in social interaction. In many cases a child with autism develops normally for the first year or two of their lives. Autistic disorder follows a life-long course; in some cases individuals improve with age, in others they deteriorate. Yet, partial independency is possible in around 33% of cases (APA, 2000, p. 73).

2.5.5 Causes

No one knows the definite causes of autistic disorder; many studies have been undertaken and therefore there are many theories about possible causes. It is accepted that autism is a neurodevelopmental disorder that has multiple causes involving more than one type of brain abnormality (Nevid, Rathus & Greene, 2000, p. 455).

2.5.5.1 Psychological, environmental and social

Autism is not a mental or a behavioural problem and is not caused by bad parenting. No psychological factors have been shown to cause autistic disorder, neither does

education or lifestyle increase the cause of autism. There is much controversy with regard to the possible role of vaccinations in children with autism; some experts believe that the MMR (measles-mumps-rubella) combination vaccine is implicated in autism disorder, while evidence suggests that some children with ASD had the measles virus detected in their gut, blood and spinal fluid (Turkington & Anan, 2007, p. 31). Findings in Japan and Denmark suggest, however, that there is not enough evidence to link MMR with autism (Baron-Cohen, 2008, p. 97).

Environmental problems that could play a role in the development of ASD include:

- Oral antibiotics: Excessive use may cause intestinal problems, such as yeast/bacterial overgrowth, and prevent mercury excretion, although research in this area is controversial.
- Prenatal exposure to mercury: Pregnant women who eat seafood high in mercury (such as swordfish or tuna) could be exposing their unborn children to toxic levels.
- Essential minerals: Lack of zinc, magnesium, iodine, lithium, and potassium may lead to problems.
- Pesticides and other environmental toxins (Turkington & Anan, 2007, p. 31).

2.5.5.2 Genetic

Recent research has proved that autism has a genetic component as studies have shown that families with one autistic child have a 5 to 10% risk of having a second child with ASD (Barlow & Durand, 2009, p. 513). As autistic disorder affects the normal development of the brain, research has linked it to biological and neurological differences in the brain (Baron-Cohen, 2008, p. 87). Ongoing studies are investigating whether there is involvement with numerous chromosomes that are different in children with autism. One area that has been studied is the gene responsible for neuropeptide oxytocin. Oxytocin has been shown to play a role in our social memory and how we bond with others (Barlow & Durand, 2009, p. 515).

As mentioned above, there is no concrete evidence on the cause of Autistic Disorder; many possible causes are still being researched and until there is proof of a specific cause or causes, it will be impossible to pinpoint or give an actual reason for Autistic Disorder (Barlow & Durand, 2009, p. 516; Nevid et al., 2000, p. 455). A discussion of research studies related to the current research topic follows.

2.6 RESEARCH STUDIES (RELATED TO THE TOPIC) CONDUCTED ON PARENTS', MOTHERS', FATHERS' AND SIBLINGS' EXPERIENCES

Various studies relating to this research topic have been undertaken in the past. These have mainly taken place abroad (Grindle et al., 2009; Nevas & Farber, 2001; Moes & Frea, 2002; Hillman, 2006; Meadan et al., 2010) and very few South African studies that deal specifically with the research topic could be found. Various findings pertaining to the research topic are discussed below.

A South African-based case study to investigate the "lived experiences of a sibling during the implementation of an Applied Behaviour Analysis intervention program" found that the participant experienced feelings of anxiety, insecurity, anger and sadness because she felt that her needs were not as important of those of her brother with autism (Lighthart, 2002). Parents have reported that they tend to forget to praise other siblings and do not spend as much time with them as with their child with autism as their time is taken over by the needs of the autistic child (Bishop, 2012, p. 102). Another South African study was undertaken to investigate the "experiences of a tutor during the implementation of an applied behaviour analysis programme" (Van Wyk, 2003). The focus of this study was on the experiences of tutors who worked with a child with Autism Spectrum disorder and Down syndrome. In this study, the tutors reported that ABA programmes could be emotionally draining and tiring and had had an immense impact on their personal lives. Tutors reported becoming irritable with parents, yet they were aware that parents needed encouragement after tutors left at the end of the day (Van Wyk, 2003, p. 55).

The above studies were helpful as they provided a brief overview of the experiences of the tutor and the sibling who were both directly involved with the research participants in this study. Both the tutor and other siblings in the family may have a profound impact on the experiences of parents.

Various findings have revealed that parenting a child with Autism places strain on the relationship between parents (Meirsschaut et al., 2010, p. 673), often resulting is a higher risk of divorce (Hartley et al., 2010) and marital discord (Higgins, Bailey & Pearce, 2005). Most parents have reported their experiences of having a child with autism as stressful (Hutton & Caron, 2005; Yamada et al., 2007). Parents who have a child with

autism have reported financial difficulties specifically due to therapy needed for their child (Meirsschaut et al., 2010, p. 664). Financial difficulties have been associated with the cost of medical interventions and therapy (Sharpe & Baker, 2007, p. 247).

Parents of young children with autism stated that their family functioning was impaired in various ways. Families, for example, could not do spontaneous activities due to the planning and structure needed with a child with autism (Meirsschaut et al., 2010, p. 665). Parents have also reported concerns regarding what the future holds for their child with autism (Meirsschaut et al., p. 664).

According to a study done in the USA by Lopez-Wagner et al., parents who have children with autism have recorded that these children have more sleep problems than typically developing children (2008). In this study, it is indicated that sleep difficulties experienced by these children could independently contribute to high levels of stress in parents. Sleep problems occur more frequently in children with developmental problems and exacerbate symptoms in children with autism. Problems with sleeping can also negatively affect the functioning of parents by increasing depression and burnout (Gallagher, Phillips & Carol, 2009). Sleep difficulties have been associated with high levels of stress in mothers (Hoffman et al., 2008, p. 160). These parents often miss social activities and experience relationship difficulties due to high levels of exhaustion and stress (Lopez-Wagner et al., 2008).

In their study, Pottie and Ingram (2008) sought to understand the relation between coping, stress and mood in parents who are rearing a child with an Autistic Spectrum Disorder (p. 856). According to them, one needs to account for personality and contextual factors of parents. Positive mood was predicted by social support, optimism, regulating emotions and positive reframing, whereas daily decrease in positive mood was associated with withdrawal, blaming, worrying, escape and helplessness (Pottie & Ingram, p. 861). There were a few limitations in their study; these included a lack of ethnic diversity; all the participants had high socioeconomic status and there was no comparison group (Pottie & Ingram, 2008, p. 863).

An exploratory research study was done in the United Kingdom by Grindle et al. (2008) to investigate "parents' experiences of home-based applied behaviour analysis programmes for young children with autism" (p. 43). This study reports on interviewing

53 parents (both mothers and fathers) whose children had received early intensive behavioural intervention (EIBI) for two years. The reason for the study was to research the experiences of parents and the benefits and pitfalls of a home-based ABA programme, as well as the impact the programme may have had on family life and support systems. Parents in this study were positive about behavioural therapy and experienced many benefits for themselves, their child and their broader family (Grindle et al., 2008, p. 50). Reported benefits for the child with autism included improvement of language, communication and social skills. A positive factor in ABA Therapy was the involvement of siblings in therapy sessions; the sessions helped in teaching them skills for playing with their brother or sister with autism. All parents reported an improvement in their relationship with their children; approximately 80% of parents felt that this was because of better communication (Grindle et al., 2008, p. 52).

Certain factors were reported as stressful when implementing this intensive behavioural therapy programme. The management of therapists and the presence of therapists in the home were stressful for many parents. Parents felt a lack of privacy in their own home as therapy often took place in different areas of the home and administrative duties were reported as stressful and time consuming for parents (Grindle et al., 2008, p. 52).

Many studies have focused on the experiences of mothers of children with autism, thereby neglecting fathers' perspectives. A study by Kuhn and Carter titled *Maternal self-efficacy and associated parenting cognitions among mothers of children with autism*, found that mothers reported elevated depressive symptoms and significantly high stress levels which are negatively associated with self-efficacy (2006, p. 571; Meirsschaut et al., 2010, p. 666). Kuhn and Carter indicate that depressive symptoms such as low motivation and hopelessness may interfere in mothers' abilities to engage in interventions (2006, p. 565). Research has indicated that, even in the cases where mothers and fathers share parenting roles, mothers tend to assume a larger portion of the responsibility of meeting their child's needs (Meadan et al., 2010, p. 22) and tend to show higher levels of stress (Meirsschaut et al., 2010, p. 665; Yamada et al., 2007, p. 655) and a lower quality of life than fathers (Meirsschaut et al., 2010, p. 666). In a study titled *Parenting Stress in Mothers of Children with Autism Spectrum Disorder*, Phetrasuwan and Miles found that the highest sources of parental stress involve

managing behaviour in public places, discipline, and managing demanding behaviours. This study further indicated that parents experience further stress from the stigma from society (2009).

In Van der Walt's study, *Resilience in families with an autistic child*, parents reported that having faith in God was a contributing factor in adapting to having a child with autism (2006, p. 112) as well as having a positive outlook (p. 111) and willingness to learn (p. 105).

It is evident from previous research studies that parents experience various stresses due to the nature of their child's disorder.

2.7 CHAPTER SUMMARY

This chapter consists of a review of relevant literature, which is used to set the background against which the research data and findings were interpreted.

The concept of Behaviour Therapy was referred to, including some of the history and past studies done on Behaviour Therapy. The definition of Applied Behaviour Analysis therapy was presented. Pervasive Developmental disorders were discussed with a specific focus on Autistic Disorder, which is the basis of the study and earlier research findings regarding the experiences and coping strategies of parents who have children with autism were explored. The literature overview ensured that the researcher was able to link the outcomes to previous findings relevant to the research question in the current study.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

The researcher of this study experienced a year as an ABA home-based therapist in 2006. Many difficulties and strains experienced by parents were encountered by the researcher during the process of therapy. Parents seemed to struggle with consistency with regard to behaviour programmes and discipline in the home. As mentioned in Chapter 1, various research studies investigating parents' experiences with children with autism have been undertaken in other countries, yet research of this specific nature has not been as widely focused on in South African studies. Addressing this gap in knowledge could show where South African parents lack support and assist in understand their experiences better.

Parents who have children with autistic disorder are at risk of suffering from depression and personal strain (Hastings & Johnson, 2001; Hillman, 2006; Schwichtenberg & Poehlmann, 2007; Hartley et al., 2010), therefore it is beneficial to have family-level interventions in place to help the family cope (Schwichtenberg & Poehlmann, 2007, p. 603).

As discussed in Chapter 1, this study was aimed at investigating the experiences of parents who have a child who is or has been in an Applied Behaviour Analysis therapy programme. The focus of this chapter is on the research process as discussed in Chapter 1 and a description of how the researcher structured the research design in order to answer the questions of the study.

3.2 RESEARCH QUESTIONS

One needs to look at the research questions again in order to further discuss the research design and methodology. The research questions as formulated in Chapter 1 are as follows.

- What are parents' experiences with a child with autism doing Applied Behaviour Analysis therapy?
 - How do they experience their child's behaviour before and after ABA?
 - What are parents' experiences of their relationship with others (friends, family, husband, other children and the public) and what role does autism and/or ABA therapy play in these experiences?
 - What coping strategies and support do parents experience?
 - What support and advice do parents have for others who have a child with autism?

3.3 RESEARCH PARADIGM

As mentioned in Chapter 1, a paradigm comprises a set of 'beliefs' or 'assumptions' about different aspects of reality that guide our actions and give rise to a specific worldview (Nieuwenhuis, 2010, p. 47).

Paradigms represent what we think about the world (but cannot prove). Our actions in the world, including the actions we take as enquirers, cannot occur without reference to those paradigms: As we think, so do we act (Nieuwenhuis, 2010, p. 48).

In describing one's paradigmatic perspectives it is useful to look at ontological assumptions, epistemological assumptions and methodological considerations (Maree & van der Westhuizen, 2010, p. 31).

3.3.1 Ontology

Ontology concerns the 'nature of reality' and how social reality is understood (Adams et al., 2004, p. 356). In this research study the participants' social reality was understood through words that described their experiences (Maree & Van der Westhuizen, 2010, p. 31). According to Terre Blanch and Durrheim (1999, p. 6) the ontology of the interpretive paradigm says, "The reality to be studied consists of peoples subjective experiences of the external world". Thus every person's view of his or her experiences of the external world forms the basis on which they build a frame of reference. The aim of this study was to understand the frame of reference of parents who have a child with autism who

was undergoing or had in the past undergone ABA therapy, as well as the coping strategies and challenges experienced by the parents and their families.

3.3.2 Epistemology

Epistemology concerns the "nature of knowledge" as well as the relationship between what is known (researcher) and what would be known (the participant) (Adams et al., 2004, p. 356). The researcher examined the knowledge (experiences) of the participants and linked this knowledge to the information (experiences and studies) already known by the researcher. This researcher constructed the acquired knowledge socially from an interpretive stance. The interpretive paradigm maintains a more subjective view of social reality and therefore rejects the standard methods of social science (Maree & Van der Westhuizen, 2010, p. 32).

3.3.3 Methodology

The research for this study was within the interpretive paradigm; therefore the methodology of this study was qualitative in nature. Qualitative research with reference to this study focused on a process of gaining in-depth understanding of the processes and the contexts of parents' experiences of their child who has been diagnosed with autism, and was receiving or had received ABA therapy. Parents make meaning of the reality of their experiences and of their process of coping (Babbie & Mouton, 2001, p. 270).

The qualitative researcher's main interest is in understanding how people have constructed meanings in order to make sense of their world. Their world or reality is not fixed or measurable; instead there are numerous interpretations of reality that change over time (Merriam, 1998, p. 2). Qualitative researchers always attempt to study human action from the emic (insider's) perspective, their goal is to understand and describe human behaviour (Babbie & Mouton, 2001, p. 53). Researchers therefore study people's interpretations of and interactions with their world in a particular context at a specific point in time. This is done by means of interviews, observations and written documents (Merriam, 1998, p. 14). During the data collection phase of research the documents are analysed to identify recurring themes, which become the research findings.

Qualitative research is the study of behaviours and attitudes which occur in one's natural setting where the researcher desires to be as nonintrusive as possible. The researcher focuses on the process over time and aims to view the world through the eye of the participants (phenomenologist view). The research process is inductive in nature and emphasises the development of new theories and interpretations in order to provide a rich description of the research findings (Babbie & Mouton, 2001, p. 271). According to Babbie and Mouton, objectivity is understood in two different ways within the qualitative paradigm. Firstly, it is acknowledged that the most important instrument in the research process is the researcher. There is an added responsibility on the researcher to be unbiased in his or her interpretations. Second is the challenge of the qualitative researcher to get close to the 'research subject' in order to generate legitimate and truthful 'insider' descriptions. The two meanings of objectivity therefore concern establishing rapport and gaining trust (p. 271). The researcher interviewed participants at the Therapy School, in a natural environment where they felt comfortable, and the researcher aimed to be objective and unobtrusive when speaking to the participants.

The study that was undertaken was classified as descriptive in the sense that the aim was to identify, understand and describe the experiences of parents and the support they had.

3.4 RESEARCH DESIGN

A research design is the blueprint of how the research is conducted. The research methods are established according to the research design. The purpose is to find suitable answers to research questions (Babbie & Mouton, 2001, p. 74). As discussed (in Chapter 1.6), a qualitative design was chosen for this study as best suited to the aims of the study, which involved exploring the experiences of parents with children with autism who were in an ABA therapy programme.

The research design is an important element of the research study as it provides a detailed plan of the research process to ensure that the methods used will lead to the answering of the research questions. The research design is informed by a mode of inquiry. As mentioned above, the mode of inquiry adopted in this research study was qualitative (Maree & Van der Westhuizen, 2010, p. 33). Two very important aspects of

research design involve specifying clearly what one would like to find out (why) and deciding the best way to do this (how).

3.5 RESEARCH METHODS

The term 'method' refers to a way of doing something (Henning et al., 2010, p. 36). The research methods and procedures used were determined by the nature of the research problem and what was required to address the problem. The methods used in this study included purposive sampling, two data collection methods and qualitative content analysis.

3.5.1 Participants / Sampling

The participants in this study consisted of parents who have children with autism, who are doing or have in the past done intensive ABA Therapy in a school in the Western Cape.

Sampling refers to the process of selecting a proportion of the population for a study. Non-probability sampling is the primary method implemented in qualitative research; this is practised in situations where one is unable to select larger samples such as are used in large-scale social surveys. There are various types of non-probability sampling that can be used in qualitative research (Babbie & Mouton, 2001, pp. 166-168). This study made use of purposive sampling, which is one of the types of non-probability sampling. Purposive sampling is based on the assumption that the investigator wants to discover, understand and gain insight and therefore must select a sample from which the most can be learned (Merriam, 2009, p. 77). Participants were selected because of certain defining characteristics determined by the research problem of the study in question. Purposive sampling decisions include settings, events, incidents and activities in data collection (Nieuwenhuis, 2010, p. 79).

When considering what or whom the researcher wants to describe, explore or explain, one refers to the unit of analysis of the study. The research in this study was empirical as it concerned the study of real-life objects (World 1 objects) (Babbie & Mouton, 2001, p. 85) and the unit of analysis was the experiences of parents who have children with autism doing Applied Behaviour Analysis therapy.

The purposeful sampling used in this study was criterion-based selection. In criterion sampling the specific characteristics and number of participants are included in the design stage of the study. Participants who are selected should have experience or insight into the topic of the research study (Nieuwenhuis, 2010, p. 79).

The following criteria were formulated to select the sample of this study:

- The sample had to be drawn from a list of parents from a School in the Western Cape, where Applied Behaviour Analysis is used along with a variety of other treatment methods that are adapted to the needs of the individual child with Autism.
- Children of parents questioned had to have been diagnosed with 299.00 Autistic Disorder by a medical professional (The criteria are provided in Chapter 2).
- Therefore the sample could include parents (which could be a male and female, a male and male, a female and female, a male or a female) who had a child with autism (biological or adopted) who was undergoing or had undergone Applied Behaviour Analysis therapy in the therapy school.

3.5.2 The researcher

The main research instrument in this study was the researcher, as (as mentioned in 1.6.4), "the researcher is the primary instrument for data collection and data analysis" in all forms of qualitative research (Henning et al., 2010, p. 10). The researcher has presented verbatim what the participants said in their interviews and has linked this data to the other sources of literature provided in Chapter 2, in order to challenge the data collected through the interviews and written reflections. This was done to provide a "thick description" of the phenomenon. The researcher discusses possible bias in Chapter 5 (Henning et al., 2010, pp. 6-8).

3.5.3 Methods of data collection and analysis

The methods of research in this study needed to be congruent with the research paradigm and methodology of the study.

The methods used in the study consisted of individual semi-structured interviews and a brief written narrative / self-reflection from each participant. Research was done on past

studies relating to the topic; a questionnaire was developed on the basis of past research, with the aim of answering the research question. A pilot interview was conducted with a parent who met the sample criteria. Following this interview, the time and relevance of the questions were reviewed and the interview schedule was refined.

3.5.3.1 Data collection

The data obtained during the interviews were recorded on a digital voice recorder and were then fully transcribed. The same questions were asked in each interview. The time period for interviews was approximately 30 to 45 minutes each.

3.5.3.1.1 Narrative

Parents were asked to write a brief narrative and reflection (minimum one page) on their experiences of having a child with autism receiving Applied Behaviour Analysis Therapy. This was done in their own time, before the semi-structured and focus group interviews took place. An example of a transcribed narrative is provided in Addendum F.

3.5.3.1.2 Individual semi-structured Interviews with parents

"The aim of qualitative interviews is to see the world through the eyes of the participant" and "to obtain rich descriptive data" in order to understand the participants' "construction of knowledge and social reality" (Nieuwenhuis, 2010, p. 87). The researcher wanted to understand parents' meaning making of their experiences with their child with autism who was receiving Applied Behaviour Analysis treatment, as well as their views of their role in the therapy process.

Individual qualitative semi-structured interviews were conducted. A pre-determined interview schedule was used with open-ended questions in order to ensure that the same questions were covered in all the interviews and to allow flexibility and probes (Patton, 2002). This followed a pilot study for which the researcher conducted an interview with a respondent who fitted the same criteria as those for the main study. This was done to establish whether pertinent data could be obtained from the research participants. The interview guide was then modified in order to provide an interview of better quality (Strydom & Delpont, 2011, pp. 395-395). The final modified interview was used in the research study. This process is presented in Figure 3.1.

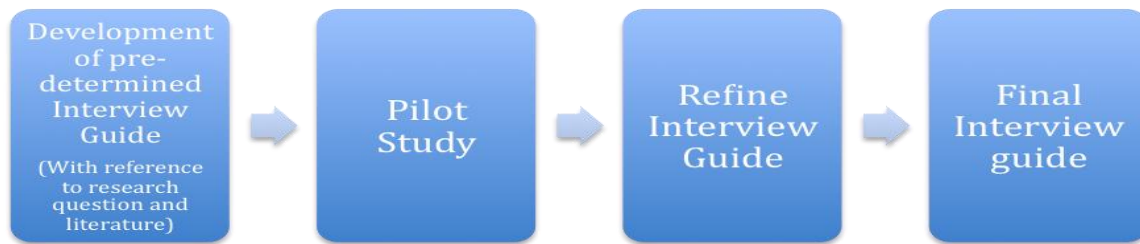


Figure 3.1: Development of interview guide

The semi-structured interview guide that was used to guide the interviews consisted of fourteen open-ended questions. This is provided in Addendum D.

The researcher aimed to establish a trusting relationship with research participants. Before interviewing the participants, the researcher had given consideration to the ethical issues suggested by Babbie and Mouton (2009). These required acknowledging privacy; ensuring no harm to participants; voluntary participation; anonymity; and confidentiality (pp. 521-523). All the participants signed a written consent form that provided an explanation of the reason, aims and purpose of this research study (Mouton, 2008, p. 244). This form is provided in Addendum C.

As mentioned previously, permission was given by the participants to record the interviews on the digital voice recorder and these interviews were later transcribed by the researcher.

3.5.3.1.3 *Reflective notes*

After each individual semi-structured interview, the researcher wrote reflective notes describing how she had experienced the interview and what her feelings were during the interview. The researcher recorded any possible ways in which she could have been biased during the interview.

3.5.4 Data Analysis

The data were analysed according to qualitative content analysis in order to make meaning of the gathered data (Mouton, 2008, p.165). This data analysis process is illustrated in Figure 3.2 and is discussed below.

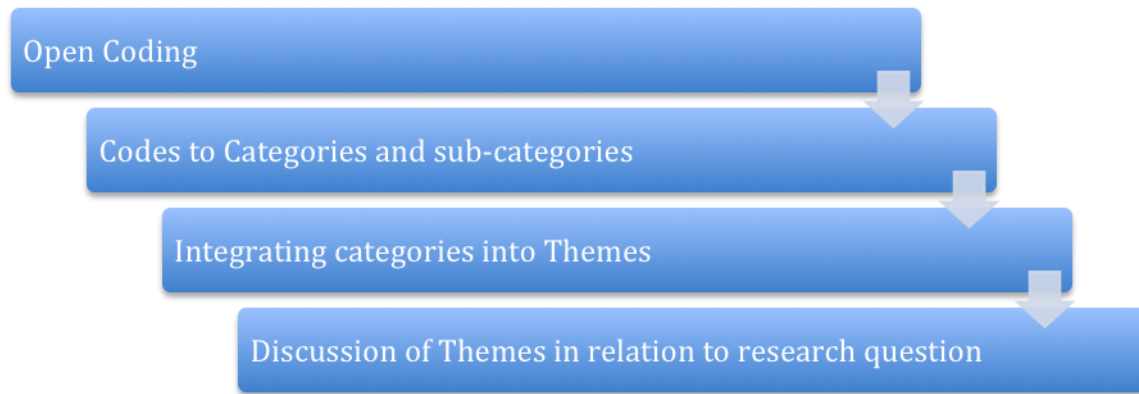


Figure 3.2: Data Analysis Process

Source: Bothma, Greeff, Mulaudzi and Wright, 2010, p. 222

Open coding is the process of inductive meaning making and comprised the first step used by the researcher when she read through the text of the transcribed data in order to get an overall impression of the content (Bothma et al., 2010, p. 224).

The next step consisted of transferring codes into categories: each transcript was coded (raw data), and the broad categories and sub-categories were indicated. In this process, indicating the categories is an important part of research as it brings the broader context into play (Henning et al., 2010, p. 106).

Once the coding and categorisation of data are complete, the researcher needs to form a holistic view. Henning et al. (2004, p.106) state that the following questions should be addressed:

- What are the relationships in meaning between all these categories?
- What do they say together?
- What do they say about each other?
- What is missing?
- How do they address the research question(s)?
- How do these categories (together) link with what I already know about the topic?
- What has been the foreground in the analysis?
- What has moved to the background?
- What additional data gathering and/or analysis have to be completed?

Having completed the categorisation, the categories were integrated into themes. When the researcher was satisfied with the themes, they were organised in table format with each main theme followed by the categories according to which common views were identified. Finally, the themes were considered in relation to the research question(s) (Henning et al., 2004, p.107). An example of an analysed transcription is provided in Addendum E.

3.6 DATA VERIFICATION

A researcher needs to ensure that the verification of data is facilitated by referring to the validity and the reliability of the study (Maree & Van der Westhuizen, 2010, p.37). The terms validity and reliability are used in quantitative research but are not as relevant in qualitative research because of its subjective nature. Terms such as transferability, credibility, dependability and confirmability are frequently used to increase trustworthiness and thoroughness in qualitative research studies (Merriam, 2009, p. 211; Babbie & Mouton, 2001, p. 276). A qualitative study has to be credible before it can be considered transferable (Babbie & Mouton, 2001, p. 277).

3.6.1 Credibility

Credibility in qualitative research is equivalent to the term internal validity in quantitative research. Internal validity refers to the similarity between the findings in research and reality, credibility recognises that reality is subjective and is influenced by many perspectives. Credibility looks at the way the researcher presents and interprets the research findings with the value and perception of the research participant (Merriam, 2009, p. 213-215). There are different strategies that can be used to promote credibility. These include triangulation, referential adequacy, peer debriefing and member checks (Babbie & Mouton, 2001, p. 277). The credibility strategies used in this study are discussed below:

- The researcher took part in peer debriefing with a colleague who works in the same field and had a general understanding of the study, yet was outside the context of the study. Perceptions, insights and analyses were reviewed where the peer was able to question the researcher's working hypotheses and assist in decisions regarding the research process.

- Member checks were done, with the researcher going to the participants with the data and checking for errors as well as giving the participants an opportunity to volunteer to provide any additional information. In this process, the overall adequacy of the data was assessed.

3.6.2 Transferability

Transferability is equivalent to external validity in quantitative research; it refers to the degree to which the findings can be applied to other respondents in other contexts. "All observations are defined by the specific contexts in which they occur" (Babbie & Mouton, 2001, p. 277) and qualitative research does not claim that knowledge gathered in one context will be relevant in another context, or in the same context in a different time frame. The following strategies were used to determine transferability:

- The researcher collected detailed descriptions (thick descriptions) of information in context and recorded this information with adequate detail and accuracy. This was done to allow the reader to make judgments about transferability (Babbie & Mouton, 2001, p. 277).
- The location and participants were purposely selected in order to maximise the precision of the information obtained in the specific context (Babbie & Mouton, 2001, p. 277).

3.6.3 Dependability

"Here the researcher asks whether the research process is logical, well documented and audited" (Schurink, Fouche & De Vos, 2011, p. 420). One needs to first determine whether research is credible (valid) in order to establish dependability (reliability). An audit trial was implemented in the research study to promote dependability. Chapter 3 functions as an audit trial, whereby the research process is described; the focus in this chapter is on data collection and analysis (Merriam, 2009, p. 223). The following classes of data can be reviewed in an audit trial:

- Raw data: recorded videotapes, written field notes, documents, and survey results
- Data reduction and analysis products: write-ups of field notes, summaries and condensed notes, theoretical notes such as working hypotheses, concepts and hunches
- Data reconstruction and synthesis products: themes that were developed, findings and conclusions, and a final report
- Process notes: methodological notes, trustworthiness notes, and audit trail notes
- Material relating to intentions and dispositions: inquiry proposal, personal notes and expectations
- Instrument development information: pilots, forms and preliminary schedules, observation forms and surveys (Babbie & Mouton, 2001, p. 278).

3.6.4 Confirmability

Confirmability is the extent to which the findings are the product of the research focus and not the predispositions of the researcher – it involves the subjectivity of the study (Babbie & Mouton, 2001, p. 278). Strategies used to promote confirmability of research include an audit trail (which is described under dependability) and reflexivity.

It is imperative for researchers to reflect on their own assumptions and beliefs and consider how these may affect the research findings. In this study, the researcher wrote reflective notes after every interview to reflect on how possible biases could have affected the research findings.

3.7 ETHICAL CONSIDERATIONS

According to Reber and Reber (2001), ethics is "concerned with that which is deemed acceptable in human behaviour, with what is good or bad, right or wrong in human conduct in pursuit of goals and aims" (p. 251). A moral code is "a doctrine or set of principles for action" and is derived "from a social codification of right and wrong" (Reber & Reber, 2001, p. 445).

Various ethical issues are likely to arise during the research process. University institutions therefore establish ethics committees to assist and monitor ethical matters. The University of Stellenbosch Research Ethics Committee (REC) granted ethical approval for the commencement of the study; this letter of approval is provided in Addendum A, with the reference number 312/2010. This was done to ensure that the rights and interests of the participants were being protected. Permission to conduct research was granted by the Head of the Therapy School in the Western Cape, and the school provided a sample of participants who met all the criteria that were required.

Other important ethical principles that formed an integral part of the implementation of this study are discussed below.

3.7.1 Anonymity and confidentiality

The relationship between the participants and the researcher is one based on trust; it is the researcher's responsibility to protect the interests of those being studied (Neuman, 2000, p. 91).

Researchers must be aware of the human rights of the participants as they may confront issues concerning civil and political rights (Allan, 2008, P. 7). Privacy and confidentiality is considered essential for preserving people's dignity and psychological, physical and spiritual well-being. Respecting privacy and confidentiality of participants affirms their autonomy and demonstrates deference to their rights and dignity. Participants who feel that they can trust the researcher tend to share information, irrespective of how controversial or embarrassing it may be. This enhances the effectiveness of the research process (Allan, 2008, pp. 124-126).

To establish a trusting relationship with the research participants the researcher, explained the research study in detail prior to commencement of the research. The participants were informed that participation in this research was voluntary and that their identity would be protected. Participants were identified by means of a code, for example P1 for participant 1. In the transcripts of interviews, names of children, professionals or friends used by the participants were replaced with a pseudonym. Confidentiality and acknowledging privacy are of utmost importance. Therefore a written consent form explaining all the relevant details of the study and ensuring the protection of participants was provided. This form is provided in Addendum C. Participants were asked for

permission to record the interviews and informed that the dictaphone would be kept in a safe and the interviews would be deleted after the transcriptions had been done (Babbie & Mouton, 2001).

3.7.2 Non-maleficence

Non-maleficence comprises the duty of the researcher to do no harm to others and to minimise harm when it is unavoidable (Allan, 2008, p. 131). When working with human participants, unintentional harm is often difficult to avoid, therefore the researcher needs to have steps in place to amend any potential harm (Allan, 2008, p. 132). Because of the sensitive nature of this topic, the interview could have caused discomfort for parents, therefore the researcher held a debriefing session after the interviews. If the participants felt they needed further debriefing they were offered the choice of a therapy session with a qualified psychologist (Strydom & Delpont, 2011, p. 122).

3.8 SUMMARY

In this chapter, the discussion was focused on the research paradigm and methodology, as well as the research design. The focus was on how the theoretical basis of this research study supported the attempt to answer the research questions of the study. In addition to this, the validity of the study and the ethical considerations were presented.

The next chapter contains the presentation of the research outcomes and a discussion thereof.

CHAPTER 4

RESEARCH OUTCOMES

4.1 INTRODUCTION

The purpose of this study was to gain understanding of the parents' experiences as well as the challenges they may face whilst their child is receiving Applied Behaviour Analysis (ABA) therapy. Secondly, it attempted to identify support needs and strategies that may help parents and others to cope with the demands of ABA therapy.

4.2 PARTICIPANTS, SETTING AND PROCEDURE

Table 4.1 below provides an overview of the demographic details of all the parents who participated in the study. As discussed in section 1.6.3 and section 3.5.1, the participants were purposefully selected from a list of parents whose children attended a school in the Western Cape where ABA therapy is taught and practised one-on-one with children with autism. The participants were selected on the basis of particular selection criteria which required them to be parents (who could be male and female, male and male, female and female, or a male or a female), who had a child with autism (biological or adopted) who was receiving or had received Applied Behaviour Analysis therapy in the therapy school, and the children of the parents who were interviewed had to have been diagnosed previously with 299.00 Autistic Disorder by a medical professional (The criteria are provided in Chapter 2).

The data were gathered at the therapy school in a private area where participants could feel comfortable. In order to adhere to the ethical principles and to protect the anonymity and privacy of the research participants, their names were replaced with a 'P' (for participant), followed by a number, and their children's or any other names mentioned in the interview were replaced with pseudonyms.

The purposeful sampling used in this study is referred to as criterion-based selection. In criterion sampling, the specific characteristics and number of participants are included in

the design stage of the study. Selected participants should have experience in or insight into the topic of the research study (Nieuwenhuis, 2010, p. 79).

The biographical details of all of the participants, as well as the data production techniques that were used, are presented in Table 4.1.

Table 4.1: Biographical data of all the research participants

Data production technique	Participant Code	Home Language	Father/Mother	Years of ABA therapy	Age of Child	Siblings
Individual interview	P1	Afrikaans	Mother	5	7	Sister
Page reflection						
Individual Interview	P2	Afrikaans	Father	5	7	Sister
Page reflection						
Individual interview	P3	English	Mother	5	7	Sister Brother
Page reflection						
Individual Interview	P4	English	Father	5	7	Sister Brother
Page reflection						
Individual interview	P5	English	Mother	2	7	Brother
Page reflection				1 ½	5	Brother
Individual Interview	P6	English	Father	2	7	Brother
Page reflection				1 ½	5	Brother

4.3 PRESENTATION AND DISCUSSION OF THEMES

The data in this research study are presented according to the most important themes and categories that were presented during the analysis process. These themes and categories illustrate the personal experiences of parents that emerged from the data sources (i.e. individual transcripts and written reflections). These themes and categories reflect the most important aspects related to the participants' experiences during their journey from the initial concern about their child's behaviour to the child's diagnosis of autistic disorder and to implementing an ABA therapy programme. An overview of the themes and categories is presented in Table 4.2 to provide the reader with an outline of the findings, which will be discussed in the following section. There is a significant level of overlap between some of the categories presented; in the sections that follow, the reader will be informed when an overlap occurs.

Table 4.2: Themes and categories

Themes	Categories
Early behaviour and the road to a diagnosis	Behaviour experienced before diagnosis (B) Diagnosis (D) Early emotions (E)
Applied behaviour analysis as an Intervention	Intervention (I) Home Intervention (HI) Finances (F)
Experiences with the public and professionals	Therapists and Professionals (T) Public's Perceptions (PP)
Family experiences	Sibling experiences (SE) Marriage (M)
Emotional experiences and coping strategies	Feeling of ABA (FA) Coping and support Strategies (CS)
Outcomes and expectations	Expectations (EX) Results (R)
Support and coping strategies that may help other parents	Support and coping strategies for others (SO) Advice for others (A)

The themes are discussed in greater detail in the section below and the most suitable and relevant quotations from the research data are presented to support the findings of this study.

4.3.1 Early behaviour and the road to a diagnosis.

The first theme discussed by the researcher concerns the parents' experience of the child's behaviour before diagnosis and the experiences leading to the diagnosis of their child. Some experiences with diagnosis will be discussed in further detail in section 4.3.3.1, under *therapists and professionals*. As mentioned in Chapter 2, the behaviour of children with autistic disorder is expressed in degrees and in severity that can be vastly different from one to another (Mash & Wolfe, 2005, p. 288).

4.3.1.1 Behaviours experienced before diagnosis

All participants experienced difficult behaviour in their children before they were diagnosed with Autistic disorder. A list of behaviours mentioned by the participants in the data analysis is presented in Table 4.3. These behaviours are what led to major concern and eventually to a diagnosis.

Table 4.3: Behaviours experienced by children

Behaviours Experienced	P1	P2	P3	P4	P5	P6
Child irritates people and was seen as a naughty child	X	X	X			
Sleeping difficulties	X	X		X		
Speech not developed or lost words / communication difficulties	X	X	X	X	X	
Tantrums and screaming	X	X	X	X	X	X
Difficulties with breathing	X					
Sensitive to sounds and hearing	X	X	X		X	
Spinning or / and lining up objects	X		X		X	

A common behaviour experienced by all the participants involved tantrums and screaming. P1, P2, P3, P4 and P5 experienced communication difficulties. Some examples of behaviours experienced by parents are presented verbatim below:

"The big problem then was the fact that he was not talking and he was having temper tantrums and he was just disruptive, he would throw the entire contents of the fridge out looking for something to eat but he couldn't tell me what he wanted to eat. He would just scream and make funny noises and throw everything out, then he would go the cupboard to find out that what he wanted was actually in the cupboard, after he threw everything in the fridge out." (P1)

"He struggled with sleeping and tantrums in the beginning." (P2)

"I was in Pick 'n Pay about two years ago when Daniel* was still screaming and he would just scream in bursts as we were walking ..." (P3)

"Sounds used to freak him out, we couldn't reverse in the car and sunlight hurt his eyes and sudden noise, and he hated being confined or restrained because he is hyper sensitive ..." (P5)

P1 also indicated that she was struggling to stay awake at her workplace because of the effect her son's sleeping patterns had on her. A study conducted by Lopez-Wagner et al. indicated that parents who have children with autism reported that their children had more sleeping problems than was reported by parents of neurotypical children (2008). This correlates with the data in this research study as three participants (P1, P2 & P4) indicated the occurrence of sleep difficulties in their children. P1 experienced difficulty with concentrating at work due to lack of sleep. A study conducted in 2009 indicated that sleep problems could influence functioning negatively by increasing depression and burnout (Gallagher et al., 2010, p. 735). Another study indicated that children's reported sleep problems contributed to maternal stress, as well as maternal sleeping difficulties (Hoffman et al., 2008, pp. 160-162).

4.3.1.2 *Diagnosis and early emotions*

The children of all participants were diagnosed after the age of two, P5 and P6 had two children on the spectrum; their second child was diagnosed earlier and did not show the normal signs of classical autism, therefore the focus in this study was more on their first child, Bob*. This section overlaps with the *perceptions of public and professionals*,

specifically the experiences with professionals (doctors and therapists), which will be discussed in 4.3.3.1. Participants experienced the diagnosis of their child in different ways. P3 found an article in a magazine, where a list of 18 symptoms was published and recognised that her son had nine of the symptoms, which was cause for concern. This motivated her to do further research on the internet and take her child to a neurologist. P1 and P1 went to government professionals and reported some difficult experiences and feelings as noted below:

"We were told when we went to Tygerberg that he was, they call it ontoetsbaar, which means un-testable. They said they couldn't work with him and couldn't do speech therapy because he is not looking at them and he is not sitting in the chair so they just told us no there is nothing they can do." (P1)

"I think when I walked out of Tygerberg on the 21st of August my child was dead to me, I remember writing I lost my child, because that is what I felt. I didn't have any expectations for him at that stage. The message we got was "he is not going to get better, there is no medicine to make him better, this is a life long disability" so there were no expectations whatsoever." (P1)

"The doctors we went to before the therapy school told us our child is going to be a little monster and we must institutionalise him. My wife and I both didn't accept that well we just went out there and sought [sic] more help and we got the help we needed. We didn't just give up." (P2)

All participants revealed that they had little or no history of autism before their child was diagnosed, yet they realised that their child was presenting different behaviours. P5 did say that she did not realise early differences as it was her first child and she did not have another child to compare his behaviour to and began noticing a change when he was around other children.

"I didn't know anything about autism, I just imagined those children who were rocking and had severe symptoms." (P3)

"I noticed that there was something different because I spent time around other kids and noticed that he wasn't interested in playing with anyone." (P5)

"I realized there was something wrong but up until that point there wasn't any history or knowledge of autism, so everyone said Bob* was going through his terrible two's ..." (P5)

"I wouldn't say I didn't accept it, I just didn't really know what it was in the beginning." (P2)

According to Valentine "parents of newly diagnosed children are presented with an array of treatments and a bewildering amount of information about them" (2010, p. 951). Not only did these parents have little or no knowledge on autism they now have to decide on an intervention programme that is the best for their child. For participant 1, these experiences left her lonely and helpless.

4.3.2 Applied Behaviour Analysis (ABA) as an intervention

All participants had used various types of intervention, some including speech therapy, occupational therapy, ear, nose and throat specialists, psychologists, psychiatrists, and the therapy school (ABA therapy). P5 and P6's children were both attending a specialised school for children with autism and also did horse riding therapy, which they found was beneficial. P1, P2, P3 and P4's children were still attending the therapy school where they were in a small class and did less one-on-one ABA therapy. Parents did experience a lot of financial strain because of the cost of therapy. This will be discussed under *finances*.

4.3.2.1 Intervention

Not all of the participants gave a detailed description of the process of obtaining a diagnosis and the most suitable intervention. P1 and P2 were told that their son should be institutionalised but they both refused to accept that specific outcome and searched for other interventions, which later led them to the therapy school. This had cost them a lot of time and money and P2 lost his job due to all the time he needed to drive his son around.

All participants mainly relied on ABA therapy, which included speech therapy, as an intervention strategy. Behaviour intervention represents the predominant intervention for autism spectrum disorders and has been studied widely (Volker & Lopata, 2008, p. 265). Children who have received intensive ABA therapy have shown significant progress in

language and communication (Zachor, Ben-Itzhak, Rabinovich & Lahat, 2007, p. 313). The son of P1 and P2 had difficulty with speech and therefore the therapy school incorporated makaton (a type of sign language) into their therapy in order to improve communication. P4 and P5 also included horse-riding therapy in their son's programme. ABA intervention was intensive and all participants' children went to the therapy school three to five times per week for three to four hours. It was noted that intervention did not only occur at the therapy school; participants learnt the principles of ABA therapy and incorporated them into their everyday lives.

"I found that the morning sessions were completely useless if we didn't incorporate the programme at home as well." (P5)

In a study by Erba, successful outcomes were reported when doing intensive (40 hours per week) Discrete Trial Training (DTT) using ABA techniques with children with autism. These programmes were individualised and included family involvement (2000, pp. 82-94). Some parents who took part in the present study incorporated one-on-one ABA therapy at home with their children; their experiences are discussed below.

4.3.2.2 Home intervention

P1, P2, P3 and P5 all tried to do home-based intervention themselves, and P5 and P6 had outside therapists come into their home to do ABA therapy daily. P3 and P5 discussed the difficulties of doing therapy as a mother and how they felt that they were too emotionally attached to continue.

"We bought everything that was needed for therapy and did it at home, everything was learning, learning, learning whether it was sitting and eating, whether it was bathing. Everything had to be taught over and over again." (P1)

"It is difficult for a parent to do the sessions, I tried but I thought I was going insane, because you are like going 'oh I am not meant to lose my temper', but ..." (P5)

"I was trying to teach him something we would both get frustrated and he would fight me and because he was my child I felt like I could slap him. There were times when I would lose it and cry in the bathroom and I hated it, I hated doing it." (P3)

Participants expressed feelings of frustration and reported getting very emotional when doing home-based intervention; this seemed to be a substantial stress factor for these parents.

4.3.2.3 Finances

Five out of the six participants reported difficulties with finances. The cost of therapy and other interventions has had a major impact on these participants' quality of living. Some of the participants have had to sell possessions and downgrade their living in order to afford their child's therapy. Another factor of concern for P1, P5 and P6 was the lack of support from the South African government. Participants recorded the following comments with regard to finance:

"My husband lost his job because he was missing work a lot having to drive our son to hospitals and doctors ..." (P1)

"There were times when there was not electricity because we didn't have the money. We would use candles and make a fire outside." (P1)

"There is no support in South Africa. In other countries people get a monthly payment from the government, we don't get that here." (P1)

"It was expensive so there was strain on the family, you know because we would put in probably about R15 000 on therapy every month for the two of them and we were living in a tiny little bachelors flat because we couldn't afford anything else." (P5)

In a study on financial issues associated with having children with autism, financial difficulties were associated with the use of medical and therapeutic interventions (Sharp & Baker, 2007, p. 247). In various studies parents have reported that having a child with autism has had a negative effect on them financially (Jarbrink, Fombonne & Knapp, 2003, p. 400; Sharpe & Baker, 2007, pp. 247-264).

4.3.3 Experiences with the public and professionals

The participants' experiences with medical professionals, therapists and the public are discussed below.

4.3.3.1 Therapists and professionals

Initially P1 and P2 had some difficult experiences with medical professionals who were not aware of autism and told them their child should be institutionalised. There was also a lack of understanding from some professionals when faced with the child's behaviour. For these parents the road to a diagnosis was difficult; due to lack of funds they had to go to government hospitals where they felt the doctors and therapists were inexperienced.

In the therapy school, most experiences with therapists were extremely positive. Participants felt that their children received lots of love from the therapists. What was also mentioned was the continuous support received from therapists and from the director of the school. Some of the comments made by the participants about their experiences with the therapists and the therapy school director are presented below:

"They taught me to love him, they gave him hugs and everything was so positive". (P1)

"I really have a lot of respect for them and they supported me from day one until now, I can phone any time day or night if there is a problem". (P1)

"It was enlightening when I sat in with them in the first two weeks yes they opened our eyes." (P2)

"... they have been a good support, especially the director of the school, we can phone her any day or night, she also checks up on us as well." (P2)

"I am amazed at these tutors, they really love my child, I can see it in their eyes when they are teaching him, they love him." (P3)

"One can actually see a genuine love for the children. Sometimes you watch them through the window, without them knowing you're watching and you can actually see that these tutors actually love children and really love the children, and because you can see that, it makes a big difference." (P4)

"They become part of your family because they are helping your child ... um ... but more than that, your child develops a relationship with the therapists and in that way they are able to learn because I believe that without the relationship you

can do ABA until you are blue in the face but they are not going to do anything because they don't want to." (P5)

"It was nice to be around people who knew about the condition because then you don't feel so isolated, it was nice to be able to ask people if you didn't know like the director of the therapy school, you could actually speak to her and see if she had seen it before." (P6)

As shown above, participants mentioned many rewarding experiences with the therapists and the director of the therapy school. P6 did feel that there was not a big choice of qualified and experienced therapists, on one hand there were student therapists who he felt were out of their depth and on the other hand the more experienced therapists were more hardened. P5 found it difficult to have therapists in and out of their home. Parents have reported difficulties with having therapists in their home due to reduced privacy for family members and disruption in domestic routines (Grindle et al., 2009, p. 48). In Nevas and Farber's study on the parent's attitude towards their child's therapist, parents reported higher ratings of positive feelings towards the therapists who were working with their children (2001, p. 168). Hillman mentions the unique position of the psychologist in assisting parents to make difficult decisions on their child's treatment, as well as assisting the families emotionally (Hillman, 2006, pp. 349-358).

4.3.3.2 *The perceptions of the public*

All the participants were impacted by the perceptions and actions of people around them, who they felt were not educated about autism and therefore often did not deal with their children in an understanding manner. Some participants did speak about the understanding of strangers who made an effort to help them with their children. P1 found it helpful to educate people by giving them cards that explained autism. Below are some of the comments the participants made with reference to the public.

"I couldn't believe the way people were looking at my child and he would pull off his pants and pee wherever and then everybody would laugh not realizing how we felt about it." (P1)

"People will be accommodating if you educate them." (P1)

"People help, sometimes they would give a meal for free, and you know that really helped." (P1)

"people staring doesn't bother me at all anymore, like what are you staring at. I mean it bothered my wife more than me, she would get upset, I tried to get her to accept it as well, don't worry what other people think. Our son used to irritate people and they don't know they think it is a naughty child, we often have to tell them what the problem is." (P2)

"The thing that stresses me out is the public and people. I was in Pick n Pay about two years ago and Daniel* was still screaming and he would just scream in bursts and we were walking and I heard this woman go shut up, shut up." (P3)

"... they are very energetic, very boisterous, throw tantrums, scream, bump their heads against the wall sometimes, they will do crazy things and it can be destructive, and one of the difficult things is going out in public." (P4)

"He would just scream in shops like he would actually hurt his head and not register any pain so pretty much the whole of the neighbourhood knows us because they all remember my kids as babies, they would always hear us coming." (P5)

"It was hard, I would try and avoid it ... seriously ... it would be ... It would be a feeling of impending doom you would dread because you always knew how it would go". (P6)

"... with restaurants I still suffer anxiety, almost like an anxiety attack with the boys." (P6)

"... you always have an escape plan, you always have a plan like, if things deteriorate to the point where you have to leave, you leave." (P6)

Participants described the anxieties and stress associated with taking their child out in public places, specifically when their children were first diagnosed. The participants appeared to show less stress after intensive ABA therapy.

4.3.4 Relationships

Having a child receiving intensive ABA therapy appeared to have an impact on parents' relationship with each other and with their other children. This is discussed below.

4.3.4.1 Experiences with siblings

Some of the participants reported difficulties with their children who are neurotypical. P1 mentioned that she struggles to remember stages of her daughter's life because she was so busy with her son. P3, P4, P5 and P6 sent the siblings of their child with autism to the therapy school for a couple of sessions. P3 did say that it was helpful for her other child to know where his brother was going and what he was doing as he did not feel left out. Below are some comments on parents experiences with siblings:

"Only when she started with behaviour problems, we realized that we have neglected her attention." (P1)

"She blames us for not loving her the same as her brother." (P1)

"We tend to forget about her, well not forget about her but we spending much more time with the other one ... it is wrong." (P2)

"He was very hesitant to approach other children because I think he thought they were going to hurt him, it took him a while to realize that they weren't going to hurt him like his brother does". (P3)

"he is affected by his brother's behaviour at home." (P4)

"They got jealous of the time they spent with the therapists and they wanted the time with the therapist themselves they always felt like they were missing out. (P5)

"They found common ground because certain activities the therapist would do with both of them that helped them play together." (P6)

Siblings reported that they felt that their parents liked the child with disability more than themselves and they felt that their accomplishments often went unnoticed (Bishop, 2012, p. 84; Ligthart, 2002). Parents do tend to forget to praise other siblings and do not spend as much time with them as with the other child, as their time is taken up by the needs of their child with autism (Ligthart, 2002).

4.3.4.2 Marriage

All participants spoke about the impact that having a child with autism has on their marriage. One participant (P2) felt that it had brought them closer, yet he did mention that they seemed to only talk about their child and did not have other things to talk about. Another participant (P3) felt that her husband blamed her mothering skills for their son's diagnosis. Parents also mentioned that they had different expectations for their child, which caused tension in their relationship. P5 mentioned that she wanted to be independent and had worked, but she had to quit because nobody could handle looking after the children. P1 and P3 mentioned that they did not spend time alone with their partners because of the constant care their child needed and the lack of support from others, especially family members. Some comments about relationship difficulties are presented below:

"My husband and I have nothing to say to one another now, we just talk about the children and about the programme, that's all. We went out last year for the first time in six years together for coffee and we probably stayed for half an hour and went home because we said we are not going to talk about the children or the programme and we had nothing else to talk about. Its consuming (getting emotional) everything in your life remember our son did not sleep, so we didn't sleep, we would have shifts. I would stay awake until two o'clock and then we would swop." (P1)

"It obviously doesn't help the relationship, I mean we have been living with that kind of dysfunction for a long time so we really don't agree on those sorts of things. I think like in the marriage sort of thing, I endure him; I don't know how one can go on like that. I mean in a normal marriage it is difficult and hard work but when you are devastated by your child's disabilities and there are things you disagree on but I think you can't. I mean from my point of view I feel trapped, because if I am going to leave and be on my own how am I going to cope." (P3)

"... you want to attribute blame because you want to divert from yourself, I think it is very easy to take it out on your partner in that respect or to blame yourself for the way that your children are ..." (P4)

P5 did mention that ABA therapy was a positive factor in their relationship:

"But for our relationship the ABA therapy helped us because it gave us the skills to try and understand them [children] and taught us to calm down enough so that we can hear what they have to say as well." (P5)

A study undertaken in England reported that a third of the parents did not spend enough time together as a couple and therefore their relationship deteriorated; none of the couples believed their relationship had improved as a result of therapy (Grindle et al., 2008, p. 50). Another study found that the prevalence of divorce was higher among parents with children with an Autistic Spectrum Disorder, yet in the same study three fourths of the marriages survived despite having a child with autism (Hartley et al., 2010, p. 452). Families have reported marital strain for different reasons, such as conflict about the upbringing of their children (Meirsschaut et al., 2010, p. 667).

4.3.5 Emotional and coping strategies

In a study done by Pottie and Ingram, social support,¹ emotional regulation,² positive reframing,³ and compromise coping⁴ were associated with an increase in positive moods in parents with children with autism, whereas negative moods of parents were associated with worrying,⁵ helplessness,⁶ escape,⁷ withdrawal coping⁸ and blaming⁹ (2008, p. 858). Emotional stress levels reportedly were higher in mothers than in fathers who have children with PDDs; mothers are often more involved in the care of children (Yamada *et al.*, 2007, p. 655; Meirsschaut et al., 2010, p. 664). Feelings participants have experienced with regard to ABA therapy and the coping and support strategies they have used are discussed below.

4.3.5.1 Feelings and experiences related to ABA therapy

While all the participants expressed positive feelings related to ABA therapy, two of the participants felt that it became too rigid and therefore was difficult for their child when the

¹ Social support: Reaching out to others for emotional or practical assistance.

² Emotional regulation: Expressing or controlling emotional distress in a constructive way.

³ Positive reframing: Changing the view of a situation in order to see it in a more positive light.

⁴ Compromise Coping: Working out a compromise between the needs of the individual and the limits of the stressful situation.

⁵ Worrying: Constant thinking about negative aspects of a stressful situation.

⁶ Helplessness coping: Giving up because the situation is overwhelming.

⁷ Escape: Removing oneself from the stressful situation or refusing to accept the reality of the situation.

⁸ Withdrawal coping: Preventing people from knowing about a stressful situation or its emotional effects.

⁹ Blaming: Frustration, anger, passive aggression or blaming (Pottie & Ingram, 2008, p. 858).

routine changed. P1 and P4 felt that there should be more than one type of intervention. P3 began ABA by practising it herself at home and found it difficult to apply therapy as a mother: she felt frustrated and angry and found progress slow, yet her feelings were more positive when her son started doing more intensive therapy at the therapy school. A summary of some of the feelings experienced by the participants during ABA therapy is presented below:

"There were many tears but now there is a lot of laughter." (P1)

"Too rigid and structured sometimes." (P1)

"In the beginning I felt that nothing would work." (P1)

"Our whole life runs around the programme." (P1)

"Happy with the results of ABA." (P2)

"It is a long, hard road but I am satisfied." (P2)

"Definitely recommend ABA to other parents." (P2)

"Difficult when I was doing the ABA – Frustrated and angry and felt no progress."
(P3)

"Really saw a difference when he was doing one to one therapy." (P3)

"Feelings of joy when something succeeds." (P3)

"It has created lots of hope for us." (P4)

"Very uplifting for us." (P4)

"Mixed feelings from the point of view that there are actually growth spurts ..."
(P4)

"Can be quite exhausting because you can get excited when he's going through a growth spurt and you can get a little bit disheartened when it looks like he is not going forward." (P4)

"It gave me time to be with my youngest." (P5)

"There was some hope that there was some form of help for them." (P5)

"Gratitude ... that there were some people willing to help us understand our child." (P5)

"It gave us parents the feeling that we were in control of our kids." (P5)

"Generally whilst the boys were going under ABA our experiences were positive I suppose. There was light at the end of the tunnel and we could see the rewards."
(P6)

4.3.5.2 Coping and support strategies used

Participants in this study used different coping and support strategies. Comments were also made about the lack of support provided by the South African government. All participants received little support from their families; P1 mentioned that other family members failed to understand autism and did not feel any need to support them. P5 and P6 mentioned that their families lived far away and therefore were unable to help them with taking care of their children. According to Romanczyk et al. "Social support, and even the perception of social support, is critical for parents, in terms of reducing stress and selecting treatments" (2008, p. 376). Presented below are comments made by participants on their personal coping strategies they had received:

"I write I have a diary that I write for my son and for me." (P1)

"I read what happened the year before and I would laugh at the things in the past." (P1)

"I deal with things inside, for me it is fine." (P2)

"I like to go through everything in my head (laughs) and explode later." (P2)

"I have faith in God, which is the biggest coping strategy is our faith because I couldn't do it without God." (P3)

"I pray and I believe in God and I trust that God is in control and that he is helping us." (P4)

"I would get to the place where I would tell every granny on the street corner."
(P5)

"I am very introverted, prefer to deal with it myself." (P6)

Below are some comments on the support that participants had received:

"My mom has always been supportive." (P1)

"... go to support meetings twice a month and I go to the therapy school support meetings." (P1)

"My support is my mom and my doctor friend." (P1)

"Not a lot of support with exception of my wife's mother." (P2)

"It is basically the staff here, my wife and her mother, there is nobody else." (P2)

"My mom will phone and ask how is it going and so on, but that is about it." (P2)

"We didn't have support in the beginning." (P3)

"My mom just thought Daniel* was the naughtiest child alive and I got no support from her no understanding or anything and I was just devastated." (P3)

"Our church has been quite supportive ... they made a room available to us." (P3)

"For myself, its been a bit of a solo walk, really. I just trust in myself and my prayers, although I must say that the teachers are very supportive and encouraging and they always look for the positive." (P4)

"I must say that the teachers are very supportive and encouraging and they always look for the positive. The teachers and the actual staff at the school." (P4)

"There is nothing in the country really, financially to support you." (P5)

"I honestly don't have a support structure myself except for my husband's parents but they live in New Zealand." (P5)

"... that is one thing that we do lack is support structure of any form." (P5)

"Basically we don't have any family support, there is no financial support so its all self funded." (P6)

"I would say there is self-support between my wife and myself, so its small family support, localised family support." (P6)

In a study conducted in Belgium, mothers reported feelings of isolation and lack of understanding from their families and the external environment, as well as feelings of loneliness (Meirsschaut et al., 2010, p. 667). Overall, participants received little or no support from their families, some received support from the therapists at the therapy school and P3 received support from her church.

4.3.6 Outcomes and expectations

The children of all the participants showed some different and some similar behaviours before they were diagnosed and before beginning ABA therapy. These were discussed in detail in section 4.3.1.1. All participants reported improved behaviour and were happy with the results of ABA therapy. These improvements were beyond the expectations of most of the participants. A discussion of the expectations of the participants and some of the outcomes experienced by the participants during the ABA therapy programme follow below.

4.3.6.1 Expectations

In the beginning all the participants' expectations for their child were slightly different depending on the severity of the child's behaviour. They had set lower expectations to begin with and felt that their children had far exceeded those expectations. P3 mentioned that her expectations and her husband's expectations were different and this seemed to have created some tension in their marriage; whereas she had accepted that her child would not attend a mainstream school, her husband felt that he would reach mainstream at some stage. Some participants reported being afraid of what would happen to their children when they were no longer around to take care of them.

"He actually exceeded my wildest expectations." (P1)

"I never thought my child would read, never in my wildest dreams did I think he would sit with a book and really read the words in the book. I believe that he must develop at his own pace. I believe that he must develop at his own pace ..." (P1)

"I want him to do the best he can, I am not going to push him over the limit, I think one day at a time, whatever he comes up with is fine. I expect him to live a normal life, which they can, at the rate he is going now I am not even worried anymore." (P2)

"... stop his screaming, have him potty trained, let him be able to talk just the basics like 'I want, I don't want' ..." (P3)

"Definitely my expectations have been exceeded and that's why I am so happy, just to be happy with what I have got. When you speak to my husband it is going to be different". (P3)

"I think our expectations were nothing in the beginning because we had no idea what we were facing then they were high because we knew and we thought this was it, and then we were happy because they were saying things. So I would say our expectations were definitely met because we far outweighed what we thought we were first facing." (P4)

"I think our expectations were nothing in the beginning because we had no idea what we were facing then they were high because we knew and we thought this was it, and then we were happy because they were saying things. So I would say our expectations were definitely met because we far outweighed what we thought we were first facing." (P5)

"I think our expectations were realistic because at the therapy school there was never rose tinted glasses. No one ever said it was going to be easy or this was the therapy that was going to cure your child." (P6)

"Bob has come leaps and bounds." (P6)

In a study of children who had been in an ABA programme for two years, two thirds of the parents reported happiness in that their previous expectations for their child had been met or exceeded (Grindle et al., 2009, p. 50).

4.3.6.2 Results

All the participants in the current study reported that their child had good results from ABA therapy. One of the most satisfying results experienced for most participants was being able to control their child's behaviour and communicate better with their child. Most participants reported that their expectations concerning their child's improvement during therapy had been exceeded. Some of the participants' comments on the results of ABA therapy for their child are presented below:

"He can verbalise with me and he is getting there with things that are abstract and so difficult but overall he can communicate with me." (P1)

"In the first few weeks of therapy he went from 13 words to 100. At the moment he is top of his class at the therapy school so we are quite happy with him. His eye contact is like a normal child's." (P2)

"It has definitely improved behaviour, the thing we struggled with most with Daniel* was behaviour, I mean it was just like getting out of control." (P3)

"I think it has improved his speech, obviously, I think it's improved his actual discipline, I think it has helped him focus, he was speaking a little bit, but he was a lot less teachable." (P4)

"It definitely helped because it helped him to understand himself a bit better."

"He was learning how to slow down his brain so that he was able to organise and think clearly ..." (P5)

"I think it improved a lot of his basic functions that he was struggling with and for him I think it helped particularly with his self-esteem just doing the one-on-one and relationships because he forms relationships with the therapists ..." (P6)

Benefits reported from parents of children with autism using ABA therapy included language and communication skills, improved social skills such as sharing and taking turns and the development of play skills (Grindle et al., 2008, p. 45).

4.3.7 Strategies that may help other parents

It is helpful for parents who have a child with autism who has done intensive behaviour therapy to help other parents who may be at the beginning of this process. All six participants recommended ABA therapy for other children with autism, but suggested it in combination with other types of intervention. Some participants described a lack of support from others, as well as from the government. Discussed below are some support and coping strategies participants felt might help other parents who have children with autism. One of the aims of this research study was to find support and coping strategies to help other parents who have a child with autism.

4.3.7.1 Support and coping strategies

All participants used different coping strategies and had different support structures in place for themselves, depending on their different personalities and situations. The following coping strategies were recommended for other parents who have a child with autism: support groups with other parents in the same position; a baby-sitting group in order to give parents time to spend with each other; family involvement; and educating others on autism. P1 mentioned the importance of the three Ps: persistence, patience and perseverance, she also spoke about choosing your own battles: if you are exhausted, leave the battle for another day when you have more energy.

"I would tell parents despite everything they must get down to the simplest smallest things and ask themselves what they want now." (P1)

"I say to parents its three p's – persistence, patience and perseverance. It would take us three hours thirty minutes to get dress, but every day gets less and today it is quick. If we didn't persist and persevere, we would still have had to dress him." (P1)

"Choose your battles." (P1)

"Go out there, educate people, I mean that is a way of dealing with it ... don't be embarrassed." (P2)

"Try to get your family involved ..." "try and do that, friends, every person, see if they can look after your child for a few hours so you can get away and have a breather. That is one of the ways you can cope." (P2)

"I mean you must try and get support from friends and family. Even at the therapy school you can get someone to look after him. But make time for yourselves as well." (P2)

"I think it would be helpful to have supportive family and get them involved, although for us it hasn't been possible. Also to attend groups or functions with other parents who have children with autism, it helps you feel like you are not judged. It is also good to have faith, in our family we have a strong faith in God and a church community that is very supportive." (P3)

"I would say if they have a religion it can be a good support system. Also support from the school by means of support groups can help, they seem to help my wife a lot." (P4)

"... knowing that, someone who's been through this thing could seriously help someone else who's not sure about their child or what the situation is." (P4)

"the biggest thing that would help parents is to have some form of baby sitting group that are experienced in autistic children and all the different types of behaviours because the biggest thing that you don't have is time to talk as a couple, either the child is making noises and sounds or screaming, it emotionally just drains you, you don't have time together even if you are a single parent, you don't have time even away from the situation." (P5)

"I am sure outside of the home unit there are support groups out there that I think would be worthwhile maybe for people with different personalities to explore those further and maybe can gain some support inside from those." (P6)

Parents found it important to educate friends, professionals and society about the unique characteristics of children with autism (Woodgate, 2008, p. 1081).

4.3.7.2 Personal advice for others

One of the aims of this research study was for participants who have experienced the process of ABA therapy and autism to give other parents some advice in order to help them with their process. As mentioned by P5, autism is a spectrum disorder and every child with autism is different. This also goes for parents, who will each have a different experience depending on their personalities and personal situations. P3 and P4 did report that they felt one should begin ABA therapy as soon as possible. Early intervention has been linked to significant improvements in young children with autism (Zachor et al., 2007, p. 315). Below are some comments made by participants on advice for other parents who have children with autism:

"I have cards I keep – when people make comments, I will tell them it is autism and I will give them a card to read about it." (P1)

"Speak out, let your feelings be known." (P2)

"My wife attends support groups; that is important." (P2)

"Don't forget about the other siblings. Try and spend as much time with them as with the other one, educate them as well." (P2)

"Don't hide your child." (P2)

"Don't be put off with what doctors say and what people say, just go out there and seek help." (P2)

"It doesn't end at school, it is a 24 hour thing." (P2)

"Start your child in ABA as young as possible and do as much as you can to make it smoother". (P3)

"If you are going to do other therapies do them together with ABA." (P3)

"One needs to start, really, when the child is about three, maybe even two going on three." (P4)

"Expect a very hostile start. The child, when you start the therapy, in my experience, and from seeing other children as well, doesn't want to go to therapy in the beginning because it's hard work for them and they're actually quite happy the way they are, in their own world and for you to get them out of that world, they are not happy with at the beginning." (P4)

"I think if you take yourself out of the equation and your ego, you know even the personalities of the people that you meet along the way and you just really learn about the process of ABA therapy and how it works and what it does because it is not enough to just pay for it you have to understand how it works and how it helps." (P5)

"It is very easy to take it out on your partner in that respect or to blame yourself for the way that your children are and you go ok maybe because it is some of my traits and maybe it is something I have done and maybe it is something on my family's side. I think that the sooner that you accept that that is not the case and get on with it the better and the worst thing you can do is start to tribute blame for the actual diagnosis on your partner because I mean that would be destined to failure". (P6)

4.4 REFLECTIVE NOTES BY RESEARCHER

The researcher wrote a personal reflection after each interview where she discussed her feelings and thoughts of the interviews. The topic was sensitive in nature and there were times when participants would be very emotional specifically when discussing personal experiences with their child and the negative impact having a child with autism has on their marriages. Below are some quotes from the reflective notes of the researcher:

“I was inspired by the participants’ courage and persistence”

“I do feel angry at the education and government system in our country”

“I was interested in the religious aspect. The parents are ostracized from others, even thought of as crazy and blamed for their child's disorder.”

“The participant was very emotional and in tears at times, I did feel there were times when the conversation needed to be guided in another direction because the participant was getting worked up.”

4.5 SUMMARY

The overall aim of this chapter was to introduce and confirm the findings of this study in relation to other studies conducted in relation to the research questions. The demographic details of the participants were provided, as well as a brief outline of the research process followed for data collection and analysis.

Chapter 5 consists of a summary of the research findings, recommendations for further research and a discussion of the strengths and limitations of this research study.

CHAPTER 5

DISCUSSION AND RECOMMENDATIONS

5.1 INTRODUCTION

In previous chapters, the purpose of the study is stated and a review of the literature is provided along with the research design and methodology and a discussion of the research findings.

The aim of this chapter is to provide the final interpretation of the research findings from the study. In addition, the strengths and limitations of this study are discussed and recommendations for further research are provided.

5.2 SUMMARY RESEARCH AND FINDINGS

This study set out to explore the key research question of "What are parents' experiences of a child doing Applied Behaviour Analysis therapy?"

The researcher also attempted to answer the subsidiary research questions: "What are parents' experiences of their relationship with others (friends, family, husband, other children and the public)" and "What role does autism and/or ABA therapy play in these experiences?" "How did parents experience their child's behaviour before ABA therapy?" "What coping strategies and support do parents rely on?" and "What support and advice do parents have for others who have a child with autism?" Presented below is a brief discussion of the results for each question.

5.2.1 What are parents' experiences of a child doing Applied Behaviour Analysis therapy?

The parents in this study have revealed many different experiences and emotions with regard to living with a child with Autistic Disorder. Participants' children initially displayed difficult behaviours, which led participants to seek help from professionals.

All parents experienced significant improvement in the behaviour and communication skill of their children after intense one-on-one ABA therapy (Zachor et al., 2007, p. 313). It was reported that intervention needed to be incorporated into parents' everyday lives to achieve the most desired improvement. All the parents experienced improvement in their child beyond their initial expectations. Parents also reported experiencing less anxiety when in public places with their children. Most parents mentioned financial stressors because of the cost of ABA therapy and reported a change in their living conditions, as they did not have enough disposable income. The high cost of medical and therapeutic interventions for children with autism have been associated with financial difficulties (Sharpe & Baker, 2007, p. 247).

One participant reported that having her child with autism receive ABA therapy gave her more time to bond with her other (neurotypical) child. Two parents reported on the challenges they experienced in doing home-based ABA therapy themselves. Both experienced situations where they would get angry with their child, or become emotional and cry often. Two parents had therapists come into their home to give their son therapy; both felt that their privacy was invaded. A few parents felt that ABA therapy was too rigid, which made it difficult when routines changed. Parents did mention that the ABA therapists often were supportive and helped them understand certain aspects of autism.

In a study investigating two years of intensive ABA therapy, almost 50% of the children improved drastically and were leading fairly normal lives and the remaining 50% improved significantly (Turkington & Anan, 2007, p. 38; Lovaas, 1987, pp. 3-7).

Parents all had positive feelings of ABA therapy and recommended it to other parents who have children with autism. Parents reported that ABA therapy gave them hope that there was something that could help their child.

5.2.2 What are parents' experiences of their relationships with others (friends, family, husband, other children, professionals and the public) and what role does autism and/or ABA therapy play in these experiences?

Parents reported strained relationships with their family, spouse, friends and other children. The most significant relationship difficulties mentioned was the relationship with their other children and with their spouse.

Parents reported that they spent less time with their neurotypical children. Two parents reported that this caused their child to feel that she was less important and loved less than her brother with autism. Lighthart found that a child who had a sibling with autism doing ABA therapy felt that her needs were not as important as her brother's needs; this caused her to feel sad, anxious and insecure (2002). The current study found that parents experienced feelings of guilt due to missing parts of their other child's life. Parents felt that having their child receive ABA therapy gave them some time to spend with their other children.

The majority of the parents mentioned experiencing difficulties in their marriage. Because of the constant care needed by their child and the lack of outside support, they had less time to spend with each other. One participant mentioned that the relationship with her husband consisted of talking about their child and his therapy only; she felt that they had nothing else to talk about. Another participant felt that her husband blamed her for their son's disorder. Studies have reported that having a child with autism can lead to marital strain (Grindle et al., 2008, p. 50; Meirsschaut et al., 2010, p. 67; Hartley et al., 2010, p. 452). Only one of the participants felt that having a child with autism had strengthened his relationship with his partner.

Parents also discussed their experiences with therapists, professionals and the public. Two parents had bad experiences with doctors and were told that their child needed to be institutionalised; these parents felt that health professionals needed to be educated about PDDs. Parents had mostly positive experiences with the therapists; they felt that the therapists had a genuine love for their children. Parents reported that therapists were very supportive. That parents show positive feelings towards therapists working with their children has also been reported by Grindle et al. (2001, p. 168). Parents who had therapists coming into their home to do therapy found it disruptive and difficult at times.

Therapists in the home environment can disrupt domestic routines and invade family members' privacy (Grindle et al., 2009, p. 48).

Parents also reported difficult experiences with the public and feelings of anxiety when having to go to public places. Parents felt that other people often did not understand what autism was and told them they needed to discipline their children. Parents did report a lessening of feelings of anxiety after their child had been in an intensive ABA therapy programme. Some parents did have good experiences with people who were helpful and made some effort, for example giving them a free movie ticket or meal.

5.2.3 How did parents experience their child's behaviour before ABA therapy?

Parents experienced feelings of hopelessness and loneliness prior to their child's diagnosis, as well as a lack of knowledge on autism. Feelings such as low motivation and hopelessness have been known to interfere with mothers' ability to engage in interventions (Kuhn & Carter, 2006, p. 565). Behaviours exhibited by children that caused problems included: difficulty with sleeping, underdeveloped speech, screaming and tantrums. Parents experienced embarrassment in public when their child screamed and threw tantrums. One parent lost his job, as he had often been absent from work due to driving around finding a diagnosis and treatment for his son. Another parent reported her experiences with sleeping problems which had a negative impact on her performance at work. Children's sleeping problems contribute to maternal sleeping difficulties and stress (Hoffman et al., 2008, pp. 160-162). Difficulty with sleeping has a negative influence on functioning and may cause depression and burnout (Gallagher et al., 2010, p. 735).

5.2.4 What coping strategies and support do parents rely on?

Parents who participated in the study made use of different coping strategies; it appears that the coping strategies that are used may depend on the participants' personality. Coping strategies included: Writing in a personal diary – this participant would read what was recorded in her diary a year earlier and enjoy the achievements of her son over the year that followed; Prayer and faith in God – two parents regularly sought support from their local church and found that their faith helped them to cope; Two fathers described themselves as introverted and mentioned that they liked to deal internally with their feelings.

Parents did report the lack in support and finance from the South African government, as well as a lack of support from friends and family who had not been educated about autism. Only one parent had a very supportive mother. All of the parents found the therapists and the head of the therapy school extremely supportive. A couple of parents reported that the therapists had babysat their children for them, giving them a chance to have some time to themselves. Parents have reported positive feelings towards the therapists who were looking after their child, as also reported by Nevas and Farber (2001, p. 168).

5.2.5 What support and advice do parents have for others who have a child with autism?

All the participants were willing to suggest strategies to other parents to give and advice to help them cope with their process. The strategies and advice that were recommended are presented below in no specific order.

Strategies and advice that may be helpful for other parents

- Start with the simplest things.
- Consider three 'Ps': Persistence, patience and perseverance.
- Choose your battles. For example, if you are exhausted refrain from beginning a difficult battle which you may not have the energy to follow through with the consequences.
- Educate people, for example make cards to explain autism and hand them out. There are many people who do not have any knowledge of autism, these people may think you have a child who merely misbehaves because of poor parenting skills.
- Speak to others about how you feel.
- Attend support groups where there are other parents who have children with autism in an ABA programme; speaking to others who are going through the same thing may help you to feel less alone.
- Don't hide your child.

- Don't forget about the other siblings.
- Start with ABA therapy as soon/young as possible.
- If you would like to try other therapies, do them in conjunction with ABA therapy.
- Expect a hostile start, it will get better.
- Educate yourself about ABA.
- ABA does not end at school, incorporate it into your home.
- Don't be put off by what doctors say – seek more help.
- Don't attribute blame to your partner.
- Try and get your family and friends to be involved.
- Organise a baby-sitting group.
- Make time for yourselves.
- Have faith (P1, P2, P3, P4, P5 & P6).

Participants did mention that the way one copes with the situation depends on one's personality. Some participants suggested coping strategies that they thought would help someone with a different personality to theirs.

5.3 RECOMMENDATIONS

There is scope for further investigation in this field:

- Further research could be undertaken to explore the experiences of parents with adolescent children with autism. Adolescence is a different stage of development in which relationships are often more complex.
- The situation of having a child with autism in a single parent family could be explored.

- Research could be conducted on the impact that having a child with autism has on marriage and relationships.
- A study could be done on the impact of home-based ABA therapy conducted by a parent.
- The impact of socio-economic and cultural differences on parents' experiences could be explored.
- The experiences of parents who have a daughter with autism could be investigated. All the participants in this study had male children and who may have exhibited different behaviours to a female child with autism.
- A study could also investigate the views and understanding of autism of the extended family (siblings and grandparents).

5.4 STRENGTHS AND LIMITATIONS OF THE RESEARCH

One of the strengths in this study was that parents were given the opportunity to share their experiences and feelings with others. Secondly, the study could make other professionals aware of other parents' experiences and their needs and they might be able use this study as a guideline to provide other parents of children with autism with various coping and support strategies.

A limitation of this study is the small size of the sample; the researcher also struggled initially to find participants who could find time in their busy schedules to take part in a research study. Participants' children in this study were all boys; parents may have different experiences with children who are girls. According to the literature, boys are more frequently affected by autism than girls, whereas girls show more severe symptoms.

Another limitation is the geographical location of the participants; all participants were from Cape Town or the surrounding suburbs. Care has to be taken in generalising the results, specifically with regard to families living in more urban areas. People in rural areas may experience greater difficulty in accessing medical and educational services and may be of lower socioeconomic status than participants in this study. The age of

participants' children can also be seen as a limitation; all participants' children were between the ages of five and eight and parents may have different experiences with adolescent and adult children with autism.

5.5 REFLECTION

The researcher gained valuable insight into parents' experiences during the research process. It was a positive experience for the researcher to provide parents with a safe place to talk and acknowledge their thoughts and feelings. Some parents were very emotional and were in tears, specifically when talking about the difficult behaviours that they had to cope with in the past and about their marital relationships. There were times when the conversation needed to be guided in another direction because the participant was getting worked up. The resilience of these parents was inspirational; they all put up a fight for their children and continue to do everything in their power to give their children a better life. The national healthcare system has let these parents down, especially those who are in a lower income bracket.

5.6 CONCLUSION

Little support is currently available to parents of children with autism in South Africa; they often are left isolated and helpless, which may leave them depressed and stressed. Awareness of autism also needs to be addressed; it appears that many medical professionals as well as the lay public have little or no knowledge about autism. Parents may cope better in public situations, and children with autism may be diagnosed earlier, if professionals and the lay public were better informed of this disorder.

Parents with children with autism deal with a variety of challenges on a daily basis. They are often faced with difficult situations and experiences, yet have reported that ABA therapy has improved their child's speech and behaviour, and made life much more pleasant for them. Parents spoke highly of ABA therapy, but did experience difficulties with regard to the cost of therapy and the rigidity of the therapy process. Parents were willing to suggest strategies and advice for other parents who may be at the beginning of their journey with a child with autism.

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ADDENDUM A



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7 June 2010

Tel: 021 - 808-9183
Enquiries: Sidney Engelbrecht
Email: sidney@sun.ac.za

Reference No. 312/2010

Ms PL Linden
Department of Educational Psychology
University of Stellenbosch
STELLENBOSCH
7600

Ms PL Linden

LETTER OF APPROVAL RE APPLICATION FOR ETHICAL CLEARANCE

With regards to your application, I would like to inform you that the project, *Children doing applied behaviour analysis therapy: parents' experiences*, on condition that:

1. The researcher remain within the procedures and protocols indicated in the proposal;
2. The researcher stay within the boundaries of applicable national legislation, institutional guidelines, and applicable standards of scientific rigor that are followed within this field of study;
3. Any substantive changes to this research project should be brought to the attention of the Ethics Committee with a view to obtain ethical clearance for it; and
4. The researcher will implement the foregoing suggestions to lower the ethical risk associated with the research.

We wish you success with your research activities.

Best regards



Sidney Engelbrecht
Mr SF Engelbrecht
Secretary: Research Ethics Committee: Human Research (Non Health)

ADDENDUM B

DEAR PARENTS

My name is Paola Linden and I am currently doing a master's degree in Educational Psychology at Stellenbosch University. This year I am doing a master's (MEd Psychology) thesis, which will be on *Children doing Applied Behaviour Analysis: Parents' Experiences*.

After some experience as a Applied Behaviour Analysis (ABA) home based therapist in 2008, I found great interest in studying parents' experiences of having a child doing ABA therapy. I encountered many difficulties and strains experienced by parents during the process of therapy. Parents seemed to struggle with consistency with regards to behaviour programs and discipline in the home as well as lack of support from friends and family outside the home. According to the literature there are not many South African based studies on parents' experiences of a child doing Applied Behaviour Analysis therapy. Studies abroad have found that parents struggle with problems in sleeping, depression, low motivation and high stress levels.

The aim of this study is to understand parents' experiences and the challenges that they may face whilst their child is doing Applied Behaviour Analysis (ABA) therapy. As well as to identify support strategies that help them cope with the demands of ABA therapy. In order to understand experiences parents face I would like to conduct semi-structured individual interviews and focus group interviews. These interviews will take place in March 2011 and will be arranged to best accommodate you. The research will consist of one individual interview of 1 hour and a brief written reflection, which will take approximately 20 minutes and can be done in your own time. Participants who take part in the study will remain anonymous and confidentiality will be dealt with the utmost respect.

For this study I will need to find 6 parents (a parent could consist of a male or female parent who is single or married) who are willing to volunteer as participants in this study.

If you are interested in volunteering please contact me on 0836290186 or e-mail me at paolalinden@hotmail.com with your contact details in order to discuss the study further.

Kind Regards

Paola Linden

ADDENDUM C



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CONSENT TO PARTICIPATE IN RESEARCH

You are asked to participate in a research study conducted by Paola Linden, a Masters in Educational Psychology student (MEd Psych) from the Department of Educational Psychology at Stellenbosch University. You have been selected as a possible participant in this study because you are a parent of a child with who is doing Applied Behaviour Analysis Therapy and therefore will be able to make a rich contribution to this research.

According to literature there are not many South African based studies on parents' experiences with a child doing Applied Behaviour Analysis Therapy. Studies abroad have found that parents face several successes and challenges. ALL IDENTIFYING INFORMATION INCLUDING PARTICIPANTS NAMES WILL BE OMITTED AND PSEUDONYMS WILL BE USED IN THE STUDY.

1. PURPOSE OF THE STUDY

The purpose of the research study is to gain more knowledge about the experiences of parents in South Africa who have a child doing Applied Behaviour Analysis therapy. In this study the research participants could share coping strategies to help other parents who have children doing ABA. The research data will culminate in a research thesis/report and the outcome could help develop support networks/strategies for parents. This study will provide the academic community with a more wholesome understanding of parents' experiences.

2. PROCEDURES

If you volunteer to participate in this study, you will be asked to do the following:

- Take part in an introductory interview where the study will be explained in more detail and the consent form will be discussed. The time for this interview will be 30 minutes.
- Write a brief reflection or Narrative on your experience of having a child doing Applied Behaviour Analysis therapy. The time for this should take approximately 20 minutes.
- Take part in individual interviews, where you will be asked information on your experiences with your child, whether you have experienced any challenges and your role in the therapy process. This interview will take approximately one hour.
- The total length of your time will be approximately 1 hour 30 minutes and we will meet on 2 different occasions in a one-month period.
- Where the procedures will take place will be discussed at a later stage.



Departement Opvoedkundige Sielkunde • Department of Educational Psychology

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3. POTENTIAL RISKS AND DISCOMFORTS

A possible discomfort could be discussing private, sensitive detail on your experiences, this will be managed with empathy and you will be free to take a break or continue on another day if required. A qualified Psychologist will be available for a debriefing session if required.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

From this research study there is hope to develop support network programmes for parents. People in society who have children with autism could benefit from various coping strategies discussed in the research.

Potential benefits for science could include a better understanding of Applied Behaviour Analysis treatment and a basis for further research on the topic.

5. PAYMENT FOR PARTICIPATION

This research is voluntary and therefore no payment will be given to participants to take part.

6. CONFIDENTIALITY

All information that is obtained from the study will be stored anonymously and treated as confidential and will be disclosed only with your permission or as required by law. Information will not be used for any other purposes besides the research. Only the researcher and supervisor will have access to the information. As a participant you have the right to request a copy of the transcription or review the interview on the Dictaphone. The recorded interview will be erased within two weeks after the researcher has transcribed the interview.

7. PARTICIPATION AND WITHDRAWAL

You are free to choose whether to participate in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Paola Linden on 0836290186.

9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, you may contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622].

SIGNATURE OF RESEARCH PARTICIPANT

The information above was described to me, by Paola Linden in English. I am in command of this language. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

1 Name of Participant

.....

2 Signature of Participant

Date

.....

.....

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [*name of the participant*]. [*He/she*] was encouraged and given ample time to ask me any questions. This conversation was conducted in English.

.....

.....

Signature of Investigator

Date

Consent Form

I _____ am willing to be interviewed and to voluntarily participate in the research study; "*Applied Behaviour Analysis Therapy: Parents experiences*", conducted by Miss Paola Linden. The reason, purpose and the aim of the study have been explained to me in detail. I am aware that all the identifying details will be kept confidential and will be for the sole knowledge of the interviewer (Miss P Linden). However, I am aware that the interview will be recorded and that the information discussed in the interview will be printed anonymously in a research thesis and will be available to the social science academic community.

.....

Interviewee

Date:

.....

Interviewer

Miss Paola Linden

Date:.....

ADDENDUM D

DATA COLLECTION

1. **WRITE A PAGE REFLECTION ON YOUR EXPERIENCE OF HAVING A CHILD WITH AUTISM DOING APPLIED BEHAVIOUR ANALYSIS THERAPY** (parents will each do a reflection before interviews begin)

2. **SEMI-STRUCTURED INTERVIEW SCHEDULE**
(Parents will do this interview separately in 30 to 45 Minutes)
 1. Demographic Details:
 - How old is your child? Is your child Male/female?
 - Does he/she have siblings? If yes how many and how old?
 - How long has he/she been doing ABA therapy?
 - How many times a week does he/she have therapy?
 - Is there any home-based therapy? How many hours are home based and how many hours are in a centre?
 2. What have been the results of ABA therapy for your child?
 3. What has changed for the family since ABA therapy began?
 4. What experiences have you faced with the ABA therapy process?
 5. What has your experience with therapists been?
 6. How has his/her sibling(s) reacted to the therapy process?
 7. Describe your feelings throughout the programme.
 8. What emotional responses do you have relating to expectations for your child?
 9. What coping strategies do you use?
 10. What support do you have?

11. Are there any other coping and/or support strategies that you think would be helpful (or are needed) for yourself as well as other parents?
12. Would you recommend ABA therapy to other parents who have a child with autism?
If yes, what would you tell them to expect during the process?
13. What advice would you give to make the process smoother for other families who are considering ABA therapy?
14. Any other comments you would like to include?

ADDENDUM E

Interview with Participant 3 (Mother)

R: Researcher

P3: Participant

* name replaced with pseudonym

Transcript	Codes
R: How old is your child? Is your child male/female?	Demographic details
P3: My child is a boy and he is seven, now turning 8.	Male, 8
R: Does he have siblings? If yes, how many and how old?	Sister – 24
P3: Yes he has a sister; she is 24 and a brother who is 4.	Brother – 4
R: How long has he been doing ABA therapy?	
P3: He started when he was 3, so four years; nearly five, February it is five years.	5 years
How many times a week does he have therapy?	
P3: He is in the grade R class this year, which is preparation for grade one. I am not sure how many ABA principles they use in the class. He does that every morning and then 3 times in the afternoon he does one-on-one therapy sessions for three hours – ABA therapy.	Grade R every morning 9 hours/week one-on-one ABA
I: Is there any home-based therapy?	Home Intervention (HI)
P3: Not at the moment, but when we first started with therapy I did it for about a year; I did a programme with him at home, but not any more.	HI: currently no home-based
I: Would you say you incorporated all the skills of therapy into your life at home 24/7?	HI: Did programme & incorporated therapy at home.
What happened was we were referred to a woman who had an organisation who provided the ABA programme and you pay for the programme and she was my supervisor. I would go through the programme with Daniel* at home and then I would go to her. It was like a point system and I would say "Daniel* tap table" (she taps the table) and he would have to copy me. I would have to do it with him, like ten times in a row for one week before I could say it was mastered. I would work through what she	HI: Repetitive HI: New updates weekly HI: Wasn't enough HI: Not a natural teacher

gave me and when he had mastered it all, she would come and I would show her that he had mastered it all and she would give us a new update on what he needs to do the following week. So we went from something really basic to "Daniel* come and sit". From that it went to "Daniel* go to the kitchen and get me a cup of water and come back". That was good, but it just wasn't enough. It was tremendously hard because I am not a natural teacher. I never felt that I wanted to teach or anything like that. My strength is Admin, I'm organised and I like to work in positions like that so this was very different and difficult for me. And because it is my child and if I was trying to teach him something we would both get frustrated and he would fight me. And because he was my child I felt like I could slap him. There were times when I would lose it and cry in the bathroom and I hated it, I hated doing it. Every day when it was time to do therapy at home with him I would dread it; if I could get out of it in any way I would be happy, like when we went on holiday, I was relieved I didn't have to do therapy that day. Eventually I was at the stage where I thought it was better for someone else to do the therapy. Any mom that does it herself – it is wonderful if moms can do it themselves – but not me. Funny enough, I could probably teach someone else's child, but because it was my child it was difficult.

I: What have been the results of ABA therapy for your child from when he started up until now?

P3: It has definitely improved behaviour; the thing we struggled with most with Daniel* was behaviour. I mean it was just like coping out of control.

He listens very well, he listens better than his brother, he doesn't have the same problems. If you ask him to do something he does it, generally. It has given him a measure of self-control and it has also helped with his speech because he could virtually say nothing; now he is able to tell me what he needs, what he wants and even sometimes how he feels about something. Like the other day he hit his brother, you know why? "Why did you hit him?" And he says "I was cross with him". So it is really amazing that he is able to identify an emotion and give a reason. In learning: colours, numbers, shapes, animals all those kinds of things have come along tremendously.

P3: What had happened was he was two to two and a half, I had actually noticed that his speech wasn't developing long before then, but we only started really getting worried when he was two and a half. We really

Feelings of ABA

FA/Hi: Got frustrated, tremendously hard and Emotional

FA/Hi: I would dread therapy

Hi: my child = get frustrated and he would fight me, I felt like I could slap him.

FA: Cry in bathroom, dread therapy. Relieved when I didn't have to do therapy

Results (R)

R: Improved behaviour

R: He listens well

Behaviour before diagnosis (B)

B: Out of control behaviour

R: Helped with speech, communication.

Example:

R: He is able to identify emotion

B: Speech wasn't developing

Diagnosis (D)

D: 2 - 2 ½ got worried, read a

started talking about it, I read a magazine article and it had a tick list of eighteen points and if you had ticked more than five of them you should have your child assessed, because there is a possibility that he has a type of autism, and he had 9 of the symptoms on the list of eighteen. Then I thought, well how could he be half autistic. I didn't know anything about autism. I just imagined those children who were rocking and had severe symptoms. I looked it up on the Internet and I saw Pervasive Development Disorder and then said, ok, now we go and see a neurologist. First we went to the paediatrician, and then the speech and the hearing therapist, and then it was the neurologist who confirmed that he had Autistic Disorder – by then he was 3 years old. Between two and two and a half he started screaming all the time; I think everything until that point was fine. He would do little quirky things like moving objects and spinning objects, and we thought, oh, look how clever! He can spin that plate so nicely. Until he started screaming we thought everything was fine, and then the more we would try and stop the screaming the more he would scream. The doctor who we took Daniel* to see pointed us in the right direction; he didn't say what he thought it was, I think they need to protect themselves. But he was a great help. A lot of the doctors say "Don't worry, it will get better and they don't refer you to other specialists so we were lucky that way. I've spoken to parents who are underprivileged and they can't afford to get all this help; how are they going to afford the thousands that it cost for an assessment? They really need help. He was screaming, having tantrums and self-harm he would take his nails and rake them down his face. As a parent you are so shocked and afraid and everything is weird and horrible. I always say I didn't think of it as day-to-day, it was hour-to-hour because I couldn't face a day. There were times where to think of the next day and what it would entail, you just don't want to carry on "I can't, I just can't actually do this". It was also me getting hurt: there was pinching and biting and all sorts of things, you just feel so abused, as well as the fact that you have to deal with every one else's (like the public) perceptions and views. If we went to a restaurant, when he was very bad in the beginning, I mean, people don't understand because physically your child looks normal. I life felt terrible, we were suffering like anything. As things started (intervention) you had your improvements in certain areas, like when he was potty trained – we were so happy, because nobody wants to change a teenager's nappy beside from the fact that it is expensive to buy

magazine article and he ticked the symptoms.

D: Paediatrician, speech and hearing than Neurologist confirmed it was autistic disorder at 3 years old

B: Screaming all the time, moving and spinning objects

Therapists and professionals (T)

T: Doctor pointed us in right direction.

T: A lot of doctors say don't worry it will get better & don't refer to other specialists

Finances (F)

F: Parents who are underprivileged cant afford therapies and need help

B: Tantrums, self harm.

Emotion (E)

E: Shocked and afraid, I couldn't face the day = hour to hour

E: It was also me getting hurt, you just feel so abused

B: pinching, biting me

Public Perceptions (PP)

PP: You have to deal with everyone else's perceptions, people don't understand because your child looks normal

R: Potty trained

E: So happy

<p>nappies and everything else you need.</p> <p>In the beginning of the therapies, the progress was slow, because I think having his mother as a tutor was difficult because he was very manipulative and he knew exactly what to do to get me to cry. He would derail the entire session and I would be in the bathroom sobbing in a towel and he would be eating Smarties at the desk that were meant for the reward. Later on, when he had gone to school situation very much like the Grade R classes, where there were, there are like 6 children with a teacher and an assistant. The teacher can't concentrate solely on him. When we really saw a difference was when he was doing one-on-one; he was having 6 hours a day and we carried that on at the therapy school for a year and then we saw it really take off. He needed to be constantly put in place or disciplined because he was just out of control, he didn't have any control. After that year, things started improving for us (family) where, you know, like I don't always feel like I am just surviving. You do get those days where you think, aagh, I just wish he would do this... or that... but it is like every week or so, not every day, every minute or every hour like it was in the beginning. I'm glad it got better, because I'm sure human beings are just amazingly adaptable and we were made like that because you just have to make it, you have to accept it and find strength, but I don't know where I would have found strength if it had carried on like it was. I am just so thankful that it did improve because where would I be? I would be like a basket case.</p> <p>I: What has changed for the family since ABA therapy began?</p> <p>P3: His sister was studying in college when he was going through the diagnosis and I think the noise level was difficult for her because he was a very noisy kind of child. When he was born, she went to live with her Dad for a while and then she came back and studied. I can't remember it affecting her too much. But for Sam*, the younger brother, I think he will often look at Daniel* when he does something and not understand why he does the things he does and realise that his behaviour is not accepted. In some ways Sam* is overtaking Daniel* now and almost becoming the older brother; if Daniel* takes something, he will wave his finger and say "Daniel* don't you take my toys, you put it back right now or I am telling daddy" or he will say "You put it back or I am going to send you to your room". Sam* is starting to get all bossy because he realises that he has this power and Daniel* is surprisingly compliant with that. Sam* feels that every toy</p>	<p>HI/R: Progress was slow in the beginning – mother as tutor was difficult</p> <p>B: manipulative & knew how to get me to cry</p> <p>HI/E: I would be in the bathroom sobbing and he would be eating smarties.</p> <p>R: Saw a difference when he was doing one-on-one & having 6 hours/day</p> <p>B: Out of control</p> <p>R: After year of one-on-one we really saw a difference things started improving for us</p> <p>E: I don't know where I would have found strength if it had carried on like it was.</p> <p>B: Noisy kind of child</p> <p>Sibling experience (SE)</p> <p>SE: Younger brother doesn't understand why he does the things he does & realizes his behaviour is not accepted.</p> <p>SE: getting all bossy because he knows he has the power</p>
---	---

belongs to him and Daniel* is not allowed to touch anything, even though I say "Sam* those were Daniel's* toys long before they were your toys so he can play with them". Daniel* will have something and Sam* will say "No those are my toys" and take it away and Daniel* just does it, he doesn't fight or anything. What I do is I rush with him to the bathroom and say, "Here are your toys" but he doesn't really play, he just throws them around a bit and then he loses interest. I think sometimes it is because he can't have it that he wants it and then he realises. "Oh it irritates Sam* to do that so I am going to keep doing it". I think for Sam*, in terms of other children, when he was small, he was very hesitant to approach other children because I think he thought they were going to hurt him; it took a while for him to realise that they weren't going to hit him like Daniel* does. I think he learnt that his brother is different and children aren't going to behave like, that so he got over that. Sam* is much smaller than Daniel* but he has got tough; if Daniel* comes and hurts him, he will grab something off the floor. For example, if Daniel* gets hold of him – Daniel* likes to grab him and hold him tight and takes his chin and digs it into Sam's* scalp, and Sam* will take everything he has and smack him; he has learnt to defend himself. My husband gets cross if I say: "Go Sam* hit him, hit him". I am not supposed to be encouraging him, but I just want Sam* to be able to stand up for himself. Daniel* has got a good method of control now where if you speak to him and say "Listen, think about what you are doing" and he can control it, so for all of us it is much better because he is gaining control over himself... sometimes.

I: What experiences have you faced with the ABA therapy process?

P3: In terms of when I was doing therapy with Daniel*, I would get frustrated and angry and all the feelings you go through. It is such hard work and you are not seeing that much improvement... there were so many emotions that go with that. When he has been at school and doing therapy with them I would think, like, why is he so loud, why haven't they been able to control that, why can't they stop that? and, you know, maybe if you had an expectation it is like going through more than it has brought out, like the aggression; the next thing is that drops off and it stops, he didn't pinch and bite or self-harm or any of those things and then all of a sudden it comes back and then you just think "We thought that we made all of this progress and now he has just gone back two years in behaviour". Why? How? I would just think it was terrible. You think you are getting on and suddenly

Example:

SE: Sam* hesitant to approach other children because he thought they would hurt him like Daniel* does

B: Hurts his brother

SE: Sam* has learnt to defend himself

Example:

R: Daniel* has a good method of control now

FA: Frustration, anger = hard work and not seeing improvement

FA: Why is he so loud – why have they been unable to control that

R: the aggression stops but sometimes it comes back

R: you think you are getting on and suddenly he would regress in one area.

he would regress in one area – it is horrible.

I: What has your experience with therapists been?

P3: When we initially started, Daniel* was very volatile and very difficult to deal with. He has become a child now that therapist will say "I was so excited to work with him" or "I cant wait, I have Daniel* this afternoon" they have come to enjoy working with him, but in the beginning nobody wanted to work with him. They not allowed saying that but I could sense it. The one day when I had come to fetch him he left his bag in the class, so I had to go back to the class to go and get it and the teacher was crying on somebody else's shoulder and she was saying "I'm a terrible teacher" and people would say "No, you are not, you are doing a great job". I was still coming in his classroom and I just felt there was a personality clash between Daniel* and this teacher and that because she would get upset because of him, she may have disliked him, and he could pick up on that. Daniel* is very sensitive and can tell when people are being genuine or sincere or they just trying to be nice because they have to. Daniel* has no time for that and I think that he picked up that this person doesn't like me. It made it more difficult, he would think "Oh she doesn't like me so I am going to do that" and I spoke to them and said "Look he doesn't like this teacher and she doesn't like him so put him with someone else" and they said "Look he is going to have to learn to be with many teachers over the years, and some he will like and some he won't like", but I told them that it was just the beginning of therapy while he was so volatile so I felt they should put him with someone he likes, but I didn't get my own way. They carried on and persevered. But fortunately it was like two more weeks and that teacher left. After that I never felt any problems with any other teachers he was with, I really felt the opposite, I am amazed at these tutors, they really love my child, I can see it in their eyes when they are teaching him, they love him. I can see when I drop him off in the morning and he runs to the tutors and hugs them and gives them a kiss and they are happy to see him and he is happy to see them. It is lovely and I think maybe I just don't have a teacher's heart or anything, but I think it is always easier to love your child because it is your child and you have that natural love. But when you have someone else's child, to love them like that is very special, I think. They are amazing. The children are like horses you have to break them in and like I've seen when new children come in at the workshops they give them the tutors they know can really deal with these tough ones and Daniel* in the beginning was one of them and

T: First he was volatile to work with but now they are excited to work with him.

Example:

T: There has been a personality clash with Daniel* and a teacher before.

Example:

T: school said he is going to have to learn to be with many teachers, but it was the beginning – thank goodness the teacher left after 2 weeks

T: never felt any problems with other tutors, they are amazing, they love my child, it is lovely

he screamed and tantrums and fights and the parents are in tears because they got to a point where they couldn't work around it and they give in and that's why they have the tantrums. But once they are at the school they expect the child to obey and he is saying "Oh no, I don't want to do it" but once they are at the school it is better. It was like with Daniel* he had to be broken.

I: What was it like in your household?

P3: It was difficult at home, there was that phrase that really made it different for us, I can't think of it right now, it really made all the difference. The one thing I can say, we used the phrase "I am counting to three and then I am going to help you". It really worked because it was a warning this is how long I am waiting and then I am going to assist you to listen. Very quickly, if you are very consistent and work with that you get the results. I can't think of the other thing – maybe it will come to me later.

I: How has his/her sibling(s) reacted to the therapy process?

P3: Well, with Sam* I can't really say because he hasn't really sat in with Daniel* in therapy. Just by himself, Sam* himself has been to a few one-on-one sessions because we picked up a few problems with him, with resistance to learning and everything. So we brought him for a few sessions and it really helped as well. It just sorted him out like that. Just a few sessions and he was listening and there were no problems. It was actually quite interesting to see it happen. With my daughter, the only way we might have helped her is if we picked up a certain thing and we would tell her this is how you deal with this. I can't really say it was therapy, but Sam* will use our phases to control Daniel* and take our role, like with the little bossy thing. We would say "Daniel*, you do that and you are in big trouble".

I: How did he feel with his brother getting all the attention?

P3: He never really had a problem, but when we came to the therapy school for his sessions he was very thrilled to be like Daniel*. To also have his little lunch bag and his bag and go off into his classroom. After the first few sessions he felt "mmm, maybe I don't like this so much". It was a nice thing to let him experience what Daniel* experiences and he knows when Daniel* comes to the school this is what he is doing. The thing that I remembered, the advice we got, was that you speak once, don't keep on continuing to reprimand and repeat

A: Difficult at home, if you are consistent and work with that you get the results.

SE: Brought our other child to a few sessions

SE: Never had a problem = thrilled to do therapy sessions like Daniel*

Advice (A)

A: The advice we got was that you

"Don't touch it, I said don't touch it, leave it alone, leave it alone", the child just picks up: "You know she is just going to keep repeating instructions and I am just going to ignore it, she is not doing anything about it", you speak ONCE and then we move onto the consequences, so that was one way in whatever they were doing in ABA, that was one of the things they did that we were able to carry over to our home, "You speak once".

I: Describe your feelings throughout the programme?

A: The frustration and anger ... and there is also joy, like when something succeeds, like when I was tutoring him; you would be working on something, working on something and there is nothing happening and then you get the breakthrough and then it was like "You could do that the whole way along, couldn't you?" You are just holding out the entire time and one day he will just do it, and I just thought "You little cheeky thing just holding out and holding out just for that reaction". So, yes also tremendous joy when you can see your child doing something that you couldn't do or maybe say something that was totally unexpected. Like, I would say "Daniel* what colour is this?" And then he would say "blue" and then he would say "It's a blue plate" and you would be like "What? (laughing) he actually said a sentence". I think like, now, in the programme that he is doing now, I don't know – the teachers probably experience it; some anger, etc.. but in the results that we experience there is no anger or anything left. We are enjoying the celebrating and the victories. So for me as a parent I am not feeling the anger any more in relation to therapy. Obviously, at home, if he pinches me or something like that or when he is destructive, I feel damn angry or cry – not a lot.

I: What emotional responses do you have relating to expectations for your child?

P3: Well for me I was rather on the side that he is going to stay with me for the rest of his life, that he is not going to improve to the point that he will be able to live anywhere else. He is going to have to be with me because I would rather be, like, where we are now is fine; if he didn't progress any further beyond this point, I would be OK with that because the hardest thing was not being able to communicate when he was screaming and screaming because his ball is on the roof and he can't tell me that his ball is on the roof and there is no ways I can know he has gone totally beyond the point where he will tell you why he is screaming. He can communicate; I mean; what more can I ask for, really, than to be able to

speak once, don't continue to reprimand. We were able to carry that home.

E: Frustration and anger as well as Joy when you get a break through.

E: tremendous joy when you see your child doing something that you couldn't do or maybe say something that was totally unexpected.

Example:

EX: On the side that he is going to stay with me for the rest of his life, that he is not going to improve to the point that he will be able to live anywhere else - if he didn't progress any further beyond this point I would be OK with that.

EX: he has gone totally beyond the point where he will tell you why he is screaming. He can communicate; I mean what more can I ask for, really, than to be able to understand him

EX: I want him to enjoy life more, sometimes he seems so sad and out of place – things that other children

understand him? The thing is, in terms of expectations, I just want him to enjoy life more, because I think that sometimes he seems so sad and so out of place and things that other children enjoy are like a trial for him and that's what makes me sad. I just wish for him that he could enjoy life more. Expectations wise I don't expect him or have to have him in mainstream school, I just don't see that happening. I don't think that he is at that point on the spectrum that he would be able to go mainstream. He is always going to need special help. But if you speak to my husband he has totally the opposite expectations, he expects Daniel* to be mainstream and to live a totally normal life, so in those things we are totally worlds apart, so we can't discuss that part of it, because he says I'm being a drip, but I say I'm just being realistic. I would rather be surprised that I'm doing something more than what I hoped for, than hope for something and be disappointed in the end.

I: What were your expectations in the beginning?

P3: All I wanted was him to stop the screaming, I didn't care if he never spoke, all I wanted was him to stop the screaming. I remember thinking "I can't take this any more". And finally the screaming stopped (laugh). Well I say it has stopped but Daniel* is still the loudest child here, our house is never quiet, it is always very loud, Daniel* has a loud thing going on, I think it is a verbal stim, where others might flap their hands or pull funny faces and have tics, Daniel's* stim is loud; he likes the sound of his voice – it gives him some kind of reassurance. So that was the expectations: stop him screaming, have him potty trained, let him be able to talk just the basics like "I want, I don't want", just to be able to not be so frustrated because I first thought that the screaming was because he couldn't talk. Now that he can talk, he is still loud. Definitely my expectations have been exceeded and that's why I am so happy, just to be happy with what I have got. When you speak to my husband it is going to be different.

I: What coping strategies do you use?

P3: I have faith in God, which is the biggest coping strategy – is our faith because I couldn't do it without God. The hope that for me that one day heaven – which is eternity, because that is what we believe – that I will have a perfect child. The time on this earth that I am going through a difficult time is really only a small amount of my life, my existence. That it is going to carry on much better so that's how I cope. And trying not to be too far down the

enjoy are a trial for him and makes me sad

EX: I don't expect him or have to have him in mainstream school, I just don't see that happening.

EX: I would rather be surprised that I'm doing something more than what I hoped for, than hope for something and be disappointed in the end.

EX: in the beginning all I wanted was for him to stop the screaming

EX: So that was the expectations: stop him screaming, have him potty trained, let him be able to talk just the basics like "I want, I don't want" just to be able to not be so frustrated because I first thought that the screaming was because he couldn't talk.

EX: Definitely my expectations have been exceeded and that's why I am so happy, just to be happy with what I have got.

Coping & Support (CS)

CS: Faith in God, one day in heaven =perfect child

E: If I start thinking about it, I get

road, living more, as I would say day to day. Because when school holidays are coming up and I have three weeks with Daniel* and I have got to keep him busy, I have to go out into public with him. If I start thinking about it, I would get depressed and I think "Ah, I am just going to stay at home, I am not going to go anywhere. I don't want to go anywhere with Daniel*, so if I don't think about it and then, when the holidays come, on that day I will think about what we are going to do and I will take Daniel* somewhere on that day. So definitely taking day by day with Daniel* and also to try and have some time away to just go out with me and Sam*, or sometimes dad will take Daniel* and I will take Sam*

depressed

CS: Taking day by day

I: What support do you have?

CS: Not a lot in the beginning

P3: Well we didn't have a lot of support in the beginning because my husband's dad is elderly and not a spritely old man and for a while my husband didn't want to tell anybody what was wrong – you know what I mean – he was hiding it from the family. So we couldn't ask them to babysit for us then it was too hectic – there was no way, and then my family all live in Johannesburg and when we did go there for some reason – I don't know why –, my mom just didn't make any allowances. She didn't believe that there was anything wrong with him; she just thought that he was naughty. My mom just thought that Daniel* was the naughtiest child alive and I got no support from her – no understanding or anything – and I was just devastated (emotional), I mean, really, "I am telling you (mother) that this is the diagnosis" and she never understood. She never bonded with Daniel*, she didn't like him, I could tell. She just doesn't like him. It was very hurtful. And then, as I said, he could pick up that she doesn't like him and he would walk past the passage and hit her butt, you know, (laughing) and do something to irritate her. That was tough, so no support on that side. So we didn't have anybody to babysit for us, we couldn't get baby sitters, we were too afraid because of the way Daniel* was behaving and stuff. I am trying to think when was the first time and who did babysit for us; it was one of the tutors, yes, she said she would babysit for us so for a while we would use tutors. And then a friend of ours would actually come and play with Daniel* in the afternoons to kind of be like a tutor, but she did no training and didn't have to do any formal work with Daniel* but just to keep him occupied and stimulated and whatever and then her daughter started wanting to see clients so she ended up doing the ABA course and all of that stuff. At the end we started getting more support. I think on my husband's side of it, he struggles to talk about

CS: Husband was hiding it from the family – couldn't ask them to babysit.

PP/CS: My mom didn't believe anything was wrong, thought Daniel* was naughtiest child

CS: no support from my mom

CS: didn't have anyone to babysit for us

CS: we would use the tutors to baby sit and a friend of ours comes and plays with Daniel*

CS: In end we started getting more support

it (autism), whereas I am very open about it, like, if we are somewhere and Daniel* is acting weird and there are people around who are complaining and I will say "He has autism, by the way" or if I am really cross I will say "mentally retarded", then they really feel bad. Because sometimes people are so judgemental, so I would rather leave them with a term that is really going to get to them; some people don't know what autism is, so I don't want to bother even using the term. My husband just wants to die if I say something like that. Ya, we haven't had any other support, like my friends, my girl friends that are great. I've got one friend whose son is in grade one here and she is totally the most wonderful person. I mean, Daniel* is difficult, but we can go to her house and she is totally relaxed. And then like our church has been quite supportive. When Daniel* was little, the babies' room was Danieles*, but he can't go to Sunday school because he is just not interested in what they are doing. But they made a room available to us and they call it the special needs room and so we can go and we don't have parents in with their babies who can't get used to him, They think "what's your child doing here? They not allowed in our room that's our room". Its really nice; they have been really supportive, it is like a safe haven for us. There aren't any support groups for us, when Daniel* was first diagnosed, I contacted Autism Western Cape and asked is there a support group and they said "no" because hardly anybody comes around. Even here at the Therapy School, if they have a braai for parents and they can just come and lots of people don't support it, they just don't come, I don't understand why, because I come, because the thing is its so nice to be with people who aren't judging you and who let your child be who they are without being stared at or whatever, because all the people are in the same boat. I don't understand why parents aren't more supportive of support groups, they don't go, I don't know what it is, but I genuinely try to do it because I just love that feeling of acceptance, because everywhere we go we worry about behaviour. It's so nice just to go somewhere where you don't have to worry. I've got another friend, Angela*, and if I go to her house it's so nice, you know what happened to her, she adopted a little girl of colour, so they are different colours and she was at the shopping centre and her child had a tantrum and their car was on the other side of the shopping centre so they had to walk through the busy shopping centre to get to her car and the child was having such a big tantrum that she took her into the toilets to calm the child down and two of the workers at the Spar phoned the police because they thought that she was kidnapping this child, because

PP: Some people are so judgemental

CS: One wonderful friend – we can go to her house

CS: The church – special room

SC: there aren't any support groups for us, Autism WC said nobody goes

SC: Therapy School had braai's, I go – nice when people aren't judging you

SC: Don't understand why parents don't go to support groups, I love the feeling of acceptance.

PP: Everywhere we go we worry about behaviour

they thought it wasn't her child and everything, so they had to get proof and the police wanted to question her and she said "It's my child," she said, "I don't carry papers" with my child. I said to her, "Aah you must have cried your eyes out". I mean, I would have been so devastated I would have been a puddle on the floor; it was terrible. Eventually they released her. Shame for her – it's complicated because she gets stared at anyway because she is a different race, so people will stare and think "Oh what's that, that white woman..." and then she has got an autistic child who is crazy, so it is all compounded for her – you know what I mean, it is very hard.

I: How is it taking Daniel* to public places?

P3: We take him to restaurants; we also just go to our local little Spur but Daniel*, because we live in Blaauwberg*, he is a celebrity in town: everybody knows him, because since 2 he has been screaming around the place. So when we go to Pick 'n Pay it's "Hello Daniel*, Hello, Daniel*", in actual fact, I can go to Pick 'n Pay and Daniel* just runs around and someone will come and bring him to me. It's become quite nice, except for the time he took the head off the chocolate Father Christmas. And I thought to myself, "No, wait, this is forty rand". So, ja, we can take him in public to places very familiar like the Pick 'n Pay; its ok, but generally its unlikely that I do this because people stare. It's the worst part of it, going out in public. My husband and I were so caught up in the whole thing with Daniel* that we didn't have time to spend with each other. My mom and dad are divorced and re-married and my dad and his wife lived in Israel for two years and they are now back and they live close by and they are very supportive. They babysit for us and my dad's wife – she's like a crazy woman, a dynamo woman – and so the kids like her; she is very good for them as well. The thing that stresses me out is the public and people. I was in Pick 'n Pay about two years ago when Daniel* was still screaming and he would just scream in bursts as we were walking and I heard this woman go "Shut up, shut up", so we got to the point at the end of the aisle and I met her and I said "Listen, my son has autism, but what excuse do you have for saying shut-up?" so she said, "You need to learn to control your child". She didn't even hear what I said. I said, "There is something wrong with his brain", so she said "Ya, but still, even if there is something wrong you must control your child." So I said to her, "Just think of the excuses you can have sometimes. Listen," I said, "I can't believe your attitude." And then I just walked away. I mean, I was crying and

PP: He is a celebrity in town – since 2 he has been screaming all over the place.

PP: Pick & Pay – took head off chocolate Father Christmas

PP: People stare – worst part is going out in public

M: Caught up in the whole thing we didn't have time to spend with each other.

CS: Dad and wife are supportive

PP: Horrible experience with woman

Example:

when I got to the parking lot I was crying and everything because it is just such a horrible confrontation. You expect someone to at least say, "Oh, I didn't know" or "I'm sorry, I didn't know", but she still persists after she has found out, you know. These are the things people do, even your friends, they expect you to keep your child under control but sometimes you just can't or you are trying to and they are not listening or whatever but Sarah* (owner of therapy school) wouldn't agree with that. She says you have to control your child (laughs). But I mean I've done some horrible things; we were out and they had like a little swimming pool net and Daniel* got splashed with water and Daniel* was saying, "I don't want splash, I don't want splash," and I said "That's fine Daniel*, we are not getting splashed" and then he had got himself into a thing about it, so I said, "Daniel*, if you can't stop we are going to have to leave", I gave him the warning about 10 times, otherwise he will say, "Oh, sorry, oh sorry, I won't, I won't, I won't". Eventually I had to go through with the threat. But then Daniel* – he is a huge big child and he wasn't co-operating – so I eventually just took him by his hands and dragged him down the road and then I still had to go back to get packed. It was so embarrassing; I thought "What must these people think of me, I'm abusing my child by dragging him along the gravel to get him into the car". You know, it was just awful. I thought "I'm never going out again, I just can't do this anymore". So now school holidays are coming up and I'm thinking what am I going to do... this year? I'm a full-time mom at the moment but I might want to go to work next year and my husband's hours are quite flexible; a lot of his work is from home, so if he is at home it doesn't benefit him if Daniel* makes too much noise.

I: is your husband supportive?

P3: Um, I would say no, not really; it's taken, like I said, his expectations and mine are really poles apart. Which could actually be a strength if you combined them, my pessimism to temper his optimism; he doesn't expect maybe too much and the fact for him to say "we can expect a bit more". Initially in the beginning he didn't expect a diagnosis; he said there is nothing wrong with Daniel*. He said it was my fault; that I didn't provide him with enough stimulation and everything and if I had been a better mother.... I had already researched everything and there was a piece this guy wrote on refrigerator mothers, I said "I think you should go and write a book with him", because that is such an outdated and wrong thing, I mean, I really had to stand up for myself and I said I don't agree with you. It took ages to get that out of

E: I've done some horrible things

Example

PP: I thought what must these people think of me; I'm abusing my child.

E: Anxious about school holidays

M: Husband not really supportive – we are poles apart.

M: In the beginning he said there was nothing wrong and it was my fault; I didn't give enough stimulation

M: I really have to stand up for myself

his head and I never got an apology for that; he has never said "Aah, it was wrong". And in actual fact, I'm getting it with Sam* now too, that its my fault that Sam* is delayed. I think he feels kind of like responsible for the boys and he blames himself, but he's not blaming himself; he is blaming me because he doesn't want to blame himself – you know what I'm saying. It obviously doesn't help the relationship; I mean, we have been living with that kind of dysfunction for a long time. So we really don't agree on those sorts of things. I think, like in the marriage sort of thing, I endure him; I don't know how one can go on like that. I mean, in a normal marriage it is difficult and hard work, but when you are devastated by your child's disabilities and there are things you disagree on ... but I think you can't, I mean, from my point of view I feel trapped, because if I am going to leave and be on my own, how am I going to cope? I mean, I must say I would definitely agree with the statistics that it takes a toll on a marriage.

I: Are there any other coping and/or support strategies that you think would be helpful (or are needed) for yourself as well as other parents?

P3: I think it would be helpful to have supportive family and get them involved, although for us it hasn't been possible. Also to attend groups or functions with other parents who have children with autism, it helps you feel like you are not judged. It is also good to have faith; in our family we have a strong faith in God and a church community that is very supportive.

I: Would you recommend ABA therapy to other parents who have a child with autism?

P3: Yes, I think that just from my own experience and books and other things, because you get a lot of stuff (therapies), diet, oxygen chambers, all the therapies you get. I think ABA for one appears to be the one that works for most or has the most results. Just from what I have read about it – there is nothing else that comes close to it. But I think the thing with ABA, for me, is that it has got to be intense. When I was doing ABA with Daniel* for an hour and a half each day it just didn't make an impact, but when you speed it up – I don't know the things to convert it into hours, but I think they said up to 15 hours a week will make a really significant impact, but anything less than that you are kind of just playing around. With ABA you have got to put in the hours, like I know in other countries they have volunteers and they can work out the hours, but for parents to do it on their own or to pay

M: I think he feels kind of responsible and he blames himself but he is not blaming himself, he blames me.

M: It doesn't help the relationship, we have been living with that kind of dysfunction for a long time.

M: I endure him, I don't know how one can go on like that

M: I feel trapped, if I am going to leave and be on my own how am I going to cope

Support for others (SO)

SO: Get family involved

SO: Attend groups or functions with other parents who have children with autism

SO: It is good to have faith

FA: Recommend it = YES

FA: ABA appears to be the one that works for most

FA: It has got to be intense (15 hours a week)

FA: You have got to put in the hours

FA: Problem with ABA = difficult to pay for

somebody to do it is difficult. I think that is the big problem with ABA.

I: If you were speaking to a parent who was about to begin ABA, what would you tell them to expect in the process?

P3: First I would say that there is hope, that you know, for me personally, that a picture of your child rocking back and forwards and putting their hands in front of their eyes for the rest of their lives – that is how in reality you think – but they are going to improve. I would especially say that ABA should start at as a young age as possible - not to delay and try other things but immediately start with ABA and that initially it might seem like it is getting worse, and you may think, Ah, man this is not going to work, ya – initially it is going to be tough but eventually it is going to improve. Every child is going to improve in some way; some more than others, but you will see an improvement for sure.

I: What advice would you give to make the process smoother for other families who are considering ABA therapy?

I: I would just say what I said earlier, start your child in ABA as young as possible and do as much as you can, to make it smoother. I mean, we messed around. Daniel* was diagnosed at 3 and I did the ABA with him and then he went to school, which was just not enough, so by the time he went into the full-time ABA, how old was he... 5, so it was two years that we wasted on our child and those were like two very vital years, we could have been a lot further along the path if we hadn't messed around – you know what I mean. I would say if you are going to do ABA, start as soon as possible, as much as possible. Don't mess around, don't start off with other silly things. If you are going to do other therapies, do them together with ABA. ABA is still for me the one thing that has proven to help – go for that and then do all the other weird stuff.

I: How does it financially impact one?

P3: We have been very fortunate as my husband works for a foreign company and he gets paid in Euros and because of the exchange rate being so high at one stage he was earning a very good salary. And we thought about it and said let's do everything we can now while the rate is high, until we can, but now the rand has strengthened his salary has dropped, like 40 percent – you know what I mean – so all of a sudden our income has dropped and

A: There is hope, they are going to improve.

A: ABA should start at as a younger age as possible

A: Initially it may get worse but will eventually improve

A: Send child as young as possible

A: Do as much ABA therapy as possible

A: If you are going to do other therapies do them with ABA

F: We have been fortunate

F: Income has dropped and we just can't afford it

we just can't, we just can't afford it, but I do feel that the time that we had was optimum time and we got the most out of it, and we were very, very fortunate to be able to do that because it made a huge difference. It was only really when he started the one-on-one that we saw a difference and even though, like in class – there is a little class he goes to with tutors – the tutors can see if he is slipping back, going back into some of those behaviours, but I think it will be ok, I hope so, because he has done what he can for the last while.

I: Any other comments you would like to include?

P3: Another therapy that we used that was really good, we did auditory integration, I don't know if you have ever heard of it; we did. A woman wrote a book called the sound of a miracle and her daughter was very, um, sensory noise sensitive to the point that later on she could hear the sound of her blood system, you know blood rushing through her veins and her heart beating, and it was all just too distracting, like that noise you can hear in the background would be like a whine in her ear and she couldn't concentrate and then they played music at different frequencies and her hearing normalised and she could concentrate and this girl makes this huge recovery. I read about it because I thought Daniel* is so hearing sensitive and I thought, even if it doesn't do anything – because in the book they have on the one section that nobody has the same results, so I thought I would just try it with Daniel* and, even if it makes his comfort level better, I will do it for that reason and also it wasn't too expensive and we thought, 'if it doesn't work then we haven't wasted a lot of money' so we took him for the therapy; it was incredible, in fact his noise sensitivity was gone, like that noise there (a lawnmower or something in the background), he would say "Oh, stop it! no!" and cover his ears, and after he could listen to any noise and it didn't bother him. We had terrible behaviour for the first two months after the therapy, but all of a sudden he just calmed and we had the kind of child that I had always hoped to see, all his loudness and everything went right down and everyone was amazed, like what happened. He improved, he started talking using words, his fine motor skills, concentration everything; I mean that was one of those moments when I was like, uh (facial expression of shock), it happened... I have the child I wanted (laughter), like complete. And then it lasted for about three months and then the behaviour slowly started slipping back and the noise sensitivity started coming back. I was just devastated and so unhappy. He could only do it (therapy) once a year and it is very intense for

R: It was only really when he started the one-on-one that we saw a difference

Another therapy used Auditory Integration – helped – lasted for 3 months and then behaviour came back

two weeks; we haven't done it again, most gains stopped but what fairly improved was his speech and a lot of the stuff that he was learning, so, for me, that therapy was really worth it; aside from ABA that was the other therapy that worked – for us it was like a miracle.

What I mentioned in the reflection is that the programme at the therapy school – what I like about it is not only ABA. They have incorporated it with other therapies like speech therapy and Occupational therapy. Therapies that you would usually be paying for, so a little bit of everything is incorporated, which is nice. So it is not just ABA. It is great.

FA: What I like is it is not only ABA they incorporate it with speech and occupational therapy

ADDENDUM F

P5	4 November 2010
Page Reflection	Units of meaning
<p>My Journey with Autism</p> <p>My son had normal development up until the age of 18 months. I really cannot remember when the regression started or if I just did not want to see it, but at his 2nd year old party, I knew he was different. It was my mother that kept on complaining that I must sort him out as he is becoming stronger by the day. Seeking help for my son was a journey on its own. It took us 18 months to get a diagnosis of autism. My son was 3 years and 2 months old when we arrived at the therapy school. At that stage we went through Doctors, specialists, hospitals, Church, OT's, psychologists, E.N.T specialist and even parental/ marriage counselling, we were so tired, so lost and I had no hope for my son.</p> <p>His behaviour when we got to the therapy school:</p> <ul style="list-style-type: none"> • He could not talk. • He could not keep clothes on his body. He was running around naked. • He was totally unaware of us. • He would line things up. • He would spin around for hours and then fall to the ground staring into space (I will never forget those empty eyes). • He would clap his ears until they bled. • He was totally unaware of danger. • He would eat anything, scratch in bins; eat snails and even his own poo. • He would walk around with two bottles one with pink milkshake and the other with juice. • He would only eat bread, bananas and chicken. • He would go 2 days with no sleep. Dropping down any time. • He would stand in the toilet bowl, flushing for hours...etc. <p>There is no way I can explain what this did to me as a mother, a wife, and to who I was. I cried for hours. I wished my son dead. I could not sleep at night. I seeked help for my son almost everywhere. I lost friends and family and my</p>	<p>B: Normal up until 18 months</p> <p>B: 2nd party different</p> <p>D: 18 months</p> <p>E: Tired, lost & no hope</p> <p>B: not talking, unaware, line things up, spin around for hours, clap ears until bleeding, eat anything, no sleeping, stand in toilet bowl and flush for hours.</p>

hope for a "perfect" family was lost...forever.

My husband lost his job, because he was constantly absent, driving my son around for appointments. We had no relationship like a husband and wife. We did not share a bed for more than 3 years, somebody has to stay awake with my son at night and somebody had to sleep with him.

I cannot remember certain stages in my daughters' life. She just grew up on her own. She was left with grannies or had to be quiet at the doctor. Only when she started with behaviour problems, we realized that we have neglected her in attention. She is so much more mature than children her age, but then again she would have these moments. She blames us for not loving her the same as her brother.

In the beginning it was so hard. The first 2 days we forced and restrained him to the Therapy School. He refused to even sit on the chair. It was intensive. For the first week every day from 9:00 - 16:00. By day 3 my son sat on that chair and looked at the tutor. By the end of the week my son had 20 words.

We did not have home tutors or somebody assisting us at home. We had to continue the therapy at home. It was every day and every hour of the day. We argued a lot! We had to change the way we spoke to our son, how we discipline and how we treat him. Even my daughter had to help with tutoring him. The *Therapy School* was all the support to us and I could phone any time of the day or night for help, advice, support and to keep me motivated.

It was all about the 3 "P's" – PATIENCE, PERSISTENCE, and PERSEVERANCE!

I don't know how I did it! I believe in a power bigger than me. All I know is that the Therapy School was there for us as a family from day 1. They never in the 4 years let me down. All night when I could not sleep – I would write! I wrote to companies for donations and sponsorships for my son. I believe that if parents open up and organize support groups it would be great. We need to educate our families and communities around autism and let our children be part of this world.

E: Cried for hours, could not sleep & wished my son dead

CS: lost friends and family

F/M: Husband lost his job

M: We had no relationship, did not share a bed for more than 3 years

SE: cannot remember stages in daughter's life – left with grannies.

SE: when she started with behaviour problems – realized we neglected her attention

SE: Blames us for not loving her the same as her brother

FA: Hard in beginning – forced and restrained him to school.

FA: intensive

R: 20 words in first week

HI: no tutors – continued it ourselves – changed how we spoke & how we discipline & treat him.

CS: Therapy school was all the support to us – I could phone any time of day

A: 3 Ps: Patience, Persistence & Perseverance.

CS: I believe in a power bigger than me, I would write – to companies for donations and sponsorships for my son.

A: Organize support groups, and educate families and communities around autism.