

**Parental perceptions of the role of Applied Behaviour Analysis  
intervention for children with autism during the transition from  
early childhood education settings to primary school.**

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## ABSTRACT

The transition to school time for children with autism may represent a period of an increased stress for the whole family. Some parents choose to try the Applied Behaviour Analysis (ABA) intervention for their children as a way of reducing that stress and to assist the child's transition. This study focuses on the role the ABA intervention might play during this period of time from a parental point of view.

A qualitative approach grounded in an interpretive methodology has been used for this study. Data were collected through nine families participating in email surveys, and four of them then agreed to participate in semi-structured follow-up interviews. In all nine families, the ABA intervention of various intensity had happened with when their children were transitioning from pre-school settings to primary school. Three themes emerged in the course of the study: *ABA intervention, even though chosen to facilitate the transition phase, does not seem to be the only factor that contributes to the successful transition to school; Language skills improvement with help of ABA therapy during transition time is seen as a stress decreasing factor; The influence of the ABA intervention during transition time was not always positive towards the younger siblings.*

All nine families emphasised that the financial aspect of the ABA intervention (namely, high cost) was seen as an extra stress factor during transition to school time. The high cost of the therapy was also linked to this study's difficulties with recruitment.

The findings, although only limited to the perspectives of nine participants, highlight the importance of families with children with autism to be prepared for the possible challenges during transition to school time. They also demonstrate the importance of further study in the field of the role of early interventions during transition phases of the young children with autism and imply that other factors apart from the interventions might play an important role in a child's with autism transition to school time.

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## CHAPTER 1

### INTRODUCTION

#### *1.1 Personal interest in the topic*

The word *autism* is not a rare one to hear today. The amount of the world research in the area of autism is growing, and equally so too does the number of families with children diagnosed with this condition. While various types of intervention for children with autism are being offered to families worldwide, at present, there is no single treatment that would claim to be most efficient one to treat Autism Spectrum Disorder (ASD).

My interest in children with autism and their development in the mainstream educational settings began through my own experiences as an early childhood teacher. I have encountered a few young children with autism and met their parents. Through my observations of the work of early intervention team and early intervention teachers, my interest was sparked not only in the area of autism but also in certain interventions available to and experienced by families of children with ASD.

My first encounter with an Applied Behaviour Analysis (ABA) therapist happened back in a day when I was a trainee teacher at one of my teaching practicums, when a therapist worked with a child with autism during the child's transition to school. Back then, I remember perceiving this early intervention as the "magic treatment" that everyone whose child was diagnosed with autism should try. However, much later, after years of experience in a classroom as an early childhood teacher, I realised how many other components apart from early intervention were important for a child with autism and his/her family to make a successful transition to school and settle in a mainstream educational environment.

The choice of an early intervention can be a hard task for a parent of a child with autism. In this research, my interest revolves around the role the ABA intervention might be playing in the course of transition to primary school of a child with autism. In particular, I would like to unveil the wider picture of the effects this type of intervention might have on the family during their child's transition time from pre-school to primary settings.

### *1.2 Purpose and justification of study*

Peters (2010) pointed out that defining a “successful” transition to school could be complex, as many features could be considered and each participant may have a different perspective of what success might look like. One view of success might depend on the nature of the relationships between all involved (Peters, 2010). While, as Chapter 2 will show, a lot has been said about the early interventions and in particular the effects of the ABA intervention on a child with autism, the research reflecting its impact on family life is rare to find. In this work, I was specifically interested in the part ABA intervention might be playing in easing parental stress during such a challenging period of time as transition from early childhood education settings to primary school.

Research suggests that particularly for children with Autism Spectrum Disorder, transition process from pre-school to primary may represent an important developmental milestone and may pose unique challenges on the children themselves, their families and teachers (Sterling-Turner & Jordan, 2007). Children diagnosed with Autism Spectrum Disorder may be at heightened risk for transition difficulties given their deficits in communication, problem-solving, and adaptive behaviour (Quintero & McIntyre, 2011). In addition, this transition may be stressful for the parents. Being a parent is hard work but it can be many times more difficult when we speak about parenting a child with special needs, where additional emotional and psychological aspects need to be taken into account. The role of early interventions for a child and its impact on the family during this potentially stressful period of time does not appear to be researched yet. In particular, research examples regarding the influences an intervention such as Applied Behaviour Analysis and its role during transition times for a family of a child with autism do not appear to exist currently.

The aim of this study was not to attempt to assess the effects of ABA intervention on a child during transition from pre-school to primary, I feel this should be a prerogative of the specialists in the field. This research is about identifying and discussing the possible impacts that this type of intervention might have on families, their daily life and well-being. Raising a child with developmental disability is a big challenge and I would like my research to be helpful for the parents considering such a serious investment as the ABA therapy in order to help their child with the transition to school. I would like parents to have more reading available to them in the area of early interventions when it comes to choosing between the ones that potentially help their child make a step into a school environment. Reading about the opinions and experiences of those parents who have already used the service will hopefully be helpful in taking such a serious decision as starting the ABA intervention. While all of the advertising information about ABA is widely available, its impacts on families seem to be somewhat left unspoken. In my view, this research might be of interest to parents of children with autism considering ABA as an early intervention during transition period and later in primary school. It may also be a beneficial reading to the educational professionals working with children with autism in inclusive classrooms.

### *1.3 Research question and organisation of the thesis*

The main research question for this study is: What is the role of Applied Behaviour Analysis intervention for children with autism during the transition period when children are moving from early childhood education settings to primary school: parental perceptions.

Within the main question, the project also intended to find answers to the following questions:

- What are the factors influencing parents' choice of this particular intervention and those preventing them from choosing it?
- What overall impact does this type of intervention have on the family?

The thesis is organised in the following format: Chapter 1 has given an overlook of the researcher's interest and background, it also contains the research question and justification of the study. Chapter 2 reviews relevant literature on the characteristics of autism, the impact diagnosis might have on parents of a child with autism and an overview of early interventions. Chapter 3 explores the literature sources available on the ABA intervention. Chapter 4 focuses on the family of a child with autism, it also discusses the nature of relationships of children with autism with their siblings and gives an insight into potential challenges that transition to school might bring to the routine of a child with autism. Chapter 5 outlines and discusses the research design and methodology. Chapter 6 reveals the findings and Chapter 7 provides discussion and some concluding comments and recommendations.

## CHAPTER 2.

### AUTISM

#### *2.1 Introduction*

In this chapter, I will be giving a general picture of what is usually associated with the term “autism”, its historical background, symptoms and typical challenges that a child with autism might be experiencing. I will also be talking about parents of children diagnosed with Autism Spectrum Disorder, in particular, parental views and experiences while raising a child with this condition. Parents’ choices of an early intervention for their child often play an important role in both supporting parents through the early years that are crucial to their child’s development, as well as in helping the child with autism to gain the necessary social, academic and everyday life skills. Therefore, I believe it is important to give an outline of the early interventions available to parents of children with autism today.

#### *2.2 Autism: at a glance*

The term “*classic autism*” (which is sometimes named “Kanner’s autism”), according to Baron-Cohen (2008) refers to early works of the child psychiatrist Leo Kanner (1943), who had first described a group of children demonstrating the same behavioural abnormalities. He recognised eleven children in his clinic in Baltimore who had what he called “autistic aloneness”, showing so little interest in people that they may as well have been “furniture in his office. The word “autism” itself comes from the Greek word “*autos*” that literally means “*self*”. Baron-Kohen (2008) suggested it was maybe the most precise word to describe the condition, “because autism involves a profound difficulty in appreciating another person’s different perspective, as if one’s own perspective were the true, correct view” (p.16).

Although Leo Kanner is considered to be the first person to have given a name to the autistic condition, some sources point out that historically, many similar cases had been described much earlier than the famous report of Kanner in 1943 (noted above). For instance, Morgan (1981) provided an historical insight on possible

cases of autism, referring to perhaps the earliest description in Haslam's (1809, cited in Morgan, 1989, p.17) book "Observations on madness and melancholy". A child described in this book was admitted to Bethlehem Asylum in England in 1799 and according to Haslam's observations, the boy never entered into play with other children or showed any personal attachment to any of them. Instead, he played in a preoccupied solitary manner with toy soldiers for long periods of time.. He never referred to himself directly in the first person as "I" or "me" but instead used the third person, referring to himself by name or as "he".

Amongst similarities of symptoms described in Kanner's (1943) work, five major ones stand out: inability of children with autism to interact in the ordinary way to people and to situations from the beginning of life; an anxiously obsessive desire for the maintenance of sameness; failure to use language for the purpose of communication; the fascination for objects and the ability of a child with autism to handle these objects with dexterity, and autistic child's good cognitive potentialities as inferred from the extraordinary skills he/she demonstrated in certain isolated areas. Although the children with autism relate effectively to objects rather than people, the problem, according to Kanner, was not simply their lack of awareness. He described three children as aware of others, but choosing to restrict their interactions. For example, if intruded upon by another person, they would form a temporary relationship, but a detached one with only part of the person (e.g. hand, foot) rather than with the whole person.

Since Kanner's work, a significant amount of literature on autism was published; the term itself and the description of the symptoms have expanded as more and more research was done in the field.

Today, according to Rotheram-Fuller and MacMullen (2011), Autism Spectrum Disorders (ASD) is a global term that represents a wide array of cognitive delays that are often diagnosed within the first two years of life, but persist across a lifetime. ASD includes autism, high-functioning autism, Asperger syndrome, and pervasive developmental disorders. These cognitive delays are most often recognized by behavioural manifestations of social, language, and/or emotional difficulties (American Psychiatric Association, 2000). The Mental Health Foundation of New Zealand (2002) adds that experts understand ASD as

occurring on a spectrum ( or scale) ranging from severe at one end where classic autism is found, to milder high functioning forms such as Asperger syndrome, at the other. Classic autism affects around one child in every thousand, with four out of every five children diagnosed being boys (Mental Health Foundation, 2002).

American Psychiatric Association (APA) (2000) stated that core features of Autism Spectrum Disorders include qualitative impairments in social interaction and communication and restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities. White, Koenig, and Scahill (2007) added that children with ASD have difficulty initiating social interactions, interpreting others' perspectives, and functioning in reciprocal interactions. Similarly, Tawbin, Mauk and Batshaw (2002) pointed out that the central impairment in Autism spectrum disorder was seen in social reciprocity, which means that the child simply does not have the skills needed for social perception (which includes picking up non-verbal aspects of behaviour such as body language), social knowledge (which involves being aware of feelings and intentions of other people) or social functioning (in other words, the ability to relate to others).

In her book, Lawson (1998), describing her personal life journey with the diagnosis of ASD, in particular says, “*..throughout my life, I have been unable to identify, understand and express my emotions, and so have always felt misunderstood and alienated from those around me...* (p.1)

Baron-Cohen (2008) also noted the communication and social difficulties and pointed out that children with autism usually tend to understand speech literally and use speech inappropriately for the social context, which may mislead their listeners and eventually result in misunderstanding. Children with autism can be seriously delayed in their development of language, and this delay is often what prompts families to seek a diagnosis. Yet language outcomes are also highly variable among these children. Some children develop age-appropriate language skills, while others remain nonverbal (Kasari et al., 2008). Francis (2005) adds that communication disruption puts a child with autism at risk for developing problem behaviours: challenging behaviours are more likely to emerge in the absence of suitable means of communication.

Children with autism also have difficulty reading other people's emotional expressions, in their face, or voice, or posture. According to Mental Health Foundation (2002), the child's ability to respond to others does not develop normally in the first three years. The child will often make bizarre responses to their environment, seems to lack interest in others and act as if they were deaf. Some research suggests that social deficits could be the primary difficulties in autism. Developmentally, children with autism do not seem to be programmed for social interaction in ways similar to other children. At relatively young ages these children often fall behind everyone else in the development of their social interactions and this gap widens as they grow older. (Schopler & Mesibov, 1986). However, there are other opinions suggesting that many of children with autism, even those who were most detached and distant in the preschool period, developed in a positive way from the social point of view and progressed in their social development throughout adolescence into adulthood (Peeters & Gillberg, 1999).

In addition to the general characteristics, many individuals with ASD experience secondary characteristics including displaying sensory sensitivities, behaviour challenges, and additional mental health diagnoses such as anxiety disorders and depression (Schall & McDonough, 2010). Repetitive behaviours in children with autism are often referred to as the ritual behaviours, which are often regarded as problematic by parents and professionals who work with these children. These behaviours often interfere with the daily activities experienced by individuals with ASD, and these types of behaviour can often be quite disturbing to others (Wen-Shing & Mei-Hwei, 2009). Baron-Cohen (2008), describes in his characteristics of ritualistic behaviours identifies hand flapping, spinning of the body, obsessional interests (like touching everything, becoming mesmerized by spinning objects, other), lining things up, severe tantrums at change, need for sameness and unusual memory. The child is usually unable to develop the forms of imaginative play that other children do: they will often have fixation on a particular object or objects and would often insist on certain routines or rituals (Mental Health Foundation, 2002).

The exact cause of autism remains unclear and the research has not been able to pinpoint any single causation; there are currently no consistent biological markers

to diagnose it (Diehl, 2003; Schoen, 2003; Autism Society, 2008), however it is generally accepted that it is the result of developmental brain abnormalities, with significant genetic influence (Towbin, Mauk & Batshaw, 2002). According to Hall and Graff (2011), even though researchers do not understand why the phenomenon occurs, the chance that another child in the family will develop autism increases 2% to 8% when one child in the family is diagnosed with autism.

It is evident in this literature that while there are common features, no one child with autism is exactly like another.

### *2.3 Getting a diagnosis*

Morgan (1981) noted that the symptoms of autism usually appear early in the life of a child with autism although the parents may acknowledge them or realize their significance only in retrospect. DeMyer (1979) in her extensive study of a life journey of individuals with autism added that as the infants with autism grow into toddlerhood, parental worries grow apace. According to Werner et al. (2005), some parents reported that their children seemed “different” from birth, while other parents reported many months of typical development, followed by a regression, usually between the child’s first and second birthday. Morgan (1981) added that in most cases parents, when questioned carefully, can trace the onset of the symptoms of autism back to early infancy. However, he also pointed out that some parents sometimes show denial towards the subtle signs in their child and may even wait until the child is six or seven before they actually acknowledged that there is a significant problem and seek help.

Early recognition of autism is crucial because it can promote good management and treatment, as well as provide access to support groups, services and state allowances; the early recognition also relieves parents of the burden of feeling guilty about their child’s behaviour (Peeters & Gillberg, 1999; Keenan et al., 2010; Zwaigenbaum et al., 2005). Early intervention, which is a support system for children with developmental disabilities and their families (APA, 2000) is often offered by the specialists to address the challenging behaviour and other issues. Keenan et al. (2010) and Wiggins, Daio and Rice (2006) suggested that for better effects, the early interventions have to be started as early as possible.

Milshtein et al. (2010) stated that resolution with the diagnosis of one's child involves coming to terms with and accepting the diagnosis and its implications. While examining the resolution status amongst mothers and fathers of children diagnosed with Autism Spectrum Disorder, Milshtein et al. suggested that compared to resolved mothers, unresolved mothers in a period of time after getting a diagnosis of ASD for their child reported a higher perceived negative impact of the diagnosed child on some aspects of family life such as the family's social life and negative feelings about parenting and marriage. Contributing to the discussion of the possible perceptions of the diagnosis, Solomon and Chung (2012); Gray (1995) and Schall (2000) added that while for some parents receiving the diagnosis of autism for their child is a straightforward journey (they are referred to neuropsychologist who assigns the diagnosis and helps the family with further treatment plan), for others, the journey to diagnosis can be long and winding, and while waiting to receive it, parents may have already developed a suspicion and mistrust in helping professionals, feeling that clinicians rather minimised their concerns, thereby delaying diagnosis. Goin-Kochel, Mackintosh and Myers (2006) who conducted their study with over 400 families with children with autism, added that the journey of diagnosis can be more frustrating for parents with lower levels of education and income as they seem to have lack of or no access to information about the condition and have less financial opportunities to examine the possible support systems available. However, although many parents appeared to be well informed and well-read about autism, and therefore "ready" to get the diagnosis, even in the best of situations, the moment of actually getting a diagnosis was devastating, and could become a "traumatic, scripted chapter in the parents' story" (Solomon & Chung, 2012, p.255).

#### *2.4 Early intervention*

Autism is incurable (National Institute of Child Health and Human Development, 2008). Hence, it can create serious challenges for families and may represent a certain crisis for some societies (CDCP, 2010). Carothers and Taylor (2004) pointed out that there is an extensive amount of research indicating that early diagnosis and early, appropriate intervention can positively impact children with autism and assist them in mastering as many adaptive behaviours as possible.

Solomon and Chung (2012) pointed out that once parents get to the “A” word, they are launched into a complicated world of treatment choices. There are many available therapies, and parents are likely to spend countless hours Googling the word “autism” and feeling overwhelmed about how to create a plan for intervention. Byron-Cohen (2008) noted that it might be better for parents to only have one source of information where they can read unbiased accounts of the different interventions and can see the evidence for or against each one, so that they can make informed choices as to which intervention to follow.

Peeters and Gillberg (1999) noted that even though there is no known cure for autism, many children improve over time, and interventions tend to play a very important role in this improvement. Some are even able to eventually live an independent, almost normal life, while others, more severely affected, need life-long care. Itzhak and Zachor (2009) point out that with early and intensive treatment, some children with autism improve, and some improve dramatically.

The traditional therapies for a child with autism involve Applied Behaviour Analysis, art therapy, music therapy, speech therapy, occupational therapy, physical therapy, biomedical and medical intervention, one-on-one educational support (Byron-Cohen, 2008; McCarthy, 2007). While therapies greatly vary in approach, they tend to give the child an opportunity to gain social relational, play and academic skills, usually in one-on-one or small group setting (Solomon and Chung, 2012). The hours and the group or individual choice depends on the personal characteristics of the child and often on the financial status of the family. I will give a brief outline of what is understood under certain types of interventions when they are mentioned in the context of supporting children with autism.

The *biomedical intervention* addresses the physiological imbalance underlying the condition of autism. (Buie et al., 2010). The biomedical treatment may be based on additive-free, allergy-free, casein-free, detoxification , phenol and purine-free, yeast and gluten-free types of diets and others (Research Autism, 2012). There is a large amount of research reflecting the possible efficacy of biomedical treatment on children with Autism Spectrum Disorder, however, there is no certain prove

known so far in biomedical treatment and more longitudinal research is needed to confirm the results.

Speaking about *medical intervention* for children with autism, Byron-Cohen (2008) argued that there are as yet no medical treatments known for this condition: “if there were a medical treatment for the social and communication difficulties, this might well be desirable” (p.115). He adds that despite using antidepressants has shown some effect on certain features of behaviour, such as reduction in repetitive behaviour, there are concerns of using such drugs in children because of the risk of inducing other side-effects (such as for example agitation).

In particular, while pointing out the most efficient therapies for children with autism, Byron-Cohen (2008) spoke about the *occupational therapy* which targets supporting a child with Autism Spectrum Disorder in his/her in a broad range of everyday activities. According to Schaaf et al. (2012), this type of intervention is safe and feasible to implement. Components of this intervention include a sensory-rich, playful, child-centred approach, providing a just-right challenge (scaffolding) and facilitating progressively more sophisticated adaptive behaviours by engaging the child in individually tailored, developmentally appropriate play interactions (Baranek, 2002; Schaaf et al., 2012). Treatment is usually carried out by a therapist trained in the approach and goals are mainly focused on improving sensory and motor abilities of a child with autism, in order to develop better sensory modulation for attention and behavioural control needed as a precursor for greater participation in school, play, social and daily living activities (Baranek, 2002; Dickie et al., 2009).

*Music therapy*, according to Byron-Cohen (2008), proved to have positive effects on children with autism. The effectiveness of this type of therapy is especially related to the level of intuition in children with autism when it comes to analysing, reproducing or producing music (Byron-Cohen, 2008; Katagiri, 2009). The findings of Katagiri’s (2009) study suggested that the background music can be an effective tool to increase emotional understanding in children with autism, which is crucial to their social interactions.

*Art therapy*, according to Byron-Cohen (2008) is also now a widely available intervention for children with autism. Again, this is because it builds on an area of strength in autism spectrum conditions, since many children with autism spectrum disorder prefer to think visually rather than verbally. Similarly, Cooper and Widdows (2004) noted that art therapy is particularly appropriate for children on the autism spectrum because they are often visual, concrete thinkers. Epp (2008) added that art therapy as a component to social skills training may increase the willingness of children to participate because art is an activity that they find acceptable. Artistic skill can also be developed in a highly systematic way, such that some people with autism produce hundreds of the same kinds of drawings over and over again, until they have perfected a technique. Byron-Cohen (2008) pointed out that many individuals with autism enjoy and benefit from art therapy as it is an opportunity to interact with another person without a strong verbal component, and to take pride in their work.

*Physical therapy* can be one of the popular accompanying interventions in the life of a child with autism. The results of Lang et al. (2010) study suggested that specific types of physical activity might be very beneficial for children on the Autism spectrum when incorporated into daily activities. For example, a 10 week swimming intervention program researched by Pan (2010) suggests that it not only improved aquatic skills in participants but has demonstrated the improvements in social interactions. The study of Bass, Dukhowny and Liabre (2009) pointed out the efficacy of horseback riding for children with autism. In particular, after the 12 week intervention, children exhibited greater sensory seeking, sensory sensitivity, social motivation and less inattention and sedentary behaviours. The study of Anderson-Hanley, Tureck, and Schneiderman (2011) that explored the effects of exergaming (the physical intervention for children with autism that teaches physical exercise through play) suggested that it is possible that an improvement in executive control functions in children with autism could work together with direct benefits of physical exercise and may indicate a mechanism behind increased control of repetitive behaviours. The video games created for exergaming are also a type of exercise: for example, the actions shown on computer screen are accompanied by verbal instructions that encourage a child to repeat them. This may be a simple task like focusing attention on the

right or left part of the body, or a more complex task requiring multi-staged repetition. Exergaming used for children with ASD may be useful for management of behavioural disturbance and for increasing cognitive control in these children.

However, the systematic review of Petrus (2008) that examined the area of the effectiveness of physical therapy (in particular, swimming) as an intervention for children with autism indicates that it only produces the short term decreases in stereotypic behaviours and that further research using more rigorous methods with greater number of participants on different autistic spectrum is needed.

Towbin, Mauk and Batshaw (2002) pointed out that children with autism are often severely delayed in language acquisition and the development of both expressive and receptive language is hindered. Speech that does develop may be idiosyncratic or echolalic. Therefore, *speech and language therapy*, according to Byron-Cohen (2008) is seen as one of the core interventions for children with autism. Diehl (2003) clarifies that speech therapists working with children with autism typically do not focus just on world and verbal skills but also social skills such as joint attention (pointing and gaze following), as it serves like a building block for social skills. During joint attention, the child and adult establish a shared focus of attention on an object – which is, in conversational terms, equivalent to establishing a topic. Speech therapists may also focus not just on a child's ability to increase their vocabulary but also on how language skills are used. This entails helping the child with pragmatics, or the social use of language. Goldstein (2002) and Gillis and Buttler (2007) suggested that speech and language intervention is able to improve the communication skills of children with autism.

It is worth suggesting that prior to any choice of intervention being made by parents, the majority of them need to gain more knowledge about the condition itself. The Ministry of Education of New Zealand (2012), pointed out that involving parents is an important part of early intervention for children with autism.

I have to mention that all of the interventions discussed above refer to the overseas research, predominantly from the United Kingdom and the United States

and that there are not many New Zealand studies exploring the early interventions available to children with autism living in New Zealand. There are only a few programs designed to support parents of children with autism in New Zealand. Namely, the Early Bird intervention for families of children diagnosed with autism is one of these interventions which was created in 1997 in the United Kingdom and started in New Zealand in 2001. The program, according to the Ministry of Education (2012) and Autism New Zealand (2012) was set to help parents support their child with autism during their early years. Litmus (2010) undertook the research in 2003-2004 in order to explore the probable effectiveness of the Early bird program. Their findings suggested that the program is an effective part of an integrated and seamless range of services and interventions for children with autism.

Another early intervention informational program for parents available in New Zealand is “ASD Plus”, which is sponsored by the Ministry of Social Development and is delivered through IDEA Specialist services (Intellectually Handicapped Children, 2012). The key findings of the research conducted by Litmus (2010) on the effectiveness of this intervention suggested that it increased participants’ knowledge about autism, as well as an increased use of a range of strategies and tools provided during this intervention improved communication and social interaction of a child with autism. The program has reportedly increased parents’ use of strategies to manage difficult behaviours (Litmus, 2010).

### *2.5 Summary of the chapter*

In this chapter, I have given an outline of what autism is and what interventions are now available to reduce symptoms of this condition. I feel it is important to give a detailed portrait of the ABA intervention in a separate chapter to enhance the reader’s understanding of what is meant by the words “Applied Behaviour Analysis” and therefore prepare them for the later chapters of this research.

## **CHAPTER 3.**

### **APPLIED BEHAVIOUR ANALYSIS**

#### *3.1 Introduction*

At the core of most educational approaches to autism and Asperger syndrome is the teaching of social skills and finding ways to overcome challenging behaviour in these children (Byron-Cohen, 2008). One of the early intensive behavioural interventions that target the enhancement of social skills in children with autism is the Applied Behavioural Analysis (ABA). The ABA service is delivered by private providers in New Zealand and is not funded by the government. In this chapter, I will give a general overview of the Applied Behaviour Analysis and I will provide some examples of how it might work in practice.

#### *3.2 Behaviourism and the historic roots of ABA*

Skinner (1974) in his book “About behaviourism”, wrote: “Behaviourism is not the science of human behaviour; it is the philosophy of that science” (p.1).

Much of the early research on behaviour with human subjects was conducted in clinic or laboratory settings (Schoen, 2003; Cooper et al., 2007). Although the participants typically benefited from these studies by learning new behaviours, the researchers’ major purpose was to determine whether the basic principles of behaviour discovered in the laboratory operated with humans. For example, Bijou (1955; 1957) researched several principles of behaviour with typically developing subjects and people with mental retardation; Baer (1960; 1961) examined the effects of punishment, escape, and avoidance contingencies on pre-school children. These early researchers clearly established that the principles of behaviour are applicable to human behaviour, and they set the stage for the later development of applied behaviour analysis. Snell (1983) later wrote that Applied Behaviour Analysis has its beginnings with laboratory experiments on animals and trials with humans in severely retarded range of functioning, which ended up with the technique successfully used in clinical settings, and therefore extended to additional exceptionalities of children in classroom settings. During the 50s and

into the early 60s researchers used the methods of the experimental analysis of behaviour to determine whether the principles of behaviour demonstrated in the laboratory with nonhuman subjects could be replicated with humans (Cooper, Heron & Heward, 2007).

The rise in awareness of autism, along with increasing incidence of the condition, has resulted in a range of alternative interventions developed (Green, 1996). One of them is the Applied Behaviour Analysis which is often regarded with the name of Ivaar Lovaas as synonymous. ABA as an intervention was specifically developed for children with autism. Beginning in 1965, based on his early work, Lovaas published a remarkable series of articles that transformed ABA and services for autism. He and his colleagues soon built on the methodological foundation from these studies, as they reported the first demonstration of an effective way to teach non-verbal children to speak, a study on establishing social reinforcers, a procedure to teach children to imitate, and several studies on interventions to reduce life-threatening self-injury and aggression. Lovaas proposed starting the intervention during pre-school years instead of later in childhood or adolescence, involving parents in the intervention, and implementing intervention in the family home rather than institutional settings.

### *3.3 ABA intervention: at a glance*

Baer, Wolf and Risley (1968) described Applied Behaviour Analysis as the technology side of a scientific discipline known as Behaviour Analysis. It is the science in which tactics derived from the principles of behaviour are applied systematically to improve socially significant behaviour and experimentation is used to identify the variables responsible for behaviour change (Cooper, Heron & Heward, 2007). It involves the process of systematically applying interventions based upon empirically derived principles of behaviour to improve socially meaningful behaviours, and to demonstrate that the interventions employed are responsible for the improvement in behaviour (Baer et al., 1968). Steege et al. (2007) added that comprehensive ABA programs use a wide range of assessments and interventions that are aimed at developing a broad range of cognitive, social, academic, leisure and functional living skills needed for success at schools, home and in the community. These programs are usually characterised by the use of

interventions that have been empirically shown to be effective with a given population in a particular context. According to Callahan et al. (2010), Applied Behaviour Analysis is among the most widely known comprehensive intervention model that features several decades of development and use with children with autism. Gresham et. al (2004) added that ABA therapy was amongst the most broadly requested and implemented treatments by parents, educators and service providers.

#### *3.4 Positive reinforcement as the core of ABA intervention*

Positive reinforcement strategies represent a powerful component among the array of behaviour support interventions for children with autism (Luiselli et al., 2008). By rewarding children for appropriate behaviour, or for the absence of inappropriate behaviour, this category of intervention leads to decreases in challenging behaviour. Positive reinforcement relies on providing something desirable after the child exhibits the behaviour that one wishes to increase. This requires an understanding of exactly what is “desirable” for each individual. Because preferences can be highly idiosyncratic, an indispensable and underlying requisite of reinforcement-based approaches is to accurately identify desirable items, activities, or events. It is useful to consider the function of the challenging behaviour that is targeted for reduction. For example, if challenging behaviour frequently occurs to obtain access to a particular video, it is likely that item is highly preferred and can function as a reinforcement. Similarly, if problem behaviour occurs because a child prefers to be alone, rather than completing instruction with an adult, time alone can be provided after completion of a task.

The process of ABA is very systematic: children are first individually analysed in order to assess the behaviour that needs to be altered. Once this type of behaviour is identified, intervention strategies to suit the situation are determined and then used to modify the behaviour. During this time, a qualified ABA therapist provides reinforcement to elicit and maintain the desired behaviour. Evaluations are made throughout the modification process to assess the effectiveness of the intervention (Simpson, 1995). When an intervention is found to be ineffective, another strategy is substituted (Schoen, 2003). One of the typical ABA interventions can be described as follows: the child is provided with the stimulus,

such as a question, a set of blocks and a pattern, or a request to go and ask someone to give him/her a pencil, along with the correct response, or a strong prompt at what the response should be. He/she is rewarded for repeating the right answer or desired behaviour (the reward might include some sweet treats or simply a happy verbal reinforcement like “well done!”, “good job!”), whereas the incorrect response is either ignored or corrected very neutrally. Human beings, fortunately, are able to respond to a wide range of reinforcements and the therapist would typically start with rewarding a child with the «edibles» and gradually move on to other reinforcers. As his/her response becomes more reliable, the prompts are withdrawn until the child can respond independently. This is usually done one-one-one, with pre-planned requests, timing, wording and the therapist’s reaction to the child’s responses.

An example of using social-positive reinforcement and social-negative reinforcement is presented in Luiselli’s et al. (2008) work as the following:

*A 6 year old boy diagnosed with autism is engaged in repetitive saliva-play by placing fingers in his mouth, rubbing together his saliva-coated fingers, and drooling saliva onto his chin. This behaviour has developed a repetitive pattern and takes place every day in the classroom. The ABA therapist who is giving 10 minute sessions addressing this particular problem, sits beside the boy but does not interact with him. When saliva play occurs, the therapist responds with the verbal directive, “No, don’t put your hands in your mouth”. Using learning tasks that have been selected for the boy, the therapist provides instruction during the session. Prompts are given by the therapist if the boy does not respond independently. Every time the boy engages with saliva-play, the therapist removes materials and ceases interaction for 30 seconds.*

Kern and Kokina (2008) stated that in general, best practice with respect to challenging behaviours dictates a comprehensive approach that combines preventative interventions with reinforcement for appropriate behaviour, new skill instruction, and consequences for challenging behaviour. This collection of interventions arranges the circumstances so that optimal learning will occur.

### *3.5 Controversy around ABA therapy*

Many studies revealed the successful application of ABA and many advocacy groups support its use (Schoen, 2003). According to Jacobson (2000), the only data that shows consistent improvements with children with autism is the Applied Behaviour Analysis. A review of Elkeseth (2009) on psycho-educational interventions for children with autism aged around six years old or less claimed that after assessing five high-quality studies on ABA treatments, this type of intervention can be named as a well-established method and that it proved effective in enhancing global functioning in pre-school children with autism when treatment is intensive and carried out by trained therapists. Weiss and Delmolino (2006) stated that the demonstration of benefits of the intensive ABA intervention program for pre-school aged children with autism has been compelling.

However, there are quite a few questions researchers have been attempting to address around ABA treatment.

One of these questions is simply what ABA should involve. For parents of a child with autism, learning more about ways to help their child is another step toward their role as a researcher, therapist, advocate, and a host of other future responsibilities. Therefore, selecting the “right” ABA components for their child can be a very important decision for the whole family. Frea and McNerney (2008) noted that the field of behaviour analysis has not always made parents’ paths easier. The various descriptions and terminologies used by ABA programs often have controversial results. Terms such as “discrete trial training”, “pivotal response training”, “verbal behaviour”, “Lovaas method”, “incidental teaching”, “milieu teaching”, and a long list of others make each family’s research a difficult process (Frea & McNerney, 2008). Compounding this dilemma is the fact that within each behavioural camp there exists serious debate as to which methods are most important within each approach. An individual child may benefit more from a particular ABA approach, or may need to move between one approach and another, depending on the goals of a program at a given time. The decisions as to which approaches to use will be based more on what is working for the child than what has been prescribed by a therapist who just follows a certain method.

Another controversial issue around ABA method is the “right” weekly intensity of the program. There is general consensus that the intensity, or number of hours, in a child’s program has a significant impact on developmental outcomes. (Luiselli et al., 2008). According to Lovaas’s recommendations, the number of hours necessary to achieve a strong therapeutic effects should be no less than forty hours per week (Lovaas, 1987). Many ABA therapists today would prefer to stand by the classic figure of 40 hours per week (Luiselli et al., 2008), although the research data on the intensity of the program allows to suggest that the positive effect of a program is more reliant on its behavioural emphasis than on the total number of hours (Luiselli et al., 2008).

Some studies report that just under a half of the children receiving 40 hours per week of one-one-one intervention with the therapist achieved essentially normal educational and intellectual functioning (Weiss & Delmolino, 2006; Luiselli et al, 2008; Frea & McNeerney, 2008). Birnbrauer and Leach (1993) provided an average of 19 hours of the ABA instruction per week and had very positive results at the end of the program. Similarly, Luiselli and colleagues examined 16 children who received the ABA treatment before and some after 3 years of age. According to the results of this study, there was no significant difference between those who had the ABA program of 15 hours per week and those who were receiving over 35 hours per week: both groups were still able to reach the same results targeted by the program.

The long time effect and sustainability of the results of the program over the years is another question around ABA intervention. Weiss and Delmolino (2006) who have examined the effectiveness of the ABA program delivered at home and the possible effects it has had four years after the children received it, came to an interesting suggestion: the initial learning rates might be playing an important role in the overall impact of this intervention on children with autism. Namely, children who initially learned quickly during their pre-school years (when the intervention was delivered at home), continued to demonstrate rapid acquisition rates in all curriculum areas later in school years. While half of the children-participants were able to be fully included into their educational placements during primary school years, the remainder continued to require highly specialised instructions to learn skills. One of the recent longitudinal studies by Kovshoff,

Hastings and Remington (2011) revealed that despite the fact that ABA intervention was associated with greater likelihood of children with autism attending mainstream educational settings afterwards, the results of their work have indicated that for at least some proportion of children who had received the same treatment, initial gains from the therapy were not maintained after the cessation of the intervention. The follow-up study was conducted after a two year period after the ABA intervention had terminated. At a time of follow-up, 41 children-participants were aged between 6.5-8 years old, which allows us to assume that all of them had had their ABA intervention during transition period from pre-school to school. At the follow-up time, all of these children continued to meet criteria for a diagnosis of autism and the initial results of intervention were not quite maintained at a level they had been at a time of intervention.

Lovaas (1987) argued that empirical results from behavioural intervention with children with autism have been both positive and negative. He stated that treatment is frequently primarily effective in the original learning environment, although he emphasised that the reports about the “magic” recovery from autism are false. Schreibman (2000) added that the most scientifically effective treatment seems to be based upon a behavioural model (which may not necessarily be the ABA intervention), which is done intensively and early in the child’s life. Schoen (2003) contributes with the statement that whatever the overall findings about the ABA intervention are, treatment for autism depends on the individual characteristics of a child, as well as on the family variables.

### *3.6 The possible effects of ABA intervention on families*

Schwichtenberg and Poelmann’s (2007) research results revealed that the effects of the ABA therapy on families have not yet been researched to the full, especially its efficacy and intensity influencing the everyday family life and well-being. Their findings report that families participating in ABA experienced elevated depressive symptoms and found that ABA intensity related to maternal depression and personal strain, which may negatively influence the whole family’s functioning and well-being. Unfortunately, the literature base for the probable effects that the ABA treatment might have on families appears to be scarce, which makes it difficult to see the full picture of what changes and

difficulties a family with a child with autism might be undergoing while their child receives full-time ABA treatment during his/her transition process to primary school. I would like my research to become helpful for parents considering ABA intervention for their child by filling a certain niche in a literature surrounding ABA today.

### *3.7 Summary of the chapter*

In this chapter, I have discussed what can be usually associated with the term “ABA intervention”, I have also given some examples of how it might work in practise and depicted some controversy around the method. Before moving on to the participants' experiences with the ABA intervention during their child's transition to school, I will discuss what this period of time might be like for these children and their families in Chapter 4.

## CHAPTER 4.

### FAMILY OF A CHILD WITH AUTISM AND THE TRANSITION TO SCHOOL TIME

#### *4.1 Introduction*

To understand what challenges life with a child with autism might bring, it is important to consider the whole *microsystem*, which according to Bronfenbrenner (1994) is an environment where individual lives, and involves family in the first instance. In this chapter I would like to talk about parents of children with autism, as well as to have a look at the possible relationships children with autism might develop with their siblings. To depict what the transition to school of a child with autism might be like, I will speak about the meaning of change in a life of these children and their families. I will also discuss the potential difficulties this period of time may represent and will link transition to other layers of the Bronfenbrenner's (1994) ecological system.

#### *4.2 Parents of children with autism: “ a rough, isolating road...”*

Speaking about their family journey with a child diagnosed with Autism spectrum disorder, McCarthy (2007) revealed: “When your child is diagnosed with cancer, neighbours stop by your home bringing precooked meals, hugs, and support. When your child is diagnosed with autism, families who see you in the supermarket, will slip away down another aisle” (p.9). Koegel and LaZebnik (2004), referring to personal experience added that “there are few things in life scarier than having a child diagnosed with any kind of special need, and autism is one of the scariest disabilities, because the diagnosis tells you nothing about a child's prognosis. No one can say honestly to you, “We know exactly what your child will be like when he is twenty” (p.13).

Studies by Lyons et al. (2010) and Shieve et al. (2007) both found that parenting a child with Autism Spectrum Disorder could be highly stressful and challenging

for many parents. In particular, the latter study that involved 459 parents of children with autism whose levels of stress were compared with parents of children with special care needs other than autism, revealed that parents of children with autism were more likely to score in the high aggravation range than other parents. The results of Dabrowska and Pisula's (2010) study revealed that parents of children with autism differ from parents of typically developing children in social diversion coping (particularly, emotion-oriented coping appeared to be a predictor for parental stress in sample of parents of children with autism). Mori (2009) added that increased levels of parental stress have been numerous reported amongst parents of children with autism compared to parents of children with other chronic conditions, such as mental retardation, Down syndrome and cystic fibrosis. Hodge, Hoffman, and Sweeney's (2011) findings reported that parents of children with Autism Spectrum Disorder have demonstrated significantly more depression, interpersonal sensitivity, paranoid ideation, and obsessive-compulsive behaviours.

The parental stress is mostly associated with the disorder-related characteristics and the severity of symptoms, the ambiguity of those (Mori, 2009), dependency and lifelong care (Bouma & Schweitzer, 1990). Study by Lyons et al. (2010) suggested that it is very often that parents tended to use the emotion-oriented coping responses (for example, emotional responses, self-preoccupation, and fantasizing reactions) in their struggle to manage stress, which on its turn may lead to increased parent and family problems, as well as it is linked to parental pessimism when autism symptomatology (like, for example, repetitive behaviours, frequent tantrums and refusal to co-operate, minimal social response) is high.

In addition, family stress has also been researched and this factor is often related to the long process and delay in obtaining a diagnosis (Gray, 2003), lack of social acceptance and understanding (Dunn et al, 2001; Mori, 2009), lower levels and self esteem, difficulties in accepting a diagnosis (Peeters & Gillberg, 1999), a child being less "appropriate" than desired, and overall parental vulnerability to mental health problems including depression (Ghaziuddin & Greden, 1998). In their study, Altieri and Von Kluge (2009) pointed out that families with a child with autism are less likely to engage in social and recreational activities than families

of typically developing children. The recent review of Meadan, Halle, and Ebata (2010) revealed that in addition to all stress factors previously named, the additional sources of stress can be the economic burden or raising a child with Autism Spectrum Disorder, including the negative impacts on parents' career and/or income, parents' concerns about the future for their children, specifically problems that may arise when the children reach adulthood.

Altiere and Von Kluge (2009) noted that regardless of the severity of the characteristics, a child with autism presents unique challenges and stressors for the family because of the ambiguity of the diagnosis, the severity and duration of the disorder, and problems of the child's lack of adherence to social norms. A family with a child diagnosed with Autism Spectrum Disorder must make significant adjustments to cope and function adequately. In many cases, one or both parents' employment would also need to be re-adjusted to the increasing needs of their child. In particular, the study of Gray (2002) revealed that half of the mothers interviewed reported that their child's autism prevented them from either working at all, or restricted their hours and/or type of employment.

Hall and Graff (2010) reported that parents described the maladaptive and adaptive behaviours of their child with autism as sources of stress. According to Sivberg (2002), these families rate their stress level higher than typical families. He assumed that higher scores reflected deterioration of social support due to stress on the family system. Therefore, families of a child with autism may gradually lose their friends because of their limited availability due to most of their time being spent supporting their child.

Interestingly, the research that investigated difficulties that parents face while raising a child with autism and the levels of stress associated with this process is mostly focused on the mother-child relationship and typically would not include an analysis of the father. Meadan, Halle, and Ebata (2010) suggested that this is probably due to the fact that whereas mothers and fathers share parenting roles, mothers typically assume a larger part of the responsibility of meeting the needs of the child with Autism Spectrum Disorder. Lamb and Tamis-Lemonda (2004) emphasised the importance of assessment of fathers of children with autism for understanding family functioning. A study by Altieri and Von Kluge (2009)

attempted to explore the difference in perception of the quality of life amongst mothers and fathers of a child with autism. The results reported that while mothers of children with autism who received more social support experienced less somatic problems and depressive symptoms, fathers of children diagnosed with Autism Spectrum Disorder felt they lost friends because they (friends) did not comprehend the struggles associated with raising a child with autism. Fathers also reported that losing friends was associated with the fact that they were not able to spend significant time with them. In contrast, many mothers indicated that their social support came from other mothers they met through support groups and related functions. Hastings, Beck and Hill (2005), writing about raising children with developmental disabilities, reported that especially mothers showed more positive experiences than fathers. The findings of these studies contrasted to the recent results of Meadan, Halle and Ebata's (2010) work which concluded that it is primarily mothers of the children with Autism Spectrum Disorder who reported significantly more stress and lower levels of well-being than mothers of children with other developmental disabilities. Apart from differentiating the levels of stress in mothers and fathers, the major part of research on the impacts on a family raising a child with autism concludes that the increased stress could have a negative impact on both parents, leading to depression, anger, anxiety, marital discord and overall ill health (Bromley et al., 2004; Higgins, Bailey & Pierce, 2005; Koegel & LaZebnik, 2004; Weiss, 2002).

Cottle (2012, p.4) identifies parenting of a child with autism as "a rough, often isolating road". Woodgate, Ateah, and Secco (2008) agreed and added that parenting a child with autism could feel very isolating and this isolation is particularly heightened by the unpredictable behaviour of a child with autism, which can make even the most extroverted parents to feel anxious about attending social events and family gatherings. Other research agrees that although there is evidence of high levels of appropriate and very good parenting among parents of children with autism (Siller & Sigman, 2002), these parents are reportedly suffering more stress than those of children with physical disabilities or other developmental disorders, and typically developing children (Baker-Erikzen, Brookman-Frazer, & Stahmer, 2005; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2004; Erguner-Tekinalp & Akkok, 2004; Schieve et al., 2007;). Sadly, parents of

a child with autism are nearly twice as likely to divorce as parents without a child with autism. Further, the risk of divorce for parents without a child with autism decreased as the child reached late childhood and early adulthood, while the risk of divorce for parents with a child with autism remained high through adolescence and early adulthood. (Hartley et al., 2010). At the same time, there is a contrasting view of Bayat (2007) who argued that for many families with a child with autism, the diagnosis may play a unifying role and some families report that they have become stronger as a result of a disability in the family.

Hall and Graff (2011) pointed out that as society seeks to find answers to assist families of children with autism, support groups or parent groups continue to be recommended. However, parents appear to have differing opinions about the benefits of support groups and may not be always interested in becoming a part of those. In particular, Gupta and Singhal (2005) and Sivberg (2002) summarised that parents may choose to isolate themselves from such social meetings, especially when they are convinced that those meetings offer no benefit to them.

#### *4.3 Siblings of children with autism: mixed findings from research*

Munteanu and Dillenburger (2009) stated that there is little information on the impact of living with a child diagnosed with Autism Spectrum Disorder on the whole family. Recently, there has been a growing interest in research in regards to the effects of a sibling with autism on other children in a family. It has been suggested that siblings' relationships in early childhood provide a model for the development of future social relations and for acquiring social skills. (Levy, Goldstein, & Weinstock, 2010). This particular study compared parents' self-reports with self-reports from 27 children who have siblings with autism and 27 children with no sibling with disability. Interestingly, findings suggest that siblings have markedly lower levels of participation in extracurricular activities (which may be related to simply lack of time or insufficient financial resources, which are mostly directed to aid the child with disability). At the same time, parents and siblings tend to define the attributes of "helpfulness/responsibility" in different ways: whereas parents considered these to be positive attributes of their healthy child, self-reports suggest that for siblings these same attributes may be a source of distress. Siblings are generally expected to grow up sooner than other

children as they may need to learn to look after themselves while their parents are caring for their brother or sister (Strohm, 2002). However, they may themselves also be required to spend time caring for their brother or sister. While this may lead the child to feel valued and useful, it may also interfere with their social development and ability to establish independence (Strohm, 2002).

At the same time, there are contrasting research findings of Ferraioli and Hassis (2010) suggesting that the majority of brothers and sisters with autism function well, despite some other research results suggesting that relationships between siblings when one has a disability are not identical to the relationships that exist between typically developing siblings (Stoneman, 2001). Siblings with positive perceptions and experiences related to their siblings with a disability are likely to adapt successfully to the impact of having a disability on the family (Taunt & Hastings, 2002). When siblings perceive their parents and peers as reacting positively to the child with a disability, more positive relationships are reported (Petalas, 2009).

Kaminsky and Dewey (2001) found that siblings of children with ASD reported lower levels of intimacy, pro-social behaviour, and nurturance by their brother or sister with ASD compared to siblings of children with Down's syndrome and to typically developing children. Their later (2002) findings indicated that siblings with autism are well-adjusted and reported low levels of loneliness. It is worth noting that the participants of this study received high levels of social support in their lives. As has been shown in various studies, social support is an important factor to assist with functioning within the family, as families with effective support networks exhibit lower levels of pessimism, have a lower risk of exhaustion and burn-out, and report lower levels of stress (Boyd, 2002).

The influence of children with ASD on their siblings is modified by several factors relating to the characteristics and dynamics of the individual family members and of the family as a whole, such as gender, age, birth order, family size, socio-economic status, parental response to the child, temperament, and coping styles. (Moyson & Roeyers, 2011). Moyson and Roeyers (2011) also suggested that recent qualitative studies on the experience of siblings of children

with ASD not only confirm that these children experience stressful life conditions but also reveal some previously hidden themes, such as being afraid of and being a victim of violent behaviour from the side of the sister or brother with autism. Pilowsky et al. (2004) who researched social and emotional adjustment of siblings of children with autism suggest that severity of the form of autism seems related to poorer sibling adjustment. Another significant finding in this study revealed that the larger the family was, the greater the delay in siblings' socialization skills. This finding contradicted the earlier one of Kaminsky and Dewey (2002) who suggested that large family size appears to facilitate healthy adjustment in siblings of children with autism. Similarly, the earlier study of Hornby (1994) indicated that the extended family can play an important role in determining how well families cope with the additional stresses of raising a child with a disability and supportive and understanding family members had a significant positive influence on family functioning, whereas if there was little contact the family lacks an important source of support.

Kaminsky and Dewey (2002) also emphasised that the stress experienced by parents of children with autism was related to socialization difficulties among the siblings. This association may be attributed to the relation between parent-child interaction and peer-related social competence, where stress may play a role by impacting on parents' availability to model social rules and cues during interactions, thus potentially affecting the emotional regulation difficulty and therefore affecting peer relationship (Pilowsky et al, 2004). Tsao, Davenport and Schmiege (2001) pointed out that future studies on siblings of children with autism should take a life course approach and consider the context of life stages, as well as the impact on the family system as a whole.

#### *4.4 Transition time and a child with autism*

All individuals, regardless of disability status or age, are moving, or transitioning between multiple tasks and activities throughout their daily life. Transitions occur naturally, between activities of daily living, but they also occur in structured settings, including the educational environment (Dunlop, 2002). Beach (2003) defined transition as a developmental change in the relation between an individual and one or more social activities. Changes in their relation can occur through a

change in the individual, the activity, or both. Dunlop and Fabian (2002,p.118) on their turn, portrayed the transition as “being the passage from one place, stage, style or subject to another over time”. In this study, I would like to focus on the transition period from early childhood settings to primary school and on possible challenges it entails for a family of a child with autism. To see what kind of challenges the transition time might bring to these families, it is important to first understand the possible difficulties a child might be going through during this period of time.

As the literature tells us, it is widely accepted that the passage through major changes in our lives can have lasting effects on how we see ourselves, the value we feel others place on us, our sense of well-being and consequently how we are able to learn. (Dunlop, 2002). While transitioning from one educational setting to another may be easy for one child, it may turn up as a challenging process to another. Fabian (2002) pointed out that it is unlikely that all children will respond to starting school in the same way simply because people react to change in different ways and there are variations in their experiences of the transition.

According to Peters (2010), despite the excitement and anticipation of starting school that many children may experience, the move from home and/or early childhood education settings to school is not always smooth, and researchers are looking for ways of facilitating the transition. Peters (2010) also critiqued the earlier approach based on the idea that the child simply “adjusts’ to school, by drawing attention to the lived experiences of children, teachers and families, and describe the transition as a multifaceted and dynamic process. According to Vrinioti, Einarsdottir and Brostrom (2009), when children move from early childhood to primary school settings, they experience a change of identity from being a *child in pre-school* to a *student in school*. It may mean, they are expected to behave in certain way and follow the classroom rules, learning the language of the classroom and learning to “read” the teacher. Fabian (2002) adds that many children who have attended a pre-school setting with children of their own age, simply might not have had the opportunity of relating to older children. It is about entering a larger physical environment, which can be quite challenging for a child who belonged to the eldest group of children in early childhood settings and suddenly, he/she is the youngest and is expected to relate to other children in a

new class. Another important aspect that contributes to a successful transition, is according to Brostrom (2002), feeling “suitable” in a new environment. It is crucial to the child’s learning and development, as well as to a fundamental and continuous sense of well being. The author suggested that children who feel suitable, relaxed, and well adjusted in pre-school settings, are much more likely than children who do not feel well adjusted to experience school success beyond pre-school walls.

Bronfenbrenner’s (1979; 1994) ecological development model can be helpful in understanding the meaning of transition to a child. It offers four nested and interrelated levels: macro-, exo-, micro-, and meso- systems, which in the light of transition depicts three environments of *microsystems*: children’s home world, the early childhood world and the new school world. The interrelations between these three worlds form a *mesosystem* where all the three worlds are working together, empowering the child and providing a certain direction for the development of transition process. Families, pre-school environment and school environment together make the most important areas in child’s life before and after starting school and each of them plays an important role in supporting the transition. The areas the child does not interact directly with (for example, the support service providers) can be defined as an exo-system, and the macrosystem comprised of cultural values, customs and laws.

When a child with autism is starting school, particularly due to atypical social behaviour and anxiety problems reported in many children with autism (Gillot, Furniss & Walter, 2001), interventions are often needed to fully include these children into regular education classrooms (Rotheram-Fuller et al., 2010). As mentioned earlier, transition to school or within the settings may sometimes be a challenging process for a typically developing child, and in case of a child with autism, it may represent a greater difficulty (Sterling-Turner & Jordan, 2007). In addition to difficulties in social relationships and communication, some individuals with autism may exhibit behavioural difficulties associated with changes in routines, including transition times (American Psychiatric Association, 2000). Sterling-Turner and Jordan (2007) added that although not an exhaustive list of possible behaviours, individuals with autism may resist transitions by exhibiting noncompliance, aggressing towards others, or engaging in stereotyping

and tantrums to avoid changing activities or settings. Similarly, Waters, Lerman and Hovanetz (2009) pointed out that the problematic behaviour during transition time may be maintained by avoidance of non-preferred activities, demanding of access to preferred activities, or escape from transition. In their study, they describe a typical situation of non-cooperative behaviour from the side of a child with autism, portraying two typical attributes that often accompany this difficult period of time: *aggression* (hitting, kicking, biting, scratching the therapist who was supporting the transition) and *disruption* (throwing objects, pushing furniture over, hitting objects and falling onto the floor in tantrum). Even when certain visual interventions were implemented by the therapists in order to help decrease problematic behaviour, high levels of it still persisted (Waters et al., 2009).

The exact reasons why children with autism may resist transitions, either routine or unplanned changes in routines, are unclear (Sterling-Turner & Jordan, 2007). However, Byron-Cohen (2008) pointed out that routines and order may be the source of enjoyment in a life of a child with autism as they represent a certain way to cope with everyday life. Routines often serve an important function – they introduce order, structure and predictability and help to manage anxiety. Therefore, it can be very distressing once a routine is disrupted. The predictability hypothesis, most often attributed to Flannery and Horner (1994), suggested that individuals with autism have a greater need for predictability in their environments than individuals not diagnosed with autism. The lack of awareness, coupled with the characteristic restrictive patterns of behaviours, interests, and activities associated with autism, may serve to evoke problem behaviours when children with autism are presented with disruptions to ongoing activities. Sterling-Turner and Jordan (2007) suggested that although the predictability hypothesis may be a viable explanation for transition difficulties, it does not fully explain why some individuals with autism have problems with consistent, routine transitions.

Unfortunately, the research examples on transition time from pre-school settings to primary school are scarce, therefore it is difficult to suggest whether these transition period would be more stressful for a child with autism and his/her family than any other transition period in his/her life. However, there are numerous research examples of the implementation of the early intervention

programs that may play an important role in facilitating the child's difficulties associated with the change in routines and therefore easing the family stress during this challenging period of time.

#### *4.5 Understanding transitions*

I have already spoken about Bronfenbrenner's (1979; 1994) ecological development model and I find it helpful particularly in understanding the meaning of transition in a life of a child with autism and his/her family. Namely, family members play the most important role in a life of a child with autism (Werner, 2005) and the relationships within the family represent a *microsystem*. According to Bronfenbrenner (1994), it is within the immediate environment of the microsystem that proximal processes operate to produce and sustain development. In the context of this research, the microsystem is central, with the connections and relationships within it and the possible influences considered. The ABA intervention therapist thus would be a part of mesosystem, a certain bridging link between the child's home or early childhood settings environment and the totally new world (which is also a part of the mesosystem), primary school. Bronfenbrenner (1994) stated that mesosystem comprises the linkages and processes taking place between two or more settings containing the developing person (in this study – the child). Despite the ABA therapist may sometimes even become a part of a home environment, I still consider this person being a part of a mesosystem, for their role is to connect a child with autism to the wider world and to prepare him/her for a step into a larger and more complex environment (the primary school).

Taking into account the earlier discussion in this chapter about parents of children with autism and their sometimes uneasy relationships with their siblings, I would suggest that the microsystem of these children can be quite vulnerable. Therefore, the influences that the relationships within the microsystem might have on these families can sometimes put extra strain on them, especially if during transition time some of them need to cope with several things at once: preparing a child with autism for school, make sure other children in a family are not lacking of parental attention and choose a suitable intervention to help with their child's transition to school.

The school on its turn, as a new microsystem for the child, may sometimes put extra strain on parents of children with autism, depending on the experiences within the microsystem and the nature of the mesosystem links with home (and possibly ECE services, too). While the transition to school, as discussed earlier, might be stressful to any child, a child with autism may need more support than their typically developing peers (Rous, Teeters Meyers & Buras Striklin, 2007). In particular, the New Zealand Curriculum (Ministry of Education, 2007) suggests that the transition to school may be considered supported if it fosters a child's relationships with the teachers and other children, affirms their identity and builds on learning experiences that a child brings with them. For a family of a child with autism, the transition time can be a totally different experience and more support is needed for the children to make a successful step into the new environment. One of the important points for discussion here is the level of inclusiveness of the educational settings, both early childhood and primary.

Jones et al. (2008) defined inclusion as the process of identifying, understanding and breaking down barriers to participation and belonging, the therefore going beyond education to cover the total experience of a child or young person on the autism spectrum and his/her family. Guldberg (2010) suggested that the inclusion should happen in an environment where staff are willing and able to be flexible in terms of how the curriculum is delivered and to adapt the routines and physical environment within which the child is being educated. Interestingly, Rietveld (2005), in regards to inclusive classrooms in New Zealand context pointed out the lack of professional support and infrastructure needed to implement inclusive education for children with special needs. In her later study, Rietveld (2010) identified the mismatch between what children experienced and what teachers thought children had experienced. In particular, teachers' uncritical claims of inclusion seemed to be based just on children's presence rather than the quality of their participation. The nature of educational environment thus needs to be viewed as an important part of transition to school, with inclusive approach being one of the key success points in this process.

An inclusive environment would not be possible to create without many parties involved. According to Newsome (2000), social work professionals and teaching assistants have much to offer parents and children coping with autism given their

traditional focus on assisting individuals and families. The British study of Symes and Humphrey (2011) looked at the role of teacher's assistants in creating the inclusive environment for children with developmental disabilities. The authors called for more training for teaching assistants supporting pupils with special needs in the mainstream and emphasised the lack of specialised training in some cases led to the teaching assistants not being used to their full potential, thus creating a barrier to the inclusive atmosphere in the classroom. Interestingly, Preece and Jordan (2009) who interviewed 14 pupils with autism aged 7 to 18 years in regards to their daily experiences particularly with social workers found that most of the children reported that their activities during the day were solitary and none of them really understood the role of social worker. Transition to school and settling in a new (preferably inclusive) environment thus should be viewed from different angles as a multi-faced process that involves many parties to make this process successful.

To facilitate their child's transition to school, some families choose the ABA intervention as a linkage between the microsystem worlds, with the hope that this will eventually provide their child with the necessary social and academic skills needed for the transition to school.

In Chapter 3, I have already identified the gaps in literature on the ABA intervention and its role in transition to school time. Unfortunately, to date, there appears to be no New Zealand research exploring the nature of transitions of children with autism to school and the meaning of this period of time to their families. Peters (2010) emphasised that the limited picture for New Zealand children with special educational needs was provided in research. I can only add that while collecting materials for this literature review, I could not allocate a single study conducted in New Zealand that would look into transition time of a child with autism and the interventions helping (or not) them and their families to cope with the change. In this study, my intention was not only to fill this unexpected gap but also try and understand whether the ABA intervention might be considered one of the factors helping bridge a child with autism with the wider world and therefore help his/her microsystem to function harmonically as a whole during this uneasy period of time. The wellbeing of a family is central to this research and I hope it will make it more transparent to other families wanting to

find out what to potentially expect from the transition to school and whether the ABA intervention plays a crucial role in this process.

#### *4.6 Summary of the chapter*

In this chapter, I have depicted the transition to school process and possible difficulties it might entail for children with autism and their families. In Chapter 5, I will describe the research methodology that I used to investigate the role the ABA intervention might be playing in transition to school time.

## CHAPTER 5.

### RESEARCH DESIGN AND METHODOLOGY

#### *5.1 Introduction*

In this chapter, I will be giving an outline of the methodology for this study, the research methods, and issues pertaining to ethics, and consider how the quality of this research has been maintained. To understand what type of methodology used for this research, it is important to consider the views on the types of research more broadly, as well as to provide some justification for the selection of a particular paradigm, framework for this study, as well as the research methods that I used for this the research.

To answer my research question, I chose to work within the interpretivist paradigm and I used online surveys and semi-structured interviews as a data collecting method. In this chapter, I will justify my choice, as well as I will conclude it with the discussion on validity of research, ethical concerns for this study and a summary of research process.

#### *5.2 Research paradigms*

According to Mertens (2005, p.7), “a paradigm is a way of looking at the world” within which are inherent philosophical assumptions that guide and direct thinking and action, and therefore approaches in research. Three main directions would help to define a paradigm: the ontological question asks about the nature of reality; the epistemology question asks about the nature of knowledge; and the methodological question asks about the process and procedures used for obtaining knowledge (Mertens, 2005; Schnellker, 2006).

The two paradigms which are most frequently referred to in educational literature are positivist paradigm and interpretivist paradigm. Those who research from positivist perspective believe that the social world can be studied in the same way as the physical world, and that research methods used for the physical world can be utilised as effectively in the social sciences (Mertens, 2005). Positivist assumptions suggest that social reality is external to individuals and that human

beings are a product of their environment, conditioned by external circumstances (Cohen, Manion & Morrison, 2007). The nature of knowledge is accepted as being objective and real. According to Robinson and Lai (2006), the work of researcher here is to uncover new facts and add them to the existing body of knowledge. The researcher and the researched are independent and are not thought to influence each other. Mertens (2005) states that the methodology used by positivists is mainly quantitative, although sometimes qualitative methods can also be used. The result of a positivist study is usually either confirmation or rejection of an existing hypothesis (Cohen, Manion & Morrison, 2007). Positivist research is normally written in a detached style of a scientific method, often using the passive voice.

Different to positivist paradigm, researchers working in the interpretivist paradigm (the one that interests me most) believe that the social world is a complex world of human intentions and that knowledge is socially constructed by those who are active within the research process. It appears that the epistemology within interpretivism is that knowledge is personal, subjective and unique (Mertens, 2005). People are deliberate in their actions, and make meanings in and through the activities (Cohen et al., 2007). The word of the researchers is to determine relationships and explanations from the data collected (Johnson & Onwuegbuzie, 2004).

According to Mertens (2005), researchers aim to understand this complex world from the point of view of those who live in it. It seems that the researcher's goal here is to understand the multiple social constructions of meaning and knowledge. Cohen et al. (2007) emphasise that the researcher will be involved with their participants in an interactive process. He/she will also recognise that own beliefs and values will be evident in their study. In order to answer my research question, I find working within the interpretivist paradigm to be the most suitable as I seek to understand people's views and opinions regarding a particular experience in their life.

The methodology used in interpretivist research is predominantly qualitative. In this research, I have interacted with the research participants through the online surveys and the interviewing process (described later in this chapter) and I have

analysed the data received using thematic analysis that incorporated some narratives in order to make participants' voices heard throughout the study. According to Johnson and Onwuegbuzie (2004), interpretivist research is generally written in a relatively informal, narrative style providing a rich, detailed description often given from the first-person perspective. This is what I intend to do in this study.

### *5.3 Approaches to research*

Mertens (2005) and Cohen et al. (2007) described three main approaches to research as quantitative, qualitative, and mixed methods. While quantitative research uses deductive logic which often involves the researcher proving or disproving the idea that supports a certain hypothesis, qualitative research is different (Cohen et al., 2007). It uses inductive logic whereby the key idea or theory arises out of the data. Lindlof and Taylor (2002) argued that fundamentally, qualitative researchers seek to preserve and analyse the situated form, content, and experience of social action, rather than subject it to mathematical or other formal transformations. Unlike naturalistic inquiry, qualitative research is not always carried out in the habitat of cultural members.

Bryman (2010) noted that because qualitative research typically entails the intensive study of a small group, or of individuals sharing certain characteristics (that is, focusing on depth, rather than the breadth preoccupation one might find in quantitative research), qualitative findings tend to be oriented to the contextual uniqueness and significance of the aspect of the social world being studied. Qualitative researchers are encouraged to produce what Bryman (2010) named *thick description* – that is, rich accounts of the details of a culture. This thick description provides others with what they refer to as a database for making judgements about the possible transferability of findings to other milieux.

While there has been much debate around quantitative and qualitative research approaches, Cohen et al. (2007) suggested these approaches are not as separate as they first appear. The authors point out that many educational research projects nowadays draw on both approaches to answer different questions within the

research topic. It is apparent that whichever approach a researcher selects, it is crucial that this choice is made early in the research so that a clear planning framework is used to allow the researcher to have an understanding of the intent of their research.

#### *5.4 Methodology: surveys and semi-structured interviews*

In this research, I have used the email surveys and semi-structured interviews as a method of data collection. I will give some details on strengths and weaknesses of the selected methods and justify my choice for this study.

##### *Surveys*

According to Inoue (2003), surveys can be an efficient way to collect data from large numbers of people at a relatively low cost. Fink (1995, cited in Inoue, 2003, p.3) defined surveys as “a system for collecting information to describe, compare or explain knowledge, attitudes and behaviour”. It is often that the terms “survey” and “questionnaire” can be interchanged.

According to Cohen, et al. (2007), surveys generate numerical data which can be manipulated statistically, and they also often collect descriptive information that can undergo more complex relational analysis. Financial limitations, time-frame and , central to all, research questions are to determine the type of survey used. Mertens (2005) pointed out the survey methods as following: mail, telephone, interview, or Internet use and states that survey types include simple descriptive, cross-sectional and longitudinal approaches.

I used email surveys in this research as I found them to be the most convenient and fast method of initial data collection for this particular study. Prior to sending out the questionnaires to the research participants, the informed consent that was incorporated into the Research Introduction Letter (Appendix A) was gained from all of participants. Mertens (2005) noted that research questions about people’s knowledge, attitude, behaviours or level of satisfaction are commonly addressed through surveys. By using this method, a researcher can also question about how often something occurs, or how widespread an identified view is held. I sought to understand how a particular experience in family’s life (using the ABA

intervention) has or has not affected the levels of stress during their child's transition to school. As my study was seeking some of these kinds of details, I felt that email surveys would be the most suitable method to start with in data collection.

Bryman (2010) emphasised the importance of creating the right questions while doing a questionnaire research design. It is important to develop the questions for the questionnaire from the research question itself and therefore to make sure that all of the questions are related to it. From various literature sources, I understood that there are two main question types: closed and open formats. While designing the survey questions (see Appendix B), I have mostly used the open-ended type as I hoped the answers would produce a more descriptive and unexpected picture compared to if I used the closed questions. The open-ended questions also allow for a richer discussion and create an atmosphere of unexpectedness for the researcher (Cohen et al., 2007).

From Bryman (2010) I have found out that that surveys typically rely on large scale data, e.g. from questionnaires, test scores, attendance rates and similar, all of which enable comparisons to be made over time and between groups. Although in this research I was not looking at large groups of participants, I was confident that email surveys would give me an opportunity to find similarities and contrasts amongst participants' views.

### *Strengths and weaknesses of the surveys*

#### *Strengths*

Tolich and Davidson (2011) pointed out that email surveys seem to offer a useful compromise between the speed of interviewer-administered questionnaires and the complexity possible in self-completed questionnaires. They argue that email surveys offer several additional benefits in comparison with interviewer-administered questionnaires, including lower costs, faster turnaround, higher response levels, lower respondent error and flexibility in question structure. Kervin et al. (2006) and Robinson and Lai (2006) added that the greatest strength of surveys is that data can be collected from a large number of respondents and this can often be achieved at a relatively low cost and in a short period of time.

Robinson and Lai (2006) also emphasised that survey data is often representative of a larger group, is context-free and is generalisable to the population it represents. As the questions are asked in the same way to all respondents the data generated is standardised and readily collated and counted. Cohen, et al. (2007) noted that a particular advantage of Internet-based questionnaires appears to be low-cost, easy to distribute (using e-mail) and the opportunity for researchers to reach difficult populations keeping anonymity.

As one more important advantage of email surveys, I found the possibility for the participants to complete the questionnaires at a suitably convenient time. Nine out of 10 surveys were emailed to the participants after the Information Letter that contained the informed consent was received back by post. The consent forms were signed and the email addresses were provided by the participants in order to complete the surveys (see Appendix B for survey questions). All nine surveys returned to me approximately in 30 days period.

### *Weaknesses*

According to Glover and Bush (2005), if the survey is too long, it can affect the number of people willing to undertake it and therefore reduce the response rate. Participants will simply become bored and uninterested.

According to Kervin et al. (2006), surveys rely on individual's self-report and therefore the validity of the information gained is reliant on the respondent answering truthfully. They also point out that a researcher would have to be aware that respondents tend to over report good behaviours and under report bad behaviours.

In regards with the possible weakness of surveys, Cohen et al. (2007) add that a major difficulty in using surveys as a method may be securing a sufficiently high response rate to give credibility and reliability to the data. The level of response can compromise the reliability of the data very considerably as there can be a significant difference between the intended and the achieved sample. To achieve maximum possible response, the authors suggest pre-notifying the potential participants, arranging follow-ups and polite reminders, ensuring survey questions are easy to read and understand, making surveys look unlike junk mail and

considering the optimal length of the questionnaires themselves. Due to the cost of the ABA intervention in New Zealand and as a result, not many families being able to afford this service, the low number of participants was anticipated. The level of response however turned out to be high: nine out of ten initially contacted families agreed to take part in the research and eventually completed and returned their surveys via email.

### *Semi-structured interviews*

Interviews, according to Cohen et al. (2007) enable participants – be they interviewers or interviewees – to discuss their interpretations of the world in which they live, and to express how they regard situations from their own point of view. Seidman (1998) defines interviewing as a mode of inquiry aimed at understanding an experience and the meaning that persons make of that experience. Cohen et al. (2007) noted that “...the interview is not simply concerned with collecting data about life: it is part of life itself, its human embeddedness is inescapable”. (p.349). Similarly, Holstein and Gubrium (2003) suggested that interviews are more than just a data-gathering technique, they are rather a social encounter where knowledge is constructed. Rubin and Rubin (2003, p.4) added that in qualitative interviewing, “you can understand experiences in which you did not participate”. According to Connelly and Clandinin (1990) informal interviews are a way of collecting narrative data where both parties have a voice. I felt that following up online surveys with interviews would be very beneficial for this research as it would give both the researcher and participants an opportunity for a live, face-to-face open talk. A conversational manner during the interview, in my view, was important in order to create a nice, relaxed atmosphere that allowed for free expression of participants’ thoughts. Mutch (2005) pointed out it is advisable to conduct an interview in an environment that is quiet, comfortable and free from interruptions. Therefore during this research process, I ensured the participants were given the opportunity to choose where they would like the interview to take place.

In a situation where I have selected to conduct semi-structured interviews, while planning the questions, it is important to make sure the clarity and precision of each question is maintained, as well as no assumptions are made in the questions

and there are no hypothetical or speculative directions in the interview (Bryman, 2010; Cohen et al, 2007). The open-ended questions that are most likely used in semi-structured interviews, according to Cohen et al. (2007) have a number of advantages. In particular, they are flexible and allow the interviewer to probe so they may go into more depth if they choose to, or to clear up any misunderstandings. This type of questions also enables the interviewers to test the limits of the respondents' knowledge and encourage the cooperation. Tolich and Davidson (2011) added that they also help establish rapport and allow the interviewers to make a truer assessment of what the respondent really believes. I have designed the interview questions (see Appendix C) in a way that they give a participant room to think and allow for a discussion. I found that interview that uses open-ended questions provided a rich foundation for later analysis and interpretation, as well as it enabled the participants to build up a clear picture of their experiences in context.

When face-to-face interviews are not possible, according to Lichman (2012), a benefit of Skype interviewing, as opposed to telephone interviews, has to do with getting a sense of the other, even if that other is a long distance apart. This can assist the participant to trust the interviewer and, hopefully, share their private and social worlds. Booth (2008) added that Skype is a tool easily accessible and free for download, which is easy to use and which provides its users with a range of communication options for research – as such, Skype offers researchers the opportunity to conduct inexpensive, synchronous online interviews. Skype interview is also easy to re-schedule or, in case it is interrupted due to any reasons, it is easy for the participant to give a video call back later on a day. As one of the advantages, Booth (2008) pointed out Skype's geographical flexibility and its easiness of audio-recording.

## *Strengths and weaknesses of the interviews*

### *Strengths of interviews*

Semi-structured interviews allow for a flexible, conversational manner that on its turn can produce more in-depth discussion and enrich the data. It is a flexible tool for data collection that allows for spontaneity and at the same time is guided by the questions prepared by the interviewer in advance (Bryman, 2010). Desimone and LeFloch (2004) pointed out that the interviews allow participants to “think aloud” or talk through their thoughts processes as they answer questions. Connelly and Clandinin (1990) added that informal interviews are a way of collecting narrative data where both parties have a voice. To portray the advantages of Skype interviewing, Booth (2008) in the first place points out Skype’s geographical flexibility. It allows for a quality interview to be conducted at any convenient time and place and its easiness of audio-recording is also seen as an advantage. In a situation where I am unable to be physically present at the interview, I used Skype as the most convenient tool to talk to a participant.

### *Weaknesses of interviews*

Cohen et al. (2007) pointed out that the researcher using interviews has to be aware that they are expensive in time, they are open to interviewer bias and may in some situations be convenient to respondents. At all times, a researcher must remember that an interview is not an ordinary everyday conversation and to bear in mind that it the researcher’s perception of the research question should not be influencing the flow and outcome of a semi-structured interview (Bryman, 2010; Cohen et al., 2007). During the interviews, I noticed that several times the direction of our conversation seemed to be changing due to some details participants were discussing that did not quite relate to my research question (and hence the interview questions). I ensured I did my best to gently bring the participants back to the topic and re-direct our conversation so it became relevant to my study.

In regards with weaknesses of Skype interviewing, Booth (2008) cautioned a researcher that there may be lags in the conversation, which can break the flow of an interview and the technology itself can fail, resulting in disconnection

problems or even loss of data. I would also add that Skype does not quite provide the real human contact, which is so important when a relaxed, conversational manner is targeted.

### *5.5 Recruitment of participants*

As Bell and Cowie (1999) found when the research purpose has been clearly outlined and the information is clear, people will be positive about participating. For the purpose of recruitment of the research participants, I introduced myself to the organisations providing ABA services around New Zealand (further referred to as Organisation A and Organisation B) first by phone and then I sent them my introduction letter and the approved ethics form via email. In my introduction letter to these organisations (Appendix A), I asked them to forward the information sheet and the informed consent to those families who had already used the ABA service during the transition period from early childhood education settings to primary school for their children. My contact details were included in it, therefore families who wanted to participate in the study, were able to contact me directly. Out of ten information letters sent, nine returned with the signed consent form. Potentially, there could have been more participants in this study, however most of them (7) were found via my own contacts and only a few (2) with help of external organisations. Frequent follow-up contacts via phone or email with them (the organisations) unfortunately, did not produce any difference in participants' numbers.

Where my professional contacts are used, I forwarded the introduction letter and the informed consent to the families prior to start of the research process. I made myself available to discuss any questions or issues with them before I began my study by providing my contact details in the introduction letter. To maximise the protection of participants' identity, I communicated to the participants that in case their names were needed during the research, pseudonyms would be used.

### *5.6 Informed consent*

I ensured participants were well informed and provided with detailed information in the information letter (Appendix A). This made them aware of the nature of their involvement and any possible implications of being involved in the study. It was important that participants were given all of the relevant information about the research process, were able to make informed decisions about their role and were under no pressure to participate (Cohen et al., 2007).

### *5.7 Research participants*

The study was conducted in two phases. In phase one, there were nine participants, who were from different parts of New Zealand, with Auckland being the predominant location. All the families had used the ABA service, and the average time of ABA intervention received by children-participants at the time of their transition to primary school was reported by the families as 10-15 hours per week. In all nine cases, transition to primary school was also accompanied by support specialists from Ministry of Education Early Intervention team. At the time of the interviews, eight children were already attending primary school and one remained in early childhood education settings.

Data were initially gathered through emailed questionnaires. Prior to emailing questionnaires, 10 information letters were distributed and nine returned with families' consent to participate in the study. Nine surveys were then emailed to the participants and all nine returned in a moths' time, which allows me to conclude with the 100% response rate for this small study. Out of nine participating families, four expressed their interest in taking part in an interview. In phase two of the study these four families were interviewed. Both parents took part in two cases and mothers only in two other interviews. No children were present at any of the interviews. These four families came from different location: two from Auckland, one from Wellington and one from Dunedin. Due to participants' location and for their own convenience, upon discussion, it was decided to hold two face-to-face interviews and two interviews via Skype as a mediator. All four interviews lasted for approximately 30 minutes and took place at a time convenient and most suitable to each participant In all four families

participating, children had already made their transition to primary school and their transition was accompanied by the ABA intervention of various intensity: in two families, children were receiving 15 hours per week and in two other families, 10-12 hours per week of the therapy. All four children are continuing with this intervention at present, however weekly hours vary depending on the family's financial situation.

A summary of questionnaires' findings (phase one) and an interview summary (phase two) was then written and the interview participants were invited to comment to ensure their comments had been accurately represented. For the reader's convenience, in the section on the interviews' findings, participants are referred to as Family A, B, C and D. Each of the families interviewed started using the ABA intervention during their children's transition time to school, with some variations: families A, B, and C were already familiar with the ABA service a while before the transition to primary school started, and family D started using the service only a month prior to their child going to the mainstream classroom.

#### *5.8 Reliability and validity of research*

There is much to be considered from the beginning of any research project to ensure quality is maintained including in particular the reliability, validity and credibility of the research. Although the term "reliability" is a concept used for testing or evaluating quantitative research, the idea is most often used in all kinds of research (Golafshani, 2003). While some researchers in the field of the reliability in qualitative studies argue that in case qualitative research is discussed within reliability as a criterion, the consequence is that the study is rather no good (Stenbacka, 2001), some like Patton (2002) pointed out that validity and reliability are two factors which any qualitative researcher should be concerned with while designing a study, analysing results and judging the quality of the study. He also notes that in qualitative study, the researcher should be involved and immersed into the research. Golafshani (2003) added that both qualitative and quantitative researchers need to test and demonstrate that their studies are credible. While the credibility in quantitative research depends on instrument construction, in qualitative research, the researcher is the instrument (Patton, 2002).

Validity, according to Joppe (2000) determined whether the research truly measures that which it was intended to measure, or how *truthful* the research results are. Although some qualitative researchers have argued that the term validity is not quite applicable to qualitative research, they at the same time have realised the need for some kind of qualifying check or measure for their research. As a result, many researchers have developed their own concepts of validity and have generated or adopted what they consider to be the most appropriate terms, such as quality, rigor, or trustworthiness (Golafshani, 2003; Lincoln, 1995). Denzin and Lincoln (1998) added that through the association of the mentioned terms the way to achieve validity and reliability of research gets affected from the qualitative researcher's perspectives which are to eliminate bias and increase the researcher's truthfulness of a proposition about some social phenomenon. In a situation where my own contacts were used in order to recruit participants for this study, I made sure that none of those contacts was used to put pressure on participants to answer certain questions of the surveys and interviews in a way that this could alter the course of the study. I made sure the neutrality was maintained all through the study to eliminate any potential influence from my side and therefore to make my research valid and credible to the maximum level.

The participants' voices are central to this research and the importance of keeping an accurate record of them was obvious from the early planning stage of research. To make this research trustworthy, I ensured that the data received was documented and safely stored. The questionnaires were filed, dated and kept on researcher's personal computer. The interviews data were filed in both voice and transcript manner and the transcripts were available to all participants after the voice files were decoded. Although the interviewed participants were then invited to comment on their data, none of them expressed their interest in doing so.

### *5.9 Ethical considerations*

According to Smith (2005,p. 98), "respect, like other social values, embraces quite complex social norms, behaviours and meanings... in any given social situation". Olsen (2003) stated that in the context of research, respect can be demonstrated to individuals and communities and includes confidentiality, security and the

protection of privacy, as well as showing consideration for the community's values and protecting them from harm.

Wilkinson (2001,p.13) found that “the key topic in ethics is how we should treat others” and states that in research, “benefits to some do not justify burdens on others”. (p.15) Therefore, even if the benefits of the research are obvious to the researcher, the probability of harm of any form should be considered before making the initial steps to research. I agree with Cavan's (1977, cited in Cohen, et al., 2007, p.51) assertion that “while truth is good, respect for human dignity is better”. Alderson and Morrow (2004, cited in Flewitt, 2005) pointed out that one purpose of ethical reflection is to balance the potential risks of research against the likely benefits.

When selecting surveys as a research method, I was mindful about the fact that the questionnaire would always be an intrusion into the life of the respondent, had it been in terms of time taken to complete the instrument, the level of threat or sensitivity of the questions, or the possible invasion of privacy (Cohen et al., 2007; Bryman, 2010). In all cases, the completion of the questionnaire was not to be forced upon the research participants and was subject to informed consent where the participants' rights to withdraw at any stage of study or not to complete particular items of the questionnaire and guarantees of confidentiality were clearly stated.

In regards with the ethical issues in interviewing, Cohen et al. (2007) noted that interviews do have an ethical dimension as “they concern interpersonal interaction and produce information about the human condition” (p.382). Patton (2002) added that interviews are interventions that affect people and a good interview lays open thoughts, feelings, knowledge, and experience, not only to the interviewer but also to the interviewee. Therefore, I took into account such important points as: the extent to which any potential benefits outweighed the potential harm done by the research; ways to maintain confidentiality or anonymity; in what way the research actually benefitted the participants; who had access to the data and how accessible the study's results would be to all of the participants.

To maintain quality and trustworthiness in the study I adhered to the ethical regulations and guidelines as set out in the Ethical Conduct in Human Research and Related Activities Regulations (University of Waikato, 2009). This document clearly sets out the ethical responsibilities of the researcher towards the participant. Ethical guidelines such as these are designed to help researchers understand the importance of ethics in research. The relevant approval from the Ethics committee of the University of Waikato was obtained before the actual research began. As mentioned earlier, all data collected were safely filed and stored on my personal computer. The data received from the interviews were stored in both voice and transcript version, with further sharing of data with the participants in case they wanted to make any amendments. None of them expressed any willingness to do so.

#### *5.10 Cultural considerations*

For a researcher to have an understanding of these and other key elements that relate to the notion of respect of both parties, they should be reflexive in their practice (Guillemin & Gillam, 2004). The reflexivity, according to authors, requires the researcher to be aware and sensitive to each participant's culture and values and how the researcher in their turn, will respond to these. In this study, there could be significant cultural issues arising that needed to be considered and fully understood to ensure there was a high level of respect maintained between participant and researcher. I made sure I took into account the families' possible sensitivities in relation to the field of research. Children with autism and their parents were central to it and it was important to not create any ethically inappropriate questions in surveys and interviews in order to not hurt participants' feelings. I tried to demonstrate maximum flexibility and worked in a way where people felt most comfortable working with me through respecting their possible differences. I made sure I was flexible to offer any opportunities to participate in the study depending on participants' culture and I communicated this to the families prior to start of the research.

### *5.11 Data analysis*

Kervin et al. (2006) pointed out that data analysis involves not simply describing the research findings but interpreting the data and searching it for meaning.

Before starting to analyse the survey data, I undertook a data reduction process. This process, according to Cohen, Manion and Morrison (2007), includes some form of coding, which may be by assigning to individual answers or sorting and categorising data and looking for categories and themes (Cohen et al., 2007). I decided to use the table (see Table 1) in order to divide the received data into themes and then analysed those. In Table 1, I also aimed to reflect the participants' voices by giving quotations from the questionnaires.

In regards with analysing the interview data, Bell (2005) pointed out that raw data taken from an interview needs to be recorded, analysed, categorized and interpreted before it means anything. I used digital during the interviews and I transferred the data onto a more reliable device (the Compact Disc) in order to not face possible data loss. In order to analyse data received from surveys and interviews, I used thematic analysis, which according to Braun and Clarke (2006), is a tool for identifying, analysing and reporting patterns (themes) within data. It minimally organises and describes data in details and tends to interpret various aspects of the research topic. I think it was beneficial to use thematic analysis in order to analyse my data as in my view, dividing findings into clear themes gave the analysis more structure and provided more clarity for a reader. It also allowed for a later discussion of individual themes that arose during the study. Unlike quantitative approach that pre-determines categories, the thematic analysis is a qualitative strategy that receives its categories from the data. While gathering data from semi-structured interviews, I worked within an interpretive paradigm in order to interpret the participants' experience with ABA intervention and its helpfulness (or not) in decreasing stress in their family during their child's transition period. In a qualitative research like this, I used inductive approach whereby I tried to generate theories and hypotheses from the data that emerge. Kervin et al. (2006) suggested that in order for researchers to become familiar with the data they have gathered, they should be reading it over and over again to give them an understanding of it as a whole. I ensured I fully followed this recommendation and I found it very valuable in the process of data analysis. For

this study, the participants were emailed a draft of interview transcripts and any comments and suggestions regarding using (or not) a particular part of the interview were welcomed to ensure the summary provided accurately reflected their answers. None of the four interviewed families expressed any need to do so.

#### *5.12 Presentation of results*

The findings from nine online surveys and four interviews in this study revealed what role the ABA intervention played during the transition time of a child with autism from early childhood education to primary settings to the nine participants. These findings may stimulate debate and discussion about whether ABA is actually the right choice during transition time as a facilitating strategy in order to reduce stress in a family. I ensured careful attention was paid to findings and that they were presented in a clear, reader-friendly, disciplined manner. Cohen et al. (2007) stated that it is important to be aware that the findings and new knowledge from this research will become public documents and subject to ongoing critical review by my peers. Hence, careful planning and safeguards were required to ensure these findings were protected from misuse and abuse at all times. As mentioned earlier, I have kept the data safely on my personal computer in filed form (for the questionnaire) and in both voice and text files for the interviews. The interview drafts were offered to the interview participants to first read and comment in regards to any amendments or unwanted parts to be taken out, however no comments from the participants followed. All nine participants were informed that on completion of this research, they will all be given access to it. It is anticipated that the hard copy will not be available to everyone (due to only three of them being made for this thesis), so I will ensure there is a suitable online access to this study.

#### *5.13 Summary of the chapter*

In this chapter, I have discussed and justified the methodology used for this study, the research methods, and issues pertaining to ethics, and considered how the quality of this research was maintained. I will be presenting the research findings in the following chapter.

## CHAPTER 6

### FINDINGS

#### *6.1 Introduction*

This study revealed interesting and at times unexpected findings about the opinions of parents of children with autism transitioning from early childhood settings to primary school and being involved with the ABA intervention during this period of time. To answer the research question (parental perceptions of the role that ABA intervention played in their children's transition to school time), data were gathered from nine questionnaires and follow-up discussion with four families who had expressed their interest in doing so. The experiences that the participants shared significantly enriched the data and provided a broader insight into the process of transition to school of a child with autism, the role of ABA in this process and the difficulties his/her families might be facing during this time.

In this chapter, I will present findings from both the questionnaires and the interviews. I will provide some narratives from parents in order to enrich the findings' story with the real voices of the participants. The data from questionnaires have been analysed and presented in summary form in section 6.2. These provide an overall insight into the experiences of the families. These are picked up on and explored further through the three key themes that emerged in the interview data. These findings are presented in the following sections: Good teamwork versus ABA; Language skills improvement as a stress-reducing factor; ABA component putting more stress on young siblings during transition time.

#### *6.2 Findings from data received from the questionnaires*

As noted in Chapter 5, nine questionnaires were completed and sent back via e-mail by participants from different New Zealand locations (Auckland - 6, Wellington - 1, Dunedin - 2). While general results are presented below, it is worth noting that some participants pointed out that accessibility of the ABA intervention, particularly in Wellington region, appeared to be difficult. The participants were predominantly from Auckland region where, according to their comments, the accessibility to ABA services does not appear to be problematic.

Table 1 below represents the summary of findings from the questionnaires. These have been organised into four main categories of “Findings”: general help with transition time and stress reduction; communication skills; understanding boundaries of acceptable behaviour; reducing sensitivity to specific noises. In the table, the “Details” column provides the detail stated for each theme that emerged, and some “Example quotations” provide participants’ opinions in relation to each finding.

**Table 1. Summary of findings from questionnaires**

<b>Finding</b>	<b>Details</b>	<b>Example quotations from research participants</b>
<b>General help with transition time and stress reduction</b>	Collaborative work of teachers, support workers and ABA specialists during transition viewed as a positive contributor to reducing levels of stress	<i>“Our son’s transition has been challenging at times but both pre-school and primary teachers, as well as support people and the therapist worked together to make the transition as easy as possible for him”</i> “It’s probably been an achievement of all people involved”.
	Challenging behaviour during transition time still remained while the therapist was not present and when there were other siblings in the family	<i>“The therapy was of a great help but lots of disruptive behaviour at home was still on when there was no therapist around”; “we had to get lots of help from our extended family just to cope with him”; “it’s been quite a challenge, especially with three children of different ages on board”; “we’ve also got two other children and our son’s time of changes has been quite harsh on them at times. At some stage they both stayed at grandparents”</i> . “We also have a small

		<i>baby and it's a bit hard to handle both of them when one starts screaming and unsettles the other one".</i>
	Positive reinforcement as a strategy is seen by some parents as affecting younger siblings and therefore adding more stress	<i>"Her little brother now wanted the same treats as his sister was getting from the therapist (lollies, praise, stickers, etc.) as that was described to us as positive reinforcers"</i>
<b>Communication skills</b>	Making simple requests	<i>"Our daughter's communication has improved, she is now able to verbally express her needs"" "he can now communicate simple requests on his own"</i>
	Notable progress in vocabulary	<i>"He has learned a lot of new words in a really short time"; "he has gained lots of language"; "her language has become more advanced, especially naming things around her"</i>
	Getting the message across to a child made easier	<i>"We now have the knowledge of how to get the message across to him in an effective manner"; "it is now easier to explain that hurting others is not such a good idea"</i>
	Getting into obsession with labelling everything around	<i>"Sometimes our daughter becomes obsessed with naming just about everything, her current goal is to learn more linking words in order to make proper sentences"</i>
	Language barrier between a therapist and a child whose native language is not English	<i>"... our son's first language is sometimes a barrier in understanding between him and the</i>

		<i>therapist</i>
<b>Understanding boundaries of acceptable behaviour</b>	A child is gradually gaining an understanding that there are consequences to negative behaviour; a “no” word is acquiring the meaning	<i>“Our son is now more aware of the boundaries, that there are consequences to his actions, he is better with other children than before”; “he is now accepting “No” instead of just screaming or throwing a tantrum”.</i>
<b>Reducing sensitivity to specific noises</b>	Improvement in acceptance of certain noises	<i>“Our son is now becoming more confident with things that used to freak him out: lawn mower’s noise, vacuuming, loud music at childcare centre etc”.</i>

As Table 1 shows, the predominant number of participants (8) viewed the transition time to school for their child as quite a challenging period of time, with most of them describing this experience as “*stressful*”, sometimes accompanied by the child’s “*tantrums*”, “*screaming*”, “*overall being unsettled*”. The nine participants made a decision to try the ABA intervention during transition to school for various reasons: “*we heard it might be good for school preparation*”; “*our friends advised it (ABA) is a really good thing to try to battle our son’s behaviour*”; “*we thought ABA might help him our son) settle in a new school*”.

The nine participants were unanimous in noting that having used the ABA intervention for a while they had eventually come to see the ABA intervention component as an “*additional*” one, rather than something that played a central role in transition to school process. Even though some families spent up to 18 hours per week with the ABA specialist working with their child, they still sought additional support from the wider family or the special needs support organisations, and found these components equally important aspects in the transition process. The participants noted that each of the 9 children needed the individual support during time they were transitioning to primary school. This meant that the families looked for external sources of support: “*our TA was with*

*him (our son) every day”; “we had to have grandparents over for as long as they could stay”; “the individual support person was just great, we wouldn’t have coped without her”.*

Despite the fact that ABA intervention was only seen as a component accompanying the transition time, 6 families saw a significant improvement in their child’s language acquisition and linked this achievement to the ABA intervention emphasising that the improved mean of communication with their child helped reduce some stressful moments during transition to school and most importantly, set up some behaviour boundaries at home.

Interestingly, not only the wider family (like grandparents) appeared to be involved into transition to school process. Other family members who seemed to be “silent participants” in the process, were also mentioned in the questionnaires. In particular, two families pointed out that the transition to primary school time for their older child turned out to be quite a stressful period of time for their younger siblings, especially when positive reinforcers (or rewards) were used at home as an effort to maintain the main principles of the therapy. The young children had their own perception of the rewards system and while the positive reinforcement might have been working for their older brother or sister, the young siblings felt the unfairness of the situation and started insisting on the same rewards to be given to them, too. As a result, it led to more stress for parents who now had to be trying to satisfy the additional demands from their younger children. The parents also noted that they felt there was an attention deprivation for the younger siblings because the main parental focus during transition to school was on the child with autism and this was also seen as an additional stress factor for both parents and younger children in the family.

One of the research questions was: What are the factors influencing parents’ choice of this particular intervention and those preventing them from choosing it? From the data received from the 9 questionnaires, it was obvious that all 9 families made a decision to start with the ABA intervention after receiving an advice from a family’s friend who had already tried this type of therapy with their child during transition to school time. Interestingly, none of the participants identified other factors which influenced their choice of this intervention. The

actual reading about the positive sides of the therapy appeared to come later than the decision to try the ABA service influenced by family friends.

Although the cost of the ABA intervention is not quite directly linked to this study's research question, this secondary theme is well worth mentioning as it is linked to the family's additional stress during their child's transition to school time and therefore is linked to the family's overall wellbeing. All families pointed out that the cost of the ABA therapy (which is currently not being funded or subsidised in New Zealand) was quite of a concern to them, with some families pointing out they could have chosen more ABA hours for their children but were unable to do so due to its high cost. As a result, these families experienced being exposed to extra levels of stress during transition to school time having to cope with both their child's challenging behaviour and the financial pressures.

### *6.3 Findings from the interviews*

The major findings from the interviews can be divided into *three themes*: the ABA intervention only represented a part of their child's transition to school process, with other support needed and used during this period of time; the ABA intervention was seen as a helpful aspect in supporting their child's language skills enhancement; in some families, the effects of the ABA component were perceived as a factor putting more stress on the younger siblings.

When characterising their child's transition process, all four families agreed they had faced difficulties of different levels during this period of time. As a background for exploring the parents' perceptions of role played by ABA, it is important to first depict what the actual transition time looked like to these families and what led families to select the ABA intervention for their children. These experiences are explored in the following section, followed by the findings for the three themes relating to parents' perceptions of the ABA intervention's role in this transition.

## *Experiencing difficulties with transition to school*

The transition to school seems to have been an uneasy time for all four participant families, as the following comments show.

**Family A:** *At times I thought we'd never be able to get through... We thought school visits are a good idea and our doctor also confirmed that, so minding (our son) has difficulties getting used to the new places, it was decided he'd start visiting his new class about 3-4 months before he was due to go to school. It ended up in a nightmare. He behaved like he absolutely hated the new place and to our disappointment, he also started to reject his childcare centre! We've been through a lot of tears, even fights at times...*

**Family B:** *He (our son) was real hard to manage, despite all the support we were getting back those days. If you ask me to give you a brief description of what that time felt like, I'd say not enough sleep, lots of tears and tantrums, sometimes not really understanding where night or day is..... All of it was enough to turn the whole process of going to school into a nightmare. Eventually things settled but thinking about the beginning of it all, don't ask me!*

**Family C:** *... it was quite a challenge, minding that straight after our first school visit, her (our daughter's) sleeping habits changed, me and my husband had to have some kind of a "night shift" each as sometimes all we could get is a couple of hours sleep. I'm not mentioning the whole day after that would have been ruined as she'd fall asleep in childcare and one of us would need to come and pick her up in a couple of hours after we'd dropped her off! We went through tantrums, total refusal to go and visit the new place...*

**Family D:** *It was quite hard, especially saying good-bye to the support person who used to work with him since he was 3, she just had to go because of bureaucracy I guess...When he (our son) got off to school the first few weeks were quite challenging I think. He's been very curious about the environment, spent a lot of time looking at the fish bowl and stuff like that. He spent a lot of time running and escaping.....He was definitely challenging for the school for the first few weeks. In a way it worked well eventually when he settled into a routine.*

### *Good team work versus just ABA*

All four families made their choice to try ABA intervention during the transition to school mainly for the reason of preparing their child for the school environment and as an extra professional support in order to reduce parental stress, to direct their child into learning social skills, to gain more verbal skills acquisition and to deal with specific individual problems (fear for noises, obsessive behaviours, other). Despite parents overall being pleased with the results of the therapy (especially the development of language skills which was also acknowledged earlier in this chapter), all of them admitted that the success of their child's transition and therefore family's stress reduction was not solely the achievement of the continuous ABA intervention. In different ways, parents pointed out that it was a collective effort that involved quite a few people around the child, rather than just the ABA therapist working with him/her during transition time. This finding is reflected in Table 1 and the interview data gave further insights. For example, for Family A, there were many people involved in this process including the Teacher Aide and the child's aunt. Such thing like housekeeping support is often not taken into account as a stress-contributing factor, however, according to Family A, the amount of housework that built up at the time when the child was transitioning to school made the situation significantly more difficult, with the mother trying to handle many things at once and the child needing the most of her attention at the same time. The support received from the mother's sister (with the house work) and the Teacher Aide was also highly valued by this family who claimed that the whole transition to school "*would not have been possible*" without support of these people.

***Family A:** ...thinking about what was that what helped us cope with our stress then... well, I think everyone who was involved did their share – the childcare teachers, the teacher aide, the ABA therapist, the family. The teacher aide was almost a part of our family and (our son) had developed a real bond with her, he wouldn't have coped without her. At some stage, my sister came over to help with some housework – you know, things just don't get done when you're constantly on your toes looking after an autistic child. And yes when those things build up, they simply add more stress! I'm really grateful to everyone who*

*was there to help then. The therapist did a brilliant job and (our son) was able to actually go to a mainstream school, I'm so proud of him now.*

For families B and C the children's grandparents were important, as were the teachers and support workers in ECE and the new school.

**Family B:** *We did have lots of support and I can say we're lucky compared to some other families I know. Both mine and my wife's parents were very supportive. Yes we did end up going for an ABA but this was mainly for giving (our son) some academic and social skills that he still lacks of. It's only 10 hours a week and the rest of the time you just need someone there, and that "someone" can't always be you! I have to say the teachers at our son's childcare were very patient and supportive, they've got a great team there! The ABA did its job as well and we also had a part-time support person for a few mornings a week. I'd say it all ended up in his (our son's) success in settling into his new school fast enough.... We're still with the ABA and special services support but if we look at things from parental stress point of view, I'd say good teamwork is the key!*

**Family C:** *If you ask me about stress and what's actually helped to take it away... well, for sure it was everyone's contribution! My husband's sleepless nights, my parents who were there to help when we almost gave up, the amazing support person that (our son) was lucky to have and the tireless work of the therapist. The thing is, nothing to say against the (ABA) service, that was of a great help to us but once the therapist is not there, you're basically left one-on-one with the same sort of problems and it's only with all that brilliant support of those who were around in hard times, we could manage. ... For instance, when we started her (our daughter) on ABA, she was still having those sleeping disorders and had it not been my parents arriving and being there all the time till she actually went off to school, I'm not really sure that only ABA or support services would have worked. We were just of the edge of being over-exhausted, we tried just about everything we could try .....and yes, tireless support of our family together with the (special) services eventually worked... Actually thinking about it now I'd probably say that my parents' support did the most back those days.*

Family D did not mention the involvement of wider family, but for them ABA was part of a team of professional support from teachers and teacher aide.

***Family D:** ... The teachers themselves worked very well and were actually very supportive. It kind of all worked out really well because when he actually left Montessori and went to primary school, the TA just travelled with him. .... the new school and school principal were quite supportive, we only decided to carry on with mainstream school because it had Montessori class in it..... The main thing is that the school is quite inclusive, they have other special needs children, and the rest of the children really interact with them and support them, so there's quite a strong cooperation around. We're very lucky with the supportive environment at this school! The school transitioning, mainly because he was moving from one familiar environment to another and was taking the support person with him, as well as ABA therapist and already knew some of the children, there was a continuity of learning and teaching styles. It was a lot less challenging than it could have been I think. It was hard but could have been a lot worse.*

#### *Language skills improvement seen as a stress-reducing factor*

Although, as noted above, the parents found the transition stressful, the four families interviewed confirmed that the ABA intervention did alleviate the experience. One way in which they felt the ABA made the experience less stressful than it might have been was through their child's language improvement (this finding also corresponds with the one from questionnaires, presented in Table 1). In particular, parents noted:

***Family A:** ... it was great to see progress in him (our son's) language in such a short period of time! ....he used to just be able to name a few things around but with the therapist working with him three days a week, he started naming things around him and was even able to make short meaningful sentences after a while.... it looked like a whole new world's opened to him.*

***Family B:** .. despite all the stress we've been through with this whole transition time, I have to say that on a positive*

*note, we've seen a lot of improvements in his (our son's) language.... we were now able to get a message across to him and I'd be sure he'll get it... in simple things like dressing up independently, washing hands, overall self care skills like those that we were never be able to ask him about if he didn't have a language... this achievement's made some stage of transition much easier.*

**Family C:** *... she (our daughter) was initially quite resistant to the whole idea of ABA.... however I think as soon as she was given some sort of a "key" (I mean language here) and as soon as she realised she could use that key to ask something, she started making a good progress... of course it was (and still is) all about asking us for something but we're happy with it.. she wasn't able to do it before...*

**Family D** *noted that when it came to language development, it was important to have a consistency in the therapy being delivered by the same trained person {this point will be discussed later in this chapter}. : ... he probably knew all these words around him but he didn't quite know in what manner to respond. So ABA therapist pushed him in the right direction... He made quite a progress then and we sort of lost quite a bit while looking for a trained person.... he's definitely understanding a lot more, he really benefits from ABA, he can request more. ....he's quite verbal when he's requesting stuff.*

#### *ABA component putting more stress on younger siblings during transition period*

In addition to the main research question this study was also interested in a sub-question: What overall impact does this type of intervention have on the family? The previous section has already drawn attention to the fact that other family members paid a key part in the process for some families. Parents talked about the children's grandparents and in one case an auntie being involved and offering support. For these adults the impact of the therapy and the transition phase was perhaps quite stressful, given that they had to ask for extra support from either teaching team or the wider family (things they did not have to do during less disruptive period of time). Within the immediate microsystem of the home there was a more direct impact of the ABA intervention on the younger siblings. Some families where younger children were present at a time of their other child with

autism transitioning to school noted that as soon as the ABA appeared in their child's life, together with obvious positive effects (like enhancement in communication skills, appearance of visible boundaries of acceptable behaviour stated earlier in the survey's findings), it also brought some stressful moments when younger siblings were around. In particular, the use of positive reinforcement led to increased demands from all children in a family when it came to rewards. Family A pointed out that while the positive reinforcement stayed positive in terms of what was meant to be a reinforcement for their child with autism, it seemed to have negatively impacted the whole family's routine and, the situation with the younger children in particular. They now constantly demanded a "treat" from parents after observing their older sibling receiving those as a reward.

*... we've got two other children and honestly, the whole thing with (our son) going to school turned out to be quite harsh on us.... As soon as we had the ABA on board, we also wanted to learn some of its major principles so we could also have some sort of continuity at home... We realised "praise" was something they call "reinforcement" and we tried to do simple things like sticker board, eating bribes (we both made sure a lolly or biscuit packs were never far away)..... at some stage, we had all three children constantly being there just waiting for a treat! It would have been real hard to explain it to the little ones what those lollies were for... we simply wanted to follow what we've been told.... later on, we just gave up this idea as it was just getting out of control and was adding up more stress on all of us.*

Another issue that arose for two families was the impact on the other children of the time and attention focussed on the child with autism. This left families feeling that the younger children were disadvantaged:

The deficit of attention factor for the younger children was viewed as quite a disturbing one by Family B. While the main focus was on their child with autism transitioning to school, they felt that their younger child lacked attention and an attempt to address this resulted in the parents hiring a babysitter to help satisfy the needs of the toddler.

**Family B** :.... there were a couple of moments though when we had to have extra help with the baby as he turned out to be the one missing out on our attention... at some point I just realised all my energy was directed on (our older son) and there was simply no space left for the baby. We ended up having a part-time caregiver while we were waiting for my parents to arrive. That short period of time I can say was quite stressful as it also put extra financial pressure of us – we now had to pay for a babysitter, and the most frustrating was that at that time I was at home trying to deal with my other child's tantrums! The idea with ABA was great but when the therapist was not around it was purely me and him (my son) and whether those new strategies worked or didn't work didn't matter at that moment, the only thing I could think of was how to calm him down!

**Family C**:... I guess (our younger child) has been through a lot with all this time of big changes in our daughter's life, it's not just about the ABA and our whole attention being focused on this new thing, it's about him missing out on parental attention, on simply not having mum and dad and having all that screaming around him instead...

#### *Financial aspect of ABA adding more stress to families*

All participants of the study noted that the cost of the ABA intervention was seen as significant stress factor that added on to general stress experienced by the families during transition time. Due to ABA intervention not being funded in New Zealand, all four families had to pay full fees for the therapy, which resulted in some families having to select less hours of intervention for their child simply because of the affordability question.

**Family A:** We've heard and read so many good things about ABA and to us there was no question whether to do it or not.... however had it not been the cost, we'd have probably decided to go for more hours....with three children in our family and just with all those extra expenses we had to have due to (our son) having autism, the ABA fees just added more pressure.... there's nothing wrong with the program itself, it's just that the state could be a bit more helpful to families like ours... as soon as (our son) started school we

*reduced the number of hours, we just had to minding one of our other kids was due to start at a childcare and we had to pay for that, too.*

Similarly, **Family B** noted:

*.... with the baby and having to pay for a babysitter as well, financially we were just cracking! We did manage to stay on 15 hour a week for him but we had to cut it down to 10 as soon as he went to school, minding we're now also paying for childcare for our other child.... we just don't want to stop him on the ABA as we see it really does work and it did make a lot of changes but we wish it was less expensive or at least partly subsidised.*

**Family C:** *...we appreciate the therapist's hard work and overall the program itself's been brilliant for (our daughter).... it's just that the cost was quite harsh on us, although we'd been well aware of it before we started the ABA – a friend who'd advised it to us told us we had to be ready for big expenses...*

**Family D:** *...All that bureaucratic funding just added on more stress, it doesn't really have anything to do with ABA or school, or people!... due to it, we had a delay in care...and that delay in care was quite stressful, we definitely need the teacher aide hours funded, having to fund that as well as ABA is just ridiculous!*

#### *Inconsistency of ABA services in Wellington region*

**Family D** emphasised the importance of the consistency of ABA service and it being delivered by the same trained person. They had experienced significant difficulties finding the “right” ABA specialist in the Wellington region and pointed out that the inconsistency and “gaps” in intervention entailed more stress during transition period and the start of primary school for their family. In particular, they shared:

*... when our son started school, the ABA therapist went there with him. She worked with him twice a week and stayed there for the first term and then other people in training worked with him, but they didn't work as well... eventually she left and Students – they just disappeared so the next few terms were quite hard. It is actually quite hard employing therapists! We also had to fund them to get the training! The lady who trains students comes from Auckland but we can employ the therapists here in Wellington, she just suggests what to do. So we got some students and we paid them to get that training done by this lady who flew down from Auckland. They ended up working with our son for the first 2-3 terms. It was not very good at all, obviously they lacked experience and they weren't as committed I guess, that was quite rough. When they train them, they only give them basic introduction skills of ABA, or do short courses..... It's probably enough to get you started but it's obviously not as good as an experienced therapist..... Eventually he (our son) went backwards during all these terms.*

#### *6.4 Summary of the chapter*

The main research question of this study was: What is the role of Applied Behaviour Analysis intervention for children with autism during the transition period when children are moving from early childhood education settings to primary school: parental perceptions? The study also set out to explore the factors influencing parents' choice of this particular intervention and those preventing them from choosing it? The impact of this type of intervention have on the family was also of interest.

After analysing the data from the interviews, I can conclude with the three key themes emerging regarding the role of Applied Behaviour Analysis during the children's transition to school: firstly the families saw smoother transitions and family's stress minimization as a collective effort rather than solely the achievement of the ABA intervention; ABA intervention was seen as a factor contributing to the reduction of stress in terms of supporting the child's language skills enhancement; the impact of the ABA intervention on other siblings in family was not always positive. The secondary findings revealed that the actual

cost of the therapy was perceived by the families as one of the stress factors; one family also shared that a significant stress was experienced by both parents due to inconsistency of ABA service in Wellington region. All families agreed the time their child was transitioning to school was quite a challenging period in their life.

These findings are discussed in the following chapter.

## CHAPTER 7

### DISCUSSION AND CONCLUDING COMMENTS

#### *7.1 Introduction*

In this study, I have made an attempt to find out what parents think about the role of ABA intervention during transition time to primary school for their children. From their opinions, I have also tried to see whether this type of intervention can be a positive factor that decreases the family's stress and makes the transition time easier for all family members.

In the course of this study, the following three major themes emerged. Firstly, *ABA intervention was not viewed as a single factor positively impacting the successful transition to school. Secondly, it was obvious that families see their child's language improvement with help of ABA as a positive aspect that helps bringing the stress levels down. The third theme revealed that in some families, the influence of the ABA intervention during transition time was not always positive towards the younger siblings.* I would identify the following findings as secondary ones: all participants pointed out that the cost of the ABA therapy in New Zealand puts a significant amount of stress on parents during transition; the access to qualified ABA specialists in the Wellington area appears to be difficult for some families and thus contributes to overall family stress while a child is making a transition to school.

The first theme, *ABA intervention not viewed as a single factor positively impacting the successful transition to school*, brings us to a discussion about the importance of factors other than just the ABA therapy accompanying the successful transition to school. From the findings of this study, it became apparent that the family support, the individual support person and the teaching team all play important role in the transition time, apart from ABA intervention. The second theme, *language skills enhancement with help of ABA therapy during transition time as a stress decreasing factor*, clearly emphasises the benefits of

the therapy in regards to the apparent improvement of language skills in children with autism and hence the opportunity for parents to use this newly acquired communication skill as a helpful tool in order to pass a message across to their child and sometimes set up the behavioural boundaries at home, especially during the challenging transition time. Within the theme, the following factors are discussed: transition time being a challenging period of time for the families with children with autism; children gaining verbal language in a short period of time after starting the ABA intervention. Finally, the third theme, *the influence of the ABA intervention during transition time was not always positive towards the younger siblings*, allows us to suggest that the younger siblings of children with autism might need to be taken into a careful consideration when parents are planning to start the ABA intervention in order to help with transition to school. Findings imply that for some families, the transition period turned out to be quite stressful for both parents and younger siblings due to both parents lacking time for other children while trying to concentrate on the promising intervention for their children with autism.

## *7.2 Discussion of key findings*

While the major findings are going to be discussed further, it is important to contextualise these by first considering some other important points that came up in the course of the study. All nine families who had participated in this study depicted their child's transition to school as a challenging period of time that brought stressful moments and a certain levels of disruption into a family's life and everyday routine. The picture drawn by the interviewed parents is consistent with research findings of the APA (2000) and Sterling-Turner and Jordan (2007) who pointed out that the transition phase for children with autism may represent greater difficulty than for the typically developing peers. The transition to school period is often portrayed as challenging, often accompanied by behavioural difficulties associated with changes in routines and tantrums to avoid changing activities or settings (Sterling-Turner & Jordan, 2007; Walters, Lerman & Hovanetz, 2009). Given the difficulties, the focus of this study was the parents' perceptions of the ABA intervention and its role in facilitating the transition to school time.

*1. Applied Behaviour Analysis was not viewed as a single factor contributing to stress reduction during transition time*

The findings of this study indicated that for these nine families the ABA intervention, although deliberately selected by them to prepare their child for the journey to school and to ease this step, was not viewed by parents as the only stress-decreasing factor. All nine families, and in particular those four who had taken part in the interviews, pointed out the obvious advantages of the ABA intervention and justified their choices by the trust in academic and social success of their children, at the same time, they noted that the successful transition would not have been possible without other helpers (apart from themselves as parents) involved into transition process building a strong team around the child. In many cases, family members such as the children's grandparents and in one case an auntie, played a vital role in providing support. This was consistent with Werner (2005) who found that families play the most important role in a life of a child with autism and their support during transition time is crucial. However, when considering claims like Werner's (2005), this study drew attention to the fact that the meaning of "family" can be understood in different ways: for some children, these are just parents who do not have any opportunity to ask for anyone else's help, and for others, this meaning is extended to the wider family where support is available and can be asked for.

It is clear from this study that for some families, transition to school would have been experienced as a lot more stressful without strong support from early childhood teachers, individual support people and the teaching team at primary school. Newsome (2000) emphasised the importance of social workers' and teacher's assistants' collaborative relationships with parents to define their transitional situations, address the stress they experience, and organise the support families need. In a situation where the wider family's support is not available to parents, the support from professional services is vital. To ensure that all possible support is provided to a child with autism, special training in the area of working with children with developmental disabilities is very important to receive by all parties involved in transition to school process. Symes and Humphrey (2011)

emphasised that to promote effective inclusion of pupils with autism in mainstream settings and to ensure a child and his/her family is provided with professional assistance, extra training is needed for educational workers. It is difficult to see from this study whether all teaching and support staff were trained in the field of autism, however some families' positive feedback uncovers the fact that all these staff played an important supportive role in facilitating transition to school.

In all nine families who participated in this study, children became (or were expecting to be) a part of a mainstream primary classroom environment. Although the focus of this study was on the experience of the ABA intervention, one family pointed out that the inclusive environment in both early childhood and primary settings played a facilitating role during their child's transition to school time, with teachers from both early childhood and primary settings using the inclusive approach and offering specific tactics and strategies to make the step into primary classroom easier. Jones et al. (2008) depicted inclusion as the process of identifying, understanding and breaking down barriers to participation and belonging, and therefore going beyond education to cover the total experience of a child or young person on the autism spectrum and his/her family. The inclusive approach thus can play a very important role in child's transition to school. According to one family-participant who experienced the benefits of the inclusive classroom for their child with autism, the transition to school was eased by their child being accepted like other peers by the classroom teacher and the school principal, irrespective of the autism condition.

While according to Peters (2001) researchers are looking for ways of facilitating the transition to school, inclusive approach could be one of the efficient steps to take towards smooth transition process. The inclusive environment, if being consistent thorough the early childhood and primary school settings, can create a certain predictable environment for a child with autism: if he/she was accepted as other peers in a childcare centre, with inclusive approach used, he/she can expect the same in primary school. This can be consistent with Flannery and Horner's (1994) predictability hypothesis that suggested that individuals with autism have a greater need for predictability in their environments that individuals not diagnosed with autism. The predictable environment also establishes some sort of routine for

a child with autism, which according to Byron-Cohen (2008) often serve an important function – it introduces order, structure and predictability and help to manage anxiety during transition to school time.

The nature of the environment thus forms a very important element of the transition to school of a child with autism. Feeling accepted and included into a mainstream educational environment is crucial to a child with autism and his/her family, it makes the child's microsystem more protected and the new step in life more predictable. The inclusive environment in both early childhood and the new school settings empowers the whole family and provides a solid foundation for the successful transition process. The transition to school for a child with autism therefore should be taken as a complex process that involves different parties (not necessarily the family) to make it successful.

Speaking about different parties involved into transition to school time, social support was seen by parents as a significant and very important stress reducing factor during transition time. While the results of Altieri and Von Kluge (2009) reported that particularly mothers of children with autism who received more social support experienced less somatic problems and depressive symptoms, it can be concluded from this study that both parents felt relieved when they received an adequate amount of social support. Support might have included care for other children in a family, help with domestic work, care for a child with autism when parents or therapist were unavailable. I have to note though that the meaning of social support in the context of this study can only be referred and limited to the wider family members, pre-school and primary teaching teams and support persons (not the social groups). This brings us back to an earlier point regarding Bronfenbrenner's (1994) ecological model, particularly the microsystems: children's home world, the early childhood world and the new school world. The complexity of the transition process for a child with autism revealed in the course of this study made me think of the actual vulnerability of the child's microsystem: once one of its components is affected (parents, relationships with peers or teachers in early childhood or school settings, relationships with other family members), a microsystem may become an uncomfortable and insecure place to be. Parents, educators and other family members need to make sure all parties involved into child's transition to school are harmonically working in order to

help the successful transition happen. The mesosystem that refers to the interrelations between the microsystems, is an important component that contributes to a smooth transition to school. In particular, the adequate communication between all parties involved into child's transition to school is crucial to make this process less stressful for a family. This study discussed the importance of improvement in communication skills of a child with autism, however apart from the connection that the child established with his/her family with help of ABA, that connection should also be extended across the whole mesosystem: from child to parent and other family members, from parent to Teacher Aide, therapist, early childhood teachers and primary school teachers. Once the communication links are established, working and everyone's voice in this chain is being heard and taken into account, transition to school may be considered from a different angle, less stressful, more consistent and even enjoyable process for the child and the family.

None of the parents who participated in this study mentioned the social support groups and organisations supporting families with children with autism. In their questionnaires, 8 out of 9 participants noted that their main source of finding out more about the ABA intervention was "a friend" or "a family we know", however in the course of the interviews with four of them, none of those families mentioned that they belonged to any social group or that help from other families played a stress-reducing role during their child's transition to school time. As mentioned earlier, the help from wider family was acknowledged, as well as support from teacher aides and individual support people, however other social connections and their role in facilitating the transition to school time were not identified. This leads to an implication that the future study is needed in order to identify whether social support groups can be effective in reducing stress, particularly during transition time from pre-school to primary school. Their availability and networks in New Zealand could also be an interesting area for future research.

Unfortunately, the literature examples of the role the ABA intervention might be playing during transition time to primary school of a child with autism are scarce and it is difficult to make any judgements in regards with what factors might be playing a crucial role in bringing the parental stress levels down. However, from

this study (which is limited to the perspectives of 9 participants), it can be seen that all participants considered each party involved into their child's transition and their level of collaboration equally important.

2. *Language skills enhancement with help of ABA therapy during transition time as a stress decreasing factor.*

As mentioned earlier, transition to school may sometimes be a challenging process for a typically developing child, and in case of a children with autism, it may represent a greater difficulty (Sterling-Turner & Jordan, 2007). In addition to difficulties in social relationships and communication, some individuals with autism may exhibit behavioural difficulties associated with changes in routines, including transition times (American Psychiatric Association, 2000).

All participants of this study noted that transition period from early childhood settings to primary school was challenging to different levels. For some, a child with autism's disruptive behaviour (such as frequent tantrums, screaming, kicking, and overall non-cooperative behaviour) was only present during transition time, for others it persisted all through the first terms at primary school, which made the parental stressful time significantly longer. According to Sterling-Turner and Jordan (2007), the exact reasons why children with autism may resist transitions, and exhibit non-cooperative behaviours are unclear.

Although the ABA intervention was selected by families for different causes, two main unifying reasons can be clearly seen: to prepare their child for school (both socially and academically) and to deal with challenging behaviour. All families reported that they had experienced a significant amount of stress during transition time, even when the ABA therapist already started working with their child. Finding the transition stressful is consistent with other studies. For example, Sivberg (2002) identified that families of children with autism rated their stress level higher than what Sivberg called "typical families". In addition, many of them describe maladaptive and adaptive behaviours of their child with autism as sources of stress (Hall & Graff, 2010).

Although stress was still persistent, all families reported that the ABA therapy helped them find a very important means of communication with their child –

verbal language, which in its turn, helped reduce some amount of parental stress. They noted that the fact that it was possible to not only have one-way communication but actually now see some response in their children, according to participants, made the transition time easier than it might otherwise have been. Given the often-cited finding that children with autism who speak by the time they are 5 or 6 years of age have the best outcome , (Diehl, 2003; Goldstein, 2002) parents and professionals are understandably concerned about interventions that emphasise language development during the preschool years. ABA therapy is one of such interventions and participants of this study have reported a significant progress in their children's language development. In some families, due to this newly acquired tool of communication, it was now possible to set up some boundaries of acceptable behaviour, which brought the parental stress levels down during transition time. Thus, we can probably consider the ABA therapy as an important aspect of transition, a certain technical tool providing some necessary communication skills needed to deal with challenging behaviour and overall contributing to the child's speech development. However, it is difficult to determine whether solely ABA intervention brings the parental stress levels down and is responsible for successful transition. Despite all families linking the ABA intervention to their child's rapid speech development, some part of this success may still be dependent on the active participation in communication of the child with other family members, teacher aides and the teaching teams at pre-school and primary school settings. The proportion of language acquired only from ABA intervention during transition time should rather be researched by health and psychology professionals. In the frame of this study, it can be concluded that the boost in child's language that the participants tended to link to the ABA intervention was credited by the participants as being responsible for taking away a significant amount of their parental stress during transition time.

3. *The influence of the ABA intervention during transition time was not always positive towards the younger siblings.*

Findings of this study revealed the increased amount of stress in some of the families who had younger children apart from a child with ASD. According to some participants, the increased stress levels appeared when the parental attention

was mainly focused on a child with autism, the brand new ABA intervention and overall on finding a solution to challenging behaviour. At the same time, younger siblings were put in circumstances where they had to try and adapt to the overwhelming atmosphere in the family and in case they could not (taking into account their age and stage of development), it simply produced more stress for parents who were now trying to handle more than one child with problematic behaviour.

In some families, parents attempted to implement the main principles of ABA intervention in home environment with *positive reinforcement* being the major component to maintain. While the reward system worked with the children with autism, it turned out to be confusing when the younger siblings were present. Parents shared that the rewards system, when implemented in presence of younger children, simply increased their other children's demands (in order to be fair, parents now had to share the rewards with the younger children, too), made home atmosphere quite challenging and thus caused more parental stress. Some families however pointed out that what was meant to be positive reinforcement and the way it should work in a home environment was not very well explained to them by the therapist, resulting in a confusing situation with the younger siblings. This brings us back to Bronfenbrenner's (1994) model and the mesosystem that refers to the communication between all parties involved. It can be seen from this study's results that the effectiveness of the communication, particularly between parents and the ABA therapist, is crucial to make the whole transition process easier for a family. The sibling factor also needs to be taken into account when such an important choice as the choice of the new intervention (in this case, ABA) is considered. The possible effects of its components on other family members should be discussed with the ABA therapist prior to start of the intervention and the appropriate levels of communication need to be maintained all through the transition process.

It was discussed in Chapter 4 that there are contrasting research findings in regards with siblings of children with autism, their adaptation to having a brother or sister with this condition and their role and place in the family. On the note of the possible impact of the ABA intervention on other family members, Schoen (2003) points out that the effects of certain sides of the therapy might highly

depend on the family variables. In my study, age of siblings seemed particularly important. Given the nature of the effects, it appeared that younger siblings were potentially more likely to experience the issues that were reported. The influence of children with ASD on their siblings is modified by several factors relating to the characteristics and dynamics of the individual family members and of the family as a whole, such as gender, age, birth order, family size, socioeconomic status, parental response to the child, temperament, and coping styles (Moyson & Roeyers, 2011). Due to the siblings relationships not really being the main focus of this study, it would be quite difficult to make any links to these criterions, however what it possible to conclude from this research is that the influence of the ABA intervention was definitely felt by the younger siblings in a family.

Kaminsky and Dewey (2002) emphasised that the stress experienced by parents of children with autism might also be related to socialization difficulties among the siblings. This association may be attributed to the relation between parent-child interaction and peer-related social competence, where stress may play a role either by impacting on parents' availability to model social rules and cues during interactions, affecting the child's knowledge of such social beads, or through negative emotions experienced during the interaction, that may affect vulnerability to emotional regulation difficulty, and then in turn, affect peer relationship (Pilowsky et al, 2004). While the mentioned studies were conducted with the older children, in this research, the issues all arose for we can only speak about the younger siblings of children with autism (namely, toddlers).

### *7.3 Other findings:*

#### *a. Cost as stress-contributing factor?*

All participants' selection of the ABA intervention was deliberate and each participant was pursuing their own target by choosing this intervention for their child. Some of them were discussed in this study, however the question and focus of this research revolves around parental stress and the role of the ABA intervention in bringing the stress levels down. As one of the secondary findings, I would like to point out the cost of therapy itself and the families struggling to cover the hours of the ABA intervention and thus experiencing certain financial

stress which on its turn, impacts the general stress during transition time and makes it more difficult for parents to cope with it. Like it was pointed out in the literature review, parents of children with autism may have an additional source of stress, what Meadan, Halle and Ebata (2010) call an economic burden of raising a child with autism. All nine participants of this study pointed out that even a small amount of ABA hours for their child turned out to be a larger amount of stress for parents because they had to find funds to not only cover basic needs of their child with autism but also plan extra expenses to cover the cost of the therapy.

Although the financial aspect is not the direct cause of therapy itself, it is still an important finding reported by each family-participant. The high cost of the therapy seems to be limiting the families in trying other interventions or increasing the ABA hours, it puts more financial strain on parents and therefore brings the stress levels up. At the same time, the choice of this intervention itself was described by the participants as the one with promising results in stress reduction during the transition to school time. Thus, what was employed by the families to bring the stress levels down, in some cases, increased their stress. As mentioned earlier, it is a fully private service and although prices vary across the country, they stay high enough for some families to consider less hours of ABA or seek less expensive or subsidised alternatives.

*b. Inconsistency of ABA service in Wellington area as a stress increasing factor*

In the course of this study, one family reported difficulty finding a qualified ABA specialist in the Wellington area. The search process fell on their child's settlement time at primary school and put a significant stress on both parents struggling to find one permanent ABA therapist to work with their child. The importance of consistent environment for a child with autism, their social deficits and need for routine (Schopler & Mesibov, 1986; Mental Health Foundation, 2002) and the disruptive behaviour associated with frequent changes (Wen-Shing & Men-Hwei, 2009) is reflected in previous chapters. Both parents pointed out that sometimes they were even offered students in-training which put the quality of the intervention under question. Symes and Humphrey (2011) emphasised that simply providing teacher aides for pupils with autism is not enough to ensure they are receiving the support they need in order to achieve their full potential.

Elkeseth (2009) emphasised that this type of intervention can be named as a well-

established method and that it only proves effective when treatment is carried out by *trained therapists*. The case of this family also proves that the absence of consistency, especially in the ABA intervention, may lead to more stressful and disruptive time for the whole family and may set the child back in his/her achievements until a permanent therapist is found.

#### *7.4 Discussion of findings within the Bronfenbrenner's ecological model*

This study indicated that in the context of transition to school, the situation for a family with a child with autism can be quite complex and represent a stressful phase not only for a child with autism, but for the whole family system. Although the findings have been presented and discussed separately, they are all interrelated parts of the picture.

This study represents the parents' perspectives in regards to the possible role the ABA intervention played in their children's transition to school time. However, to fully understand the impact of the therapy and the overall transition process, the different levels of the ecological model need to be considered. The individual and his/her characteristics are at the centre of Bronfenbrenner's (1994) model, and the child's microsystem was highly dependable on some of the autistic characteristics. The interaction of the child's characteristics with the environment was perceived by parents as a stress factor during this period of time.

In the light of Bronfenbrenner's (1994) ecological model, where the microsystem is the layer closest to the child and that contains not only his/her family but the structures this child has direct contact with (in the context of this study, the ABA therapist, school teachers, support people). The ABA intervention represented a certain facilitating link between the child and the step into the new (school) environment.

It is apparent from this study that the ABA intervention was viewed as a positive component that influenced the child with autism's personal characteristics through language development, which on its turn, appeared to have reduced the parental stress levels. However, this finding would need to be considered within the nature of the roles and relationships within the microsystem: language was not the only key strategy to facilitate the transition to school time. To make it successful, all

components of the microsystem and the mesosystem links had to be harmonically communicating and functioning, including the whole family, the external support systems and the availability and nature of the inclusion of the educational settings the child with autism was attending. It is worth noting that the importance of the functioning of the microsystem as a whole was affected by siblings in families of a child with autism. According to the earlier discussed findings, these relationships were not always easy and did have an impact on the functioning of the microsystem.

The external, exo- and macrosystem influences like the high cost of the therapy and its availability appeared to also have impacted on the nature of the transition to school time, contributing to overall stress levels experienced by the families. Thus, the role of the intervention to assist the transition to school for a child with autism and his/her family should be considered in the context of the child's microsystem but also take into account the nature of relationships between the other contextual layers. The success of the transition phase proved to be very dependable on the interactions between the layers and the nature of the relationships established between all parties involved.

#### *7.5 The effectiveness of the methodology used*

Working within an interpretive paradigm proved to be an effective approach for this study. All participants have experienced a significant amount of stress during their child's transition time to primary school and all shared their experiences and were involved in discussion regarding whether the ABA intervention proved to be a stress reducing factor during this time or not. The qualitative approach and the choice of online surveys and semi-structured interviews as a method allowed the participants to share examples from their lived experiences (Cohen et al., 2007). The semi-structured interviews have gathered interesting data and enabled me to gain a deeper understanding of the participants' experiences with the ABA intervention during their child's transition from early childhood to primary school settings. The open-ended questions of the semi-structured interviews designed to encourage the participants to fully engage in discussion (Desimone & LeFloch, 2004) and it also provided an opportunity for parents to construct meanings of their experiences during the interview. Interestingly however, it was noted that

some participants willingly shared some of their experiences in their online surveys but preferred not to discuss those during face-to-face interviews. This could probably lead to suggestion that to some parents, digital recording and presence of an interviewer represents a certain barrier and they prefer to share some of their experiences in writing.

### *7.6 Limitations of the study*

It was quite challenging to recruit the participants for this study. I tend to link this fact to the cost of the therapy and thus only limited number of families using it. In addition, some organisations that I initially contacted asking for possible support in recruiting participants, either did not come back to me at all or briefly answered during the follow-up call that there were no families interested to participate in this study. At the same time, all of the organisations contacted were specifically involved into supporting families with children with autism and bringing more information to those families was stated as one of their main mission. Having research link on their websites and presumably knowing the research on autism is particularly limited in New Zealand, has left me with the strange impression that they felt that this research was simply not needed. However, other factors may have been involved.

There are other limitations to this research that must be taken into consideration. This is a small study limited to only nine participants, with four of them having participated in one-on-one interviews. To gain a better insight into the research question, having a greater number of participants could have provided a wider focus and offered a greater range of data to draw from. In addition, the study has only considered the ABA intervention in the New Zealand context and the researcher had no intention to make any generalisations in this field of research beyond New Zealand context. For the purpose of this study, only the experiences of children aged 6-7 years and their families were considered. The data were gathered retrospectively and rely on how the parents recalled the experiences. A further consideration is that since the purpose of this study was not to assess the effects of therapy itself during transition time from pre-school to primary, the term *ABA intervention* was used by researcher for convenience; the researcher

fully understands that families may perceive this term differently and therefore leaves the quality components of the therapy to its providers.

The findings highlighted the importance of other factors during transition, especially the involvement of wider family members. This could have been explored further by creating more questions on the survey and during the interviews, which could probably have shed more light on the support systems available to parents and children during transition to school time.

As one of the difficulties of conducting this study, I saw a certain technology impact discussed above on the participants' willingness to speak. Namely, the presence of a digital recorder on the table in some cases appeared to affect the participants' willingness to share some more points with the researcher. I felt that families were more comfortable to openly speak once the recording device was out of sight. This makes me imply that the mobile phone with the recording function could perhaps have been a better choice to record the interviews than a digital recorder as it is a widely used device that most people are used to and may be more comfortable with.

## *7.7 Conclusion and recommendations*

### *Conclusion*

The research question for this study was: The role of Applied Behaviour Analysis intervention during the transition period for children with autism from early childhood education settings to primary school: parental perceptions. In addition, this research project aimed to seek answers to the following questions: What are the factors influencing parents' choice of this particular intervention and those preventing them from choosing it? What overall impact does this type of intervention have on the family?

- (i) The predominant number of participants admitted that ABA intervention played a beneficial role in their child's language improvement, what resulted in bringing the stress levels down during transition time from early childhood to primary settings.
- (ii) Some families admitted that the effects of ABA intervention were not always positive towards younger siblings in a family. The transition to

school time for their child with autism was seen by the majority of families as a challenging, disruptive period drawing a lot of attention to a new type of intervention (ABA) for a child with autism and therefore leaving less parental time and attention for the younger children in a family. Findings of this study suggest that in some families, it resulted in more stress experienced by parents during transition time and the settlement time in a primary school environment.

The study also indicated that the cost of the ABA intervention in New Zealand may sometimes become a significant stress factor as the choice of the length of therapy directly depends on the financial status of the family. Some families eventually had to reduce the number of hours of the intervention due to its high cost, which in its turn, prevented them from choosing full-time therapy and contributed to parental stress. Findings also revealed that the inclusive educational settings, both early childhood and primary school, can play an important role in facilitating transition to school of a child with autism and decrease levels of stress in his/her family. Finally, it appeared that the quality providers in Wellington region were difficult to access which led to a certain pressure and stress experienced by a child with autism and his parents during transition time to primary school.

### *Recommendations*

The following recommendations have been drawn from this study to inform families seeking to start ABA intervention for their child, early childhood teachers and other interested parties:

1. ABA intervention appears to be only a small part of transition process where a lot of other support for a child with autism might be needed. Wider family support is seen as vital during this period of time helpful in reducing parental stress. Future research might consider the ways in which ABA intervention fitted (or not) within other support systems or interventions used by parents during the transition to school time.

2. ABA intervention might be helpful in reducing the family stress levels during transition time from early childhood to primary school settings due to its effectiveness in child's language skills development and improvement. Language, in its turn, is viewed as a powerful tool of communication supporting transition time, as well as helping reduce challenging behaviour through negotiation.
3. While ABA intervention can be viewed by parents as beneficial for a child with autism, it should be seen as a time and attention consuming process that involves not only parents but younger siblings as well. The parental attention is crucial for all children in a family and before the choice of intervention is made, to prevent the family from increased stress levels, parents need to ensure adequate time and support will be available for each child. Siblings' relationships in a family with a child with autism receiving certain type of intervention is seen as an implication for future studies.
4. Findings also emphasised an important role the inclusive approach in the educational settings may play in the transition to school time. Although the question of inclusion is discussed in many studies, the question of inclusive environment particularly for children with autism during transition to school time should be an implication for future research in New Zealand. The Early Childhood and Primary teacher training and the extent to which the topic of children with intellectual disabilities and their inclusion into mainstream education system should be covered could also be an implication for future investigation.
5. Findings of this study suggested that the cost of the ABA intervention could be a significant stress increasing factor as there is no current subsidy/funding available to cover part of the costs of this therapy in New Zealand. It may sometimes prevent parents from selecting this particular type of intervention and make them search for other, less expensive or state-funded alternatives.

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## **Appendix A.**

### **The Introduction Letter and the Informed Consent**

#### **Copy of letter sent to all the participants**

Dear .....,

I am Galina Stebletsova and I am currently writing my Master's thesis at The University of Waikato.

The working title of my research project is "The role of Applied Behaviour Analysis intervention during the transition period for children with autism from early childhood education settings to primary school: parental perceptions". Through this study, I will be exploring the opinions of parents who have already used the ABA service in New Zealand for their child during such a potentially challenging time in their life as the transition from early childhood education settings to primary school. I am approaching you to ask whether you would be willing to share your opinion through completing an online survey questionnaire. Your participation in this research project may be very beneficial for those families who are considering the ABA intervention for their children. Reading about your family's experiences could influence their choice of intervention for their child during pre-school and early primary years.

In consultation with you, I may later ask if you would be interested in participating in a short follow-up interview. The interview will take place at a time and place most convenient for you, and there is an option of Skype interview in case this is more suitable. I anticipate that the interviews will take about 30 minutes. All participants' names will remain confidential and names of the families and the ABA providers being used will not be disclosed in any circumstances. Data will be treated confidentially and stored securely. You may withdraw from the study at any time and your data may be withdrawn up until you have approved your transcript.

Any reports of this research will use pseudonyms to help maintain confidentiality. An electronic copy of the thesis will become widely available, as the University of Waikato requires that a digital copy of Masters thesis is lodged permanently in the University's digital repository: Research Commons.

If you wish, I am happy to discuss the project with you further before you decide whether or not to take part.

I hope that you will be interested in participating in my research and I have attached a copy of the general research questions for your information. There is also a consent form accompanying this information sheet. If you have any questions, please contact me via contact details provided below. The stamped addressed envelopes will be posted together with this Information sheet and consent form. If you feel like you are willing to take part in this project, please complete the form below and send it back to me. Alternatively, in case it is more suitable, you may scan the form and email it back to me.

Please do not hesitate to contact me if you have any queries, concerns or would like more information, now or at any time during project.

Yours sincerely

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In addition, please feel free to contact my research supervisors:

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*Attachments: 1. Research questions*

*2. Informed Consent*

## **Research Questions and Consent Form**

### **Permission from families/whanau**

The project aims to address some of the current gaps in research in the field of Applied Behaviour Analysis and the role it plays in lives of families of children with Autism Spectrum Disorder. In my study, I am intending to search answers for the following questions:

- What are the factors influencing parents' choice of this particular intervention and those preventing them from choosing it?
- What overall impact does this type of intervention have on the family?

In order to explore these questions, data will be gathered in a range of ways, namely through online surveys and face-to face or Skype interviewing (depending on your location and personal preferences). You are free to choose which part you would like to participate in. Participation in the project is voluntary. If you choose to take part, your permission is needed before any data is collected.

The findings of this research project might become an important reading for other families considering entering the ABA program for their child during his/her transition time from early childhood education settings to primary school. They may also be of an interest to some families who are thinking of continuing with ABA in their child's primary years. It may also be a beneficial reading to the educational professionals working with autistic children in inclusive classrooms.

*Please return this form using the addressed envelope (enclosed) or return a scanned copy by email (please find my email address above)*

I am willing to take part in an online survey (please circle)      **YES**   **NO**

I am willing to take part in an interview (please circle)      **YES**   **NO**

If YES, I prefer a face-to-face interview/Skype interview (please circle the preferred type of interview)

**I have read and understood the information letter and have had my questions about this project answered. I agree to take part in this project and I consent to the publication of the information as described on the information sheet. I understand that my participation in this project is voluntary. I can withdraw from the study at any time and I understand that to do so, I do not have to give a reason. However, the information that had already been approved prior to this point would remain with the project.**

**Name:**

*If there are other members of your family/whanau who would like to be included in this project, please request additional consent forms.*

Contact

details:.....

Email:.....

Signature:.....

Date: .....

## **Appendix B. Survey questions.**

1. Has your child started primary school yet or is due to start soon? (variants of answer: already at primary/due to start soon)
2. How long have you been using the ABA intervention for?
3. Has the ABA service been delivered at home or at school? For how many hours per week?
4. Describe in brief, what is/has the transition period from early childhood education settings to primary school been like for your child and family?
5. How did you come to choose ABA intervention?
6. Has there been any other intervention accompanying the transition time?
7. How have you found your family's experience with the ABA program?
8. Has your experience with the ABA service overall helped you to reduce the level of stress in your family during transition time?
9. How has the ABA program supported your child's transition to primary school?
10. Are there any barriers in accessing the ABA services in your region? Please say which region of New Zealand you live in.
11. Would you be interested in a short follow-up interview at some point? (the interview will approximately take 30 min.) If yes, please say which way would be the most suitable for you – face-to-face/Skype?

## **Appendix C. Interview Questions**

1. Tell me some more about your child (his/her age; is he/she already at primary school; does he/she attend the mainstream early childhood education settings; is he/she having home pre-school education, etc.)
2. Who are the most important people in your child's life? Does he/she have siblings?
3. What is/was the transition time to primary school like for your family? Has it been a stressful experience?
4. How much support have you been getting all through this period of time? What kind of support (if any)?
5. How did you come to choose the ABA service?
6. Has the program been delivered at school or at home? If at home, have there been other family members present at a time the therapist was working with our child?
7. How did you find the whole experience with ABA intervention for your family? (if your child has siblings, has the intervention had any influence on them?) Has it made the transition easier?
8. Can you say that the program has helped in reducing parental stress? If yes, in what way? If no, why?
9. If your child is already in primary, are you going to go on with ABA – if no, why?
10. Would you recommend this intervention to other parents?

*Approximate time of the interview: 30 minutes.*