

2016

# Exploring Barriers to Fathers' Implementation of Behavioral Interventions for Nonverbal Children with Autism

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*Walden University*

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# Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral dissertation by

Michael Lafasakis

has been found to be complete and satisfactory in all respects,  
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2016

Abstract

Exploring Barriers to Fathers' Implementation of Behavioral Interventions for Nonverbal

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by

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MSEd., Touro College, 2007

Advanced Certificate, Queens College, City University of New York, 2004

MA, John Jay College of Criminal Justice, City University of New York, 2003

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Clinical Psychology

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## Abstract

Many families, regardless of their ethnic and cultural background, find it challenging to raise a nonverbal child with autism. Parent-implemented behavioral interventions can contribute to positive behavior change related to joint attention, imitation, and communication. However, many parents face barriers that prevent them from implementing behavioral interventions in the home. Very little research has been conducted on fathers of nonverbal children with autism to ascertain their perspectives on these barriers. In this qualitative study, a phenomenological design was used to obtain input from 12 fathers of diverse ethnic and cultural backgrounds residing in New York City regarding barriers to implementing behavioral interventions in the home with their nonverbal child with autism. Behavioral and humanistic theories constituted the theoretical framework. Thematic analysis resulted in the identification of themes and patterns within and across cases. Recommendations for parents and professionals include on-going in-home parent training from preschool to age 21 that focuses on acquiring instructional control over behavior and establishing effective communication with the nonverbal child with autism in the home. Study findings may help psychologists, counselors, parents, advocates, and autism treatment organizations improve parent training and counseling methods with the goal of promoting positive therapeutic outcomes.

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## Dedication

I would like to dedicate this to my mother and father, who continued to support me throughout my academic endeavors and life goals. To my sister Angela, who will always be my hero and true inspiration in my life. To my wife, who put up with long work hours and held down the fort at home with our sons and daughter while I attended residencies or spent consecutive days finishing coursework requirements. To both my sons and daughter, who are the true joys of my life, I love you so much! You are my world, you mean everything to me!

I also would like to dedicate this to all nonverbal children with autism and their families, who through my work, have taught me about some of the true meanings of life. Lastly, to my Father in Heaven; my Lord and Savior Jesus Christ, who helps me stay in Grace. Without Your Unconditional Love, I wouldn't have the Ultimate Example to look up to and try to emulate.

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## Table of Contents

List of Tables .....	vi
List of Figures .....	vii
Chapter 1: Introduction to the Study .....	1
Problem Statement .....	1
Nature and Purpose of the Study .....	3
Research Questions and Theoretical Framework.....	4
Definition of Terms .....	5
Assumptions.....	6
Scope and Delimitations.....	7
Limitations of the Study.....	7
Significance.....	7
Summary.....	9
Chapter 2: Literature Review.....	12
Introduction.....	12
Literature Search Strategy.....	15
The Nonverbal Child with Autism.....	15
Symptoms and Charateristics.....	15
Treatment Findings.....	17
Parental Involvement.....	19
Parenting a Child with Autism.....	19
The Inclusion of Parents in the Special Education Process.....	20
Changes in Legislature.....	20



Parent Implemented Interventions & Therapeutic Outcomes.....	22
Barriers Faced by Parents of Children with Autism.....	25
Communication with Treatment Providers.....	25
Poverty.....	26
Fatigue.....	27
Gender Roles.....	27
Family Disruption.....	28
Perceptual Differences.....	28
Disability.....	29
Lack of Child Progress.....	29
Language.....	30
Cultural Factors.....	31
Behavioral and Humanistic Based Interventions.....	32
Behavioral Skills Training.....	32
Humanistic Counseling.....	33
Summary.....	35
Chapter 3: Research Method.....	41
Introduction.....	41
Research Design and Rationale.....	42
Research Questions.....	42
Research Tradition.....	44
Role of the Researcher.....	45

Methodology.....	46
Participant Selection Logic.....	46
Site Selection.....	47
Ethical Concerns and Participant Protection.....	48
Methods of Data Collection.....	48
Document Collection.....	48
Interviews.....	49
Data Analysis.....	49
Validity and Reliability.....	52
Ensuring Reliability.....	52
Validity Concerns.....	52
Validation of Findings.....	53
Summary.....	54
Chapter 4: Results.....	56
Introduction.....	56
Setting.....	57
Demographics.....	58
Data Collection.....	59
Data Analysis.....	60
Evidence of Trustworthiness.....	60
Credibility.....	60
Transferability.....	61

Dependability.....	61
Confirmability.....	62
Peer Debriefing Results.....	62
Member Checking Results.....	63
Results.....	64
Research Question Analysis.....	64
Research Questions.....	64
Summary.....	89
Case Assertions.....	89
Chapter 5: Discussion, Conclusions, and Recommendations.....	96
Introduction.....	96
Key Findings.....	97
Successes and Challenges.....	97
Barriers and Experiences.....	98
Thoughts and Emotions.....	99
Interpretation of Findings.....	100
Conceptual Framework Analysis and Interpretation.....	106
Limitations of the Study.....	106
Recommendations.....	107
Recommendations for Educators and Autism Treatment Professional.....	108
Recommendations for Fathers and Parents.....	114

Recommendations for Advocates and Policy Makers.....	116
Recommendations for Future Research.....	118
Empirical Implications.....	118
Potential Impact for Positive Social Change.....	118
Empirical Implications.....	120
Recommendations for Practice.....	120
Conclusion.....	121
References.....	123
Appendix A: Letter of Study Information.....	142
Appendix B: Invitation to Participate in Research.....	143
Appendix C: Interview Protocol .....	144

List of Tables

Table 1. Demographics .....	58
Table 2. Interrater Agreement.....	63

## List of Figures

Figure 1. Overview of themes discovered – cross-case analysis.....	65
Figure 2. Emergent themes based on each participants’ identified barriers.....	73
Figure 3. Overview of themes discovered.....	92

## Chapter 1: Introduction to the Study

According to the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed., [DSM-5]), children with autism spectrum disorder (ASD) exhibit delays in their ability to interact socially and acquire functional speech and language skills (American Psychiatric Association, 2013, p. 53). Between 25-61% of children with autism may exhibit little or no functional speech by the time they reach 2 years of age (Schlosser & Wendt, 2008). Moreover, as many as 50% of children with autism may not develop communicative language by age 13 (Kasari, Paparella, Freeman, & Jahromi, 2008) and 25% may fail to produce communicative speech at all (Koegel, Shirotova, & Koegel, 2009). Because of these data, many parents of nonverbal children with autism seek quality behavioral treatments as part of early intervention and preschool special education for their children (Kasari et al., 2008).

### **Problem Statement**

Parents of children with autism report higher levels of stress than parents of children with any other conditions (Rivard, Terroux, Parent-Boursier, & Mercier, 2014). Parent training, which has been found to help parents adjust immediately after a child has received an initial diagnosis, is one behavioral intervention for nonverbal children with autism (Estes et al., 2014). Training parents to implement behavioral interventions can also improve parental interactions with children with autism and reduce parenting stress levels (Bendixen et al., 2011). However, most research has focused on mothers because they are often the parent that intervenes the most (Elder et al., 2011). Little is known about fathers' interactions with their children (Donaldson, Elder, Self, & Christie, 2011).

As parental roles become more alike, fathers are increasingly caring for children with autism (Boström & Broberg, 2014). Coinciding with the increasing diagnosis of autism in the United States (US), the Centers for Disease Control and Prevention (CDC, 2014) have highlighted the need for psychologists to examine the experiences of parents of children with autism. In response, Dardas and Ahmad (2015) found that quality of life amongst fathers of children with autism can be impacted by their perception and abilities applied to their situation. Studies suggest that some parents may either fail to implement behavioral interventions with their children with autism, or do so with low procedural fidelity (Schultz, Schmidt, & Stichter, 2011), defined as the extent of which each step of the procedures are conducted correctly.

Common barriers to parental implementation of home-based behavioral interventions children with autism include lack of time and financial support (Leyser & Dekel, 1991). Families of different ethnic and cultural backgrounds may face other barriers (Kissel, Nelson, Dulaney, Bing, & Currans, 2010). For example, Matthews (1998) found that some Jewish families of children with autism face barriers related to a lack of child care and social support. Dardas and Ahmad (2014) discovered that Arab parents are impacted by cultural factors. A study of fathers in Ireland indicated that the difficulty of tasks can be a factor when engaging in interactions with their children with autism (O'Halloran, Sweeney & Doody, 2013). Australian parents have been found to experience challenges when addressing their children's externalizing behavior (McStay, Trembath & Dissanayake, 2014). Similarly, difficulties in addressing behavior problems of children with autism living in China were found to be a major aspect of parent-child



interactions (Gong et al., 2012). Swedish fathers reported that managing the responsibilities in their lives around their child's disability was a recurring factor for the first 5 years after the initial diagnosis (Boström & Broberg, 2014). These examples indicate that regardless of ethnicity and cultural background, parents face challenges when caring for their child with autism.

Barriers faced by fathers from diverse ethnic and cultural backgrounds has been scarcely examined in research on parental implementation of home-based behavioral interventions for nonverbal children with autism (Kissel et al., 2010). No studies were found that have explored how fathers of diverse ethnic and cultural backgrounds residing in New York City (NYC) personally experience such barriers. Therefore, this study identified barriers to the implementation of behavioral interventions for nonverbal children with autism by fathers of diverse ethnic and cultural backgrounds living in NYC. In the study, the researcher examined how these fathers experience and feel about these barriers.

### **Nature & Purpose of the Study**

The purpose of this exploratory qualitative study was to analyze the narratives of fathers from diverse ethnic and cultural backgrounds residing in NYC. Participants were asked to identify and describe their experiences with barriers to implementation of behavioral interventions for their nonverbal children with autism. The researcher collected data by conducting one-time, semistructured interviews with participants. Open-ended questions were used in the interview. A thematic analysis highlighted

themes across participants' narratives. Each interview lasted 60 minutes. The thematic analysis was completed by reading the interview transcripts line-by-line.

### **Research Question(s)**

In order to obtain a deeper understanding of the perspectives of participants, the researcher investigated several phenomena through the following research questions:

RQ1. What are barriers faced by fathers of diverse ethnic and cultural backgrounds residing in NYC when implementing behavioral interventions with their child with autism?

RQ2. How do fathers of diverse ethnic and cultural backgrounds residing in NYC experience barriers to implementing behavioral interventions with their child with autism?

RQ3. How do fathers of diverse ethnic and cultural backgrounds residing in NYC feel about these barriers to implementing behavioral interventions with their child with autism?

### **Theoretical Framework**

When working with parents of children with autism, integrative psychologists and counselors often draw from behaviorism principles and humanism concepts (Hannon, 2014). Training parents to implement behavioral interventions can address the behavioral symptoms exhibited by children with autism (Miltenberger, 2011). However, counseling interventions that use humanistic approaches such as narrative interventions and person-centered interventions may provide parents with opportunities to share their experiences in an effort to facilitate change, improve "self-capacities", and feel enabled when faced

with daily stressors (Rogers, 1986). When a parent develops their capacity to cope with stress in a positive and healthy manner, their quality of life may significantly improve.

Practices in psychology such as counseling involves six conditions that are necessary for psychologists to understand the lived experiences of their clients (Rogers, 1957). One key principle of humanistic counseling is understanding that individuals actively assign meaning to their experiences (Mize, 2003). When providing therapy, humanistic counselors seek to relate to clients in an empathically respectful and growth-producing manner (Scholl, McGowan & Hansen, 2012). Therefore, in this exploratory study, the researcher sought to gain a more in-depth understanding of how fathers identify, describe, and experience the barriers to implementing behavioral interventions with their nonverbal children with autism. With empirically-supported data, practitioners may be better able to understand the experiences of fathers of children with autism. Study findings may inform interventions for fathers who seek parental training and counseling support. Findings of this study may also provide insight for future researchers investigating related areas.

### **Definitions**

The following terms are defined due to their repeated usage throughout this study and the importance of their precise meaning:

*Autism spectrum disorder (ASD)*: is diagnosed in early childhood and characterized by persistent deficits in social interaction and social communication across multiple settings and restricted repetitive patterns of behavior, interests, or activities,

which cause clinically significant impairment in social, occupational, or other important areas of current functioning (APA, p. 53, 2013).

*Generalization*: occurs when behavior is emitted under conditions that are different from the training setting (Stokes & Baer, 1977).

*Imitation*: is a nonverbal type of learning associated with the observation and reproduction of another human being's movements, sounds, or intended actions (Moore, 2013).

*Joint-attention*: involves the sharing of attention with others, through eye-contact, facial expressions, nonverbal gestures, pointing, showing, and coordinated looks between a person and object (Kasari, Freeman & Paparella, 2006).

*Language*: is a body of words, signs, symbols and/or gestures of particular meaning in a system by which human beings communicate (Algeo, 2013).

*Speech*: is considered one or more vocalized utterances, vocal sounds, or spoken words, which are used as an oral communicative method for people to interact with each other (Serra, Ribeiro, Freitas, Orvalho, & Dias, 2012).

### **Assumptions**

In the present study, it was assumed that data provided by each participant were based on their understanding of the open-ended questions asked during the interview. It was also assumed that participants' responses were truthful in all respects. Since eligibility to participate in the study required the participant to reside with their child with autism in the same household, there was another assumption that each father had

knowledge of their child's diagnoses and multiple experiences with their child's symptoms.

### **Scope and Delimitations**

The focus of this study was to (a) identify barriers faced by fathers of diverse ethnic and cultural backgrounds residing in NYC when implementing behavioral interventions with their nonverbal child with autism and (b) explore how these fathers individually experience and feel about these barriers. Data included the fathers' narratives, which were obtained in semistructured interviews using open-ended questions. Research on mothers and fathers are included in the literature review. The results of this study provided much knowledge and insight to practitioners who aim to individualize parent training methods to the needs of families from diverse ethnic and cultural backgrounds with nonverbal children with autism.

### **Limitations of the Study**

One limitation of this study involved the methods of sampling, as fathers were chosen based on having a nonverbal child with autism. Another limitation involved generalizability of data from the number of participants. Since the sample size of fathers from diverse ethnic and cultural backgrounds residing in NYC was 12, it is possible that the results of the present study were limited to similar populations living in similar urban areas in the US or abroad.

### **Significance**

This study is unique because it addressed an understudied area of research. Firstly, fathers of children with nonverbal children with autism are underrepresented in

both parent research and parent implemented intervention studies (Flippin & Crais, 2011). This is discouraging because fathers have been argued to display interaction styles that contribute to social and language development in their children with autism. Second, parents of children with autism have been found to experience a variety of long-lasting stressors that can impact marital satisfaction and family functioning (Solomon & Chung, 2012). Fathers who reported higher levels of stress than mothers indicated that their paternal stress was associated with symptom severity, their child's age, intellectual quotient, gender, and failure to acquire adaptive behaviors (Rivard et al., 2014). In addition, Kissel et al. (2010) argued that ethnic and cultural factors may be contributing to parent-child interactions in the home. Parent training methods that are individualized to incorporate the identified barriers while considering the parents' ethnic and cultural background along with their personal experiences with these barriers may facilitate parent implementation of behavioral interventions in the home. Moreover, father implementation of behavioral interventions can promote increases in social interaction and functional speech and language by their nonverbal child with autism in the home (Elder et al., 2011). If social and communication skills are acquired, it is possible for fathers and families in general to experience a significant improvement in their quality of life. This therapeutic outcome is meaningful because fathers have identified that communicating with their child with autism is one of the most rewarding aspects of engagement (Hannon, 2014).

Therefore, the results of the present study indicated ways to help practitioners improve their parent training methods, especially for fathers. As a result, father

implementation of behavioral interventions will increase and improve. Center- and home-based autism treatment and special education programs that target deficits related to social interaction and functional communication in nonverbal children will experience more success in promoting changes in behavior. Increases in child correct responding associated with the ability to interact socially and acquire communication skills will be observed to facilitate behavior changes in others (e.g., primary caregivers, siblings), which in turn will foster additional learning opportunities across individuals and settings. These changes in behavior will reduce parent stress and will have a profoundly positive effect on the quality of life for these children with autism and for their families.

### **Summary**

Children with autism exhibit symptoms that impact their ability to communicate and engage in functional skills, which has prompted parents to seek services from autism treatment professionals. When compared to other childhood disorders, parents of children with autism experience greater stress levels. Parent training can improve interactions in the family, which can alleviate stress but a large percentage of studies have been conducted on mothers while very little research has been done with fathers of children with autism. Fathers' roles in the treatment process have increased due to the rise of autism in the US and changes in parenting roles. Therefore, it is important to understand the experiences of parents of children with autism, especially fathers.

A child's quality of life and that of their family's can improve when fathers use their abilities to assist the treatment process; however, some fathers have been found to make errors or fail to implement behavioral interventions with their nonverbal child in

the home. Several common barriers have been identified regarding parent implementation of behavioral interventions but a family's ethnic and cultural background can contribute to, or provide additional barriers.

No studies to date have examined barriers to father-implemented behavioral interventions in the home for nonverbal children with autism from diverse ethnic and cultural backgrounds who reside in NYC (Kissel et al., 2010) and no research has investigated how fathers of diverse ethnic and cultural backgrounds residing in NYC personally experience barriers to implementing behavioral interventions in the home with their nonverbal children with autism. There is a need to identify barriers as well as examine fathers' perceptions about these barriers to implementing behavioral interventions with their nonverbal children with autism. An area that needs further investigation are barriers faced by fathers of diverse ethnic and cultural backgrounds. Research that explores these issues informs practitioners to help them incorporate the identified barriers and father's personal experiences with these barriers in parent training to promote parent participation and the implementation of behavioral interventions in the home. This is critical to the treatment of autism as father implemented behavioral interventions can promote increases in functional communication and social interaction in nonverbal child with autism in the home and community.

Therefore, the aim of this study was to explore the perspectives of fathers from diverse ethnic and cultural backgrounds who reside in NYC regarding barriers to implementing behavioral interventions in the home with their nonverbal children with autism. An understanding of the following was attempted: (a) identification of current



and previous barriers to father implementation of behavioral interventions in the home; (b) fathers' personal experiences with each specific barrier to implementing behavioral interventions with their nonverbal child with autism; and, (c) fathers' feelings about these barriers to implementing behavioral interventions with their nonverbal child with autism. The insight gained filled a large gap in the literature on the perspectives of fathers from diverse ethnic and cultural backgrounds residing in NYC. The ultimate goal of this study was to inform individuals, parents, educators and autism treatment providers on the topic of barriers faced by fathers from diverse ethnic and cultural backgrounds when implementing behavioral intervention with their nonverbal children with autism. An understanding of fathers' perceptions can promote positive therapeutic outcomes by assisting psychologists and counselors in the treatment process. It is expected that parent training methods will become more individualized to the child's and family's needs and some families may experience changes in socially significant behavior through the fathers' implementation of behavioral interventions in the home. Positive changes in child behavior may contribute to an alleviation of parent stress, which has been shown to improve the quality of life for children with autism and their families

In the following chapter, a comprehensive review of the literature was presented, including a description of the nonverbal child with autism, parental involvement in the special education process, parenting issues, parent training and therapeutic outcomes. Barriers associated with autism treatment process and implementing behavioral interventions were also explored and discussed.

## Chapter 2: Literature Review

### **Introduction**

In one of the earliest studies on families of children with autism, Eisenberg (1957) examined the roles and impact of fathers in families. Despite his call for more research on fathers of children with developmental disabilities made more than 50 years ago, there is still scant research regarding fathers of children with developmental disabilities (Hunt-Jackson, 2007). Very few studies have been conducted on fathers' participation in parent training programs for families of children with autism (Winter, 2006).

According to the CDC (2015), approximately 1 out of 68 U.S. children are diagnosed with autism. The condition is five times more prevalent in boys, but it occurs across all ethnic, racial and socioeconomic groups (CDC, 2015). Parents with a child with autism have a 2-18% risk of having a second child diagnosed with the disorder (CDC, 2015). Families with two children with autism have been found to be 50% more likely to have a third child diagnosed with the disorder (Wood et al., 2015).

Autism training often consists of teaching parents to implement intensive behavioral interventions in the home; however, some parents face barriers that can impact their compliance with treatment protocols and maintaining treatment efficacy (Mackintosh, Goin-Kochel, & Myers, 2012). For example, parents of children with autism have indicated that they did not use their skills acquired as a result of their parent training with their child in the home as consistently as they did during their parent training sessions (Moore & Symons, 2011). Some parents also neglect to perform treatment steps when implementing these behavioral intervention (Sullivan, 2011).

In approximately half of U.S. families of children with autism, parents do not adhere to treatment recommendations, which reportedly costs the U.S government billions of dollars each year (Moore & Symons, 2011). Nonadherence to treatment protocols by parents is therefore a great concern because intensive behavioral interventions for children with autism annually cost between \$40,000-60,000 per child in “direct and in-direct costs, from medical care to special education to lost parental productivity” (CDC, 2015) These outcomes can affect the child’s autism treatment and may impact the quality of life for families. For example, some parents do not implement behavioral interventions that are designed to teach early communication skills such as pointing, their nonverbal children with ASD may fail to acquire the pointing response. This can result in increases in problem behavior and immature requesting behavior such as crying and grabbing (Thomas et al., 2010).

Parents of children with autism face specific challenges such as managing maladaptive behaviors, stigmatization, and disruption of family life (Ludlow, Skelly & Rohleder, 2011). As a result, some parents may have difficulties when addressing severe symptoms and experience negative feelings that may contribute to stress, depressive and anxiety-related issues. Implementing home-based treatments is also challenging for some parents of children with autism (Hendrickson, Baldwin, & Allred, 2000). Clinicians in autism treatment programs have attempted to address this issue by teaching parents to implement interventions such as early intensive behavioral intervention (EIBI); however, little is known about parents’ perspectives when implementing this intervention with their nonverbal child with autism in the home (Tzanakaki et al., 2012).

Implementing behavioral interventions in the home has been used as a measure of treatment adherence, but a large percentage of parents do not comply with autism treatment recommendations (Moore & Symons, 2011). Studies on the perspectives and experiences of parents of children with autism have neglected fathers and their roles in the autism treatment process (Vacca, 2013). The lack of research on father-implemented interventions is concerning because paternal involvement has been found to be correlated with decreases in problem behavior (Bagner, 2013) as well as improvements in communication and play skills that positively improved parent-child interactions (Donaldson et al., 2011).

In order to gain a better understanding of the perspectives of fathers in the treatment of nonverbal children with autism, the researcher reviewed research that describes barriers faced in the autism treatment process. Barriers when implementing behavioral interventions in the home associated with personal, familial, and cultural issues were presented. Parenting issues were reviewed. The researcher also considered parents' experiences with training programs. Mothers' and fathers' perceptions were presented. The researcher provided this comprehensive examination to assist readers in understanding barriers faced by these parents, especially fathers of children with autism. In describing the perspectives of fathers from diverse ethnic and cultural backgrounds nonverbal children with autism, there are expectations that parent training programs will use the knowledge to evolve through the development of better treatment protocols that consider the growing needs of ethnically and culturally diverse families of nonverbal children with autism residing in the US. This review was consistent with the

phenomenological approach, as acquiring information and awareness of the phenomenon of which little is known will contribute to its understanding.

### **Literature Search Strategy**

The literature was reviewed using the following online databases: PsycINFO, Science Direct, Academic Search Complete/Premier, Psychology: A SAGE Full-Text Collection, ProQuest Central, PubMed, and Google Scholar. Search terms used were *autism spectrum disorder, barriers, parent training, father implementation, nonverbal, behavioral interventions, home-based and developmental disabilities*. This study reviewed textbooks as well as doctoral dissertations related to autism.

### **The Nonverbal Child with Autism**

#### **Symptoms & Characteristics**

Communicating with nonverbal children with autism can be a difficult task (Berry, Firth, Leeming & Sharma, 2014). Typical-developing infants begin to point to items for other persons from around 11 to 12 months (Tomasello, Carpenter & Liszkowski, 2007) but some children with autism have been found to emit the pointing response much later (Itoh, 2000). The ability to request preferred items or activities by gesture (e.g., pointing) or by vocalizing a single word can provide children with a way to control their environment in a functional manner (Scattone & Billhofer, 2008). However, many children with autism exhibit delays in their ability to communicate nonvocally, produce speech sounds and acquire functional language (APA, 2013, p. 53), including displaying low rates of conventional vocal requests for preferred items from their families and natural environments (Thomas, Lafasakis & Sturme, 2010).

Stimulus overselection (also known as overselectivity) is a behavioral phenomenon commonly observed in nonverbal children with autism (Broomfield, McHugh, & Reed, 2010). It occurs when behavior is controlled by one or more elements of the environment at the expense of relevant aspects of the environment (Bijou & Baer, 1961). For example, some children with autism may excessively stare at the details of ceiling fixtures, repetitively flap their hands or fingers in front of their eyes, twirl or balance small pieces of paper between their fingers, perseverate on sounds or words, and rock their bodies for extended periods of time. Commonly observed self-stimulatory behaviors such as these are believed to be under the control of one or more components of a stimulus complex, and may be associated with an interaction between automatic (i.e., internal) and environmental (i.e., external) stimuli that offer predictable visual, auditory, tactile, proprioceptive, and vestibular sensory stimulation (Bijou & Ghezzi, 1999; Bickel, Stella, & Etzel, 1984). Depending on the frequency, intensity and duration, stimulus overselectivity is believed to contribute to deficits in joint attention, imitation and speech delays in young children with autism (Brown & Bebko, 2012; Bickel et al., 1984). Overselection can also impact joint attention skills, which are important in a child's development because nonverbal gestures and the ability to communicate through the production of speech sounds are developmentally related behaviors (Kasari, Gul-sard, Wong, Kwon & Locke, 2010).

Young children diagnosed with ASD also exhibit delays in the development of their imitative and mimetic repertoires (DeQuinzio, Townsend, Sturmey & Poulson, 2007). For example, some children may have difficulty in copying simple actions with

objects and gross-motor movements while others may be unable to mimic simple sounds and words. There is a percentage of children that display poor generalized imitation skills, which has been defined as the ability to imitate novel models in untrained settings (Kymissis & Poulson, 1990). This is truly a heartbreaking finding because generalized imitation has been associated with the acquisition of language and learning of many types of behavior across important developmental domains.

### **Treatment Findings**

Systematic reviews of communication-based behavioral treatments for nonverbal children with autism have found strong empirical support for Applied Behavior Analysis (ABA) and naturalistic-based procedures that target social skills and developmental-based behaviors in home, classroom, and community settings (Brunner & Seung, 2009). Despite the fact that speech and language interventions in naturalistic teaching approaches use similar methods such as prompting, prompt fading and differential reinforcement (LeBlanc, Esch, Sidener, & Firth, 2006), Paul, Campbell, Gilbert and Tsiouri, (2013) demonstrated that some severely autistic children with limited receptive and expressive language repertoires may show better improvements to discrete-trial treatments when compared to naturalistic language treatments. Further, studies show that parents can be taught to induce first instances of vocal imitation and functional verbal communication through a discrete-trial approach (Tsiouri, Simmons, & Paul, 2012; Lafasakis & Sturmey, 2007).

Teacher-implemented classroom-based behavioral interventions were found to improve joint attention in preschoolers with autism (Lawton & Kasari, 2012). Preschool-

based joint attention activities resulted in significant increases in social interaction between the child with autism and his teacher, which further generalized to longer durations of social engagement with the mother (Kaale, Smith, & Sponheim, 2012). Even though school-based interventions can promote important preverbal communication skills in children with autism, studies show that training parents can have longer-lasting effects when compared to only training the therapist (Kaiser & Roberts, 2013).

Behavioral interventions in ABA have been shown to positively impact the quality of life of the child with autism and also of their family's (McPhilemy & Dillenburger, 2013). Parents have been found to choose center-based ABA programs and home-based behavioral interventions based on factors related to accessibility, availability, and empirical support (Carlson, Carter, & Stephenson, 2013). Quite often, parents learn that the empirically-supported treatments in ABA and Applied Verbal Behavior (AVB) can facilitate socially significant changes in both children and caregiver behavior (Matson et al., 2012). Not surprisingly, parents report high satisfaction with using interventions in ABA (McPhilemy & Dillenburger, 2013).

Meta-analytic reviews have gathered a plethora of evidence that supports the effectiveness of EIBI for children with autism (Peters-Scheffer, et al., 2011). EIBI teaches certain developmental skills in small, progressive steps using empirically-supported procedures in ABA (Copeland & Buch, 2013). Further, AVB methods consisting of comprehensive assessments that break down communicative behaviors into simple objectives are often used when teaching children with autism who are nonverbal and/or have limited vocal repertoires (Weiss & Demiri, 2011). Since these treatments



involve the teaching of simple objectives (e.g., pointing, imitating actions with objects), parents can be trained to implement ABA and AVB techniques in the home with their nonverbal child with autism.

### **Parental Involvement**

Parent involvement is critical in the life of a child with developmental disabilities (Tamzarian, Menzies, & Ricci, 2012). Several categories of parent involvement include applying behavioral principles to daily tasks, regular communication with supervisors, learning about ABA, facilitating communication between providers, and implementing programs with their child (Granger, des Rivières-Pigeon, Sabourin, & Forget, 2012).

Parent involvement in the educational and therapeutic process can have positive results on the child's development (Granger et al., 2012). Significant improvements in the family's quality of life have been shown to occur when parents learn to manage their child's treatment (Mackintosh et al., 2012). When parents are involved, siblings of children with autism show an increased awareness of autism, which was found to contribute to more "nurturing" relationships (Sage & Jegatheesan, 2010). Cobb (2014) suggested that parent involvement can be facilitated when a reciprocal interaction between the family and treatment provider develops to form a pattern of collaboration.

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

A child's diagnosis of autism can impact each member of the family differently. For example, some mothers have been found to experience negative feelings and emotions (e.g., worry, guilt, stress) that can manifest into depression and anxiety (Nealy, O'Hare, Powers & Swick, 2012) whereas fathers have reported feeling "powerless and

hopeless” (Huang et al., 2012). Parents have also reported negative experiences with more severe symptoms (Theerasilp & Sherer, 2013). For instance, fathers have reported that their child’s behavioral issues were the most challenging aspect of raising a child with autism (Hannon, 2014). In contrast, fathers have indicated that establishing clear communication with their sons is one of the most rewarding aspects of parenting a child with autism (Hannon, 2014)

Seeking assistance from providers and implementing treatments in the home have been reported to be frustrating and stressful experiences for mothers of children with autism (Hendrickson et al., 2000). For example, mothers face challenges associated with providing an equal amount of attention and time to their other child and the challenges between “the dual roles of parent and educator” (Granger et al., 2012). Parents have also been found to face specific challenges such as handling problem behaviors, contending with judgment from others, and dealing with the negative impact on members of the family (Ludlow et al., 2011).

### **The Inclusion of Parents in the Special Education Process**

#### **Changes in Legislature**

The Individuals with Disabilities Education Act (IDEA) passed in 1975 as PL 94-142 mandates the inclusion of parents as full participants in the special education process (Tucker & Schwartz, 2013) and ensures that families attain services for their child with developmental disabilities (Hendrickson et al., 2000). It wasn’t until recently that changes in federal and state legislature across the US have included autism as a condition with symptoms that have a medical necessity for intensive behavioral intervention. In

November 2013, health insurance laws in New York State (NYS) were passed that permitted the funding of autism treatment, which includes the training of parents. With these recent changes in law and sudden rise in the rates of autism over the last decade, it is imperative that psychologists, counselors, medical and behavioral treatment providers in NYC seek to maximize parents' involvement in the treatment of their child with autism (Granger et al., 2012).

Parent involvement in the special education process has been shown to contribute to positive therapeutic outcomes (Fishman & Nickerson, 2014). Parents have also been found to contribute to success for students with severe disabilities throughout their school age years and into adult life (Thompson, 2014). In contrast, some parents from diverse ethnic and cultural backgrounds may face barriers that hinder their involvement in their child's special education (Cobb, 2014). In addition, even though parent involvement has been associated with improvements in cognitive abilities in children with autism, many families do not seek these special education services (Hendrickson et al., 2000). For example, studies suggest that about 90% of children who are entitled for EI services do not obtain them (Jimenez, Barg, Guevara, Gerdes & Fiks, 2012).

To ensure treatments are effective and individualized to the needs of the family, the increase in ethnicities in the US is an important issue to consider when programming and providing services to children with developmental disabilities (Jegatheesan, 2009). Moreover, cross-cultural competence is essential to address the diversity of U.S. families (Cheremshynski, Lucyshyn, & Olson, 2013). To facilitate our knowledge and understanding of other cultural backgrounds and to help cultivate this very important skill

when interacting with these diverse families, Peterson (2014) argued that researchers should focus their studies on more cultures from different ethnic and cultural backgrounds. This learning is important, as ethnically diverse parents are impacted by their cultural backgrounds, which can cause barriers that lead to a decreased parental involvement, particularly in the Individualized Education Program (IEP) process (Tamzarian et al., 2012). ABA is recognized as one of the most effective treatments of autism in early childhood; however, the increased number of non-English speaking children diagnosed with autism in the US has caused barriers to obtaining intensive behavioral intervention (Blane, Johnson & Long, 2014).

### **Parent Implemented Interventions & Therapeutic Outcomes**

A mother's participation in her child's education can contribute to positive outcomes (Tamzarian et al., 2012). Mothers have been trained to implement ABA procedures such as discrete-trial teaching, which was shown to contribute to significant improvement in gross-motor and vocal imitation in nonverbal children with autism and other developmental disorders (Lafasakis & Sturmey, 2007). Treatments that incorporate EIBI can contribute to positive therapeutic outcomes when implemented by parents in the child's natural environment (Fava & Strauss, 2011). Mothers who received Child-Parent Relationship Therapy, a behavioral intervention method designed to educate parents on "the developmental perspective of the child to improve the parent-child relationship", have reported feeling calm, confident and more connected with their child (Sullivan, 2011). Mothers trained to implement parent-infant based interventions that focus on developing relationships with their children with autism have experienced improvements

in social interaction but they also reported issues with “getting dad on board” (Freuler et al., 2014). Not surprisingly, fathers have reported feeling like the “odd man out” when navigating through the special education system (Mueller & Buckley, 2014). Fathers' participation in parent training programs for families of children with autism have been underrepresented in the literature (Winter, 2006). This is concerning because taking measures to include the father and working to involve both parents in the decision making process can lead to positive therapeutic outcomes (Huang et al., 2012). For example, in a study of 44 families who were trained to implement a behavioral intervention called Parent-Child Interaction Therapy, paternal involvement was associated with lower levels of parent-reported behavioral problems (Bagner, 2013). Similarly, father-directed interventions that target play- and communication-related behaviors in the home may improve parent-child interactions (Donaldson et al., 2011). Additionally, in-home training of fathers of nonverbal children with autism has been associated with positive communication outcomes such as increases in one-word utterances through increased use of imitation by parents (Seung, Ashwell, Elder, & Valcante, 2006). Children from father-involved families were also found to be more compliant during adaptive tasks (Bagner, 2013). Furthermore, fathers have been trained to implement child-directed behavioral interventions in the home such as pivotal response training that resulted in significant improvements in social interactions with their children with autism (Elder et al., 2011).

Encouraging a father's involvement can impact their participation in a parent training program (Peterson, 2014). After parent training, fathers have reported making

changes in their interactions and expressed the need to do everything right and do exactly as the therapist instructs (Elder et al., 2003). Fathers are motivated to become more involved in the therapeutic process when they perceive their role is important (Peterson, 2014). An investigation of seven fathers and their relationships with their sons with autism found fathers were sensitive to their sons' emotional needs and developmental milestones, which supported the researcher's notion that counselors and psychologists can help fathers develop appropriate relationships with their children as well as assisting them in coping with "expectations of fatherhood, developing desired fatherhood roles, and finding appropriate shared activities with their children" (Keller, Ramisch & Carolan, 2014).

In recent years, researchers have studied the perspectives and experiences of culturally and ethnically diverse parents and their involvement in the special education system (Cobb, 2014). Parents from diverse backgrounds who participate in parent training programs have been taught to implement a wide variety of behavioral interventions. Positive Behavior Support is an effective set of ABA procedures in the treatment of autism but there is virtually no research on the participation of families from diverse cultural and cultural backgrounds (Cheremshynski et al., 2013). The paucity of research on parents from diverse cultures is of great concern, as conducting a cultural and functional assessment to incorporate a family's values and beliefs in the behavioral intervention can promote positive therapeutic outcomes (Cheremshynski et al., 2013). For example, Pakistani children with autism have been shown to improve when their families receive parent training that incorporated the family's cultural needs (Anjum &

Ajmal, 2012). Cobb (2014) recommended exploring the perceptions of these parents by creating opportunities for them to articulate their perspectives. Understanding the challenges parents from diverse ethnic and cultural backgrounds face is crucial in ascertaining what kinds of parent training methods are necessary (Nealy et al., 2012).

### **Barriers Faced by Parents of Children with Autism**

Implementing behavioral interventions in the home has been used as a measure of treatment adherence in parents (Moore & Symons, 2011). However, many parents face barriers that can affect treatment compliance and treatment efficacy (Mackintosh et al., 2012). Unfortunately, nonadherence to treatment recommendations occurs between 24% and 50% and costs the US billions of dollars (Moore & Symons, 2011). For example, parents have reported not using their mastered skills with their child with autism in the home as consistently as during the training sessions (Moore & Symons, 2011). Parents have also been found to omit steps when implementing behavioral interventions with their child with autism in the home (Sullivan, 2011).

Generally, families trained to conduct intensive home-based early behavioral intervention programs with their children with autism have reported general barriers associated with: (a) personal and family resource constraints; (b) problems in dealing with education authorities; (c) support from family/friends in using the interventions; and, (d) progress of their child.

### **Communication with Treatment Providers**

Parents have reported that they value when the clinician informs them with honest and up-to-date information (Giallo, Wood, Jellett, & Porter, 2013). Despite these

findings, one out of five parents report challenges in their relationships with professionals (Mackintosh et al., 2012). For example, Caucasian mothers have indicated barriers associated with a lack of information when communicating with doctors (Hendrickson et al., 2000). This barrier may be impacting parent implementation of behavioral interventions in the home.

Culture can impact interactions between parents and autism treatment providers (Cheremshynski et al., 2013). Some parents from diverse cultural and cultural backgrounds have viewed autism treatment professionals that strictly follow formal bureaucratic procedures (e.g., documentation) as “impersonal” (Tamzarian et al., 2012). As a result, some parents develop negative perceptions of school professionals and experience communication difficulties with providers (Tucker & Schwartz, 2013). For example, Chinese fathers have been found to experience barriers related to a lack of communication and being left out from treatment decisions (Huang et al., 2012). Similarly, Asian-American mothers have been found to experience challenges associated with cultural differences which resulted in a reported lack of understanding. (Jegatheesan, 2009). These barriers may also contribute to parent implementation of behavioral interventions in the home.

### **Poverty**

Barriers related to poverty prevent families from receiving training and/or implementing interventions with their children with autism (Blane et al., 2014). For example, some parents from lower socio-economic backgrounds living in impoverished areas may have limited access to health care information and available resources in the



community. Further, the high cost of health care for the entire family and especially for autism prevents many families from accessing quality treatment providers (Blane et al, 2014). As a result, families living in poverty may not receive parent training, which would impact their ability to implement behavioral interventions in the home with their child with autism.

### **Fatigue**

Mothers of children with autism have been found to experience more fatigue caused by lack of sleep and social support when compared to mothers of typically developing children (Giallo et al., 2013). Interestingly, fatigue has been reported by mothers of children with autism from many different ethnic and cultural backgrounds from each continent. This common barrier experienced by mothers of children may contribute to other unfavorable outcomes associated with mood, anxiety and disturbances in sleep, which may also impact familial relationships. Fatigue may contribute to nonadherence to treatment when parents fail to implement behavioral interventions in the home.

### **Gender Roles**

Parent training programs have mostly focused on mothers of children with autism while very few studies have investigated the perspectives of fathers and what variables contribute to their active participation in their child's treatment in the home (Winter, 2006). When implementing behavioral interventions in the home, fathers have been shown to prefer tasks designed to support children's growth and development and activities that involve all members of the family; however, barriers that prevent their

participation have been reported such as challenges in scheduling time, lack of energy and/or resources, and the mother preferring to be more involved (Peterson, 2014). Elder et al. (2011) suggested that inconsistent implementation of behavioral interventions can occur when fathers “assume background positions or become absent, leaving training primarily to mothers”. Conflicting philosophies between the mother and father on what procedures and interventions should be used also create barriers (Tamzarian et al., 2012).

### **Family Disruption**

Mothers who had their children in an EIBI program for an average of 25 months found that disruption of family life was associated with implementing behavioral interventions in the home (Giallo et al., 2013). For example, mothers reported issues with spending time with their other children and spouse. Family routines and weekly schedules may also experience some disruption when there are multiple treatment providers working with the child with autism in the home. Family disruption may prevent some parents from implementing behavioral interventions with their child with autism.

### **Perceptual Differences**

Differing perceptions and interpretations of disability have been known to cause barriers, as some parents see their child’s behavior as a problem and not as a disability (Tamzarian et al., 2012). If a family decides that there is no problem, it may prevent them from seeking and obtaining services and parent training, which will prevent them from learning to implement behavioral interventions in the home. In addition, some parents reportedly perceive themselves as the experts on their child and what

interventions should be provided (Jimenez et al., 2012). When this occurs, parents may be less likely to implement the behavioral intervention as they were trained, leading to low treatment fidelity.

### **Disability**

A parent's disability can be a barrier to implementing treatments in the home (Stalker, Brunner, Maguire, and Mitchell (2011). Some parents may be contending with a physical disability that may prevent their motor abilities to implement the behavioral intervention with their child with autism. Similarly, a parent that contends with an intellectual disability or mental disorder may be unable to correctly perform a behavioral intervention with their child with autism.

### **Lack of Child Progress**

In an extensive study of 486 parents (92% mothers) of children with autism made up of Caucasian (86.7%), with 6.2% biracial, 2% African American, 2.2% Hispanic, and 2.8% Asian, Native American, or children of other races or ethnicities, who resided in almost all states in the US (77%) as well as Canada (5.6%), Australia (2.4%), New Zealand (1.5%), England (3.4%), Ireland (3.2%), and "other outside the US", it was shown that parents feel deeply frustrated when their child is not able to make the progress that they expected them to make (Mackintosh et al., 2012). The lack of the child's progress is therefore impacting parents' decisions to continue implementing behavioral interventions, which further contributes to less favorable treatment outcomes. Since this common barrier is reported amongst many parents from various ethnic and cultural

backgrounds, it is important to consider when training parents to become part of the therapeutic treatment process.

### **Language**

Language is a major barrier for Latino families seeking a diagnosis and treatment services from health care providers (Zuckerman et al., 2013). Immigrant families contend with language barriers that may impede verbal communication during interactions with school-based staff and health care providers (Tamzarian et al., 2012). Some Latino families rely on third parties to facilitate communication with school personnel because of a “lack of expertise in using effective ways to collaborate with culturally and ethnically diverse families” (Ruiz, 2012). Due to cultural differences, some Latino mothers residing in California have been found to experience common barriers that impacted their understanding of how programs are implemented and ability to fill out paperwork via “speaking, reading, or writing English” (Iland, Weiner, & Murawski, 2012). Language is therefore important to consider when training parents to implement behavioral interventions through written instructions and explanations of the techniques, as it can be a barrier that may prevent understanding and correct implementation.

When working with immigrant families, it is important to accommodate to the parents’ culture when communicating and individualizing intervention approaches (Cheremshynski et al., 2013). Some parents have expressed concerns over the use of complex behavioral terms during their experiences in parent training programs. For example, fathers have requested information be provided to them in a “male vernacular”

(Hunt-Jackson, 2007). To facilitate the parents' understanding, the need to address the individual culture of the family is crucial to their involvement in their child's autism training program, which may affect the implementation of behavioral interventions in the home.

### **Cultural Factors**

In certain cultures, a child's disability is perceived as a stigma on the family (Tamzarian et al., 2012). South Korean parents experience guilt and shame, which impacts their behavior in the assessment and therapeutic process (Kwon, 2015). Parents from India report that the most burdening barriers are associated with their child's display of maladaptive behavior and lack of "normal" interactions with others in the real world, which can be stigmatizing (Desai, Divan, Wertz, & Patel, 2012). When parents are not involved in their child's treatment because of cultural factors such as stigmatization, their children with autism do not receive the benefits of parent implemented behavioral interventions in the home. As a result, a child may fail to acquire skills or the child's skills may fail to generalize to the home settings, which may cause some parents to experience continued stress and possibly a poorer quality of life.

It is clear that the aforementioned barriers consisting of communication with treatment providers, poverty, fatigue, gender roles, family disruption, perceptual differences, disability, lack of child progress, language, and cultural factors can impact parental involvement and participation in the autism treatment process, which may affect treatment adherence in parents (Moore & Symons, 2011) and contribute to poor treatment compliance and efficacy (Mackintosh et al., 2012). In order to address this issue of

parent adherence to autism treatment recommendations, psychologists and counselors have adopted several approaches that target important skills in different ways.

### **Behavioral- & Humanistic-Based Intervention**

#### **Behavioral Skills Training**

Children can acquire new skills when their parents are taught to implement empirically-supported teaching procedures in ABA such as discrete-trial teaching (Lafasakis & Sturmey, 2007). Teaching parents to implement interventions with their child with autism can be accomplished through Behavioral Skills Training (BST), which consists of instructions, modeling, rehearsal and feedback (Lafasakis & Sturmey, 2007). First, parents are given written instructions before the instructor models the steps of the intervention with the child in front of the parent. Then, the parent performs the steps while receiving positive feedback on steps done correctly and solution-based corrective feedback on steps to improve. This cycle in which the instructor models a few trials and the parent rehearses a few trials is repeated until the parent meets a predetermined performance criterion. BST has been shown to be effective in teaching parents to implement highly complex behavioral interventions with their nonverbal children with autism that contributed to socially significant behavior change in important developmental domains such as imitation and speech sound production (Lafasakis & Sturmey, 2007). Furthermore, BST has been found effective with parents from diverse ethnic and cultural backgrounds (Lafasakis & Sturmey, 2007).

Over the last several decades, a plethora of research has been conducted on behavioral interventions in ABA for infants and toddlers with autism such as EIBI;

however, very few investigators have studied the parents' experiences when implementing this program in the home with their nonverbal child with autism (Tzanakaki et al., 2012). Similarly, research on the perspectives and experiences of parents of children with autism have overlooked the roles of fathers in the behavioral treatment process (Vacca, 2013). This is a great concern because fathers have expressed frustration when simple interactions with their nonverbal child lack communicative and play-related responses (Elder, Valcante, Won & Zylis, 2003). In order to facilitate positive behavioral outcomes, mothers and fathers of children with autism must share their experiences with autism treatment practitioners in Early Intervention when working together to jointly determine the services needed for their child (Epley, Summers, & Turnbull, 2011).

### **Humanistic Counseling**

Developing an empathic understanding of the parent's internal frame of reference is a necessary component of humanistic counseling (Rogers, 1992). To facilitate this, psychologists, counselors and autism treatment providers who subscribe to patient-centered care must include an analysis of parent perceptions (Hodgetts, Nicholas, Zwaigenbaum, & McConnell, 2013). Assessing the barriers faced by families of children with autism is essential in ascertaining what resources are required (Nealy et al., 2012). Interestingly, parent training programs can impact perceptions, which have been shown to increase intervention through treatment adherence to recommended protocols (Moore & Symons, 2011). Therefore, there is a need for counselors to understand the lived

experiences of parents, especially of fathers of children diagnosed with autism (Hannon, 2014).

Knowledge of fathers' perceptions is necessary to understand their experiences and begin the process of empathizing with their individual circumstances (Rogers, 1951). Developing empathy is key to understanding the culture and point of view of others (Tamzarian et al., 2012). Moreover, demonstrating genuine empathy can possibly assist counselors in their work with these fathers (Hannon, 2014). During individualized counseling sessions, for example, it is possible that some parents may experience perceptual reorganization, which appears to affect perception of the world at large and not just objects or the environment during the therapy session (Rogers, 1951). Further, perceptual reorganization is seen to occur during therapy because the clinician provides an atmosphere of safety, protection, and acceptance allowing the boundaries of self-organization to relax. This aspect of humanistic counseling is in line with studies that have found fathers to value collaboration and conflict resolution (Mueller & Buckley, 2014).

For immigrant families of children with autism residing in the US, it is crucial to understand their biculturalism to ensure appropriate services are received (Kwon, 2015). The study of ethnically diverse parents could yield data that may generalize to a broader population in similar geographical areas (Hannon, 2014). Therefore, learning more about the perspectives of fathers from diverse ethnic and cultural backgrounds will facilitate our understanding of multicultural and immigrant issues (Kwon, 2015). Including fathers from more varied backgrounds would vary the demographic of fathers sampled (Mueller



& Buckley, 2014). In addition, conducting this research with a larger population of fathers from the US could be beneficial (Nealy et al., 2012) and would also shed light on the experiences of fathers from similar ethnic and cultural backgrounds residing in suburban, urban and rural areas of the country (Kwon, 2015).

Kwon (2015) argued for more gender-balanced research, in order to get both the perspectives of mothers and fathers. This assertion is vital to autism treatment, as parents' perceptions surrounding their level of responsibility to support their child's education have been associated with home- and school-based parental involvement (Fishman & Nickerson, 2014). Evaluating parent perceptions to facilitate their involvement in home-based early intensive behavioral intervention is essential in the treatment of autism (Blacklock, Weiss, Perry, & Freeman, 2012). This is important as Moore & Symons (2011) found agreement between parents on behavioral intervention strategies is necessary for treatment adherence.

Since an autistic child's delays can impact multiple domains of family life, therapists can utilize an integrative approach with parents, "enabling them to flexibly work with the domains of action, meaning, and emotion" (Solomon & Chung, 2012), which could lead to increased parent implemented behavioral interventions in the home and child responses.

### **Summary**

Based on the literature reviewed, Chapter 2 focused on parents of children with autism and issues related to barriers faced when involved in their child's treatment during the special education process. Nonverbal children with autism exhibit poor

communication skills, a tendency to engage in stimulus overselection (attending to irrelevant stimuli to obtain sensory stimulation) and a lack of generalized imitation skills (ability to imitate novel behavior in untrained settings). There is strong empirical support that shows behavioral interventions in ABA can be effective in treating the nonverbal child with autism (Brunner & Seung, 2009). ABA procedures possess various approaches from discrete-trial methods to naturalistic-based strategies. To ensure child success, parental involvement is essential for children with autism. Parental involvement consists of implementing strategies when teaching simple tasks across the day, communicating with treatment professionals and their supervisors, becoming knowledgeable about ABA and implementing behavioral interventions with their child with autism in the home. Quality of life can improve when parents learn to manage their child's behaviors. However, parenting a child with autism can be challenging. Mothers experience emotions and negative feeling that can develop into depressive and anxiety disorders. Fathers have also reported feelings of hopelessness.

IDEA ensures parents are included in a child's special education. Recent changes in federal and state laws across the US have enabled families of children with autism to obtain treatments from their health insurance. Psychologists and counselors must involve parents in the therapeutic process, as their involvement contributes to success across many domains and into adulthood. This is especially the case for parents from diverse ethnic and cultural backgrounds as the rates of autism rise in the US.

Mother implemented behavioral interventions have contributed to positive therapeutic outcomes. For example, social interactions have improved as a result of

mother implementation of behavioral intervention in the home; however, including the father in these interventions has been challenging for some mothers (Freuler et al., 2014). There is a paucity of research on fathers and less on fathers' participation in parent training programs for children with autism (Winter, 2006). This finding is concerning because paternal involvement can contribute to decreases in problem behavior in the children with autism (Bagner, 2013).

Research focused on the perspectives and experiences of culturally diverse parents and their involvement in the special education process show that parents can learn to implement behavioral interventions in the home with their children with autism. This is important because children's functional behavior can improve when families are treated based on their values and cultural beliefs are incorporated into the treatment program. Allowing parents to articulate their perspectives will promote our understanding of the challenges they face, which can result in more individualized parent training programs. Parents face barriers that can affect their ability to comply with treatment protocols when implementing behavioral interventions in the home. Not only does this impact treatment adherence, but also treatment efficacy, as parents have been found to omit steps or not use their mastered skills with their child in the home as they did when in the training session. More specifically, parents experience barriers associated with: (a) communication with treatment providers, (b) poverty; (c) fatigue; (d) gender roles; (e) family disruption; (f) perceptual differences; (g) parent disability; (h) lack of child progress; (i) differences in language; and, (j) cultural factors. There are several approaches that psychologists, counselors and autism treatment providers have utilized to

address barriers experienced by parents of children with autism. Behavioral-based parent training programs aim to teach parents how to implement behavioral interventions in ABA to promote socially significant behavior change. When parents implement treatments in the home, their children show increased imitation and the production of speech sounds. There is much research documenting the effectiveness of ABA for infants and toddlers with autism; however, very few studies have explored the experiences and perceptions of parents when implementing ABA programs in the home with their nonverbal child with autism (Tzanakaki et al., 2012). The roles of fathers and their perspectives regarding these roles in their child's treatment have been overlooked in the literature. This is concerning because fathers have been reported to become frustrated when they are not able to communicate and play with their child with autism (Elder et al., 2003).

To promote positive therapeutic outcomes, both mothers and fathers of children with autism must communicate their experiences and perspectives with autism treatment providers during the process of determining the need and services for their child. The development of empathy and understanding of the client's internal frame of reference is an intricate part of the humanistic approach. Assessing parent perceptions and the barriers they experience may help determine specific resources to address the child's and family's individual needs. This is essential in the autism treatment and parent counseling process, as parent perceptions have been shown to change and contribute to increases in treatment adherence.

Counselors need to understand the lived experiences of parents but more specifically fathers of children with autism. Obtaining knowledge about fathers' perceptions is crucial to understanding their experiences and to begin empathizing with their personal circumstances (Rogers, 1951). The development and genuine display of empathy during individualized counseling sessions will facilitate and communicate our understanding of the culture and views of these fathers. As a result, some parents experience perceptual reorganization, which can impact their perceptions of autism and the therapeutic process. To ensure appropriate services are received, it is important to assess issues related to biculturalism of immigrant families of children with autism residing in the US. Research on ethnically diverse parents could produce findings that may transfer to populations sampled in similar geographical areas (Hannon, 2014). Knowledge regarding perspectives of fathers from diverse ethnic and cultural backgrounds will promote our awareness of multicultural issues and lend insight on the experiences of fathers from similar cultures residing in other suburban, urban and rural areas of the country. More gender-balanced research is needed on the perspectives of both mothers and fathers. This is important in the treatment of autism because home- and school-based parental involvement has been associated with parents' perceptions surrounding their level of responsibility to support their child's education (Fishman & Nickerson, 2014). To help promote their involvement in home-based early intensive behavioral intervention in the treatment of autism, it is critical to evaluate the parent perceptions. Moreover, treatment adherence has been found to improve when parents agree on behavioral intervention strategies.

Autism can affect multiple domains in the life and functioning of the child and family. Psychologists and counselors can employ an integrative approach with parents to help enable them to work more effectively with their child, which could result in an increase and improvement in children behavioral interventions implemented by mothers and fathers in the home. Therefore, this study explored the perspectives of fathers from diverse ethnic and cultural backgrounds residing in NYC regarding barriers to implementing behavioral interventions in the home with their nonverbal child with autism. An understanding of the following was attempted: (a) identification of current and previous barriers to father implementation of behavioral interventions in the home; (b) fathers' personal experiences with each specific barrier to implementing behavioral interventions with their nonverbal child with autism; and, (c) fathers' feelings about these barriers to implementing behavioral interventions with their nonverbal child with autism.

The added knowledge contributed to the literature by filling a large gap in the research on the perspectives of fathers from diverse ethnic and cultural backgrounds residing in NYC. Fathers' perceptions associated with the barriers they face when implementing behavioral interventions provided insight on their needs to assist psychologists and counselors in the treatment process and to help promote positive therapeutic outcomes. In the following chapter, the methodologies, framework, approach, and data collection procedures that were used in this study will be discussed.

## Chapter 3: Research Method

### **Introduction**

Fathers can contribute to the therapeutic treatment of children with autism (Bagner, 2013). However, some fathers may experience barriers to implementing home-based behavioral interventions. When ethnic- and culture-based factors are added, it is highly plausible that some fathers may experience these barriers very differently. To promote positive therapeutic outcomes, it is imperative that autism treatment and parent training programmers consider how fathers from diverse ethnic and cultural backgrounds experience barriers to implementing behavioral interventions with their own children in the home. Learning more about how fathers perceive these barriers may help autism treatment providers and parent counselors in addressing them during individualized training or parent counseling sessions.

The goals of this study were to identify barriers to implementing behavioral interventions in the home that are experienced by fathers of diverse ethnic and cultural backgrounds residing in NYC as well as explore how these fathers experience and feel about the identified barriers. Understanding how fathers residing in NYC experience and feel about barriers to implementing behavioral interventions with their child with autism will not only assist treatment providers in this and other urban areas in the US, but will also provide insight on how ethnic- and culture-based factors are involved, which can be explored by practitioners serving parents in local ethnic community organizations or in various international communities.

In this chapter, the researcher provided an overview of the research design, research questions, and justification for the approach. The role of the researcher was explained along with related ethical issues for participants. The participants and site selection were discussed. Lastly, data collection procedures as well as concerns regarding external validity and the limitations of the study were reviewed.

### **Research Design and Rationale**

This study used a phenomenological approach consisting of one-time, semistructured interviews. The researcher produced open-ended questions and asked them during the interview. The open-ended interview has high fidelity (Rudestam & Newton, 2007). Its use helps researchers uncover multiple perspectives from a wide array of individuals on various research topics (Morse, 2015). Therefore, this method was most appropriate to this study because of the diversity of participants from various ethnic and cultural backgrounds. In addition, this approach enabled the researcher to analyze collected data directly from the source and then categorize the data into themes, which helped identify patterns to facilitate comparisons between study participants.

### **Research Questions**

To facilitate understanding of the perspectives of fathers from diverse ethnic and cultural backgrounds residing in NYC regarding their experience of barriers to implementing behavioral interventions with children with autism, the researcher investigated several phenomena through the following research questions:



RQ1. What are barriers faced by fathers of diverse ethnic and cultural backgrounds residing in NYC when implementing behavioral interventions with their child with autism?

RQ2. How do fathers of diverse ethnic and cultural backgrounds residing in NYC experience barriers to implementing behavioral interventions with their child with autism?

RQ3. How do fathers of diverse ethnic and cultural backgrounds residing in NYC feel about these barriers to implementing behavioral interventions with their child with autism?

This investigation was accomplished using the following interview questions, which were presented in this study's interview protocol (see Appendix C).

1. Tell me about being with your child in the home, what you do together, how often you are together, and what successes you experience when together with your child.
2. What are the challenges when you are together with your child?
3. After receiving parent training from your autism treatment provider on how to work on important goals with your child in the home, what barriers prevent you from implementing behavioral interventions with your child in the home?
4. How do you experience each of these specific barriers to implementing behavioral interventions with your child in the home?
5. How do you feel about each of these specific barriers to implementing behavioral interventions with your child in the home?

6. Is there anything else that you would like to share that is related to barriers that prevent you from implementing behavioral interventions with your child in the home and how you experience and feel about these barriers?

The results of this study provided insight into an important area in the treatment of autism that can be used by psychologists, counselors, teachers, medical professionals, autism advocacy groups, and parents, especially fathers of children with autism. It was assumed that barriers do have an effect on father implementation of behavioral interventions in the home, which also impacts the fathers' individual experiences with their children and feelings. In addition, ethnic and cultural factors may contribute to the individualized experiences of these fathers residing in NYC. In analyzing study data, the researcher sought to be mindful that barriers as well as differences in ethnicity and culture may influence the implementation of behavioral interventions. Conclusions drawn were based on generalizations made between the identified barriers the participants and their experiences and feelings surrounding these barriers.

### **Research Tradition**

This study required a qualitative approach and was therefore the most appropriate method to investigate this research topic. Qualitative research consists of sampling, instrumentation and data analysis (Morse, 2015). To generate discussion surrounding a major research question, the qualitative researcher typically considers the interview as the instrument of choice. Exploring the perspectives of fathers from diverse ethnic and cultural backgrounds residing in NYC that are related to barriers to implementing behavioral interventions with their children with autism in the home is needed because it

will enable an in-depth study of a population that is under-researched (Hannon, 2014) and will uncover variables involved in the phenomena. Therefore, this study was only achieved by a qualitative approach.

The narratives of this study's participants cannot be fully conveyed through quantitative-based statistical methods. Since these fathers were asked to provide their personal experiences and feelings regarding their own children with autism, the humanistic approach suggests that the "meaning of their perspectives" is most important to understand (Mize, 2003). It is believed that this can only be assessed through a qualitative approach.

### **Role of the Researcher**

The overall aim of the researcher was to assess and understand the meaning from the fathers' perspectives regarding barriers to implementing behavioral interventions with their children with autism in the home. Therefore, the role of the researcher was that of an objective observer, interviewer, gatherer of data, examiner of documents, and data analyzer. In addition, the researcher followed the qualitative approach by objectively interpreting the data and accurately presenting the study's findings in a non-biased manner. Moreover, the researcher's role was to follow all ethical guidelines for the protection of the study's participants. Lastly, a crucial aspect in the role of the researcher for this study was to ensure his beliefs and morals, as well as his ethnic and cultural background did not bias the interpretation and presentation of this research. Rogers (1986) strongly argued that clinicians must lay aside their own judgments and values in

order to grasp, with delicate accuracy, the exact meaning of what the client is experiencing.

Working with nonverbal children with autism and their parents has been the focus of the researcher's academic and professional endeavors as a clinician for over 15 years. As a clinician and father, it is important for the researcher to understand the perspectives of other fathers as they relate to their children with autism. Through an empathic understanding of their experiences, parent training methods will be developed and individualized, which in turn will contribute to better treatment outcomes.

## **Methodology**

### **Participant Selection Logic**

This study's participants included fathers of nonverbal children with autism who reside in NYC who are from various ethnic and cultural backgrounds. Each participant was 18 years or older and a consenting adult. Participants were prescreened for having received parent training on implementing behavioral interventions with their child in the home.

The sample size for this study was 12. Since phenomenological studies typically provide findings that are extensive and in-depth, there are often few cases considered for selection (Braun & Clarke, 2006). Furthermore, the phenomenological approach involves induction and the development of theory "as the data is collected and explored". The amount of participants ensured an in-depth analysis of data that was able to generalize across individuals and settings (Braun & Clarke, 2006).

Through the recruitment process, participant eligibility criteria (e.g., having a nonverbal child with autism, having received parent training on implementing behavioral interventions) was established automatically via consultations with directors of the referring private autism treatment agency. Letters of invitation were provided by the referring professional organization. The Letter of Invitation to Participate indicated that: (a) the choice to become a participant in this study is voluntary; (b) participation can be terminated by the participant at any time for any reason; and, (c) participating in the study will not affect any services received (or otherwise entitled to receive) by the referring professional organization.

### **Site Selection**

Participants for this study were non-randomly selected from the five boroughs in the areas of NYC, which include Brooklyn, Queens, Bronx, Manhattan and Staten Island. Since the targeted population was limited to fathers of nonverbal children with autism, a non-random selection procedure was used.

The participants were accessed through direct contact with directors from a private agency located in NYC. The referring agency had knowledge of families with fathers of nonverbal children with ASD. As each candidate was identified and contacted for their possible participation in the study, the referring agency was provided with a packet consisting of additional study information and the researcher's personal contact information to mail to the potential participant. Once this was completed, it was the responsibility of the individual to contact the researcher to begin their participation in the study.

### **Ethical Concerns and Participant Protection**

The present study was not anticipated to pose any risks to the participants or target audience. The researcher informed the participants of the benefits and purpose of the study (i.e., valuable information will be used by treatment providers to improve parent training and counseling methods, which will promote interactions between the father and child to facilitate positive therapeutic outcomes). The researcher guaranteed confidentiality and further assured the participants that their withdrawal from the study can occur at any time for any reason.

Since the participants of this study were from diverse ethnic and cultural backgrounds, the researcher carefully reviewed the consent form in its entirety and then asked each participant to vocalize the information to the researcher to ensure the written information on the consent was understood. To address confidentiality issues (i.e., possible identification of study participants), the researcher kept all identifying information for the duration of the study solely for use in this study.

### **Methods of Data Collection**

#### **Document Collection**

This study collected data through face-to-face interviews as well as audio recording of face-to-face interviews. Each face-to-face interview was conducted a neutral location such as a coffee shop, fast food restaurant or public library. To ensure privacy and avoid any breaches in confidentiality, all interviews were conducted in a private area or room when possible. The researcher kept all data locked in a filing cabinet and was the only person who had access to the research. All data will be kept for

a five year period, which is a requirement of Walden University. After five years, the researcher will shred the paper data mechanically and will dispose all audio files.

### **Interviews**

Face-to-face, semi-structured interviews consisted of open-ended questions produced by the researcher. The perspectives of fathers from diverse ethnic and cultural backgrounds residing in NYC regarding barriers to implementing behavioral interventions with their own child with autism were examined. This study explored the following: (a) specific barriers faced by fathers of diverse ethnic and cultural backgrounds residing in NYC when implementing behavioral interventions with their nonverbal child with autism; (b) fathers' personal experiences with each specific barrier to implementing behavioral interventions with their child with autism; and, (c) fathers' personal feelings about each specific barrier.

The researcher audio recorded the interview and transcribed the contents at a later time. Before the interview, the participant's demographic information was collected. In addition, the researcher's written notes from the interviews was included in the collected data to ensure that impressions, thoughts and overall understanding of the fathers' experiences were documented. Once the study was completed, the researcher contacted the study's participants to review the collected data and discuss findings.

### **Data Analysis**

The researcher analyzed the detailed descriptions of the participant's experiences to uncover recurrent themes or perspectives. Moreover, the researcher interpreted the data to help bring out the father's personal meaning of their experiences (Rogers, 1957).

A careful analysis of the collected data enabled the researcher to not only identify the barriers faced by fathers when implementing behavioral interventions but was also crucial to understanding how these barriers were experienced and felt about. Through this understanding, the data contributed to the conclusions regarding recurring themes or perspectives on barriers to father implementation of behavioral interventions with their nonverbal child in the home.

The Hyper-Transcribe® computer software program was used to digitize, categorize and manage the collected data while the QSR NVivo® computer software program was used in the analysis and interpretation of the collected data. Since the participants were from diverse ethnic and cultural backgrounds, the researcher included all findings whether similar or discrepant because it is often the case that individuals perceive and assign meaning to their experiences based on their personal beliefs and feelings (Rogers, 1957), which can be impacted by factors such as culture and ethnicity.

To facilitate the study of each case and to assist in content description while seeking to discover themes found within each case, each interview was analyzed using a within-case analysis. The researcher provided an overall interpretation of the individual cases. Finally, a cross-case analysis was conducted to bring forth more knowledge (Khan & VanWynsberghe, 2008), which shed insight on the similarities and differences of the participants' perspectives.

The principles of the humanistic approach helped guide the interpretation of the study's findings to enhance our understanding of the lived experiences of fathers of children with autism. Rogers (1949) discussed that the primary point of importance in



humanistic perspective is the attitude held toward the worth and the significance of the individual. In addition, the belief that the individual is competent and has the sufficient capacity to deal constructively with the daily stressors of their life is essential to promoting therapeutic change. Therefore, Rogers (1949) believed that the clinician's goals should be to "perceive as sensitively and accurately as possible all of the perceptual field as it is being experienced by the individual" by indicating to the individual the extent to which he is experiencing the issue through the individual's eyes. Furthermore, focusing "attention and effort on understanding and perceiving as the client perceives and understands" is a "demonstration of the belief in the worth and the significance of this individual client" (Rogers, 1949). When interpreting the data, the researcher was mindful of these concepts. By examining study participants' perspectives regarding barriers to implementing behavioral interventions, the goal of closing gaps in the parent training literature and providing insight to parents but more specifically fathers to develop their the ability to change their particular situations, was accomplished. Insight has been defined as an understanding of the planning of one's behavior and the development of new and more satisfying ways in which the self can adjust to reality (Rogers, 1944). This was achieved by providing knowledge and much needed information on this particular population to those that practice parent training and counseling to improve their policies and overall procedures. Therefore, the humanistic approach provided the basis for the interpretation of data. The importance of demonstrating empathy, providing insight and "instilling hope by focusing on the rewards of the fathering experience" can help

psychologists or counselors in their work with fathers of children with autism (Hannon, 2014).

### **Validity and Reliability**

Research data must be considered valid if applied to practice in a useful manner (Morse, Barrett, Mayan, Olson, & Spiers, 2008). The term validation has been defined as the process of evaluating the accuracy of the collected data. For a qualitative study, validation is facilitated through extensive work in the field, meaningful interactions during time spent with the participants, and accurate transcriptions of the collected data (Morse et al., 2008).

### **Ensuring Reliability**

The researcher ensured the reliability of this study's findings by: (a) preventing errors when accurately transcribing the data; (b) reviewing the data and documenting each step in the review process; and, (c) carefully assigning codes that are consistent within and across cases with no deviation from case to case.

### **Validity Concerns**

Since the present study used a phenomenological qualitative approach to explore the personal perspectives of the study's participants, there may be an issue with the validity of the findings. Therefore, through an accurate transcription of the collected data, the researcher validated any conclusions and interpretations based on the careful analysis of the perspectives of the participants, which are being considered as honest and trustworthy in order for this study's findings to be valid (Morse et al., 2008).

### **Validation of Findings**

The accuracy of the collected data was assessed by each participant through a member check of the findings (e.g., perspectives, themes) during a follow-up interview conducted by the researcher, which contributed to the validity of the study's findings (Hsieh & Shannon, 2005). In addition, the participants were able to add any further perspectives to the collected data through their input during this follow-up interview. This validity strategy ensured that the study's findings were accurate and the researcher's conclusions and interpretations were based on the representation of the participants' actual perspectives (Morse, 2015). Another strategy to ensure validation of this study's findings was to provide a very detailed, in-depth description of the fathers' perspectives.

To further validate the findings of the study, the researcher conducted another strategy called peer debriefing (Morse et al., 2008). Peer debriefing is different than member checking because the collected data along with conclusions and interpretations was reviewed by a peer debriefer, who was an independent professional in the field of autism treatment. Coding was reviewed by the peer debriefer to make certain similar codes and emergent themes were established between the researcher's analysis and theirs. The researcher used a blind coding procedure to accomplish this and to preserve confidentiality of the participants (Morse, 2015). The researcher and peer debriefer agreed to criterion regarding codes and themes. To establish inter-rater reliability, the researcher first coded the transcripts independently and then met with the peer debriefer to review codes and themes. The researcher and peer debriefer continued to code independently to guarantee that codes were consistent in their application and emergent

themes were similarly identified. When the narratives are similarly coded and emergent themes were also similarly identified, intercoder agreement was reached. This study's goal of 80% inter-rater reliability on coding was anticipated.

### **Summary**

This chapter described the research design and rationale, which justified a qualitative approach to exploring the perspectives of the study's participants. Therefore, the methods of this study and its approach was best at contributing to the reader's understanding of the perspectives of fathers from diverse ethnic and cultural backgrounds residing in NYC. Several phenomena such as: a) specific barriers faced by fathers of diverse ethnic and cultural backgrounds residing in NYC when implementing behavioral interventions with their nonverbal child with autism; (b) fathers' personal experiences with each specific barrier to implementing behavioral interventions with their child with autism; and, (c) fathers' personal feelings about each specific barrier, were explored.

Some barriers identified in previous studies included difficulties communicating with the child, a lack of time and limited social support; however, there may be many other factors that can impact father implementation of behavioral interventions with nonverbal children with autism in the home. These factors may also influence fathers' beliefs in their self-capacities (Mize, 2003) and could contribute to less favorable familial and treatment outcomes. Very few studies have investigated the perspectives of fathers regarding barriers to father implementation of behavioral interventions in the home and no research has been conducted on fathers of nonverbal children with autism from diverse ethnic and cultural backgrounds residing in NYC. By understanding the

perceptions, feelings and beliefs surrounding this phenomena, we can discover the meaning of the fathers' experiences with these barriers and how they may relate to their perceived self-capacities. Therefore, the results of this study provided useful information to psychologists, counselors, parents, autism advocates, and professional autism treatment providers regarding barriers that fathers of diverse ethnic and cultural backgrounds residing in NYC face when implementing behavioral interventions with their nonverbal child with autism in the home. From this data, programs that train and counsel parents of nonverbal children with autism can be individualized to address the specific needs of each family.

Ethical issues associated with confidentiality were discussed as well as the participants and the locations from where they were selected from. Issues regarding reliability and validity as well as the collection and analyzation of data were also discussed and described in detail. The following chapter contains this study's findings through a detailed description of conducted research.

## Chapter 4: Results

### **Introduction**

Fathers are important in the lives of children with autism. Positive interactions while engaging in activities across a variety of settings can impact learning in ways that improve the father-child relationship. These therapeutic outcomes are crucial for parent training programs in the treatment of autism; however, many fathers experience challenges when attempting to implement program content with nonverbal children in the home (Minjarez, Mercier, Williams, & Hardan, 2013).

This study's purpose was to understand the perspectives of fathers from diverse ethnic and cultural backgrounds regarding the barriers they face when applying behavioral interventions in the home with their nonverbal child with autism. The researcher investigated several phenomena, including (a) identifying specific barriers to father implementation of behavioral interventions; (b) understanding how fathers experience each identified barrier; and (c) understanding fathers' feelings toward each barrier.

By providing a better understanding of this understudied population, the researcher sought to minimize the gap in parent training research related to fathers from diverse ethnic and cultural backgrounds. The belief that this research directly impacts the overall goal to address parent training and counseling methods and improve the father-child relationship fueled the researcher to initiate this investigation. The findings of this study may assist parents, educators, and autism treatment providers (e.g., special education teachers, behavior analysts, psychologists, and pediatricians) in promoting

positive therapeutic outcomes among children with autism. This goal was achieved through this qualitative study by providing information on the perspectives of fathers of nonverbal children with autism from diverse ethnic and cultural backgrounds.

In the following chapter, data were described through the use of a qualitative approach, which enabled participants to share their perspectives and ensured that their responses were accurately recorded and interpreted. Each participant's perspectives were presented in overviews followed by a discussion of recurrent themes. Themes found were supported by direct oral responses (e.g., quotes and statements) provided by participants. In addition, member checking assisted in ensuring the validity of the findings, which further supported the accuracy of participant responses. This chapter also described setting events, such as the interviews and demographic information relevant to study findings. Information regarding data collection was also discussed, along with evidence of trustworthiness. The results of this study were provided in the form of quotes, tables, and figures in order to accurately reflect the participants' perspectives.

### **Setting**

Data collection protocols were directly followed as specified in Chapter 3. All participants agreed to take part in the study; informed consent was obtained before the beginning interviews. Several participants stated that they chose to share their experiences to help other parents in similar situations. All interviews were conducted at a predetermined location chosen by the participant as most convenient to their schedule. Similarly, the times scheduled for all interviews were chosen by the participants.

### Demographics

The participants consisted of 12 fathers of nonverbal children with autism from diverse ethnic and cultural backgrounds who resided in NYC. All participants were between the ages of 34-59 years. All participants were born in another country except for one. All 12 participants were from diverse ethnic and cultural backgrounds. Table 1 below illustrates participant demographics such as country of birth and ethnicity as well as children's ages and years in the US.

Table 1

#### *Demographics*

Participant	Age	Country of birth	Ethnicity	Years		Occupation
				in USA	Child's age	
Participant 1	59	Bangladesh	Bengali	30	12	Government worker- public transportation
Participant 2	48	Bangladesh	Bengali	24	10	Government worker- public transportation
Participant 3	41	Guyana	East Indian	36	9, 12	Stay-at-home dad Sculptor
Participant 4	38	India	South Indian (Dravidian)	14	4	Government worker- corporate tax auditor
Participant 5	36	USA	Irish & Italian	---	4	Karate instructor
Participant 6	44	China	Chinese	26	6	US postal worker



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Participant 7	34	China	Chinese	23	5	Produce delivery truck-driver
Participant 8	45	Ukraine	Jewish	23	19	Financial analyst
Participant 9	47	Greece	Greek	26	6	Dairy distribution Company owner
Participant 10	47	Trinidad	African	13	7	Construction Independent contractor
Participant 11	37	Jerusalem	Arab (Palestinian)	30	6	Driver – transportation Services
Participant 12	54	Nigeria	African (Yoruba)	9	6	Security guard

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### **Data Collection**

Data was collected through face-to-face interviews consisting of several open-ended questions. All interviews were audio recorded and occurred between February 2016 and April 2016. To initiate the recruitment process, direct contact was made with directors of a private evaluation and treatment agency in the NYC area. The agency directors prescreened participants who met all criteria for eligibility according to study's requirements. The agency directors then provided each potential participant with a Letter of Study Information (see Appendix A) in order to inform them about the purpose of the research and objectives of the study. Potential participants were also sent a Letter for Potential Study Participants (Appendix B). This letter contained other study information that included instructions on how to contact the researcher directly if interested in participating in the study.

All interviews lasted between 45 and 60 minutes and were conducted in neutral settings chosen by study participants such as a local coffee shop (e.g., Dunkin Donuts), meeting room at a library or office, or dining area of a fast food restaurant (e.g., McDonald's, Burger King). A digital audio recording device was used to collect all interview data, which were then transferred to an external hard drive and transcribed at a later time. To ensure accurate data collection, notes were written by hand during the entire interview.

### **Data Analysis**

A computer software program called QSR NVivo was used to transcribe and organize data, which assisted in the development of themes. To facilitate the analysis, information was also transcribed to Microsoft Word to facilitate the creation of a chart that visually represented all collected data. A within case analysis of individual cases resulted in the emergence of several themes. Similarly, a cross case analysis was conducted, which identified emergent themes across cases. Lastly, a case assertion was conducted to enable an overall interpretation of cases.

### **Evidence of Trustworthiness**

#### **Credibility**

Credibility of data was ensured through a confirmation that study participants were fathers of nonverbal children diagnosed with autism. Potential participants were contacted directly by agency directors who had knowledge of the individual's information based on office records as a client who previously received professional services such as an autism evaluation, diagnosis, behavioral treatment and parent training.

In addition, credibility was further enhanced as researcher bias was eliminated to the maximum extent possible by providing an objective, detailed account of the study's findings while remaining mindful to keep personal views, cultural beliefs and ethnic background away from the research and its overall purpose. Credibility was also evidenced through a method called data triangulation, as fathers greatly varied in terms of countries of birth, ethnic backgrounds and residence in NYC. Moreover, the diversity in the participants facilitated the validity of the study.

### **Transferability**

Transferability was supported through a comprehensive description of the perspectives (e.g., thoughts, experiences, feelings) of the participants in the context of their role as a father of a nonverbal child with autism. Each case was described in detailed narrative form using direct quotes and multiple exemplars. Moreover, the diversity of the participants in terms of their ethnic and cultural backgrounds greatly enhanced the transferability of the study's results to populations from other backgrounds and settings.

### **Dependability**

In order to maintain dependability, processes used to collect and analyze data were systematically followed and consistent across all participants. This type of trustworthiness was also shown through the presentation of themes found during the data collection process, regardless whether they were associated with the original research questions. Furthermore, the accurate and thorough account of the methods used to collect

and analyze data supported the dependability of this research to enable replication to other sample populations across other settings.

### **Confirmability**

Peer debriefing and blind coding were used to ensure confirmability of this research. The peer debriefer had extensive experience in psychology, autism, and social work, which facilitated a comprehensive assessment of the data. Another method used to enhance confirmability was member checking. All participants contacted for follow-up interviews were offered the opportunity to share additional information and provide feedback regarding the data's accuracy and discovered themes.

### **Peer Debriefing Results**

The results of peer debriefing found “strong” levels of agreement between the researcher's and peer debriefer's findings. Both raters were expected to code similarly and discover analogous themes in order to attain a necessary degree of validity. Similarity in the study's conclusions was achieved, as there was an 82% agreement indicating a strong level of agreement for cross case themes discovered in the analysis. The data from peer debriefing and member checking presented below in Table 2 as well as the comprehensive account of this study's findings as shown in a thorough presentation of discovered themes were characteristic of trustworthy research that support the accuracy and credibility of results.

Table 2

*Interrater agreement*

Themes	Within case themes	Cross case themes	Assertion
Theme agreement	61 out of 71	41 out of 50	6 out of 8
Interrater agreement	0.859 (85.9%)	0.82 (82%)	0.75 (75%)
Level of agreement	Strong	Strong	Moderate

*Note.* The following values were used to determine the level of agreement (based on value of Cohen's Kappa): 0 - 0.20 = none, 0.21 - 0.39 = minimal, 0.40 - 0.59 = weak, 0.60 - 0.79 = moderate, 0.80 - 0.90 = strong, above 0.90 = almost perfect.

**Member Checking Results**

All participants received a request for a follow-up interview to discuss the results and to provide feedback. Out of the 4 of 12 participants that responded back, only 1 participant indicated a need for a follow-up interview. During the follow-up interview, the participant approved of the findings but wanted to add another barrier and stated: "I want to add lack of governmental programs and social services". He explained that "I don't know how to get any public or social services that can help me and my son in the home". The participant further stated that "If there was some kind of support in the home, I would be more able to work together with my son".

The other three participants that responded back to the request provided feedback on the findings. One participant indicated that "there was nothing more to add" and thanked me for the opportunity to participate in the study. Another participant shared that the results were "a good summary" and "accurate". This participant also requested that I change "swimming" to "once per week in the summer". The last participant to

respond back with feedback shared that the findings “look fine” and that he was “glad to participate” in the study.

## **Results**

To facilitate the presentation of research data, a number was assigned to each participant according to the order of their interview. Overviews of participants and findings for each research interview question were followed by a presentation of themes discovered through a cross case analysis for each question. Additionally, themes that emerged from the within case analysis were discussed in the question analysis and presentation of themes. Finally, a case assertion that included an overall interpretation of all cases was presented.

### **Research Question Analysis**

#### **Research Questions**

This study’s research interview questions were designed to facilitate an understanding of the perspectives of fathers from diverse ethnic and cultural backgrounds regarding how they experience barriers to implementing behavioral interventions with their own child with autism. Several phenomena were investigated, which were based on the following research questions: (a) What are the barriers faced by fathers of diverse ethnic and cultural backgrounds residing in NYC when implementing behavioral interventions with their child with autism?; (b) How do fathers of diverse ethnic and cultural backgrounds residing in NYC experience these barriers to implementing behavioral interventions with their child with autism?; and, (c) How do fathers of diverse ethnic and cultural backgrounds residing in NYC feel about these barriers to

implementing behavioral interventions with their child with autism? Appendix C shows the Interview Protocol, which consists of all the questions asked during the interview with the participants/

All the participants' responses were transcribed verbatim and coded according to similarity and frequency of occurrence, which enabled the emergence of themes. All themes found were based on fathers' feelings and experiences with their nonverbal child with autism. Figure 1 shows the themes found per interview question. These findings are detailed below.

Figure 1

*Overview of themes discovered – cross-case analysis*

Research interview	
questions	Themes
Research interview question	Activities
1	<ul style="list-style-type: none"> <li>Play and recreation</li> <li>Functional family routines</li> <li>Daily adaptive activities</li> <li>Cuddling/physical affection during naps/sleeping</li> <li>Visiting relatives/vacation and travel</li> <li>Homework/academics</li> </ul>
	Frequency
	<ul style="list-style-type: none"> <li>Every day</li> <li>1-4x per week</li> </ul>
	Successes
	<ul style="list-style-type: none"> <li>Decrease hyperactivity/child calmer</li> </ul>

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	Child enjoys it/positive mood changes
	Completing the task
	Increased compliance
	Reciprocal affection
	Less self-stimulatory behavior
	Positive interaction and communication
Research interview question	Lack of child performance/ noncompliance/ avoidant behavior
2	Lack of communication
	Lack of teaching skills/unsure how to handle situations
	Keeping child safe/supervising child
Research interview question	Noncompliance/lack of child performance
3	Lack of training, knowledge, or expertise
	Time/schedule conflicts
	Siblings/other children
	Lack of communication
	Fatigue
	Work
	Frustration/Lack of patience
	Cultural/ perceptual beliefs
	Lack of social support
	Family issues
	Financial issues
	Conflicts with spouse
Research interview question	Child does not follow instructions and displays maladaptive/avoidant
4	behavior
	Fathers unsure what to do and unable to teach or handle problem behavior

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	Child's therapy/school schedule conflicts
	Taking care/spending time with other children
	Father unsure of what child understands/Child can't indicate all needs and wants
	Tired and need rest
	Working 40+ hours with travel time
	Stressed
	Learned role/dynamics of father as parent and not teacher
	No help from family or respite care
Research interview question	Acceptance/Compromise
5	Pride/Optimism
	Anger/Upset
	Helpless/Worried
	Frustrated/Stressed/Overwhelmed
	Sad/Depressed/Not happy
	Guilty/Disappointed/Self-doubt
	Wish for more time
Research interview question	No responses were recorded; no themes were discovered
6	

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*Figure 2.* Overview of themes discovered – cross-case analysis.

**Interview Question 1: What activities do you do with your child, how often do you do them, and what successes do you experience?** Major themes associated with this interview question were the following:

Activities

- Play and recreation

- Functional family routines
- Daily adaptive activities
- Cuddling, physical affections, during naps/sleeping

#### Frequency

- Everyday
- 1-4x per week

#### Successes

- Decreased hyperactivity/child calmer
- Child enjoys it/positive mood changes
- Completing the task
- Increased compliance
- Reciprocal affection
- Less self-stimulatory behavior
- Positive interaction and communication

This question helped provide insight into the personal lives of these fathers that facilitated an understanding of the relationship with their child. In addition to activities, fathers shared how they experience the successes when interacting together with their child. Even though this question was designed to obtain basic information from the participants, the data analysis revealed several themes. One major theme associated with these questions was “play and recreation” with a frequency theme of “everyday” and “1-4x a week”. The theme for successes was “decreases in hyperactivity/child calmer” with themes “child enjoys/positive mood changes” and “increased compliance”.

The second theme was “functional family routines”, with themes for frequency of “everyday” and “1-4x a week”. Themes for successes were “decreased hyperactivity”

and theme “child enjoys/positive mood change”. Daily adaptive activities were the third theme with a frequency theme of everyday and success themes of “reciprocal affection” and “completing the activity”. Another activity theme was cuddling, physical affections, naps, or sleeping. Interestingly, seven fathers indicated that they engage in these behaviors “every day”. The themes linked to successes were “child enjoys it/positive mood changes, “positive interaction and communication”, and “reciprocal affection”. Another theme associated with these questions was “visiting relatives or vacations” with a success theme of “child enjoys it/positive mood changes”. The last theme “homework or academic activities” was associated with a frequency theme of “everyday” and success theme of “completion of task”. Only one father mentioned that “teaching new skills to the child” was a success.

**Interview Question 2: What are the challenges when you are together with your child?**

The following themes were associated with this interview question:

- Lack of child performance/ noncompliance/ avoidant behavior
- Lack of communication
- Lack of teaching skills/unsure how to handle situations
- Keeping child safe/supervising child

A theme that emerged for this interview question was lack of child performance, noncompliance, or avoidant behavior. P10 stated that his challenge is “when I try to teach him, he doesn’t listen”. P5 mentioned that his daughter “tries but is inattentive and becomes noncompliant and avoidant”. P1 said that his son displays “hyperactivity, high

rates of stimming, and a lack of focus or attention”. P4 indicated that his child is very hyperactive and “can’t sit still”. When teaching new skills, P2 stated that his challenge was “non-compliance to simple instructions”, as his son is “uncooperative with instructions”. He also said that his child is noncompliant, and will “tantrum during transitions” or “run away”. Similarly, P6 indicated that his son is also noncompliant and avoidant and then went on to say his child “refuses to do tasks like brushing his teeth or taking meds”. P11 said that his issue was lack of child performance and shared that “when we bring him to family events, he doesn’t know how to act, so we avoid bringing him”. P7 shared that he experiences challenges when his son “runs around, and won’t sleep when he is not tired”.

Another theme for this interview question was a lack of communication. P2 stated that his son “cannot share how he feels”. P5 revealed this challenge is “huge” because “he sometimes can’t understand his daughter and what she wants”. Likewise, P8 stated that “I don’t know what he understands” and “I don’t understand what he wants”. P1 stated that his child “still doesn’t have spontaneous speech or language, so speech and language communication skills” are a challenge. When together with his son, P8 further mentioned “I would like for him to communicate with me”. P3 declared that “communication is the biggest challenge”. P10 stated “you don’t really know what he wants as he can’t show emotion or how he feels”; “It’s very hard to communicate, the hardest thing is that I don’t really know what he wants because he can’t tell you”. P9 discussed that his son “can’t answer questions or tell me how he feels”.

A theme for this interview question was having to supervise their children and keep them safe. P3 reported issues with “keeping them safe because of their behaviors”. For example, P7 mentioned that his child will run away and “I will run after him”. P4 mentioned that his child “needs constant supervision, and I have to watch him all the time”. P6 talked about keeping his child safe, as “he sometimes hurts himself, and will fall off his bicycle or scratch himself”.

Another theme was a lack of teaching skills and knowledge of what to do in certain situations. For example, when his daughter “tantrums”, P5 stated “I don’t know how best to deal with it”. P9 said “I don’t know how to teach him or handle his noncompliance”. P12 simply stated that “when he doesn’t listen, I don’t know what to do”. P10 discussed how teaching his son “is difficult and not easy for me, I don’t know what to do”.

**Interview Question 3: What are the barriers that prevent you from working with your child?** The following themes were associated with this question

- Noncompliance/lack of child performance
- Lack of training, knowledge or expertise
- Time/schedule conflicts
- Siblings/other children
- Lack of communication
- Fatigue
- Work
- Frustration/lack of patience

- Cultural/perceptual beliefs
- Lack of social support
- Family issues
- Financial issues
- Conflicts with spouse

Interview Question 3 intended to lay the groundwork for this investigation. This question was intended to identify barriers each participant faces that prevent them from implementing behavioral interventions in the home with their nonverbal child with autism. The question aimed to gather information and begin the discussion regarding each barrier identified by the participants. Information was used to facilitate the analysis of data found from previous and subsequent research questions in addition to supporting generalizations made between the identified barriers and how each participant experienced and felt about each barrier. The identification of barriers was beneficial to the development of recommendations for parents, educators, psychologists, behavior analysts and autism treatment providers as well as parent training and counseling programs.

Themes that emerged showed the great majority of study participants (10 out of 12) indicated noncompliance or lack of child performance a barrier. Another theme was lack of training, knowledge or expertise, which was found in 8 out of 12 participants. Several fathers such as P5 mentioned a “lack of intensive training”, who shared:

I need training on how to deal with certain situations that arise, like when she has a tantrum. Having that knowledge to just recall from and take it when you need it.

P2 stated that he had a “lack of expertise in applying strategies” while P1 indicated “I could use some guidance in the home”. Figure 2 below shows data regarding the themes that emerged based on each participants’ identified barrier.

Figure 2

*Emergent themes based on each participants’ identified barriers*

Themes	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Noncompliance/lack of child performance		•		•	•	•	•	•	•	•	•	•
Lack of training, knowledge or expertise	•	•			•	•			•	•	•	•
Time/schedule conflicts	•			•	•	•				•	•	•
Siblings/other children		•		•			•	•	•		•	
Lack of communication					•	•		•	•	•		
Fatigue	•		•	•	•				•			
Work	•	•							•		•	•
Frustration/lack of patience	•			•	•	•						
Cultural/perceptual beliefs			•	•				•				

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Lack of social support		•		•		•
Family issues	•	•	•			
Financial issues				•		•
Conflicts with spouse		•				•

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Seven out of 12 fathers identified time conflicts as a barrier whereas siblings/other children was mentioned as another barrier by 6 out of 12 participants. Lack of communication and fatigue were both indicated by 5 out of 12 participants. Regarding the lack of communication between him and his daughter, P5 stated: “It is the biggest barrier that we have”. P10 stated “communication is the biggest barrier”. Four participants mentioned patience or frustration while cultural or perceptual beliefs, lack of social support, and family issues were mentioned by 3 out of 12 participants.

**Interview Question 4: How do you experience the barriers?** The following themes were associated with this interview question:

- Child does not follow instructions/displays maladaptive/avoidant behavior
- Father unsure what to do and unable to teach or handle problem behavior
- Child’s therapy/school schedule conflicts
- Taking care of/spending time with other children
- Father unsure of what child understands/child can’t indicate all needs and wants
- Tired and need rest
- 40+hours working with travel time
- Stressed



- No help from family or respite care
- Learned role/dynamics of father as parent and not teacher

Interview Question 4 directly related to the core of the investigation. This question intended to generate a dialogue regarding the participant's personal experiences with the barriers they identified. The information and knowledge acquired contributed to the conclusions of this study. In addition, the gained insight and understanding of how fathers from diverse ethnic and cultural backgrounds individually experience barriers further facilitated the development of several recommendations for parents, educators and autism treatment professionals.

The theme that emerged for participants who identified noncompliance or lack of child performance as a barrier was child does not follow instructions, or displays maladaptive and avoidant behaviors. P2 reported: "When I give commands, he doesn't listen". P4 shared that his child "runs up and down stairs and doesn't listen". When together with his daughter, P5 indicated that "she tries but is "inattentive and becomes noncompliant and avoidant". He also said "I always try to deal with it, but she's not focusing or almost ignoring me in a way". P7 stated that his son "doesn't listen and throws himself back" and that "he avoids me and doesn't allow me to touch him". P10 indicated that "when I try to teach him, he doesn't do it". When spending time with his son, P8 stated that "he hisses and gets upset". P12 said "I try to teach him letters, but he runs off to the computer". P11 reported, "When we bring him to family events, he doesn't know how to act, so we avoid bringing him".

Participants reported that they were unsure about what to do and unable to teach or handle the problem behavior. P6 stated that “a behavior occurs and I don’t know what I have to do, I don’t know what I’m doing”. P1 indicated that he experiences this barrier as “I’ve been trained in workshops and in the home, but I need more training in the home”. P9 said, “I don’t know how to teach him or handle his noncompliance, when I raise my tone that always works”. P2 discussed his experiences as follows: “When I give a command, he doesn’t comply, I have difficulty troubleshooting and don’t know what to do next. I wish I knew more than I know”. P3 declared that he experiences “a lack of skills”. When asked about his daughter, P5 explained that when “she has tantrums, I lack the training on how to troubleshoot, I don’t know how best to deal with it”. P6 said, “I don’t know what, how, and when to do what”. P12 stated, “When he doesn’t listen, I don’t know what to do”. P10 shared that “teaching my son is difficult and not easy for me, I don’t know what to do”.

Time or schedule conflicts were another barrier that arose when the child’s therapy and/or school schedule conflicted with the father’s schedule. P10 shared that his “work schedule fluctuates so scheduling is difficult; “I work late sometimes. Scheduling difficulties are one of my biggest problems. When the parent trainer comes, I can’t make it”. Another participant, P6, mentioned that work contributed to time conflicts, as he stated: “I work in New Jersey, wake up early at 6:15am and work 13 hour days with travel”. P11 said that his child “has after school and home services;” “When I am home, and when services are done, it’s dinner time and then bed time which leaves no time”. P1 spends time “on the phone, writing emails, and going on important visits” whereas P4

reported that his child “has no time because he is in school and therapy almost all day”.

In his experiences, P5 stated that “work, her therapy schedule, and spending time with my other kids, and wife” result in time conflicts. P12 said, “When the teacher is working with my child, if I am available for him and come in, I feel that I am distracting him”.

Taking care of or spending time with other children was another theme that emerged from the data. P9 revealed, “I can’t do 1 to 1. They have to do things together, so, we include both of them in all activities we do together”. P2 said, “I take his brother swimming and I spend time with him as well”. P11 indicated that “there are things I can do with my other 3 kids that I can’t with my son, so, I step back and modify to accommodate all 4 children”. He added, “When I work with him alone, the other kids ask about me”. P7 shared that “3 or 4 times a week, I have to take care of two children” while P4 declared “I have to take care of the baby”. When P5 spends time with his daughter along with his other children and wife, he indicated that “they are a distraction because I can’t separate them, it’s like taking her out of the moment”.

A theme emerged among all participants who identified lack of communication as a barrier in which fathers revealed that they were unsure about what their child understands and that they knew that the child was unable to indicate all their needs and wants. P10 described his experiences as follows:

You don’t really know what he wants as he can’t show emotion, or how he feels.

It’s very hard to communicate. The hardest thing is that I don’t really know what he wants because he can’t tell you.

P8 stated, “When I try to teach him something, I don’t know what he understands”. P5 said, “I can’t understand her and what she wants”. P6 indicated that “he cannot tell me his needs or wants”. P9 reported that his son “can’t ask or answer questions or tell me how he feels”.

Another theme highlighted that participants experience fatigue as in terms of being tired, and needing rest. P5 reported his experience with fatigue as feeling “drained”. P1 stated, My body has little or no energy, I get tired and I want to, but my body doesn’t let me”. P4 indicated that “I work 9-5, the child has therapy, and we are both tired by 8 or 9pm”. P3 shared that he is “the night person and also the day person. I take care of their nightly needs. The kids wake up at 3am. I take care of the house and their morning routines. I change their diapers at night and in the morning, and I only rest from 8am to 2:30pm”. P9 indicated that he is “tired of doing everything and I need 30 minutes of rest, I just want to sleep sometimes”.

Several participants reported that they work 40+ hours with travel time. P12 indicated that he “works long hours and late at night, I see him mostly on weekends”. P9 mentioned that he “owns a distribution company”, is “on call 24/7”, “very busy”, and “there is travel time” P1 said, “Travelling to and from work takes a lot of time” while P11 reported that he “works long hours, 5am-8pm”. P2 stated “I work 40 hours a week plus weekends;” “I work 11 hour days, and my wife is not working.”

Stress was the emergent theme associated with participants who were experiencing frustration and a lack of patience. P5 stated:

I experience stress as frustration. I have mental and physical stress at work, I'm stressed with going through the special education process, all the calls back and forth, I feel like it's another job sometimes with all the phone calls, I'm stressed about the autism treatment and whether it's going well. I lose my patience.

P6 revealed that "after 100 times of teaching, he still doesn't do it, so I give up and let him do what he wants". P1 reported that he experiences stress from "figuring out what to do and troubleshooting to teach in a positive manner". P4 said, "I raise my tone" [when stressed].

Cultural or perceptual beliefs were associated with the theme referred to as "learned role or dynamics of father as parent and not as teacher". To illustrate this finding, P8 indicated that "the dynamics are set and engrained: He knows how I am. I cannot implement a lot of things because I am a parent and don't have a teaching relationship". Likewise, P4 eloquently stated:

My sons know my role, they know the dynamics, and that I make things better. I am the guy that makes it better, not a teacher. My children become agitated and upset when I try to teach them.

Lack of social support was associated with the theme "no family or respite care". P9 stated as follows: "I don't have family. If my family was able to watch my daughter she would be happy and I could work with my son. I don't have that comfort". P3 shared that he has "no family to drop off the kids. I cannot take a true break. With a true break, I would be able to work more with them. I don't trust child-care agencies". P6 said, "I have no respite home care. I know the government has programs but I don't know

how to get them. I know that he is my son and it's my problem, but I just think that maybe the government should do something to help".

The barrier identified as family issues was associated with paying bills and performing tasks. P4 declared, "I must pay bills and handle house paperwork". P2 stated that his "family needs help overseas". Financial concerns were also mentioned; thus, P6 stated, "I am the only breadwinner. I pay everything. We live off credit cards". P9 said, "If we had more money, I wouldn't have to work 7 days a week 365 days a year, money makes a big difference". Conflicts with spouse was another experience, as P2 reported: "My wife becomes mad and I don't disagree because I don't want to make things worse, so, I try to avoid conflict, but I understand that she is tired, she spends more time with him than me". P10 stated as follows:

I grew up in a different environment in the West Indies. My wife is American. There are big differences in how we handle things. We disagree on topics. I am more straightforward and have I have a one track mind. I don't restrict him but the American way is a restricting environment.

**Interview Question 5: How do you feel about each of these specific barriers to applying teaching strategies with your child in the home?** The following themes were linked with this question:

- Acceptance/compromise
- Being proud/optimism
- Anger/feeling upset
- Helpless/worried

- Frustrated/stressed/overwhelmed
- Sad/depressed/not happy
- Guilty/disappointed/self-doubt
- Wish for more time

Interview Question 5 intended to bring about a rich amount of information related to participants' feelings surrounding their experiences with each of the barriers they identified. This question helped provide an intimate glimpse into the hearts and minds of these fathers, which laid the foundation of the study and fulfilled the purpose of the interview. Understanding what fathers from diverse ethnic and cultural backgrounds may be feeling about their individual experiences with barriers was crucial to the development of general conclusions and recommendations.

Ten of 12 participants indicated that they experienced feelings of acceptance and compromise as well as being proud and optimistic. When discussing his son, P7 talked about the lack of performance barrier and how he "accepts it; this is him, as long as he's happy". P3 discussed the barrier associated with his child's learned role of him as a father and shared that he felt "helpless, defeated, but then I come to an acceptance". P6 shared his feelings regarding the time barrier, saying "I am upset that I don't have the time, but I accept it, that's all I can do". P11 talked about his feelings related to schedule conflicts and shared that he is "not happy but happy that his son is getting services. That's what he needs the most, even though he probably needs more time from a parent than a social worker". This father continued by saying, "I try my best to dedicate the little time I have to him". P12 also talked about schedule conflicts, and stated "I don't

want to distract him, I accept it because I know he is learning”. When talking about the barrier of having another child, P4 said that “I accept that I am tired [to spend time with all my children], it’s part of life”. P4 also spoke about the barrier of having other children and declared that “it’s my responsibility, it’s my duty, and I’m proud”. P8 spoke about his feelings on the barrier of having other siblings and said “I feel good about it, I accept it”. P7 also shared his feelings on the barrier of having other children to take care of and indicated that “after periods of being overwhelmed, there is acceptance, this is my family. There is nothing I can do about it”. P9 voiced his feelings on the barrier of work and said, “I wish I had a 9-5 job, but I accept it, I have to pay the bills”. He also told talked about his feelings on the barrier of finances and stated as follows:

I’m 47, I’ve never been unemployed, I am happy and accept it, bills are being paid, I don’t have it all, but my kids have a lot. Everyone wants more, but I’m happy with what I have.

P9 went on to discuss the barrier of fatigue, saying “I take multi-vitamins, energy pills but they don’t work. I’m very disappointed that I can’t provide what I need when I’m tired, but I accept my limitations that I have surpassed. I am tired but accept it”. P10 discussed his feelings on the barrier of cultural differences between spouses, indicating that he is “frustrated, but I accept the difference between me and my wife and try to avoid conflict. I let mom handle it, but I handle it when I think I’m right”. P2 stated, “I understand that my wife is tired, I don’t agree, but I compromise and give up to avoid conflict”. P2 also added that “this prevents me from working the way I want to with him”. P11 spoke about the barrier of work and shared that it “doesn’t feel good, I would



rather be with my son and I want to give him more time, but I can't because I need to work so I accept it. Instead of doing a double shift, maybe I could spend that time with him". This father also discussed his feelings with respect to lack of child performance, indicating that while he is upset, he is "happy with getting him help, hopefully one day he'll get there." I have a lot of hope, I have a lot of hope with him".

Another prevalent theme were feelings of worry and helplessness, which were described by 8 of 12 participants. P11 explained his feelings about the lack of child performance and stated as follows: "I don't feel good, I want him to have good memories about our experiences, I'm not happy, I would love to see him interact with family members and it really hurts me a lot." P12 also shared his feelings regarding the lack of child performance and went on to say, "I feel bad, helpless, I can't help him, I think I need additional training". He also discussed his feelings about the lack of training and stated "I do not feel good that I cannot help my son. I see myself lacking. I lack the knowledge and want additional training to handle him". P10 discussed his feeling about the lack of child performance and added that he feel "helpless; I really want to help him but I can't". P1 talked about the barrier of being frustrated, stating, "I want to do more but can't figure out what the issue is". He also expressed his feelings about having little to no expertise in applying strategies and said, "I'm sad and worried because I don't know what to do next. I need more training in the home that is accommodating to my work schedule". Further, he said, "I wish I knew much more than I know and I feel bad because I don't know what I should do next, I need training, but I don't have enough time". P6 spoke about his feelings regarding the lack of training and knowledge barrier,

saying “helpless, guilty, and a lack of direction. I don’t have the time, or financial support, I can’t be what I want to be. I want to be a good father”. P9 spoke of his feelings on the barrier of lack of training and knowledge and said “I would like to know what to do in situations when you do have 20-30 minutes, I want to learn how to teach conversational skills”. P3 expressed how he feels about the barrier of the child’s learned role of him as a father, stating: “I don’t want to agitate them; I want to learn how to troubleshoot, and I need training on troubleshooting. I want clarity on how to fix this”. P2 discussed his feelings about family issues and said “I’m worried about my family, I wish I could help them”.

Seven of 12 participants reported feeling angry or upset. P5 described feeling upset at the lack of intensive training and lack of communication, stating “I get upset when I can’t help her”. P10 also expressed how he becomes upset at the lack of communication, mentioning “It’s very hard to tolerate, I want him to communicate better to tell me if he is angry or sad”. P6 also discussed his feelings about the lack of communication and revealed the following:

It’s the worst, the major barrier. I am upset, depressed and angry at myself. I blame myself and I feel horrible. Is my son learning anything? Is he hungry? Does he want water? When he can’t respond, how do I know where his pain is? Why did God do this to me? I have lost my faith. I blame myself, what did I do in my life to cause this? Or in my past life? This is Chinese tradition.

In discussing his child’s display of noncompliance, P4 shared he feels “angry, upset, and sad, I want him to listen and calm down”. P8 referred to similar feelings regarding the

barrier of noncompliance and avoidant behavior, stating “It upsets me and stops me from progressing.” P4 shared his feelings on having little patience, saying, “When I become upset, I raise my tone and that works”. P6 expressed how he feels about having a lack of patience and said, “I feel upset, I give up, and I choose to address the issue at another time, but that time never comes”. In discussing the barrier of physical and mental fatigue, P5 stated “I’m annoyed at myself for getting tired, but I use it to motivate myself; You have to just get over it and do what you need; Sometimes, I succumb and break, but that’s rare.” P3 spoke about the lack of social support from family barrier and said that it’s “unfair; I’m angry, everyone else has family and I don’t, all me and my wife have is each other”. In talking about the lack of social support, P9 indicated that he felt “pissed off and angry, I do have family but they don’t want to be involved”. P6 shared his feelings on the lack of social services and said he is “angry, I have given requests for social services but I only receive no. I know there are special programs, but how do I get them? It would help if they could give us training, tell us what to do, and give us someone to help in the home”. P6 spoke of time as a barrier and said “I am upset that I don’t have the time”.

Another theme that emerged in most participants was feeling frustrated, stressed, and/or overwhelmed. Regarding the lack of child performance and lack of intensive training, P5 shared that he feels “extremely frustrated and almost negligent, I want to have the knowledge to get her to perform; I don’t know how to help her, and get her through that moment”. P1 mentioned a lack of expertise, stating “I feel very frustrated, stressed, and want to do more but can’t figure out what the issue is; I would like more

written guidelines and 1:1 training on how to handle all of my son's behaviors. As a parent, we are not trained and we do not know how to handle it, we handle it in our way". P8 voiced his feelings about the communication barrier and stated that it is "very frustrating, I don't have any insight to reflect on his understanding, "I don't understand what he wants and can't explain to him in a functional manner, I would like for him to communicate with me". P2 mentioned that the lack of communication is "upsetting and frustrating", which makes him feel "sad and helpless. He added, "I need more training on communicating with (my daughter)". P1 talked about the barrier of stress regarding family matters and shared that he is "stressed, money management and dealing with bills and family crises". Regarding the barrier of time spent on other services, P1 further explained that he felt "stressed, frustration, I wish I had someone to help me with other services for my son". P10 talked about his feelings regarding the lack of time, and said it is "frustrating, I want to spend more time and I wish I was a bigger part of his progress". P2 spoke about his feelings on the barrier of work, saying, "I feel stressed, I wish I had more time off work but I can't because I need the money, I feel so bad when I'm working extra hours." P7 offered his views on the barrier of having other children and revealed that he is "overwhelmed, it feels like taking care of 7 children". P5 discussed the barrier of stress and stated, "I don't want to feel stressed, mad, or aggravated".

Approximately half of all the participants indicated feeling sad, depressed or not happy. In discussing the lack of communication, P9 indicated that he is "sad, I don't care if he curses me, I just want him to have a conversation with me". P5 talked about feelings on the communication barrier and said he is "sad, and helpless, I need more

training on communicating with (daughter's name)". P2 spoke about the lack of child performance and added that he is "sad, my son knows I am easy going and I try to troubleshoot by finding another reinforcer but it doesn't work, whatever I say to him, he won't do it, and he knows I'm easy going". In sharing his feelings about noncompliance, P4 said he is "sad, I want him to listen and calm down". P11 expressed his feelings about the lack of child performance and said it "doesn't feel good, I want him to have good memories about our experiences, I'm not happy, I would love to see him interact with family members and it really hurts me a lot". During our discussion about the barrier of maladaptive behavior, P2 said, "I feel bad for my son because he doesn't understand, I try to make him process what he has to do in others' homes, I wish he was more typical and did not do these things in others' homes. P11 expressed his feelings about conflicts of time due to therapy schedules and shared that he is "not too happy but happy that he is getting services, that's what he needs the most, I try my best to dedicate the little time I have to him". P2 also spoke about his feelings regarding time conflicts and mentioned that he is "sad because I have no time but happy because he is making improvement in therapy". P2 further explained his perspectives on the barrier of having other children and revealed that he is "sad" because the children are not functioning similarly, and "they cannot play together easily; I have to spend time with them separately doing different activities". He added, "I feel bad because I wish my son was okay so I can spend time with both of my sons, because one is typical and the other is not." P6 talked of his feelings regarding the barrier lack of financial support and said that

“after taxes, all the money is gone to expenses, I have no choice. I have to do it. I feel depressed, and I’m upset, but I accept, because at this point, it’s all I can do”.

The final themes that emerged were feeling doubt, self-guilt, and/or disappointed and wishing they had more time with their child. P3 discussed fatigue and how it makes him feel “defeated, guilty that my fatigue is impacting my performance”. I wish I could have more energy for them”. While speaking about lack of training, P6 reported that he feels “guilty, and lack of direction I don’t have the time, or financial support, I can’t be what I want to be. I want to be a good father”, He also indicated he feels “disappointed, lost, and I begin to doubt myself” when discussing the lack of child performance. When asked about feelings regarding the barrier of fatigue, P3 replied, “I wish I had more time off so that I could have more energy for them”. P12 spoke about work as a barrier and shared, “I don’t like it, I would like to spend more time with him, but I need to sleep”. Work was also discussed by P11 who stated, “I’d rather be with my son and I want to give him more time, but I can’t because I need to work”. P2 also revealed similar feelings in talking about work as a barrier, saying, “I feel stressed, I wish I had more time off work but I can’t [take more time] because I need the money”. P4 also mentioned time as a barrier, stating, “If I had more time, then maybe I could see much more improvement”.

**Interview Question 6: Is there anything else that you would like to share that is related to barriers that prevent you from applying teaching strategies with your child in the home and how you experience and feel about these barriers?**

The last interview question ensured that all study participants were offered another opportunity to add any additional barriers or convey any other experiences and feelings that prevent them from implementing behavioral interventions in the home with their nonverbal child. Data was not provided for this question, as all 12 participants indicated that there was no additional information to offer. Therefore, no themes were discovered for this interview question. Several reasons could be associated with this finding. For example, it is possible that some participants experienced fatigue after the first 45 minute period of time of the interview. There is also another possibility that other factors such as work, lack of time or familial obligations contributed to the lack of responses to this interview question.

### **Summary**

#### **Case Assertions**

- Father-child interactions limited to activities of daily living, recreation, and family routines while in and out of home
- Increases in prosocial behavior and other positive behavior change associated with repeated father-child interactions
- Deficits in communication impact father performance and understanding of child's specific needs and internal state (e.g., physical, emotional)
- Poor to no instructional control over child behavior
- Very little to no time spent implementing behavioral interventions directly with child in the home

- Failure to implement behavioral interventions in the home associated with lack of knowledge regarding the implementation of instructional procedures and application of behavior modification techniques
- Lack of time associated with competing environmental contingencies necessary for maintenance of family and child's therapeutic outcomes
- Awareness of stress and negative feelings associated with positive coping skills and self-determination

The comprehensive results of the present study indicated that almost all father-child interactions reported were limited to activities of daily living, recreation, and family routines while in and out of home. All participants reported positive behavior change and increases in their child's display of prosocial behavior due to repeated father-child interactions. However, participants also reported that deficits in communication impacted their performance and understanding of their child's specific needs and internal state (e.g., physical, emotional). In addition, all participants indicated that they had poor to no instructional control over their child's behavior. Surprisingly, all participants indicated that very little to no time is spent implementing behavioral interventions directly with their child in the home. Further, the failure to implement behavioral interventions in the home was directly associated with a lack of knowledge regarding the implementation of instructional procedures and application of behavior modification techniques. Almost all participants reported their lack of time was associated with balancing competing environmental contingencies necessary for maintaining their family's well-being and child's therapeutic outcomes.



Another finding was an awareness of various negative and positive thoughts or emotions. The vast majority of participants reported some form of stress and several negative feelings, which were associated with several types of positive coping skills and acts of self-determination. Participants' reported feeling "frustrated", "stressed", "overwhelmed", "helpless" and "worried" while others stated that they felt "anger", "upset" "sad", "depressed" or "not happy". Some participants reported feelings of guilt, disappointment, and self-doubt. Almost all participants have made "compromises" and reported feelings of acceptance, pride and an optimistic view of the future. Similarly, almost all fathers reported wishes for more time with their child.

The following chapter concentrated on describing the study's findings, and discussed ways in which this research data compared to, or extended knowledge in the area of autism treatment and parent training or counseling methods. Study findings were found to be empirically-supported by current research published in peer-reviewed scientific journals. Study findings were interpreted in the framework of humanism and behavior analysis. The study's limitations were discussed as well as suggestions for additional research. Several methodological and theoretical implications for the facilitation of positive behavioral change were made. An overview of within case themes, cross case themes, and case assertions discovered during this study are present in Figure 3 below.

Figure 3

*Overview of themes discovered*


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Within case themes	<p>Considerable time spent with child following daily routines during a variety of activities across multiple settings</p> <p>Periods of success mixed with various levels of challenging behavior</p> <p>Absence of child communication regarding thoughts and feelings</p> <p>Limited skills to teach or address child behavior</p> <p>Limited time due to work or other familial obligations</p> <p>Periods of negative and positive thoughts or emotions</p> <p>Recognition of need for additional parent training</p>
Cross case themes	<p>Interview question 1: Activities &amp; Successes</p> <p>Activities</p> <ul style="list-style-type: none"> <li>Play and recreation</li> <li>Functional family routines</li> <li>Daily adaptive activities</li> <li>Cuddling or physical affection during naps or sleeping</li> <li>Visiting relatives or vacation and travel</li> <li>Homework or academics</li> </ul> <p>Frequency</p> <ul style="list-style-type: none"> <li>Every day</li> <li>1-4x per week</li> </ul> <p>Successes</p> <ul style="list-style-type: none"> <li>Decrease hyperactivity/child calmer</li> </ul>

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Child enjoys it or positive mood changes

Completing the task

Increased compliance

Reciprocal affection

Less self-stimulatory behavior

Positive interaction and communication

Interview question 2: Challenges

Lack of child performance, noncompliance, or avoidant behavior

Lack of communication

Lack of teaching skills or unsure how to handle situations

Keeping child safe or supervising child

Interview question 3: Barriers to implementing behavioral intervention

Noncompliance or lack of child performance

Lack of training, knowledge or expertise

Time or schedule conflicts

Siblings or other children

Lack of communication

Fatigue

Work

Frustration or lack of patience

Cultural or perceptual beliefs

Lack of social support

Family issues

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Financial issues

Conflicts with spouse

Interview question 4: Experiences with barriers

Child does not follow instructions and displays maladaptive or avoidant behavior

Fathers unsure what to do and unable to teach or handle problem behavior

Child's therapy or school schedule conflicts

Taking care or spending time with other children

Father unsure of what child understands or child can't indicate all needs and wants

Tired and need rest

Working 40+ hours with travel time

Stress

Learned role or dynamics of father as parent and not teacher

No help from family or respite care

Interview question 5: Feelings about barriers

Acceptance or compromise

Being proud or optimism

Anger or feeling upset

Helpless or worried

Frustrated, stressed or overwhelmed

Sad, depressed, or not happy

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Guilty, disappointed, self-doubt

Wishes for more time

Interview question 6: Additional information

No data was provided

Case assertions    Father-child interactions limited to activities of daily living, recreation, and family routines while in and out of home

Increases in prosocial behavior and other positive behavior change associated with repeated father-child interactions

Deficits in communication impact father performance and understanding of child's specific needs and internal state (e.g., physical, emotional)

Poor to no instructional control over child behavior

Very little to no time spent implementing behavioral interventions directly with child in the home

Failure to implement behavioral interventions in the home associated with lack of knowledge regarding the implementation of instructional procedures and application of behavior modification techniques

Lack of time associated with competing environmental contingencies necessary for maintenance of family and child's therapeutic outcomes

Awareness of stress and negative feelings associated with positive coping skills and self-determination

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## Chapter 5: Discussion, Conclusions, and Recommendations

### Introduction

Fathers face challenges when attempting to teach children with special needs, which may be more difficult when their child is nonverbal and diagnosed with autism (Minjarez et al., 2013). For example, some nonverbal children with autism may lack the ability to communicate or may exhibit high rates of self-stimulatory behavior that interfere with learning that can impact the quality of the father-child relationship. In addition to these challenging behaviors, some fathers may face barriers that may prevent them from teaching their nonverbal child with autism.

The aim in carrying out this study was to advance an understanding of the perspectives of fathers from diverse ethnic and cultural backgrounds regarding the barriers they face when implementing teaching strategies with their nonverbal child with autism. This goal was accomplished in order to fully understand the answers to the following research questions:

RQ1. What are the barriers faced by fathers of diverse ethnic and cultural backgrounds residing in NYC when implementing behavioral interventions with their child with autism?

RQ2. How do fathers of diverse ethnic and cultural backgrounds residing in NYC experience these barriers to implementing behavioral interventions with their child with autism?

RQ2. How do fathers of diverse ethnic and cultural backgrounds residing in NYC feel about these barriers to implementing behavioral interventions with their child with autism?

Study findings may assist parents, autism treatment professionals, psychologists, counselors, behavior analysts, special education teachers, pediatricians, and advocates who serve children with autism. Findings may help these individuals have an understanding of the perspectives of fathers of nonverbal children regarding barriers they face when implementing behavioral interventions and how they experience and feel about these barriers. This improved knowledge may facilitate the development of better clinical programming, particularly in the area of parent training and counseling, with the aim of building self-capacities and teaching skills to improve the parent-child relationship.

### **Key Findings**

**Successes and challenges.** Results indicate that participants spend a considerable amount of time with their nonverbal child engaging in daily routines. Across multiple settings, participants engage with their children in a variety of activities such as play or recreation, functional family or adaptive tasks, cuddling or physical affection during naps or sleeping, visiting relatives or vacation and travel, and completing homework or academic work. Increases in prosocial behavior and other positive behavior change were associated with repeated father-child interactions. For example, fathers reported periods of success such as decreased hyperactivity, positive mood changes, task completion, increased compliance, reciprocal affection, less self-stimulatory behavior, and increased interaction. Despite these successes, various levels of challenging behavior were

reported such as absence of child communication regarding thoughts and feelings, lack of child performance, noncompliance, or avoidant behavior. Deficits in communication were found to impact father performance and understanding of a child's specific needs and internal state (both physical and emotional).

Fathers indicated that they had limited skills to teach or address their child's behavior and reported often being unsure of how to handle situations. Some participants shared that they experience difficulties in supervising or keeping their child safe. All fathers recognized the need for additional parent training. Limited time due to work or other familial obligations was also reported. These situations were coupled periods of negative and positive thoughts or emotions.

**Barriers and experiences.** The identified barriers to father-implementation of behavioral interventions were (a) noncompliance or lack of child performance; (b) lack of training, knowledge or expertise; (c) time or schedule conflicts; (d) siblings or other children; (e) lack of communication; (f) fatigue; (g) work; (h) frustration or lack of patience; (i) cultural or perceptual beliefs; (j) lack of social support; (k) family issues; (l) financial issues; and (m) conflicts with spouse. Participants who identified noncompliance as a barrier reported that their child does not follow instructions and displays maladaptive or avoidant behavior. Lack of training, knowledge, or expertise was associated with being unsure about what to do and being unable to teach or handle problem behavior.

Overall, it was found that fathers had poor to no instructional control over their child's behavior. As a result, very little to no time was spent on implementing behavioral interventions directly with the nonverbal child in the home. Failure to implement



behavioral interventions in the home was associated with a lack of knowledge regarding the implementation of instructional procedures and application of behavior modification techniques. Participants who identified time or schedule conflicts reported that their child's therapy and school schedule often conflicts with their own schedule. In addition, siblings or other children were experienced as taking care of or spending time with other children.

Fathers who identified the barrier of lack of communication reported experiencing uncertainty about what their child understands, as they were reportedly unable to indicate all needs and wants. Work was associated with working 40+ hours with travel time while experiences of fatigue were linked with being tired and needing rest. Fathers reported experiencing stress that corresponded with the barrier of frustration or lack of patience. Cultural or perceptual beliefs were associated with the learned role or dynamics of father as parent and not teacher. Fathers who reported barriers related to lack of social support stated that they receive no help from family or respite care.

**Thoughts and emotions.** Participants' awareness of stress and their negative feelings was associated with positive coping skills and self-determination. For example, fathers reported accepting their child's disabilities and a willingness to compromise with daily challenges. All participant fathers acknowledged the need for additional parent training in the home. In addition, fathers reported being proud of their child and optimistic of the future. However, participants also reported being angry or upset, feeling helpless or worried, frustrated or stressed, and overwhelmed. Some participants felt sad or depressed and not happy while others mentioned feelings of guilt and self-doubt.

Finally, the majority of participants expressed a desire for more time with their nonverbal autistic child. Lack of time was associated with competing environmental contingencies necessary for family maintenance and child's therapeutic outcomes.

### **Interpretation of Findings**

Current statistics from the US indicate the rise in the prevalence of autism to approximately 1 of 68 children has led to an increased need for autism treatment and parent training programs (CDC, 2015). Teaching parents to implement behavioral interventions in the home with their child with autism has been shown to promote positive behavior change across key areas of development and can also reduce levels of stress (Bendixen et al., 2011); however, many parents face barriers that impact their ability to comply with their child's autism treatment program (Mackintosh et al., 2012). Very little research exists about parents' perspectives regarding the implementation of behavioral interventions with their nonverbal child with autism in the home (Tzanakaki et al., 2012) and no research on the participation of families from diverse cultural and cultural backgrounds (Cheremshynski et al., 2013). Further, since the vast majority of studies have focused on mothers, there is a profound lack of research on the perspectives and experiences of fathers in the autism treatment process (Vacca, 2013), which is concerning because father involvement has been shown to improve skills across several domains and decrease problem behavior in children with autism (Bagner, 2013). In this study, several findings assisted in expanding the research on the perspectives and experiences of fathers from diverse ethnic and cultural backgrounds regarding barriers

faced when implementing behavioral interventions with their nonverbal children with autism in the home.

Father involvement in an autism treatment program entails the application of behavioral strategies across daily routines (Granger et al., 2012). Findings of this study confirm that all participants successfully engaged in daily activities with their nonverbal child while in and out of the home. All fathers reported positive behavior change due to repeated father-child interactions. For example, when engaging in recreational and/or adaptive tasks, their children were reportedly calmer, more compliant and exhibited less stimulus overselection (i.e., self-stimulatory behavior). The frequency and intensity of these father-child interactions were reportedly very high, with almost all participants indicating daily moments of “connecting” with their child through reciprocal affection during functional family routines. These “brief” moments of mutual gaze and sharing of affect along with the child display of prosocial behavior were the most rewarding aspect of the participants’ relationship with their nonverbal child and a major finding of this study with significant clinical importance discussed later in this chapter. Participants indicated that they felt “normal” or like a “normal family” doing “normal things” during these repeated father-child interactions when taking long walks around the neighborhood, shopping, driving in the car or when eating together, watching TV, bathing and sleeping together.

Despite these successes, findings of this study confirmed earlier research that communication with a nonverbal child with autism can be a challenging task (Berry et al., 2014). Communication difficulties were commonly experienced by these fathers of

nonverbal children with autism. Lack of communication impacted father implementation of behavioral interventions in the home. The child was unable to communicate their needs and the father was often not able to understand how their nonverbal child felt from moment to moment. This is quite saddening because Hannon (2014) found that that establishing clear communication is one of the most rewarding aspects of parenting a child with autism. These findings are significant and point to clinical concerns related to teaching functional communication skills to both parents and their nonverbal children with autism. Findings of this study also add to previous research which found a lack of child progress is a common barrier reported amongst many parents from various ethnic and cultural backgrounds that impacted decisions to continue implementing behavioral interventions (Mackintosh et al., 2012). Noncompliance and child display of maladaptive behavior confirms previous reports that behavioral issues (Hannon, 2014) and more severe symptoms (Theerasilp & Sherer, 2013) can impact the treatment process. Lack of time due to schedule conflicts between work and child's therapy as well as family obligations (e.g., spending time or taking care of other children) reportedly prevented father implementation of behavioral interventions and also confirmed earlier studies with ethnically diverse parents (Boström & Broberg, 2014). Nonverbal children with autism and other severe developmental disabilities often receive a wide array of services across several disciplines such as speech therapy, occupational therapy and physical therapy. It is therefore no surprise that children with autism will have a limited amount of time due to their daily therapy schedule. Several participants reported that "balancing" work and

time spent with other children along with their autistic child's therapy schedule was essential to the family's well-being.

Another crucial aspect of father involvement in an autism treatment program is implementation of instructional programs with their child (Granger, et al., 2012). Unfortunately, about 50% of parents in the US fail to follow the recommendations of their child's autism treatment program, (Moore & Symons, 2011). According to the CDC (2015), nonadherence to treatment protocols by parents is a concern that may negatively impact the therapeutic process. Based on the perspectives of study participants, the findings of this study add to the literature by showing that a lack of parent training in the home and knowledge of the application of ABA behavior modification techniques in the home was a barrier that prevented father implementation of behavioral interventions with their nonverbal children with autism. Little to no time was reportedly spent on direct instruction with their child. As a result, participants acquired poor to no instructional control over their child's behavior, which may have impacted the child's display of noncompliance and avoidant behavior. Not surprisingly, all participants indicated that attending autism treatment workshops and parent trainings in other settings (e.g., clinic, hospital, or office of private agency) was "not enough". Moreover, all participants recognized that additional individualized home-based parent training was needed to be able to effectively communicate and teach their child as well as address maladaptive behavior in the home.

Based on the legal requirements of IDEA and recent changes in health insurance law currently in place both at the state and federal levels, the mandated inclusion of

parents as full participants in the special education and health care process entails the provision of autism treatment and parent training services when a child is diagnosed with autism. Autism treatment workshops and parent trainings at the school, clinic, hospital, or office of a private agency are reportedly being conducted; however, it appears that some may not have directly addressed barriers that parents face when attempting to apply teaching strategies with their nonverbal child in the home. For example, all participants reported that they were unable to communicate effectively with their nonverbal child in the home. It is possible that these parent training procedures in the home have not yet been developed or the child did not have an effective communication system to be taught to the parents in the home. Another possibility is that home-based parent training was not offered or available by the school and autism treatment provider, which could stem from a multitude of reasons. Despite receiving parent training as part of the autism treatment process, these fathers reportedly lacked the ability to communicate with their nonverbal child in the home and also lacked the skills to directly teach their nonverbal child in the home. These were major findings of this study that confirm previous research on parents of children with autism who reported the underutilization of their skills in the home acquired during parent training sessions conducted in other settings (Moore & Symons, 2011).

Participants' reports of frustration and anger coupled with worry and feelings of helplessness were consistent with earlier research which showed similar reports (Huang et al., 2012). Findings of this study add to previous research by showing that fathers of nonverbal children with autism from diverse ethnic and cultural backgrounds residing in

NYC experienced similar barriers related to stress which corresponded with negative emotions or feelings. Most participants expressed these feelings in relation to not being able to help their child more than they wanted to. Participants wished for better communication with their child. In contrast, participants also reported multiple acts of self-determination. For example, all fathers actively spent a considerable amount of time with their nonverbal child. Due to these repeated father-child interactions, the child learned what to expect each time the father signaled that the activity will begin. The development of this positive outcome makes sense as nonverbal children with autism benefit from rote-learning experiences (Kroncke, Willard & Huckabee, 2016). As a result, children were reportedly more compliant and exhibited less problem behavior during these learned daily routines. Participants also reported feelings associated with positive coping skills such as acceptance of their child's diagnosis and a willingness to persevere during adverse situations. Fathers indicated that they attended autism workshops and parent trainings as well as IEP meetings and school conferences. Fathers reported doing "all that they can" within the limits of their time and physical abilities. Remarkably, all participants recognized their positive and negative emotions and feelings.

Parent training and autism treatment goals for these fathers would be to become fully trained to communicate with their child's preferred manner of communication, to successfully implement all behavioral interventions in the home, the development of instructional control with decreases in maladaptive behavior, increased positive thoughts

or emotions and a significant improvement of the quality of the father-child relationship in general.

### **Conceptual Framework Analysis and Interpretation**

Findings from this study were interpreted using both a behavioral and humanistic approach. The former of these theories encompasses a perspective based on an analysis of environmental contingencies and function (Miltenberger, 2011, p. 246) while the latter embraces the concept of interpretation and personal meaning (Rogers, 1986). Both approaches lay the ground work for gaining a deeper understanding of the perspectives of fathers from diverse ethnic and cultural backgrounds and the barriers faced when trying to teach their nonverbal children with autism in the home. The main goal was to obtain knowledge and subsequently empower parents, as well as autism treatment providers, educators, psychologists, behavior analysts, counselors or those who support and advocate for children with autism to actively address this issue in their work with nonverbal children, with the overall purpose of developing parent training methods for the improvement of therapeutic outcomes. Most importantly, this study provided these fathers with a “voice” with which to express their perspectives and offered a plethora of evidence to help make changes to existing parent training curriculums for this unique, underrepresented parent population.

### **Limitations of the Study**

The limitations of this study’s findings were consistent with those mentioned in Chapter 1. A non-random sampling method was required to ensure all participants were fathers of nonverbal children with autism. Furthermore, since the sample size of fathers



from diverse ethnic and cultural backgrounds residing in NYC was 12, the generalizability of these findings may be limited to similar populations living in similar urban areas in the US or abroad. In addition, it was expected that not every ethnicity and cultural background would be included in this sample of participants; however, the lack of data from participants in the Hispanic or Latino community and other ethnicities in NYC may be another limitation of this study.

### **Recommendations**

Based on the experiences and feelings of fathers regarding the barriers that prevent the implementation of behavioral intervention in the home as evidenced by the results of the present research in this qualitative study, the following recommendations are indicated. These recommendations should be interpreted with respect to issues related to the challenges surrounding the funding of public schools and more specifically, acquiring sufficient staff to implement the study's recommendations. For instance, the current student population in the State of New York where this study was carried out was 2,512,656 for the 2015-2016 school year. The total number of instructional staff (e.g., teachers, principals supervisors, consultants, guidance counselors, librarians, psychologists, and other instructional staff) for the same 2015-2016 school year was 206,515 as compared to 193,875 for total number of teachers (National Education Association, 2016). Since instructional staff included the position of teachers in the total number, this left 12,048 instructional staff for over 2.5 million children, equaling approximately 198 students for each staff member in this group. Moreover, since children with autism need highly-skilled teachers and supervisors with experience in

ABA and behavior modification techniques, the number of instructional staff may further decrease as some would not be credentialed and/or able to implement interventions for these nonverbal with autism. Private autism treatment organizations funded by health insurance may also experience staffing issues with direct-care ABA providers and supervision (Gerhardt, Cicero & Mayville, 2014).

### **Recommendations for Educators and Autism Treatment Professionals**

It is recommended that public school systems and organizations in autism treatment consider adopting policies that specifically program for individualized and extensive on-going in-home training of parents of children with autism from preschool to age 21. Currently, New York only provides mandatory in-home parent training in Early Intervention for autistic children from birth to 3 years but these services end when the child ages out of this program. Unfortunately, the NYS Education Department (NYSED) does not offer mandatory in-home parent training for children with autism that is ongoing from preschool through school age and into the adolescent years. According to Section 200.1 of the Regulations of the Commissioner of Education (NYSED, 2015), parent counseling and training is defined as “assisting parents in understanding the special needs of their child; providing parents with information about child development; and helping parents to acquire the necessary skills that will allow them to support the implementation of their child's individualized education program”. Further, Section 200.6 states that these services have a purpose of “enabling parents to perform appropriate follow-up intervention activities at home” (NYSED, 2015). Therefore, this recommended programming for on-going in-home parent training should incorporate empirically-

supported parent training methods published in peer reviewed scientific journals in the field of behavior analysis, autism treatment, special education, psychology and ABA. The following procedures are provided as examples of procedures found in ABA, one of the most effective approaches for teaching a variety of skills to typical-developing and developmental disabled individuals.

1. Conducting behavioral skills training with parents in the home (Lafasakis & Sturmey, 2007)
  - a. Instructions, modeling, rehearsal and feedback could be used to teach parents to implement behavioral interventions in the home with their own child with autism.
2. Teaching nonverbal students and their parents to communicate effectively in the home
  - a. Augmentative and alternative communication (AAC) devices with applications that offer innovative digital Picture Exchange Communication Systems (PECS) (Sulzer-Azaroff, Hoffman, Horton, Bondy & Frost, 2009) may be very beneficial for nonverbal children that are able to form receptive associations and who emit very few speech sounds or have a comorbid diagnosis of apraxia and may be unable to produce any speech sounds. AACs and PECS could be thoroughly trained to all nonverbal children with autism and implemented across school and home settings. The aforementioned mandate for extensive and individualized on-going in-home ABA parent training could therefore include the implementation of AAC devices that offer digital PECS. Results from this study indicated that this necessary component of the nonverbal child's autism treatment program was

missing, which was acknowledged by all participants as an area of need. In other words, these fathers recognized the lack of communication with their child and need for parent training in the home to help address this important aspect of the father-child relationship/.

- b. Nonverbal children with emerging mimetic repertoires who are able to imitate some echoic prompts would benefit greatly from vocal mand training (Thomas et al., 2010) and PROMPT training (Dale & Hayden, 2013).
  - i. The vocal mand (e.g., request) is sequentially taught in steps by first teaching the child to independently point to a preferred item in view. Then, the child is taught to look at the communicative partner. After the child is consistently emitting the pointing and looking response, the child is taught to imitate an oral-motor or lip movement (e.g., child puckers their lips into an “O” shape) and finally learns to mimic an echoic prompt (e.g., “oooh” for juice) to obtain the item in view (Thomas et al., 2010). This is an important consideration, as the results from this study indicated that fathers were not effectively communicating with their nonverbal child with autism in the home. Effective programming will help ensure that basic needs and wants as well as more advanced mands (e.g., places to go, people to be with, emotions, feelings, states of physical pain) are actively taught and monitored as the child ages and preferences change.
  - ii. A typical PROMPT session involves “vocal modeling and physical manipulations of the child's speech mechanisms that include touch, pressure,

positioning, and movement to promote structural integration within the child's vocal apparatus” (McCleery, Elliott, Sampanis, & Stefanidou, 2015)

- c. Nonverbal children with autism who lack spontaneous language and only emit immediate or delayed echolalic vocalizations would benefit greatly from errorless learning procedures, scripts and script fading procedures (Krantz & McClannahan, 1993). As previously mentioned, parents can be taught to bring these echolalic vocal responses under instructional control through discrete-trial instruction and more naturalistic incidental teaching methods.
3. Training parents in the home to acquire instructional control over their child's behavior
    - a. Generalized imitation training through both discrete-trial teaching (DTT) and incidental teaching could help bring the child's imitative repertoire under instructional control. As a result, children may be more likely to comply with the parent's model and echoic prompts, which would address the barrier of noncompliance found in this study. Imitation training also contributes to increases in joint attention and the development of many other cognitive, speech, social and adaptive skills.
    - b. Discrimination training through DTT and incidental teaching assists in developing the child's ability to discriminate between 2 or more environmental stimuli (Park et al., 2015). If parents help their own autistic children learn to make more advanced receptive (and expressive) associations in their presence, then the children may be more likely to expand their ability to communicate by selecting

more pictures of reinforcers, activities, places to go, emotions (e.g., “happy”, “sad”) and internal states (e.g., “hungry”, “tooth hurts”).

- c. Motivational systems (e.g., visual choice boards, token economy, and photographic/written activity schedules) can bring the child’s behavior under instructional control (Krantz, MacDuff, & McClannahan, 1993). Programs such as TEACCH that developed from the literature on photographic activity schedules have been taught to parents to implement in the home, which resulted in positive behavior change (Welterlin, Turner-brown, Harris, Mesibov & Delmolino, 2012).
4. Training parents in the home to implement a behavior plan of proactive and reactive procedures to address their child’s maladaptive behavior
    - a. Recent change in NYS law such as Section 200.22 of the Regulations of the Commissioner of Education (NYSED, 2015) mandate the provision of Functional Behavioral Assessments (FBAs) and Behavioral Intervention Plan (BIP) to address problem behavior through an analysis of antecedent triggers and maintaining consequences; however, the FBA and development of a BIP is not mandatory. Results from this study strongly support the need to train parents to address their child’s maladaptive behavior in the home, as all participants experienced challenges related their child’s behavior. If parents learn about what stimuli may be triggering or maintaining their child’s maladaptive behavior, they may be more likely to modify these stimuli when implementing the proactive and reactive procedures in the BIP. To ensure decreases in maladaptive behavior are maintained over time, the BIP could be extensively monitored on an on-going

monthly basis during parent training sessions from preschool through age 21.

Therefore, it is recommended that public school systems and private autism treatment organizations adopt policies that help ensure all incoming and current students with a classification of autism on their IEP are prescreened to assess the need for an FBA and BIP not only at school but for the home as well. The FBA and BIP should consider factors at home and include the parents and family members as behavior change agents. It is crucial that the FBA and BIP are updated as the child learns and develops with age.

5. Curriculum development and staff training

- a. Programmers should consider specifically designing in-home parent training protocols that target all levels of nonverbal communication such as manual signs (Carbone, Sweeney-Kerwin, Attanasio & Kasper, 2010), AAC and PECS as well as verbal communication (e.g., vocal mands, intraverbals). Children with emerging imitative and echoic repertoires can be taught to mimic simple phonemes to obtain a preferred item in view (Thomas et al., 2010). Therefore, procedures that teach simple to more advanced types of nonvocal and vocal communication should be standardized across all levels of child functioning. Nonverbal and verbal children with autism will then have individualized training curriculums for learning to communicate with their parents in the home.
- b. Schools and organizations ought to consider recruiting seasoned therapists skilled in ABA to conduct in-home parent training, as BST requires modeling as a necessary component in the learning process. The parent trainer must be able to

acquire instructional control over the child's behavior by successfully implementing the aforementioned ABA procedures. By obtaining functional consequences in the front of the parents, the trainer will facilitate the parents' observational learning (Iani, Rubichi, Ferraro, Nicoletti & Gallese, 2013).

### **Recommendations for Fathers and Parents of Nonverbal Children with Autism**

Based on the findings of this study, it is recommended that parents and especially fathers actively seek direct in-home ABA training of the aforementioned and other empirically-supported behavioral interventions. Not only is it important to receive these services, it is crucial that parents maintain their participation in on-going in-home parent training from preschool to when their child reaches 21 years of age. Since ABA and in-home parent training services may or may not be offered by the child's school or available in the child's school district, it is recommended that parents request these services at their child's IEP meeting or by contacting their school district's chairpersons. In addition, fathers and parents must inquire about the funding of ABA and in-home parent training by contacting their health insurance carrier. Working closely with the child's PROMPT-certified speech therapist and learning to teach vocal mands in the home or use the child's AAC device will result in increased communication between the parent and child. Implementing ABA interventions in the home will also result in the acquisition of instructional control over the child's behavior. For example, fathers can learn to present a visual board of pictures and deliver tangible reinforcement contingent of correct responses, which will impact the child's motivation and thus begin the instructional process. Child compliance with instruction will in turn promote additional



positive therapeutic outcomes thereby improving the parent-child relationship. Nonverbal children can learn to nonverbally and vocally communicate basic wants, imitate others and respond to verbal instruction as well as to token economies and photographic activity schedules in the home. Even though not all parents will be regularly available to engage in the role of a teacher, it would still be greatly beneficial to any extent possible. It is also important for parents to conduct their own research on other empirically-supported behavioral interventions by reading scholarly articles published in peer-reviewed scientific journals. Attending autism treatment workshops and conferences may be very beneficial in staying abreast of current ABA methods under investigation. For example, relatively recent innovations in treatment curriculums developed from ABA such as the Early Start Denver Model (ESDM) have emerged and early research shows much promise in promoting positive behavior change in children with autism ages 12 to 48 months (Vismara et al., 2016).

Parents of children with autism can vary greatly in how they feel and manage stress (Bendixen et al., 2011). It is important to first reflect and then acknowledge the stressors in our lives in hopes of possibly alleviating any of the negative effects that stress can possibly contribute to. It is therefore recommended that parents contending with negative thoughts (e.g., guilt, self-doubt) and emotions (e.g., hopelessness) or chronic daily stress regarding their child's diagnosis of autism consider seeking counseling by a state licensed mental health professional trained as an integrative psychologist with a background in humanistic and cognitive-behavioral therapy (CBT). Not only will elements of CBT such as reframing and cognitive restructuring help address negative

thought processes (Anclair & Hiltunen, 2014), the person-centered methods used in the humanistic approach will examine “the inner world” of the father and parent through the empathic understanding of the meaning of their experiences (Rogers, 1986). Through meaningful dialogue, these parents will have an outlet to share their feelings and emotions in order to develop their coping skills and improve their self-capacities. Since the majority of participants noted feeling acceptance that corresponded with acts of self-determination, it is highly possible that counseling rooted in both behavioral and humanistic principles will have a profound effect on the functioning of these parents of children with autism. If parents acquire additional coping skills related to their child’s diagnosis, they may experience less impairments from stress and negative thoughts or emotions.

### **Recommendations for Autism Advocates & Policy Makers**

To support parents after the initial autism diagnosis and throughout the school-age years, adolescence and early adulthood, it is recommended that advocates and policy makers promote on-going in-home parent training through empirically-supported ABA procedures for nonverbal students on the autism spectrum from preschool to age 21. Parent training should be mandatory and the curriculums must directly address (a) establishing effective communication skills between the parent and nonverbal child with autism in the home; and, (b) teaching parents to implement instructional programs and behavior modification procedures in the home with their child. During IEP meetings with parents, classroom teachers, school administrators and the child’s team of related service providers, autism advocates should share knowledge by citing research findings

regarding the challenges of raising a nonverbal child with autism. Discussing information on how parents experience their child's symptoms, the barriers they face and their feelings about the diagnosis could help the IEP team make more informed decisions during this step of the special education process.

Addressing the current lack of mandated ongoing in-home parent training for autistic students across preschool to 21 years of age may require a united group effort. Based on the reported positive behavior change associated with repeated father-child interactions and participants' wishes for more time with their child, it is recommended that federal and state law makers consider designing policies to allow parents of children with autism to have paid time off work to undergo monitored monthly parent trainings in the home to work directly with their autistic child. For example, a parent can choose to leave work 2 hours early each Friday or come to work 2 hours later on a particular day that would most benefit their child's in-home ABA program. Having two paid hours off of work per week means parents would have between 8-10 extra instructional hours per month to work on important goals with their autistic children and also not worry about any loss of income. Of course, all small businesses and major corporations in the US would require significant payroll tax benefits or rebates to offset the loss of work hours from each employee. If fathers and parents have more time to work with their child, new skills will be acquired and in turn, the child will obtain reinforcement from naturally-existing environmental contingencies in their home to improve their overall functioning across key developmental domains such as communication, socialization and adaptive skills. Since communication has been reported to be one of the most rewarding aspects

of the father-child relationship, it is expected that the quality of life of these fathers and parents will improve with their active and continued involvement and participation in their child's ABA program.

### **Recommendations for Future Research**

It would be beneficial to increase the amount of total participants by sampling a larger number of fathers who reside in other urban areas as well as in suburban and rural areas in the US. Also, sampling other ethnicities may reveal perspectives regarding fathers' feelings and experiences with additional barriers. These recommendations would yield valuable data that add to an under-researched area of parent training, psychology and autism treatment.

### **Implications**

#### **Potential Impact for Positive Social Change**

Several implications that could potentially impact social change have been generated by this study. Research findings offer information which could help a specific population of parents who are in need of specialized training and counseling due to issues having a nonverbal children with autism.

1. Educators must take responsibility for ensuring quality on-going in-home parent training is provided to families of nonverbal students with a classification of autism on their IEP and assure these services will be implemented with high treatment fidelity. Even though there may be requirements in place to ensure on-going in-home parent training are considered, it must be guaranteed that these in-home parent trainings will not only be considered but will be implemented for all nonverbal

- students on the autism spectrum from preschool to age 21. Provision of these trainings in establishing effective communication and implementing instructional as well as behavior modification techniques will aid this unique parent population in having more positive interactions with their child both in home and community settings, which will facilitate positive therapeutic outcomes.
2. Fathers and parents must actively seek specific knowledge regarding empirically-supported procedures proven to be successful for nonverbal children with autism. In addition, fathers and parents must request on-going in-home parent training services from their school districts and health insurance carriers. This training will assist these parents in developing better communication and improved instructional time with their nonverbal children while in the home and out in the community, which in turn will positively impact the parents' thoughts and emotions.
  3. Autism advocates and policy makers must support on-going in-home parent training for all nonverbal students diagnosed with autism. The provision of these services must be mandatory from preschool to age 21. Skills learned during preschool and school-age that generalize to the home and community settings must be maintained over time, which could result in the development of additional prosocial behaviors during adolescence and early adulthood such as prevocational skills (Ramey et al., 2016). Inclusion of nonverbal students with autism and other developmental disabilities into the mainstream community is essential to enhancing their quality of life, and that of their family's and those in society around them.

### **Empirical Implications**

Based on the data collected regarding the barriers participants' experienced, research findings have produced empirical knowledge which found a need for on-going in-home training of parents related to specific areas such as establishing an effective communication system with their nonverbal child with autism in the home and acquiring instructional control through the implementation of behavioral interventions and behavior modification techniques in the home. It is possible that current programming of parent training by NYSED and NYC public schools may not mandate the inclusion of these goals and/or may lack the empirically-supported procedures and staff resources to achieve these outcomes. Therefore, these results lead to a much needed discussion as to crucial changes in parent training and the special education of autistic students placed in public or private school settings and who are treated by private autism treatment professionals. Moreover, these findings point researchers in several very specific directions when developing parent training procedures and assessing their effectiveness through single-subject experimental designs.

### **Recommendations for Practice**

The present research adds to the field of autism treatment and special education by providing parents, teachers, psychologists, behavior analysts and counselors with knowledge which could influence current counseling practices and programming of parent training curriculums in public and private school settings as well as for private organizations. Changes to existing parent training protocols or school policy mandates made as a result of the recommendations suggested in this study are consistent with

current research as well as conclusions based on the findings of this study. It is imperative that proactive measures be taken in regards to the provision of on-going in-home training of parents of children with autism ages 3-21. Effective programming must be commenced in order to ensure successful therapeutic outcomes for an underserved parent-child population which clearly is in need of these interventions.

### **Conclusion**

The rising population of parents of children with autism experience numerous barriers that strongly support the need for the provision of on-going in-home parent training with very specific programming from preschool through early adulthood, which can have a tremendous impact on improving the parent-child relationship and their overall quality of life. The provision of these services as part of an autism treatment programming must occur for all students diagnosed with autism, especially nonverbal students. Fathers and parents currently struggle to communicate with their autistic children and it is challenging to implement teaching strategies in the home as well as modify their child's behavior during times of noncompliance. The findings of this study as well as current literature indicate a need for on-going in-home parent training from preschool to age 21 so that parent involvement is maintained with high treatment fidelity. This programming will ensure the child's autism program is monitored and maintained when it evolves over time as the child ages and learns to acquire new skills and preferences. When parents are involved in the special education process, their child may have a better likelihood of reaching their full potential. It is imperative that all nonverbal children with autism be assisted and, in the case of fathers and parents, they must be

specifically taught skills to communicate with their child and apply teaching strategies in the home. The goal is not to change the parent-child dynamic, but to improve the parent-child relationship. In the words of Dr. John Elder Robison, a scholar in neurodiversity also diagnosed with autism: “Our duty in autism is not to cure but to relieve suffering and to maximize each person’s potential”.

A goal of this study was to bring about new knowledge regarding the perspectives of fathers of nonverbal children with autism from diverse ethnic and cultural backgrounds in the hopes of better serving this unique population of parents. By training fathers and parents to become an active participant in their child’s autism treatment program, therapeutic outcomes will be facilitated, which will help alleviate stress and any negative thoughts or emotions associated with their child’s diagnosis of autism.



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## Appendix A: Letter of Study Information

**Letter of Study Information**

*Based on your position at a private school/educational institution, medical provider's office, autism treatment agency and/or parent advocacy/support group, your assistance is being requested in order to recruit potential study participants for a doctoral-level study.*

**Below is a description of this study**

A behavioral intervention is a set of steps that teach important behaviors such as speech/language, academics, social, play and/or daily living skills. The purpose of this study is to identify barriers that prevent father implementation of behavioral interventions for nonverbal children with autism of diverse ethnic and cultural backgrounds residing in New York City. This study will also gather information on how these fathers experience and feel about these barriers. The goal of this research is to provide information which will be useful in designing effective parent training and counseling interventions, autism treatments, supports and special education services for parents of children with autism spectrum disorders.

**Type of Assistance Requested:**

Your assistance is requested in order to gain access to potential study participants. This would require you or your designee to ONLY mail a packet to parents who have participated in your autism evaluation and treatment program that meet the following criteria:

- father of a nonverbal child diagnosed with autism spectrum disorder
- at least 18 years of age and over
- able to read and speak English
- have participated in parent training to implement behavioral interventions with their child
- reside in New York City with their child in a private home and not in a facility (e.g., prison, treatment facility, nursing home, assisted living)

You are being asked to ONLY mail a packet containing the forms: **“Invitation to Participate in Research”** and **“Informed Consent Forms”** to the potential study participant(s) so that they may in turn contact the researcher directly. You can also provide the potential participant with the researcher's telephone number and email address so that they may directly contact the researcher.

**Plan for Dissemination Study Results:**

Dissemination of study results will occur through a 1-2 page summary to the community partner and participants. Further dissemination of data can be provided to private school/educational institutions, medical provider's offices and/or autism treatment agencies upon request through presentations at their respective centers. These presentations can also be conducted for participating parent advocacy/support groups.

**Thank you greatly in advance for your cooperation in the recruitment of potential study participants!**

Respectfully,

Michael Lafasakis, MS Ed., BCBA  
Clinical Psychology Ph.D. Student  
Walden University

## Appendix B: Invitation to Participate in Research

**Invitation to Participate in Research**

Please accept this letter as an invitation to participate in a doctoral research study, which focuses on exploring the perspectives of fathers from diverse ethnic and cultural backgrounds. This study will explore barriers faced when fathers apply teaching strategies in the home with their nonverbal child with autism. A teaching strategy is a set of steps that positively change important behaviors such as speech/language, academics, social, play and/or daily living skills.

If you agree to participate in this study, you will be asked to participate in an audio-taped, face-to-face interview which will last approximately one hour as well as a follow-up interview in order to determine the accuracy of findings. The interviews will take place in a mutually agreed upon neutral location (like a coffee shop or private room at a library) on a date and time which is convenient to you.

This study is voluntary. Your decision of whether or not to participate will be respected. If you decide to join the study, you can still change your mind later. You may stop at any time. All information will be kept strictly confidential.

If you are either: (a) diagnosed with a mental or emotional disability; (b) dealing with a crisis (such as natural disaster or family member's acute illness); (c) an economically disadvantaged individual; or (d) an elderly individual 65 years and older, any of which you feel would keep you from freely participating in this study without undue influence, you should not feel any pressure to participate. As stated above, if you do decide to participate, you can change your mind at any time during the study by revoking your consent to participate.

If you are interested in participating in this study please contact Michael Lafasakis, the researcher, via telephone at \_\_\_\_\_ or email at \_\_\_\_\_.

Benefits include knowing that your participation in this research will help others learn from your lived experiences and provide for further understanding and change to the area of parent training and counseling interventions for parents of children with autism spectrum disorders.

Your time and participation would be greatly appreciated!

Respectfully,

Michael Lafasakis, MS Ed., BCBA  
Clinical Psychology Ph.D. Student  
Walden University

## Appendix C: Interview Protocol

**Interview Protocol**

**Study Title:** Exploring Barriers to Father Implementation of Behavioral Interventions for Nonverbal Children with Autism from Diverse Ethnic and Cultural Backgrounds

**Interviewer:** Michael Lafasakis, Walden University Clinical Psychology Doctoral Student

**Interviewee:** \_\_\_\_\_ **Date of Interview:** \_\_\_\_\_

**Introductory Protocol:**

The following interview will be audio-taped to supplement note-taking and facilitate data collection. The audio tape will be destroyed after it is transcribed and only the researcher will have access to it. You will be asked to sign an Informed Consent Form (which indicates all data will be kept confidential, your participation is voluntary, you may terminate participation in this study at any time for any reason, and no harm is anticipated to be imposed on you as a result of your participation in this study).

This interview will last no longer than 1 hour and during this time, several questions will be covered.

You are volunteering to participate in this study to share your experiences as a father of a nonverbal child with autism spectrum disorder. This research project will focus on learning about your perspectives regarding the barriers faced when applying teaching strategies with your nonverbal child with autism in the home. The present study seeks to learn more about how fathers from diverse ethnic and cultural backgrounds residing in New York City experience and feel about barriers to applying teaching strategies with their nonverbal child with autism in order to help improve parent training methods and to promote positive treatment outcomes.

**Interviewee Experience:**

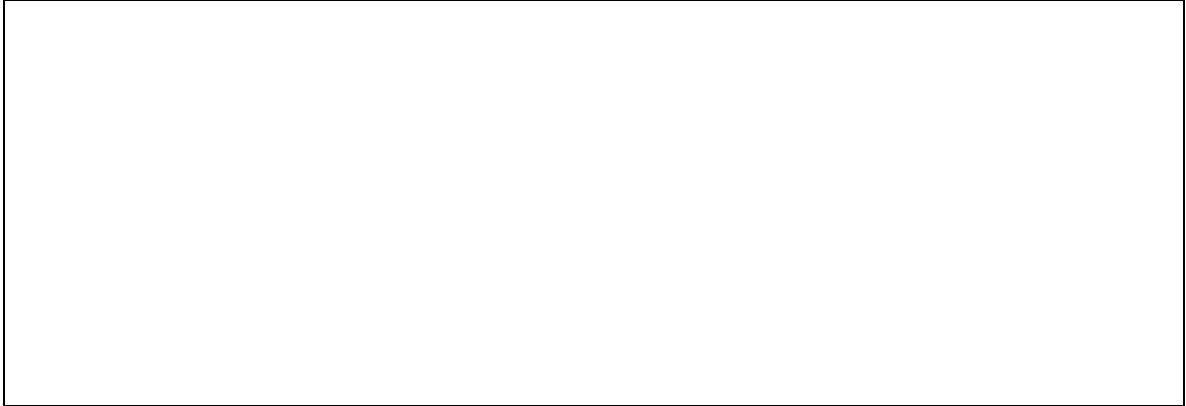
Tell me about being with your child in the home, what you do together, how often you are together, and what successes you experience when together with your child.

What are the challenges when you are together with your child?

After receiving parent training from your autism treatment provider on how to work on important goals with your child in the home, what barriers prevent you from applying teaching strategies with your child in the home?

How do you experience each of these specific barriers to applying teaching strategies with your child in the home?

How do you feel about each of these specific barriers to applying teaching strategies with your child in the home?



Is there anything else that you would like to share that is related to barriers that prevent you from applying teaching strategies with your child in the home and how you experience and feel about these barriers?

