

2019

# The Experience of Parents of Children with Autism Participating in ABA Treatment

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# Walden University

College of Social and Behavioral Sciences

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Monica L. LaBrie

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2019

Abstract

The Experience of Parents of Children with Autism Participating in ABA Treatment

by

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MA, University of Houston Clear Lake, 2007

BA, University of Houston, 2003

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Educational Psychology

Walden University

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## Abstract

Having a child with autism results in a unique set of challenges for both parents and siblings. Applied behavior analysis (ABA) has significant empirical support demonstrating its effectiveness as a treatment for children with autism. However, effective behavioral interventions should also consider how the family is affected. The purpose of this phenomenological study was to explore the lived experiences of 8 parents of children with autism who have received ABA treatment and their perceptions of how the family system is impacted by ABA outcomes, specifically focusing on parental well-being and sibling relationship quality. A family systems theoretical framework and phenomenological research method were used. Data were analyzed using content analysis to find the common themes that emerged, which were: parents of children with autism face a high level of stress, but ABA treatment results in a decrease of some sources of stress. Having a child with autism produces strains in family relationships; however, ABA treatment outcomes can help with improved communication between spouses and interactions between siblings. Parents acknowledge challenges associated with ABA treatment but believe that the benefits are worth it. Insights gained from this study were meaningful and practical for professionals who provide ABA treatment to children with autism, as well as for parents of children with autism who may be interested in seeking ABA treatment. Positive social change resulted from the identification of perceived benefits of ABA treatment, such as reduced parental stress and improved relationships amongst all members of the family.

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## Dedication

I dedicate this study to all parents and siblings of children with autism.

## Acknowledgments

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## Chapter 1: Introduction to the Study

### **Introduction**

Autism spectrum disorder (commonly referred to as ASD or autism) is a neurological condition that affects how individuals perceive and interact with the world around them (Durand, 2014). The percentage of children with autism has increased greatly from 2002 to 2010, and one in 68 children has autism as of 2012 (Centers for Disease Control and Prevention [CDC], 2018). This surge in the number of children diagnosed with autism has resulted in an increase in research related to the disorder. Many studies have evaluated the key characteristics of autism and/or how symptoms impact relationships and interactions with others.

Given the broad spectrum of symptoms and characteristics associated with a diagnosis of autism, caring for a child with an ASD presents a unique set of challenges for parents and siblings. Parents of children with autism often face higher levels of stress and have difficulty finding support and acceptance from others (Altiere & Von Kluge, 2009; Kakkar & Srivastava, 2017; Ludlow et al., 2011). Siblings of children with autism also face challenges that can result in negative feelings and feelings of sibling rivalry toward their disabled sibling (Kakkar & Srivastava, 2017; Ward, Tanner, Mandelco, Dyches, & Freeborn, 2016; Williams et al., 2010). As such, relationship quality amongst children with autism and their siblings is also impacted by this diagnosis (Cebula, 2012; Dillenburger et al., 2010; Tomeny, Ellis, Rankin, & Barry, 2017).

In addition to studies exploring the characteristics of autism and how having a child with autism affects families, research has been conducted to evaluate the most

effective treatments for ASD. Common approaches to treating autism include speech therapy, occupational therapy, behavioral interventions, dietary interventions, and applied behavior analysis (Carlson, Stephenson, & Carter, 2014; Shepherd, Landon, Goedeke, Ty, & Csako, 2018). The majority of evidence-based approaches to treating autism are rooted in the principles of applied behavior analysis (ABA; Durand, 2014) and those interventions are more likely than other treatments to result in favorable and sustainable outcomes (Howard, Stanislaw, Green, Sparkman, & Cohen, 2014).

Although there has been an extensive number of empirically-validated studies demonstrating the effectiveness of ABA as a treatment for children with autism, there has been little research within the field that focuses on how participating in ABA treatment affects families. While there has been some research evaluating parental views on ABA treatment, there remains a lack of literature that explores how participation in ABA treatment affects the family as a whole. Studying the lived experiences of parents of children with autism and their perceptions of how the outcomes of ABA treatment have an influence on family dynamics could provide valuable insights to both professionals within the field of ABA, as well as families who are considering ABA treatment.

In this chapter, information is provided about autism, ABA, and how having a child with autism impacts parental stress and sibling relationship quality by summarizing relevant research. The problem statement and purpose of the study is presented. Finally, the theoretical framework and research questions are presented along with a discussion of the assumptions, scope, limitations, and significance of the study.

## **Background**

Autism is a developmental disability with the most common symptoms and characteristics including impaired social interactions, communication deficits, stereotypical or ritualistic behaviors, and challenging behaviors such as aggression and self-injury (CDC, 2018). Difficulties with social interactions and communication can make it difficult for children with autism to establish and maintain relationships (Lerner et al., 2018). Ritualistic and stereotypical behaviors, as well as rigidity and insistence on sameness, can make it difficult for children with autism to accept changes and participate in daily routines and activities (Rispoli et al., 2014; Wolff et al., 2014). Both communication deficits and interrupted ritualistic behaviors can be risk factors for challenging behaviors such as tantrums, aggression, and self-injury (Klaiman et al., 2015).

Caring for a child with a disability creates a new set of challenges for parents which can include economic strain, disrupted family functioning, and emotional or health concerns (Faw & Leustek, 2015). Parents of children with autism tend to experience higher self-reported stress levels due to the complex nature of the disorder (Ludlow et al., 2011). In addition, parents of children with autism generally experience lower quality of life when compared to parents of typically developing children (Vasilopoulou & Nisbet, 2016). Dillenburger et al. (2010) reported that 80% of parents of children with autism experience stress, as evidenced by a positive correlation between psychological measures of stress and parents' perceived stress level. The sources of stress experienced by parents of children with autism can include confusion and isolation related to their child's

diagnosis, interpersonal relationship issues that develop, financial, caregiver, and marital burdens, and lack of acceptance, support, and recognition from friends, family, and the community (Altiere & Von Kluge, 2009; Kakkar & Srivastava, 2017).

Sibling relationships also appear to be negatively impacted by having a special-needs child, which can lead to the development of feelings of resentment, frustration, loneliness, embarrassment, and envy related to their disabled sibling (Williams et al., 2010). Hastings and Petalas (2014) found that siblings of children with autism self-reported lower levels of warmth/closeness and increased conflict with their siblings with autism who exhibit behavior problems. There may be some positive impacts of having a sibling with autism, namely increased tolerance and understanding of disabilities (Ward et al., 2016). However, siblings of children with autism also report increased worry about the future of their sibling with a disability. Having a sibling with autism can also negatively impact relationships with parents and interactions with friends (Mandleco & Mason Webb, 2015; Ward et al., 2016).

Parents of children with autism often seek treatment for their child using ABA which is endorsed as the most effective treatment for children with autism leading to noticeable improvements in functioning and abilities (McPhilemy & Dillenburger, 2013). Many parents also express positive views about the effectiveness of ABA in creating beneficial outcomes for their child with autism such as improvements in communication, challenging behaviors, and independence (McPhilemy & Dillenburger, 2013). When comparing intensive early intervention treatment based in ABA for children with autism to less intensive early intervention, children receiving ABA treatment demonstrated

improvements in full scale and non-verbal IQ and adaptive behavior scores, as well as increases in receptive and expressive language (Peters-Scheffer et al., 2011).

The strategies used within ABA have been empirically validated as the most effective treatment for autism, which serves to teach new skills and reduce the occurrences of challenging behaviors (Anagnostou et al., 2014; Durand, 2014). To accomplish this, ABA treatment for children with autism makes use of general principles of learning such as reinforcement, extinction, shaping, prompting and prompt fading, and discrete trial training (Anagnostou, 2014; Durand, 2014; Fani-Panagiota, 2015; Peters-Scheffer et al., 2011). Many ABA treatment programs for children with autism involve one-on-one teaching in clinical or home settings and often rely heavily on continued implementation of treatment packages by the parents to promote maintenance and generalization (Makrygianni, Gena, Katoudi, & Galanis, 2018; Peters-Scheffer et al., 2011). Because parent involvement is so crucial to successful outcomes, behavioral approaches to treatment often incorporate parent training as a component of the treatment package. However, parent training protocols are often specifically focused on teaching parents to use the behavioral strategies that have been effective with their child (Powers, 1991). A study examining these variables should be conducted because it could advise providers of ABA treatment regarding the importance of considering family functioning and family interactions when developing treatments for children with autism.

### **Problem Statement**

Having a child with a severe handicap or disability affects the entire family (Powers, 1991). Caring for a child with autism is particularly challenging due to the

characteristics and symptoms of the disorder (Ludlow et al., 2011). Children with autism often have difficulty with communication and social interaction and may engage in repetitive and ritualistic behaviors. They may also have restricted interests and be resistant to changes, and engage in problem behaviors that can be hard to manage (Ludlow et al., 2011). There are challenges for families of children with autism in terms of parental stress, sibling relationships, and support from others (Mount & Dillon, 2014). Research evaluating how these challenges and stressors can be mediated would be beneficial to families of children with autism.

ABA treatment for autism provides notable benefits to the diagnosed child; however, there has been limited research evaluating the outcomes on families of children who participated in ABA treatment. McPhilemy and Dillenberger (2013) indicated that while some parents credit ABA treatment with lower stress levels and improved quality of life for the whole family, guilt related to time away from siblings was still a source of concern. Cebula (2012) noted that participation in ABA treatment did not seem to produce clinically significant effects on the psychosocial adjustment of siblings, nor on the quality of sibling relationships with the child with autism. Observational and naturalistic research focusing on sibling interactions for those children with autism receiving in-home ABA treatment was specifically identified by Cebula (2012) as an area for future study. Hastings and Petalas (2014) suggested further research into how the quality of sibling relationships could affect parental well-being in families of children with autism. Kovshoff, Cebula, Tsai, and Hastings (2017) developed a theoretical framework for studying outcomes specifically for siblings of children with autism and



noted that further research focused on family systems and sibling relationships is needed to understand the impact of having a sibling with autism on well-being and adjustment. When it comes to evaluating the effectiveness of interventions to treat children with autism, family interactions and family dynamics are rarely considered within the literature and in practice. A study exploring the how parents experience changes to the family system after their child with autism has received ABA treatment could be a valuable addition to the literature.

### **Purpose of the Study**

The purpose of this study was to find meaning in the experiences of parents of children with autism who have received ABA treatment and to explore their perceptions about how the family system is affected with a specific focus on the areas of parental well-being and sibling relationship quality. This was done by using a qualitative phenomenological research method to explore the lived experiences of parents of children with autism who have received ABA treatment.

### **Research Questions**

The central research questions (RQs) for this study and their corresponding sub-questions (SQs) are included below.

*RQ1:* What are the family dynamics experienced by parents of children with autism who have received ABA treatment?

*SQ1:* What are the experiences of mothers and fathers of autistic children related to parents' interactions with each other?

*SQ2:* What are the experiences in terms of the relationships between parents and the autistic child's siblings who do not have autism?

*RQ2:* What are the experiences of well-being according to parents of children with autism who have received ABA treatment?

*SQ3:* What are the experiences regarding parental stress levels as a result of the autistic child's participation in ABA treatment?

*SQ4:* What are the parental experiences involving support and acceptance due to the autistic child's participation in ABA treatment?

*RQ3:* What are the experiences in terms of the quality of parental relationships with non-autistic sibling due their autistic child's ABA treatment?

*RQ4:* What are the parental experiences in terms of observing non-autistic and autistic sibling relationships as a result of the child with autism's ABA treatment?

### **Theoretical Framework for the Study**

The theoretical framework for this study was family systems theory. According to Powers (1991), systems models such as Miller's living systems theory and Bertalanffy's general systems theory provide a valuable framework for serving the needs of children with severe handicaps because those needs often extend beyond treatment of the child to include the needs of the family system. Salvador Minuchin, specifically, used general systems theories to develop structural family therapy, a mode of psychotherapeutic intervention which treats the family as a relationship system, emphasizing the importance of structure, boundaries, and functional attachments in determining family functioning (Guerin & Chabot, 1997). As Powers (1991) identified,

many behavioral interventions incorporate parent training, which focuses on teaching parents the skills required to manage challenging behaviors associated with the child who has a severe handicap. However, the structure and functioning of the entire family system must be considered by clinicians providing behavioral treatments in order for any treatment approach to be the most effective (Powers, 1991). In viewing the family as a system where members are interconnected and mutually influence one another, it is impossible to evaluate any individual member without examining the whole system (Cox & Paley, 1997). With this family systems theory approach in mind, this study explored the lived experiences of parents of children with autism who have participated in ABA treatment and their perceptions of how their family was affected, with a specific focus on the areas of parental well-being and quality of sibling relationships.

### **Nature of the Study**

The nature of the study was qualitative using a phenomenological research strategy. Qualitative methods, phenomenology in particular, were consistent with the purpose of the study, which was to understand what it means to parent a child with autism who has received ABA treatment. Phenomenology allowed for exploring how parents experienced changes to their family system that resulted from their child with autism's ABA treatment, with a focus on parental well-being and sibling relationship quality, free from assumptions and preconceptions about these experiences. A full range of experiences was explored by asking the participants to share both positive and negative experiences.

Data were collected in the form of interviews with parents of children with autism. The data analysis method for this study involved coding the data collected through interviews and organizing it into the common key phrases that emerged across participants. The first step was to review all interviews to get a good sense of the data as a whole. During this process, notes or phrases were recorded next to the data for preliminary analysis. Once the data from all interviews had been reviewed, codes were classified and defined to organize the data into the common key phrase categories. From the coded data, emerging themes that answered the subquestions were interpreted. Together, these themes served to answer the central research question.

### **Definitions**

*Autism spectrum disorder (ASD):* A developmental disability producing impairments in communications and social skills, as well as behavioral challenges (CDC, 2018).

*Applied behavior analysis (ABA):* The science of human behavior which applies the basic principles of learning to teaching new skills and reducing challenging behaviors (Anagnostou et al., 2014).

*Family systems theory:* A theoretical framework for viewing the family as an organized system with various connected subsystems whereby changes in one part of the system results in changes to the others (Cox & Paley, 1997; Guerin & Chabot, 1997; Powers, 1991).

*Family:* For the purpose of this study, family was minimally defined as parents and children living together in the same household (Oxford Living Dictionaries, 2019).

*Parental well-being:* A measure of overall parental emotional functioning which can include perceived or reported stress level, psychological functioning, and/or level of acceptance or perceived social support from the community (Kakkar & Srivastava, 2017; Ludlow et al., 2011; Tint & Weiss, 2016).

*Phenomenology:* Research methodology aimed at describing a phenomenon based on finding meaning in the experiences of those who have lived it, free from preconceived notions of the researcher (Sorsa et al., 2015; Yuksel & Yildirim, 2015).

*Sibling relationship quality:* Attitudes or perceptions about siblings; level of interactions between siblings (Hastings & Petalas, 2014; Ward et al, 2016; Williams et al., 2010).

### **Assumptions**

It was assumed that the parents who participated in the study were truthful about their child's autism diagnosis and participation in ABA treatment. It was also assumed that they answered interview questions openly and honestly and shared experiences that answered the research questions. While truthful responses could not be explicitly demonstrated as true, it was critical to the study to assume data collected through interviews was truthful because the nature of phenomenological studies required exploring meanings within lived experiences of participants. Another assumption of this study was that having a child with autism participate in ABA treatment would have an impact on parents, and that the parents would have a perception about the influence of their child's ABA treatment outcomes on the entire family.

### **Scope and Delimitations**

This study contributed to the body of literature aimed at understanding the true meaning in how ABA treatment outcomes for children with autism are experienced by the family as a whole. This was accomplished by interviewing eight parents of children with autism in order to explore their lived experiences and their perceptions of how ABA treatment outcomes had an impact on the family system, specifically in the areas of parental well-being and sibling relationship quality. Parents (mothers and/or fathers) of children with autism were the primary participants. Parents chosen to participate each had at least one other child without an autism diagnosis. Parents of children with autism who had received ABA treatment for at least 6 months were selected, as these parents were equipped to remember their experiences before their child had started ABA and gave insight into how their lives have changed after their child received ABA treatment.

### **Limitations**

The study may have been limited by the small number of participants. Although phenomenological studies are not typically characterized as having large sample sizes, a study having eight participants does fall below the 12 interviews commonly recommended for reaching thematic saturation (Hagaman & Wutich, 2016). While a small sample size of eight allows for rich conceptualization of the experiences of parents who have a child with autism who has received ABA treatment, those experiences may not be shared by all parents of children with autism who have received ABA.

As a provider within the field of behavior analysis, the researcher could have been biased toward responses from participants that supported positive changes in parental

well-being and sibling relationship quality due to participation in ABA. However, in order to overcome this potential bias, the concept of bracketing was used. The process of bracketing required the researcher to acknowledge any preconceived assumptions that the experiences of parents of children with autism who have received ABA treatment would be meaningful and positive for themselves and their families. Those assumptions were set aside in order to fully appreciate and analyze the experiences shared by the participants.

### **Significance**

ABA is an effective treatment for children with autism (McPhilemy & Dillenburger, 2013); however, comprehensive treatment often involves the family as a whole (Powers, 1991). This study contributed to the literature by providing insight into the experiences of parents of children with autism who have participated in ABA treatment and their perceptions of how their families have been changed. The results of this study were meaningful and practical to both professionals who provide ABA treatment and families of children with autism who are interested in seeking ABA treatment. Findings also identified areas in which ABA treatment could be expanded from the perspectives of parents of children who have participated in treatment. A push for ABA approaches to consider the family as a whole, which could result in even more effective treatments for children with autism, is an identified positive social change.

### **Summary**

In this chapter, the major characteristics and symptoms of ASD are presented. The challenges faced by parents and siblings of children with autism are discussed. An

overview of ABA and its demonstrated effectiveness as a treatment for teaching new skills and decreasing challenging behaviors in children with autism was also provided. The purpose of this phenomenological study was to explore the experiences of parents of children with autism who have received ABA treatment and their perceptions of how ABA treatment resulted in changes to their family system, focusing particularly on parental well-being and sibling relationship quality. This was identified as an area within the literature where more research was needed. The study contributed to the body of literature on the effectiveness of ABA treatment extending beyond a focus on outcomes for children with autism. The insights gained from this study are helpful to families of children with autism who are considering ABA treatment. This study also provided valuable insight that could drive positive social changes in terms of approaches of ABA treatment providers. In Chapter 2, a full review of the literature on characteristics and symptoms of autism, challenges faced by families of children with autism, and the effectiveness of ABA as a treatment for autism is presented.



## Chapter 2: Literature Review

### **Introduction**

Parenting a child with autism produces a unique set of challenges due to the broad spectrum of deficits that are characteristic of ASD (Ludlow et al., 2011). For children with autism, difficulties with communication and socialization are often present (Lerner et al., 2018). The presence of ritualistic or stereotypical behaviors can make handling changes difficult and leads to the propensity for children with autism to have challenging behaviors such as aggression and self-injury (Klaiman et al., 2015; Ludlow et al., 2011). Siblings also face challenges related to their brothers or sisters with autism, which can include the development of feelings of jealousy or resentment (Williams et al., 2010) and increased concerns about the future of their sibling with a disability (Ward et al., 2016). Ultimately, these challenges often have a negative impact on the quality of the relationship between children with autism and their siblings (Cebula, 2012).

Treatment using ABA is the most commonly used intervention for children with autism with empirical evidence supporting its effectiveness in teaching new skills and reducing challenging behaviors (Anagnostou et al., 2014). Despite the large amount of empirical support for ABA treatment as an intervention for children with autism, family interactions and family dynamics are rarely considered when evaluating the effectiveness of behavioral treatments (Jellet et al., 2015). In order for ABA treatment to produce long-lasting and meaningful outcomes for children with autism, there is often a requirement that interventions be carried out by parents and siblings in the home in order to promote maintenance of skills learned in therapy and generalization of those new

behaviors and skills to all settings (Peters-Scheffer et al., 2011). Because successful child outcomes depend on the behaviors of all members of the family, research related to how interventions designed to treat children with autism and other developmental disabilities impact the family as a whole would be beneficial to ABA service providers. Knowledge about the experiences of parents and siblings of children with autism who have received ABA treatment and their perceptions of how family interactions are changed could lead ABA professionals to develop more comprehensive and effective ABA treatment protocols that take into consideration family dynamics. The purpose of this phenomenological study was to explore the lived experiences of parents of children with autism who have received ABA treatment, specifically in the areas of parental well-being and sibling relationship quality.

In this chapter, the literature search strategy is presented. The theoretical framework is also considered. A full literature review of all key concepts is included. Finally, the summary and conclusions are discussed.

### **Literature Search Strategy**

The following databases were used to search the literature for relevant studies pertaining to the key concepts of interest within this study: PsycINFO, PsycARTICLES, Academic Search Complete, Thoreau Multi-Database Search, ProQuest Central, and Google Scholar. Search terms used to find articles were: *autism characteristics, parents, siblings, applied behavior analysis, parental well-being, sibling relationships, family systems, and systems theory*. Combinations of these search terms were used with the Boolean AND operator in order to narrow searches to articles specifically related to

problem being studied. Initial searches were conducted related to parental well-being and autism, as well as ABA and parents. These searches produced literature discussing the challenges of raising a child with autism. Many of these articles also included descriptions of challenges faced by siblings of children with autism. Many of the research studies about parenting children with autism discussed ABA as a treatment for children with autism. Additional searches were conducted related to ABA and characteristics of autism. Finally, searches on family systems and systems theory were conducted related to the theoretical framework used to guide this study.

Upon review of the relevant literature produced by these searches, a gap in the literature related to how ABA affects family interactions and family dynamics was found. For the purpose of this study, the contents of the literature review focused on autism, what it means to be a parent and a sibling of a child with autism, and ABA as a treatment for autism. In addition, the concept of how ABA treatment outcomes are experienced by parents and siblings was also a focus of the literature review.

### **Theoretical Framework**

The theoretical framework for this study was family systems theory. According to Powers (1991), using a family systems approach to assess, treat, and evaluate outcomes for children with disabilities is necessary because it expands the utility of behavioral interventions to include an analysis of the significant components of family structure and functioning that might impact treatment. While the purpose of this study was not to assess or evaluate behavioral treatment outcomes for children with autism, the importance of how those outcomes are experienced by other members of the family

provides the context for use of family systems theory as the framework for grounding the scope of this study. General systems theory is founded on the idea that in all areas of knowledge, it is necessary to think of complex phenomena in terms of wholes (Bertalanffy, 1968). To truly understand a phenomenon requires going beyond the exploration of each part in isolation or even the sum of each part. Phenomena must be looked at as wholes which requires the study of interactions amongst each part (Bertalanffy, 1968). General systems theory is most simply defined as general science of wholeness and spans across mathematical, biological, physical, and psychological domains (Bertalanffy, 1968).

General systems theory is the underlying framework for family systems theory. The basic principles of general systems theory that have been incorporated into many family systems theories include this idea of wholeness as well as the idea of the family being a hierarchical structure with identified systems and subsystems (Cox & Paley, 1997). In addition to these principles, the idea that systems have the ability to compensate for and adapt to changes in the environment to reach a stage of homeostasis are also included in most family systems theories (Cox & Paley, 1997).

Family systems theorists have evolved from nearly every theoretical orientation within the field of psychology, including psychoanalysts, experientialists, and structural family therapists (Guerin & Chabot, 1997). Salvador Minuchin developed a structural family systems model which viewed the family as a relationship system. His theory was grounded in the concept of the family being defined by its structure, boundaries, and functional attachment amongst individuals (Guerin & Chabot, 1997). According to

Minuchin (1974), family structure encompasses the functional demands that organize how family members interact with and relate to each other, which defines the family system and regulates each family member's behavior. In addition, within the family system, each individual belongs to various subsystems that further differentiate how family members interact with each other. Minuchin (1974) identified that family systems maintain themselves by following both the universal rules of family organization and the mutual expectations of particular family members. However, family structure must also be flexible enough to adapt to any changes that might arise (Minuchin, 1974).

In Minuchin's theory, the immediate family was defined as members living within the same household, and the family system was described in terms of whether or not the family structure reflected appropriate boundaries (Guerin & Chabot, 1997). Boundaries serve the role of protecting the differentiation of subsystems within the family system, and clear boundaries are required to maintain proper family functioning (Minuchin, 1974). Inappropriately defined or dysfunctional boundaries can be categorized as either enmeshed or disengaged. Enmeshed family systems are those in which boundaries are very fluid or missing altogether. Disengaged family systems are those in which boundaries are extremely rigid to the point where sufficient relationship attachment is impacted (Guerin & Chabot, 1997). Minuchin (1974) noted that many family systems can include both enmeshed and disengaged subsystems. In enmeshed family systems, weak boundaries and differentiation of subsystems lead to crossover between the different subsystems where individual stressors then affect the entire family. As such, when adaptive mechanisms are needed to handle stressors, enmeshed families tend to

respond impulsively and intensely (Minuchin, 1974). With disengaged families, only high levels of stressors experienced by an individual member are strong enough to cross over the extremely rigid boundaries between the individual family members and family subsystems that exist. When the need for adaptation occurs in disengaged families, there is often no response or attempt to adapt, even when warranted (Minuchin, 1974).

According to Minuchin's family systems theory, understanding the structure, boundaries, and functional attachments within the family system are crucial to overcoming any type of dysfunction that might be present within the individual (Guerin & Chabot, 1997). The complex influences of family structure and boundaries on each individual member of the family emphasized in Minuchin's family systems theory sets the framework for the concepts explored within this study. The parental and sibling subsystems identified by Minuchin (1974) are of particular importance. The parenting process impacts both the spouse subsystem and the developing child while sibling subsystems often provide the first social context for developing peer relationships (Minuchin, 1974). In order for the positive outcomes experienced by children with autism who have received ABA treatment to be long-lasting and meaningful, it is important to consider how those outcomes are experienced and perceived by other members of the family system as well. It is with a family systems theoretical framework in mind that this phenomenological study exploring the lived experiences of parents of children with autism who have received ABA treatment to understand their perceptions of how family systems are impacted was conducted.

## **Literature Review**

The following literature review provides an overview of the key concepts important to this study. The first concept discussed is autism including a discussion of its prevalence, diagnosis, and defining characteristic symptoms. Next, the concepts of parenting a child with autism and having a sibling with autism are discussed, including relevant research related to these experiences. Finally, the concept of applied behavior analysis is discussed including an overview of research demonstrating the effectiveness of ABA as a treatment for autism and the areas of research still needed related to how ABA treatment and its outcomes for children with autism are experienced by parents and siblings.

### **Autism**

Autism is a developmental disability that is defined by characteristic impairments in communications and social skills, as well as significant behavioral challenges (CDC, 2018). In this section, the prevalence and diagnosis of autism is discussed. The characteristic symptoms of the disorder are also reviewed.

#### **Prevalence and Diagnosis**

According to the CDC (2018), the prevalence of autism is about 1 in 68 children as of 2012. This identified number of children diagnosed with autism has exponentially grown over the last 12 years from the prevalence of 1 in 150 children that was established in 2000 (CDC, 2018). The CDC has developed a surveillance system to monitor the case status of autism, which includes an evaluation of both prevalence and characteristics. This system is known as the Autism and Developmental Disabilities Monitoring Network

(ADDM) and includes 11 cities across the United States (Christensen et al., 2016).

Monitoring of the prevalence of autism has occurred since the 1960s and 1970s with estimates of prevalence being four to five cases per 10,000 children (Christensen et al., 2016). Since that time, the development and subsequent revision of diagnostic criteria for autism through the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* has likely contributed to changes in prevalence across the years. However, substantial increases in the prevalence of autism were initially noted to occur starting in the 1990s (Christensen et al., 2016).

Two studies conducted in the late 1980s determined the prevalence of autism to be about 3.5 cases per 10,000 children from three to 18 years of age (Christensen et al., 2016). Various systems for measuring the prevalence of autism have existed since that time, using data from various sources including special education, national surveys, and public health surveillance through the CDC. In 1996, the prevalence of children diagnosed with autism was estimated to be about three cases per 1,000 children (Christensen et al., 2016), a drastic increase from the prevalence reported in the 1980s. The AADM Network has been in place since 2000, conducting estimates of autism prevalence every two years. In 2000, the prevalence of autism was about 6 per 1,000 compared to the most recent estimate of prevalence in 2012, which has grown to about 14 cases per 1,000 children (or 1 in 68) (Christensen et al., 2016).

With the growing number of cases of children with autism being reported, the need to recognize the signs, symptoms, and characteristics of the disorder becomes increasingly important, as does the need for early screening and diagnosis (CDC, 2018).



Zwaigenbaum et al. (2015) conducted a comprehensive review of the current literature regarding early screening and diagnosis of autism spectrum disorder. The American Academy of Pediatrics (AAP) has recommended early screening for autism spectrum disorders for all children during well-children exams conducted at 18 months and 24 months of age (Zwaigenbaum et al., 2015). Based on a review of the literature, a number of screening tools, despite the presence of increased false positives prior to 24 months of age, have been identified to provide valuable information related to autism screening (Zwaigenbaum et al., 2015). Level 1 screening tools (those which are universally administered to all children regardless of risk status) that have been identified in the literature to be the most useful include the Modified Checklist for Autism in Toddlers (M-CHAT) and the First Year Inventory (FYI), both of which are screening questionnaires completed by parents (Zwaigenbaum et al., 2015).

Level 2 screening tools are those that should be used with children identified as high risk for an autism spectrum disorder due to family history, concerns noted by parents, or a positive level 1 screening (Zwaigenbaum et al., 2015). The Screening Tool for Autism in Two-Year-Olds (STAT) and the Systematic Observation for Red Flags have both been identified as observational assessments, in addition to broadband developmental screening tools such as the Communication and Symbolic Behavior Scales Developmental Profile (CSBS DP) have all been shown to be effective in detecting autism (Zwaigenbaum et al., 2015). In addition to early screening, the AAP also recommends that those children who receive positive results from screening immediately

be referred for further clinical evaluations and being the process of securing early intervention treatments.

Clinical diagnosis of an autism spectrum disorder is done using the diagnostic criteria found within the *DSM-V*. Changes to the classification and criteria for an autism diagnosis were modified with this most recent edition resulting in two main domains of symptoms: deficits in communication and social interaction and the presence of restrictive, repetitive behaviors (Constantino & Charman, 2016). Each of these broad categories of symptoms include several different examples of particular deficits or behaviors that would satisfy the criteria for diagnosis. In addition to the presence of symptoms within these categories, symptoms must first appear in the early stages of development, must result in significant impairments in social or occupational functioning, and they must not be explained by the presence of an intellectual disability (Constantino & Charman, 2016).

Several diagnostic tools have been developed and standardized to assist clinicians and practitioners with determining the presence of symptom severity needed to satisfy the criteria listed in the *DSM-V*. The Autism Diagnostic Interview, Revised (ADI-R) and the Developmental, Dimensional, and Diagnostic Interview (3di) are checklist questionnaires which are often used in clinical settings. In addition, the Autism Diagnostic Observation Schedule, second edition (ADOS-2) is a tool that relies on observations of children to determine the presence of symptoms of autism (Constantino & Charman, 2016). Data obtained from the use of the diagnostic tools (which may involve information from parents, teachers, caregivers and direct observations from the clinician, as well as the

presence of a developmental history consistent with autism, result in a diagnosis of autism (Constantino & Charman, 2016).

### **Symptoms and Characteristics of Autism**

**Communication and socialization deficits.** According to the DSM-V, the first criteria for an autism diagnosis is the presence of long-standing deficits in social skills (American Psychiatric Association, 2013). Over 30% of the population of individuals with autism are considered as non-verbal or have limited verbal abilities and/or intellectual disability which directly impacts the ability to engage in basic functional communication (Lerner, Mazefsky, White & McPartland, 2018). Deficits in social interactions can be represented by a broad variety of examples including lack of conversational reciprocity, the inability to detect emotions or affect, difficulty with initiating social interactions or recognizing social cues, inadequate nonverbal communication including lack of eye contact or difficulty using gestures, and deficits in building and maintain relationships with others (APA, 2013).

In addition to these more commonly discussed deficits in communication and social interactions identified within the DSM, individuals with autism also display several other notable issues on the social-emotional continuum (Lerner et al., 2018). For example, large amounts of social stimuli such as crowded or unstructured settings and confined spaces can be overwhelming for individuals with autism leading to avoidance of or anxiety associated with social situations where these factors may be present (Lerner et al., 2018). Difficulties with emotional processing for individuals with autism is not only reserved for the emotions of others, but can present in difficulty processing their own

emotions as well. This can further complicate social interactions with others when individuals with autism are unable to regulate their emotional responses to others (Lerner et al., 2018).

Many individuals with autism also have issues with self-regulation, in general, which can present in various different manners such as difficulty engaging in classroom learning settings due to the amount of self-regulation required to stay on task and attend or the displaying of problem behaviors when faced with frustration or disappointment (Lerner et al., 2018). Finally, many individuals with autism experience a lack of or delayed development of social self-awareness, which means they are unable to identify or understand their roles within a social context (Lerner et al., 2018). However, for some individuals with autism, an understanding of differences between themselves and others begins to emerge in adolescence, which only contributes to social challenges, particularly in the area of establishing and maintaining friendships or relationships (Lerner et al., 2018).

**Stereotypical behaviors, rituals, need for routine.** The next criteria for an autism diagnosis listed within the DSM-V is the presence of at least two of the following characteristics which represent restrictive or repetitive patterns of behavior: repetitive or stereotypical motor movements, inflexibility or insistence on routine or sameness, restricted or fixed interests, and hypersensitivity to sensory input (APA, 2013). Because insistence on sameness has been identified as a key defining feature of autism spectrum disorders, research related to this characteristic is often focused on understanding exactly how the lives of children with autism and their families are affected by it.

Wolff et al. (2014) conducted a longitudinal study of toddlers with autism in an attempt to provide clarity as to the development of ritualistic or repetitive behaviors over time. Parent-report measures were used to determine the presence of repetitive behaviors (including stereotypical, self-injurious, compulsive, ritualistic, sameness, and restrictive behaviors) in children with autism at 12 months old and 24 months old (Wolff et al., 2014). Comparisons were made amongst groups of children identified as high risk for being diagnosed with autism due to family history and typically developing children. Results indicated significant group effects across all of the identified categories of repetitive behaviors, supporting the identification of repetitive behaviors as a good early sign of the presence of an autism spectrum disorder (Wolff et al., 2014).

Kirby, Boyd, Williams, Faldowski, and Baranak (2017) conducted naturalistic observations of children with autism engaging in stereotypical behaviors during home activities in order to further categorize both the sensory modalities associated with sensory and repetitive behaviors, as well as the activities contexts in which they were most likely to occur. Observations were conducted with 32 children with autism between the ages of two and 12 years. Results indicated that hyper-responsive behaviors (those associated with avoiding sensory input) were observed most frequently during activities of daily living (bathing, tooth-brushing, dressing) and were usually family-initiated (Kirby et al., 2017). Sensory seeking behaviors (those associated with excessive interests in items within the environment that provide prolonged sensory input) were most likely to occur during free play and were typically initiated by the child (Kirby et al., 2017). Finally, repetitive or stereotypical behaviors (i.e., rocking, flapping, lining of objects, or

repeating sounds or phrases) were most often observed in the same contexts as sensory-seeking behaviors; however, this was based on descriptive findings; however, these results were not statistically significant in this study. Hypo-responsive behaviors (delayed responses to sensory input) were only observed by one participant, thus the hypothesis that these would be most likely associated with family-initiated social activities could not be tested (Kirby et al., 2017).

**Challenging behaviors.** According to the CDC (2018), some of the challenging behaviors that might be found in children with autism include aggression, self-injury, temper tantrums, and unusual sleeping or eating habits. Behavioral challenges typically emerge as a result of limited communication skills which makes getting wants and needs met difficult (Klaiman, Fernandez-Carriba, Hall & Saulnier, 2015). Aggression, self-injury, tantrums, and other behavioral challenges may also occur as an expression of anxiety associated with navigating difficult social situations or adapting to unexpected changes (Klaiman et al., 2015). Other challenging behaviors such as disruptive, destructive, or defiant behaviors may occur as a result of difficulties with attention, impulsivity, and emotional regulation commonly found in individuals with autism (Klaiman et al., 2015).

There is an association between sleep difficulties and symptoms of autism spectrum disorders, specifically note that sleep disturbances can make certain characteristic symptoms of autism such as stereotypy, hyperactivity, and impulsivity worse (Adams & Matson, 2014). Studies also indicate that children with autism who have sleep issues tend to exhibit more challenging behaviors such as aggression. Adams

and Matson (2014) were specifically interested in studying the relationship between the severity of sleep disturbances and the frequency of challenging behaviors. Results of their study indicated that children with autism who experience sleep problems displayed higher rates of challenging behaviors compared to those with no sleep problems. Severe sleep problems contributed to more “externalizing” challenging behaviors such as aggression, tantrums, and property destruction than mild sleep problems, while there was no difference in rates of “internalizing” challenging behaviors such as self-injury or stereotypy depending on the severity of sleep issues (Adams & Matson, 2014).

In summary, children with autism display a wide range of symptoms and characteristics that result in many types of challenges for both the child with autism and their families. Communication and social deficits can make it difficult for children with autism to get their needs met and to develop and maintain meaningful relationships. Stereotypical and ritualistic behaviors can make adjusting to changes very difficult. Many children with autism often display challenging behaviors such as aggression or self-injury, as well as disrupted sleep patterns or restricted eating habits which can also be a hardship for families and caregivers of children with autism.

### **Parenting a Child with Autism**

Given the increase in prevalence in the diagnosis of autism spectrum disorders over the last 20 years and the wide variety of symptoms and characteristics of the disorder, more and more research related to autism has been conducted. Of particular interest within the field of autism research is the study of how parents are affected by having a child with autism. Having a child with a developmental disability often leads to

issues with parental well-being and emotional health, acceptance from extended family and friends, and challenges finding appropriate resources and social supports.

**Impact on well-being and emotional health.** The well-being and emotional health of parents of children with autism has been studied frequently within the autism literature. Some studies have focused on parent reports of their own feelings and well-being while other studies have focused on quantitative, clinical measures of psychological well-being. Altieri and Von Kluge (2009) conducted semi-structured interviews with 26 married couples to learn about their experiences raising a child with autism. Questions were asked related to their child's development, when they started to notice the presence of symptoms of autism in their child, their feelings and experiences when their child was first diagnosed, and how they coped with the diagnosis. All of the families experienced feelings of sadness and anger when learning of their child's autism diagnosis, as well as denial and confusion (Altieri & Von Kluge, 2009). Extreme emotions such as depression and despair were also reported by all of the parents in this study (Altieri & Von Kluge, 2009). In addition, parents reported that their emotional and psychological well-being was impacted by raising a child with autism, specifically referencing the development of symptoms of anxiety and depression (Altieri & Von Kluge, 2009).

According to DePape and Lindsay (2015), parents often experience a sense of relief following diagnosis because there is finally a name for the signs and symptoms they noticed in their child prior to diagnosis. However, this relief is short-lived as parents begin to feel guilt and blame themselves and worry about what to do next (DePape &



Lindsay, 2015). Dillenburger et al. (2010) indicated that most parents of children with autism report high stress levels with 48% of the parents scoring above the stress threshold indicating the need for additional psychological assessment (Dillenburger et al., 2010). Some of the parents in this study noted that parenting a child with autism presented new challenges that they were unprepared for (Dillenburger et al., 2010).

Dillenburger et al. (2010) also indicated that social and communication deficits were the most difficult issues to deal with as parents of a child with autism. Ludlow et al. (2011) stated that parents of children with autism also noted their child's difficulties with social interactions and isolation from others leading to concerns and sadness. Ludlow et al. (2011) also discovered that dealing with challenging behaviors such as tantrums, repetitive behaviors, and aggression, as well as responding to changes in routines were also significantly stressful for parents of children with autism. Parents in this study reported impacts on their emotional well-being including feelings of depression, desperation, and lower self-esteem with regard to their parenting skills (Ludlow et al., 2011). Mount and Dillon (2014) also found that parents noted challenging behaviors, rigid thinking, and resistance to change exhibited by their child with autism as a source of daily stress. In particular, parents within this study reported that having a child with autism led to changes in their approach to parenting, making them more anxious, affecting their overall psychological well-being (Mount & Dillon, 2014).

According to Baghdadli, Pry, Michelon, and Rattaz (2014), the perception of quality of life for parents of children with autism is affected by the severity of their child's symptoms, as well as the interventions the child receives. Parents of children who

exhibit more severe characteristics of autism had decreased scores on measures of quality of life. In addition, parental quality of life also decreased as the number of reported challenging behaviors such as irritability, stereotypy, and hyperactivity increased. Life satisfaction in parents of children with autism also decreased as the level of independent functioning decreased (Baghdadli et al., 2014). These results were also supported by a study conducted by Pozo, Sarria, and Brioso (2014) who found that parents of children with autism who exhibit more severe challenging behaviors may perceive their lives as less manageable or predictable, resulting in higher levels of parental stress. In addition, Jellet, Wood, Giallo, and Seymour (2015) also found that the presence of higher levels of challenging behaviors in children with autism corresponded to higher reports of depression, stress, and fatigue in parents.

Financial and employment burdens associated with parenting a child with autism can also contribute to parental stress. Saunders et al. (2015) examined the impact of financial and employment burden on families of children with autism who were also diagnosed with an intellectual disability. Using data compiled from the 2009 – 2010 National Survey of Children with Special Healthcare needs which consisted of 40,242 telephone interviews of families of U.S children with special needs, Saunders et al. (2015) conducted statistical analyses comparing the employment and financial burdens of 2,406 families of children with only an autism diagnosis, the 1,363 families of children with only an intellectual disability diagnosis, and the 620 families of children with both diagnoses. These analyses also included a comparison to 12,121 families of children with a medical diagnosis of asthma without a diagnosis of autism or intellectual disability

(Saunders et al., 2015). Results of the study indicated that families of children diagnosed with both autism and intellectual disability reported higher issues with financial and employment burdens. Almost one-third of the caregivers of children diagnosed with both autism and an intellectual disability reported out-of-pocket expenses in excess of \$1000 per month and more than one-half reported having to stop work in order to care for their child with both diagnoses. Across all measures, financial and employment burden for families of children diagnosed with asthma were significantly lower than those diagnosed with both autism or intellectual disability, as well as those with either autism or intellectual disability alone (Saunders et al., 2015).

Davis and Kiang (2018) studied the association between parenting a child with autism and parental stress, as well as the mediation of religious coping on parental well-being. For their study, 47 mothers of children with autism participated by completing a series of questionnaires designed to measure parental stress, positive religious coping, spirituality, social support, positive and negative affect, depressive symptoms, and satisfaction with life. Results of this study indicated that parental stress levels were positively associated with the presence of depressive symptoms and negative affect and negatively associated with satisfaction of life and positive affect. Results of this study also showed that there was not an association between religious coping or social support and well-being outcomes (Davis & Kiang, 2018). This aligns with previous research studies indicating the impact of parenting a child with autism levels of parental stress and overall parental well-being. David and Kiang specifically identified the need for research and

interventions designed to understand and mitigate these stresses in order to provide positive outcomes for children and families affected by autism (Davis & Kiang, 2018).

Benefit finding, or the ability to find positive meaning when faced with adversity, is one coping strategy that was explored by Lim and Chong (2017) with respect to its possible impact on negative affect in parents of children with autism. In their cross-sectional, correlational study, the researchers provided a self-report questionnaire to 302 parents of children with special needs. While benefit finding as a coping strategy was positively correlated with positive affect, this statistically significant relationship was not found when moderating for the autism diagnosis (Lim & Chong, 2017). The researchers identified the limitations of correlational research in evaluating the specific variables, relationships, or core characteristics of autism that might contribute to or impact coping strategies and parental stress. Further research using qualitative methods was identified in order to tease out these nuances on how coping strategies such as benefit finding influence parental well-being in parents of children with autism (Lim & Chong, 2017).

**Acceptance from extended family and friends.** Because parenting a child with autism results in unique challenges that can negatively impact parental well-being, support and acceptance from extended family and friends becomes even more important. In some cases, loss of acceptance from others can also be a source of additional stress. According to Altieri and Von Kluge (2009), parents of children with autism reported that the increased responsibilities associated with caring for their child led to less time for friends. Some parents also indicated a loss of support from their church and increased struggles with extended family members who did not understand autism or showed

embarrassment toward their child. As such, parents of children with autism reported lack of contact with friends and extended family (Altiere & Von Kluge, 2009).

Ludlow et al. (2011) indicated that judgment from others was a significant source of stress associated with parenting a child with autism. Parents in this study indicated the perception that others saw their children as naughty and judged their parenting skills as lackluster whenever their child displayed challenging behaviors in public. According to Jellet et al. (2015), challenging behaviors can also make it difficult for parents of children with autism to spend time with extended family members and may limit their ability to engage in other preferred activities. Limited engagement in preferred activities could also result from parental depression that contributes to a lack of enthusiasm or initiation as a result of low moods (Jellet et al., 2015).

**Challenges finding appropriate supports and services.** Finding and financing adequate services, treatments and supports are a significant source of stress for parents of children with autism. According to Dillenburger et al. (2010), parents reported that applications for funding of services are lengthy and confusing and that attempting to seek multidisciplinary support services was a distressing experience. In addition, DePape and Lindsay (2015) reported that families face other issues with navigating the system in order to find the best therapeutic and educational supports for children with autism.. Communication issues and financial issues associated with accessing services were noted as additional sources of parental stress (DePape & Lindsay, 2015). Milbourn et al. (2017) similarly found that parents faced frustration early in the pre-diagnosis phase with many medical professionals refusing to formally diagnose their child at an early age

despite the need for early intervention. These frustrations were only further extended after diagnosis by the struggles of accessing and funding interventions (Milbourn et al., 2017).

According to Ludlow et al. (2011), many parents seek the support of other parents of children with autism, as well as support from local and national organizations. In this particular study, parents reported professionals such as pediatricians and psychologists as a source of help and support (Ludlow et al., 2011). Mount and Dillon (2014) similarly found that some parents cited a support group through their child's school as being a useful resource for coping with their child's diagnosis. The development of positive and problem-solving coping strategies was found to predict improvements in psychological well-being for mothers of children with autism in the study conducted by Pozo et al. (2014).

In summary, the current literature shows that parenting a child with autism can provide a unique set of challenges. Most notable are the impact of having a child with autism on parental psychological and emotional well-being. Many parents face increases amounts of stress, loss of social support from friends and family, and difficulty securing services for their child or social support for themselves. Although there have been many studies that evaluate the influence of having a child with autism on parental well-being, there are few studies that explore how participating in specific forms of treatment for autism influences parental well-being.

### **Having a Sibling with Autism**

Much like parents, siblings of children with autism face a number of challenges which can include difficulties with coping and adjustment, as well as impaired relationships with their disabled sibling. There have been many studies conducted evaluating the impact of having a sibling with a disability; however, fewer studies have focused on the unique challenges that exist when one has a sibling that is diagnosed with an autism spectrum disorder. For siblings of children with autism, emotional well-being, relationships with parents and peers, as well as sibling relationship quality can all be impacted by an autism diagnosis.

**Emotional well-being and feelings toward sibling with autism.** Williams et al. (2010) noted that siblings of children with autism expressed both positive and negative outcomes associated with being the sibling of a child with autism. Negative feelings reported included frustration, resentment, depression, embarrassment, and jealousy. The sources of these feelings included both the child with autism's disability as well as feeling isolation from parents due to the needs of their disabled sibling (Williams et al., 2010). Despite these negative feelings, positive outcomes were also reported such as family closeness, increased sensitivity and caregiving, and personal growth in the sibling with autism which occurred as a result of needing to be more self-reliant as well as helping out with the disabled sibling (Williams et al., 2010).

Ward et al. (2016) found siblings of children with autism acknowledged their experiences as both positive and difficult. The presence of challenging behaviors in their siblings with autism as well as difficulty communicating with and being understood by

their siblings were noted to be particularly difficult (Ward et al., 2016). Many of the participants in this study acknowledged that their siblings with autism often received more attention from their parents and required constant caregiving. Despite this challenge, having a sibling with autism made the participants more empathetic and capable of assuming a caregiver role (Ware et al, 2016). All of the siblings participating in this study were able to describe a sense of appreciation and being proud of their siblings with autism; however, there was still some concern and desire to change problematic behaviors (Ward et al., 2016).

Walton (2016) examined the risk factors related to behavioral and emotional problems in siblings of children with autism with respect to both externalizing behaviors such as aggression or defiance and internalizing behaviors such as anxiety and depression. Results of the study indicated that male siblings from smaller families and those with lower economic status were at higher risk for externalizing behaviors, while male siblings who had older siblings with autism were at higher risk for internalizing behaviors (Walton, 2016). In addition, the presence of challenging behaviors in the sibling with autism placed siblings at higher risk for both internalizing and externalizing behaviors (Walton, 2016).

**Impact on sibling relationships.** Hastings and Petalas (2014) explored sibling relationship quality and behavioral problems in siblings of children with autism. Using self-report measures of both, results indicated no significant evidence of abnormal emotional adjustment or behavioral problems in siblings of children with autism. However, elevated scores within the clinically concerning range were discovered across



participants in the domain of peer relationships (Hastings & Petalas, 2014). Siblings of children with autism have increased difficulty maintaining relationships with peers which is an additional source of stress. In addition, there was some evidence that the extent of behavioral problems present within the sibling with autism was associated with the level of sibling relationship quality. Specifically, there were lower levels of warmth and closeness toward siblings with autism who displayed increased behavioral challenges (Hastings & Petalas, 2014). Because these were preliminary findings, additional research on sibling relationship quality was specifically identified as an area for future research by Hastings and Petalas (2014).

Roper et al. (2014) also explored caregiver burden and sibling relationships in families of children with disabilities. In their study, they specifically used a family systems theoretical framework to evaluate the associations between type of disability and caregiver burden and sibling relationships. Mothers of children with autism self-reported higher levels of caregiver burden than parents of typically developing children, and when higher levels of caregiver burden were reported, it was associated with less positive perceptions of sibling relationships (Roper et al., 2014). These researchers postulated that increased caregiving needs for the child with autism could divert attention away from siblings, thus impacting the parents' perceptions of sibling relationship quality. Roper et al. (2014) identified the need for more understanding of how family systems are impacted by interventions designed to treat children with disabilities so that interventions focused on alleviating caregiver burden and fostering positive sibling relationships could be developed.

In summary, having a sibling with autism can be stressful and lead to feelings of frustration, disappointment, and concern. Despite evidence in the literature for some positive outcomes associated with having a sibling with autism, there is also evidence to support that siblings of children with autism are at higher risk for issues such as depression and anxiety or aggression and defiance. In addition, research indicates that sibling relationship quality between the child with autism and the sibling is impacted. Further research related to sibling relationship quality between children with autism and their siblings has been identified as a need in this area.

### **ABA**

Children with ASD face challenges in the areas of communication, social interactions, and difficulty adapting to changes, and the presence of ritualistic or problem behaviors such as aggression or self-injury. These characteristics of autism spectrum disorders can make life very challenging for both parents and siblings. Given the multitude of issues families of children with autism experience, including concerns with parental well-being and sibling relationship quality, it is important to consider what types of interventions are the most effective for children with autism. While there are many different interventions available including speech and occupational therapy, sensory integration, medication and dietary restrictions or supplements, and social skills training (Carlson, Stephenson, & Carter, 2014), applied behavior analysis has been identified as the most effective method for treating autism which results in improvements in the core deficits of the disorder (Fani-Panagiota, 2015). The following section will include an

overview of the basic principles of ABA, how ABA is used as an effective intervention for children with autism, and how ABA affects the family.

**ABA as treatment for children with autism.** Many of the evidence-based practices used to treat autism spectrum disorders are grounded in the principles of applied behavior analysis (Durand, 2014). For example, discrete trial training (DTT), one of the most well-known techniques used with ABA treatment for children with autism, incorporates antecedent manipulations, prompting, reinforcement, task analysis, response interruption or redirection, and differential reinforcement to teach new skills (Durand, 2014). These principles of behavior analysis are also used to teach a variety of skills such as communication and self-help skills, and they are also used to assess challenging behaviors through functional behavior assessments. Once the function of a problematic behavior such as self-injury or aggression is found, principles of learning can be used to teach a replacement or alternative behavior (usually some form of communication) that is more appropriate (Durand, 2014).

Quality ABA interventions are implemented in a one-to-one ratio to systematically teach a large number of skills using the principles of applied behavior analysis (Makrygianni, Gena, Katoudi, & Galanis, 2018). ABA programs should be delivered as early as possible (before the age of 3) and can occur in center, home, or school settings typically for a duration of 15 to 40 hours per week (Makrygianni et al., 2018). The effectiveness of ABA interventions is measured by observable changes in targeted skills and behaviors as a result of the interventions put into place which should include increases in language and communication skills and adaptive behaviors as well as

decreases in challenging behaviors and other noticeable autism symptomology (Makrygianni et al, 2018). The incorporation of strategies to move beyond one-to-one student to teacher ratios and the inclusion of parent training are used to promote maintenance and generalization of acquired skills (Makrygianni et al., 2018).

Peters-Scheffer, Didden, Korzilius, and Sturmey (2011) evaluated the effectiveness of early intensive behavioral interventions (EIBI) based in the principles of ABA for children with autism using changes in full scale, verbal, and performance IQ as well as adaptive behavior scores as measures. Results of their study indicated that children with autism who received EIBI based in ABA obtained better IQ and adaptive behavior scores than children who participated in other forms of treatment (Peters-Scheffer et al., 2011). Reichow (2012) conducted a meta-analysis of EIBI for children with autism. The results of this study which included an overview of five different meta-analyses of EIBI for children with autism resulting in the determination that early intensive behavioral interventions based in the principles of ABA is the most comprehensive and effective treatment available across definitions of “evidence-based treatments” available (Reichow, 2012). According to an up-to-date meta-analysis of the effectiveness of ABA interventions in treating children with autism conducted by Makrygianni et al. (2018), ABA treatments continue to demonstrate high levels of effectiveness in improving intellectual capabilities and communication skills, as well as moderate effectiveness in improving IQ scores assessed through nonverbal testing and adaptive behavior scores.

**ABA and the family.** Given the amount of empirical support for ABA as an

effective treatment for children with autism which results in significant behavioral changes and the acquisition of new skills, it is important to also consider how ABA treatment affects the family. Within this area of research, there have been several studies conducted related to parent views of ABA compared to other autism treatments. There have also been a few studies exploring how siblings are affected by the child with autism's participation in ABA treatment.

Grindle, Kovshoff, Hastings, and Remington (2009) explored parents' experiences with home ABA programs, specifically seeking to learn more about how ABA programs impacted their personal and family life. All families participating in the study were able to identify at least one benefit of participating in an ABA in-home program for the child with autism. In addition, 75% of the parents were able to identify benefits for themselves including having additional support within the home and therapy time freeing up some time for themselves to do other things (Grindle et al., 2009). Some parents also reported that the in-home ABA program made it easier to broaden their own social networks and that they were also able to learn some effective behavior management strategies from observing their child's therapists. In families that had at least one typically developing sibling, 25% of parents reported some benefit to that sibling. The two most common benefits reported were siblings enjoyed participating in the therapy program and that they learned how to interact with their sibling with autism by observing the child's therapist (Grindle et al., 2009). Parents also expressed some difficulties with participating in an in-home ABA therapy program, namely the difficulty with managing ABA therapists, the lack of privacy for the family associated with having

therapists in the home, and the time commitment of administrative duties such as replacing therapy materials becoming stressful (Grindle et al., 2009).

Shepherd, Landon, Goedeke, Ty, and Csako (2018) assessed parental views of five of the most popular treatments for autism used in New Zealand: behavioral therapies (BT), intensive applied behavior analysis (iABA), speech language therapy (SLT), occupational therapy (OT), and dietary interventions (DI). A total of 585 parents participated in an online survey in which they were asked about intervention status (ongoing, engaged, or abandoned) and the symptom the intervention was primarily supposed to address. Additionally, parents were asked to report on their expectations prior to starting the intervention and how well those expectations were met, as well as how the intervention affected their parental stress levels (Shepherd et al., 2018). Some of the notable results amongst the various comparisons made within this study were that the average effectiveness ratings for iABA were higher than the remaining four interventions and iABA was the only intervention in which parents whose child was currently engaged and whose expectations were being met. In addition, the greatest mean impact on parental stress levels was obtained from iABA interventions (Shepherd et al., 2018).

Cebula (2012) explored the impact of ABA treatment on siblings of children with autism, specifically testing the hypotheses that in-home ABA programs would have a positive impact on both psychosocial adjustment and sibling relationship quality. Results of this study did not produce statistically significant differences in sibling psychosocial adjustment between the ABA group and the control group (families not participating in any type of intensive treatments) (Cebula, 2012). Some support for the hypothesis that

participation in ABA would have a positive impact on sibling relationship quality was evident in parent and sibling reports of improved positive interactions between siblings and parent reports of fewer negative interactions (Cebula, 2012). This finding was of particular interest because parents' perceived ABA to be more beneficial to sibling relationships than siblings did. Cebula (2012) noted the impact of ABA on sibling relationship quality specifically as an area for future research.

McPhilemy and Dillenburger (2013) also explored the impact of ABA treatment on the family, including siblings. Fifteen families participated by filling out questionnaires asking about their experiences with ABA-based services. All of the participants indicated that ABA services had produced positive outcomes for their child with autism, especially in the areas of communication, independence, and behavior (McPhilemy & Dillenburger, 2013). Parents also expressed improvements in family life, including more manageable family outings and overall lower parental stress levels. Participants acknowledged some guilt related to the lack of time available to spend with their other non-autistic children due to increased time commitments associated with intensive ABA intervention. However, they hoped that in the long run ABA treatment would result in long-term improvements in sibling relationships (McPhilemy & Dillenburger, 2013). Overall, parents who participated in this study expressed a high level of satisfaction related to their experiences with ABA treatment due to positive impacts on both their child with autism and on the family (McPhilemy & Dillenburger, 2013).

Chadwell, Sikorski, Roberts, and Allen (2018) highlighted the lack of literature that focuses on client preferences with respect to treatment process rather than treatment effectiveness within the field of applied behavior analysis. While client preference is commonly evaluated in applied behavior analysis methodology and treatments, components such as the characteristics or behaviors used by therapists who deliver ABA treatment is rarely considered or empirically studied. In their study, Chadwell et al. (2018) explored specifically whether or not parents seeking behavioral treatment for their children were more concerned with choosing empirically supported treatments or if they would be willing to discount treatment effectiveness for specific characteristics in the therapist delivering services (Chadwell et al., 2018). A total of 71 parents completed a client preference questionnaire consisting of 16 questions. Results of the study indicated that parents had a preference for therapists who were warm, accepting, and experienced, and would accept slower progress overall to work with therapists who had those (Chadwell et al., 2018). These researchers identified, as a primary implication of their study, the need for research in the field of ABA to broaden emphasis outside of the effectiveness of treatment to consider client preferences about treatment delivery and how that might impact outcomes.

In summary, ABA has been demonstrated to be the most effective intervention for treating children with autism spectrum disorders. There have been limited studies which have focused on how families are impacted by participation in ABA treatment. Some researchers have explored parental views on ABA treatment with most parents expressing positive views; however, studies in this area continue to be sparse. A limited number of



studies have evaluated how ABA affects sibling relationships, and while there appears to be some evidence of a positive impact, research in this area in particular is still needed.

### **Summary and Conclusions**

In Chapter 2, the literature review presented current literature related to autism and its diagnosis and characteristics, how parents and siblings are impacted by having a child with autism, and ABA treatment for autism. The increasing prevalence in the diagnosis of ASD has broadened research interests within this area. Many studies have been conducted related to how the prevalence of autism has changed over the years, the best methods for screening and diagnosis of ASD, and exploring the impact of the various characteristics and symptoms of autism. In addition, there have been studies that explore the impact of parenting a child with autism and how siblings of children with autism are affected.

Evaluating the various available treatment options for ASD is another prominent area of research related to this topic. ABA has been empirically validated as the most effective intervention for children with autism leading to meaningful changes such as the learning of new skills and minimized challenging behaviors. Based on preliminary studies conducted within the last 10 years, parents of children with autism report positive views of ABA treatment, not only for their child with autism, but also for the family in general. While there have been some studies evaluating parents' perceptions of how ABA impacts the family, this continued to be an area where gaps in the literature were identified, especially because many ABA programs require training and implementation

of interventions by parents and siblings in order to maintain and generalize skills obtained by the child with autism.

This study filled a gap in the literature by using a family systems theoretical framework to explore the lived experiences of parents of children with autism who have received ABA treatment and their perceived changes to the family systems. There was a specific focus on the areas of parental well-being and sibling relationship quality. In Chapter 3, the research method is presented including the research design and rationale, an explanation of the methodology, and a discussion of trustworthiness and ethical procedures.

## Chapter 3: Research Method

### **Introduction**

The purpose of this qualitative phenomenological study was to find meaning in the experiences of parents of children with autism who have received ABA treatment and to understand their perceptions of how ABA treatment outcomes were experienced by the family as a whole. There was a specific focus on the areas of parental well-being and sibling relationship quality. ABA treatment is the most commonly used intervention for children with autism with empirical evidence supporting its effectiveness in teaching new skills and reducing challenging behaviors (Anagnostou et al., 2014). Family interactions and family dynamics are rarely considered when evaluating the effectiveness of behavioral treatments (Jellet et al., 2015). The problem that was addressed in this study was how parents of children with autism experience outcomes that result from ABA treatment.

In this chapter, the research design and rationale are presented. The role of the researcher is discussed. The methodology of the study is described. Finally, issues of trustworthiness are addressed.

### **Research Design and Rationale**

The central research questions for this study and their corresponding sub-questions are included below.

*RQ1:* What are the family dynamics experienced by parents of children with autism who have received ABA treatment?

*SQ1:* What are the experiences of mothers and fathers of autistic children related to parents' interactions with each other?

*SQ2:* What are experiences like in terms of the relationships between parents and the autistic child's siblings who do not have autism?

*RQ2:* What are the experiences of well-being like according to parents of children with autism who have received ABA treatment?

*SQ3:* What are the experiences regarding parental stress levels as a result of the autistic child's participation in ABA treatment?

*SQ4:* What are the parental experiences involving support and acceptance due to the autistic child's participation in ABA treatment?

*RQ3:* What are the experiences in terms of the quality of parental relationships with non-autistic sibling due their autistic child's ABA treatment?

*RQ4:* What are the parental experiences in terms of observing non-autistic and autistic sibling relationships as a result of the child with autism's ABA treatment?

The central phenomenon of this study was the experiences of parents of children with autism who have received ABA treatment and their perceptions of how the outcomes of that treatment impacted the family system with a focus on parental well-being and sibling relationship quality. As noted, ABA treatment for children with autism results in meaningful outcomes for the diagnosed (Durand, 2014). While most behavioral interventions include some form of parent training, a focus on family interactions is needed to ensure overall treatment effectiveness (Powers, 1991). In order to develop a better understanding of how family dynamics might be impacted by ABA treatment, a

qualitative phenomenological approach was used in this study to explore the lived experiences of parents of children with autism and the perceived changes to the family system that resulted from their child's ABA treatment.

The aim of phenomenological research is to capture the essence of a given phenomenon (Yuksel & Yildirim, 2015). This is typically done by conducting in-depth interviews with a small sample size to condense the individual experiences of each participant into common themes described by all (Creswell, 2013). In order to understand the true essence of a phenomenon and find meaning in the experience, the phenomenological approach requires exploring the feelings, thoughts, perceptions, and judgments of those who have experienced the phenomenon (Yuksel & Yildirim, 2015). Another key concept of phenomenological study is that it does not lead to theories of cause and effect but rather describes the concept without preconceived notions or biases about the experience (Sorsa, Kiikkala, & Astedt-Kurki, 2015).

Because there has been minimal research evaluating how ABA treatment affects family dynamics and family interactions, a study that focuses on the lived experiences of parents of children with autism who have received ABA treatment and their perceptions of how the outcomes of ABA treatment impacted the family system would provide valuable information about this phenomenon. The heterogeneity of the experiences that were encountered by each parent resulted in a robust description of the meaning of ABA treatment outcomes for the family system. A specific focus of this study was on parental well-being and sibling relationship quality.

### **Role of the Researcher**

The role of the researcher in qualitative methods is to act as the instrument of data collection and analysis (Yuksel & Yildirim, 2015). In phenomenological studies, the researcher collects data through in-depth open-ended interviews with the participants (Creswell, 2013). The participants are considered coresearchers whose narratives provide the meaning of the phenomenon which the researcher interprets. After data have been collected, the researcher's role is to reduce the data into common themes that describe the phenomenon of study (Yuksel & Yildirim, 2015). In phenomenological studies, the researcher's role is also to acknowledge and address any personal biases that could detract from the task of data analysis (Creswell, 2013). One method for doing this is the process of bracketing, which requires the researcher to be aware of and set aside presumptions about the phenomenon so as not to influence the participants' experiences or understanding of the phenomenon (Sorsa et al., 2015).

For this study, the researcher was keenly aware of personal experiences regarding ABA treatment for children with autism and their potential to influence the analysis and interpretation of the data. This was addressed by the researcher making every effort to bracket herself out of the study so that the researcher's preconceived notions about how meaningful the benefits of ABA treatment for children with autism are to the rest of the family system would not distract from the true lived experiences of the participants. In this study, the research had no personal relationships with the parents of children with autism selected for participation. Although the researcher works in the field of ABA, recruitment efforts were not conducted with families with whom the research had

previously or was currently providing services. There was also no concern related to supervisory or instructor relationships for this study. As already noted, bracketing was used to minimize any potential researcher biases related to ABA treatment and its influence on family dynamics. However, it is important to acknowledge that bracketing does not completely eliminate the perspective of the researcher; it merely brings the focus of the research on the experiences of the participants (Sorsa et al., 2015).

## **Methodology**

### **Participant Selection Logic**

The targeted population for this study was parents of children with autism. In order to select a sample of parents who were best suited to answer the research questions, a purposeful sampling method was used. When using purposive sampling methods, participants are selected because they meet pre-selected criteria that is of importance to the phenomenon being studied (Padilla-Diaz, 2015). This type of sampling method is significant in qualitative research because of the in-depth, information-rich methodologies that form the cornerstone of qualitative approaches (Patton, 2015). The type of purposeful sampling that was used in this study was criterion sampling. The aim of criterion-based sampling methods is to select participants which meet certain pre-selected criteria, thereby making comparisons to those who do not meet the criteria (Patton, 2015). For this study, parents of children with autism who had received ABA treatment were selected for participation.

In order to be selected for participation in this study, parents needed to have a child diagnosed with autism. There were no selection criteria related to the severity of

autism or the presence of specific symptoms or characteristics. The child with autism should have participated in ABA treatment for at least six months. In addition, parents needed to have at least one other child that did not have autism. Selection criteria related to other familial characteristics such as demographics, marital status, or specific family composition were not included. A sample size of eight parents of children with autism who had participated in ABA treatment were used for this study. Research suggests that phenomenological studies should include from six to ten participants (Hagaman & Wutich, 2017). However, in all qualitative studies the idea of thematic saturation should always be considered (Saunders et al., 2018). Most prominent qualitative researchers agree that effective sample sizes in qualitative research cannot be determined by an arbitrarily designated number of participants. However, research has shown that new definitions, codes, and themes rarely emerge following the data analysis of 10 to 12 interviews (Hagaman & Wutich, 2017; Saunders et al., 2018). Factors such as the homogeneity of the group and the complexity of the phenomenon being studied will also influence the sample size needed to reach data or thematic saturation (Saunders et al., 2018). A sample size of eight was selected because it falls within the range of six to ten participants and was sufficient for achieving thematic saturation.

### **Instrumentation**

Data were collected through open-ended interviews with the participants. Interview questions were researcher-developed using a review of other phenomenological studies exploring the lived experiences of parents of children with a disability or autism. A total of 10 interview questions with seven additional probe questions (see Appendix A)



were developed and modeled. Prior to asking participants the interview questions, four demographic questions were asked: age, race, highest education level, and annual family income level.

Interview questions one through three, as well as question nine and question 10 served to answer the research question: What are the perceived changes to family dynamics experienced by parents of children with autism who have received ABA treatment? Interview questions four through six answered the research question: What are the perceived changes to parental well-being experienced by parents of children with autism who have received ABA treatment? Interview questions seven and eight served to answer the research question What perceived changes to the quality of sibling relationships do parents of children with autism experience due their child's ABA treatment?

Content validity was established through various methods of verification throughout the course of the study. Verification strategies assist with making certain the methods used by a researcher measure what the researcher intends to measure (Morse, Barrett, Mayan, Olson, & Spiers, 2002). The first step of verification includes methodological coherence which means ensuring the chosen research method matches the research question (Morse et al., 2002). For this study, a phenomenological approach was well-suited for answering the central research question. Another process of verification to ensure content validity is making sure the sample is appropriate (Morse et al., 2002). This was accomplished by using a criterion-based sampling method and choosing a sample size that allowed for thematic saturation. Another strategy for

verification that was used for this study was collecting and analyzing data concurrently (Morse et al., 2002). This strategy allowed for comparison between what was known about the phenomenon and what still remained to be known during the process of collecting data. In addition to the strategy of collecting and analyzing data at the same time, the strategies of thinking thematically and focusing on thematic development were used (Morse et al., 2002). By using these strategies, emerging themes were reconfirmed by new data collected while new ideas were also verified by data previously collected (Morse et al., 2002). All of these strategies used in combination helped to ensure content validity was achieved.

### **Pilot Study**

A pilot study was conducted in order to assess the reliability and validity of the interview questions. The pilot study was conducted using the same methodology described for the main study. A smaller sample size of two participants was used for the pilot study to determine if any changes to instrumentation were needed to successfully answer the research questions. Following completion of the interviews, data analysis and coding, and the derivation of common themes completed by the researcher, results were reviewed by the dissertation committee including the committee chair, second committee member, and URR. Results of the pilot study are included in Appendix G.

### **Procedures for Recruitment, Participation, and Data Collection**

Participants were recruited from local ABA clinics providing services to children with autism. Initial contact was made with the owners or clinical directors of the following ABA clinics: Tangible Difference Learning Center, Autism House, and Social

Connections Learning Center. Additional recruitment efforts were initiated at other local ABA clinics during the course of the study. This was done via an email (see Appendix B) explaining the purpose of the study and including a flyer (see Appendix C) to distribute to clients in order to recruit participants. Letters of Cooperation were obtained from each agency granting permission to recruit participants from their ABA centers (see Appendix D). In addition, the recruitment flyer was posted online in several Facebook support groups for parents of children with autism. The flyer included my contact information for parents to call or email if they were interested in participating in the study.

Parents who expressed an interest in participating were screened through a short questionnaire (see Appendix E) designed to verify that they met the identified selection criteria. The screening process occurred via email. Screening questions included asking if the parents had a child with autism and at least one sibling without autism, verifying that they had participated in ABA treatment and for how long. Parents who met the selection criteria were then provided informed consent via email in order to acknowledge that they agreed to participate. After informed consent was received, interviews were scheduled.

Data were collected via face-to-face, online Zoom conference, or phone interviews with participants. All data were collected by the researcher. Interviews were audio-recorded and transcribed following the interview by the researcher. Transcripts were emailed to each participant to make sure none of the essence of the interviews was overlooked. Only 2 participants responded to requests to review the interview transcript and neither participant offered additional responses or changes to the transcribed

interviews as written. Interview sessions lasted from 30 to 45 minutes in duration in order to establish initial rapport with participants and to obtain answers to all interview questions, as well as any follow-up probe questions that were asked. Face to face interviews were held at the home of the participants or in private conference rooms at local libraries to ensure privacy. Phone or video conference interviews were conducted in the researcher's private office.

Participants exited the study after data analysis had been completed and they were given the opportunity to review and provide feedback to the researcher on the derived themes. The researcher provided a draft of the themes derived from data analysis via email and asked the participants to provide feedback as to whether or not the common themes adequately described their lived experiences. Participants were also encouraged to share any additional information or input related to their own experiences. Only two participants responded to this final step of the study. Both of these participants acknowledged that the derived themes were indeed representative of their lived experiences. At that time, the researcher contacted the participants via email and provided a copy of the debriefing (see Appendix F) to the participants.

### **Data Analysis Plan**

Data were analyzed using content analysis. Audio-recorded interviews were transcribed into written transcripts. Interview transcripts from all participants were read over several times to get a sense of the information as a whole. This stage of content analysis is called decontextualization (Bengtsson, 2016). While reviewing the interview transcripts, notes or phrases were written as memos to aid in the development of codes

while going through all of the data. The next step of data analysis involved classifying and defining codes (Creswell, 2013). To accomplish this, the researcher used the method of horizontalizing to clean the data. Starting with the very first participant transcript, the researcher identified specific phrases or sentences directly related to the phenomenon of interest. These phrases were then translated into the researcher's own words, capturing the definition for each category which also linked the data to the central research questions and sub-questions. The data from the remaining interview transcripts was sorted and organized by the codes established. These stages of content analysis are referred to as recontextualization and categorization (Bengtsson, 2016). During the process of coding, common themes that emerged and described the essence of the experience were identified which made up the final phase, compilation (Bengtsson, 2016). As new interviews were completed and new data coded, the researcher evaluated if derived themes needed to be revised or if new themes had emerged. Content analysis was accomplished by the use of hand coding. The summary of themes was shared with the participants to allow for feedback in order to make sure themes derived from data analysis matched the participants' experiences (see Appendix H). Revisions to emerging themes were made as needed.

### **Issues of Trustworthiness**

In research using qualitative methods, it is important to establish credibility, dependability, transferability, and confirmability to demonstrate trustworthiness in the results produced from the study (Graneheim & Lundman, 2004). Credibility refers to ensuring that the focus of the research remains true to the intended phenomenon of study

(Graneheim & Lundman, 2004). Credibility also produces confidence in the truth of the study results (Cohen & Crabtree, 2006). The researcher can begin to consider and represent credibility from the start of the study beginning with the selection of participants and continuing through data analysis (Graneheim & Lundman, 2004). In addition, credibility can be established through the use of prolonged engagement in which the researcher spends enough time in the field to learn about the phenomenon being studied (Cohen & Crabtree, 2006). Prolonged engagement is especially useful with establishing rapport and building trust with participants, thus making them more likely to give true accounts of their experiences (Cohen & Crabtree, 2006). Prolonged engagement was one strategy used to establish credibility within my study. Because there were multiple steps between recruitment efforts and the scheduled interview, the researcher and participant had the opportunity to interact several times to establish a certain level of comfort and familiarity. The timeframe from initial contact to the interview date varied with each participant from the minimum of one week to up to one month. Multiple email exchanges between the researcher and participant often occurred during this timeframe in order to complete the screening process, obtain informed consent, and schedule the interview. Frequent communications facilitated rapport between the researcher and participant. In addition, the shared experiences of the researcher and participants with respect to exposure to children with autism and ABA treatment created a common ground that helped to build a level of trust contributing to credibility.

Dependability refers to the consistency of the data collected over time and the degree to which the findings of the study could be replicated (Graneheim & Lundman, 2004). In phenomenological methods using interviews, all participants should be asked the same questions; however, it is possible that insights gained during a particular interview could lead to new or different follow-up questions. While this is encouraged in order to explore the phenomenon fully, it is important that the researcher not stray too far from the focus of the study (Graneheim & Ludman, 2004). One method for ensuring dependability is to have an external auditor who is not a part of the study review both the procedures and results of the study in order to verify the accuracy and validity of findings (Cohen & Crabtree, 2006). For this study, external audits were completed by the researcher's dissertation chair, who reviewed raw data and data analysis in addition to procedures and results reviewed by all dissertation committee members.

Transferability examines whether or not the results of a qualitative study can be generalized to other settings or groups (Graneheim & Lundman, 2004). One strategy for ensuring transferability is to make sure the study clearly outlines the selection criteria of the participants, as well as data collection and data analysis processes (Graneheim & Lundman, 2004). In addition, transferability can be increased with the use of thick description, which includes a robust description of the phenomenon of study (Cohen & Crabtree, 2006). Both of these methods for ensuring transferability were used in this study.

The final component of establishing trustworthiness is confirmability, which aims to demonstrate that the results of the study come from the responses given by the

participants rather than from the influence of the researcher (Cohen & Crabtree, 2006). The method used to establish confirmability for this study was an audit trail in the form of a reflection diary, which included descriptions of all steps of the research process (Cohen & Crabtree, 2006). The audit trail also included raw data collected and all notes taken during the data analysis process that described how categories and themes were derived and how data was synthesized to draw conclusions (Cohen & Crabtree, 2006). In addition to this, notes related to methodological processes and the development of the instrument for data collection were included in the audit trail (Cohen & Crabtree, 2006).

### **Ethical Procedures**

Before beginning the study, approval was obtained from Walden's Institutional Review Board (IRB), approval number 08-22-17-0296265. Once approval was received, the recruitment process began. When contacting potential participants that expressed an interest in the study, the researcher explained the purpose of the study including procedures to ensure protection of the participants. There were no foreseeable or anticipated risks to participation in this study. The participants were parents of children with autism who had the capacity to decide if they wanted to participate in the study or not. Those parents who met the selection criteria and agreed to participate were scheduled for an interview. At the face to face interview, consent forms were provided and signatures obtained before the interview started. For interviews conducted via online Zoom conferences or phone, interviews were not scheduled until informed consent documents had been sent to the participant and returned via email to the researcher. The details of the study and an offer to answer any questions were provided again prior to



beginning each interview. Parents were informed that they were free to withdraw participation from the study at any time, and the limits to confidentiality were explained. Finally, participants were informed that no incentives to join the study were being offered.

To ensure participants of confidentiality, they were informed that real names would not be matched to data collected or included with the results. In addition, participants were informed that only the researcher would have access to all data collected (audio recordings, written transcripts, field notes, etc.). This data was stored in a locked drawer in the researcher's home office. All data stored on the researcher's computer hard-drive or cloud storage were password protected. Participants were informed that following completion of the study, data would be maintained for five years and then destroyed.

### **Summary**

The purpose of this study was to find meaning in the lived experiences of parents of children with autism who have received ABA treatment and to understand their perceptions of how the family system is affected. Chapter 3 outlined the phenomenological research design and included a rationale for selecting this approach, as well as an overview of the researcher's role. The methodology was discussed including how participants were selected, what instrumentation was used to collect data, how participants were recruited, and how data were analyzed. Finally, issues of trustworthiness were discussed and ethical procedures were addressed. In Chapter 4, the findings of this study are presented including the setting, demographics, and results.

## Chapter 4: Results

### Introduction

The purpose of this study was to explore the lived experiences of parents of children with autism who have received ABA treatment and their perceptions of its influence on the family system in terms of parental well-being and sibling relationship quality. This study used a qualitative phenomenological research design. The research questions were:

*RQ1:* What are the family dynamics experienced by parents of children with autism who have received ABA treatment?

*SQ1:* What are the experiences of mothers and fathers of autistic children related to parents' interactions with each other?

*SQ2:* What are experiences like in terms of the relationships between parents and the autistic child's siblings who do not have autism?

*RQ2:* What are the experiences of well-being like according to parents of children with autism who have received ABA treatment?

*SQ3:* What are the experiences regarding parental stress levels as a result of the autistic child's participation in ABA treatment?

*SQ4:* What are the parental experiences involving support and acceptance due to the autistic child's participation in ABA treatment?

*RQ3:* What are the experiences in terms of the quality of parental relationships with non-autistic sibling due their autistic child's ABA treatment?

*RQ4:* What are the parental experiences in terms of observing non-autistic and autistic sibling relationships as a result of the child with autism's ABA treatment?

This chapter will discuss the results of the pilot study, data collection, data analysis, evidence of trustworthiness, and results of the study.

### **Pilot Study**

A pilot study was conducted using the same methodology as the main study in order to assess the reliability and validity of the interview questions. A smaller sample size of two participants was used for the pilot study to determine any changes needed to instrumentation to successfully answer the research questions. Data analysis using the responses given during the first two interviews was conducted. A total of 11 codes were developed and the data collected from the first two interviews were then categorized into those codes. After categorization, a total of nine common themes were derived. Finally, those common themes were reviewed alongside the research questions, and it was determined that the data obtained from the interview questions used during the pilot study were sufficient enough to answer the research questions (see Appendix G). No changes to the instrumentation resulted from the pilot study, and these data were also included in the main study analysis.

### **Data Collection**

Data were collected during the time period between December 2017 and September 2018 via interviews. A total of eight interviews (including two from the pilot study) were conducted for this study. Interviews were held face-to-face, online via Zoom meeting, or by phone. During each interview, participants were asked a series of open-

ended interview questions, and their responses were audio recorded using a voice recorder on an iPhone device using Zoom software. The total duration of interview sessions varied from 30 to 45 minutes in length. The first three interviews were conducted during face-to-face meetings. Zoom meetings and phone calls were added as an additional method of data collection (with IRB approval) after recruitment efforts were expanded beyond local ABA agencies and Facebook parent support groups to include two closed Facebook groups with members located in all areas of the United States.

Flyers were posted in the ABA group which is dedicated to the dissemination of the field of ABA, “promoting behavior analysis by making information about it available to the public through presentations, discussions, and other media” (BACB, 2018, p. 15). The membership of this group includes professionals in the field of ABA as well as parents and caregivers of those receiving ABA services. Group guidelines allow for the posting of content related to ABA or designed for professional networking without permission from the admins or moderators. Additionally, a recruitment flyer was posted in the Autism on the Seas Community group, a closed Facebook group for families who have used the Autism on the Seas travel agency to book autism-friendly cruises. Permission to post the flyer in this group was not required. Parents who expressed interest in participating via public comments on the Facebook group posts were initially contacted privately via Facebook Messenger. After giving a brief overview of what participation in the study would entail, prospective participants were asked to provide their email address so that the researcher could contact them from an official university email to proceed with the screening questions.

Initial selection criteria (parents with children under the age of 12 who had received ABA treatment for at least 6 months to no more than 3 years) were expanded due to slow and unsuccessful recruitment efforts yielding participants that did not meet all required criteria. Parents expressing an interest in participation who had a child with autism of any age who had received ABA treatment for any length of time were invited to participate in the study. Expanding these selection criteria did not have an impact on the consistency of responses across interview questions and did not result in any significant changes to already established codes or derived themes.

### **Demographics**

Demographic information related to age, race/ethnicity, educational level, and annual household income level were collected for all participants and is represented in Table 1. All of the participants were between the ages of 35 and 50. Five participants identified the race/ethnicity of their family as Caucasian, one participant identified their family as Hispanic, one participant identified their family as Asian, and one participant identified their family as both Hispanic and Caucasian. All participants indicated some degree of college education with four parents identifying a Bachelor's degree as the highest education level within the family, three parents identifying a Master's degree as the highest education level, and one parent identifying some college as the highest education level. Annual household income level varied from \$30,000 up to \$200,000 per year.

Table 1

*Demographics of Participants*

Participant Number	Age	Gender (Mother or Father)	Race/Ethnicity	Education Level	Annual Household Income Level
001	35 - 40	Mother	Hispanic/Caucasian	Some college	\$50 – 60,000
002	40	Mother	Asian	Master's	\$80,000
003	36 - 41	Both	Hispanic	Bachelor's	\$200,000
004	46 – 50	Mother	Caucasian	Bachelor's	\$110,000
005	45 – 50	Mother	Caucasian	Bachelor's	\$120,000
006	46	Mother	Caucasian	Master's	\$30,000
007	38	Mother	Caucasian	Bachelor's	\$90,000
008	44	Mother	Caucasian	Master's	\$150,000

**Data Analysis**

Data from each of the transcribed interviews were reviewed and key statements correlating to spousal relationships, parental stress levels, support and acceptance from others, sibling interactions, and the effects of participation in ABA treatment in all of these areas were derived. These key statements were organized in tables by participant number. From the key statements extracted from participant 001 and 002, 14 universal codes were created as representative meanings from those statements. A selection of key statement examples (with participant numbers indicated in parenthesis), as well as the universal codes derived from those statements, are included in Table 2. During the next phase of data analysis, data from each interview that supported the universal codes were categorized. Finally, 10 common themes across all coded and categorized data were developed.

Table 2

*A Selection of Key Statements and Universal Codes*

Key Statements	Universal Codes
<ol style="list-style-type: none"> <li>1. Good relationship with husband but takes a lot of work</li> <li>2. Stronger relationship with spouse. Now able to lean on each other.</li> <li>3. A lot of stress is felt as a parent of a child with autism</li> <li>4. Relationship between siblings has improved since starting ABA because son with autism is learning and improving.</li> <li>5. ABA reduces stress because it helps your child be more independent.</li> <li>6. ABA helps make important behavioral changes and teaching new skills</li> <li>7. ABA made public outings easier because he learned rules and expectations for how to behave in public.</li> <li>8. ABA is time consuming and challenging. It is a way of life, not just a therapy.</li> </ol>	<ol style="list-style-type: none"> <li>1. Good relationship with spouse</li> <li>2. Relationship with spouse improved after starting ABA</li> <li>3. ABA helped parents work together</li> <li>4. Effort is needed to make time for the child without autism</li> <li>5. Experiences a high level of stress</li> <li>6. Improvements in stress level since starting ABA</li> <li>7. Accepted by close family</li> <li>8. Family members notice a change in child since starting ABA</li> <li>9. Acceptance from others in the community has improved since ABA</li> <li>10. Siblings developed their own way of communicating</li> <li>11. Siblings experiences some negative emotions about having a sibling with autism</li> <li>12. Improvements to sibling relationships since starting ABA</li> <li>13. Improvements in child with autism is benefit</li> <li>14. Consistency is a challenge but ABA is worth it despite challenges.</li> </ol>

This process of selecting key statements and categorizing data from each interview was conducted with each subsequent transcribed interview for all eight participants. A total of 113 key statements related to the experiences of parents of children with autism who had received ABA treatment were extracted from the eight participant interviews. After data analysis was completed for a transcribed interview, results were compared to previously analyzed transcripts and the emerging themes were reviewed to see if conflicting views or new themes would emerge. At the conclusion of data analysis, the ten common themes outlining the lived experiences of parents of children with autism and their perceptions about how the outcomes of their child's ABA treatment impacted family dynamics, parental well-being, and sibling relationship quality were then organized into theme clusters (see Table 3).

Table 3

*Theme Clusters*

Theme Clusters	Associated Common Themes
Family interactions	<p>Theme 1: Parents of children with autism have overall good relationships with their spouses, but communication and mutual respect for each other becomes more important after diagnosis. Participating in ABA treatment helps parents speak the same language and stay on the same page.</p> <p>Theme 2: Relationships between parents and siblings without autism can become strained, with less attention given to the child without autism; however, parents put forth efforts to make time for their other children.</p>
Parental well-being	Theme 3: Parents of children with autism face a high level of stress and worry. <i>(table continues)</i>



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	<p>Theme 4: Participating in ABA treatment results in a decrease in some sources of stress.</p>
	<p>Theme 5: Parents of children with autism typically receive some acceptance from close family members but feel validated and accepted even more once family members notice changes in the child that occur after starting ABA treatment.</p>
	<p>Theme 6: Acceptance in public settings was a challenge noted by parents of children with autism and an additional source of stress; however, participation in ABA lead to improvements in access to or acceptance within public settings.</p>
Sibling relationship-quality	<p>Theme 7: Sibling relationship quality can be strained due to difficulty interacting with the sibling with autism because of communication or behavioral challenges.</p> <p>Theme 8: Siblings develop their own unique ways of communicating with each other. Participation in ABA treatment leads to changes in the behaviors of children with autism that facilitate better interactions with their siblings. Overall, the relationship quality between siblings appears to improve.</p>
Benefits and challenges	<p>Theme 9: Parents acknowledge that participation in ABA treatment produces noticeable changes and progress in their child with autism, but consistency is important and can be a challenge.</p> <p>Theme 10: Overall, parents of children with autism belief that benefits of participation in ABA treatment are worth it despite the challenges.</p>

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### **Evidence of Trustworthiness**

The method of prolonged engagement was used to establish credibility.

Prolonged engagement occurs when the researcher spends enough time in the field to learn about the phenomenon being studied (Cohen & Crabtree, 2006). The researcher for this study has spent many years working in the field of ABA with families of children with autism prior to the start of the study. This was likely helpful in establishing rapport with the participant families. In addition, the researcher engaged in several email exchanges with each participant prior to the interview. It is likely that this also helped the participants feel comfortable sharing their experiences with the researcher when answering the interview questions. Following completion of data analysis, the researcher engaged with each participant by providing them with an opportunity to review the common themes to verify if they adequately described their lived experiences.

Transferability methods used for this study were designed to clearly outline the selection criteria and methods for data collection and data analysis. The researcher acknowledges that adjustments to the selection criteria were made over the course of the study with regard to the age of the child with autism and the duration of time spent in ABA treatment. This shift was made due to the shallowness of the prospective participant pool meeting the specific criteria for participation that was initially selected. Despite these adjustments, the data collection and data analysis methods remained consistent. In addition, changes to selection criteria did not result in data that were inconsistent with that of participants meeting all criteria. In order to ensure dependability, the same interview questions were asked to all participants. The

dissertation chair served as external auditor by reviewing each step of the procedures for participant selection and data collection, as well as the results of the study, to verify the accuracy of the findings. Finally, confirmability was achieved through the use of an audit trail. In addition to memo notes used to develop key statements, universal codes, and common themes, a reflective diary was kept by the researcher outlining thought processes during each step of data collection and analysis.

## **Results**

The participants of this study shared their experiences parenting a child with autism and perceptions about how their child's participation in ABA treatment influenced family dynamics. Their responses to the 10 interview questions and associated probe questions resulted in nine common themes organized into four main theme clusters.

**Cluster 1: Family interactions.** Theme 1 was parents of children with autism have good relationships with their spouses, but communication and mutual respect for each other becomes more important after diagnosis. ABA treatment helped parents speak the same language and stay on the same page. All of the participants in this study indicated that their relationship with their spouse was good or "typical" prior to their child starting ABA. After their child started to receive ABA treatment, spouses had to begin to communicate even more. Participant 002 noted "we moved up to a whole new level of understanding with one another... and it's actually very good." ABA gave spouses a common language to speak and helped them work together. According to Participant 004, "[ABA] has helped us so much because now we can talk as adults about what we need to do with [our son]." Participant 005 also noted that ABA "helped us with

our parenting style and getting on the same page.”

Theme 2 was relationships between parents and siblings without autism can become strained, with less attention given to the child without autism; however, parents put forth efforts to make time for their other children. Participant 001 shared the following experience about her older daughter who does not have autism:

I noticed there was a strain in that relationship too. She tries to be a little more sneaky because she knows our focus is more on [my son]. So, she tries to sneak around, you know, with the makeup and the boys. So, I noticed that. But at the same time, we still try to make time for her and focus on what she’s doing too.

Participant 002 shared a similar experience with her older daughter:

She was the one who used to get most of my attention until then. And ever since the other kid came and ever since he was diagnosed, it actually went down gradually and she wasn’t obviously getting as much. There are some, you know, things where I have to put her aside, but there are most of the things where she is my total priority.

For participant 003, making time for the older son without autism is a priority for both parents.

We make sure that we spend time with him alone. I’ll do reading or I’ve done junior achievement in his class. And I like doing that because it’s me with him at his school and his environment. And Dad does the same with the boy scouts. We have open communication with him, we talk to him all the time.

**Cluster 2: Parental well-being.** Theme 3 was parents of children with autism face a high level of stress and worry. Parent 001 noted feeling “like I’m spread really thin in everything.” Participants 002, 003, 004, 005, and 006 all expressed high levels of stress associated with worrying about the future of their children with autism. Participant 006 said “it’s very stressful. You worry about his future, you worry about who is going to take care of him. You worry about every second of the day.” Participant 005 indicated worries related to financial stress. For Participants 004 and 007, communicating with or understanding their child with autism, as well as managing challenging behaviors, can be sources of stress. According to Participant 004 “when I can’t get things across to [son] that can be very stressful. And when we go out. You know when he acts up, trying to get him back under control and then getting looks from people is very stressful.” Participant 007 expressed a poignant fear related to her oldest daughter with autism’s meltdowns given she has a 17-month old baby in the home:

she has a history of aggression which we manage with medication and ABA. But there’s always this thing in the back of my head that says what if she’s like this and having a meltdown and not in control of her anger... if she lashes out. What then? Because the baby is a lot smaller than she is. So, there’s always sort of that small paranoia in the back for my head that something is going to happen.

Theme 4 was ABA treatment results in a decrease in some sources of stress. ABA treatment provided parents with some hope, as indicated by Participant 002 who said stress levels “improved, I feel, because at least we are doing something productive.” Participants 001 and 003 noted improvements in stress levels after their child started

ABA treatment due to the progress they noted in their child with autism: “we feel he’s getting what he needs. And we see progress.” Participant 005 noted that ABA treatment increased stress initially due to the financial concerns associated with paying for therapy. However, she also credits the teaching methods used within ABA as a source of stress reduction:

I think starting ABA actually brought more stress because of the financial impact of that stress. But, completely and 100% worth it. He stayed at grade level, he learned social skills... I mean, he’s always going to have a deficiency in recognizing facial expressions, but ...if it weren’t for breaking down those skill sets, he would never have learned it until today. Which then reduces your stress.

Participant 007 and 008 both acknowledged a reduction in stress due to decreases in their child’s challenging behaviors after receiving ABA treatment. Participant 007, who was a step-mother to two daughters with autism, stated, “when they first came to live with us, they were little tyrants. We were having multiple hour-long meltdowns a day when they first came to live with us. But that sort of meltdown never happens anymore.” Participant 008 similarly stated “the therapists would give me little tips and things to help out” when it came to handling and teaching her son with autism which improved her stress levels.

Theme 5 was parents of children with autism typically receive some acceptance from close family members but feel validated and accepted even more once family members notice changes in the child that occur after starting ABA treatment. Participant 007 shared, “So on my side of the family, everyone is very welcoming and everyone bends over backwards to try to accommodate the girls.” This same parent indicated that

due to ABA treatment “my family cannot stop lavishing praises on how well they’re doing in life in general. It feels less charitable now. It feels like they genuinely enjoy spending time with them.” Participants 001, 003, 004, and 008 indicated that they had support from everyone in their family. Only one participant shared an experience differing from those of the remaining participants in which she indicated absolutely no familial support “Zero. Zero. My sister still thinks that I taught [son] the rituals. But zero... if there’s a minus/negative, I would say negative.”

Family members begin to notice a change in the child with autism after they have received ABA treatment. Participant 001 responded, “My mom has really noticed a change in him with his eye contact and when you call his name and he’ll come to you and stuff like that. So yes, they’ve noticed it.” Participant 002 said “people whom I know very closely have noticed the good changes in him and they come to me and tell me.” Participant 007 indicated “My family cannot stop lavishing praises on how well they’re doing in life in general. It feels less charitable now. It feels like they genuinely enjoy spending time with them.”

Theme 6 was acceptance in public settings was a challenge noted by parents of children with autism and an additional source of stress; however, participation in ABA lead to improvements in access to or acceptance within public settings. For example, Participant 003 stated that her son was able to participate in baseball after receiving ABA treatment and noted “without ABA, that probably would not have been possible.” Other parents noted that improvements in problem behavior and the ability to accept no made it

easier for families to go into community settings without receiving judgmental looks or comments from others.

For Participant 004, ABA treatment was especially helpful with going into grocery stores. She shared:

In the beginning, like I said, he could not accept no. And when we were in a grocery store, and he saw something he wanted to eat, which was usually junk food, I would tell him no and he would have a complete meltdown. Very rarely does he act like that so it's much, much better. I'll tell you ABA has been a lifeline for us.

According to Participant 005, ABA was helpful with being accepted in public settings "because it taught him rules that he needs to follow in public places." Participant 007 similarly noted "because the girls are better behaved in the stores and not having so many meltdowns, we don't get as many dirty looks."

**Cluster 3: Sibling relationship-quality.** Theme 7 is siblings relationship quality can be strained due to difficulty interacting with their sibling with autism because of communication or behavioral challenges. Siblings of children with autism may show signs of jealousy or embarrassment, or they may become the victim of their sibling's challenging behaviors. For Participant 008, her younger son without autism was often the victim of his brother's physical aggression. "[Son with autism] was very rough with him, would grab him, would hit him, would squeeze him. Wouldn't let him touch any of his toys."



For Participant 001, her daughter without autism displayed some signs of jealousy at the attention her younger brother with autism was receiving, and she was embarrassed and grossed out by his challenging behavior of eating inedible items.

I noticed that she does get jealous sometimes, I think that's where the struggle with my daughter and son came in because she would try to play with him and he would elope within a minute. The challenging behavior was the pica. Initially, she was grossed out by everything he did.

Parents also begin to experience some guilt as they have to give more attention to their child with autism. Participant 003 noted:

I think he's probably now getting a little bit more of the short end of the stick. Because you know, when he wants to play with a toy, and [son with autism] will come and want the same toy... you know to avoid conflict, many times we say "well, just let him borrow it." And he reluctantly will do it. So, I think it's affected him that way.

Theme 8 was siblings develop their own unique ways of communicating with each other. ABA treatment leads to changes in the behaviors of children with autism that facilitate better interactions with their siblings. Overall, the perceived relationship quality between siblings appears to improve. Despite challenges with interactions among siblings, parents' note that their child without autism often shows a great amount of care for or understanding of their sibling with autism. Participant 002 indicated "I think being siblings they have their own language. Though, they do have verbal communication. But still, she can read him so well. She understands him so well." According to

Participant 003, the siblings “have a love/hate relationship” but the sibling without autism is “very accepting of [his brother] being different.” Participant 006 stated that her son without autism “used to know him better than us... at his level. Used to be able to figure him out and was very protective of him.” Participation in ABA treatment lead to improvement in sibling interactions. For example, Participant 001 noted that improvements in the ability to sit for an extended period of time and remain engaged in an activity increased her daughter’s ability to interact with her brother with autism. “When he wasn’t in ABA, he wasn’t engaged at all. But after the ABA, she can actually sit and play with him and he’ll engage with her.”

ABA also taught the children with autism appropriate social skills and play skills needed to respond to and initiate appropriate interactions with their siblings. Participant 001 also noted “But now that he’s gotten better and she knows how to reinforce good behavior with him, it’s gotten much better. Like she enjoys... she actually seeks him out now and it didn’t use to be that way.” According to Participant 005, “If ABA had not taught him how to interact more appropriately, he would not have been able to communicate with his sister which helps foster the relationship. So, ABA did teach him basic skills needed to foster relationships.” Participant 007 similarly indicated “They’re better at playing with each other. The ABA has helped facilitate the baby being able to play with her sisters.” Participant 008 said “the relationship between the 2 of them excelled and really changed between [son with autism] and his younger brother. There was a huge change in their relationship and the way [he] stopped grabbing him and hurting him and fighting him and everything.”

**Cluster 4: Benefits and Challenges.** Theme 9 was parents acknowledge that participation in ABA treatment produces noticeable changes and progress in their child with autism, but consistency is important and can be a challenge. Decreased problem behaviors were noted as the biggest benefit for Participant 001 who said “behaviors will decrease dramatically. We’ve seen like a tremendous change in [son] since we started ABA.” According to Participant 003, her son’s decrease in tantrums is a benefit as well his acceptance to try things that were previously intolerable. She noted, “I think he is learning to accept that he has to do things he doesn’t like.” Participant 005 indicated that increased generalization of skills was the biggest benefit:

ABA is wonderful for pre-teaching, it is wonderful for breaking down a skill that is difficult. It teaches them a basic skill that then they can begin to generalize, that’s the biggest part of ABA. My son learned how to play independently because of ABA. You can generalize so many things from ABA. And that’s the biggest benefit he got and the biggest benefit we got.

Participant 006 gave a similar response about the benefits of ABA: “it would help with being able to motivate the child, being able to teach new behaviors.” Participants 007 and 008 both indicated the usefulness of ABA strategies in their day to day lives.

Participant 007 said “the language program was really beneficial. And we can actually use ABA drills in order to circumvent problem behaviors from happening. And that has been incredibly useful in our day to day lives.” According to Participant 008, ABA is beneficial because “It helps them learn better. I think that the discipline of it and repetitive nature of it helps them understand what’s going on a little more.”

All of the participants commented on the importance of consistency and the amount of follow through needed for ABA to produce these benefits. Many of the participants indicated consistency as the biggest challenge. Participant 001 said “follow through. It’s exhausting. You have to follow through at home. it has to be consistent. If you’re not consistent, it’s not going to work.” Participant 004 also stated “I would say the biggest challenge is finding the time to do it. And the following through... because no matter how much a therapist can come in and work with a child, if the parents are not involved, it’s not going to work.” Similarly, participants 006, 007, and 008 all commented on that parents must be invested and carryover strategies outside of session and cannot rely on ABA therapists to do all of the work.

Theme 10 was that overall, parents believed that the benefits of ABA treatment are worth it despite the challenges. Participant 001 stated that she “would highly recommend ABA to a lot of parents,” and Participant 003 indicated, “I would tell people who need it, yeah definitely try it.” Participant 004 stated “I don’t know what I would have done without ABA therapy.” Participant 008 indicated “I think that the structure and routine of it is what they need and what they like, so I am a very big proponent of it.” Participant 007, in particular, pointed out the overall benefits of ABA, not only with her daughters with autism, but also with her toddler. She said “I think every parent should actually have to do ABA!”

In conclusion, the parents of children with autism who have received ABA treatment participating in this study shared similar experiences and perceptions of the impact of ABA treatment on family interactions, parental well-being, and sibling

relationship quality. Each of the participants were able to identify similar benefits and challenges associated with participation in ABA treatment. Overall, for the parents participating in this study, their lived experiences as parents of a child with autism who has received ABA treatment is that the benefits to their families were worth it despite the challenges.

### **Summary**

According to the results of this study, parents of children with autism who have received ABA treatment experience perceived improvements to family dynamics and family interactions. Spouses are able to communicate with each other better and stay on the same page. Although strains may develop within relationships amongst their other children, parents attempt to make time for their children without autism. Outcomes received from ABA treatment improves parental well-being by reducing stresses associated with parenting a child with autism. Parents feel validated when family and friends notice changes in their child with autism following participation in ABA treatment and they observe more acceptance or access to community settings. Parents perceive improvements in sibling relationship quality between their child with autism and his or her siblings. Outcomes from ABA treatment leads to improvements in the siblings' ability to communicate, interact with, and relate to or accept their sibling with autism. In Chapter 5, the purpose and nature of the study is reviewed and a concise summary of key findings as they relate to the overall lived experiences of parents of children with autism who have received ABA treatment is provided.

## Chapter 5: Discussion, Conclusions, and Recommendations

### **Introduction**

The purpose of the study was to explore the lived experiences of parents of children with autism who have received ABA treatment and understand their perceptions regarding how ABA treatment outcomes influence family dynamics with a particular focus on parental well-being and sibling relationship quality. A qualitative phenomenological methodology was used to accomplish this task as it produces rich data that finds meaning in the phenomenon based on the experiences of those who have lived through it (Davidsen, 2013). Based on the lived experiences shared by the eight parents of children with autism who were interviewed for this study, their child's participation in ABA treatment had an overall positive and meaningful impact on parental stress levels and sibling relationships. Parents specifically indicated that despite some of the challenges presented by participating in ABA treatment such as the need for consistency and follow through, progress for their child with autism made the benefits of participating in ABA treatment worth it. The improvements noted after participating in ABA treatment in turn reduced parental stress and improved interactions amongst siblings.

### **Interpretation of the Findings**

The results presented in Chapter 4 in the form of clusters of common themes served to answer the research questions central to the purpose of this study. These resulting common themes are rooted in the theoretical framework of family systems theory. Minuchin's structural family systems model, which focuses on familial boundaries, functional demands, and family interactions lies at the core of the research

questions designed to explore the experiences of parents of children with autism and their perceptions of how ABA treatment outcomes influence the entire family. The interpretation of the findings as it relates to each research question is included below.

*RQ1:* What are the family dynamics experienced by parents of children with autism who have received ABA treatment?

*SQ1:* What are the experiences of mothers and fathers of autistic children related to parents' interactions with each other?

*SQ2:* What are experiences like in terms of the relationships between parents and the autistic child's siblings who do not have autism?

Challenges within the areas of family dynamics and family interactions indicated by the participants in this study confirmed the results found in other studies discussed in the literature review in Chapter 2. All participants in this study experienced high levels of stress or anxiety associated with parenting a child with autism. Guilt over the amount of attention or time taken away from siblings without autism was another common challenge amongst the interviewed participants. The participants in this study noted stresses associated with many different factors including deficits in communication, rigidity or insistence on sameness, and challenging behaviors present in their children with autism and how those symptoms of autism had an impact on their other children. In addition, worry about the future of their children with autism due to these characteristic symptoms were a big source of anxiety for the participants of this study. One extension of the literature indicative of the results of this study is that parents of children with autism regard their child's participation in ABA treatment as a catalyst for improving

communication between spouses and making more time for their children without autism a priority. Improved communication varied from simply checking in with each other more often and making time for their other children to helping spouses learn parenting styles. Parents participating in this study credited ABA with giving them a common language to speak when it came to handling issues with their children with autism. For most of the participants of this study, family interactions and family dynamics appeared to improve following their child's ABA treatment.

*RQ2:* What are the experiences of well-being according to parents of children with autism who have received ABA treatment?

*SQ3:* What are the experiences regarding parental stress levels as a result of the autistic child's participation in ABA treatment?

*SQ4:* What are the parental experiences involving support and acceptance due to the autistic child's participation in ABA treatment?

Many of the participants indicated a reduction in stress levels as a result of their child's participation in ABA treatment. In addition, the reasons participants acknowledged as to why participation produced a reduction in stress levels were improvements in their child in terms of behavioral issues and social interactions, as well as more manageable community outings with more acceptance from others in those settings. Parents similarly noted a reduction parental stress by attributing participation in ABA treatment with alleviating some of the worries and concerns for their child's future. For the participants in this study, ABA treatment increased their children's progress through learning various important skills for independence. Because worry about the



future was a strong source of stress for many of the participants, seeing progress due to ABA reduced some stress levels and gave parents more hope for the future. Overall, the participants in this study saw a positive impact on their own well-being due to their child's participation in ABA treatment.

*RQ3:* What are the experiences in terms of the quality of parental relationships with non-autistic sibling due their autistic child's ABA treatment?

*RQ4:* What are the parental experiences in terms of observing non-autistic and autistic sibling relationships as a result of the child with autism's ABA treatment?

Jealously or embarrassment on the part of the sibling without autism, as well as difficulty with relating to or interacting with their sibling with autism were common to the experiences shared by all of the participants in this study. Several of the participants acknowledged some sense of jealousy on the part of their children without autism, especially when it came to the use of reinforcement procedures associated with ABA treatment. Some siblings told their parents that they were not treated fairly and should also be receiving similar rewards. Two participants also expressed that siblings without autism experienced embarrassment with respect to some of the behaviors their siblings with autism engaged in. All participants expressed there being some form of difficulty related to interactions or communication amongst siblings; however, sibling relationship quality showed resiliency as siblings developed their own form of communication or understanding of each other. The results of this study extended the literature in the area of how participation in ABA treatment influences sibling relationship quality. Positive changes in children with autism that resulted from participation in ABA treatment, such

as a reduction in challenging behaviors or an increase in the ability to sustain and/or tolerate interactions with others served as a catalyst for fostering improvements in sibling relationships.

The participants in this study collectively found ABA treatment to be beneficial, aligning with the positive impact of ABA on family life, parental stress level, and sibling relationships already noted in the literature. Several participants reported increased tolerance of new things and reduced challenging behaviors in their children with autism following participation in ABA treatment. As a result, families were able to participate in new experiences such as baseball or boy scouts, as well as to enjoy previously difficult activities such as going to the grocery store. Many of the participants who noted that their children without autism had previously seemed embarrassed by or had fallen victim to challenging behaviors exhibited by their sibling with autism acknowledged that sibling relationship quality was perceivably improved. These parents noted that siblings found new ways to interact with each other as a result of positive outcomes produced by ABA treatment. These types of improvements in sibling interactions that resulted from ABA treatment produced reductions in stress levels and improved parental well-being. Overall, the experiences of the parents of children with autism who participated in this study were positive and ABA treatment was regarded as beneficial to the family as a whole.

### **Limitations of the Study**

One limitation of this study is the small sample size. Despite the fact that phenomenological studies often have a small sample size in order to allow for in-depth interviews to capture the true experiences of the participants (Creswell, 2013), the sample

size of 8 is fewer than the identified sample size of 12 at which thematic saturation is typically met (Hagaman & Wutich, 2017). It is possible that using a sample size of 8 could limit transferability and that the common themes derived from the 8 participants of the study are not common to the experiences of other parents of children with autism who have received ABA treatment. Although this limitation exists, it is important to acknowledge the overarching similarity in many of the responses to interview questions given across all eight participants.

Another limitation and possible threat to transferability is the variance in selection criteria that evolved throughout the course of data collection. Although initially a very strict selection criteria of parents of children with autism under the age of 12 years old who had participated in ABA for at least six months but no more than three years was sought, this was expanded to include children with autism of any age who had participated in ABA at any point in life for any amount of time. Despite this change to selection criteria, a very homogenous sample emerged, which could be another possible limitation of this study impacting transferability. The majority of the participants in this study were middle aged, Caucasian, college-educated, and fell within the middle to upper middle class in terms of socioeconomic status. While this served to unify the overall lived experiences of the participants in this study and allowed for the derivation of common themes that adequately described their experiences, these similarities could also negatively impact the ability to assume that those experiences would be shared by every parent of a child with autism who has received ABA treatment.

One final limitation noted for this study is that some specific characteristics relating to participant selection were not specified at the onset of the study. For example, the term family was defined very broadly (aside from needing a child with autism and a sibling). There were also no stipulations as to whether or not mothers, fathers, or both parents needed to participate in the interview. Defining these requirements prior to participant selection may have contributed to a more robust sample involving the perspectives of multiple family members. In addition, no specifications related to severity or type of ASD the affected child was diagnosed with were included. Severity of symptoms of autism could have a direct impact on ABA treatment outcomes and the lived experiences of parents.

### **Recommendations**

In this study, a qualitative phenomenological method was used to find meaning in the lived experiences of parents of children with autism who had received ABA treatment and to explore their perceptions of how ABA treatment outcomes were experienced across the family system. Selection criteria was not specific as to whether participants should be mothers, fathers, or both. For this study, all of the participants were mothers with the exception of one interview in which both the mother and father participated. In addition, although sibling relationship quality was one of the primary components of interest within this study, siblings were not interviewed directly. One recommendation to extend the results of this study and the literature within the area of how ABA treatment outcomes impact families as a whole would be to include mothers, fathers, and siblings in the interview process.

Given the identified limitations of the study with respect to the homogeneity of the sample, another recommendation would be to obtain a more heterogeneous sample of families of children with autism in order to evaluate if the lived experiences transcend across families of varying demographical characteristics. This could be accomplished by expanding the sample size and selection criteria to make sure families from different age groups, ethnic and socioeconomic backgrounds, education levels, as well as complex or unique family compositions such as blended family, same-sex couples are included.

Additional areas for future research should address some of the challenges associated with participation in ABA treatment that were noted by the participants in this study. Several of the parents indicated that time constraints or difficulty with follow through and consistency of implementation related to ABA principles were a challenge. Continuing to develop research-based methods that will help to facilitate parent training in ABA principles, as well as to incorporate the entire family into ABA service provision, are important areas for future research for service providers within the field of ABA.

### **Implications**

The purpose of this study was to capture the lived experiences of parents of children with autism who participate in ABA treatment with a focus on exploring the perceived influence of ABA treatment outcomes on family systems with respect to parental well-being and sibling relationship quality. For these parents, having a child with autism resulted in unique challenges and a high level of stress, all of which were tied to the presence of characteristic symptoms of autism such as difficulty with communicating and social interactions, insistence on sameness, and challenging

behaviors. The common themes amongst all of the participants was that the positive outcomes received from their child's participation in ABA treatment such as improvement in communication or behavioral issues were beneficial to the family as a whole. ABA treatment led to a perceived reduction in parental stress levels and appeared to fostered better interactions amongst siblings. The results of this study provide implications for families of children with autism who may be interested in seeking ABA treatment. All of the parents noted that despite some of the challenges associated with participation in ABA, the benefits to both the child with autism and family interactions as a whole make it all worth it.

The results of this study also have implications for service providers within the field of ABA. The focus of most ABA treatment programs is on progress and outcomes for the child diagnosed with autism. This study provides evidence of how much ABA treatment outcomes have an influence on the family as a whole. For service providers of ABA treatment, this sheds new light on important factors to consider when designing ABA treatment programs including ease of implementation and how to help parents be consistent, as well as how to incorporate or consider sibling interactions into behavioral interventions.

### **Conclusion**

Parenting a child with a disability creates a huge amount of stress (Powers, 1991). For parents of children with autism, in particular, challenges are even more complex due to the unique characteristics of the disorder such as limited communication and social interaction, rigidity and insistence on sameness, and the presence of problem behaviors

such as aggression or self-injury (CDC, 2018; Ludlow et al., 2011). Siblings of children with autism are also affected by the disorder, often experiencing negative feelings toward their sibling with a disability (Williams et al., 2010) or having difficulty interacting or relating to their sibling with autism (Cebula, 2012; Dillenburger et al., 2010; Ward et al., 2016). ABA has been empirically validated as the most effective treatment for children with autism leading to improvements in many of the characteristic symptoms of the disorder (Anagnostou et al., 2014; Durand, 2014). Despite the fact that many ABA treatment programs require continued implementation of treatment packages by the parents to promote maintenance and generalization of improved skills (Makrygianni et al., 2018; Peters-Scheffer et al., 2011), there has been a deficit within the field of ABA research focusing on how participation in ABA treatment truly affects families as a whole.

This study explored the lived experiences of parents of children with autism who have received ABA treatment and their perceptions of how ABA treatment outcomes are experienced by the family system. The findings are an important addition to the literature demonstrating the benefits of ABA for children with autism. Increased communication amongst parents, an overall reduction in parental stress levels, easier access to community settings, and improvements in the relationships between their children with autism and his or her siblings are the meaningful ways in which positive ABA treatment outcomes for a child with autism are shared by the family as a whole.

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## Appendix A: Interview Questions

Demographic Information:

Age:

Race:

Highest Education Level:

Annual Household Income:

1. What is the typical day to day routine for your family?

Probe: What changes to your day to day routine have you noticed since starting ABA treatment?

2. What is your relationship like between you and your husband/wife?

Probe: What changes have you noticed between how you and your husband/wife interact with each other since starting ABA treatment?

3. What is the relationship like between you and your children that do not have autism?

Probe: What changes have you noticed about how you and your other children interact since starting ABA treatment?

4. How much stress do you feel as a parent of a child with autism?

Probe: How has your stress level changed since starting ABA treatment?

5. How would you describe the amount of support and acceptance you have received from your extended family and friends?

Probe: In what ways has your support or acceptance from others changed since starting ABA treatment?

6. How has starting ABA treatment impacted how you and your children are treated in public settings?
7. Tell me about the interactions between your child with autism and his/her sibling(s)?
  - Probe 1: How does your child with autism communicate with his/her sibling(s)?
  - Probe 2: Does your child with autism display any challenging behaviors and how does his/her sibling(s) feel/react when those occur?
8. How has the relationship between your child with autism and his/her siblings changed since starting ABA treatment?
9. What would you tell families of children with autism about the benefits of ABA treatment?
10. What would you tell families are the challenges of ABA treatment?

## Appendix B: Recruitment Email

Dear \_\_\_\_\_:

My name is Monica Labrie, and I am a PhD student in the Educational Psychology program at Walden University. I am conducting a study to explore how participation in ABA treatment for children with autism affects the family system with a focus on parental well-being and sibling relationship quality. I am contacting you to request permission to recruit participants for my study through \_\_\_\_\_ (name of ABA agency). I have attached a recruitment flyer that contains additional information about the purpose of the study and the selection criteria for participation which can be distributed to families who receive services through your agency. If you have any additional questions or concerns related to the study, please feel free to contact me at this email address or the phone number below. I look forward to hearing from you.

Thank you for your time!

Sincerely,

Monica Labrie, M.A. BCBA

## Appendix C: Letters of Cooperation

Tangible Difference Learning Center  
7000 NW 100 Dr. Ste B104B  
Houston, TX 77450

4/30/17

Dear Monica Labrie,

Based on my review of your research proposal, I give permission for you to conduct the study entitled The Experience of Families of Children with Autism Participating in ABA Treatment within Tangible Difference Learning Center. As part of this study, I authorize you to recruit participants who receive ABA services through our organization. Individuals' participation will be voluntary and at their own discretion.

We understand that our organization's responsibilities include: disseminating the recruitment flyer to our clients via our email distribution list and posting the flyer on our bulletin boards in all clinic locations. We reserve the right to withdraw from the study at any time if our circumstances change.

I understand that the student will not be naming our organization in the doctoral project report that is published in Proquest.

I confirm that I am authorized to approve research in this setting and that this plan complies with the organization's policies.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the student's supervising faculty/staff without permission from the Walden University IRB.

Sincerely,



Michael Conteh

Walden University policy on electronic signatures: An electronic signature is just as valid as a written signature as long as both parties have agreed to conduct the transaction electronically. Electronic signatures are regulated by the Uniform Electronic Transactions Act. Electronic signatures are only valid when the signer is either (a) the sender of the email, or (b) copied on the email containing the signed document. Legally an "electronic signature" can be the person's typed name, their email address, or any other identifying marker. Walden University staff verify any electronic signatures that do not originate from a password-protected source (i.e., an email address officially on file with Walden).

Autism House  
8911 West Lane  
Magnolia, Texas 77354

Date 5/8/17

Dear Monica Labrie,

Based on my review of your research proposal, I give permission for you to conduct the study entitled The Experience of Families of Children with Autism Participating in ABA Treatment within Autism House. As part of this study, I authorize you to recruit participants who receive ABA services through our organization. Individuals' participation will be voluntary and at their own discretion.


We understand that our organization's responsibilities include: disseminating the recruitment flyer to our clients via our email distribution list and posting the flyer on our bulletin boards in all clinic locations. We reserve the right to withdraw from the study at any time if our circumstances change.

I understand that the student will not be naming our organization in the doctoral project report that is published in Proquest.

I confirm that I am authorized to approve research in this setting and that this plan complies with the organization's policies.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the student's supervising faculty/staff without permission from the Walden University IRB.

Sincerely,  
Authorization Official  
Contact Information

 JESSICA Cordara, BOBA  
281-259-5561 J.Q.Cordara@yahoo.com

Walden University policy on electronic signatures: An electronic signature is just as valid as a written signature as long as both parties have agreed to conduct the transaction electronically. Electronic signatures are regulated by the Uniform Electronic Transactions Act. Electronic signatures are only valid when the signer is either (a) the sender of the email, or (b) copied on the email containing the signed document. Legally an "electronic signature" can be the person's typed name, their email address, or any other identifying marker. Walden University staff verify any electronic signatures that do not originate from a password-protected source (i.e., an email address officially on file with Walden).

## Appendix D: Recruitment Flyer

**How Does ABA Treatment Affect the Entire Family?**

*Be part of a psychological research study!*

- *Do you have a child with autism that is 12 years of age or younger?*
- *Do you have at least one other child who does not have autism or another disability?*
- *Have you been participating in ABA treatment for at least 6 months but no more than 1 year?*

*If you answered YES to all of these questions, you may be eligible to participate in a psychological study.*

*The purpose of this research study is to explore how participation in ABA treatment affects the family in the areas of parental well-being and sibling relationship quality. Benefits include an opportunity to share your experiences of having a child with autism and receiving ABA treatment. No additional incentives for participation will be offered.*

*All parents who meet the criteria above are eligible to participate.*

*If interested, please contact Monica Labrie for more information.*



Appendix E: Participant Screening Questionnaire

1. Does your child receiving ABA services have a diagnosis of autism?
2. How old is your child with autism?
3. Do you have at least one other child who does not have autism?
4. Do you have any other children with special needs?
5. How long have you received ABA services?

### Appendix F: Debriefing

Thank you for participating in the study *The Experience of Families of Children with Autism Participating in ABA Treatment*. The purpose of this study is to explore how ABA treatment affects the family as a whole, particularly how parental stress/well-being and the quality of sibling relationships are influenced. This study is important because the evaluation of ABA outcomes for children with autism should also consider how family dynamic and family interactions are affected. In this study we asked participants to answer questions about their experiences having with having a child with autism and how their family lives have been changed by starting ABA treatment. We expect to find an overall positive change in parental well-being and sibling relationships due to starting ABA treatment. Previous research has shown that parents have positive views about ABA treatment and its outcomes for their child and family. If you would like to learn more about this topic, I can give you some references.

Do you have any questions about this study?

When you were participating in the study, what did you think the study was about?

Was there any part of the study that was difficult?

What would you change about the study?

Again, thank you for your participation in our research. If you have any questions you can ask me now or you can contact Monica Labrie at a later date. If you would like to receive a copy of the results, they can be emailed to you at the end of the study.

## Appendix G: Pilot Study Preliminary Data Analysis and Coding

**Key phrases/ideas from Memo-ing**

001	002
Good relationship with husband but takes a lot of work	The daily routine is the same as before starting ABA
Strained relationship between mother and child without autism.	Family had to make accommodations to adapt to therapy
Effort to make time for her	Good relationship with spouse. Improved even more with diagnosis and ABA therapy to accommodate needs.
Sibling gets jealous.	Daughter without autism is understanding.
Feels a high level of stress; stretched thin trying to make time for everything	Although attention to other child changed with diagnosis, mother still tries to find ways to make time for other child
Stress level has gotten better since starting ABA because child with autism is now able to do activities alone or with sister.	Everyone makes child with autism the priority
No longer has friends outside of autism community.	Feels a lot of stress as a parent, especially about progress and the future
Family is supportive but didn't believe it was autism	Improvements in stress level since starting ABA
Family has noticed changes in child with autism and now believe he has autism.	Acceptance from others increased once she accepted the diagnosis herself.
Stand out more due to using ABA strategies in public	Family and others close to them have noticed changes in her son since starting ABA treatment.
ABA has made trips into community easier.	Siblings have a good relationship. He knows she will help him with what he needs.
The siblings communicate by the child without autism finding something that interests her brother to motivate him to interact with her.	Daughter is able to read son and understands him so well.
Initially sister was grossed out by brother's pica behavior. Understanding how to reinforcer good behavior (ABA technique) has improved her feelings toward her brother.	Daughter knows how to handle challenging behavior and how to calm him down.
Benefit: ABA leads to a decrease in behavior and tremendous changes in the	Good changes in relationship between daughter and son since starting ABA

child. Highly recommended for parents.	because they all use the same strategies
Challenge: Consistency is key which can be exhausting.	Benefit: You will see progress and noticeable changes to behaviors even if the progress is slow.
	Challenge: consistency is needed and you just have to wait and see if progress will be made.

### Codes

Good relationship with spouse  
 Relationship with spouse improved after starting ABA  
 Effort is needed to make time for the child without autism  
 Experiences a high level of stress  
 Improvements in stress level since starting ABA  
 Accepted by close family  
 Family members notice a change in child since starting ABA  
 Siblings developed their own way of communicating  
 Improvements to sibling relationships since starting ABA  
 Improvements in child with autism is benefit  
 Consistency is a challenge

### Categorization

Yellow – 001 Green - 002

#### **Good relationship with spouse**

It's good. It takes a lot of work... But it's ok.

Very good.

#### **Relationship with spouse improved after starting ABA**

we moved up to a whole level of understanding from one to the other actually. The way we both, you know, make each other's available for himself or the other child is completely different and it's actually very good.

#### **Effort is needed to make time for the child without autism**

I noticed there was a strain in that relationship too. She tries to be a little more sneaky because she knows our focus is more on Jacob. So, she tries to sneak around, you know, with the makeup and the boys. So, I noticed that. But at the same time, we still try to make time for her and focus on what she's doing too. Like at school, with her grades and stuff like that.

She was the one who used to get most of my attention until then. And ever since the other kid came and ever since he was diagnosed, it actually went down gradually and she wasn't obviously getting as much. There are some, you know, things where I have to put her aside, but there are most of the things where she is my total priority.

**Experiences a high level of stress**

A lot. A lot. I feel like I'm spread really thin in everything.

It's a lot of stress. A lot. It is stressful if you are thinking about tomorrow.

**Improvements in stress level since starting ABA**

It's better. It's much better. It has improved.

It has improved, I feel, because at least we are doing something productive.

**Accepted by close family**

My family has been really great; they've been really supportive. Because they're so supportive, it helps a lot. My mom is my backbone.

It is very good. I mean the bottom line was me accepting it and then I can make the other person accept it.

**Family members notice a change in child since starting ABA**

My mom has really noticed a change in him with his eye contact and when you call his name and he'll come to you and stuff like that. So yes, they've noticed it.

People whom I know very closely have noticed the good changes in him and they come to and tell me.

**Strains in relationship between sibling without autism and child with autism**

I noticed that she does get jealous sometimes.

I think that's where the struggle with Jaylen and him came in because she would try to play with him and he would elope within a minute.

The challenging behavior was the pica. Initially, she was grossed out by everything he did.

**Siblings developed their own way of communicating**

So, Jaylen, if he wants something, he'll like come to Jaylen and he'll grab her and tell her. If she's singing to him, he'll enjoy it. That's his reinforcer from her. The tickles is reinforcement. If she has like a popsicle when she wants his attention, she's going to get like an edible that's a reinforcement for him to bring it and then they'll sing and they'll play and she'll have him copy.

I think being siblings they have their own language. Though, they do have verbal communication. But still, they could read... she can read him so well. She understands him so well.

**Improvements to sibling relationships since starting ABA**

Because when he wasn't in ABA, he wasn't engaged at all. But after the ABA, she can actually sit and play with him and he'll engage with her.

But now that he's gotten better and she knows how to reinforce good behavior with him, it's gotten much better. Like she enjoys... she actually seeks him out now and it didn't use to be that way.

she knows when to calm him down and how to calm him down and she handles it very smoothly. We have noticed good changes. whatever the tips we get from the ABA therapists, we all as a family try to apply it when we are being with him.

### **Improvements in child with autism is benefit**

It's the behaviors will decrease dramatically. But we've seen like a tremendous change in Jacob since we started ABA.

they are some good progress that you will be seeing. I would say it's a very good thing because it is mostly associated with the behavior and the challenges you will be noticing outside.

### **Consistency is a challenge**

Follow through. It's exhausting. You have to follow through at home. it has to be consistent. If you're not consistent, it's not going to work.

You don't know if you're going to see the progress or not. Any treatment is the same way. You just have to try it; give it your best shot and just sit and wait for the result. But the consistency is what just yields the results.

## **Themes**

Parents of children with autism have overall good relationships with their spouses, but communication and mutual respect for each other becomes more important after diagnosis and starting ABA treatment.

Relationships between parents and siblings without autism can become strained, with less attention given to the child without autism; however, parents put forth efforts to make time for the other child.

Parents of children with autism face a high level of stress, but participating in ABA treatment results in a decrease in some sources of stress.

Parents of children with autism receive acceptance from close family members, but feel validated and accepted even more once family members notice changes in the child that occur after starting ABA treatment.

Siblings relationship quality can be strained due to difficulty engaging with or relating to the child with autism.

Siblings with and without autism develop their own unique ways of communicating with each other. Participation in ABA treatment leads to changes in the behaviors of children with autism that facilitate better interactions with their siblings. Overall, the relationship quality between siblings appears to improve.

Parents acknowledge that participation in ABA treatment produces noticeable changes and progress, but consistency is important and can be a challenge.