The Impact of a Diagnosis of Autism Spectrum Disorder on Nonmedical Treatment Options in the Learning Environment from the Perspectives of Parents and Pediatricians

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The Impact of a Diagnosis of Autism Spectrum Disorder on Nonmedical Treatment Options in the Learning Environment from the Perspectives of Parents and Pediatricians

Abstract
The purpose of this qualitative study was to identify the impact of a diagnosis of autism spectrum disorder on treatment options available, within the learning environment, at the onset of a diagnosis of autism spectrum disorder (ASD) from the perspective of parents and pediatricians. Utilizing a qualitative methodology to identify codes, themes, and sub-themes through semi-structured interviews, the research captures the lived experiences of five parents with children on the autism spectrum and five pediatricians who cared for those children and families. The researcher utilized the theoretical frameworks of behaviorist and psychologist, B. F. Skinner, as well as psychologist Uri Bronfenbrenner's ecological theory. The research study results conclude that the parents had little to no information available to them at the onset of their children's diagnosis. Furthermore, the parents were unable to identify what treatment options were available within their children's learning environments at the point of diagnosis. The research also notes that the pediatricians were dependent upon outside resources to fully determine the child's autism spectrum diagnosis, and they conceded that they did not provide information to parents at the onset of the diagnosis nor did they give treatment recommendations. Additional results of the study indicate that the initial training received by the pediatricians was not enough to address the needs of the children diagnosed with autism. The recommendations include: (a) hands-on training for parents, (b) ongoing additional professional development for pediatricians, (c) support groups for parents, and (d) resources immediately available for parents at the time of diagnosis.

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The Impact of a Diagnosis of Autism Spectrum Disorder on Nonmedical Treatment Options in the Learning Environment from the Perspectives of Parents and Pediatricians

By

Cecilia Scott-Croff

Submitted in partial fulfillment of the requirements for the degree Ed.D. in Executive Leadership

Supervised by

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St. John Fisher College

December 2017
Dedication

This journey has taught me the true meaning of Proverbs 3:5-6, “Trust in the Lord with all your heart, and lean not on your own understanding; in all your ways acknowledge Him, and He shall direct your path.”

I dedicate this work to my son, Matthew Scott Croff, a precious gift from God. To my husband, Patrick Croff III, thanks for your patience and understanding of the many nights I did not make it home on time. Your tolerance of my cantankerous moods is a testament, in itself, to your unyielding devotion. To my wonderful niece, Mamie Juanita Croff, I thank you for being such a light and for your dedication to your cousin. Without your support to your uncle and me, this would not have come to fruition. I thank my mother, Agnes Scott, for always believing in me. To my siblings, I thank each of you for your patience during this trying time.

I would like to take this time to thank the chair of my dissertation committee, Dr. Jennifer Schulman, for her continuous support throughout this process. I would also like to thank Dr. Janice Lyons, my committee member. In addition, I would like to give thanks for the hard work and efforts of my editing team.

Lastly, and very importantly, I would like to thank the parents and the pediatricians, who volunteered to be participants in my research, for their insight and support. Your contributions were invaluable to this study.
Biographical Sketch

Cecilia Scott-Croff is currently the Executive Director of the Early Childhood Center at Borough of Manhattan Community College (BMCC) and Past Chair of the Child Care Council at City University of New York (CUNY). A New York State-certified early childhood special educator and administrator, Mrs. Scott-Croff has more than 20 years of experience in the fields of early care and education, special education, and advocacy. Mrs. Scott-Croff has two graduate degrees, one in Early Childhood Education and the other in Administration and Supervision from City College of New York/City University of New York. She is a level-three credentialed trainer with the New York State Association of the Education of Young Children. She holds the New York State Certified Professional Administrator Credential (CPAC) and has also completed the Leadership Development Institute with the National Black Americans Council. She is also a Borough of Manhattan Community College Leadership Fellow. She came to St. John Fisher College in the summer of 2016 and began doctoral studies in the Ed.D. Program in Executive Leadership. Mrs. Scott-Croff pursued her research on the impact of nonmedical treatment options in the learning environment from the perspectives of parents and pediatricians for children diagnosed with autism spectrum disorder under the direction of Dr. Jennifer Schulman and Dr. Janet B. Lyons and received the Ed.D. degree in 2018.
Abstract

The purpose of this qualitative study was to identify the impact of a diagnosis of autism spectrum disorder on treatment options available, within the learning environment, at the onset of a diagnosis of autism spectrum disorder (ASD) from the perspective of parents and pediatricians. Utilizing a qualitative methodology to identify codes, themes, and sub-themes through semi-structured interviews, the research captures the lived experiences of five parents with children on the autism spectrum and five pediatricians who cared for those children and families. The researcher utilized the theoretical frameworks of behaviorist and psychologist, B. F. Skinner, as well as psychologist Uri Bronfenbrenner’s ecological theory.

The research study results conclude that the parents had little to no information available to them at the onset of their children’s diagnosis. Furthermore, the parents were unable to identify what treatment options were available within their children’s learning environments at the point of diagnosis. The research also notes that the pediatricians were dependent upon outside resources to fully determine the child’s autism spectrum diagnosis, and they conceded that they did not provide information to parents at the onset of the diagnosis nor did they give treatment recommendations. Additional results of the study indicate that the initial training received by the pediatricians was not enough to address the needs of the children diagnosed with autism. The recommendations include: (a) hands-on training for parents, (b) ongoing additional professional development for
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Chapter 1: Introduction

Autism spectrum disorder (ASD) is a complex neurological disorder characterized by pervasive impairments in social communication and restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association [APA], 2013). The term autism has gone through many stages of classification. For many years, autism was recognized as a psychiatric disorder instead of a neurological disorder (Rimland, 1964). During the 1940s and ’50s, the Diagnostic and Statistical Manual: Mental Disorders (DSM-1) (APA, 1952) classified autism as a psychological disorder. The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; APA, 2013) is a scientific manual that provides a common set of terms and a subset of symptoms that supports clinicians in diagnosing disorders. During the aforementioned era, children with autism often received a diagnosis of childhood schizophrenia (Cook & Willmerdinger, 2015). This was due to the social features and social dysfunctions indicative of each disorder (Yuhas, 2017). Autism is a neurological and processing disorder (Rimland, 1964).

The research of Smith and Eikeseth (2011) asserted that a diagnosis of autism can be determined once a child exhibits deficiencies in social interaction, communication, and behavior. These researchers also noted that children with autism spectrum disorder have restricted interests and have difficulty transitioning. Smith and Eikeseth further asserted that children with autism demonstrate inappropriate behaviors. Inappropriate behaviors include head banging, tantrums, aggression, and attempting to escape tasks. Children with autism are also unable to detect social cues, and they have difficulty...
developing peer relationships. Additional symptoms of ASD are poor eye contact, lack of emotional reciprocity, delayed speech, difficulty sustaining conversations, repetitive mannerisms, and spinning (Moldrich & Marraffa, 2013).

Autism has become the number-one diagnosed developmental disability in the United States (Centers for Disease Control and Prevention [CDC], 2014). The research from the Autism Society of America (Autism Society) (2013) indicates that one in 45 children are diagnosed with ASD each year. According to the Centers for Disease Control and Prevention (CDC) (2014), the rates of diagnosis have increased over 80% in the last 10 years. The increased rates of autism are attributed to: (a) the broad range of the symptoms of the disorder, (b) improved methods of assessment, (c) improved identification from health care professionals, and (d) increased awareness of symptoms among parents (CDC, 2014; Daniels & Mandell, 2013). Moreover, the CDC revealed that there are twice as many boys diagnosed with autism as girls. The CDC (2014) also asserted that the higher rate in boys is due to the greater risk of gene mutation in males. According to Blumberg et al. (2013), the prevailing rates of autism leave parents anxious and perplexed by the disorder.

In the educational spectrum of working with children with autism, Section 504 of the Rehabilitation Act of 1973 protects the educational and civil rights of individuals with disabilities (Wrightslaw, 2015). Other acts, such as the Individuals with Disabilities Education Act (IDEA) of 1975 and the Education for All Handicapped Children Act (EHA) of 1986, also known as Public Law 94-142, were signed into law to provide equality in education for children with special needs. Researchers Ryan, Hughes, Katsyannis, McDaniel, and Sprinkle (2011) asserted that autism spectrum disorders
affect more than one million people in the United States. They also revealed that the increased rates of diagnosis of children with autism have implications for public schools and the educators that serve them. Ryan et al. (2011) stated that parents, desperate for answers, may choose treatments that are not validated and interventions that are marketed to provide immediate solutions.

The research of the Rhode Island Department of Health (2011) indicates that parents attempting to access support to uncover the most effective treatments find this to be a daunting task. Their research further notes that the amount of information available, the level of accuracy, and the treatment options that are explored, vary with each family. Moreover, their research indicates that families encounter feelings of guilt, shame, fear, and loss at the onset of their children’s diagnosis. The Rhode Island Department of Health study further states that through increased awareness, parents begin to understand the complexity of their children’s needs and slowly replace their feelings of guilt with a pursuit for knowledge. The researchers further contended that this acquired knowledge allows parents to actively participate in their children’s developmental plans and treatment interventions (Rhode Island Department of Health, 2011).

Regarding diagnosis and treatment, the importance of the age of a child diagnosed with autism influences treatment options, parents’ attitudes, and the child’s overall prognosis (Adelman, 2010). Adelman’s study captured the lived experiences of Northeasterners at the age of their diagnosis of autism. Adelman used a survey model to collect the data. A survey model captures the perspectives of the participants (Creswell, 2014). The data collection occurred in Baltimore, Maryland, and it included more than 600 participants. The participants were of African American, Native American, and East
Islander descent. Her study determined the median age of diagnosis as 37 months. The study results reveal that the age of diagnosis for children with autism is becoming earlier. The study results also summarize that children diagnosed with autism from the Midwest region received a diagnosis at an earlier age than children from the Northeast and Southeast regions of the United States (Adelman, 2010).

Throughout this writing, the term *autism* or *autism spectrum disorder* refers to individuals diagnosed with autism. The term *social and communication disorder* identifies individuals who do not exhibit classic signs of autism. Prior to 2013, children with social and communication disorders were identified as individuals with Asperger syndrome (APA, 2013). Asperger syndrome, named after pediatrician Hans Asperger (1944), is a disorder with symptoms of high intelligence and an inability to communicate and socially relate to others (APA, 2013). The research of Autism Speaks (2013), Cohen, Dickerson, and Forbes (2013), and Wing (1981) utilize the term *spectrum disorder* or *children on the spectrum* to categorize children with autism. These terms represent the wide variance in the type and severity of autism symptoms (Wing, 1981). The terms are used interchangeably throughout this writing. The following sections address the history, causes, and controversy relevant to children diagnosed with autism spectrum disorders and treatment options.

**History of autism.** The history of autism dates back to 1798 (Itard, 1801). Itard is known as the *Father of Special Education* as a result of his work with intellectually disabled children (Smith, 1998). A physician by training, serving deaf and mute children during this time, Itard’s seminal work described the symptoms of a young child, Victor, who was possibly living with autism (Wolff, 2004). Autism was unknown term during
Itard’s time (Cook & Willmerdinger, 2015). Itard characterized Victor as the *Wild Boy* (Lane, 1979), as a child who was unable to speak and who was developmentally different than his peers (Lane, 1979). He pulled adults toward him and the items he wanted. Due to his time living in the woods, suckled by wolves, Itard (1801), who became his tutor, believed Victor lacked social interaction and language skills (Lane, 1979). Itard (1801) was able to assist Victor in his social and cognitive functioning in the 5 years he worked with him (Lane, 1979). Researchers differ as to whether Victor presented with the typical neurobiological symptoms of an individual with autism spectrum disorder; however, they do agree that Victor’s symptoms paved the way for understanding developmental differences in young children (Moore, 2013).

Related to the term autism, Dr. Leo Kanner’s (1943) research is the first publication in English to use the term *infantile autism* (Feinstein, 2011). Kanner used the term to describe 11 children, eight boys and three girls, who he worked with in Baltimore, Maryland. The 11 children demonstrated difficulty with communication, intellectual competencies, and social interactions. Kanner (1943) noted the children demonstrated echoic, otherwise known as repetitive, speech. The children also had difficulty with transitioning or changes in their routines (Mandal, 2014).

According to Mandal (2014), the term autism originated from the seminal work of Bleuler (1911). The term comes from the Greek word *auto*, meaning self (Stein & Urdang, 1966). Bleuler (1911) used the term to describe a subset of his schizophrenic patients who were withdrawn and socially isolated. According to Leestma (2015), there were no measures available to diagnose individuals with autism during this time. Some symptoms of autism and schizophrenia are similar: obsessive-compulsive behavior,
picking of the skin, difficulty with socialization, and tendencies toward isolation (APA, 1980). Many clinicians in the early ’70s used the term autism and childhood-onset schizophrenia interchangeably (Yuhas, 2017). With little known about autism, the similarities, as well as the symptoms, led to comparisons and age in history of the two (APA, 1980; Kanner, 1943; Meyer, Feldon, & Dammann, 2011). Subsequent research revealed there is no clinical relationship between the two conditions (Leestma, 2015).

“Autism spectrum disorder (ASD) and schizophrenia are two distinct disorders with unique characteristics, they share similarities in social dysfunction” (University of Texas at Dallas, 2012, para. 1).

The term *infantile autism*, published in the 1980 edition of the *Diagnostic and Statistical Manual of Mental Disorders DSM-III-R* is significant (Feinstein, 2011). As mentioned earlier, the 2013 version of the *Diagnostic Statistical Manual of Mental Disorders, Fifth Edition, Revised, DSM-V-R* provides the criteria for identifying psychiatric and developmental disorders. Social workers, psychologists, developmental pediatricians, and others use this manual to identify many developmental disorders, which are relevant to this study, in the delays of young children (Ozonoff, 2012). In 1980, the *DSM-III-R* supplanted infantile autism with an expanded definition of autism. The *DSM-V-R* (APA, 2013) outlines the characteristics of autism. The manual includes a checklist for diagnosis. The manual’s revisions are discussed later in this chapter.

As noted earlier, for more than 30 years, the clinical and biological similarities of schizophrenia and autism led to a linkage of the two disorders (Yuhas, 2017). Likewise, the research of Meyer et al. (2014) suggested similarities. The research of Burbach & van der Zwaag (2009); Dvir & Frazier (2011), Eisenberg & Kanner (1956), and Meyer et al.
(2011) explored the characteristics of the disorders as well. The American Psychiatric Association created its own categorization of autism in the *DSM-3* (APA, 1980). This highlighted the significance and the separation of the two disorders. Moreover, distinctions between the two disorders provided clinicians with the ability to establish a separate and more accurate diagnosis of each. The proper categorization has assisted families with accessing appropriate services for their children (Smith & Eikeseth, 2011). It has also provided support for pediatricians diagnosing children with autism (Autism Society, 2013). In 2013, the *DSM 5R* collapsed all subcategories of autism: pervasive developmental disorder (Lord, Rutter, & Le Couteur, 1994), childhood disintegration disorder (APA, 1994), Rhett’s disorder (APA, 1994), autism (APA, 1994), and Asperger syndrome (APA, 1994) into two categories: (a) autism spectrum disorder and (b) social communication disorder. The DSM manual’s current continuum describes individuals with mild or severe autism as having autism spectrum disorder. An individual who presents with advanced speech, is higher functioning in adaptive skills, and who has some symptoms of autism, receives a diagnosis of a social and communication disorder formerly known as Asperger’s syndrome.

The historical perspectives of autism are significant to this current study. The history serves as a timeline to understand the evolution of the causes, diagnosis, treatment, treatment options, and parent education.

**Causes of autism.** Autism has been prevalent for years (Feinstein, 2011). ASD is a complex disorder with a complex nature that does not allow for a direct cause (Autism Society, 2013). Bleuler’s (1911) and Rimland’s (1964) research noted genetics and biological variances in brain development as root causes of autism. Due to its increased prevalence and the resulting needs of children, the federal government made autism a special education category (Smith & Eikeseth, 2011). Moreover, the research of Dionne and Martini (2011) attributed biological, environmental, and genetic factors in the etiology of autism. Seitler (2010) asserted that the genetic causes and history of autism are complicated. Further causes for the disorder include chromosomal abnormalities associated with advanced maternal and paternal age, premature delivery, and low birth weight (Ben-Itzchak, Ben-Shachar, & Zachor, 2013). Prenatal exposure to pesticides in genetically vulnerable children is another causation factor (California Department of Pesticide Regulation, 2014). Furthermore, the research of Lubin (2015) argued that the uncertainty of a direct cause of autism has led to considerable speculation among parents. Lubin (2014) asserted that the search for answers must continue to advance the quality of life of children living with ASD.

Relating to causes, a looming debate has emerged regarding autism, vaccinations, and vaccines’ possible link to autism causation (Begley & Interlandi, 2009; Reynolds & Dombeck, 2006). Begley and Interlandi (2009) reported a study by gastroenterologist Dr. Andrew Wakefield et al. (1998) in the United Kingdom (UK) that alluded to a direct link
between autism and thimerosal. Thimerosal is a mercury-based preservative that is used in the measles, mumps, and rubella (MMR) vaccine (Parker, Schwartz, Todd, & Pickering, 2004). The Wakefield et al. (1998) study was published in the Lancet and it is a highly regarded medical journal in the UK. The study conducted by Wakefield et al. included 12 children. Wakefield et al. (1998) suggested that eight of the children who were later diagnosed with autism were predisposed to autism as a direct consequence of receiving the MMR vaccine (Rao & Andrade, 2011).

Begley and Interlandi’s (2009) research details that a controversy ensued based upon the Wakefield’s et al. (1998) findings. The research of Wakefield et al. led parents to fearing for the safety of their children, discouraging vaccine compliance, and this led to a public health concern (Moreno, 2009). The anxiety among parents resulted in many refusing to have their children vaccinated (Dubé et al., 2013). Although the ongoing debate led the American Academy of Pediatrics (2003) to issue a statement warning of thimerosal, a study of thimerosal in the MMR vaccine by the Centers for Disease Control and Prevention (CDC) (2014) indicated there was no link of thimerosal to autism (Begley & Interlandi, 2009; Parmet, 2010). Due to the ongoing skepticism of parents, media attention, and continued challenges to the research, the preservative is no longer in the vaccine (Parker et al., 2004).

The General Medical Council (Godlee, Smith, & Marcovith, 2011), which regulates doctors in the UK categorized the Wakefield et al. (1998) actions as gross medical misconduct. The Medical Council further asserted it was an abuse of Wakefield’s authority as a health care professional. The Council went on to say that the Wakefield et al. (1998) linkage of thimerosal in the MMR vaccine to autism created
widespread pandemonium among parents. With many parents refusing to have their children vaccinated and with the divided debates, Wakefield’s colleagues retracted their support of his finding (Begley & Interlandi, 2009). The medical board revoked Wakefield’s license (Moreno, 2009). The controversy surrounding vaccine series continues to persist. Despite evidence to the contrary, some parent advocacy groups continue to attribute vaccines as the leading cause of autism (Patel & Greydanus, 2012).

**Diagnosis of autism.** The *Diagnostic Statistical Manual of the American Psychiatric Association* (APA, 2013) lists three core deficits that must be present to render a diagnosis of autism. These areas include social impairment, verbal impairment, and ritualistic patterns of behavior. These developmental challenges remain over the course of a child’s preschool, grade school, and adolescents development (Naigles, Kelley, Troyb, & Fein,, 2013). Recognition of autism, according to the research of Greydanus and Toledo-Pereyra (2012), did not occur until the 20th century. These researchers further noted that with the advancements in the diagnostic process of children with autism and the terms that are used have changed (Greydanus & Toledo-Pereyra, 2012). The changes in identification and diagnosis of children with autism has had a profound impact on the quality of life of children living with the disorder. Parent access and clinical partnerships have impacted the development of children with intellectual differences and the trajectory of research (Schopler et al., 1982). Schopler et al. noted the importance of clinicians working supportively and developing relationships with families impacted by a diagnosis of autism. Moreover, the significance of partnerships between professionals and parents makes a difference in parents’ ability to plan for their children and to implement teaching and behavioral strategies (Dunlap & Fox, 2007).
Additional research related to a diagnosis of autism for families revealed a path to a diagnosis of autism spectrum disorder for children included lengthy delays, multiple diagnoses, and several visits to their health care professionals (McMorris, Cox, Hudson, Liu, & Bebko, 2013). A diagnosis is established from a mix of developmental screenings, assessments, medical testing, formal evaluation, informal observations, and a variety of professionals using a set criterion. In addition, a child’s developmental pediatrician, psychologist, psychiatrist, and/or neurologist are also involved in diagnosing a child (Lord et al., 2006). For families, the levels of available screening and developmental testing vary (Moldrich & Marraffa, 2013).

Related to testing, the qualitative research of Shyu, Tsai, and Tsai (2010) in Taiwan revealed the limitations in testing available for children with autism. The researchers conducted in-depth interviews to gain the perspectives of 13 college-educated parents of children with autism. The researchers sought to determine if parents’ perspectives of the disorder influenced the treatments they chose. Another purpose of their study was to identify the knowledge levels of parents of children with autism and the treatment options they chose for their children. Parents reported the intervention chosen was influenced by (a) cultural beliefs of the cause, (b) effect of the treatment strategy, (c) the child’s preference or resistance to the implemented treatment, and (d) the relationship between the child and the parents with their therapist. The researchers indicated that cultural beliefs impacted parents’ efforts in accessing developmental screenings and testing instruments. The Shyu et al. (2010) results suggest that the parents’ cultural beliefs guided the way the parents rationalized their children’s disability to others.
The Shyu et al. (2010) study results indicate that parents attributed their children’s diagnosis to biomedical causes. The results of their research also indicated that parents chose a variety of treatment measures. The treatments were sensory integration approaches, speech and occupational therapy, vitamin supplements, modification in their diets, childcare training programs, and treatments for food allergies. The researchers’ findings encouraged clinicians to exhibit patience and sensitivity to the varied influences that shaped parents’ understanding of their child’s disorder. However, non-conventional, Shyu et al. stated that clinicians’ receptiveness to parents’ non-conventional ideas leads to a better relationship between the parents and the clinicians. Clinicians’ receptiveness creates a platform for further dialogue. Last, the findings of the Shyu et al. (2010) study recommend that health care professionals provide parents with supportive consultation during the decision-making process regarding treatment options after their child has been diagnosed with autism.

As pediatricians, researchers Cangialose and Allen (2014) asserted that they had the unique ability to hold a prominent position in the diagnosis and communication process with parents of children with autism, and as pediatricians, they have multiple interactions with children and their families as well as having ongoing relationships. The process of developmental screenings, as identified by Cangialose and Allen provides opportunities for parents and pediatricians to engage in a dialogue about a child’s developmental progress. Shyu et al. (2010) further noted the importance of the screening process in detecting children’s speech and language delays. Their research indicates that speech delays are typical signs of developmental delays in young children. For children diagnosed with autism, it is one of the first indicators of the disorder (Shyu et al., 2010).
The researchers stated that screenings by pediatricians can determine the level of risk for autism spectrum disorder in infants at 9, 12, and 15 months—before formal screening for autism is performed at 18 and 24 months.

Related to screening, the research of Mack (2008) purported that the work of general pediatricians is vital to the needs of parents seeking support in understanding their child’s diagnosis, the implications of the diagnosis, the potential screening options, and the treatment measures. Mack’s research identified barriers for families. The purpose of her semi-structured interviews of 28 pediatricians was to determine the guidelines for screening, best practices, and to reveal the challenges for parents. Mack’s (2008) research discovered the significance of implementing guidelines to support families of children with autism. Her research also outlined the importance of following the guidelines set forth by the American Academy of Pediatrics for developmental screenings (Mack, 2008).

Similarly, the Simpson et al. (2013) research reveals that early assessment and diagnosis has identified an increased number of children with autism. The researchers asserted that there are multiple variables associated with a developmental evaluation. Simpson et al. said that pediatricians are qualified to identify symptoms and to diagnose children with autism. However, due to a number of variables, such as insurance payments and the complexity of testing, pediatricians refer families to developmental testing agencies for further evaluation. Simpson et al. also noted that pediatricians’ lack of familiarity with screening and testing instruments may lead to an inaccurate diagnosis. Last, the researchers stated that pediatricians identified the time constraints of well visits as a barrier to further testing (Simpson, 2013).
Regarding testing for autism, a diagnosis involves a combination of developmental screenings, assessment instruments, parent interviews, and child observations. An instrument used in developmental screening of young children is the Early Start Denver Model (ESDM) and specific observations of behaviors associated with autism (Dawson et al., 2010). Some other notable assessment instruments used in the field are the Childhood Autism Rating Scale (CARS), the Autism Diagnostic Interview-Revised, and the Autism Diagnostic Observation Schedule. Additional instruments used to support children with autism are: the Vineland Adapative Behavioral Scale (Sundberg & Partington, 1998) and the Verbal Milestone Assessment Placement Program (VMAPP) (Sundberg, 2008).

The work of Stolzer (2011) notes the process of evaluating and diagnosing a child with autism impacts families’ ability to cope with their child’s disability. Given the many challenges parents encounter, researchers Keenan, Dillenburger, Doherty, Byme, and Gallagher (2010) underscored the importance of professional partnerships that highlight the value of collaboration between parents and pediatricians. The Keenan et al. (2010) cross-sectional survey in Ireland gathered the perspectives of 95 parents and 67 multidisciplinary professionals. The purpose of their study was to examine the lived experiences of parents. Another purpose of the study was to reveal parental plans and goals for the future. Keenan et al. (2010) used the Family Autism Needs Questionnaire (FAN-Q). The questionnaire assisted the researchers with identifying the needs of families of children diagnosed with ASD. The questionnaire queried parents about their children’s ages, gender, and age of diagnosis. The questionnaire also allowed the researchers to collect the demographic and employment statuses of the parents.
The second instrument used by Keenan et al. (2010) in data collection was the Professional Autism Needs Questionnaire (PAN-Q). This questionnaire is designed to identify the perspectives of professionals with families and children diagnosed with ASD. The PAN-Q questionnaire includes four sections of questions regarding age, gender, demographics, training, and employment. The questionnaire captures the experiences of health care professionals’ experiences working with families and children. The questionnaire also helps to examine health care providers perceptions of the impact of an autism diagnosis on families. The questions focus on the impact of a diagnosis on sibling. In addition, the questionnaire helps to identify the future needs of families.

The final component of the PAN-Q questionnaire used in the Keenan et al. (2010) study asked families to identify the treatment options they chose for their children. The study results indicate that the parents required additional support outside of their families. The Keenan et al. findings indicate that the diagnostic and planning processes for children with autism is stressful for parents. The researchers noted that the process is lengthy, and the education plans did not always include the parents. Their study suggested increased parent participation. Furthermore, the researchers stated that the reviews of plans did not consistently include treatment intervention data (Keenan et al., 2010).

The research of Steiner, Koegel, Koegel, and Ence (2012) identified parents’ participation in their children’s treatment interventions as best practice for families with children diagnosed with autism. However, their research highlighted the limited research that supports the inclusion of parents in their children’s treatment interventions. Their research detailed the importance of data-driven procedures. According to their research,
data-driven approaches improve parents’ and children’s outcomes (Steiner et al., 2012). The Steiner et al. research provided resources for professional to implement with families. Their research reported the variety of issues that arose during parent education trainings. This research marketed parent-training programs to address the challenges of parenting a child with autism. The training programs focused on toileting, self help, sleeping, and feeding issues. The Steiner et al. (2012) study highlighted the trainer models for parents. The programs increased trainer availability for parents, and they also assisted parents with teaching other parents how to work with their children. The Steiner et al. study revealed the importance of self-directed, technological programs for parents. Self-directed programs are programs parents can use independently within their homes. Web-based models are Internet programs for parents to use. The significance of the Steiner et al. study is that it provides an overview of the importance of parent-education programs for families with children on the autism spectrum. The research also underlines the importance of providing such supports to families (Steiner et al., 2012).

The research of Major, Peacock, Ruben, Thomas, and Weitzman (2013) highlighted the limitations in pediatric residency training as it pertains to children with autism. Their research uncovered the finite amount of training made available to pediatricians caring for children on the spectrum and noted that there is little available for pediatricians on how to work with families (Autism Speaks, 2013). The Major et al. (2013) study emphasized the need to improve autism education in pediatric residencies. The researchers noted that training is an essential component to supporting families. The purpose of the study was to improve the pediatric residency training with the development of a training curriculum. Their research indicates that the curriculum they
used, which was created by the CDC and approved by the Prevention and Maternal Child Health Bureau, provided strategies for residents working with families of children with ASD. The objective of the curriculum was to increase the knowledge of professionals who are caring for children with autism. The training is entitled the Autism Case Training (ACT) (Major et al., 2013). The focus of the ACT curriculum is to support those working in pediatrics. The curriculum model provided seven case-scenario-based teaching units. The hospital faculties taught the units at 26 pediatric residency programs. The curriculum underwent internal and external peer review. The curriculum reviewed: (a) early warning signs of autism; (b) screening for autism; (c) communicating concerns, such as and diagnosing results; (d) making an autism diagnosis, early intervention, and education; (e) treatments for autism; and (f) autism-specific anticipatory guidance. The American Academy of Pediatrics (2003) endorsed the training that was conducted by Major et al. (2013).

Another location that has supported training of its clinical teams is the Beaumont Health System (2017), the hospital that created the Center for Human Development, in support of their families dealing with a diagnosis of autism. The hospital is a state-of-the-art multidisciplinary-assessment center for autism diagnoses. The hospital implemented an interconnected approach to diagnosis and treatment, which is a program model that focuses on the patient, the care team, the environment, and the organization (Beaumont Health System, 2017). The hospital’s clinical team included developmental-behavioral pediatricians, psychologists, and psychiatrists. The center recognized the importance of training to assist families with the challenges of caring for a child with autism. In addition
to the training, the hospital has a series of ongoing parent and professional staff trainings (Beaumont Health System, 2017).

In support of families, the Beaumont Hospital designed three programs. The first program is known as the Lil’ Sprouts Parent Education Group Program, which teaches parents how to encourage speech, language, and play skills in children within the home environment. The program incorporates effective interactive play strategies. The program also offers parents an opportunity to apply their new learning while interacting with their children during training sessions. A speech pathologist facilitates the program (Beaumont Health System, 2017).

The second program is the Play Project approach, which offers parent training for families of children with autism from 18 months to 6 years of age. The goal of this approach is for clinicians to provide parents with techniques to encourage speech or communication in children with autism (Beaumont Health System, 2017). The third program is the Family and Community Outreach approach. This program focuses on providing low-cost in-service training and lectures for families (Beaumont Health System, 2017).

Adding to the research related to parent education and diagnosis, researchers Brentani et al. (2013) purported that early clinical diagnosis and parent education are essential to treating children with autism. The researchers posited that the multifaceted nature of ASD requires a diverse group of professionals. Brentani et al. noted that professionals must work together to obtain an accurate diagnosis and to implement an effective treatment intervention. They reported that autism spectrum disorder represents a major public health concern. Their research indicates that clinicians must work to identify
and begin interventions with children on the cusp of a diagnosis of ASD—as soon as symptoms manifest. The Brentani et al. (2013) assisted with efforts to mandate universal screening for ASD in pediatric health care.

In support of parent education and diagnosis, the research of Cohen et al. (2014) detailed the diverse developmental and cognitive needs of individuals with autism. Their research indicates the disorder presents differently from one individual to another. Autism is a spectrum disorder with varying symptoms among children. There are a growing number of families in need of support to offset the challenges of caring for a child diagnosed with autism spectrum disorder (Autism Speaks, 2013). Cohen et al. (2014) also stated that a diagnosis of autism spectrum disorder has led to changes in treatments, developments in state insurance programs, and a variety of litigation issues have arisen from the education of children with ASD.

According to Cohen et al. (2014), the provision for a free and appropriate education (FAPE) increases the quality of life of children living with autism. The researchers identified possible causes, such as low birth weight, which has been documented previously in this chapter. Given the diverse needs of families, as noted by Cohen et al., the following section addresses treatment options for children with autism.

**Treatment options for autism.** Psychotropic medications are prescribed by many pediatricians to offset co-occurring disorders in children diagnosed with ASD (Autism Speaks, 2013). Co-occurring disorders include sleep or seizure disorders, aggressive behaviors, gastrointestinal disorders, bipolar disorder, attention deficient and hyperactivity, obsessive-compulsive behavior, Tourette syndrome, anxiety disorders, clinical depression, and visual problems (Levy et al., 2010). For the purpose of this study,
the term treatment, treatment interventions, and treatment options refer to nonmedical, early intensive, cognitive, and behavioral actions to improve the condition of ASD. The researcher uses the terms instructional, treatment methods, options, approaches, and interventions interchangeably. These terms also refer to approaches used within a classroom environment. The term therapy refers to occupational, physical, sensory integration, and speech therapy, and related services refers to those provided in and out of a classroom environment to support children with autism.

To support children with autism, many interventions and therapeutic measures have been developed (Autism Speaks, 2013). Some of the treatment options are explained here. The specific treatment options found in the literature that relate to this study are detailed in Chapter 2. As identified by various researchers, treatment options can be biomedical, neurosensory, psychodynamic, and behavioral (Shore, 2008). First, according to Shore’s research (2008), biomedical treatment interventions surmise that autism originates from impurities in the body. Second, Shore uses the term neurosensory treatments to define sensory-integration methods. Shore identified this approach as “the neurological process that organizes sensation from one’s own body and the environment and made it possible to use the body effectively within the environment” (Ayres, 1968, p. 17). Third, Shore (2008) noted that children experience the world through their senses. Given this fact, children diagnosed with autism often experience adverse reactions to certain stimuli (Shore, 2008). When this occurs, the child is unable to process sensory regulation signals. This leads to children with autism responding inappropriately to certain stimuli within their environment. An example of this is when a child on the spectrum hears a loud noise. He or she might cry, scream, cover his or her ears, or run.
Similarly, children diagnosed with ASD may have adverse reactions to certain smells, sights, taste, or touch. Shore (2008) stated that these responses interfere with their learning and they affect behavior. An example of a sensory integration treatment is occupational therapy. Implementing a sensory-supportive environment consists of teachers monitoring their voice levels, providing visual schedules for children, promoting self-awareness in young children, and respecting children’s feelings (Ayres, 1968).

Shore’s (2008) research detailed other treatment options available, such as psychotherapeutic treatments. Psychotherapeutic treatments are interventions that support changes in behavior. This refers to methods that are psychotherapeutic in nature, such as holding therapies (Shore, 2008). Holding therapies use affection and human touch, along with positive affirmations. Shore stated that it is important to provide families with options to behavioral interventions, the researcher detailed the diverse needs of children and families dealing with autism. He noted a wide range of skills in children diagnosed with ASD that require a broad approach to treatment options. Shore’s (2008) research further outlined the perceptions of families that relate to treatment options that are different. His research also suggested multiple approaches to behavioral intervention plans for children with autism. Shore (2008) asserted that a broad range of interventions can support the diverse needs of individuals with autism.

Regarding treatment options, the research of Wolff (2004) detailed the numerous treatment options available to parents. She reported that a diagnosis of ASD is overwhelming and confusing to parents, thereby making parents feel desperate and discouraged by untested and expensive treatments. The array of treatments available to parents are unconventional, naturalistic, biomedical, or empirically based (Rhode Island
natural environmental treatments, or naturalistic interventions are a collection of practices that are environmental, interactive, and behaviorally based techniques. Their research provides an overview of naturalistic and scientifically based treatments. According to the researchers, science supports empirically based treatments (Granpeesheh et al., 2009).

Natural treatments focus on teaching skills in a child’s natural environment. Natural environmental treatments incorporate activities from a child’s environments. Natural treatments mirror typical adult-child interactions. This approach maximizes learning opportunities in a naturalistic way. This treatment uses the learner’s motivation as a factor in the treatment. Reinforcement from the interventionist is specific to the activity. The tasks and activities are varied and frequent. The learner selects materials, and those materials become the basis of the lesson. Naturalistic treatment strategies are child-directed interactions used by interventionists to teach functional skills in a child’s natural environment. This form of intervention arranges a stimulating environment, modeling play skills for children, providing choices, encouraging conversation, and rewarding the child’s attempts (Granpeesheh et al., 2009; Ryan et al., 2011).

Granpeesheh et al. (2009) and Ryan et al. (2011) also reported that interactive treatment options assist children with autism within the learning environment. The researchers noted that this method supports increased socialization and communication for a child with autism. The approach works to increase the level of reciprocal interaction between a child and other individuals. The individuals may be teachers, peers, or family members. Behavioral techniques, as noted by these researchers, refer to approaches known as early intensive behavioral treatments (EIBI). Early intensive behavioral
treatments include: (a) verbal analysis, (b) applied behavioral analysis (ABA),
(c) discreet trial training using the technique of manding (manding is implemented to
 teach a child to request things), and (d) the Early Start Denver model, which is an
inclusive early intervention model that has been endorsed for use with children on the
autism spectrum as early as 18 months old. The Denver model covers the needs of

Regarding early intensive models, the goal of verbal or linguistic analysis is to
increase the levels of independence and educational functioning of children with autism
(Daversa, 2001). This occurs through verbal prompting, conditioning, and increased
communication. The term applied behavior analysis, coined by Lovaas (1987), refers to
an evidence-based practice, which is based on the work of Skinner (1957). Skinner’s
research focused on verbal analysis and conditioning. Verbal analysis was developed to
teach children to communicate their wants and needs. This is applied when working with
children who possess verbal and nonverbal communication skills. Skinner’s (1957)
research detailed that inappropriate behavior can be altered with positive reinforcement.
Skinner’s approach involves ignoring undesired behavior and reinforcing the desired
behavior. Skinner (1957) used forms of positive and negative reinforcement. Positive
reinforcement is characterized as an incentive that is awarded based upon changes in
behavior. Negative reinforcement is when a stimulus is removed depending upon
behavior. As it relates to children with autism, desired behavior is reinforced, and the
interventionist works to decrease undesirable behavior or extinguish it (Salzinger, 2008).
Applied behavioral analysis is considered one of the most efficient treatments for
teaching children diagnosed with autism. It is a scientifically based model (Salzinger,
ABA uses an intense level of reinforcement, repetition, prompting, and cues to support children with autism to master various skills. They can be language, adaptive, or life skills. ABA is a treatment approach that leads to the advancement of human behavior through the method of applied science (Lovaas, 1987). ABA relies on the use of data to identify gains in behavioral and cognitive development in children diagnosed with autism. The purpose of data collection is to identify if a goal implemented as part of a behavioral treatment intervention is achieved or required modification. Data collection also determines whether a behaviorist must increase or decrease certain reinforcers to modify behavior (Lovaas, 1987).

The research of Lindgren and Doobay (2011) reported that there are more than 100 treatment options on the market available for children with autism. Their research documented the first option as complementary alternative medical (CAM) treatment. These treatments are nonmedical treatments that are eclectic in nature. CAM treatments implement special diets and sensory integration approaches. Complementary and alternative treatments include specific diets such as a chelation regime, which is a process that removes heavy metals from the body. The Lindgren and Doobay (2011) research detailed that children with autism often cope with sensory integration issues. Sensory treatments assist children with autism with sensory processing of information like sights, sounds, and smells. Lindgren and Doobay (2011) posited that sensory integration therapy assists children who experience anxiety due to certain sights, sounds, or smells. Their research further noted that children with sensory integration issues also have difficulty with certain textures or tastes. Children with autism who present with sensory processing issues may react negatively to unusual sights, smells, and noises. According to Ayres
(1968), sensory integration measures are highly effective for children with autism. To tackle this, the therapist or parent introduces a sensory integration treatment plan. A sensory integration plan provides supports to children in need of sensory stimuli or who are challenged with sensory overload.

The Lindgren and Doobay (2011) research reports that CAM treatments are highly controversial. The researchers further stated CAM treatments lack supportive evidence to support their effectiveness. Their research indicates that interventions with limited scientific evidence provides false hope to parents. Further, Lindgren and Doobay’s research reports that many parents, desperate for answers, have tried CAM treatments. A study by Hall (2011) involving parents integrating complementary alternative treatment outlined the significance of alternative treatment option used by families. The results of Hall’s (2011) study are vital because they detail the increased use of CAM treatments by parents.

The research of Shore (2008) identifies daily life therapies as a naturalistic model focused on a holistic approach as treatment interventions for children on the autism spectrum. A holistic approach includes the integration of daily life therapies, such as speech, occupational, physical therapy, and special instruction into the homes and educational settings for children with autisms. Shore noted that implementing speech and occupational therapies assist children with ASD in developing skills. Speech therapy assists children with communicating their wants and needs, and it helps children with ASD improve their communication skills. Occupational therapy assists children with autism in feeding and dressing themselves and in daily life skills. These treatment interventions support children with autism exercise more independence in their daily
environment (The National Autistic Society, 2016). The research shows that many children with autism have low muscle tone and poor balance (Autism Speaks, 2013). To address this, children receive physical therapy. Physical therapy supports children’s daily activities (Adams et al., 2012; Autism Speaks, 2013). Last, special instruction assists children with autism with their developmental delays such as helping them with their ability to develop problem-solving skills, helping them check their impulse control, helping to expand their attention spans, and how to work on their frustration tolerance. The special instruction skills also assist children with developing academic skills (Marder & Fraser, 2012; National Autism Center, 2009).

Another treatment approach explored by parents is horse therapy, known as hippotherapy (Shore, 2008). The approach involves working with horses. Hippotherapy assists children with self-soothing and regulating their challenging behaviors (American Hippotherapy Association, Inc., 2016). The research of Shore noted that hippotherapy supports children’s behavioral, emotional, sensory, and attentiveness concerns. While it is a treatment option available to parents, there is limited evidence of its effectiveness (Autism Speaks, 2013; Shore, 2008).

A study conducted by Rossignol, Rossignol, James, Melnyk, and Mumper (2007) indicates the use of hyperbaric chambers by families. A hyperbaric chamber is an instrument used to increase the cognitive functioning of children with autism. This occurs by inhaling oxygen. The study measured the chamber’s effectiveness using a sample size of 18 children over 40 sessions. Rossignol et al. (2007) stated that the chambers caused seizures, breathing disorders, and brain injury, and several studies described this
Another alternative treatment intervention implemented by parents are restrictive dietary regimens. The purpose of these diets is to eliminate potential pollutants. The objective of gluten and casein-free diets is to eliminate protein-based composites and peptides from a child’s diet. Elimination occurs by restriction of these composites from the child’s diet (Autism Speak, 2013).

The qualitative research of Pennesi and Klein (2012) detailed the benefits of a gluten and casein-free (GFCF) diet for children diagnosed with autism. Their survey model collected data from 387 parents of children with autism. A survey model is qualitative research that involves a particular population and asks questions of its participants (Creswell, 2014). Pennesi and Klein’s (2012) research provided parents of children with autism with information regarding gastrointestinal, allergy, and food sensitivities. Their data collection took place over the course of 5 months. Participants were required to complete a 90-item questionnaire. The objective of the study was to identify the effectiveness of the GFCF diet. The purpose of the research was to determine the benefits or limitations of gluten- and casein-free diets. Another objective of the study was to detail any challenges parents experienced with their children’s diets. The study results indicate improved changes in the children’s behavior as a result of their restricted diets. The results of the study suggest a correlation between behavior and diet in children diagnosed with autism. However, the researchers stated that further research is required. The significance of their study is the noted improvement in behavior, social, and physiological symptoms of children with ASD.
Researchers Whiteley et al. (2010) conducted a quantitative research that examined the benefits of gluten- and casein-free dietary interventions for children with ASD. The researchers implemented a two-stage, 24-month randomized control trial using a catch-up design. There were two groups. One group adhered to a restrictive diet and the other group did not. The researchers implemented baseline testing at 8 and 12 months; 72 children participated in the study. The children were of Danish descent. The researchers used a few developmental scales to identify core features of an autism diagnosis. They were (a) the Autism Diagnosis Observation Scale, (b) the Gillian Autism Rating Scale, (c) the Vineland Adaptive Behavior Scale, and (d) the Attention-Deficit Hyperactivity Disorder Scale. The researchers also asked parents to complete an Autism Treatment Evaluation Checklist. The participants’ scores were collected during baseline periods to record any changes in the scores related to the restricted diet. The results of the study indicate that implementing a casein- or gluten-free diet with a child with autism for short periods of time were successful, but Whiteley et al. (2010) had limited outcomes for the children. Longer periods of the casein- or gluten-free diet resulted in improved gains. Their research noted marked improvement in children’s behavior after implementation of the diets. The Training and Resource for Interdisciplinary Professionals Serving Children and Youth (TRIPSCY) affirmed their research. TRIPSCY is a training service in Vermont that supports educators, families, and children (The University of Vermont, 2010). The program model provides mentorship to professional and research supports. The research of Whiteley et al. (2010) indicates that there is a need for increased research on the effectiveness of gluten- and casein-free diets for children with autism.
When reviewing treatment options from an educational perspective, there are several nonmedical treatment intervention programs available to parents (Lindgren & Doobay, 2011). One of these treatments, which has been documented previously in this chapter and is reported here to support the research, is applied behavioral analysis (ABA) originated by Lovaas (1987). Researchers Lindgren and Doobay (2011) indicated that ABA is an early, intensive behavioral-treatment method. According to the researchers, applied behavioral analysis is a research-based approach using strategies designed from principles of behaviorism. The significance of implementing early intensive behavior programs, such as ABA with children diagnosed with autism, is to increase socially significant behavior (Cooper, Heron, & Howard, 2007). The incorporation of ABA principles involves breaking down a task into segments during treatment interventions. The goal is to simplify the task. Simplifying the task assists children with understanding it. In an educational setting, ABA uses prompts, reinforcement, visual instructional strategies, discrete trial training, shaping, chaining, extinction, motivational systems, and task analysis (Lindgren & Doobay, 2011) to reinforce learning or communication in children with autism. These approaches reinforce acceptable behaviors, social skills, and they promote language in children. Examples of these principles are:

1. Brief instruction or questions are given to the student. This serves as a stimulus. The stimulus produces a specific response. The instruction or instructions are followed up with a prompt, and

2. the child responds.
3. If the response is as expected, the student receives reinforcement, such as praise. If the response is unacceptable, the child’s response is ignored. This approach prompts the child to provide the expected response; and

4. the data is recorded.

Lovaas’s (1987) research illustrates the incorporation of the applied behavioral principles of ABA with children diagnosed with autism. In this writing, this above process is referred to as the Lovaas method or the Lovaas approach.

The research of Sallows and Graupner (2005) reveals the benefits of applied behavioral analysis. Sallows and Graupner conducted their research through the Wisconsin Early Autism Project (WEAP) (2005). WEAP (2005) focused on advancing the research of applied behavioral analysis theory. The project was developed in the 1970s, influenced by the work of Lovaas (1987) and colleagues Sallows and Graupner (2005). Their research was consistent with the research findings of Lovaas’s original work in the ’70s and his research conducted 1987. The primary purpose of the Sallow and Graupner (2005) research through the Wisconsin Early Autism Project was to further substantiate the research conducted by Lovaas (1987) and his associates Smith, McEachin, and Lovaas (1993). The goals of the one-on-one-based curriculum were to address deficits in skills of children diagnosed with autism. The core components of the curriculum included: (a) comprehension of language; (b) communication, socialization, and relating to peers; (c) building age-appropriate and symbolic play skills; and (d) increasing abstract thinking and cognitive skills. The program closely monitored the emotional responses of the subjects. The goal of this approach was to balance the
difficulty of the material and method of instruction. This approach examined the children’s ability level and rate of learning.

The purpose of the Sallows and Graupner (2005) research was to replicate Lovaas’s (1987) study. Sallows and Graupner’s study included a sample size of 24 children who were diagnosed with autism. Sallows and Graupner’s (2005) research detailed the first year of a 3-year replication design. The third year of the research is unpublished. The study results report changes in pre- and posttest scores, which demonstrated a gain of 22 intelligence quotient (IQ) points. Of the 24 children, 19 children achieved similar results as those participants in Lovaas’s (1987) initial study. Of the 24 children in the study, eight children achieved gains in their intelligence by 45 IQ points. These gains, according to the researchers, raised the children’s intelligence to an average range. The Sallows and Graupner (2005) research revealed the achievements in the children’s adaptive and social skills. Their adaptive skills, according to the researchers, increased from low to average range. Their research results were that by implementing early intensive behavior therapy, children with autism can develop an average, mid-to-low intelligence. Sallows and Graupner also posited that applied behavioral analysis techniques create improvements in children’s communication, social relationships, play, self-care, and school work, as well as improving their quality of life and independence (Sallows & Graupner, 2005).

A second treatment option is differentiated instruction. This is a child-specific learning approach that is modified to support learning instruction and the developmental needs of an individual child (Rhode Island Department of Health, 2011). In Canada, the Ministry of Education (2007) defined differentiated learning strategies as small
instructions to children of similar abilities, with instruction using visual cues and peers for instructional support. Differential learning instruction can be paired with peer-mediated instruction. According to Sperry, Neitzel, and Engelhardt-Wells (2010), peer-mediated instruction comingles the philosophies of behaviorism and social learning theory. The intervention approaches theorize that children learn from each other. As noted by the researchers, typically developing peers interact with and assist children with autism spectrum disorders. They found that with this approach, children with ASD acquire new social skills by increasing social opportunities in natural environments.

A third treatment approach, as noted previously, is discreet trials training (Lindgren & Doobay, 2011). Discrete trails training was developed by Schreibman, Koegel, and Craig (1977) from the tenets of applied behavioral analysis, and it was implemented through a series of trials or instructions given to children by Schreibman et al. (1977). Discreet trials training includes the teachable steps for children to: say, show, and do. An example is using a ball. Say the word ball, show the ball, and do (something) with the ball, such as throwing the ball to the child. Discreet trials training incorporates an approach known as manding (Schreibman et al., 1977). Manding is a verbal approach to teaching children with autism to request things. Manding teaches verbal and nonverbal children that there is value in communication (Schreibman et al., 1977). According to Hall and Graff (2012), children with autism have difficulty putting together language to articulate or request things. This causes frustration for children on the spectrum and leads to maladaptive behaviors. Maladaptive behaviors are head banging, tantrums, self-injurious behavior, aggression or sexualized behavior, and anxiety (Hall & Graff). To alleviate maladaptive behaviors, manding teaches children with autism to request or ask
for the things they want from their environment. This occurs through verbal prompting. Manding teaches verbal or nonverbal children with autism to request things with words or gestures (Schreibman et al., 1977). The research of Smith and Eikeseth (2011) indicates that manding is an essential component of verbal behavior training for any child with limited communication skills. The final objective of this approach is to decrease the amount of prompting, once the child has developed the communication skill. The objective of this final approach is to ensure the skill is developed. It is also to ensure that the child does not overly rely upon prompts to complete a task. This process is known as cue fading (Beaudoin, Sebire, & Couture, 2012).

A fourth treatment option is entitled the Picture Exchange Communication System (PECS) created by Bondy and Frost (1994). PECS is an alternative augmented communication system for children with ASD. The development of the PECS design began by incorporating tenets of Skinner’s 1957 seminal work, *Verbal Behavior*. A picture exchange system provides children with autism with an in-depth understanding of information through visual reinforcement (Bondy & Frost, 1994). The goal of PECS is to assist with the development of functional communication for children with autism. This is accomplished by incorporating visual tasks to assist the child comprehending how to request things (Bondy & Frost). Visual reinforcement might be a child’s daily schedule in pictures. PECS uses visual communication to motivate verbal and nonverbal children through visual communication. According to Shore (2008), the approach combines visual and speech supports. PECS typically starts with pictures of desired objects (such as food, places, and people) and progresses, over time, to pictures with sentence strips (for example, “I want cookies”), and then, it finally moves from pictures to words. PECS is
widely used with nonverbal children with autism. For nonverbal children PECS allows for increased independence for a child with autism (Bondy & Frost, 1994). According to Bondy and Frost, PECS does not include verbal prompts. This is to ensure that the child does not become prompt dependent.

Last, researchers Vismara and Bogin (2009) emphasized the importance of augmentative communication devices. The picture exchange communication system is a communication device that assists children who are unable to use words to communicate. The objective of PECS is to provide an alternate means of communication for children with varied communication skills. Vismara and Bogin (2009) presented an example of a child getting his or her coat on in a learning environment before going out to play. Using an augmentative communication approach, the teacher would assist the child by, first, retrieving the coat from the child’s space (teacher); then assisting the child with putting on his/her coat (teacher); and starting to zip up the jacket (teacher and child). The support would decrease by having the child finish the task by zipping the jacket up before he/she could go outdoors (teacher and child).

A fifth treatment option is the developmental interactive relationship model or floortime. The developmental interactive relationship model is a play-based intervention used to support children on the autism spectrum. The objective of this approach is to encourage interactions between the child and the adult (Wieder & Greenspan, 2003). Another objective is to have the adult engage the child based upon the his/her interest (Greenspan, 1992). As noted in the Greenspan (1992) research, the goal of floortime in an educational setting is to engage the child in interactions that encourage socialization. The purpose of this approach is to promote a naturalistic response from the child, as well
as to assist the child with developing a tolerance for frustration. The approach promotes communication gesturally and verbally.

A sixth treatment approach is the pivotal response training (PRT) approach by Koegel, Robinson, & Koegel, 2009). PRT was developed from the core components of applied behavioral analysis principles. PRT scaffolds a child’s initiated interest. It is effective in developing communication, language, play, and social skills (Koegel et al., 2009). The researchers reported that PRT teaches communicative and adaptive behaviors within a naturalistic teaching format. A natural teaching environment may be the child’s home or school. The program is designed to promote natural responses from children during interactions.

Finally, special education instruction assists children with autism with working through tasks that are cognitive or social in nature (Autism Society, 2013). The purpose of special education instruction is to develop an individualized educational plan (IEP) consisting of a child’s strengths and challenges. IEPs target the specific developmental needs of the child (U.S. Department of Education, 2010).

In addition to the aforementioned treatment interventions, Shore (2008) identified others’ work in his research. The purpose of his study was to determine the effectiveness of nonmedical treatment approaches to support children with autism. Some treatments have already been documented above and others were noted by Shore in this research. Shore’s (2008) research included written surveys and interviews. The written surveys included Shore (2008) the Delphi model. The Delphi model is a three-way query method using three stages of questions (Linstone & Turoff, 1975). The research involved three phases of interviews with participants identified by the researcher. The researcher
interviewed participants who worked closely with or helped develop the treatment approaches discussed in his research. The first phase included face-to-face or phone interviews. The next phase involved sending the participants the transcribed interview via email. The interviews were: (a) informal and relaxed in nature, (b) open ended, and (c) standardized (Patton, 1990). Shore’s (2008) research detailed that there are many treatment methods marketed to parents. His research focused on five evidenced-based practices that are effective in the treatment of children with autism (Lindgren & Doobay, 2011). Outlined in Shore’s (2008) study were: (a) applied behavioral analysis, (b) treatment and education of autistic and related communication-handicapped children, (c) daily life therapy, (d) the Miller method (2007), and (e) development individual relationship-based model.

Applied behavioral analysis is an intervention previously mentioned. Applied behavioral analysis was created using the tenets of behaviorism (Lovaas, 1987). Behaviorism is a psychological approach to studying behavior. Behavior is observable, tangible, and measurable. Behavior is also described “a muscular, glandular or neuro electrical activity” (Malott, 2014, p. 437). The second intervention is the Treatment and Education of Autistic and Related Communication Handicapped Children method (TEACCH) (Schopler & Reichler, 1971). TEACCH is a structured teaching intervention that supports task completion in children with ASD by providing explicit instruction (Schopler & Reichler, 1971). The goal of TEACCH is to develop an individualized plan for each child rather than using a standard curriculum. Its use of visual supports makes the sequence of daily activities predictable and understandable (Shore, 2008). The third model, daily life therapy, is a holistic approach focusing on the mind, body, and spirit.
This method combines group interaction, fine arts, music, and exercise in its approach. The fourth model, the Miller method (2007), involves assisting children with the atypical behaviors, such as lining up blocks, hand flapping, and spinning, to turn those behaviors into more useful behaviors. The Miller (2007) approach evaluates the significance of the child’s maladaptive behavior and attempts to transform the behavior into a functional one. According to Malott (2014) and Sundberg and Partington (1998), functional behavior assessments are a collection of methods for gathering information about antecedents, behaviors, and consequences in order to determine the reason (function) of behavior. The approach works to expand and guide a child with ASD from isolated interactions to socialization and communication. The model directs and teaches professionals and parents about approaches they can use to facilitate reading, writing, number concepts, symbolic plays, and development of typical classroom activities (Shore, 2008).

The last approach detailed in Shore’s (2008) research is of the developmental, individual-difference, relationship-based (DIR) model. The DIR model is universally known as floortime, developed by Greenspan and Wieder (1997). Floortime supports children with autism who have difficulty with communication and developing relationships. Floortime has six levels to its implementation. The six levels of this approach, and the most important aspects of floortime are described at each developmental stage, they are: (a) self-regulation and shared attention, (b) engagement and relating, (c) two-way intentional communication, (d) purposeful complex problem-solving communication, (e) creating and elaborating symbols, and (f) building bridges
between symbols. It is a parent-supported model, which supports parent input and involvement.

The two additional models detailed by Shore (2008) are the Eden model and relationship developmental intervention model. The Eden model focuses on a lifetime of services for individuals with autism. The services ensure individuals affected by autism receive continuity of care in educational, residential, and employment services. The focus of the model is to provide seamless services for individuals living with autism. This model also provides support to families (Leaf & McEachin, 1999). Lastly, Shore’s (2008) research highlights the relationship developmental intervention (RDI). Developed by Gutstein (2000), the goal of this parent-participatory training program provides training to parents with a goal is to support parents’ interactions with their children. Another objective of RDI is to use the family as an essential aspect in the child’s development. RDI consultants work with families to simplify daily routines, balance parents’ schedules, and increase the quality of life of autistic children and their families. Gutstein’s (2000) research findings indicate there was a consensus from the participants related to a need for: (a) an improved definition of autism, (b) acceptance of diverse treatment approaches, and (c) mutual respect for the contributions of individuals with autism.

A trend analysis conducted by Crosland and Dunlap (2012) highlighted the need for support for children with autism within the classroom environment. These researchers noted that an inclusive classroom must incorporate an eclectic mix of naturalistic, motivational, collaborative, and modified learning approaches. Their research highlighted the importance of different learning approaches to improve socialization in children with
autism. Moreover, the research of Ganz, Kaylor, Bourgeois, and Hadden (2008) highlighted the importance of visual cues, visual classroom schedules, and social stories as effective for supporting the learning styles of children with autism. The study of Ganz et al. (2008) measured children’s acquisition of verbal communication skills. The three participants who had children with ASD were shown pictures and a series of scripts written by professionals. The Ganz et al. research indicates that using visual cues and social stories is an effective intervention. The approaches were highly effective for the scripted statements (those asked by the professional but not written by the professionals), and they were ineffective for unscripted statements. Their study demonstrated that the use of scripts and visual cues can increase communicative speech and decrease repetitive speech. Ganz et al. (2008) concurred with Gray and Garand (1993) about the use of specific strategies in the classroom. They, too, indicated that visual cues and visual classroom schedules are an effective means for children with autism. The researchers further noted that cues and classroom schedules help children on the spectrum express their thoughts. Cues provide interventionists with strategies to incorporate structure and assist children with transitions. Moreover, social stories, according to Gray and Garand (1993), is a teaching model using situations, information, and stories to help with social interactions among children with ASD. The interventionist writes the stories, and the stories are written using the children’s interactions with others and their learning environment. The stories involve written descriptions of situations targeting specific behavioral outcomes. The stories seek to teach the components of the who, what, where, and why of social interactions to improve the understanding of these types of engagement with others for children with ASD (Ryan et al., 2011).
Families and autism. Chiang (2014) conducted a qualitative study involving nine Chinese American families. The researcher determined the effectiveness of a 10-week parent-education program using a pre- and posttests model. A pre- and posttest model involves identifying knowledge before and after the research (Creswell, 2014). The parent-education program involved 10 group sessions with 120-minute intervals. The program used a parent-centered approach, which is when professionals collaborate with families to identify the most effective treatment approaches for their children with ASD. The approach incorporates the parents’ cultural values, and it provides families with resources and supports. Chiang’s study acknowledged the importance of parent-education training. The researcher asserted that parent education assists parents with their confidence skills. Chiang further asserted that training provides parents with the confidence they need to support their children’s learning and daily needs. Last, the researcher noted that parent education helps relieve the stress associated with the parenting a child with autism (Chiang, 2014).

The small-scale qualitative, three-stage study conducted by Connolly and Gersch (2013) highlighted the lived experiences of Irish American parents. The purpose of their 5-month long research was to gather the experiences of parents at the time of their children’s diagnosis of autism. Their research also analyzed parent education using focus groups. A multidisciplinary team of educators facilitated the discussion groups. The team included the expertise of educational psychologists, speech therapists, and a social worker. In addition to the focus groups, the researchers completed semi-structured interviews with seven sets of parents. The first objective of the study was to identify parents’ experiences at the time of their children’s diagnosis of autism. The second
objective of the Conolly and Gersch (2013) study was to capture parents’ experiences of meeting with professionals who were involved in their children’s assessments. The third objective was to ask parents to describe their experiences of parenting children with autism. Last, the researchers measured the benefits of the parents participating in a short-term, parent-education programs. Their study results note that the parents experienced a great deal of stress and anxiety as they waited for their children’s diagnostic assessments. The researchers further revealed that the parents wanted more information at the onset of their children’s assessments. Connolly and Gersh stated that increased knowledge would allow the parents to collaborate with the professionals. Knowledge, according to the parents surveyed, would allow them to effectively participate in their children’s assessments. Connolly and Gersh’s results detailed the importance of collaboration among parents and practitioners. Their results note that the parents wanted additional support in implementing home-based interventions. The Connolly and Gersh (2013) research detailed the health care, parenting, cultural, and marital needs of families caring for children with autism. Their research incorporated Bronfenbrenner’s (1979) theoretical framework by using the principles of education, multifaceted layered support, and empowerment of parents (Algood, Harris, & Hong, 2013).

In addition, the use of Bronfenbrenner’s (1979) theory by Connolly and Gersh (2013) revealed the complex needs of families caring for a child with developmental differences (Algood et al., 2013). Bronfenbrenner’s theory conveyed the importance of an intertwining system of support for families (Algood et al., 2013). Bronfenbrenner’s (1979) theory helped the researchers’ to summarize the successes and challenges of parents caring for children with autism (Algood et al., 2013). First, Bronfenbrenner’s
(1979) ecological human development theory utilized five elements: (a) the micro (home school), (b) the macro (environment), (c) the meso exosystem (external forces), (d) the chronosystem (shifts in life), and (e) exosystem relates to the environmental influences that impact a child’s development (home-schools, parents’ workplace). Second, Bronfenbrenner’s theory highlighted the importance of community, home, school, and parent collaboration. Bronfenbrenner’s (1979) theory and the research of Connolly and Gersch (2013) detailed the importance of parents actively participating in their children’s service provisions as well as the significance of understanding their rights as parents.

The qualitative research of Barbera (2007) detailed the experiences of six parents demonstrating that parents are eager to learn about treatment measure and ways to address the needs of their children with autism. Barbera’s (2007) research notes that parents work to increase their levels of knowledge have served to increase the overall quality of life for families. Her research notes that knowledge increased the parents’ ability to cope with their children’s diagnosis. Barbera’s research indicates that parents identified knowledge as a factor in alleviating stress related to parenting a child with autism. She recommended increased parent and professional partnerships. Last, Barbera (2007) encouraged training programs for parents.

Similarly, Kamei (2013) outlined the perspectives of parents’ experiences in a cross-cultural quantitative research. Her research highlights the importance of parental support and increased training for families. The purpose of Kamei’s research was to gather the perspectives of 96 parents. The participants consisted of 47 parents residing in Osaka, Japan and 47 parents living in the state of North Carolina, USA. Using a survey with five Likert-scale questions, her research identified stress factors for parents caring
for a child diagnosed with autism. The surveys incorporated the parents’ native languages: Japanese or English, respectively. Kamei (2013) used a two-sample, independent $t$-test to assess the different perspectives in the sets of parents. A $t$-test and the Mann-Whitney U test analyzed the results. A $t$-test assesses if two groups’ means are different from each other (Creswell, 2014). A Mann-Whitney U test compares the means of the two populations surveyed (Creswell, 2014). Her survey emphasized Bronfenbrenner’s (1979) theoretical tenets related to parenting a child with autism. Kamei (2013) used Bronfenbrenner’s (1979) theoretical framework to convey the cultural, social, and familial influences that impact parents caring for a child with autism such as social isolation, rejection among peers, and emotional challenges with the diagnosis.

The research of Beaudoin et al. (2014) detailed there are many factors affecting families caring for children diagnosed with autism. Their research took place in Canada. With 484 parents participating, 15 studies were conducted. Some of the training took place at the participants’ homes, and at other times, the training took place at the researchers’ clinic. The purpose of the Beaudoin et al. study was to highlight the importance of parent training and early identification of autism in children. The study focused on toddler-aged children on the spectrum. Their study referenced the work of Lovaas (1987) as it relates to parent training. The study also used Lovaas’s approach as its theoretical framework. According to Beaudoin et al. (2014), the Lovaas’s (1987) work underscored the importance of early identification and training of children with autism. As previously mentioned, the Lovaas (1987) method utilizes applied behavioral analysis principles. This method is the most researched treatment intervention for children on the
Lovaas’s (1987) approach was cultivated using the tenets of Skinner’s (1957) verbal analysis theory as well as applied behavioral analysis, which simplifies skills into manageable pieces for children with autism (Kates-McElrath & Axelrod 2008). Using Lovaas’s (1987) theory, Beaudoin et al. (2014) measured the effectiveness of parent education. Another objective of the research was to determine if communication increased with the parents of their children diagnosed with autism. The study results indicate that the parents involved in a parent-training program were able to implement newly learned teaching strategies at home with their children. These strategies helped increase their children’s social and communication skills.

**Problem Statement**

Honigfeld, Chandhok, and Spiegelman (2012) postulated that a large amount has been written about treatment methods for children diagnosed with autism. However, little is known about parents’ process of determining the most effective intervention for their child. In addition, the Honigfeld et al. (2012) noted that there is limited research about the perspectives of pediatricians’ knowledge and training related to autism, which includes the information they share with families at the time of a child’s diagnosis. According to the Honigfeld et al., pediatricians are at the forefront of a child’s diagnosis of autism. The problem explored in this research is the impact an initial diagnosis of autism spectrum disorder has on the nonmedical treatment options, within the educational environment, from the perspectives of parents and pediatricians.

It is importance for families and pediatricians to receive appropriate information related to a diagnosis of autism. Appropriate information determines the best course of treatment (Finke, Drager, & Serpentine, 2015; Igwe, Ahanotu, Bakare, Achor, & Igwe,
According to a qualitative study conducted by Woodgate et al. (2008), at the time of their child’s diagnosis of autism, parents feel isolated and left on their own. The work of Finke et al. (2015) detailed information available to parents and pediatricians at the onset of a child’s diagnosis of autism. Their research indicates that parents used multiple resources to identify the most appropriate interventions and educational placements. Igwe et al. (2011) identified informational levels of families and pediatricians at the onset of a child’s diagnosis of autism. Their research detailed the lack of appropriate treatment interventions available to families. Given the lack of training and awareness within the health care communities, the researchers’ stated that families engaged in religious remedies, such as spiritual healers, spiritual homes, and cultural beliefs, before they engaged in the limited measures available. Parents, according Igwe et al., also lacked access to appropriate assessments and diagnostic measures. The researchers utilized a sociodemographic questionnaire and a point survey to identify health care professionals’ awareness of autism spectrum disorder. Their study took place in Nigeria. The data collection included 40 pediatric and psychiatric nurses. The Igwe et al. study indicated there was limited knowledge and training of health care professionals caring for children with autism in Nigeria. Their research indicates that this led to a much later diagnosis of autism for the children. The researchers suggested there is a negative connotation to a diagnosis of autism in Nigeria. Igwe et al. (2011) determined that this negativity led to rejection, stigma, and isolation within the parents’ communities. The study revealed a deficit in knowledge about autism in Nigeria (Igwe et al. 2011).
The research in Nepal by Khatri et al. (2011) affirmed the Igwe et al. (2011) research. The Khatri et al. study collected data from a cross section of 54 pediatricians. The researchers collected the data using a self-administered questionnaire. The results assert that pediatricians in Nepal have inadequate knowledge related to ASD. Finally, the research of Major et al. (2013) uncovered that the knowledge of parents and pediatricians at the onset of an autism diagnosis and the impact of knowledge on treatment options chosen by parents. The researchers conducted interviews to determine the effects of the diagnosis and the training of the pediatricians. Their study enlisted 10 Hispanic families in Florida. The Major et al. research revealed the limited knowledge of pediatricians as well as a need for training of pediatric doctors who are completing their residencies.

According to Feinstein (2011), parents encounter many challenges as they seek treatment options for their child with ASD. There is limited information available to parents at the time of their children’s diagnosis (Feinstein, 2011; Green et al., 2006; Ślipirczyk, Karajewska-Kulak, Brayer, & Maciorkowska, 2013). Furthermore, given parents’ limited knowledge, they choose treatment interventions with little scientific evidence to support their approach (Maurice & O’Hanlon, 2010).

The work of Green et al. (2006) reported that more research is required to understand the treatment selections chosen by parents. Of the 552 parent participants in a 3-month survey by Green et al., the results indicate that 52% of the parents were using at least one medication to treat their child, 27% were implementing special diets, and 43% were using vitamin supplements. Green et al. (2006) stated that future research should focus on understanding the decision-making processes that underlie treatment selections by parents of children with autism. Also, a phenomenological study of six families by
Glass (2001) noted that physicians are often the first point of contact when parents have concerns about their children’s development. Caramagno (1992) supported Glass’s (2001) research that states pediatricians have limited knowledge about autism and treatment interventions. Glass indicated that additional training and research is required from pediatricians to support families.

As noted in the introduction, the causes of autism as identified by the research are environmental, biological, and genetic in nature (Landrigan, 2010). Landrigan’s (2010) research further details the causes of autism as genetic, biological, toxic exposure, and environmental influences. According to Landrigan, children are exposed to multiple chemicals daily. The researcher attributed exposures to chemicals as the environmental causes of autism (Landrigan, 2010). The results of his study suggest increased research to identify the environmental factors attributed to autism. While, Landrigan’s research detailed environmental, chemical, and biological factors as causes of autism, his research indicated that there was no correlation between vaccinations and autism.

The research of Mercer, Creighton, Holden, and Lewis (2006) emphasized the perspectives of parents about the causes of autism. The researchers conducted a descriptive survey model study with 41 parent participants. A descriptive survey model gathered the perspectives of the participants. Mercer et al (2006) revealed multiple factors that attributed to parents’ perceptions about the causes of autism. The results indicate that 90% of parents surveyed rated genetic influences as the number-one cause of autism. The second highest cause of autism reported by parents (68.3%) were perinatal factors. Other factors noted by parents were: (a) diet (51.2%), (b) prenatal factors (43.9%), and vaccines (40.0%).
The qualitative research of Ravindran and Myers (2012) focused on causes, beliefs, and practices. A research survey model is the collection of data from a population of interest (Creswell, 2014). The researchers used a survey model to gather the perspectives of 19 mothers and 21 professionals. The interviews of the participants took place in schools, early intervention programs, hospitals, and physician’s office. The data collection took place in a large city in South India. Ravindran and Myers (2012) incorporated Bronfenbrenner’s (1979) ecological system of human behavior as their theoretical framework. Bronfenbrenner’s theory highlights the impact of the environment on a child’s development. Four themes emerged from the Ravindran and Myers study: (a) causes of autism, (b) parent expectations for treatment and services, (c) parent-professional partnerships, (d) and managing the needs of a child living with autism. According to the researchers, parents were comfortable with their relationships with their professionals. However, their study revealed that the mothers only viewed their relationships with the professionals that they interfaced with in the context of their child’s autism. The mothers did not view the clinicians as partners in their child’s treatment planning nor did the mothers view the pediatricians as a resource for, or support to, them. The results of the study outline the importance of cultivating parent and professional partnerships. The results also reveal that the research of autism is expanding in India, yet Ravindran and Myers (2012) stated that many children remain undiagnosed and untreated.

The research of Rahbar, Ibrahim, and Assassi (2011) supports this study’s problem statement because their research sought to identify what information was available at the onset of a child’s diagnosis to parents from pediatricians. The researchers
asserted that general practitioners must have a greater role in the diagnosis of a child with autism. The researchers conducted a cross-sectional survey of 348 practitioners in Karachi, Pakistan. A cross-sectional survey is identified as a descriptive design model that compares data from one group to another (Creswell, 2014). The Rahbar et al. (2011) research revealed practitioners’ knowledge and attitudes about autism. Their survey results note there are misconceptions of indicators, symptoms, and the origins of autism among general practitioners younger than 30-years old. Rahbar et al. indicated that the practitioners chosen to participate in their study had obtained their medical degrees within the last 5 years of the publication of their research. The results of the survey revealed that 44% of practitioners lacked knowledge of autism.

The work of Perryman (2009) explored the implications of culture and autism. The purpose of the researcher’s study was to identify a correlation between race and the age of a child’s diagnosis. The researcher used a survey model to obtain the perspectives of 168 families in North Carolina. The families were Caucasian and African American. As noted earlier, a survey model was used to examine the perspectives of the participants. The results of the researchers study did not reveal any significance differences in the age of diagnosis among the two groups. However, a factor highlighted by Perryman’s (2009) study was the importance of early diagnosis and developmental screenings among pediatricians. Perryman’s research also reports increased public awareness of the symptoms of autism.

An online study conducted by Rhoades, Scarpa, and Salley (2011) reiterated the importance of having a knowledge of autism among practitioners. The purpose of the study was to identify the perspectives of the perceived knowledge of practitioners by
caregivers. Caregivers were defined in the researchers’ study as the parents or primary caretakers of the individuals with autism. More than 147 caregivers participated in the online survey. The Rhoades et al. (2011) study took place in Virginia. The survey participants noted that pediatricians, neurologists, and primary care physicians were the least informed about a diagnosis of autism. First, the participants noted that approximately 40% of professionals gave additional information about ASD after a diagnosis. Second, the researchers stated that the participants surveyed indicated only 15-34% of professionals provided information on medical/educational programs. Third, only 6% of the professionals referred caretakers to an autism specialist. Last, 18% of the practitioners surveyed provided no details to parents. The overall survey results indicate that less than half of the health care professionals provided caregivers with information about ASD. Rhoades et al. (2011) indicated there is a lack of training of professionals regarding ASD behaviors. The researchers also noted that more information is required to assist families. Rhoades et al. (2011) suggested that physicians should increase their knowledgeable of autism. Last, the researchers recommended in-depth training for health care professionals caring for children and families impacted by autism.

A qualitative study by Ślifirczyk et al. (2013) assessed parental knowledge of a diagnosis of autism. The study participants consisted of 83 families from Poland, Belarus, and France. The purpose of the study was to identify the challenges of families with children diagnosed with autism. The researcher’s identified parents’ challenges as financial, emotional, and social. The parents, Ślifirczyk et al. (2013) stated, were in disbelief about their children’s diagnosis. The study’s results revealed that many of the Polish and Belarus families used inappropriate measures to control their children’s
behavior. The researchers attributed these tactics to the parents’ lack of knowledge. The study notes that the French families handled their children’s diagnosis and challenging behaviors the best. The French families did not view their children’s diagnosis as a punishment (Ślifirczyk et al.). However, families of Polish descent acknowledged their frustration and raised their voices with their children. Belarus families complained about their children’s learning progress. Behaviors examined were: disobedience, which was the least reported by French parents; persistence, which was the lowest percentage in Belarus; and lies, reported mostly by parents from Poland. The results of the Ślifirczyk et al. (2013) study yielded similar conclusions of the past research by Abbot, Bernard, and Forge (2012) and Lenne and Waldby (2011). The results detail that information is required to support parents and pediatricians related to the rendering a diagnosis of autism and recommending treatment options. Last, the results of the study recommended collaboration and dialogue among parents and pediatricians (Ślifirczyk et al., 2013).

The research of Manikan (2009) affirmed that treatment interventions for children diagnosed with autism vary. The researcher recommended individualized treatment plans. According to Manikan, singularly focused treatment interventions do not meet the needs of all children diagnosed with autism spectrum disorder. According to the researcher, children diagnosed with autism have complex needs. Manikan’s (2009) research detailed that a complex disorder requires an in-depth understanding of the interventions available. The researcher stated a lack of knowledge of appropriate treatment interventions leads to loss of time by parents. Also, inappropriate treatment regimes result in wasted energy, spending money on ineffective therapies that have temporary benefits to the families, and using treatments that could be harmful to the children (Manikan, 2009).
The purpose of a pilot study by Honigfeld et al. (2012) was to evaluate the impact of providing information and training to pediatricians about autism spectrum disorders. The researchers noted that pediatricians are often a family’s first point of reference at the onset of a diagnosis of ASD. Trainers visited 43 pediatricians. The Honigfeld et al. study results indicate that increasing the training of pediatricians improved the rates of developmental screening of children for autism, the study uncovered a massive influx of billing to Medicare to increase the screening of children for autism. The Honigfeld et al. (2012) study emphasized the importance of partnerships between parents and professionals. The researchers determined it is important for children to be assessed and diagnosed appropriately.

Johnson and Rodriguez (2013) explored the importance of partnerships between parents and health care professionals. The researchers completed a review of the literature, using 34 articles related to the challenging behaviors of children with autism, which were identified by practitioners in a pediatric setting. The behaviors detected were noncompliance, hyperactivity, sensory defensiveness, and self-injury. The study results surmised that there is a need for collaboration among health care professionals and parents to provide the parents with timely and safe care for their children diagnosed with ASD. Johnson and Rodriguez (2013) noted that partnerships are essential to developing strategies at the onset of a child’s diagnosis.

The research of DePape and Lindsay (2014) asserted that parents of children with ASD not only face challenges within their homes but also in their communities. The purpose of the researcher’s study was to identify the perspectives of parents. DePape and Lindsay noted that parental support at home and in the families’ communities is essential.
Their study brought to light a systematic approach to knowledge, care, and treatment interventions available to families. Their study outlined emerging themes in the research by searching 10 electronic databases and reviewing 4,148 abstracts. DePape and Lindsay (2014) selected 31 articles (involving 160 fathers and 425 mothers) and examined the articles through a comparison of results. The researchers identified five themes: (a) pre-diagnosis, (b) diagnosis, (c) family life adjustment, (d) navigating the system, and (e) parent empowerment. The findings indicate that information from health care workers could assist families in finding the right programs and services for their children (DePape and Lindsay, 2014).

According to the research of Liptak et al. (2008), parents and pediatricians acknowledge the need for communication. They also stated that detailed planning is needed at the onset of a child’s diagnosis of autism. Liptak et al. identified the disparities in health care costs, access to support, and the increased rates of a diagnosis. Recommendations from the researchers included screening for autism and additional programs to support underserved groups of children and their families coping with autism. Furthermore, the research of Jaarsma (2014) aligns with Liptak et al. (2008). Jaarsma (2014) and Liptak et al. (2008) noted the disparities in health care screenings and supports for underserved communities. The researchers called for universal screening and programs to diagnosis children with autism. Jaarsma (2014) and Liptak et al. (2008) highlighted that universal screening would eliminate the challenges with access to treatment and early intervention services.
Theoretical Rationale

Two theories guide this study: Skinner’s (1957) theory of verbal behavioral analysis and Bronfenbrenner’s (1979) ecological systems theory. To understand Skinner’s theory, the researcher reviewed the primary theorist of behaviorism, Watson (1913), as well as how his work relates to children with autism. In 1913, Watson published the *Behaviorist Manifesto* (Daversa, 2001). Watson’s (1930) theory determined that behavior must be observable, measurable, and tangible. In addition, Watson (1930) theorized that all behavior is connected to observable events. The theory of behaviorism identifies relationships among conditions (stimuli), behavior (responses), and consequences (reward, punishment, or neutral effect). Watson’s (1930) behaviorism theory is one of the theorists that are highlighted in this study. Watson’s (1930) research supports the treatment interventions and theorist linked to the methods largely researched. These approaches are known as verbal and applied behavioral analysis programs (Daversa, 2001). Watson’s (1930) theory supports the tenets of each, as well as the TEACCH method, another behavioral intervention program used to support children diagnosed with autism spectrum. In addition, due to its history and the fact that it serves as the precursor to all other behavioral and developmental approaches devised to support children with autism. Watson’s (1930) behaviorism theory was selected (Daversa, 2001).

B. F. Skinner’s (1957) research related to behaviorism theory and operant conditioning was developed using the tenets of Watson’s (1930) theory (Daversa, 2001). Skinner (1957) theorized that if behavior is followed by a reinforcer, there is a likelihood that the behavior will continue (Daversa, 2011). Skinner’s (1957) believed that all behavior is taught. Skinner (1957) also believed that learning is developmental (Daversa,
2001). His work supports the principles of behavioral science, which are reinforcement, prompting, fading, reinforcement schedules, extinction, shaping, discrimination, and differentiation (Sundberg & Michael, 2001). Skinner’s (1957) work is the theoretical basis of ABA (Daversa, 2001). Further significance for utilizing behaviorism theory for this study is that behaviorism is the foundation of verbal analysis theory. Furthermore, verbal analysis theory influenced the creation of applied behavioral analysis (Daversa, 2001).

Skinner’s (1957) theory greatly influenced the work of psychologist and autism expert Ivar Lovaas (1987). Lovaas (1987) was the creator of ABA. Applied behavioral analysis, an evidence-based approach, is the most widely used treatment intervention with children on the autism spectrum (Rosenwasser & Axelrod, 2001). Lovaas’s (1987) extensive research related to applied behavioral analysis led to the identification of his research and Lovaas (1987) as the largest contributor to the study of early intensive treatment approaches in support of children with autism (Martinez, 2009). Lovaas’s research capitulated similar studies and research models (Rosenwasser & Axelrod, 2001; Sallows & Graupner, 1999). Beginning in the 1960s, Lovaas pioneered ABA interventions to decrease severely challenging behaviors and to establish communicative language (Smith & Eikeseth, 2011). Lovaas’s (1987) research of applied behavioral analysis began with the theoretical tenets of behaviorism (Daversa, 2001). The conceptual framework of Lovaas’s approach is early intensive behavioral intervention (EIBI). EIBIs are an intensive program based on applied behavioral analysis principles (Reichow, Barton, Boyd, & Hume, 2014). These behavioral programs use the tenets of
Skinner’s (1957) operant conditioning. The program helps assist children with autism with learning.

The second theorist used to support the researcher’s study is Bronfenbrenner’s (1979) ecological systems theory. Bronfenbrenner (1979) was the co-founder of the national Head Start program, a child development program founded in the 1960s. The purpose of Head Start was to provide high-quality childcare for disadvantaged children. Bronfenbrenner was a trained psychologist of Eastern European descent. His theory consists of viewing a child’s development through his or her relationships. Children development relationships within their environment. Bronfenbrenner’s (1979) theory views child development in the context of a system of relationships formed by one’s environment. Bronfenbrenner compared his multifaceted ecological system in layers. The layers were relationships from the child’s environment. Bronfenbrenner (1979) compared the child’s relationships to sets of Russian dolls. The dolls were nested inside one another. Bronfenbrenner (1979) identified the following systems: (a) microsystem, (b) mesosystem, (c) exosystem, (d) and macrosystem. In 1986, he added the chronosystem. The microsystem encompasses the child’s family, extended relationships, and school environment. The mesosystem focuses on the parental figures in the child’s life and how they work together to support the child’s development. The exosystem is part of the system where individuals may have limited interaction with child, yet they still have an impact on the child’s development. The macrosystem is derived from government, society, and cultural influences. The last of Bronfenbrenner’s systemic approach, the chronosystem, takes into consideration the major events that occur throughout the child’s life. The chronosystem entails environmental influences. This system focuses on the
changes that occur throughout the child’s life, including any socio-historical occurrences (Bronfenbrenner, 1979).

The research of Estrada and Deris (2014) used Bronfenbrenner’s (1979) theoretical approach in its study of children on the autism spectrum. The researchers conducted a phenomenological study of Hispanic families, describing the influences of culture on the parents’ ability to obtain a diagnosis. Five research questions guided their research. According to their research results, Bronfenbrenner’s (1979) approach magnified the importance of parents, peers, community, and cultural influences on the outcomes for children with autism.

The work of Xu and Filler (2008) reiterates the importance of Bronfenbrenner’s (1979) theory as it relates to working with young children on the autism spectrum. Their work asserts the importance of the family dynamics and relationships as the lynchpin to best practices while working with children on the spectrum. Furthermore, the research of Xu and Filler (2008) examined the importance of cultural influences that affect the needs of children with ASD. According to their research, the ecological systems model, Bronfenbrenner’s theoretical approach (1979), is one of the very few methodologies that attempted to address the complex set of variables autism presents to families in a meaningful way. Xu and Filler stated that Bronfenbrenner’s approach supports families and serves to uncovering effective treatment interventions (Mann, 2013).

Moreover, Bronfenbrenner’s (1979) theory views children’s development within the context of all relationships (Mann, 2013). Mann’s (2013) work identifies the importance of Bronfenbrenner’s theory in the field of autism. Using a participant population from Jamaica, West Indies, Mann (2013) narrated the lived experiences of
families impacted by a diagnosis of autism. Mann’s study serves to enlighten researchers on some of the ecological and systemic factors affecting families raising children on the autism spectrum in Jamaica. Mann’s (2013) study detailed the work of Bronfenbrenner’s (1979) ecological systems theory, and it highlights how everything in a child’s environment influences how a child grows and develops.

The research of Mann (2013) outlines the impact a diagnosis of autism has on mothers. Mann’s (2013) qualitative exploratory study examined the lived experiences of 13 autistic children’s mothers who were living and raising their autistic children. Conducted in Jamaica, West Indies, Mann’s (2013) study details the families’ limited access to services and the barriers in their attempts to obtaining treatment interventions for their children. Mann (2013) reported that the mothers felt isolated, stressed, financially burdened, and they lacked support. Many sought counsel from their children’s pediatrician. The researcher noted that the parents reported that their children’s pediatricians dismissed their concern and labeled them as worrisome or too anxious. Mann’s (2013) use of Bronfenbrenner (1979) theory underscores the importance of a systems theory approach. Mann’s research, aligned with Bronfenbrenner’s community and cultural influences of ecosystems, and details the challenges and lived experiences of parents’ raising children with autism in the Caribbean.

Similarly, Lautenbacher’s (2013) qualitative study of the perspectives of parents of children diagnosed with autism, living in rural Pennsylvania, outlines the importance of relationships and how these interactions affect community development, parenting, and the child. Lautenbacher’s research highlights the importance of creating support for children and families impacted by autism. Lautenbacher (2013) noted that parents must
be proactively involved in treatment interventions provided for their children, and they should be invested in building school and family partnerships.

Last, the work of Dawson (2013) details Bronfenbrenner’s (1979) ecological theory. Dawson’s (2013) research details the experiences of parents with children living with autism from a micro to macro level. As noted earlier in the research, the micro level is the child’s direct relationships. The micro level involves the relationships and interactions the child has with his or her immediate surroundings, family, school, neighborhood, and childcare environment. The macro level consists of the families’ cultural values. Dawson’s (2013) study was influenced by Bronfenbrenner’s (1979) theoretical system on families coping with their children’s diagnosis of autism. Her research provides an in-depth understanding of how these interconnected systems, families with children on the autism spectrum and Bronfenbrenner’s theory, impact a diagnosis of autism. Dawson’s (2013) study provided parents’ perspectives of autism. Her research took place in South Africa. It included eight families and captured parents’ lived experiences using semi-structured interviews. Dawson used deductive thematic content analysis for the data collection. The researcher noted the broad ecological factors that influenced the parents’ perspectives, interventions, and access to services. The study also highlights the impact of poverty, economics, and unemployment rates on the needs of families who have children diagnosed with ASD living in underdeveloped countries.

In addition, de Wolfe’s (2013) research revealed that parents encounter many barriers after their children’s diagnosis of autism. The researcher detailed the many barriers that forced parents to become advocates for their children. The research problem of de Wolfe’s study was identified as the intense needs of parents caring for children with
autism and the need for support and resources. de Wolfe (2013) stated that parents require like-minded individuals during their community interactions. Her research further details the challenges parents faced while attempting to meet their children’s needs. de Wolfe’s 18-month study took place in Queens, New York. The researcher’s study depicts how parents have become firebrand activists. de Wolfe’s research utilized the ethnographic model. This is a model that focuses on people’s culture, and the research also captured the lived experiences of parents of children with ASD. The parents formed a local support group to collaborate, inspire, and encourage each other. They were able to create a cohesive community of parents engaged in self-education, advocacy, and ongoing activism (de Wolfe, 2013).

The work of Saggu (2015) highlights the perspectives of parents coping with autism in South Asian. Saggu identified as not only a researcher but also a parent advocate, and she developed several behavioral support programs focused on empowering parents. Her study focused on researching effective treatment options in support of South Asian families. Saggu’s (2015) research is significant because it identifies the aspects that are important to parents during the diagnostic process.

**Statement of Purpose**

The purpose of the study was to identify the perspectives of parents and pediatricians and their knowledge about nonmedical treatment options, within the learning environment, that are available at the onset of a child’s diagnosis of autism.

The research of Hebert (2014) indicates that the needs of children with autism spectrum disorder are multilayered and complex. Treatment methodologies implemented by families have a range of social, language, sensory, and behavioral implications
Hebert outlined that there are many treatments marketed to parents. Many are unsuccessful, have limited success rates, and have given parents false hope. The purpose of Hebert’s (2014) study was to: (a) document the lived experiences of parents and pediatricians, (b) identify the knowledge base about autism of families and pediatricians caring for children with the disorder, (c) determine the nonmedical treatment options available at the onset of a child’s diagnosis of autism, and (d) determine the level of success of the treatment options selected at the beginning of a diagnosis of autism.

A study by Suppo and Mayton (2014) investigated parents’ knowledge acquisition in a rural area of Pennsylvania with 12 parent participants. Using a quasi-experimental pre- and posttest design, they provided parents with access to an online parent-training program about acquired knowledge related to treatment interventions available for their children. They found that access to this information helped parents make informed decisions regarding treatment options available. Also, they noted knowledge for parents is an integral aspect of to their active participation in their children’s treatment interventions (Suppo & Mayton, 2014).

**Research Questions**

The following research questions directed this study:

1. What information is available to parents at the onset of their child’s diagnosis of autism?
2. What are the current levels of knowledge of parents and pediatricians at the onset of a child’s diagnosis of ASD?
3. How are treatment methods appropriately aligned when parents and pediatricians are better informed regarding a child’s diagnosis of ASD?

4. What are the treatment options available for children as it relates to the learning environment, and what treatments have been found to be the most effective and why?

**Significance of the Study**

The significance of this study is that the research builds upon the existing information related to the perspectives of parents and pediatricians about their knowledge of children with ASD. Further, the study reveals the treatment options within learning environments that are available at the onset of a diagnosis, and this research also contributes to a greater understanding of the strategies to teach children with ASD. The goal of this study is to help better serve the parent and professional communities.

This study will also be significant in helping to reduce parents’ stress as noted in the research of Cappe, Wolff, Bobet, and Adrien (2004). Their study, conducted in France, included 160 parents: 113 mothers and 47 fathers. According to Cappe et al. (2004), parents experience many emotions at the onset of their children’s diagnosis of autism. The researchers compared parents’ grief at the time of diagnosis to the Kubler-Ross and Kessler (1972) theory of grief, which identified the stages of grief as: (a) denial, (b) anger, (c) bargaining, (d) depression, and (e) acceptance. Cappe et al. noted that the diagnosis places the parents in one of five stages of the grieving process, which varies from 1 month to 3 years. The researchers stated that the feeling of sadness shifts to understanding. Parents experience relief once they understand their child’s behaviors. Cappe et al. noted that early intervention and parent involvement is important to
sustaining the parents’ psychological well-being. When families focus on support and services, as these researchers go on to say, this positively affects the stress levels perceived by parents (Cappe et al., 2004).

The research of Zuckerman et al. (2014) documents the importance of health care professionals and parents developing relationships. The researchers conducted five focus groups and four qualitative interviews with 33 parents of Latino descent in the Reno, Nevada. The parents, according to the researchers, had limited access to care. The researchers noted that this was because of the parents’ limited financial means. It was also due to parents’ limited proficiency in English, and the parents were not encouraged to take advantage of the services available to them. The study reveals the parents reported that the health care providers dismissed their concerns. The research details the importance of parent and pediatrician partnerships. Partnerships, according to the researchers, are essential to raising awareness of autism and creating a higher level of trust between the professionals and parents. Zuckerman et al. (2014) determined that the diagnostic process was lengthy and cumbersome. They recommended a simplistic approach to a diagnosis to assist parents.

In addition, the research of Moore (2013) was used in this study. Moore used an online survey to capture the experiences of 466 participants over a period of 4 months. The purpose of Moore’s study was to develop and validate the Family Experiences with Autism Spectrum Disorders (FEASD) Scale and to document the experiences of families with professionals in health care. The FEASD is a model that blends family support and health care approaches. Moore used family-centered care principles, developed by the American Academy of Pediatrics (2003), as part of the study. Family-centered principles
are a collection of empowering practices for families (Moore, 2013), and they, according to Moore (2013), detail the perceptions of parents in the health care and education fields. The results of the study note the importance of screening for autism.

**Definition of Terms**

The following terms are relevant to this research and the field of autism spectrum disorders, and they will assist the reader in understanding the issues, methodology, and documented programs.

*Adaptive Skills* – the ability for children to negotiate their environment. These abilities include: toileting, feeding, dressing, and/or eating. Adaptive skills are self-help skills (Autism Speaks, 2013).

*Antecedents* – events, actions, or circumstances that impede a child’s ability to participate in his/her learning environment (The National Autistic Society, 2016).

*Antecedent Manipulations* – the resultant inappropriate behavior following events that impede a child’s ability to participate in his/her learning environment (The National Autistic Society, 2016).

*Applied Behavioral Analysis (ABA)* – the study of behavior. It is also the use of systematic instructional methods to modify behaviors in quantifiable ways (Ruble & Akshoomoff, 2010).

*Augmented Alternative Communication (AAC)* – a term used to describe various methods of imparting or exchanging information that assists individuals who are unable to use verbal speech to communicate (The National Autistic Society, 2016).

*Autism Spectrum Disorder (ASD)* – a pervasive developmental disorder that is not otherwise specified (PDD-NOS) (APA, 2013).
*Behaviorist* – a person who supports, practices, or advocates approaches relating to the way in which a one acts or conducts oneself, especially toward others.

*Complementary Alternative Medical (CAM) Treatments* – alternative treatment strategies that fail to meet the standards of clinical effectiveness (McGarry, 2013). Examples of these treatments are alternative diets, vitamin therapy, and horse(equine) therapy.

*Cue Fading* – a component of discreet trials training that decreases the verbal and/or physical prompts given to children (Autism Speaks, 2013).

*Data Driven Procedures* – are systematically collecting and analyzing various types of data, including input, process, outcome, and satisfaction data, to guide a range of treatment decisions (Steiner et al., 2012).

*Daily Life Therapy* – also known as the Higashi method, is a Japanese model for educating children with autism. This model involves instruction within groups, imitation, and vigorous routines (Shore, 2008). The model focuses on the holistic approach to interventions with children.

*Developmental, Individual-Difference, Relationship-Based (DIR) Model* – “provides a framework for interdisciplinary assessment and intervention for autism spectrum and related disorders. It is a comprehensive foundation model that utilizes affect-based interactions and experiences tailored to individual need to promote development” (Weider, 2013, p. 895). Floortime was derived from the DIR model.

*Differentiated Learning* – tailoring the teaching instruction to meet the needs of the individual child (Rhode Island Department of Health, 2011).
**Discreet Trials Training** – treatment intervention that uses the principles of ABA within a well-ordered learning environment in order for a child to master a specific skill. The behavioral interventionist controls the environment and the reinforcement (Sundberg & Partington, 2011).

**Diagnostic and Statistical Manual of Mental Disorders** – publication by the American Psychiatric Association that documents behavioral, neurological, and mental health disorders. It provides health care professionals with a common language and framework for diagnosing disorders (APA, 2013).

**Early Denver Model** – a developmental behavioral assessment tool used by doctors to track developmental processes in young children (Dawson et al., 2010).

**Early Intensive Behavioral Intervention** (EIBI) – developed from the principles of applied behavior analysis (Synapse, 2008).

**Early Intervention** – the name of a program with services to assist children, birth to 3 years of age, with developmental delays or disabilities (Autism Speaks, 2013).

**Echolalia** – the repetition of words or phrases that a child has heard in their immediate environment or in the past. This repetitive form of speech replaces normal responsive language (Autism Speaks, 2013).

**Eden Model** – supports a continuum of care for individuals with autism (Daversa, 2001).

**Evidence-Based Practices** – particular activities supported by empirical research and used as such in programs to support children with autism.

**Expressive Language** – the way a child speaks or conveys his or her thoughts (Dionne & Martini, 2011).
Floortime – derived from the DIR model, it is a play-based intervention that factors in the child’s interest. The approach supports hands-on work with children, and it is child directed and factors in a child’s current level of development. The approach builds upon a child’s existing strengths and abilities (Dionne & Martini, 2011).

Inclusive Environment – the surroundings or conditions in which children with identified disabilities and typically developing children are educated together (IDEA, 2013).

Individual Education Plan (IEP) – a federally mandated written statement by a student’s education team of the educational program designed to meet the child’s individual needs. Every child who receives special education must have an IEP (Autism Speaks, 2013).

Individuals with Disability Act (IDEA) – a special-education law that protects the rights of children with disabilities (U.S. Department of Education, 2010).


Miller Method – a system that addresses the developmental needs of children on the autism spectrum. The program was created by Dr. Arnold Miller and utilizes a cognitive-developmental systems approach for children on the autism spectrum (Shore, 2008).

Occupational Therapy – a treatment that assists children with developing self-help skills to assist them with managing their day-to-day environment (The National Autistic Society, 2016).
**Peer Mediated Instruction** – teaches typically developing children methods to interact with their peers who have ASD (Neitzel, 2008).

**Physical Therapy** – a treatment that support gross motor skills, such as riding a bike, crawling, throwing a ball, balancing coordination, and strengthening of muscles (Autism Speaks, 2013).

**Phenomenological Study** – a qualitative study design that captures the lived experience of its participants (Creswell, 2014).

**Picture Exchange Communication System** (PECS) – a set of principles or procedures to provide alternative communication support for children who are nonverbal or have limited speech capability (Bondy & Frost, 1994).

**Pivotal Response Training (PRT)** – an intervention model derived from the principles of applied behavior analysis (Koegel, Robinson, & Koegel, 2009).

**Relationship Development Intervention** (RDI) – a treatment approach developed from the principles of applied behavioral analysis (Reichow et al., 2012).

**Social Stories** – a strategy to help children with ASD learn societal or organizational interactions in the context of a story (National Autism Center, 2009).

**Snowball Sampling** – Snowball sampling is a group of participants recommended for a study, or recruits them for the study (Creswell, 2014).

**Special Instruction** – Special instruction also known as special education assists children with working through task cognitive or social in nature through individualized instruction (National Autism Center, 2009).

**Treatment and Education of Autistic and Communication Related Handicapped Children** (TEACCH) – an intervention approach that supports task completion by
providing explicit instruction. It is a parent-based model that can be implemented at home (Kentucky’s Autism Training Center, 2010).

*Verbal Analysis* – the results of a detailed examination, using the principles of behaviorism theory, that are designed to measure an individual’s aptitude for working with words (Skinner, 1957).

*Verbal Prompts* – prompts that serve as a reminder to motivate a child to complete a task by telling that child, verbally, what to do. A verbal prompt may serve as a reminder to the child as to what he/she needs to do next.

*Visual Supports* – pictorial schedules and other materials to assist a child with following the daily routine (Autism Speaks, 2013).

**Chapter Summary**

Chapter 1 includes an overview of the history, causes, diagnosis, and treatment options available about autism spectrum disorders. The purpose of the study was to identify the perspectives of parents and pediatricians about nonmedical treatment options in the learning environment available at the onset of a child’s diagnosis of autism. The problem statement the investigator explored was the effects of an initial diagnosis of autism spectrum disorder from the perspectives of parents and pediatricians on nonmedical treatment options. The significance of this study is that it will enhance the existing information available to parents and pediatricians regarding a child’s diagnosis and treatment options. This research builds upon the current information available from the perspectives of parents and pediatricians about their knowledge of ASD in children. This study identifies the treatment options available at the onset of a child’s diagnosis and the learning environment recommended for the child, and it provides a greater
understanding of the interventions available for children with ASD in professional, educational, and parent communities.

The history of autism dates back to more than 200 years ago, and it has been documented in studies dating back to Itard (1801). Itard’s (1801) work identified autism in Victor, a child with limited receptive and language skills whose interactions with adults the first 12 years of his life were nonexistent (Lane & Pillard, 1978). The research of Adelman (2010) outlines that Victor was viewed as a child with severe intellectual difficulties. Many regarded him as unable to learn. However, before Itard began to work with Victor, he had been living in a forest. Itard believed Victor’s responses to others his and his lack of socialization and communication with others were attributed to his environment. Itard’s work provided a framework for many who would come to study children with autism (Feinstein, 2011). The term autism has endured many of classifications (Adelman, 2010). During Itard’s (1801) era, individuals with autism were identified as feeble, mentally challenged, uneducable, and, in many cases, schizophrenic. During Itard’s time, the term autism did not exist. In the DSM-I (APA, 1952) up until the DSM-V-R (APA, 2013), autism was classified as a psychiatric disorder. Prior to 1980, autism did not receive a separate classification in the Diagnostic and Statistical Manual of Mental Disorders. That has since changed. The classification of autism in the manual is historically significant as it has distanced autism from a prior description as a psychiatric disorder (Feinstein, 2011). Kanner used the term autism in his seminal work in 1943 (Feinstein, 2011). A complex disorder, autism has been attributed to a combination of genetic, biological, and environmental factors (Landrigan, 2010). Landrigan noted that these factors are evidence based and supported by empirical
research (Ben-Itzchak et al., 2013; Dionne & Martini 2011; Landrigan, 2012; Mercer et al., 2006).

A diagnosis of autism is challenging. There is no medical test to identify the disorder. A diagnosis is determined through parent interviews, observations of the child’s behavior, neurological testing, and symptoms indicative of the disorder. A diagnosis of autism, as identified by Adelman (2010), Blumberg et al. (2013), and Ryan et al. (2011), is vital to a child’s quality of care and development of treatment interventions. The researchers noted that appropriate and timely diagnosis leads to appropriate care.

This chapter also noted that the causes of autism include genetic, biological, and environmental factors. A diagnosis of autism can be stressful, challenging, and difficult to obtain at times. The research of Brentani et al. (2013), Shyu et al. (2010), and Simpson et al. (2013) indicates that an early diagnosis is vital to supporting families, developing a treatment plan, and critical to the lifelong development of a child. Without it, the researchers noted, child development outcomes are limited, and parents face many continuing obstacles.

Treatment options, as noted by Levy et al. (2010), Shore (2008), and Wolff (2004), within the educational setting for children with autism, can incorporate naturalistic or applied behavioral analysis principles. However, the treatment options marketed to parents are vast in nature (Shore, 2008). The array of treatment options leaves parents uncertain about which method to choose (Lindgren & Doobay, 2011). Researchers Lindgren and Doobay, indicated that pediatricians are at the center of diagnosis and assessment of children for autism. Yet, many lack the appropriate supports to assist parents (Mack, 2008; Simpson et al., 2013). The research of Bondy and Frost

The researcher used the theoretical approaches of Skinner (1957) and Bronfenbrenner (1979) for the study. Skinner’s (1957) theory aligns well with this study because Skinner’s theory related to verbal analysis, the lynch pin to the creation of applied behavioral analysis theory (Daversa, 2011). Skinner’s (1957) work is the foundation to all treatment programs supporting children on the autism spectrum (Daversa, 2011). According to Carbone et al. (2013) and Sundberg and Michael (2001), Skinner is considered to be one of the founders of behavioral science. The researchers noted that Skinner’s work continues to influence treatment interventions and the research of children with autism. Behaviorists have been influenced by the Skinner’s analysis of verbal behavior for centuries. Verbal analysis serves as a mechanism for guiding the teaching of language in existing early intensive behavioral programs for children diagnosed with autism (Daversa, 2011). In addition, Bronfenbrenner’s (1979) theoretical framework of ecological theory is used by this study because it provided the context to understanding how ecological factors greatly influence families parenting a child with autism. Moreover, Bronfenbrenner’s (1979) hierarchy of interconnected, interrelated nested ecological systems lends itself effortlessly and naturally to understanding the role of culture, environment on human development, and a child with autism.

According to Kamei (2013) biological, environmental, and genetics contribute greatly to the causes and diagnosis of autism. Mann (2013) and Dawson (2013) reported that these factors, by and large, affect children with autism and their environment.
Ecological principles of human development emphasize the dynamic and multidirectional nature of interactions between an individual’s environment. Bronfenbrenner’s ecosystem conceptual theory comprises five nested systems: microsystem, mesosystem, exosystem, chronosystem, and macrosystem (Bronfenbrenner, 1977). The microsystem represents the contexts in a child’s immediate environment, such as home or school. The mesosystem signifies interactions between settings in which a child can be located; the exosystem describes an interaction between an immediate setting, such as the home, and a remote but influential setting, such as the parent’s work situation; and the macrosystem, which takes account of the potential impact of such factors as culture and beliefs on a child’s development. Bronfenbrenner’s theory (1977) relates to the research of children with autism. Bronfenbrenner’s approach to human development connects with is the complexity of autism (Mann, 2013). Moreover, Bronfenbrenner’s human development theory connects the biological, environmental, and genetic influences that affect a child’s diagnosis of autism and treatment options (Mann, 2013).

Skinner (1957) and Bronfenbrenner’s (1979) theoretical approaches are used as in this research, as well as the research of Lautenbacher (2013), Lovaas (1987), Mack (2008), and Mann (2013). These researchers’ work identifies factors to support parents caring for children with autism along with detailing the roles of pediatricians and their work with children on the spectrum. The overarching needs of families identifies information, collaboration, and education as the primary factors to relieving parents’ stress related to their children’s diagnosis of ASD (Kalash, 2009). Parent education programs are the contributing factors to help decrease stress levels in parents of children with ASD and to increase the parents’ quality of life (Mack, 2008). As noted by the researchers,
partnership between pediatricians, parents, and autism specialists yields positive results for children and families (Keenan et al., 2010).

The review of the literature in Chapter 2 includes studies that outline the significance of parents’ and pediatricians’ knowledge at the onset of a child’s diagnosis of ASD and the influences on the treatment options prescribed. The literature review addresses treatment interventions, factors contributing to the diagnosis of children with ASD, the views of doctors diagnosing children with ASD, and a global perspective of parents caring for a child diagnosed with autism. The review of the literature provides key elements of the history of autism spectrum disorder, the importance of collaboration and parent knowledge, parent perspectives, parent training, and pediatricians’ knowledge and perspectives.

The research design, methodology, and analysis are discussed in Chapter 3. Chapter 4 presents a detailed analysis of the results and findings, and Chapter 5 discusses the findings, implications, and recommendations for future research and practice.
Chapter 2: Review of the Literature

Introduction and Purpose

According to Hall (2011), parent and clinician partnerships are essential to a child’s diagnosis of autism. Hall further stated that the volume of information parents are exposed to has become as overwhelming as their children’s diagnosis. Moreover, Hall asserted that families must begin to cultivate healthy relationships and support systems at the onset of their child’s diagnosis. She further noted that these relationships provide many benefits, long term, and serve as a measure of support during the most challenging times for parents. Moreover, Mack (2008), Mann (2013), Kamei (2013), and Hall (2011) maintained that parents face many obstacles as they navigate the diagnostic process and treatment options. These researchers identified that exploring the best treatment options available are sometimes determined by geographic location, finances, and the resources available (Mann, 2013). In addition, these researchers noted that pediatricians are critical to assisting parents with the many challenges they will face when raising a child diagnosed with autism.

This literature review provides the reader with the research studies that document the history, causes, diagnosis, and treatment options that are available and related to autism spectrum disorder. Child advocates for children with special needs indicate there must be a balance in the delivery of services, as well as advancements in the empirical research of autism, to help transform services for children with autism (Autism Society of America, 2013). The Centers for Disease Control and Prevention (CDC, 2014) indicates
that autism knows no cultural, ethnic, or geographic limits. The disorder affects close to 1% of children in the United States. Research findings around the world indicate autism may affect close to 1% of the global population (Autism Speaks, 2013).

The literature review outlines the history of theoretical models related to nonmedical, educational treatment options. The analysis of the literature highlights: the works of noted scholars in the field of autism; the history, causes, and diagnostic process; and nonmedical treatment interventions available. While this research does not focus on biomedical models of treatment, the review does note some models available to families. In addition, the literature review details the essential elements to an appropriate path for parents and pediatricians when a diagnosis of autism spectrum disorder is determined. The problem the researcher examined was what information was provided to parents by pediatricians and at the time of their child’s diagnosis of autism. The researcher further examined what impact this knowledge had on the treatment options selected.

**Theoretical framework.** Bronfenbrenner (1979) and Skinner’s (1957) theoretical framework guided this study. The research of Daversa (2001) and Dawson (2013) noted that Bronfenbrenner and Skinner’s ideology has been widely used to support children with autism. Bronfenbrenner’s (1979) research identified the importance of the family composition and how central it is to a child’s development. Bronfenbrenner (1979) posited that the environment, family, and family culture serves as the nucleus to a child’s development. His initial study of ecological and environmental influences in the 1970s laid the foundation for understanding how environmental influences affect children and the development families (Algood et al., 2013). Hall (2011) and Mack (2008) referenced Bronfenbrenner in their studies of families and children related to diagnosis and treatment.
options for children with autism. Hall and Mack’s work added to the existing knowledge of treatment options and diagnosis because of their focus on diagnosis and intervention.

Bronfenbrenner’s (1979) theoretical framework notes that socialization occurs within a context. Most notably, Bronfenbrenner referred to a set of Russian dolls that were nested inside each other with the smallest one at the core. Similar to the dolls, socialization is an intertwined context that continuously evolves. A child’s environment, Bronfenbrenner noted, has many nuances. One must fully comprehend all the facets of the environment that affect a child. Bronfenbrenner’s (1977) perspective further analyzed a child’s behavior within the context of developmental theory. This theory comprises the microsystem, mesosystem, macrosystems, chronosystem, and exosystems. This developmental theory takes place within the milieu of family, home school, community, and other external factors. Moreover, Bronfenbrenner asserted that one’s environment influences his or her culture. The ecological systems of Bronfenbrenner’s (1979) theory uses a familial approach to understand the importance of family, culture, and child development.

This study examined the theoretical framework of verbal analysis. Verbal analysis is a theory developed by B.F. Skinner (1957). Verbal behavior analysis is a behavior modification system (Maurice & O’Hanlon, 2010). Verbal analysis is a concept that seeks to understand human behavior, language, and individual responses to stimuli (Skinner, 1957). Skinner (1957) is responsible for the development of verbal analysis theory but his research was widely largely influenced by the behaviorist and psychologist, John Watson (1913).
Watson’s (1913) research focused on animal subjects, such as rats, rabbits, birds, and monkeys. Watson was able to apply his same experimental design to his study of humans. Watson’s (1913) seminal work was entitled, Behaviorist Manifesto. He also created the well-known experiment that is highly referenced in behaviorists’ work today, which established conditioned emotional responses. Watson’s research in this area, which was largely conducted with a small child, is known as the Little Albert experiment. The experimental design model exposed Albert to various small animals while concurrently signaling a loud noise. This design elicited crying from the child. The study also revealed that by frequently pairing the animals with the noise, the animals, themselves, came to elicit responses of fear, crying, and escaping behavior (Watson & Rayner, 1920).

Escaping behaviors are actions that a person or animal uses to avoid a particular action (McLeod, 2017). In young children, escaping behavior also manifests itself as resistance to participation in activities. Watson’s 1930 publication of his book, Behaviorism, and his several experiments conducted with children, helps researchers today understand behavior in young children, young children on the spectrum, and the implications of children’s environment (Daversa, 2001).

Verbal behavior therapy, the work of Skinner (1957), focused on teaching verbal behavior through a collection of highly effective teaching procedures taken from the science of human behavior analysis. Verbal behavior therapy demonstrated that language can be taught using the principles of operant conditioning. Operant conditioning incorporates positive and negative reinforcement principles. Operant conditioning helps to shape behavior in children (Skinner, 1957). Skinner’s (1957) book, Behavioral
Analysis of Language, details his theory (Daversa, 2001). Verbal analysis theory is a theoretical approach enhanced by applied behavioral analysis theory (Lovaas, 1987).

As noted, behaviorism theory is the work of Watson (1913), which was later enhanced by Skinner (1957). Watson (1913) and Skinner’s (1957) research proposed that behavior is influenced by observation and environmental factors. The research of Watson (1913) and Skinner (1957) behaviorism created the theoretical framework for future early intensive behavioral models (Daversa, 2001). Several researchers, behaviorists, psychologist, and clinicians have applied Watson’s (1913) and Skinner’s (1957) ideological principles to further advance the development of early intensive behavioral interventions methods for children with autism (Bondy & Frost, 1994; Lovaas, 1987; Schopler et al., 1982). Skinner’s (1957) research, along with the work of Eikeseth, Smith Jahr, and Eldevik (2002), Gerhardt and Holmes (1997), Leaf and McEachin (1999), Lovaas (1987), Schopler and Reichler (1970), Smith and Eikeseth (2011), and Sundberg and Michael (2001). While Watson and Skinner’s approaches were applied to this science, subsequent researchers, Daversa (2001), Lovaas (1987), and Schopler et al. (1982), emphasized the importance of parent and professional collaboration in their work. These researchers incorporated parent participation, a behavioral modification context, and techniques for increased communication development.

As mentioned previously, the link between of behaviorism and applied behavioral analysis dates back to verbal analysis theory (Skinner, 1957). Skinner’s (1957) verbal analysis theory contributed significantly to the treatment of children with autism (Sundberg & Michael, 2001). Skinner’s (1957) research of verbal analysis, behavior, and conditioning supported the development of applied behavioral analysis (ABA) treatment...
intervention created by behaviorist and psychologist, Ivar Lovaas (1987) (Daversa, 2001). Applied behavior analysis is an intensive behavioral treatment methodology widely used by behaviorists today (Sundberg & Michael, 2001). Last, the applied behavioral analysis of Lovaas (1987) advanced the earlier work of Watson (1930) and Skinner (1957), (Daversa, 2001).

According to Sundberg and Michael (2001), behavior has an antecedent or event that occurs before the behavior. The researchers contend that behavioral analysis attempts to identify causes the inappropriate behavior. Through early intensive behavioral programs, the interventionist endeavors to condition or initiate consequences that will extinguish or lessen inappropriate behaviors by implementing positive or negative reinforcers (Daversa, 2001). This is the primary objective of applied behavioral analysis (Lovaas, 1987). Applied behavioral analysis is an empirically based treatment intervention. This means the method or treatment is entrenched in science (Lovaas, 1987). Applied behavioral analysis is also the most widely accepted model associated with educational treatment interventions used by practitioners working with children on the autism spectrum (Lovaas, 1987). Practitioners may include a trained behaviorist, special educators, or psychologists. Moreover, ABA provides the framework required to teach children on the spectrum because it creates a context to teach children appropriate behaviors, socialization, and cognitive skills. The intervention helps to eliminate inappropriate behaviors (Lovaas, 1987). As noted consistently throughout this research, the tenets of behaviorism became the guiding principles for research related to children diagnosed with autism (Daversa, 2001). The concept of applied behavioral analysis was developed using the principles of behaviorism.
Lovaas et al. (1979) began using behavior modification in autism treatment in the 1960s. According to Green (1996), behavior analysis views autism as a syndrome with behavioral insufficiencies, with neurological underpinnings, marked by inappropriate behavior and communication. According to behaviorists, the behavior of children with autism can be modified if they are provided a structured, interactive intervention within their learning or educational environment (Green, 1996). A behaviorist is an individual with training in applied behavioral analysis, and he or she may have training as a special educator, psychologist, or psychiatrist (McLeod, 2017). Moreover, applied behavior analysis builds on behaviorism. As noted earlier, applied behavior analysis teaches children socially acceptable behaviors. Another objective of ABA is to reduce the most challenging behaviors. The principles of behavioral science are use as the framework for the several different models of autism interventions, which are outlined in this study.

A few of the models identified in this research were influenced by the tenets of behaviorism, and they are: (a) the Lovaas method (1987), also known as applied behavioral analysis, which is an early intensive behavioral modification program used with children on the autism spectrum to assist them with adaptive skills, communication, and learning new skills; (b) Leaf and McEachin’s (1999) Eden’s model, which was derived from the Lovaas method (Lovaas, 1987) and uses strategies created from a comprehensive curriculum that is developed to address behaviors, eating disorders, and simulating behavior; (c) the picture exchange communication system (PECS) (1994), which is a program developed to support increased receptive language development and provide functional communication skills in children with autism (Bondy & Frost, 1994). Functional communication is teaching children with autism useful or meaningful
language (Bondy & Frost, 1994). PECS was created from applied behavioral analysis principles (Bondy & Frost, 1994); (d) verbal behavior analysis (Skinner, 1957); (e) discreet trials training (Schreibman et al., 1977), which is a behavioral approach that supports the principles of ABA by simplifying tasks and breaking them down for increased learning, which requires recording data on children’s responses and the tasks completed (Smith & Eikeseth 2011); and (f) natural environmental teaching (Lindgren & Doobay, 2011), which is an approach that supports teaching children social and language skills within their natural or real-world environment (Daversa, 2001).

In relationship to families, the research of Dawson et al. (2010), Kamei (2013), Mack (2008), and Mann (2013) highlights Bronfenbrenner’s (1979) ecological system. This system views child development as an outcome of healthy parenting within the context of environmental systems. According to Bronfenbrenner’s child development theory must consider the micro to macro levels. Bronfenbrenner defined the microsystem in the context of parents, friends, and workplace. Macro relates to education, government, and religion. These variables, Bronfenbrenner asserted, impact a child’s environment.

As it relates to autism, the research of Dawson (2013) identified the importance of this multilayered approach to supporting families impacted by autism. Researchers Dawson et al. (2010), Kamei (2013), Mack (2008), and Mann (2013) utilized Bronfenbrenner’s (1979) theoretical framework to expand the importance of family and cultural factors in support of children on the autism spectrum. These researchers noted the importance of Bronfenbrenner’s theory of examining the ecology of parenting and the environment. They asserted that the key to success for families caring for children with autism is the use of an integrated approach to parenting. They further summarized the
importance of including families and community-based resources in the diagnosis, assessment, and training process. Their research indicates these approaches have significant outcomes for parents caring for children with autism. Dawson et al. (2010), Kamei (2013), Mack (2008), and Mann (2013) further reported that progress is required in the understanding the factors that contribute to successful parenting of children with autism, and that there is a need for intervention strategies that enhance awareness of developmental disorders.

As mentioned previously, Skinner’s (1957) research highlighted behaviorism and verbal analysis theory (Sundberg & Michael, 2001), and Skinner’s (1957) research created the framework for the development of applied behavior analysis theory (Sundberg & Michael, 2001). According to Sundberg and Michael (2001), Skinner’s approach was the impetus for Lovaas et al. (1979) work with the development of applied behavior analysis. The Lovaas et al. (1979) groundbreaking study began with the support of the National Institute of Mental Health.

The Lovaas (1987) work set the stage for the existing array of early intensive behavior programs (Daversa, 2001). The objective of Lovaas’s (1987) research was to validate the effectiveness of behavioral treatment programs. The criteria for participants was a diagnosis of autism validated by two or more professionals. The study was conducted at the University of Los Angeles California (UCLA) School of Medicine. The study began in the 1970s and tracked its original participants for more than 15 years. Undergraduate students administered the participants’ behavioral treatments. Graduate students attending the university served as supervisors. The students received training in applied behavioral analysis principles. A psychologist or psychiatrist supervised the
students who were implementing the treatment interventions. The sample size of each group was 19 children. Participants were assigned to either an experimental or control group. The test groups received treatment for more than 2 years. According to Malott (2014), “an experimental group is a group of research participants exposed to the presumed value of the independent variable” (p. 438). A control group is not exposed to the independent variable.

Due to resistance from parents, Lovaas (1987) was unable to use randomly assigned participants (McMorris et al., 2013). Random assignment involves arbitrarily placing the participant in one of the two groups. He assigned participants based upon staff availability instead. All of the participants in the experimental group received more than 40 hours of intensive therapy each week. The participants in the control group received few hours of ABA.

Lovaas (1987) used the following testing instruments with the groups: (a) the Bayley Scales of Infant Development (Bayley, 1955), the Cattell Infant Intelligence Scale (Cattell & Cattell, 1960), the Stanford-Binet Intelligence Scale (Thorndike, 1973), and the Gesell Infant Development Scale (Gesell, 1949); (b) videotaping of behavioral observations; and (c) 1-hour parent interviews. The study results demonstrated that nearly half of the children who received early intensive behavioral therapy achieved normal-range IQ scores (Lovaas, 1987).

(Dawson et al., 2010; Eikeseth, 2009; Sallows & Graupner, 2005; Stahmer, Akshoomoff, & Cunningham, 2011; Sundberg & Partington, 1998). Lovaas (1987) has been identified as the pioneer of the early intensive behavioral approach. His method has become the guide post for the many behavioral-intensive and evidence-based approaches created by Eikeseth et al. (2002). The Lovaas (1987) work has been replicated in the studies of Sallows and Graupner (1999) and Smith et al. (1993) to determine their effectiveness. For more than 30 years, the National Institute of Mental Health, in partnership with the UCLA, has devoted staff and funding to support the advancement of behavioral analysis treatments (Satcher, 2000). Lovaas’s (1987) work served as a precursor to all early intensive behavioral programs.

**Review of the Literature**

**History of autism.** According to Feinstein (2011), the term *autism* originated more than 100 years ago. The word originated from the Greek term *autos*, meaning self. The work describes children largely detached from social interactions (Mandal, 2014). Bleuler (1911), a psychiatrist, was the first person to use the term autism in his research. His initial use of the term was used to describe individuals with schizophrenia. According to Mandal (2014), the seminal work of Bleuler depicted 647 cases of schizophrenic patients. The study was conducted over 8 years in Germany. The participants Bleuler studied were socially withdrawn (Mandal, 2014). He used the first term, schizophrenia, to characterize what he called a form of psychosis; he used the term autism to describe a form of schizophrenia, which was characterized by the withdrawal from reality, people, and relationships (Mandal, 2014). Mandal (2014) noted that Bleuler (1911) coined two
significant terms during the height of his career. The significance of this is detailed below.

Bleuler’s (1911) participants included individuals who were diagnosed with schizophrenia, yet some exhibited classic traits of autism (Feinstein, 2011). His contribution to the autism community is that he used the terms to describe specific behaviors associated with the disorders. As previously mentioned, the earliest case of a child with developmental differences and symptoms of autism dates back to Itard’s (1798) work in the 1800s (Lane, 1979). Itard’s work described the Wild Boy of Aveyron, later named Victor. Aveyron is in the South of France. Victor was discovered by the French government. At the time of his discovery, Victor was 12 years old and unable to speak. He had been abandoned, was living in the woods, and was raised by wolves. Victor walked on his hands and knees. Upon learning of a young child wandering in the woods, seeking food and shelter, the government of France ordered his confinement. Victor escaped several times before Itard (1798), a psychologist at the home for deaf and mute children, was assigned to work with him. Itard worked with Victor for 5 years. Itard (1798), as documented by Lane (1979) believed he could teach Victor through stimulation of his senses and adaptation to social norms.

While Itard had limited success in his work with Victor, he was able to teach him some words and increase his interactions with adults (Itard, 1798; Lane, 1979). Itard’s (1801) and Lane’s (1979) work is significant to this research as it laid the foundation for recognizing the symptoms of children with intellectual differences and set a precedent for creating educational plans with children with special needs (Xu & Filler, 2008). These plans are known today as individualized educational plans (IEPs) (Cook &
Willmerdinger, 2015; Lane, 1979). Historians and researchers (Feinstein, 2011; Mandal, 2014) attributed Victor’s behavior to his environment (Wolff, 2004), and others indicated that Victor was a child with autism (Wing, 1981; Wolff, 2004). As previously mentioned, little was known about autism in the early part of the 19\textsuperscript{th} century (Feinstein, 2011; Mandal, 2014).

Also noted earlier, Bleuler (1911), a psychiatrist and psychologist, provided the framework for the understanding of the subset of conditions within individuals diagnosed with schizophrenia, and he made the distinction between the disease and autism. His work in the early 1900s began with 647 participants in the Burghölzli Asylum in Zürich, where he was an associate professor. He conducted his study through clinical observations over 8 years, and it is noted that, at time, he lived among his patients, (Moskowitz & Heim, 2011). Bleuler (1911) introduced his seminal work at a conference in Germany. His study theorized the splitting of personality and the clinical criteria for patients identified as schizophrenic. Moreover, he began to use the term schizophrenia, as opposed to the common term used at the time, known as \textit{dementia praecox}.

\textit{Dementia praecox} is a Latin term that originated with the work of Kraepelin (1919) meaning out of one’s mind. Bleuler disagreed with his colleagues’ view of the disorder. Kraepelin (1919) theorized that schizophrenia was incurable, and its onset was caused by brain damage. Bleuler (1911) did not believe that schizophrenia was curable. His work emphasized associative disorders. According to Bleuler (1911), patients with schizophrenia disassociated from others or experiences. He later expanded his work to include the term \textit{dementia praecox schizophrenia} in 1911 This term theorized that schizophrenia disorder is not a form of dementia, but a splitting of mental functions. This
splitting, according to Bleuler (1911), created a conflicted sense of reality. These contradictions, he noted, coexisted in the mind of someone suffering from the disorder.

As it relates to autism, the work of Kraepelin (1919) indicated that the roots of schizophrenia originated from a form of dementia and that it was a deterioration of the brain. However, Bleuler (1911) thought differently, and he theorized that schizophrenia was just a disharmonious state of the mind. Unlike Kraepelin (1919), Bleuler (1911) felt that schizophrenia must be inclusive of all traits of the disorder. Bleuler’s (1911) contribution to the community of autism helped to reframe schizophrenia and provided the differentiation of the disorder from autism. In addition, Bleuler’s (1911) work helped lead to the formation of the Diagnostic and Statistical Manual of Mental Disorders (DSM-I and II) after World War II (Moskowitz & Heim, 2011). To diagnosis individuals with autism, mental health professionals use this manual.

As noted earlier, little was known about autism in the 1920s and 1930s. According to WebMD (2013) in the 1940s, researchers in the United States began to use the term autism to describe children with emotional or social problems. The research that catapulted the study and the term autism has been credited primarily to Dr. Leo Kanner (1943), a psychiatrist. Kanner (1943) developed the first academic child psychiatry department at Johns Hopkins Hospital. He wrote the first book in English on childhood psychiatric disorders. His book, Child Psychiatry was published in 1935 (Kanner, 1943). Kanner’s 1943 study has been credited as the first published work that used the term infantile autism. Moreover, Kanner’s 1943 work, Autistic Disturbances of Affective Contact has been consistently referenced in the research of autism (Feinstein, 2011).
Kanner (1943) was also the first physician in the United States to be recognized as a child psychiatrist. He conducted his research in Baltimore, Maryland. Kanner was later in charge of the Johns Hopkins clinic in Baltimore. His participants were 11 children: eight boys and three girls. The 11 children ranged in language development and social and intellectual abilities from lower functioning to higher functioning. The children’s ages varied but they did not exceed 11 years of age. They were recruited through doctor referrals, parents’ concerns, and children living at the Harriet Lane Residence, the Henry Phipps Psychiatric Clinic, Johns Hopkins Hospital, and the Child Study Center in Maryland.

Kanner’s (1943) access to the children who participated in his study came about through a number of sources. Some participants were identified due to parental concerns about speech and development. These participants were brought by their parents for a series of clinic visits, some for 1 day, others with up to 2 weeks of residency. This was for the purpose of obtaining detailed information. Other study participants were referred to Kanner by their children’s doctors due to the doctor’s concerns. In such cases, parents were able to schedule visits and travel to the clinic. One child, initially brought in by his mother, was later placed in a residence in Annapolis, Maryland due to his mother’s inability to care for him. In this case, his mother provided a detailed description of his behavior.

The families of the children in the study ranged in socioeconomic status, education, and age. Kanner’s (1943) study narrated the lived experiences of the families and included direct observations of the 11 children. Parents provided extensive demographic, birth, and family history, and they gave detailed written accounts of their
children’s behavior. Kanner’s (1943) observations of the children’s behavior took place through the late 1930s in Maryland, at the Henry Phipps Clinic, the Harriet Lane Home for Invalid Children, the John Hopkins Hospital, and the Child Study Center of Maryland. Kanner used parent interviews, written accounts from the parents, direct observations, and developmental tests as instruments in his data. Several parents sent follow-up documentation detailing their children’s behavior after their initial visits. The parents noted that their children had difficulties with social interactions, difficulty in adapting to changes in routines, had good memory, were sensitive to stimuli and sound, had resistance and allergies to food, had intellectual potential, used repetitive speech known as echolalia, and had difficulties with spontaneous activities.

Through these observations from the parents and through his own observations of the following characteristics in the children, such as isolation, rigidity, an aversion to changes in their routines, spinning objects or their bodies, difficulty with speech (in some cases), and ritualistic behavior, Kanner (1943) identified these behaviors as symptoms of what he called early infantile autism. Infantile autism also included hand flapping, obsessive behaviors, spinning, pronoun reversal, echoing of language, temper tantrums, and they were happiest when they were alone.

Kanner (1943) used the Goddard Seguin Form Board Intelligence Test with his participants. This test was created in 1917 by Goddard to test intelligence the levels of children who were intellectually challenged (Goddard, 1917). According the researcher from 1917, the objective of the test was to measure children’s eye-hand coordination, intelligence, and motor and visual perception skills. Koegel, Koegel, and Smith (1997) documented that there were several limitations to standardized developmental testing
during that time and none were specific to a diagnosis of autism. However, the research credits Kanner (1943) for using a comprehensive diagnostic evaluation process that involved observations, developmental play approaches, and interviewing parents. Kanner’s work also noted his use of the Grace Arthur (1925) scale. This is an intelligence scale developed in the 1930s by psychologist Grace Arthur. The objective of the scale was to measure intelligence among children identified as hearing impaired, immigrant children, individuals who only spoke a foreign language, individuals who were native born, or were children who were deaf or nonverbal. This group point scale measured two control groups in Kanner’s study (1943) using the principles of discriminative value.

According to Arthur (1925), discriminative value is the average of the higher group. Kanner (1943) also used the Binet and Merill-Palmer test (1973) (Ramey, Campbell, & Nicholson, 1973; Thorndike, 1973). This is an enhanced version of the Stanford Binet Test (Thorndike, 1973). The use of the scale in Kanner’s work is significance as it affirmed an existing theory detailed by the national survey work of Biddle (2014). Biddle’s work indicates that some children diagnosed with autism were misdiagnosed as hearing impaired. According to the Biddle, physicians assessing atypical behaviors concluded hearing loss due to the child’s lack of responsiveness rather than testing further for autism. This was not a factor in Kanner’s (1943) research, yet it is important, as indicated by Biddle (2014), to understand the complex relationship between autism spectrum disorder and deafness.

Families served an important role in Kanner’s (1943) research. He noted that families contributed detailed accounts of their children’s behavior. Parents, he also noted, provided extensive information about their children’s birth history and developmental
challenges. In one case, a father wrote a 30-page document outlining his son’s behavior, and one mother provided detailed notes of her child’s behavior noting specifics. Kanner suggested a genetic factor and a neurological base for the causes. Using this information in his research, Kanner (1943) asserted that the parents were emotionally distant from their children, a concept known as refrigerator mother theory (Bettelheim, 1959), which is discussed later in this chapter.

Kanner’s follow-up research in 1971 of his initial study in 1943, more than 28 years later, determined that progress was still waning in the study of children with autism. Kanner postulated there were many things still unanswered in the field of autism research. In 1971, Kanner stated that there were still a number of theories, hypotheses, and speculations pertaining to the diagnosis, origin, and parents. He stated:

Parents are beginning to be dealt with from the point of view of mutuality, rather than as people standing at one end of a parent-child bipolarity; they have of late been included in the therapeutic efforts, not as etiological culprits, nor merely as recipients of drug prescriptions and of thou-shalt and thou-shalt-not rules, but as actively contributing cotherapists. (Kanner, 1971, p. 145)

Many of the children who participated in his initial research had dismal gains and had been institutionalized and their parents, he noted, were incapable of caring of their children.

According to the research of Schreibman (2008), Kanner’s (1943) work greatly influenced the view of autism as a severe behavioral disorder resulting from biological, environmental, and psychological aspects in the child’s early life. Furthermore, Kanner’s (1943) work attributed the disorder to the refrigerator theory, a popular concept in the
'40s, '50s, and '60s research of autism. The theory attributed children’s diagnosis of autism to a mother’s lack of affection and the mother being emotionally distant toward her children. This was a theory popular during Kanner’s era of research (Cohmer, 2014). Kanner (1943) eventually denounced his assumptions that the symptoms of autism could be attributed to emotionally distant mothers (Cohmer, 2014).

Asperger (1944), a pediatrician from Austria, published a study that described a high-functioning group of children with signs of autism (Wing, 1981). His work took place at the University Children’s Clinic in Vienna. Asperger’s data collection involved detailed observations over 10 years. Asperger’s (1944) research described some symptoms of a form of autism with higher levels of cognitive functioning. The children demonstrated delays in social communication. Similar to the research of Kanner (1943), Asperger’s (1944) research relied upon observations and parent interviews to describe his participants’ behaviors. Asperger’s work detailed his observations of four children who were regarded as socially awkward and highly intelligent. The children, as described by Asperger (1944), possessed exceptional memories, disjointed speech, and provided rote responses during social interactions. The children’s responses, his research further indicated, did not match the subject matter. Asperger characterized his participants as little professors. This was due to their advanced vocabulary (Asberger, 1944).

In addition, the children in Asperger’s 1944 research were unable to demonstrate empathy toward their peers and displayed signs of physical awkwardness. Although his work was published on or about the same time as Kanner’s 1943 research, and both described children with similar features, Asperger’s work, written in German, was unknown outside of German literature until it was discovered by psychiatrist, researcher,
and parent advocate, Lorna Wing (1981). Wing’s (1981) discovery led to the translation of his work by psychologist Frith (1991) into English (Cohmer, 2014). Asperger (1944/1991) described the children as having autistic *psychopathy* in his original research. The term described children who displayed abnormal behaviors (Wing, 1981). The abnormal behaviors were described as the lack of social reciprocity, inability to connect with peers, self-centeredness, and an obsession with specific topics. Wing (1981) noted that autistic psychopathy is a personality disorder primarily marked by social isolation. The comparisons of psychopathic with sociopathic behavior, such as the case of schizophrenia and autism, along with the terms inferring violence in behavior, led Wing (1981) to introduce the term *Asperger’s syndrome* in her clinical interpretation of Asperger’s (1944) research. Wing (1981) also utilized the term as a tribute to Asperger’s previously unrecognized contributions to the field of autism research. Wing’s (1981) research detailed that individuals with Asperger’s syndrome have the ability to function independently in society opposed to many individuals diagnosed with autism. Their biggest challenge, according to Wing (1981), is social reciprocity. Social reciprocity describes an individual’s ability to respond appropriately during social interactions.

According to Treffert (2004), Asperger’s (1944) dissertation thesis highlighted four children with Asperger’s syndrome. The researcher noted that although he only included four children in his final (1944) work, Asperger observed more than 200 children over 10 years. The work of Leekam, Libby, Wing, Gould, and Gillberg (2000), stated that Asperger’s research was descriptive, but it lacked a diagnostic criterion. That is, research without testing instruments was involved in the diagnosis. Asperger relied heavily upon his series of observations, which occurred at the University Pediatric Clinic.
in Vienna. According to Wing (1981), Asperger later created a school to support children that exhibited characteristics of Asperger’s syndrome. However, toward the end of World War II, the school was bombed, and a significant amount of Asperger’s work was destroyed. Although this occurred, Wing and Gould (1979) located some of his work for translation.

In addition to her discovery of Asperger’s (1944) research and the support of Kanner’s (1943) research, Wing (1981) is credited with developing the ideology of autism as a spectrum disorder (Feinstein, 2011). According to Wing, the disorder has many ranges and manifests differently in each person (Feinstein, 2011; Klin, 2006). Her work highlighted the different skills of children diagnosed with the autism. Wing was committed to advocating and supporting parents of children with autism. The mother of a severely autistic child, Wing’s work is significant to the research of autism (Feinstein, 2011). A psychiatrist by training, Wing (1981) became a pioneer in autism research (Klin, 2006), and she became the founder of the National Autistic Society (Feinstein, 2011).

The Wing and Gould (1979) study, known as the landmark Camberwell study, screened 914 children in the London Borough of Camberwell. The children had physical, mental, or behavioral impairments. The researchers study highlighted 173 children in Camberwell, South London, with symptoms of autism and IQs under 50. The Wing and Gould (1979) study, as noted by Feinstein (2011), concluded that a number of children met the criteria for autism as described by Kanner (1943). Their research characterized a subset of individuals with autism who did not meet the criteria of either group. This led to the ideology of a spectrum disorder. This philosophy led to the development of a
framework of three specific areas of impairment related to autism. These areas are identified as deficits in social relations, communication, and imagination. The researchers noted that: (a) 60% of the children had severe learning difficulties, (b) 25% had moderate developmental challenges, and (c) 15% demonstrated average or above-average intelligence. Wing and Gould’s (1979) findings indicated that autism is as a broad-spectrum disorder. These broader symptoms are prevalent and widely recognized by diagnosticians today (Gillberg, 1998).

The research on the history of methods used to assist children with autism is summarized by a few notable researchers. Bettelheim (1959) was a highly respected professor, a child development specialist, and a psychoanalyst in Chicago. During the time of his research, he served as the director of a residential children’s clinic. The clinic provided support to children with severe emotional challenges. According to Cohner (2014), Bettelheim was a huge proponent of psychotherapy with young children and was largely influenced by Kanner’s (1944) theory of psychic causation and Freud’s (1940, 1963) psychoanalysis theory. Kanner’s (1944) theory of psychic causation was developed from the work of Freud (1940, 1963), and Freud theorized that the subconscious is the cause for many actions. Developed during the 19th century, Freud’s psychoanalysis theory explored the mind as well as subconscious behavior. Freud’s theory investigated subconscious to conscious behavior (Kihlstrom, 2006).

Bettelheim (1959), a psychologist with the influences noted above, conducted his own research of children with autism. Bettelheim worked at a residential facility that cared for children with behavioral impairments and disorders. A survivor of a Nazi concentration camp, Bettelheim was intensely dedicated to studying children with autism.
He documented in his research that the behavior of children with autism served as a reminder of his experiences as a concentration camp prisoner. Bettelheim (1959) likened mothers as prison guards (Epstein, 2014). Bettelheim’s research began as a single case study of a child named Joey. In his 1959 study, Joey was described as a robotic child, and by Bettelheim’s research, Joey was described as a finicky infant, and he was placed on a strict feeding schedule. As a toddler, he was unable to speak. During Bettelheim’s interview with Joey’s mother, Bettelheim indicated that she expressed no desires to interact with her son after his birth. When Joey was 4-years old, his school observed some specific behaviors, which Joey rocking back and forth, his obsession with machines, and his act of spinning. The school concluded he might have autism.

Bettelheim (1959) continued his study of 9-year-old Joey’s behavior at the University of Chicago’s Orthogenic School over a course of 3 years. Bettelheim noted that Joey possessed an empty stare and robotic-like behaviors. Bettelheim further described his behavior as impassive, mechanical, and absent of feelings or thought. He stated that Joey spoke in a ritualistic tone and exhibited repetitive tendencies. This led to the description of Joey as, *Joey the mechanical boy.* Bettelheim theorized that Joey’s behavior could be a response to his mother’s rejection. This led to Bettelheim’s theory of the wounded child, also later known in his work as *refrigerator mother theory* (Bettelheim, 1959). His theory’s concept was that mothers of children with autism appeared to be cold, indifferent, emotionally detached, and displayed an indifference toward their children. In order, to cope with this rejection, Bettelheim (1959) concluded that the children displayed the unusual behaviors. He continued his work through the years with this theory and later wrote another book entitled, *Empty Fortress* (1972), about
the ways in which children with autism cope with their parents’ rejection. Therapy, he asserted, is important for this group of children, and it plays an integral part in the support of more appropriate behaviors from the children.

While Bettelheim (1959, 1967) contributed largely to the historical perspective of the topic, Rimland’s (1964) research challenged Bettelheim’s (1959) assertion that autism was caused by aloof and emotionally indifferent mothers. Rimland (1964) was a psychologist, researcher, and parent advocate in the field of autism (Cohmer, 2014). He founded the Autism Society of America in 1965 (Cohmer, 2014). Historically, his research shifted the focus of the causes of autism from a psychological to a biological perspective, suggesting that the disorder stemmed from a child’s genetics, and it was not psychological in nature (Cohmer, 2014). His work was published in 1964 entitled, *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior* (1964). Rimland’s (1964) work contradicted Bettelheim’s (1967) refrigerator mother theory and later supported the Lovaas (1979) theory of applied behavioral analysis.

In keeping with an historical perspective of the topic of autism, and as noted in the research of Trevett (2014), Dr. Mildred Creak (1964) was a child psychiatrist committed to improving the lives of children with autism during a time when most children who exhibited such symptoms were deemed uneducable, psychologically ill, and untreatable (Feinstein, 2011). During the 1950s, a diagnosis of intellectual and psychological deficiencies led to institutionalization (Braddock, 2002). Creak set out to uncover the causes and to establish diagnostic criteria to examine the ideology of the refrigerator mother theory by Bettelheim (1967).
In 1964, Creak developed the 9-point criteria to diagnosis autism. She created the criterion based upon the observations of more than 100 children, ages 3 to 9-years old, at the Maudsley Clinic in the United Kingdom. The criterion she established detailed: (a) challenges with interpersonal relationships, (b) obsession and fixation with ideas or objects, (c) high levels of rigidity or fixation with sameness, (d) anxiety caused by transitions in their regimented routines, (e) unawareness of their surroundings, (f) speech delays, (g) challenges with movement, (h) learning difficulties, and (i) hearing and visual perception challenges. The results of Creak’s (1964) research identify the importance of working closely with pediatricians. Her work dispelled the notion of the refrigerator mother theory and noted, historically, that the disorder originated from genetic factors (Cohmer, 2014; Feinstein, 2011).

Causes of autism. As noted in Chapter 1, Landrigan et al. (2006) and Landrigan (2010) research associated genetic, environmental, and behavioral factors as the causes of autism. Since the 1970s, Landrigan et al. have been involved in research that examines environmental causes of children’s health issues. Landrigan et al. (2006) authored more than 500 empirically based articles related to the cause of environmental factors and children’s health issues. Landrigan is also the author of five books. His initial research began in El Paso, Texas. The Landrigan et al. (2006) research uncovered the impact of lead on children living near a large ore smelters and refineries. An ore smelter is heavy-medal-based iron furnace. A refinery is a location or building where chemical and mechanical substances are purified (Landrigan, 2010). Landrigan (2010) noted that while a direct cause of autism is undetermined, he asserted that the developing nervous system may be adversely influenced by the effects of a variety of conditions, as well as the
varying ages and sex of children. The conditions noted by Landrigan (2010) were maternal rubella, tuberous sclerosis complex, deprivation of oxygen at birth, whooping cough, allergies, measles, viral infections, fetal intolerance to maternal antibodies, imbalance in the brain, and excessive levels of testosterone.

Landrigan (2010) posited that there is direct evidence that the exposure in early pregnancy to thalidomide, misoprostol, and valproic acid; maternal rubella infection; and the organophosphate insecticide, chlorpyrifos, which are all toxic chemicals, has a direct link to children later diagnosed with autism. Landrigan’s research identified that 11% of mothers exposed to these toxins gave birth to children who were later diagnosed with autism. Landrigan’s research identified that 11% of mothers exposed to these toxins gave birth to children who were later diagnosed with autism. Landrigan (2010) recommended the need for the development of methods to identify causes of autism through: (a) toxicological studies, (b) neurobiological research, and (c) epidemiological studies. The three causes mentioned above are defined in the following ways: first, toxicological studies seek to identify the effects of chemicals on individuals; second, neurobiological studies seek to identify the effects of biological factors on behavior; and, last, epidemiological studies analyze patterns, causes, and conditions in groups that are alike. Finally, the research of Landrigan (2010) maintained there is a link between pre-and post-environmental exposures for children diagnosed with autism. Landrigan (2010) contended these exposures affect brain development.

Moreover, Landrigan (2010) was successful in conducting a comprehensive research design with the National Institute of Child Health and Human Development that included the participation of 105 sites across the US. The objective of this prospective research study was to provide a framework for environmental risk and susceptible factors
for individuals with asthma, birth defects, dyslexia, attention-deficit/hyperactivity disorder, autism, schizophrenia, and obesity, as well as for adverse birth outcomes.

Landrigan’s (2010) research model was a multiyear epidemiologic study of 100,000 American-born children. The purpose of this type of study was to address public health care concerns and to provide increased awareness of health care issues. The participants were from birth to 21 years of age. A cohort of 100,000 U.S. children was established. The research provided training for the researchers and pediatricians about related environmental causes of ASD. Landrigan’s research (2010) also addressed the growing concerns about the link of the measles, mumps, and rubella (MMR) vaccination to autism. In order to test this, he conducted research in the United States, the United Kingdom, Europe, and Japan. His research determined there was no link between the two (Landrigan, 2010).

The cause of autism has been linked to vaccinations by way of the research of Dr. Andrew Wakefield et al. (1998). The original study consisted of 12 children with drastic behavioral changes after receiving the MMR vaccination, which led to a major public health concern, as well as increased anxiety among parents (Burgess, Burgess, & Leask, 2006). The Wakefield et al. (1998) research detailed their observations of 12 children after receiving the vaccinations. The research included parent observations and developmental histories of the children. Wakefield et al. indicated that after a number of the children received their vaccinations, they demonstrated a regression in their development and behavior. The researchers described the children in their study as having difficulty recalling previously acquired skills and behaving in a catatonic state, staring at things for hours. According to Jab and New (2009), the Wakefield et al. (2010) research
caused hysteria among parents. In more recent years, however, other studies have been conducted that disprove the researchers’ assertion that autism is linked to vaccines (DeStefano et al., 2004; Elliman & Bedford, 2001). These researchers further assert there is no link between vaccinations and autism.

**Diagnosis of autism.** The research of Mack (2008) applied a mixed-methodology design to gather the perspectives of general pediatricians. The study revealed the diagnosis and referral process of doctors caring for children with special needs. The pediatricians served children with a range of developmental needs, such as children with developmental delays, attention deficit disorder, and advanced health concerns, such as spina bifida and children with autism. The data collection occurred in Florida and took a month to complete. The participants were asked to complete an online survey of nine questions relating to prescreening instruments, skills the pediatricians had acquired to validate their diagnosis, barriers they perceived in using the diagnosis instruments, what strategies they used for periodic screenings, the techniques they used to support parents with limited English proficiency, how and what type of strategies they used to work with community-based organizations, how they connected parents to services, how they increased parent’s’ awareness of resources, and how they assisted parents with interpreting the developmental evaluation reports. Mack’s (2008) research methodology included transcription of the interviews, an online survey using SurveyMonkey, coding to identify themes and sub-themes, and item-level analysis. Item-level analysis is identified as a research method that examines participants’ responses to questions.

Mack’s (2008) study began with identifying more than 150 members of a chapter of an organization for doctors. This group was reduced to 28 doctors. Of the 28 doctors
who were invited to participate, each scored the highest in compliance with the American Academy of Pediatrics guidelines. From this pool, the researcher chose 19% of the general pediatricians for interviews, which was a total of seven pediatricians interviewed. The remainder of the pediatricians’ names were held in the event of attrition. Attrition in research is when there is a reduction in participant size (Patton, 1990).

Mack’s (2008) research identified the practices of general pediatricians that related to the Academy of American Pediatrics (AAP) standards. The research design was a mixed methodology. The study consisted of three phases: (a) an online survey that included information related to demographics, the amount of time participants identified they spent adhering to AAP recommendations, obstacles to implementing AAP recommendation, and the an online survey that informed participants that they may or may not be selected for a follow-up interview to gather additional data; (b) a selection of candidates; and (c) interviews. The researcher conducted semi-structured interviews with the seven chosen participants, and they were asked to elaborate on their response to the questions. This procedure included identifying the assessment used to determine the autism diagnosis. Most of the participants identified the Childhood Autism Rating Scale (Schopler & Reichler, 1971, 1972) as the instrument used. The CARS is a developmental rating scale used to detect autism. Another screening device identified by the researcher used by pediatricians is the Ages and Stages Instrument (ASQ). The ASQ is a parent-friendly screening tool that measures development skills in young children (Bricker & Squires, 1997). The pediatricians identified the Ages and Stages Developmental Screening (Brooke Publishing, 2016) as the primary developmental screening used with families. This is a parent-friendly screening instrument used to determine developmental
milestones in young children. Through the parent questionnaire, the ASQ provides parents with an opportunity to contribute their perspective of their child’s developmental history. The Denver Developmental Screening Instrument measures cognitive, social, emotional, and physical development in young children (Frankenburg, Dodds, Archer, Shapiro, & Bresnick, 1990). Most of the pediatricians were primarily familiar with the instruments for identifying Attention Deficit Hyperactivity Disorder (ADHD) (Mack, 2008).

Through her research, Mack (2008) discovered that the majority of the pediatricians referred children with developmental issues to a neurologist or to a developmental specialist rather than to complete further testing by themselves. The pediatricians identified the following reasons for not completing further testing: (a) lack of time, (b) limited reimbursement, and (c) parents’ unwillingness to pay out-of-pocket costs. Participant interviews were transcribed. Coding was used to identify common themes. Mack (2008) noted the following themes from the pediatricians surveyed: (a) limited knowledge of autism, and (b) pediatricians relied upon colleagues in their office to review the charts of children showing signs of developmental issues. Further results of the Mack’s study revealed: (a) barriers to identifying developmental disabilities in children, (b) lack of knowledge of developmental testing instruments from pediatricians, (c) limited space to complete testing, and (d) an inappropriate referral process. The other barriers identified by the researcher to obtaining a diagnosis for families was: (a) the lack of training on the part of the pediatricians, (b) limited continuing education requirements for pediatricians, (c) constraints in testing due to limited personnel, (d) limited time with patients, and (e) knowledge of screening tools. The study results demonstrated the
importance of early identification of developmental delays and the need for early intervention.

Moreover, Adelman’s (2010) quantitative study conveyed the needs of families coping with a child with autism as well as the implications of a diagnosis. Adelman’s research aimed to determine the impact of the age of a diagnosis related to the region in which the participants lived. The participants were recruited through the Interactive Autism Network (IAN) research database at the Kennedy Krieger Institute and Johns Hopkins Medicine in Baltimore. There were three regions within the United States that participated in the study, the Northeast, the South, and the Midwest regions. The participants in the study were families of African American, Asian/Pacific Island, Caucasian, Hispanic, and Native American descent.

There were 654 parent participants. The participants completed a demographic questionnaire that included questions about parent income levels, education, race, and health insurance coverage. Parents were asked questions about the age of their children at the time of their diagnosis, whether another child in the family had a similar diagnosis or any developmental concerns, their cultural origin, their history with their health care providers, if they switched pediatricians, and if any specific screenings took place as part of the diagnostic process in the diagnosis of autism. Moreover, parents were asked questions about their pediatricians’ reactions to their parental concerns.

Adelman (2010) used a quantitative method of analysis of variance and linear regression analysis. Analysis of variance is the statistical comparison of two data sets. Linear regression analysis is the study of the relationship of two variables (Creswell, 2014). Examining a comparison of regions of the United States and the age of diagnosis
in children with ASD, the study determined that the average age of diagnosis in the Northeast and South regions was 3-years old. Adelman determined that an earlier age of diagnosis occurred in the Midwest Region with an average age in this region of 2-years old. The Adelman (2010) findings report that children are being diagnosed at younger ages. Results of the study also indicate that children can be diagnosed as early as 2-years of age, thus making it easier for parents and pediatricians to provide interventions at an earlier age.

In accordance with the research on diagnosis, Saggu (2015) conducted a quantitative study in British Columbia of 63 families coping with their children’s diagnosis of autism. His correlational study outlined the following objectives: (a) to measure parent perceptions of satisfaction before, during, and after a diagnosis of autism; (b) to identify the perceptions of parents; and (c) to identify if parents received a diagnosis through publicly funded health care systems or through privately paying. The parents completed a parent satisfaction survey to measure their perceptions related to the information noted above. The purpose of the parent satisfaction survey was to measure the parents’ contentment with a particular hypothesis. In addition to the survey, the researcher used the Hochbaum Health Belief Model (Hochbaum, Rosenstock, & Kegels, 1952). According to Hochbaum et al. (1952), this approach is a psychological model that anticipates behaviors based upon perceptions of health care beliefs. This model was created by Hochbaum (1950). Hochbaum’s (1950) research examined the correlation between tuberculosis screening programs and health care belief systems (Steckler, McLeroy, & Holtzman, 2010). Saggu’s (2015) study asserted that changes in a family’s health-related decisions concerning their children with autism were based upon the
following: (a) their acceptance of the diagnosis, (b) effects of the disorder, (c) benefits and barriers to treatment, and (d) parents’ self-efficacy. As it relates to autism, Hochbaum’s (1950) framework identifies parents’ varied beliefs about autism’s causes, effectiveness of treatment interventions, and levels of acceptance. Last, the model sought to determine if parents’ health related beliefs impacted their self-worth.

The results of Saggu’s (2015) research noted that the three hypotheses outlined above were not supported by the research. According to the researcher, the only factor that mattered to parents was related to their beliefs about a diagnosis of autism and the wait time to obtaining a diagnosis. Saggu noted a comparison of parents with government health benefits and parents with private-pay options. Parents with private-pay options obtained a diagnosis sooner. This also allowed private-paying parents to seek interventions earlier. The results of the study outline the importance of future implications for social change among practitioners. Saggu (2015) outlined the importance of policy-level recommendations related to diagnosing autism. His study results indicate that changes will yield positive results for parents seeking to understand their children’s developmental concerns and diagnosis of autism for their children. Last, Saggu (2015) recommended decreasing lengthy autism assessment waitlists, improving access for all families.

In addition to the instruments mentioned in Mack’s (2008) study, there are several other instruments used in the diagnosis of autism. First, The Childhood Autism Rating Scale is a quantitative instrument used to diagnose autism, which was developed by Schopler and Reichler (1971) and Schopler, Reichler, DeVellis, and Daly (1980). Schopler and Reichler were the cofounders of the TEACCH model, an advanced
behavioral modification program based upon the earlier work of Lovaas (1987). The objective of the CARS is to determine symptoms of autism and the severity of the disorder using direct observation. This screening measure was developed to use with children 2 years of age and older (Schopler et al., 1980).

Second, the Vineland Adaptive Behavioral Scale is used to measure adaptive behaviors in individuals with autism from birth to adulthood (Sparrow, Cicchetti, & Balla, 1989). Third, the Verbal Behavior Milestones Assessment and Placement Program (VMAPP) is a criterion-referenced screening tool used with children on the autism spectrum. It was developed by Dr. Sundberg (2008) and includes the principles of verbal analysis, a concept developed by Skinner (1957). The VMAPP serves as a curriculum support and promotes language development.

Fourth, the Assessment of Basic Language and Learning Skills by creators Sundberg and Partington (1998) was an instrument developed to support language development in children with autism. Fifth, The Autism Diagnostic Interview-Revised (ADI-R) (Lord et al., 1994) is a semi-structured interview instrument that can be used by researchers and clinicians. This instrument is used to interview parents to identify behaviors exhibited by children and to create an education plan. Finally, The Autism Behavioral Checklist (ABC) can be used in combination with the ADI-R. The ABC is a screening tool questionnaire with more than 40 questions that can be completed by parents or teacher (Krug, Arick, & Almond, 2008). The tool is used for educational planning.

In addition to the above screening devices, there are other tests used to determine the intellectual levels of children, which are used with those identified with ASD. The
Bayley Scales of Infant Development, for example, was developed in 1955 to identify infants and toddlers with cognitive and motor delays. It is used widely with children who are diagnosed later with autism (Amiel-Tison, 2001). A widely used test in schools is known as the Wechsler Intelligence Scale for Children, which was created by psychologist, David Wechsler (1949). Since its original creation, Wechsler developed it to assist in the placement of children with special needs in appropriate settings. Today, it is used with diverse populations. Its population usage spans from preschool children to mature senior citizens (Wechsler 1949, 1955, 2003). The test quantifies intelligence in verbal and nonverbal children, as well. The test is global and asserts that intelligence should be measured in broad ranges. Wechsler (1949) also believed intelligence tests must be diverse and examine the varied skills of children.

The Binet test was developed in France in 1916. Psychologist, Alfred Binet, revised the test in the United States. Then Stanford psychologist, Lewis Terman, developed a revised American version of the Binet (1916) test. It is known as the Stanford-Binet test that measures five areas of cognitive ability in children, using qualitative and quantitative measures (Terman, 1905, 1908). The five areas are: (a) fluid reasoning, which means the interpretation of knowledge acquired at home or school; (b) acquired knowledge, which is the ability to use knowledge across settings and in new ways; (c) numerical reasoning and the ability to apply numerical concepts in day-to-day situations; (d) visual-spatial processing, which comprises the ability to interpret patterns, complete mathematical problems, including problem-solving skills, and using forms of reasoning; and (e) working memory, which measures concentration and sequencing skills (Marom, 2003).
For children with special needs, specifically autism, most standardized tests, which rely heavily on language development to administer effectively, are ineffective for children with autism (Koegel et al., 1997). Moreover, in Kanner’s (1944) research more than 70 years ago, which marked the first study in the United States of children with autism, he noted that some children appeared to be intellectually disabled, yet he thought otherwise. At the time of Kanner’s (1944) initial research, there were no developmental tools available to effectively measure the skill sets of children identified as having autism; whereas now, there are several instruments used in diagnosing ASD (Sarris, 2015).

In 1952, the American Psychiatric Association (APA), in the first Diagnostic and Statistical Manual: Mental Disorder (DSM-I) categorized autism as a childhood subtype of schizophrenia. This is the manual used by clinical and mental health practitioners to diagnose children with autism. The timeline for the disorder in the DSM is the following: (a) DSM-I (APA, 1952) and DSM-II (APA, 1968) where there is no term for autism or pervasive developmental disorder; (b) DSM-III (APA, 1980) uses the pervasive developmental disorders of infantile autism, childhood onset pervasive developmental disorder, and atypical autism; (c) DSM-III-R (APA, 1987) uses the pervasive developmental disorders of autistic disorder, pervasive developmental disorder not otherwise specified; (d) DSM-IV (APA, 1994); (e) DSM-IV-TR (APA, 2000) uses the pervasive developmental disorders of autistic disorder, Asperger disorder, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, and Tourette’s syndrome; (f) DSM-5 (APA, 2001) uses Autism spectrum disorder; and (g) DSM-5-V-R (APA, 2013) uses autism spectrum disorder and social communication
disorder, where autism was ultimately separated from schizophrenia, becoming its own diagnosis. However, autism and schizophrenia remained inextricably linked in many researchers’ minds until the 1960s (Cook & Willmerdinger, 2015). Cook and Willmerdinger indicated that it was only in the 1960s when the medical professionals truly began to separate the two diagnoses.

**Treatment options for autism.** While this study looked at the nonmedical treatment options for autism as it relates to the learning environment, other research has documented some alternative treatment options available to families that include complimentary alternative treatments, dietary treatments, and vitamin treatments (Shore, 2008; Smith & Eikeseth, 2011; Smith, Ellenberg, Bell, & Rubin, 2008). In addition, this section also documents the various nonmedical treatment options available to families that are used in educational environments for children with autism, which is an integral section of this study (Greenspan & Lieberman, 1980; Lovaas, 1987; Schopler, 1977).

This section details the studies of early intensive treatment and language development models. Smith and Eikeseth (2011) defined early intensive behavioral treatment models as a method of treatment for children with autism. The method focuses on offering behavioral support to children to maximize their potential as well as it addresses unacceptable behaviors. The treatment model includes language and communication, social skills and play, pre-academic skills, and daily living activities. In addition, the models use partnerships between teams of therapists and family members to increase learning in children, and support parents as interventionists, which is a concept supported by the Individuals with Disabilities Education Act (IDEA) established in 1975.
and reenacted in 2001. Moreover, the research of Smith et al. (2008) indicates a vast number of invalidated treatments are marketed to families.

According to Shore (2008), treatment options offered to parents are primarily biomedical in nature. His research sought to exam educationally based measures for children with autism rather than biomedical strategies. Biomedical treatments are defined as treatment service provisions that have medicinal underpinnings. Biomedical treatments in autism include vitamin supplements, chelation diets, and immune-system-related treatments. According to Shore’s (2008), Whiteley et al. (2010), and TRISPSCHY (2010) biomedical interventions are medical approaches to treat the underlying issues of autism in the body. It is a term used to describe the treatment of autism from a medical perspective. However, this is not the basis of this study, which is nonmedical treatment options in the learning environment.

Physicians manage biomedical treatments and individualize treatments to target a specific ailment (Levy et al., 2010). This might include vitamin supplements, as some parents believe that their child with ASD lacks enough vitamins or minerals in their bodies, which often leads them to put their child on a probiotic diet (Shore, 2008). A probiotic diet removes elements, such as gluten and casein, from a child’s diet by removing proteins.

The research of Shore (2008) examined five nonmedical treatment approaches that are widely researched in the field of autism. The research was conducted from interviews and written surveys. There were six theorists who were familiar with the historical roots of each methodology. The research was conducted via face-to-face interviews at various locations to identify the unique elements of each approach. The
purpose of Shore’s study was to compare each of the educationally based interventions in order to determine how each of these methods assist in the development of children’s communication skills, as well as the effectiveness of each strategy.

Shore’s (2008) research identified the following educational approaches to treatment: (a) applied behavioral analysis (Lovaas, 1987), which is a scientifically based behavioral approach that supports developing children’s adaptive and daily living skills by breaking tasks down for easier processing; (b) daily life therapies (Kitahara & Peacock, 2008), which is a mix of related services, diet restrictions, and behavioral support programs; (c) relationship developmental interaction (Gutstein, 2000), which is an intervention that supports an interactive approach to supporting children; (d) developmental, individual-difference, relationship-based model (DIR) (Wieder & Greenspan, 2005), which is an approach that promotes a hands-on interactive approach to supporting children in their natural environment; and (f) the Miller method (Miller, 2007), which relies upon a cognitive-developmental approach and incorporates a developing capacity for using language. The Miller method uses the child’s behavioral symptoms and transforms these symptoms, even if they do not seem to serve any purpose, into functional behaviors as opposed to focusing on preventing them.

The Miller method (2007) uses a few approaches to restoring typical developmental behaviors. The first approach involves altering the child’s unusual behaviors, such as lining things up to creating more functional behaviors, as well as increasing a child’s reaction to stimuli. The other is the introduction of developmentally appropriate activities involving objects and people. Another objective of the Miller approach is to teach specialists and parents how to guide the children toward reading,
writing, number concepts, symbolic play, and meaningful inclusion within typical classrooms (Shore, 2008). Miller’s (2007) study results determined that there is a need for: treatment-based research for developing and maintaining best practices, diversifying practices to meet the needs of people on the autism spectrum, and supporting a wide range of approaches to treat autism spectrum disorders.

Another treatment option, known as pivotal response training (PRT), is an interactive model and a nonmedical treatment option identified through the research of Koegel and Schreibman (1977) and Lovaas, Koegel, and Schreibman (1979). The principles of PRT were developed incorporating operant conditioning theory by Skinner (1957) and applied behavior analysis by Lovaas (1987). Operant conditioning focuses on how behavior is reinforced through positive stimulus (Skinner, 1957). The objective of PRT is to assist children with ASD to learn by building their language skills within a social context through the process of interactions. The Koegel and Schreibman (1977) and Lovaas et al. (1979) research focused on the problem of perceived lack of motivation in children diagnosed with autism, relating to task and treatment. The role of motivation relating to children living with autism, according to Koegel, Koegel, and Smith (1997) is important because children require motivation, which is commonly known as a prompt, to complete a task. According to their research, the lack of motivation in a child with autism may serve as an obstacle to his or her learning. This becomes evident when children with ASD attempt to complete learning tasks. Koegel and Schreibman (1977) and Lovaas et al. (1979) wanted to investigate the influence of correct versus incorrect task completion on children’s motivation.
The participants of the Koegel and Schreibman (1977) study were three children with autism, ages 6, 11, and 12 years. The findings of the study demonstrate that as a child answers a question incorrectly, their motivation decreases. Thus, the study recommended that designing treatment procedures to encourage the children to keep responding until they completed the tasks correctly helped to increase their motivation to respond to those tasks. The implications of these results determined that children with autism who receive fewer or inconsistent rewards, for attempting to respond may have decreased motivation for optimum learning outcomes, and treatment procedures designed to keep the children responding until they completed a task correctly may result in reinforcement for the child to persevere in completing learning tasks and thereby increase the children’s motivation to respond to those tasks and other future tasks.

According to Sperry and Neitzel (2011), another treatment approach, which is known as peer-mediated instruction, is an approach that supports children with autism by establishing a team to work with children with autism. It is an empirically based model. The methodology pairs typically developing children with children diagnosed with autism. The purpose of the approach is to increase socialization and pro-social learning skills of children with autism through interactions, engagement, and participation in activities, together with their typically developing peers. Moreover, peer-mediated instruction teaches children with autism new behaviors. Peer-mediated theory was developed from Bandura and Huston (1961) concept of social learning theory and Skinner’s (1938) ideology of behaviorism. Initially known as social learning theory, Bandura and Huston (1961) renamed it cognitive learning theory. Bandura’s cognitive
learning theory demonstrates how young children learn behaviors and aggressive tendencies.

Cognitive learning theory is based on the tenets of Skinner’s (1938) behaviorism theory (Daversa, 2001). It has three principles: (a) behavioral factors, (b) environmental factors, and (c) personal factors. The three elements are intertwined with one another. The Bandura and Huston (1961) research study of children’s aggression was heavily influenced by Skinner’s (1938) behaviorism and his concept of cognitive learning theory (Bandura & Huston, 1961). Behaviorism focuses on one’s reaction to his or her environment. The theory of behaviorism is influenced by an individual’s understanding of his or her surroundings (Malott, 2014). An individual’s behavior is based upon observable measures and learning (Hart, Scholar, Kristonis, & Alumnus, 2006; Sperry & Neitzel, 2011).

As documented by Sperry and Neitzel (2011), Bandura, Ross, and Ross (1963) conducted an experiment at Stanford University Nursery School, which included 72 children. The purpose of the study was to identify if aggressive tendencies in young children is a learned behavior through observations and interactions. Another purpose of the study was to determine if children exposed to aggressive behavior would imitate that behavior. The participants were 36 boys and 36 girls. The age range of the children were 42 to 71 months. The median age for the children was 52 months. There were three adults, a male and two females, that participated in the study. They were all familiar with the children and one female researcher conducted the study with the 72 children and the male and female researchers served as role models.
The Bandura et al. (1963) randomly assigned the children to one of the eight experimental groups. Each experimental group had six participants. There was one control group with 24 children. The groups were then divided into subgroups based on gender. The participants were randomly assigned to one of three groups. With the three groups were categorized so that one group viewed aggressive acts, one group viewed non-aggressive acts, and one group viewed no acts. The researchers used an inflatable toy doll, called the Bobo doll. In group number one, the children viewed adults that beat, kick, pummeled, and behaved violently toward the Bobo doll for 10 minutes. The second group viewed an adult playing with toys and ignoring the doll for 10 minutes. Once the adult left the room, each child’s behavior was observed through a one-way mirror. The study involved three phases: (a) the students watched a video of a man or woman (experimenter) behaving aggressively toward the Bobo Doll; (b) the children were placed in a room with toys they could not play with, which was to done to agitate the children; and (c) last, the children were led to a room assembled with toys they could play with.

The Bandura et al. (1963) space study results surmised that: (a) children exposed to aggression exhibit aggression, (b) boys behave more aggressively than girls and demonstrate more violence if the model is male, (c) girls demonstrate more physical aggression toward a male model than a female model, and (d) girls exhibited more verbal aggression toward female models. Moreover, the results of the experiment indicate that 88% of the children demonstrated aggressive behavior. A follow-up experiment completed by Bandura, 8 months later in 1963 but reported in 1965, yielded similar results with 40% of the children replicating violent tendencies. Bandura’s experiment
highlighted social learning theory concepts, which purport that behavior and personality traits can be learned through interactions with one’s environment (Bandura, 1965).

From this experiment, Bandura and Adams (1977) developed a four-mediational process. The foundation of this design is that behavior comes after a stimulus and prior to a response. The four approaches used in this design were: attention, retention, reproduction, and motivation. Attention implies a person cannot learn attention unless he or she is aware of his or her surroundings. Retention signifies a person must be able to recognize behavior, as well as recall it later. Reproduction includes being able to recreate an act. Motivation involves providing encouraging words or actions. For children with autism, Bandura and Adams’s (1977) study is significant. His study demonstrates that children with autism can learn new behaviors through observation, modeling, and prompting (Bushwick, 2001).

Regarding differentiated learning, the research of Gray and Garand (1993) documented the use of social stories as a strategy with children diagnosed with autism to answer who, what, when, where, and why questions. These are known as WH questions. These questions are used as part of differentiated learning instruction that was created to elicit communication and socialization among children with autism. The model helps children with autism acquire new language skills, as well as building self-awareness and some better ways to communicate. Social stories are stories created by the children, teachers, or behavior interventionists. They are developed through the environment to personalize language based what a child is directly involved in. It is a strategy used with peer mediators with appropriate social skills (Gray & Garand, 1993). The model uses
typically developing peers who are willing to participate. The children must be capable of implementing the goals established by the interventionist.

In continuing to review treatment options for autism, the legislation of Individuals with Disabilities Educational Act (IDEA, 1975) advised parents to work proactively as advocates in the educational planning for their children. The act stipulates that parents have the right participate in their children’s IEPs. The IEP determines a child’s strengths and weaknesses. The plan sets measurable goals for children and specifies the activities and methods needed to accomplish said goals. Parents, as interventionists and partners in their children’s learning, is a behavioral intervention model created by Schopler and Reichler (1971) and further supported by the work of Lovaas (1987).

In an effort to support parents seeking interventions that were more inclusive of their roles as parents, and in an effort to support diverse means of teaching and learning among children with autism that included parent support and interaction, the Treatment and Education of Autism and Communication and Related Handicapped Children (TEACCH) program was developed by Schopler and Reichler (1971). The program began as a pilot. The core principles of this model serve to teach, expand, appreciate, and collaborate for increased learning on the part of children and families (Schopler & Reichler, 1971). TEACCH is a parent-driven approach, meaning parents serve as interventionists and co-therapists in training and the implementation of their children’s education. According to Schopler and Reichler (1971), TEACCH was derived from the core principles of: (a) teaching, (b) expanding, (c) appreciating, (d) collaborating, (e) cooperating, and (f) using holistic learning approaches.
The acronym, TEACCH, which is important to the approach, encompasses the core values of the model. The first core value, teaching, involves sharing knowledge and learning the skills needed to support the autism community. The second core value, expanding, includes broadening learning through evidence-based or empirical research and continued inquiry. An inquiry-based method of teaching involves hands-on learning for children. It involves children investigating what they know through materials and asking open-ended questions. These questions lead to extensions of learning and they are not just yes or no answers to questions. During this process, a child can explain what he or she knows. Children construct their knowledge from their environment. It is a concept developed by Vygotsky (1972). The third core value, appreciating, includes the importance of valuing those within the autism community, specifically their skill sets, which include both children and parents. The fourth core value, collaborating, as well as cooperating, is characterized as working together with families and the community, collectively. The last principle, holistic learning, supports children’s development across sectors, this specifies that a child’s learning occurs from all aspects of their environment (Schopler et al., 1982).

Schopler’s (1966) work in connection with autism began in 1966 as part of his doctoral dissertation. His dissertation study results indicate that individuals with autism receptively process information visually better than verbally. His research successfully determined autism was not a disorder of emotions but neurological in nature. Schopler was a clinical psychologist who was a graduate student under the tutelage of Bettelheim (1959). During this time Schopler (1966) began to question the reasons identified by Bettelheim for the disorder (Finn, 1997).
Schopler (1966) was not in agreement with the refrigerator mother concept. This concept indicates that a mother’s indifference toward her child is the reason for the child withdrawing from the world (Bettelheim, 1959). Schopler’s 1966 research set out to not only dispute this concept, but also to create a program that encouraged parent involvement in their children’s learning. The parent-devised curriculum Schopler is widely known for is the TEACCH approach (Schopler et al., 1982). As mentioned earlier, due to the limitations in research, many children with autism were classified as schizophrenic prior to the advancements in autism etiology (Feinstein, 2011). During a child research project in 1966, Schopler, along with his colleague Reichler (1971), began to develop the TEACCH approach. The TEACCH approach relies upon parent participation and intensive behavioural therapeutic approaches as treatment options. The program design began as an experimental approach to support parents. The parents embraced the approach. They later petitioned state of North Carolina for increased funding. The concept was launched and has been in existence since their petition for funding. Grounded in empirical research, TEACCH is one of the few programs that emphasizes the effectiveness of parents as interventionist in their children’s care and treatment (Schopler et al., 1982).

Schopler’s 1966 research provided parents with a meaningful way to become involved as well as to understand the needs of their children and to continue to support their children’s development. The TEACCH model is a highly regarded model by professionals in psychiatry. It has been included in the treatment volume of the Diagnostic and Statistical Manual of Mental Disorders (Mesibov, 2006). Schopler’s (1966) research is significant as it took place during a time when parents were unfairly
blamed for their children’s disorder, and autism was viewed as a mental illness rather than a neurological disorder.

Comparable to the work of Schopler and Reichler (1971), Lovaas (1987) sought out strategies to further understand the causes, diagnosis, and treatment options available for children during a time when there appeared to be limited options for families. As cited in Daversa (2001), Lovaas (1987) is known as the creator of ABA. Lovaas, along with a team of his colleagues in Lovaas and Leaf (1981) and Smith et al. (1993) began a series of research studies during a time when many where convinced that autism was untreatable and confinement to long-term care facilities was the only viable treatment option. Lovaas viewed things differently (Feinstein, 2011).

Applied behavioral analysis (Lovaas, 1987) is an early intensive behavioral treatment approach entrenched in the tenets of verbal analysis and behaviorism. ABA is an empirically based learning technique that teaches children on the autism spectrum adaptive living skills, prosocial behavior, and cognitive skills. This is accomplished by repetitiously reinforcing concepts and breaking larger principles down for comprehension. The term, *Lovaas method* or *ABA* are used interchangeably. To implement the Lovaas method, the child receives ABA training by a behavioral therapist. This method also supports parent involvement through training. Parent training in behavioral treatment models works to ensure the skills, implemented at school or home with a behavioral therapist or teacher, are reinforced in the home setting. This is accomplished when a parent is involved in the treatment process. According to Lovaas (1987) and Schopler and Reichler (1971), this is the best way to ensure any behavioral
intensive program is effective. Moreover, they stated that this creates a home and school connection. It also empowers parents as the teachers of their children.

Motivated to improve outcomes for children with autism, beginning in the late 1960s and early 1970s, Lovaas worked with several colleagues in Freitas, Nelson, and Whalen (1967); Lovaas, Koegel, Simmons, and Long (1973); and Lovaas, Schreibman, Koegel, and Rehm (1971). These efforts, by a group of committed researchers to improve outcomes for children living with a largely unknown disorder, began the work of enhancing behavioral treatment approaches for children with autism and the research of today (Feinstein, 2011). The objective of the research was to increase the cognitive, adaptive, and functional learning of children with autism.

The researcher has outlined that autism continues to significantly impact the lives of children, parents, and pediatricians in the understanding of the disorder. Applied behavioral analysis, an early intensive behavioral treatment method that was developed from the breakthrough research of Lovaas (1987) was to address the cognitive, social, linguistic, and adaptive skills of children with autism. Prior to Lovaas’s extensive research, earlier research had determined that the quality of life and needs of individuals with autism spectrum disorder were largely marginalized. The research further indicated that due to limited resources and the complexity of the disorder, children with autism were often relegated to mental health institutions with uncertain futures. Lovaas’s research in 1987 of early intensive behavioral treatment methods paved the way for treatment that supported parent involvement and treatment interventions at home as well as in community settings.
The development of Lovaas’s research in 1987 not only supported his earlier research from the ’60s (Lovaas, 1981), it also served as the catalyst for the creation of the Young Autism Program through the National Institution of Mental Health. This project led to multiple studies that further validated the significance of ABA but also replicated Lovaas’s work. The narrative below summarizes the original research of Lovaas from 1987 as well as his collaborative work with colleagues and the subsequent studies that have supported early intensive behavioral therapy otherwise known as ABA.

First, in 1987, Lovaas’s study highlighted 38 individuals with autism. The study consisted of more boys than girls, a recurring trend in today’s research (Autism Speaks, 2013). Lovaas’s approach supported the implementation of ABA at home, in school, and the community. Lovaas encouraged parent involvement in the treatment sessions. He believed it was critical to its success. Lovaas’s earlier research implied that long-term gains might occur if the participants were younger children. With that said, he chose to work with children who were between the ages of 3- and 4-years old. For his study in 1987, Lovaas chose two groups for his study, an experimental and a control group. Each group comprised 19 children. The children’s IQs were between 46 and 53.

Lovaas’s (1987) study and follow-up research surmised that incorporating intensive behavioral therapy could provide an increased quality of life in children with autism as well as eradicate inappropriate behaviors. He also set out to determine if implementing intensive behavioral therapy would eliminate cognitive, social, and behavioral concerns.

Lovaas’s (1987) research model was supported by research assistants who were undergraduate students. The research assistants implemented the behavioral therapies
with the children and recorded the data. These students were supervised by graduate students and a clinical psychologist. The undergraduate and supervising graduate students were trained in the Lovaas method. The purpose of the recorded data collection was to track the children’s developmental progress. The data was recorded to identify patterns in the children’s behavior, their development, and their responses to interventions. It is important to note that some of Lovaas’s initial treatment included aversive methods. Aversive methods are classified as punishment or reinforces that extinguish unacceptable behaviors. This occurred during Lovaas’s (1987) initial work with the experimental group. In some instances, Lovaas utilized slapping and spanking as corrective measures when participants in the experimental group demonstrated aggressive, non-compliant, unruly, and self-injurious behaviors that interfered with the implementation of treatment measures. These measures were ultimately removed from the treatment regimens early on in the research (Buckman, 1995).

As specified earlier, the study design consisted of two groups, an experimental group and a control group. An experimental group is a group that receives the variable being tested (Patton, 1990). The variable tested in the Lovaas’s (1987) study was the effectiveness of applied behavioral analysis theory. A control group is the group that does not receive the treatment (Patton). Due to parental concerns, the children were randomly assigned to these groups.

The control group consisted of 16 boys and three girls. In addition to only receiving 10 hours of early intensive behavioral therapy (ABA), the participants in the control group received special education instruction, speech, and occupational services. These services support the cognitive development of children with autism. Speech
therapy assisted the children with their communication skills, and occupational therapy assist the children with their adaptive living skills. The participants in both groups received the treatment interventions for 2 years. According to the Lovaas (1987) study, carryover occurs when a behavioral intervention is replicated in the child’s natural environment, the home, as well as in the school setting. Children with autism have difficulty carrying over skills from one interaction or activity. The goal of an interventionist to is support the children with autism in this area (Paul, 2008).

The children in the experimental group received 40 hours of early intensive behavioral therapy (ABA). The experimental group included 11 boys and eight girls. The children from each group were independently evaluated for autism and had similar IQ ranges (53/46). As a condition of the research and prior to the implementation of the study, a consultant, independent from the research, diagnosed the children with autism. In addition to their diagnosis of autism, all 38 children met the threshold for the classification of intellectually delayed. The parents had similar socioeconomic backgrounds. Upon the completion of the study, all of the children were evaluated.

The results of the study determined that the group who received the 40 hours of early intensive behavioral therapy had considerable gains in cognitive, behavioral, and social functions. They retained those gains over a significant period of time. The results of the research indicate that there were more than 90% gains for the children in the experimental group. The children in the control group that received the lesser amount of ABA were placed in special education classes, and one was placed in a self-contained classroom. A self-contained classroom is an educational classification with children who have similar intellectual functioning.
Further, Lovaas’s (1987) research indicated of the 19 participants randomly assigned to the experimental group, nine children completed the first grade without any additional support. In addition, there were gains in the group’s IQ levels, a total of 30 points. Of the 19 participants, eight of the children in the group required continued support to complete the first grade in a special education setting. A special education setting is a setting for children experiencing developmental delays. The last two children in this group were placed in a self-contained classroom. A self-contained classroom is a regimented and controlled classroom environment with a trained teacher in the field of special education where the children with special needs are of similar developmental functions.

The results for the children in the control group, who received a limited number of early intensive therapy hours along with other supports, show that 11 children were placed in self-contained classrooms. Of this group, only one child successfully completed the first grade without support. Due to the positive results of his research, Lovaas (1987) was able to advance his earlier research by creating the Young Autism Program through the National Institution of Mental Health. This led to multiple studies that further validated the significance of ABA but also replicated Lovaas’s work. These research studies are outlined below.

Related to early intensive behavioral intervention programs, the follow-up study by Smith et al. (1993), replicating the original work of Lovaas (1987) detailed further promising results related to the application of behavioral programming. Utilizing the same criteria set forth in the study by Lovaas’s (1987) original study, these researchers reaffirmed the effectiveness of the behavioral interventions. Their study tracked the
progress of the 19 children who were randomly assigned to the initial experimental group in Lovaas’s (1987) initial research. Using a similar early intensive behavioral intervention program, the researchers noted that of this group of 19, the experimental group maintained their developmental progress over the control group. Smith et al. (1993) also indicated, at the time of their research, there was a mean age of 11, and nine of the experimental subjects were developmentally on par with their typically developing peers. Last, the researchers’ study results concluded that close to 50% of the children maintained their skills.

In 1999, Sallows and Graupner recruited participants from community-based organizations and special education support programs serving children with autism. It is important to note that these researchers ran a series of studies beginning in 1999. Sallows and Graupner completed a research study that lasted 3 years and there was subsequent follow-up study published in 2005. The researchers planned to conduct research after this timeline, however, they were unable to execute it. The results of their research in 1999 and 2005 is outlined in this section. For their research in 1999, Sallows and Graupner set the following criteria to gather participants: (a) the children had to be within 24 and 42 months, (b) their mental development range of 50 on the Bayley (1955) Scale, (c) their neurological testing had to be within normal range, and (d) to ensure the reliability of the diagnosis, the participants had to have received a diagnosis of autism from a child psychiatrist. First, the researchers used the Bayley Scale is a developmental testing measure for children with special needs. The scale measures cognitive, social, motor, and adaptive skills development in children from birth to 42 months.
Second, the researchers used a mix of testing and assessment instruments, they were: Vineland scale, the Merrill-Palmer scale of mental test, the Reynell developmental scale, and the Early Learning Measure. These assessments measure the cognitive, social, emotional, language skills and developmental ranges of young children with autism.

Last, the researchers follow-up instruments included: (a) the Wechsler Preschool and Primary Scale of Intelligence-Revised, (b) the Wechsler Intelligence Scale for Children–WISC-III, (c) the Leiter-R; the Clinical Evaluation of Language Fundamentals (3rd ed.), (d) the Woodcock Johnson III Tests of Achievement, (e) the Personality Inventory for Children, and (f) the Child Behavior Checklist. Additional assessment measures were direct observations, reports by other professionals, and parent interviews. These assessments were critical to obtaining an accurate diagnosis of the children’s developmental concerns.

Another important study conducted in 2000 highlights the Smith, Groen, and Wynn (2000). Their work was conducted through the Young Autism Project. It occurred between 1989 and 1992. The criteria for the participants in the study was: (a) they had to be between the ages of 18 and 42 months, (2) the IQs had to be in the range of 35 to 75, and (3) they had to live within an hour’s drive of University of California Los Angeles Young Autism Project. The Smith et al. (2000) study included 28 participants and they utilized a mixed methodology. The purpose of the researchers’ study was to identify the most effective form of treatment, parent training, or early intensive behavioral therapy. The participants were a diverse group in terms of gender, racial composite, demographics, gender, and economic status. Of the 28 participants, 14 had a diagnosis of autism. The other 14 participants had a diagnosis of pervasive developmental disorder,
which equates to autism-like features, but without a confirmed diagnosis. The first group consisted of 12 boy and two girls. The second group contained 11 boys and three girls. All of the children received an average of 24 hours of early intensive treatment for 1 year with the reduction in treatment over 1 to 2 years. The two groups, randomly assigned, received either intensive behavioral treatment or parent training. Smith et al. (2000) noted that both groups were developmentally similar at the onset of the program, however, after treatment, the results of the study indicate that the group that received the early intensive behavioral treatment developmentally surpassed the group that received the parent training.

The follow-up research of Sallows and Graupner in 2005, utilized a quantitative methodology and measured the effectiveness of early intensive behavioral treatment. As indicated above, Sallows and Graupner’s (1999) research was conducted to further the existing knowledge of early intensive behavioral treatments and the validity of Lovaas’s (1987) research, and their follow-up research had the same objective. Their study replication of Lovaas’s research was carried out with some modifications. These modifications were the sample size, 24 participants instead of 38 participants in Lovaas’s study. Sallows and Graupner (1999) also expanded their participant population to include participants from community-based programs. In addition, it is important to note that Sallow and Graupner’s (1999) research did not include any punitive or aversive measures. As indicated earlier, some aversives were used for a time in Lovaas’s (1987) original work with the experiment group. Aversives are forms of punishment used in ABA to extinguish undesirable behavior. To replicate Lovaas’s (1987) original research design, Sallows and Graupner (1999) worked with the National Institute of Mental
Health. The NIMH reviewed and approved the research design. Lovaas’s (1987) initial work was published through the National Institute of Mental Health. The National Institute of Mental Health is a project that began in the early 1970s to support such research.

For this body of research, Sallows and Graupner (1999) worked with the Wisconsin Early Autism Project (WEAP) (2008). Similar to the Autism project which began in the ’70s in UCLA with the research of Lovaas and Colleagues (Leaf & McEachin, 2016), this project was to support researchers devoted to advancements in autism. The WEAP program has locations in Wisconsin, Malaysia, and Vancouver. The WEAP programs were also developed from funding provided by the National Institute of Mental Health.

Sallows and Graupner (2005) used a mixed-methods design with participants diagnosed with autism. The children received the same UCLA treatment model used by Lovaas (1987). Staff at UCLA closely monitored the project. The researchers conducted their research design with a community-based organization population in Wisconsin. A community-based organization is a private or public organization with the sole purpose of serving its community. The purpose of the Sallows and Graupner’s (2005) study was to determine if a community-based organization program design, serving similar populations (children with autism), could replicate the research the research results of the Lovaas (1987) study at UCLA, using a similar supervision and support model. As mentioned previously, the Lovaas model included undergraduate students, supervising graduate students, and a psychologist. Sallows and Graupner’s (2005) research was supported by fourth-year graduate students from the University of Wisconsin. The
researchers noted there was less supervision of the students who implemented the ABA principles. However, they were equally trained. The instruments used in the data collection were a pretreatment IQ test, intelligence test, assessment test, and parent personality test. Furthermore, their research indicates that replicability, uniform assessment, and random assignment were used. A UCLA statistician randomly assigned the children. The study used multiple regression analysis (Sallows & Graupner, 2005). Multiple regression analysis is utilized when researchers want to predict the value of multiple variables.

The research of Sallows and Graupner in 2005 detailed the results of 24 participants who were placed in three groups, and the three groups of children received 4 years of treatment. The work with three groups of children at different intervals was detailed in this study. The first group consisted of 14 children who received ABA treatment in 1998-1999. The second group, in 1999, consisted of 13 children who received relatively the same number of hours of ABA treatment per week, 38 hours, as the original Lovaas (1987) group, and the third group, in 2001, with 11 children, was a parent-directed group where the children received the same ABA treatment with the parents deciding the number of hours of treatment, but the intensity level was the same as the first group. Using parents as a supportive aspect of their interventions, the researchers encouraged the parents to attend team meetings. The purpose of the research design was once again to validate as well as replicate Lovaas’s (1987) research design as closely as possible.

Last, Sallows and Graupner’s (2005) final research and the research data included consisted of two treatment groups. Participants were randomly assigned to each group.
The participants were assigned to either the experimental group or the parent-directed treatment group. The parent-directed group allowed parents to determine the number of hours of treatment per week. Group one was a clinically assigned group that received relatively the same number of hours of ABA treatment per week, 38 hours, as the original Lovaas (1987) group. Group was a parent-directed group that received the same ABA treatment with the number of hours controlled by parents, but the intensity level was the same as the first group. Using parents as a supportive aspect of their interventions, the researchers encouraged parents to attend team meetings. The third group’s data was not analyzed and was unable to be reported in Sallows and Graupner’s summation in 2005. The researchers indicated that the average amount of treatment was 31 hours per week. Each group received this regimen of treatment for 2 years. The study indicates that for both groups, there were gains of 48%.

As indicated by the studies above, early intensive behavioral therapy is identified as an effective treatment for children with autism. Last, the Lovaas institute has outlined that since 1985, there have been more than 500 articles written related to the effectiveness of applied behavioral analysis and its measurable outcomes for children with autism.

Relationship development intervention, also known as RDI, is a parent-based model developed by Gutstein (2000), and it was intended to support children’s relationship development with their parents. It is widely marketed for home use because it can be easily incorporated into a child’s daily routine. The goal of the model is to assist parents with increasing their social and emotional communication with their children through increased interactions. An example of how a parent would use this treatment
model at home would be to encourage language through the initiation of conversation and interactions. Gutstein (2000) stated that RDI promotes healthy interactions between children and parents. Healthy interactions are defined as reciprocity in language, if possible, and children responding appropriately to a request from their parents without tantrums.

RDI repetitiously introduces relationship development involving objects and people. The model uses training as an optimum component to support parents’ increased interactions and developmental progress with their children. The purpose of RDI is to use the family as a crucial element in a child’s development. RDI consultants work with families to simplify routines, balance parent schedules, and increase the family’s quality of life. RDI focuses on family empowerment and the enhanced thinking skills of children with ASD. RDI uses the principles of ABA. Gutstein’s (2000) method included: (a) emotional referencing, (b) social coordination, (c) declarative language, (d) flexible thinking, and (e) relational information.

According to Gutstein (2000), emotional referencing is the use of emotional feedback to a child in order for the child to learn from the experiences of others. Social coordination is the ability to observe and regulate behavior. Declarative language uses language and nonverbal communication to express curiosity. Flexible thinking is the ability to adapt rapidly, change strategies, and alter plans based upon modified circumstances. Relational information processing is solving problems that have no clear right or wrong answers (Gutstein, 2000).

Another treatment approach used in educational environments with young children on the autism spectrum is the developmental-interaction, relationship-based
model or floortime, as it is commonly known (Greenspan & Lieberman, 1980). Floortime is a relationship-based model developed to support parents of children autism. Greenspan and Lieberman (1980) developed the model at George Washington University in order to understand human behavior and child development of children with special needs. Greenspan and Lieberman’s approach examined how emotions relate to child development. The conceptual framework of Greenspan and Lieberman’s (1980) work began with the analysis of Skinner’s (1957) behaviorism and Piaget’s (1962) theory.

Piaget’s (1962) theoretical framework connects the concept of learning through play and child development theory. Piaget’s theory is a play-based methodology that focuses on four stages of development in young children: (a) the preoperational stage, (b) the concrete operational stage, (c) sensorimotor stage, and (d) formal operational stage. Greenspan began his research in 1979, where he was studying children with autism and developmental delays through an integration of the psychoanalytic approaches to understanding the behavior special needs children.

Greenspan used Piaget’s four developmental principles in a book he wrote in 1979, entitled, *Intelligence and Adaptation: An Integration of Psychoanalytic and Piagetian Developmental Psychology*. In this book, he outlined the important role emotional development plays in the cognitive needs of young children. Greenspan’s work evolved overtime to continually explain the importance of attachment in young children and the complexity of human emotional relationships (Daims, 2005). This became the basis of Greenspan’s (1979) later work of creating his relationship-based model. Greenspan’s (1979) research on intelligence and adaptation explored the relationship between emotional drive and children’s affect. Affect is the way a person responds to
situations. This led to his later work (Greenspan, 1987) of the development of floortime (Dionne & Martin, 2011). Greenspan’s (1987) model comingled his advanced understanding to develop his therapeutic play-based model. This was in support of children with special needs (Dionne & Martin, 2011). The model is universally called developmental interactive relationship, which is based on an approach called floortime (Greenspan, 1987). Later, he enhanced the approach during his collaborative work with Wieder (Greenspan & Wieder, 1997; Wieder & Greenspan, 2005).

According to Greenspan (1987), floortime provides support for children with special needs using practices based on developmentally appropriate practices with young children. The term developmentally appropriate practice (DAP) is the research of the Bredekamp (1997), supported by the National Association for the Education of Young Children (NAEYC). This is a research-based organization associated and known nationally as the benchmark for all best practices related to young children. DAP is a research-focused practice that seeks to create models for developmentally accepted practices with young children (Bredekamp, 1997).

Greenspan and Wieder’s (1997) research identified the symptomatic behavioral patterns of children diagnosed with ASD. The purpose of their chart reviews of 200 children from the Washington, D.C. area was to: (a) identify patterns of behavior attributed to autism, (b) examine sensory processing difficulties in children diagnosed with the disorder, (c) describe early development, and (d) document children’s response to floortime. The charts also included the developmental history and behavioral patterns of the children. The purpose of the chart reviews was to identify patterns from the clinical assessments the children received. The work included: diagnostic testing, developmental
patterns, parents’ interviews, videotaped descriptions of behavior, and family history. The chart review model also revealed the early developmental stages of the children, whether they presented with symptoms of autism, and the recommended treatment interventions. The data collection occurred over various intervals for a period of up to 8 years for some children.

Greenspan and Wieder (1997) used the Childhood Autism Rating Scale (CARS) in order to collect the data. The Childhood Autism Rating scale is a 15-point developmental behavioral rating scale created by Schopler et al. (1980), co-founders of the TEACCH model, in an effort to create a developmental framework for diagnosing children with autism. The CARS scores behavior from moderate to severe. The researchers tested the participants using the Functional Emotional Assessment Scale. This is a developmental scale used to test social, cognitive, emotional, and language development. For children who did well on the testing, Greenspan and Wieder (1997) also implemented the Vineland Adaptive Behavior Scale (Sparrow, Balla, & Cicchetti, 1984). The testing of children occurred during the initial research and during follow-up visits. Follow-up visits occurred in intervals, and of the purpose of the data collection was to chart the level of interventions received, their effectiveness overtime, and the level of developmental testing for the disorder.

The research of Bettelheim (1959), Greenspan and Wieder (1997), Kanner (1944), and others state that children with ASD are unable to connect socially and emotionally with their age-related peers. The researchers also stated that children with autism have difficulty relating to others. The researchers stated that implementing one-on-one interactions, interactive play, and positive reinforcement provides the required stimulus to
support changes in these social and emotional deficits. Greenspan and Wieder’s (1997) study results refute the notion that children with autism are unable to relate to others. Their findings indicate that given the correct stimulus and proper reinforcement, children with autism can connect emotionally and socially with others. The study demonstrated that when caregivers follow the child’s lead during play-based initiatives, this can lead to favorable outcomes (Wieder & Greenspan, 2005). Moreover, their research revealed that the children who participated in relationship-based intervention for 2 years demonstrated a 58% improvement in overall behavior.

The collaborative work of Greenspan and Wieder (1997) and Wieder and Greenspan (2005) validated the effectiveness of floortime (Dionne & Martin, 2011). The purpose of floortime is not that it is only a learning environment intervention, but it is also used to improve a parent and child’s communication skills with increased social interactions through play. The approach involves parents sitting on the floor and following their child’s lead during interactive play (Dionne & Martin, 2011).

Engaging children’s interest leads to increased communication and extended play (Dionne & Martin, 2011). The Dionne and Martin recommended that parents implement floortime in 20- to 30-minute intervals of play. To increase its effectiveness, the researchers recommended parents implement floortime 6 to 10 times a day in order to help parents teach their children, who exhibit maladaptive behaviors such as outburst or tantrums, to self-regulate and to respond appropriately in social settings. Floortime also helps increase a child’s ability to engage with others (Dionne & Martin, 2011).

Another goal of floortime is to use a child’s environment as a way to teach him or her to respond naturally. The Greenspan and Wieder (1997) and Wieder and Greenspan
(2005) approach relied heavily upon social-emotional connections, attention to developmental milestones, engagement with others, self-regulation, and reciprocal communications. They determined that an appropriate intervention program for children diagnosed with autistic spectrum disorder creates children capable of empathy, affective reciprocity, creative thinking, and healthy peer relationships. Greenspan and Wieder (1997) and Wieder and Greenspan (2005) further posited that early intensive treatment intervention approaches that focus on individual differences, developmental levels, and affective interaction can support the developmental needs of children with ASD.

Moreover, Wieder and Greenspan (2005) revealed that floortime has six developmental principles: (a) self-regulation, (b) intimacy, (c) two-way communication, (d) complex communication, (e) emotional ideas, and (f) emotional thinking. The goal of self-regulation is to assist children in their ability to control or readjust their behavior, on their own, in social situations. As noted in the Wieder and Greenspan research, and further supported by the research of Feinstein (2011), children with autism have difficulty with social interactions, and self-regulation is key to peer interactions. Intimacy or special love for others means that children are able to reciprocate an appropriate emotional response to social interactions such as empathy. Complex communication means a child’s ability to process an interaction and thereby communicate based upon the interaction. Emotional ideas and emotional thinking means a child is able to develop emotions and think about those emotions in different ways.

Similar to the research of Greenspan and Wieder (1997), Feinstein’s (2011) research highlighted the importance of social interactions and prosocial behaviors of children with autism. According to Feinstein, children with autism use scripted language
and exhibit robotic responses. Scripted language is a tool used with children on the autism spectrum in an attempt to engage them in responding appropriately to a social situation. Greenspan’s and Wieder’s (1997) approach attempted to assist children with responding naturally by providing a developmental approach environment that is child centered on the children and promotes the children’s interest.

**Families and autism.** Moore (2013) outlined the importance of a familial approach to meeting the needs of psychologically fragile, autistic children. Moore’s research identified the importance of training for parents and building clinical relationships in support of children diagnosed with autism. The researcher noted that the work of pediatricians is essential in supporting families. Derived from Bronfenbrenner’s (1979) theoretical approach, Moore’s research details the barriers, challenges, and triumphs from a family-focused perspective. Furthermore, Moore (2013) asserted that family-focused intervention is a philosophy that consistently embeds family members into the process rather than having their only connection consist of isolated therapy sessions. His research endorsed training for parents and the need to build clinical relationships in support of children diagnosed with autism.

Moore’s (2013) study included participants from 45 parts of the US, excluding Alaska, Delaware, Nevada, North Dakota, or South Dakota. The states of Massachusetts and Michigan had the highest number of participants. There were 466 families who participated in an online survey. The data were collected over 4 months and included 13 demographic questions about race, ethnicity, languages spoken at home, income, and level of education. The instrument used in the data collection was an online survey using data bases from the University of Rhode Island and Brown University to gather the
experiences of parents of children with autism. The information was related to parent and child ethnicity, birth year of the child, types of professionals that diagnosed the child, demographics, income levels, and state residence of the participants. The data were analyzed using multivariate analysis, MANOVA, and a Statistical Package Social Science (SPSS) program. Multivariate analysis is a form of qualitative research that involves more than one variable, and it is used to determine more than one statistical outcome variable at a time; and SPSS, which was developed in 1968, is a software package that is used to analyze statistical data. Convenience sampling, according to Creswell (2014), is using a group of participants that is readily available, and a snow ball approach was used to recruit the participants based upon whom they knew at the time of the study.

Moore’s (2013) research applied Bronfenbrenner’s (1979) methodology to gain an in-depth understanding of the children’s disorder and the impact it had on their families. This information was obtained by understanding the role of the family, culture, and social interactions that impacted the children’s development. This theoretical framework was used to develop a scale with the premise of the families as the experts. The scale, known as the Families’ Experiences with Autism Spectrum Disorders (FEASD) Scale, was created by Moore (2013) and focused on a holistic approach that identified the various ways the disorder affected the entire family dynamic. He also wanted to validate the FEASD Scale, which views three factors: family support, school quality, and health care quality. According to Moore (2013), a family-guided approach is when the family serves as the experts, because the family knows best, given their comprehensive work with the child, and that is important to educational planning. Moore
(2013) wanted to assess the experiences of families impacted by autism and their experiences related to health care professionals and education.

The second purpose of Moore’s (2013) study was to assess families’ experiences with professionals in the health care, education, and community/familial settings in relationship to their child’s race/ethnicity, family socioeconomic status, education, and specialty of the doctor who diagnosed the child with ASD. This included the doctor’s familiarity with the Childhood Autism Rating Scale, as noted previously as a developmental tool that is used to screen and assess children for a diagnosis of autism spectrum disorder. The significant results were: (a) families who reported their children were diagnosed by their pediatricians had more positive experiences than families whose children were diagnosed by a psychologist, and (b) parents with higher incomes, $100,000 or more, had a more positive experience with obtaining a timely diagnosis, which was due to parents’ ability to acquire outside resources.

The research of de Wolfe (2013) utilized an ethnographic approach with a group of parent participants from Queens, New York. The research was conducted over 18 months, and it examined how parents of children diagnosed with autism were able to navigate the educational and medical systems available to them. The parents shared their lived experiences of accessing services and their trials and tribulations as parents’ they were: (a) parents who were married at the time of the study, (b) parents who were no longer married to each other at the time of the study but married to other people, (c) divorced parents, and (d) single parents. There were 26 sets of parents in the study, and each set of parents had one child diagnosed with ASD. The children diagnosed with autism ranged in age from 4- to 12-years old. The study revealed a higher percentage of
parents with boys diagnosed with autism than girls. The racial makeup of the families included: (a) Pacific Islanders, (b) White, (c) African American, (d) Hispanic, (e) Asian, (d) Guyanese, and (e) Latino. The educational backgrounds of the parents were: (a) high school graduates, (b) trade school graduates, (c) bachelor’s degrees, (d) master’s degrees, and (e) doctoral degrees.

de Wolfe (2013) described parents’ desires to navigate the educational system in support their children. Her research detailed that parents were able to share strategies and their stories with one another about parenting a child with autism. The researcher noted that while parents felt isolated from the rest of the community, the mothers, specifically, felt they had more knowledge about autism than the fathers. Most significant in the study was the identification of the importance of a collaborative effort from other parents as well as professionals in helping to understand, cope, and learn about the disorder.

Kamei’s (2013) study applied a post-positivism construct. Post positivism theorizes that all research has error, is imperfect, and can be revised (Creswell, 2014). Kamei’s study also used emic and etic approaches to create cross-cultural comparisons to understand the context of participants’ experiences. Emic approaches capture the aspects of culture from those who are part of the culture. Etic, on the other hand, captures the aspects of culture from an outward perspective (Schaffer and Riordan, 2003). The study compared and contrasted differences and similarities across cultures. The study noted contrasting information in the US and Japan. Kamei (2013) highlighted the disparity in access to services within the United States and Japan. Parents living in Japan stated that they felt a great deal of shame and stigma related to their children’s diagnosis. Asian culture, according to Kamei’s (2013) research, revealed that a great deal of pressure is
placed on the children to care for their parents as well as to protect the honor of their cultural identification. Having a child with autism, the researcher contended, makes this difficult for a family and thereby creates a higher level of shame.

In further documenting the quantitative study by Kamei’s (2013), she detailed the perspectives of Japanese parents caring for children with autism spectrum disorder and compared results to parents living in North Carolina, in the United States. Similar to Mann’s (2012) research, Kamei’s study provided a global perspective for readers about the impact autism spectrum disorder and noted that Japanese mothers are underrepresented in the field of autism, as most studies document families living in Europe or in the Northeastern regions.

There were 96 participants in Kamei’s (2013) study, with 47 residing in North Carolina and 49 residing in Japan. The study utilized random sampling with two sampling frames. Random sampling is a procedure to select participants for the research in a way that each has an equal opportunity for selection (Creswell, 2014). The two geographical regions chosen for the study were (a) North Carolina, specifically the public schools for the research site; and (b) Osaka, Japan. They were chosen due to similarities in population size. The families were highly educated and were chosen regardless of the type of residential area or community in which they lived, as well, all socioeconomic statuses were removed from the criteria. Kamei (2013) used a mixed-methods approach and utilized a two-sample independent \( t \)-test to compare the differences between the two American and Japanese mother groups. A two-sample independent \( t \)-test determines if the mean score of two populations are equal (Creswell, 2014).
Kamei’s (2013) study provided a comparison of the impact of living in Japan and in the United States as it related to services and supports, and it noted the disparity in services available in Japan as opposed to the United States. However, of the two sets of parents surveyed in the study, both groups noted that they received little support outside of their immediate family.

As noted earlier and expanded upon here, there is a pronounced humiliation in the Asian culture for parents with a child diagnosed with autism. According to the Kamei (2013), Asian children are expected to care for their aging parents. Children with autism are unable to meet this obligation. The study also noted that children in Asian cultures are taught to control their emotions, which is a challenge for children with autism. The Asian culture perceives children with autism as a burden to society. Kamei’s (2013) research pointed out that children with disabilities are treated as a dishonor to their families, and it is seen as a punishment to the family from a higher order for something negative they may have done (Kamei, 2013). This creates increased stress for Asian families (Kamei’s, 2013). Due to the shame and stigma that is felt in Asian cultures, parents are less likely to ask for support or to seek out as many services as in the United States. In the United States, according to Kamei’s (2013) research, families of children with disabilities are more widely accepted. While there is more acceptance, Kamei noted that there is still a stigma associated with autism, and parents find social relationships with other parents more challenging when they have a child who has the disorder.

Mann’s (2013) study captured the lived experience of 13 Jamaican mothers raising a child diagnosed with ASD while living in the West Indies. Mann used interviews with open-ended questions for data collection in determining the kinds of
services available to Jamaican parents with children who have ASD. The study was conducted over several weeks. The researcher sought to gain a more global perspective of how services differed in various regions of the world. Mann’s study revealed a global perspective of autism using a qualitative, phenomenological exploratory design. In addition to gathering a global perspective, Mann’s study (2013) captured the cultural implications of a diagnosis of autism. A phenomenological approach captures the lived experiences of the participants. An exploratory design is used when there is little research on the topic, thus creating the groundwork for future research (Creswell, 2014).

According to Mann’s (2013) research, culture, as well as a timely diagnosis, played a role in the parents’ ability to access treatment.

Mann’s (2013) research detailed that there is limited research that explores the global perspective of autism, and it is limited to information related to the diagnostic process. She also asserted that in addition to limited services, parents sought out their children’s pediatricians for support, yet they were dismissed as being overly anxious parents. Several themes emerged through Mann’s interviews with mothers in Jamaica raising a child with ASD. The themes included a slightly higher cesarean-section rate and normal development, initially, among the children. Then developmental concerns surfaced and symptoms, such as lack of eye contact, occurred, providing cues to developmental issues requiring attention.

Mann’s study (2013) revealed a need for collaboration, partnerships with parents, and increased service options. She documented the need for advocacy among parents and support services for families, such as: (a) enhanced programs, (b) support from practitioners, and (c) support with obtaining an earlier diagnosis. Enhanced programs
identified by Mann (2013) are programs developed to assist children in developing their existing level of cognitive social or emotional skills. The results of the Mann (2013) study detailed the need for increased support from health care practitioners in providing services for families. The research also stated that obtaining an early diagnosis is important to creating interventions that can be planned and implemented.

Dawson (2013) conducted a qualitative research of eight families, using semi-structured interviews, that explored the ecological perspective of South African parents caring for children diagnosed with autism and living in indigenous and remote areas of that country. Dawson’s (2013) research utilized Bronfenbrenner’s (1979) theoretical framework. Her research sought to understand the perspective of parents’ experiences with service provisions and interventions. This included accessing services for their children using public and private resources. Public services were services offered to parents through public health care facilities and primarily through city, state, or governmental assistance. Private services, as outlined by Dawson’s (2013) research, are services parents are willing to pay for, and can afford to, pay. This research used a deductive thematic content analysis. According to Creswell (2014), deductive thematic content analysis is a qualitative research design that uses coding and themes to assist in the research. Using Bronfenbrenner’s (1979) approach, Dawson (2013) concentrated on the macro aspect of Bronfenbrenner’s theory, which focuses on the cultural environment in which a child lives, and the exo-level, which focuses on the settings in the system that impact a child, such a death of a family friend or individuals with which the child interacts on a regular basis.
According to Bronfenbrenner (1979), many factors influence a child’s environment, and Dawson (2013) discussed these factors as they relate to treatment or service outcomes for children with autism. Her research focused on the impact of financial status, parents’ ability to access health care, cultural and language implications, as well as barriers to forming partnerships with practitioners, and service providers and support services as identified by the families. Dawson (2013) noted barriers to forming partnerships due to practitioners’ ambivalence to parents’ developmental concerns of their child, as well as the vast number of services marketed to families and the different levels of services available for parents. This includes services parents may be eligible for through programs, and the many that are available that lack empirical research. Dawson further asserted that parents were apprehensive about forming partnerships with schools in instances where they felt they would be incapable of making a difference in their children’s treatment. Moreover, in situations where parents felt disempowered by the diagnostic process, they were more apprehensive about sharing information about their children.

The qualitative study conducted by Lautenbacher (2013) provides a phenomenological approach to determine the motivations and barriers to partnerships between parents of children with ASD and professionals. The study identifies the impact of family dynamics in support of treatment interventions. Lautenbacher’s qualitative case study model, using semi-structured interviews and select questions, were used with nine participants from a rural area in Western Pennsylvania. The data were collected through interviews, and they were transcribed and coded for recurring themes. The study used a constructivist paradigm and detailed parent and school partnerships. The constructivist
paradigm goal is to have the researcher and participant interlinked to influence the others’ construct of reality. Lautenbacher’s (2013) research recommended the expansion of services in schools supporting children with ASD. Her study also recommended expanding the research to include more diverse geographic settings, such as West New York State or New Jersey, to gain a broader perspective (Lautenbacher, 2013).

Furthermore, Lautenbacher’s (2013) research applied Bronfenbrenner’s (1979) theoretical framework to outline the importance of family, school, and parent partnerships as a preemptive and motivating factor to successful parent and school interventions in support of children with ASD. He used Bronfenbrenner’s work to identify a direct correlation between Bronfenbrenner’s (1979) bio-ecological theory of human development with parents who have children diagnosed with ASD. As indicated by Bronfenbrenner’s (1979) theory and Lautenbacher’s (2013) study, parents’ participatory behavior in treatment interventions involving their children are not one dimensional, but global and complex. Lautenbacher’s research revealed a strong need for continued support for families, because parents’ needs are vast and complex. The researcher also noted that Bronfenbrenner’s (1979) ecological factors and theory greatly impact families caring for children with autism, as Bronfenbrenner’s systems approach highlights family relationships. Relationships, Lautenbacher stated, impact services, diagnosis, and treatment. The significance of this concept is that parents’ needs and levels of participation in their children’s diagnosis, developmental progress, and treatment varies based upon the factors that serve as motivators. The final findings of the Lautenbacher (2013) study reveal that as families participated in endeavors with
educational professionals and the professionals worked with the parents, parents’ participatory behaviors changed to reflect the results of the interactions.

Hall’s (2011) descriptive, correlational, cross-sectional study in Alabama utilized a purposive sampling of 75 parents of children with autism. The purpose of the study was to investigate the adaptive behaviors of children with ASD and to identify family support networks and parents’ levels of stress and to note their coping mechanisms. The participant size was 70 parents whose children were primarily male. Of the parent participants, 83% had male children, and the remainder (17%) were female children. The participant pool included one grandmother and one stepfather. The racial composition of the families was: (a) 62% Caucasian, (b) 34% African American, (c) .6% American Indian, and (d) 1.5% Latino or Hispanic. The majority of the parent participants were college educated.

Hall’s (2011) study examined the maladaptive behaviors of children with autism, family supports, parental stress, and parental coping. The methodology used to collect the data was a descriptive, correlational cross-sectional study. The data were analyzed using multiple regression analysis. Multiple regression analysis, according to Creswell (2014), is a research design used to determine the value and strength of a variable based upon two or more variables, and it was used in the Hall (2011) study to examine adaptive behaviors of children with autism. Adaptive behaviors for children diagnosed with autism are adaptive skills, such as being able to use the bathroom on their own, unpacking their school bag, brushing their teeth, putting on their jacket, or unbuckling a belt. These skills are taught to children on the spectrum through a series of tasks, or the activity is broken down into the increments for increased comprehension (Lovaas, 1987; Sarris, 2015).
The results of the Hall (2011) study indicate that when parents feel supported around their children’s diagnosis of autism, their thoughts and impressions related to the disorder shift. The researcher stated that there are many variables that impact the lives of children and families coping with a diagnosis of autism. The variables outlined in the study were: stress, parent coping, and parent resources. The researcher also noted that parents often feel stress around their children’s behaviors, and this contributes to parental stress.

Supporting parents, Hall (2011) asserted also helps families shift their perceptions of their children’s quality of life and the implications for their families. Families begin to perceive the needs of their children differently. They communicate more positively and confidently as a family. Hall further stated that when supports for parents are in place, parents focus their energy around adjusting to their children’s diagnosis. These families, when given support early on, seek out the positive attributes of their situation. Last, the researcher’s results indicate that parents require support in coping with their children’s diagnosis as well as finding resources (Hall, 2011).

The Vineland Scale (Sundberg & Partington, 1998), referenced earlier, is commonly used to teach children with autism adaptive skills. Adaptive skills are skills required for everyday living, such the ability to use the toilet independently, unbuttoning an overcoat, and unpacking belongings. This is accomplished by completing a parent or primary caretaker interview to assess what the child knows. Once the parent provides information about the child’s developmental and adaptive skill level, this information is measured against what typically developing children should know. The activities related
to communication, daily living skills, socialization, and motor skills are modified to teach child new skills at home or in school (Eikeseth et al., 2002).

Moreover, Hall’s (2011) study utilized the McCubbin and Patterson’s (1983) model of family behavior as the framework for evaluating parents’ views of the adaptive behaviors of children with autism. The McCubbin and Patterson (1983) model of family-behavior-evaluated stressors, supports, and coping strategies for families dealing with autism. Their research reports that parents can regulate stress better with supportive measures. The findings of the McCubbin and Patterson study assert that parents reported that their children had significant maladaptive behaviors and the parents were ill equipped to deal with their children’s needs. The parents reported that this caused high levels of stress and limited amounts of coping skills. The study noted that the ways in which the parents coped with the situation was contingent upon their personal, social, and financial situations. Hall (2011) recommended health care providers create appropriate interventions for maladaptive behaviors to support children with autism and their families so that families can focus on teamwork and necessary adjustments that were needed in order to bring about positive outcomes.

Chapter Summary

Chapter 2 included a comprehensive overview of the literature on parents and pediatricians’ perspectives of autism at the onset of a child’s diagnosis. The review included a history of autism, as identified by Asperger (1944), Bleuler (1911), Creak (1961), Itard (1801, 1962), Kanner (1943), and Wing (1981). The history within the literature, as described by Asperger (1944), Bleuler (1911), Cook and Willmerdinger (2015), Itard (1801, 1962), and Kanner (1943) indicated that autism is a complex disorder
with a complicated history. Furthermore, the modifications of the disorder within the *Diagnostic and Statistical Manual of Mental Disorders* from 1952 to 2013 identify the historical changes noted in its origin, diagnosis, and characterization (Feinstein, 2011).

Controversial, as well as debatable, are the causes of autism (Rimland, 1964; Wakefield, 1999) and the lack of a cure (CDC, 2014). The research of Bettelheim (1959) and Kanner (1944) suggested autism was a result of an emotionally unresponsive and indifferent parent. The research of Rimland (1964) refuted this notion. The research of Creak (1961), Hall (2011), Rimland (1964), and Wing (1981) revealed the causes of autism as biological, neurological, and environmental in nature. The research of Wakefield et al. (1998) alluded to a mercury-based preservative in the MMR vaccine as an underlying cause of autism. Although the Wakefield et al. research was retracted, the controversy surrounding its connection to the MMR vaccinations still exists (Begley & Interlandi, 2009).

The Adelman (2010) and Saggu (2015) research detailed measures taken by parents to obtain a diagnosis of autism, from a 9-point diagnostic scale to the challenges parents face when receiving a diagnosis to the parent perceptions of services available, and the supports available to them in developmental and assessment screening. Medical and nonmedical treatment options, noted in the research of Hall (2011), Kamei (2013), and Shore (2008), reported the vast number of treatment options available to parents, as well as the parents’ levels of frustration with assessment, diagnosis, understanding of treatment options, and resources available.

Furthermore, the research of Lautenbacher (2013), Mack (2008), and Mann (2013) detailed the global perspectives of autism, the varying levels of knowledge
available to families pertaining to treatment interventions, and the variations among pediatricians related to screening and diagnostic practices. The research of Bondy and Frost (1994), Greenspan and Wieder (1997), Gutstein (2000), Leaf and McEachin (1999), Lovaas (1987), and Shore (2008) acknowledged nonmedical treatment intervention option available to families, which is the basis for this study. Their research also illuminates many factors that contribute to the experiences of parents during their children’s diagnosis of autism for their children. Parental perspectives of a diagnosis of autism is an important variable to examine because this experience may influence what treatments parents and professionals choose to implement.

Literature on parental perspectives of the diagnosis process demonstrate a common thread that families are somewhat dissatisfied about the diagnostic process (Adelman, 2010; Hall, 2011; Mack, 2008). Professionals, as the literature indicates, are at the forefront of the diagnostic process and can support the families in many ways (Mack, 2008). It is important that families receive scientifically validated approaches to autism treatment (Lovaas, 1987). When parents are unable to access resources from the individuals they collaborate with in their children’s treatment, parents begin to self-educate themselves about treatments for autism (Lindgren & Doobay, 2011). As noted by Lindgren and Doobay (2011) this lack of information regarding intervention may become a significant source of dissatisfaction to families. The researcher identified the information available from practitioners to families to provide a strength-based approach to families accessing care. Chapter 3 provides a detailed description of the research design and methodology used to examine the research questions.
Chapter 3: Research Design Methodology

Introduction: General Perspective

In 2014, the CDC reported that one out of every 68 children in the United States was diagnosed with autism spectrum disorder. Despite the average age of diagnosis reported at 3 years of age, parents typically begin reporting concerns to pediatricians well before their children reach their first birthday (CDC, 2014). According to Estrada and Deris (2014), many parents of children with an autism spectrum disorder are apprehensive and lack confidence in their pediatrician’s ability to advise them on treatment. Furthermore, Estrada and Deris (2014) posited that many pediatricians reported they were hesitant about their knowledge or the time they could devote to children with autism, with many citing the policies hindering their ability to obtain payment for lengthier consultation or managing complex cases.

Through a qualitative research method, the problem this researcher sought was to improve the understanding of the impact of an initial diagnosis of autism spectrum disorder on nonmedical treatment options in the learning environment from the perspectives of parents and pediatricians. The purpose of the research was to identify what information is available to parents and pediatricians at the onset of a diagnosis and how this information influences decisions for treatment in an educational environment. In order to collect data and to determine the information cited above, the investigator conducted interviews with five parents and five pediatricians.
The research questions developed as the basis for the study and supported the research, were:

1. What information is available to parents at the onset of their child’s diagnosis of autism?
2. What are the current levels of knowledge of parents and pediatricians at the onset of a child’s diagnosis of ASD?
3. How are treatment methods appropriately aligned when parents and pediatricians are better informed regarding a child’s diagnosis of ASD?
4. What are the treatment options available for children as it relates to the learning environment, and what treatments have been found to be the most effective and why?

A phenomenological study identifies the lived experiences of its participants (Creswell, 2014). Through the lived experiences of parents and pediatricians, the researcher gathered perspectives at the onset of a child’s diagnosis of autism spectrum disorder (ASD) and the nonmedical treatments options available. Incorporating the theoretical framework of Bronfenbrenner (1979) and Skinner (1957) substantiated the research of Dawson (2013), Hall (2011), and Mann (2008) and related to the topic at hand.

According to Ravindran and Myers (2012), a collaborative approach to assisting children with ASD is an important milestone and the preferred method of service delivery. Moreover, Mack (2008) posited that as autism interventions vary in their approach and methodology, early intervention programs and schools preparing to serve children with autism face great difficulty in determining which interventions are the most
appropriate. According to Perryman (2009), the timing of diagnosis and information available is critical to families, given that early diagnosis may lead to earlier interventions. Dosreis, Weiner, Johnson, and Newschaffer (2006) determined that fewer than 10% of physicians routinely test for ASD. Moreover, the research of Saggu (2015) demonstrated that parents are dissatisfied with the diagnosis process.

**Research Context**

The data collection for this research study included parents and pediatricians who lived or worked in Westchester County, New York. In addition, data were collected from parents of children with autism who formerly attended Borough of Manhattan Community College (BMCC). Established in 1963, BMCC of the City University of New York (CUNY) extends five blocks alongside the Hudson River in lower Manhattan. During the spring 2016 semester, BMCC served 25,493 students, and 26,748 students were enrolled for the fall 2016 semester. Of the students who attended, 18,189 were enrolled full time, and 8,559 enrolled part-time (Borough of Manhattan Community College [BMCC], 2016). The demographic composition of the students included 57.3% woman. Of the female students, 40% were heads of household. BMCC provides a wide range of academic programs for students with diverse and non-traditional backgrounds. BMCC students are largely dependent upon on financial aid to cover their tuition cost, and they reside well beyond the boundaries of the college’s neighborhood. Students commute to BMCC from the five boroughs in New York City, and they reflect the ethnic and racial diversity of its boroughs. The percentage and numbers of BMCC students reside in the following boroughs of New York City, other areas of New York State, and New Jersey: (a) Bronx (21.3%) 5,699; (b) Brooklyn (31.1%) 8,314; (c) Manhattan
(18.2%) 4,865; (d) Queens (20.6%) 5,514; (e) Staten Island (2.3%) 625; (f) other areas of New York State (1.9%) 521; and (g) New Jersey (1.0%) 265 (BMCC, 2016). For the 2016 school year, the median age of the students was 24 years. The ethnic breakdown of the college is: (a) Black (29.8%) 7,958; (b) Hispanic (39.9%) 10,676; (c) Asian (12.5%) 3,346; (d) White (11.5%) 3,072; and (e) American Indian/Alaskan Native (0.4%) 94 (BMCC, 2016). As reported by its Factbook Enrollment Dashboard (2017), the BMCC has 17 academic departments, 47 majors granting 2-year degrees, 21 special programs, and eight internships and experiential learning programs.

Borough of Manhattan Community College is a two-generational service-providing services to student-parents and their children. BMCC’s Early Childhood Center began in 1984. The center is a non-profit, multicultural, multiethnic institution founded by Borough of Manhattan Community College faculty and staff. In July of 1987, the center created the Family Childcare Network program. This program provides services for children birth to 2 years of age. The center-based program serves pre-school children 2 to 5-years old, and school-aged children 6 to 12-years old. Since 1984, the center has served more than 3,000 children and families. The purpose of the Early Childhood Center is to: (a) provide a quality childcare and early childhood education program for student-parents of BMCC, (b) support expansion and improvement of the program, and (c) seek to constantly improve services and keep them relevant to the needs of the college community. In addition to the aforementioned, the mission of the program is to serve as an educational resource for the college community and to promote health awareness for children and families (BMCC Early Childhood Center, 1984).
Borough of Manhattan Community College’s Early Childhood Center is an accredited through the National Association for the Education of Young Children. The program has six classrooms, operates 7 days a week during spring and fall, with daytime hours in the summer sessions at the college. The center operates from 7:45 a.m. to 9:00 p.m. from Monday through Thursday and from 7:45 a.m. to 5:00 p.m. Friday, Saturday, and Sunday. The program serves a population where more than 15% of children have special needs. Special services are provided to parents free of cost through Early Intervention and the Committee on Preschool Special Education. The center serves over 100 children each week. All of the children enrolled in the center are children of BMCC students. The ratio of teachers to students is 1:3. The head teachers are state-certified professionals in early childhood and special education. Assistant teachers have a minimum of an associate degree. The center employs a licensed social worker who operates as the program’s Family Resource Coordinator. The Family Resource Coordinator assists families with referrals for community-based services. The Family Resource Coordinator has provided more than 150 referrals for parents, 75 play therapy sessions with children, and 80 individual sessions with student parents. The Family Child Care Network, which oversees 20 family provider homes across the five boroughs, serves another 40 student-parents. The center is a site for approximately 24 student teachers and 40 federal work-study students. The center provides opportunities for over a 100 student observers, volunteers, and visitors yearly (BMCC Early Childhood Center, 2016).

Borough of Manhattan Community College’s Early Childhood Center is licensed by the New York City Department of Health and Mental Hygiene, and the Office of Children and Family Services. The governing body of the center consists of a board of
directors comprising faculty and staff. The Executive Director is a Higher Education Officer of the college. The Executive Director is responsible for the management of the day-to-day operations of the center. The Executive Director provides reports to the college and the board. The board consists of a management-level staff across a selection of disciplines within the larger college community, as well as a student-parent representative. The center complies with the American with Disabilities Act (1974) and has three on-site outdoor spaces equipped with appropriate outdoor play equipment (BMCC Early Childhood Center, 2016).

The researcher solicited participants from Westchester County. Westchester County is a county in the State of New York and, according to the 2010 Census, the county had a population of 961,670 (Westchester County, 2017a). Situated in the Hudson Valley, Westchester consists of 48 municipalities. Founded in 1648, Westchester County has: (a) six cities, (b) 23 villages, (c) 16 towns, and (d) 12 hospitals. The cities in Westchester County include: (a) Yonkers, (b) Greenburgh, (c) New Rochelle, (d) Mount Vernon, (e) White Plains, (f) Mount Pleasant, (g) Cortlandt, (f) Yorktown, (g) Port Chester, and (h) Harrison (Westchester County, 2017b).

Given that this research is specific to the medical and educational fields, it is important to document the number and names of the medical facilities in Westchester County as well as the public and private schools. The 12 hospitals are:

- Northern Westchester Hospital
- Phelps Memorial Hospital Association
- White Plains Hospital Center
- Hudson Valley Hospital Center
Westchester County also has four urgent-care facilities. There are 258 public schools and 74 private preschool programs with more than half serving children with special needs. Nine private schools serve the needs of children with autism in Westchester County. In addition, there are more than 4,000 individuals living with autism in Westchester County (Westchester County, 2017b).

The demographics of Westchester County are: (a) White non-Hispanic, 57.4%; (b) Hispanic or Latino, 21.8%; (c) Black 13.3%; (d) Asian 5.4%; and (d) two or more other races, 1.5%. The median age is 40-years old, and the population is 53% women and 46.5% men. The average income for Westchester County is $84,220.00. The percentage of residents living in poverty in 2013 was 9.7% (Westchester County, 2017b). The five boroughs of New York City served as the central locations of the study. This was due to the investigator’s close proximity to the participants through her work, and her professional and personal affiliations.
Research Participants

According to Creswell (2014), purposeful sampling is selecting participants in a purposeful manner. It is widely used in qualitative research for the identification and selection of information-rich cases that are related to the phenomenon of interest. The research study participants consisted of five parents of children on the autism spectrum disorder and five pediatricians who have treated children diagnosed with autism. At the time of the study, the participants all lived in Westchester County, New York State or in the City of New York. The researcher included parent participants who had been previously affiliated with the childcare center in which she works with children, whose children were later diagnosed with autism. The reason for this was because the families were accessible to the researcher, and it gave the set of parents an opportunity to narrate their story.

The five pediatricians in the participant group practiced in Westchester County. The researcher used a convenience sampling. Convenience sampling chooses participants due to their proximity and accessibility to the researcher and (Creswell, 2014). There was a database of pediatrician’s names available to the researcher through her child’s pediatrician office. The researcher attempted to recruit participants by way of this database. It comprised pediatricians in the Greenburgh and City of White Plains, which are within Westchester County. The researcher was unable to enlist five pediatricians for the study, so she attempted to recruit willing pediatricians through her local City Hall, through word-of-mouth, and by networking through community-based organizations in which the researcher was involved that were related to autism. A purposeful sampling allowed the researcher to select individuals for a study due to their prior involvement and
understanding of the research problem and the vital phenomenon of the study (Creswell, 2014).

The researcher included a diverse group of families to gain multiple perspectives. The number of participants selected for each group was a large enough sample for coding and capturing themes within the data. The parent participants were recruited by the researcher based on her existing relationships with families in the autism community, recruitment by word-of-mouth through a pediatrician’s office, and canvassing from former parents of children attending local early childhood program and public schools. The researcher sent an informed consent form to the participants, requesting their voluntary participation and asking for their consent to be interviewed (Appendix A). In compensation for their participation, parents and pediatricians received a $10 gift certificate from Barnes and Noble. The consent form detailed that participants could receive a copy of the study results upon request, after the study completion. In addition, the parents and pediatricians had an opportunity to receive a copy of the research results.

The type of purposeful sampling used, specifically, was the snowball approach (Patton, 2002). Purposeful sampling subjects were selected because of specific characteristics (Patton, 2002). The snowball approach identifies cases of interest that are insightful, via examples for the study, and groups who can recommend others (Creswell, 2014). Recruitment of the pediatricians as participants occurred mainly through referrals from health care and educational professionals, as well as friends of autism support groups who can refer.

All interviews were audio-recorded and transcribed to find common themes among the participants. There was a set of criteria to ensure the appropriate participants
for the study and Qualtrics (2013) software was used for this purpose. The criteria for participation included parents of children diagnosed with autism spectrum disorder who had received a diagnosis of ASD under the new DSM-V-R criteria, and pediatricians with experience diagnosing and treating children on the autism spectrum under the new guidelines.

The researcher ensured participant anonymity by coding each participant using a pseudonym (e.g., Parent # and Pediatrician #) that replaced the participants’ names. The researcher safeguarded participant privacy by coding each participant using an assigned number. The researcher avoided asking leading questions or disclosing sensitive information. As demonstrated by the informed consents, transparency in the process, anonymity, confirmability, and adherence to all applicable regulatory guidelines was ensured by the researcher. The researcher remained cognizant of the needs of the population studied, which were parents of children with special needs and pediatricians. All transcripts, notes, audiotapes, and other recordings are stored in a locked file in the researcher’s home. After 3 years, the collected data will be destroyed.

**Instruments Used in Data Collection**

The primary instrument in data collection was the researcher. The researcher conducted a qualitative study completing semi-structured interviews using phenomenological methodology. Phenomenological methodology describes the lived experiences of a phenomenon for several individuals, highlighting what they have in common (Creswell, 2014). The purpose of this study was twofold. First, the researcher gathered the perspectives of parents and pediatricians at the onset of children’s diagnosis of ASD. This was to identify what information was available to the parents and
pediatricians at the onset of the children’s diagnosis. Next, the study revealed if the information available had any impact on the treatment options chosen by the parents. Through the narration of the lived experiences of the parents and pediatricians, the researcher acquired answers to these questions.

The study addressed the research questions through interviews and a demographic questionnaire to obtain background information about each participant, such as age, ethnicity, and specific questions relating to each subject group in the sample. The study included interviews with five parents and five pediatricians. The 10 participants were selected using the set of criteria noted earlier in the text.

Data collection utilized a demographic questionnaire and interviews with the participants. Prior to distribution of the questionnaires and conducting the interviews, the interviewer obtained signed informed consent forms from the participants. The consent form indicated that the participant had the right to withdraw his or her verbal and written consent at any time. The consent form requested permission from the participants to record the interviews. Once the participants returned their signed consent forms, an initial questionnaire was emailed to them with a link to access basic demographic information. For the parents, the demographic information consisted of: (a) age range of parents, (b) number of children, (c) birth order of the child with ASD, (d) age of diagnosis, (e) type of treatment chosen, (f) where the participants lived, (g) the levels of education of the parents, (h) ethnicity, (i) marital status, (j) parent occupation, (k) age when their child was diagnosed with ASD, and (l) school environment of their child, either private or public school (Appendix B).
The pediatrician questionnaire obtained information regarding: (a) age, gender, and ethnicity of the pediatrician; (b) number of years in practice and in the current assignment; (c) size and location of the practice; (d) ethnicity of the parents served; (e) number of courses taken or training completed in ASD; and (f) the number of children in their practice identified with ASD (Appendix C).

The researcher created questions for the semi-structured interviews with the participants (Appendix D and E). Semi-structured interviews put into place a process for candidness, and the format encourages participants to expand on their responses (Creswell, 2014). The average timeline for each interview was 40-50 minutes. The parents who were interviewed answered the research questions and other questions related to the diagnosis and treatment options for their child and any information that was made available to them. The pediatricians interviewed answered questions pertaining to the research questions and the screening tools they used to assess children with special needs. In addition, the researcher took notes during the interviews to document particular body language of the participants that was associated with the answering of that question and to identify any emerging themes.

Prior to conducting the interviews with the parents and pediatricians, and in order to triangulate the data, the researcher reviewed the questions with five professional educators, working in related fields, who had worked with parents of children on the autism spectrum and to test the research and interview questions for reliability, validity, credibility, and conformability. Creswell (2014) identified four issues of trustworthiness in research design: (a) reliability, which is examining the process of the inquiry; if one’s research is reliable, another researcher can apply the same methods and receive the same
results; and (b) validity, which is an indication of the thoroughness of the research, relating to both the design and the methods used in research. Validity in data collection means a researcher’s findings represent the phenomenon he or she is asserting to measure, incorporating the complete experimental concepts, and determining the results obtained meet all of the requirements of the scientific research method (Creswell, 2014). In addition, credibility involves the trustworthiness of the research. Credibility infers that the research measures what it states it will evaluate. Confirmability explores the outcomes to attest to the findings, interpretations, and recommendations. The interview questions were developed from a review of similar questions in the peer-reviewed articles.

The data collection and the research allows for the researcher to seek out participants, obtain appropriate consents from the participants, draft letters to physicians and parents explaining the purpose of the study, and to be granted with permission to review all results, and to conduct a focus group in order to triangulate the data. As previously noted, all transcripts, notes, audiotapes, and other recordings are stored in a locked file in the researcher’s home. The data will be destroyed after 3 years.

Prior to conducting the research study, the researcher ensured all appropriate approvals were in place. She compiled the consents, copies of tools, introductory letters, and consent forms for submission to the IRB. To safeguard against any risk to human subjects, the researcher obtained approval from the IRB at St. John Fisher College and Borough of Manhattan Community College. Thereafter, the researcher finalized correspondence with the participants. The researcher contacted the parents and pediatricians to solidify dates and times for interviews. Given the research design, the
researcher anticipated an expedited IRB approval as the researcher’s study appeared to pose no risk to the human subjects.

**Data Analysis**

Coding, according to Creswell (2014), consists of short phrases that describe an accumulation of the main attributes for a portion of language-based or visual data. The participants’ responses were analyzed using thematic analysis, questions, and tables. The responses were categorized and tabulated for emerging themes and results. The coding was analyzed using the demographic information and interview responses of the parents and pediatricians. Data were analyzed from the verbatim transcription of the tape-recorded interviews. The goal during transcription was to ensure the transparency of the results (Creswell, 2014). Transparency is honest, open communication, and the expectations were understood by all. The researcher identified the emerging themes resulting from the data collection in response to the research questions. The researcher also utilized the research methodology of coding, qualitative analysis, semi-structured interviews, and questions, given that the participants provided an in-depth and detailed perspective (Fowler, 2014). The researcher hired a transcription service to protect the integrity of the research, ensure the accuracy of the transcriptions, and to reduce bias.

The researcher triangulated the data as noted above. Triangulation involves using multiple data sources in an investigation produce understanding, because a single method does not adequately provide an understanding of a phenomenon, and using several methods can help facilitate a deeper understanding (Patton, 2002). The research of Patton (2002) identifies four types of triangulation methods: (a) methods triangulation, (b)
triangulation of sources, (c) analyst triangulation, and (d) theory and perspective triangulation.

According to Creswell (2014), the method of triangulation involves using several information sources in an investigation to produce an understanding. Triangulation of sources is exploring the reliability of different data sources from within the same method. Analyst triangulation is using various analysts to review findings or using multiple observers and analysts. Theory and perspective triangulation uses multiple theoretical perspectives to exam and interpret data (Creswell, 2014). The method of triangulation used was theory triangulation. Theory triangulation consists of using more than one theoretical scheme in the interpretation of the phenomenon.

The premise of this study was to ascertain how knowledge influences treatment approaches chosen by parents or methods recommended by pediatricians and how this influences appropriate treatment options from the perspectives of parents and pediatricians, of which there has been limited research (Braiden, Bothwell, & Duffy, 2010; CDC, 2013; Shyu et al., 2010). Creswell (2014) identified qualitative researchers as individuals who gather data from multiple forms of data who then identify broad suppositions. The advantages of qualitative research are that it: (a) provides depth and detailed openness with participants, (b) accentuates participants’ lived experiences, and (c) attempts to avoid pre-judgement. The disadvantages are: (a) there are generally less participants in qualitative studies, (b) it is easy to generalize and difficult to make comparisons, (c) it is dependent upon the skills of researcher, (d) the data analysis is time consuming, and (e) it is difficult to make quantitative predictions (Creswell, 2014).
Summary of the Methodology

Igwe et al. (2011) assessed that the knowledge of health care professionals indicates that there is increased public and professional awareness of autism with early recognition, diagnosis, and interventions. Moreover, pediatricians vary in knowledge and treatment approaches when treating children on the autism spectrum, and there are core deficits in the knowledge base of childhood autism among health care professionals (Estrada & Deris, 2012; Igwe et al., 2011).

The problem the research identified was the impact of a diagnosis of autism spectrum disorder on nonmedical treatment options, within the learning environment, at the time of a diagnosis of autism spectrum disorder from the perspectives of parents and pediatricians. The researcher conducted interviews to find answers to the problem and to obtain data. The interviews took place at a mutually agreed-upon location with the participants, which included Parents 1, 3, and 4 interviews, which were conducted on a college campus; Parent 2’s interview was conducted at a Barnes and Noble, and Parent 5’s interview was conducted at her own business location. All of the pediatricians interviews were conducted at their offices. Convenience and purposeful sampling occurred with the participants. This occurred through a process of professional relationships and proximity. The instruments used during the data collection were: (a) demographic questionnaires, (b) interview questions, and (c) research questions. The analysis of the data included transcription of the data, triangulation of the data, and coding for common themes.

Chapter 4 presents the results of the study, and Chapter 5 discusses and interprets the results of the study and gives recommendations for future research and practice.
Chapter 4: Results

Introduction

The purpose of this qualitative research design was to explore the impact of a diagnosis of autism spectrum disorder from the perspectives of parents and pediatricians on treatment options in the learning environment. Furthermore, the study investigated the lived experiences of parents caring for children diagnosed with autism and examined the perspectives of the pediatricians caring for those children.

As indicated in Chapter 3, the researcher evaluated her questions that were used during the interviews by using a group of experts whose work experience related to children diagnosed with autism spectrum disorder. Their respective positions and/or professions included: (a) a teacher in education instruction, (b) an expert in early childhood development, (c) an educational psychologist, and (d) a special-instruction educator. All of the experts (two females and two males) were doctorate-level professionals. The questions were asked in a relaxed and supportive environment. This allowed the experts to provide feedback in the context of the research questions. Once the questions were answered, the researcher reviewed the experts’ suggestions and revised her questions. Table 4.1 lists the experts’ roles and recommendations with a goal to refining the researcher’s questions for the research participants. After the researcher made slight edits to the language of the questions, she submitted those questions to her dissertation chair for final approval, and the questions were included in her Institutional Review Board (IRB) application for approval.
Table 4.1

Panel of Experts’ Suggested Improvements in Questions for Participants

<table>
<thead>
<tr>
<th>Discussion</th>
<th>Expert’s Role</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussion 1</td>
<td>Special Educator</td>
<td>Revise compensation for pediatricians, advisor felt it was miniscule, and it would be more appropriate to give the physicians something more substantial and relevant to their experiences with the parents, such as books at same nominal rate as the gift card for their office. For the parents, they deemed the amount appropriate. Are you familiar with any programs to support parents caring for a child with autism?</td>
</tr>
<tr>
<td>Discussion 2</td>
<td>Educational Psychologist</td>
<td>Change the wording, the term knowledge might be intimidating for some. City of residence probably should say borough. You might want to ask what type of classroom: inclusion, self-contained, etc.</td>
</tr>
<tr>
<td>Discussion 3</td>
<td>Researcher</td>
<td>After the diversity question, use the demographic screening form to identify languages they speak at home</td>
</tr>
<tr>
<td>Discussion 4</td>
<td>Special Educator</td>
<td>Ask doctor’s ethnic breakdown of practice, different treatment modalities, what do they know, and their experience.</td>
</tr>
</tbody>
</table>

After obtaining IRB approval, the researcher began to contact prospective parents and pediatricians to explain the research context. She sent an introductory letter related to her research, along with consent forms, to all prospective candidates. In her effort to gather participants, the researcher contacted more than 30 pediatricians’ offices and 15 parents before she obtained her pool of participants consisting of five parents and five pediatricians. After each email introductory letter response, phone contact was made with the willing participant, and the researcher collected the signed consent, and the interview was scheduled. All correspondence occurred in English. The participants were a diverse group, and they were provided with a small gift card incentive for their time. They were also sent thank you notes.

Prior to the scheduled interview dates, a demographic survey was sent to each participant. The majority of the participants decided to complete the demographic survey
during the time of the interview. Two demographic surveys, one for the parents (Appendix E) and two for the pediatricians (Appendices F and G) were created by the researcher. The parents’ survey included information about (a) the ages of the parents, (b) the number of children in the family, (c) the birth order of child diagnosed with autism, (d) the type of treatment options that were chosen for the child diagnosed with autism, (e) the borough of residence, (f) the level of education of the parent(s), (g) the ethnicity of the parent(s), (h) the marital status of the parent(s), (i) the parent(s) occupation(s), (j) the age the child was diagnosed with autism, and (k) the child’s school setting.

The pediatricians’ surveys asked questions about (a) age, (b) gender, (c) ethnicity, (d) number of years in practice, (e) location of practice at the time of the interview, (f) size and location of practice, (g) ethnicity of parents served, (h) number of courses taken or training completed relating to children with autism, (i) number of children in their practices who were diagnosed with autism, (j) the practice setting, and (k) hours of operation and the best time to be interviewed.

As part of the coding process, each participant was given a number to anonymously identify their participation. The participants were assigned these numbers based upon the time the researcher was able to secure the interview. The five parents interviewed ranged in age. The youngest parent was 24-years old, and the oldest parent was 40-years old. The five parent participants were women. Of the five parents, four were married, and the fifth was in a long-term relationship with her partner. Three of the parent participants were former attendees of Borough of Manhattan Community College, and the other two parent participants resided in Westchester County. One parent had two children, a daughter and a son, who were diagnosed with autism. Another parent had
three children with one diagnosed with autism. Of the three remaining parent participants, each had a male child diagnosed with autism. Each of the three parents had an associate degree with some additional college credits. Of the two remaining parents, one had a master’s degree, and the other had a high school diploma. The parents’ work composition included: (a) two stay-at-home mothers, (b) one full-time student who worked in the medical field, (c) one speech pathologist, and (d) a parent who owned a business (Table 4.2).

Table 4.2

*Parents’ Demographic Information*

<table>
<thead>
<tr>
<th></th>
<th>Parent 1</th>
<th>Parent 2</th>
<th>Parent 3</th>
<th>Parent 4</th>
<th>Parent 5</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>26</td>
<td>38</td>
<td>32</td>
<td>27</td>
<td>41</td>
</tr>
<tr>
<td><strong>Number of Children</strong></td>
<td>1</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td><strong>Birth order of the child diagnosed with autism</strong></td>
<td>First</td>
<td>First</td>
<td>Fourth</td>
<td>Third</td>
<td>First</td>
</tr>
<tr>
<td><strong>Age child was diagnosed with autism</strong></td>
<td>15 months</td>
<td>2 years</td>
<td>3 years</td>
<td>2 years</td>
<td>2 years</td>
</tr>
<tr>
<td><strong>School environment of child with autism</strong></td>
<td>Public</td>
<td>Public</td>
<td>Public</td>
<td>Public</td>
<td>Public</td>
</tr>
<tr>
<td><strong>Type of treatment option chosen for child with autism</strong></td>
<td>Early intervention, applied behavioral analysis services, speech, and occupational therapy</td>
<td>Early intervention, applied behavioral analysis</td>
<td>Early intervention, applied behavioral analysis</td>
<td>Speech, occupational therapy, special instruction, applied behavioral analysis</td>
<td>Speech, occupational therapy, special instruction, applied behavioral analysis</td>
</tr>
<tr>
<td><strong>Borough of Residence</strong></td>
<td>Queens</td>
<td>Westchester</td>
<td>Bronx</td>
<td>Bronx</td>
<td>Yonkers</td>
</tr>
<tr>
<td><strong>Level of education of parent</strong></td>
<td>Associate degree, working on undergrad. degree</td>
<td>Master’s degree</td>
<td>Associate degree</td>
<td>Associate degree, attending an undergrad. program</td>
<td>High School</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td>Latina</td>
<td>Black</td>
<td>Ivory Coast (Cameroon)</td>
<td>Asian</td>
<td>White</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td>Not married</td>
<td>Married</td>
<td>Married</td>
<td>Married</td>
<td>Married</td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
<td>Homemaker</td>
<td>Speech Pathologist</td>
<td>Homemaker</td>
<td>Homemaker</td>
<td>Business Owner</td>
</tr>
</tbody>
</table>
In reviewing the demographic information of the parents: one parent was of West Central African descent, one was Latina, one parent was Asian, one was African American, and the last parent interviewed was of Irish ancestry.

With respect to the pediatricians’ demographics (Table 4.3), there were two females and three males, all of the pediatricians were White (unknown ancestry), and their ages ranged from 52- to 70-years old. The pediatricians’ average years of experience and in practice were more than 20 years. The ethno-demographics of the families were primarily White, Black, and Hispanic.

Table 4.3

<table>
<thead>
<tr>
<th>Pediatricians’ Demographic Information</th>
<th>Pediatrician 1</th>
<th>Pediatrician 2</th>
<th>Pediatrician 3</th>
<th>Pediatrician 4</th>
<th>Pediatrician 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>56</td>
<td>56</td>
<td>67</td>
<td>54</td>
<td>70</td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>White</td>
<td>White</td>
<td>White</td>
<td>White</td>
<td>White</td>
</tr>
<tr>
<td>Number years in practice</td>
<td>25</td>
<td>20</td>
<td>35</td>
<td>24</td>
<td>30</td>
</tr>
<tr>
<td>Location</td>
<td>Hartsdale</td>
<td>3-Croton</td>
<td>Croton Harmon</td>
<td>White Plains</td>
<td>Hartsdale</td>
</tr>
<tr>
<td>Size</td>
<td>?</td>
<td>?</td>
<td>350</td>
<td>3,000</td>
<td>5,000</td>
</tr>
<tr>
<td>Ethnicity of parents served</td>
<td>80% White</td>
<td>White</td>
<td>80% White</td>
<td>80% White</td>
<td></td>
</tr>
<tr>
<td></td>
<td>15% Black</td>
<td>Hispanic</td>
<td>15% Black</td>
<td>15% Black</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5% Hispanic</td>
<td>African</td>
<td>5% Hispanic</td>
<td>5% Hispanic</td>
<td></td>
</tr>
<tr>
<td>Number of courses taken or training</td>
<td>2-year fellowship</td>
<td>3-4 courses</td>
<td>Ongoing</td>
<td>2 years</td>
<td></td>
</tr>
<tr>
<td>completed relating to children with</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>autism</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of children in practice</td>
<td>10</td>
<td>20</td>
<td>350</td>
<td>450</td>
<td>40-50</td>
</tr>
<tr>
<td>identified with autism</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practice setting: Hospital/Private/</td>
<td>Private</td>
<td>Private</td>
<td>Suburban</td>
<td>Private</td>
<td>Private/Suburban</td>
</tr>
<tr>
<td>Urban/Suburban</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Office Hours</td>
<td>9-6, 9-2</td>
<td>9-6</td>
<td>9-5</td>
<td>9-5, 9-12</td>
<td>9-5</td>
</tr>
</tbody>
</table>
At the conclusion of the data collection from the interviews, the recordings were transcribed and coded. All transcripts were coded by an induction process. The induction process is used to search for patterns in observations (Creswell, 2014). The coded statements were organized into related groups for emerging themes.

This chapter is categorized into two sets of questions, with responses from the parents and the pediatricians.

**Parent questions.** The following questions were used to query the parents regarding their experience with a child diagnosed with autism.

1. Please tell me a little about yourself and your family.
2. Can you describe for me how you found out your child had autism?
3. What was one of the first things you did upon finding out about your child’s diagnosis?
4. Who did you seek support from?
5. Have you participated in any parent support programs?
6. Can you describe the treatment intervention programs your child has participated in?

**Pediatrician questions.** The following questions were queried with the pediatricians to further understand their experience with children and families:

1. Can you please describe your first experience caring for a child with autism?
2. What resources are available for your families?
3. Are you familiar with any programs to support parents caring for children with autism?
4. Can you describe your process for diagnosing a child with autism?
Research Questions

In addition to the participants responding to the previously mentioned interview questions, the objective of the research study was to answer the following research questions:

1. What information is available to parents at the onset of their child’s diagnosis of autism?
2. What are the current levels of knowledge of parents and pediatricians at the onset of a child’s diagnosis of ASD?
3. How are treatment methods appropriately aligned when parents and pediatricians are better informed regarding a child’s diagnosis of ASD?
4. What are the treatment options available for children as it relates to the learning environment, and what treatments have been found to be the most effective and why?

Data Analysis and Findings

In an attempt to identify ways to obtain the most-significant information for the study, the aforementioned questions were vetted with the help of four educators. The researcher ascertained the appropriateness of the research questions by a discussion of the questions with four professionals in the field of child development who had backgrounds in working with children with special needs and in diverse populations. The experts deemed the questions to be appropriate. One participant noted that the incentive for the pediatricians was aligned with the participant population for professionals and suggested that books or posters might be more suitable. One educator suggested asking the parents
questions about the types of schools (inclusionary programs or special education) rather than asking about either public or private schools. The suggestions were incorporated into the interviews and the experts’ suggestions can be seen in Table 4.1. Table 4.4 lists the parent participant questions that were created by the researcher.

Table 4.4

*Parent Participant Interview Questions*

<table>
<thead>
<tr>
<th>Question</th>
<th>Parent 1</th>
<th>Parent 2</th>
<th>Parent 3</th>
<th>Parent 4</th>
<th>Parent 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please tell me a little about yourself and your family.</td>
<td>Resides in Queens</td>
<td>Resides in the Bronx</td>
<td>Resides in the Bronx</td>
<td>Resides in Westchester</td>
<td>Resides in Westchester</td>
</tr>
<tr>
<td>Can you describe for me how you found out your child had autism?</td>
<td>Early intervention diagnosis</td>
<td>Early intervention diagnosis</td>
<td>Early intervention diagnosis</td>
<td>Early intervention diagnosis</td>
<td>Early intervention diagnosis</td>
</tr>
<tr>
<td>What was one of the first things you did upon finding out about your child’s diagnosis?</td>
<td>Cried</td>
<td>Very upset</td>
<td>Blamed myself</td>
<td>Got a second opinion</td>
<td>Cried for days</td>
</tr>
<tr>
<td>Who did you seek support from?</td>
<td>Pediatrician Early intervention</td>
<td>Pediatrician Early intervention therapist</td>
<td>School social worker Therapist</td>
<td>I did not have much support</td>
<td>Researched on Internet</td>
</tr>
<tr>
<td>Have you participated in any parent support programs?</td>
<td>Special Education Parent Teachers’ Association (SEPTA)</td>
<td>No</td>
<td>No</td>
<td>No, I tried to create a group for parents</td>
<td>Local advocacy agencies, but no parent group joined</td>
</tr>
<tr>
<td>Can you describe the treatment intervention programs your child has participated in?</td>
<td>ABA</td>
<td>ABA</td>
<td>ABA</td>
<td>ABA Therapies</td>
<td>ABA</td>
</tr>
</tbody>
</table>

**Research question 1.** *What information is available to parents at the onset of their child’s diagnosis of autism?* Of the five parents interviewed, all stated they knew nothing regarding autism at the onset of their children’s diagnosis. Parents 1, 2, and 3 immediately went to the Internet to obtain information about the disorder. Parent 4 stated
that she was able to obtain some information from her child’s pediatrician who was the first to express her concerns regarding the parent’s son’s behavior. Parent 5 stated that upon hearing the term from her child’s therapist, “I downloaded *Autism for Dummies*.” She further stated, “Without completing the first page of the book, I knew my child had all of the classic symptoms of autism.” Parent 3 stated, “As a student of life, I went to the school library, I watched videos, and read whatever I could.”

Parent 2 stated, “In 2004, when my daughter, my first born, was diagnosed with autism, there was very little information about the disorder. However, by the time my son was born, I knew a lot more, yet there was still not enough information.” She stated, “I obtained second opinions for both of them.” Parent 2 further stated, “I read an article that encouraged parents to immerse their children with autism in activities typically developing children would participate in, ‘they will learn,’ the author stated, ‘just at a slower pace.’” Parent 4 stated that she just cried, and Parent 5 affirmed she did the same, “I cried for days and days.” Parent 4 stated she enlisted the support of her pediatrician in convincing her husband of the autism diagnosis:

> Honestly, I was so upset. It took me so long to believe that my son—he’s gifted—so I was really upset, and my husband, he actually wasn’t, he wasn’t helping me because he thought, “Oh he’s a hyper kid; he’s a boy,” but I had to convince him [that] he needs help.

Parent 3 stated, “My husband stated, I need a second opinion. He just thought he was speaking late,” but I said, “I have been telling you something was wrong.”

Similar to the research of Kubler-Ross and Kessler (1972) on the theory of grief and Greydanus & Toledo-Pereyr’s (2012) study about the perspectives of parents during
the diagnostic period, the majority of the parents interviewed stated either that they or their spouses were in denial. The research of Ryan et al. (2011) asserts that once parents are able to acquire additional information about the disorder, they begin to seek out services, as well as additional information. All of the parent participants stated that they were unsure of what treatment options were available, and they did not follow up with their children’s pediatricians. All of the parents sought assistance from Early Intervention, which is a state-wide plan that supports children with developmental delays (New York State Department of Health, 2017).

Table 4.5 identifies the responses from the pediatricians’ questions as well as the resources the pediatricians identified as available for children diagnosed with autism. The pediatricians identified early intervention, a parent advocacy group, school-based programs, and resources for families. The information in Table 4.5 also outlines pediatricians’ knowledge of autism spectrum disorder, their first experiences with children on the spectrum, and their knowledge of resources for children and families.

The majority of the pediatricians stated they had limited experience with children on the autism spectrum at the onset of their careers. Most of the pediatricians’ experiences with children on the autism spectrum began during their medical residency. Each pediatrician interviewed had more than 20 years of working with children and families. Over time, each physician indicated his or her initial knowledge of the disorder was limited yet it had increased significantly over time. The pediatricians asserted that autism continues to evolve and, as outlined by each, their methodologies for diagnosis and approach with families is vastly different from one another. The majority
pediatricians interviewed indicated they relied upon community-based and related resources in their efforts to support families.
<table>
<thead>
<tr>
<th>Question</th>
<th>Pediatrician 1</th>
<th>Pediatrician 2</th>
<th>Pediatrician 3</th>
<th>Pediatrician 4</th>
<th>Pediatrician 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please tell me a little about yourself and your experience working with families of children with disabilities.</td>
<td>Pediatrician, private practice Fellowship, Kennedy Center 2-year residency Worked for Early Intervention in the Bronx</td>
<td>Pediatrician in private practice Took a few courses many years ago</td>
<td>Developmental pediatrician who has worked continuously with children with disabilities; started out in the 70s; in the beginning years, the practice included about 20% children with special needs; 15 years ago, 80%; 5 years ago, practice moved to 100% developmental</td>
<td>Pediatrician, private practice; was a nurse prior to becoming a physician She has taken several courses and her training is ongoing</td>
<td>Completed a Fellowship at Kennedy Center many years ago</td>
</tr>
<tr>
<td>Please describe your first experience caring for a child with autism.</td>
<td>1988, 1991</td>
<td>Many years ago, child is in 10th grade now; 20 years practicing accumulated a lot of children; the child described earlier went through Early Intervention, and he ended up seeing a developmental pediatrician and neurologist</td>
<td>Fifty years ago, worked with special needs kids; the autistic children, at that time, had a classical description, with minimal delays, multiple atypical behavior, and repetitive behaviors, and were treated with psychopathologic agents available at the time</td>
<td>First experience was in residency; the children seen were very ill. The majority stimmed and had self-harming behavior. Described it as overwhelming</td>
<td>In residency, as a youngster, a young man with atypical behavior and features of autism was fascinated with the subway. Probably today would be classified as having Asperger’s. Then he carried a diagnosis of mild mental retardation</td>
</tr>
<tr>
<td>What resources are available for your families?</td>
<td>Special school with an emphasis on the needs of children with autism</td>
<td>Early Intervention, a state supported agency for families of children with developmental delays</td>
<td>Autism speaks, an advocacy, research and referral agency for scientist, parents and children. “</td>
<td>Board of Cooperative Educational Services (BOCES): An organization that support children’s academic learning and progress Westchester Jewish Community Center A nonprofit that services the Westchester Community and the special needs community</td>
<td>An agency that is instrumental in ensuring the educational needs of children are met</td>
</tr>
<tr>
<td>Question</td>
<td>Response</td>
<td>Additional Information</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------</td>
<td></td>
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<tr>
<td>Are you familiar with any programs to support parents caring for a child with autism?</td>
<td>“No, but I would try to send them to family therapy; but it’s difficult to know which ones accept insurance or private pay or what costs are involved. I tend to say the Westchester Jewish Community Service.”</td>
<td>“Westchester Jewish Community Service”</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What is your process for diagnosing a child with autism?</td>
<td>Hesitant to diagnose before the age of 3. Ask parents questions during the screening process related to symptoms of autism as well as language. Completes a screening tool used for to identify children with autism. Lastly, pediatricians refers any children with speech and language concerns to early intervention.</td>
<td>Pediatrician process is not formal and was based upon his knowledge of working with children over the years.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Can you tell me about any developmental screening instruments used with families to detect autism?</td>
<td>Modified Checklist for Autism in Toddlers (M-CHAT) Communication and Symbolic Behavior Scale Development Profile (CSBC-DP) Pediatric Symptom Checklist (PSC) assesses for social problems</td>
<td>Modified Checklist for Autism in Toddlers (M-CHAT)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Modified Checklist for Autism in Toddlers (M-CHAT)</td>
<td>None, children were prescreened by others before referred to him</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>None, children were prescreened by others before referred to him</td>
<td>Modified Checklist for Autism in Toddlers(M-CHAT)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>None, children were prescreened by others before referred to him</td>
<td>Informal methods based on education, knowledge and experience</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
With the exception of the developmental pediatrician whose practice focused on the needs of children with autism, the majority of the pediatricians, although competent and capable of diagnosing children with autism, often referred families for follow-up services, testing, and support. This is similar to the research that indicates that although pediatricians are capable of completing advanced testing and are knowledgeable of some services, they typically refer parents out. Early Intervention (EI) is a program available for children ages birth to 3 years. This study indicates that EI was the primary resource clinicians relied heavily upon to assist families. Early intervention is a state-wide program that supports children with developmental delays and helps families obtain related services. Related services are identified as special instruction, and occupational, physical, and speech therapy.

Furthermore, the pediatricians provided the following responses related to the resources available to families, their familiarity with programs serving children with special needs, and their process for diagnosing children with autism. As it relates to the pediatricians’ knowledge about programs to support parents, Pediatrician 1 stated, “No, but I would try to send them to family therapy; but it’s difficult to know which ones accept insurance or private pay or what costs are involved. I tend to say the Westchester Jewish Community Center Service.” Relating to diagnosing children, Pediatrician 2 stated:

Early intervention is where I usually start to get them evaluated there. There is a developmental pediatrician in my office here. I typically refer them to him to take a look. I also try to give families moral support. I am not sure of any official programs.
Pertaining to available resources, Pediatrician 3 stated, “Autism Speaks. There are multiple support programs. Westchester Institute of Human Development also has multiple support programs.” Pediatrician 4 stated, “Board of Cooperative Educational Services (BOCES), Northeast Consortium, Westchester Jewish Community Center, School-based and private programs.” Pediatrician 5 stated, “Westchester Child Development Center. I know they see a lot of children with autism. But as far as a specific support group or parent group, no, just the school system or medical center.”

Relating to developmental screening, Pediatrician 5 stated, “I did not use any. I know there are some sort of scales or questionnaires or checklists of doctors’ observations. But, again, it’s just formalizing what, as a practitioner, I would do in my head, so to speak.”

The responses below give the pediatricians’ perspectives relating to resources for parents and the pediatricians’ processes for diagnosing children with special autism. Pediatrician 1 stated,

You can’t really diagnosis before 3. I use the Bright Futures Program, the Personality Screen for Children (PSC). I ask about behavior at home and socialization; if they are cuddly, whether they have stereotypic behaviors or language problems. I use the M-CHAT autism screen and a language screen called the CSBC DP. I try to get children with language delays into Early Intervention and encourage parents to use it.

Pediatrician 2 stated,

I start with Early Intervention and then a developmental pediatrician. Every child that comes to the office gets evaluated at 6 months, 12 months. We do an M-
CHAT at 18 and 24 months. I’m lucky, I have a developmental pediatrician next door.

Pediatrician 3 stated,

I take a history from the families. I examine the child, including mental status evaluation. I look at prior evaluations; since I am a behavior specialist, I don’t use any instruments. By the time they’ve come to me, they have been screened.

Pediatrician 4 stated, “Diagnosis can be simple, based on observation. I rely on a developmentalist and neurologist for confirming my diagnosis as well. I use the M-CHAT 1 and 2 for diagnosis then move to neuropsychic testing.” Pediatrician 5 stated,

It was nothing formal. In other words, I didn’t use a checklist, I believe they have now. I sound like I’m an old guy. When evaluating a youngster, in general, you know you touch on certain bases in development, and there are patterns. The pattern, especially with young children, one of the first signs is not diagnostic, but it’s a common syndrome, is lack of language, both expressive and receptive. When you combine lack of language, poor eye contact, and you become more suspicious. Lack of empathy, playing with toys inappropriately, and it’s a spectrum of symptoms, you change your diagnosis over time. Of course, you have to rule out other things, like it’s criminal not to get a child you suspect has autism a hearing test, that’s the first thing you rule out.

**Research question 2.** What are the current levels of knowledge of parents and pediatricians at the onset of a child’s diagnosis of ASD? Reiterating the content of the parents’ interviews, Parents 1, 2, 3, and 5 all stated they knew little to nothing at the onset of their children’s diagnosis, which is a recurring theme in the research of Hall (2011),
Lautenbacher (2011), and Mann (2013). The parents, according to their interviews, educated themselves at the onset and received support as they went along from their children’s pediatricians, a family friend, researching, their children’s schools, and individual therapists. Parent 3 stated “my child’s speech therapist told me, ‘he’s going to talk,’ and disclosed her son had autism.” Parent 5 stated that she learned about a prompt speech therapist during her research, once her son’s speech stalled.

Prompt speech therapy is an advanced methodology of speech and language pathology used within the speech and language community to assist children with severe speech and language deficits, primarily nonverbal children with autism (Rogers et al., 2006). The objective of prompt therapy is to focus on sounds, phonological awareness, and vocalization. Introduced to the research by Parent 5, she uncovered this approach with the assistance of her child’s speech and language teachers’ due to her son’s minimal verbal communication. Parent 5 stated that she was “at her wits end” attempting to work with speech and language professionals. She went on to say, “I have a high school diploma; however, I just went to every training, I fought and fought.” She also noted that her son went to independent doctors to support her goal of out-of-district placement for him, once she noticed a regression in his skills. An out-of-district placement is when parents seek to have their children placed in a different school district once they have determined the child’s needs are not being met by the child’s current service plan in his or her assigned school district (New York State Special Education, 2002).

All of the pediatricians interviewed, they stated that their training, fellowships, and initial experiences with children on the spectrum occurred more than 20 years prior to this study’s interviews. They affirmed how much the disorder has evolved and noted
the increased number of children diagnosed with autism. Pediatrician 3 stated that when he started out in the 70s working with children with developmental delays, specifically autism, 20% of his time was dedicated to that population, which was 15 years prior to this interview. The balance of his practice went from 80% primary care pediatrician and 20% developmental behavior, and then he went to 100% of his population having developmental behaviors.

Pediatrician 1 stated, “My first experience was during my fellowship in 1991, and we had a clinic. We split those kids up in different facets of treatment, so I feel like I have a sensitivity toward diagnosing children with autism.” Pediatrician 5 recalled:

One of the first cases I saw was at the Rose F. Kennedy Center. There was a teenage boy, maybe 13-years old, who was carrying a diagnosis of mild mental retardation, but, in fact, he really had some form of Asperger’s. What was unique about this young man, besides him being very eager to please and not making eye contact, uh, he would repetitively ask me where I lived and did I want to know how to get from my house to any place in New York by subway.

Pediatricians 2 and 4 stated they had watched the disorder evolve over the years. Pediatrician 3 stated, “50 years ago, typically, these children were treated with the most potent psychopathological agents available at the time.” Pediatrician 4 stated, “I complete ongoing training,” while Pediatrician 2 had completed little to no additional training since her initial training and during the evolution of the disorder. However, she did state, “we talk to each other. Luckily, now I have a developmental pediatrician right next door.” According to Pediatrician 4, “Autism was not a well-recognized entity, and the children I saw were very ill. The majority stimmed and had self-injurious behavior.” Stimming is
when a child on the autism spectrum engages in hand flapping, repeated rocking, or continuous movement of his or her body for the purpose of self-soothing (Center for Autism Research and the Children’s Hospital of Philadelphia, 2014). Self-injurious behavior is head banging, picking at skin, or hitting oneself in the head (Rao, Sudarshan, & Begum, 2008). Pediatrician 5 stated, “you get to know who in your respective community is working with certain children.” Table 4.6 identifies the themes and sub-themes that emerged from the Research Question 2 pertaining to services available to families at the onset of a child diagnosis of autism.

Table 4.6

<table>
<thead>
<tr>
<th>Theme Sub-Theme</th>
<th>Sub-Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Services available for parents</td>
<td>Early Intervention</td>
</tr>
<tr>
<td>Symptoms indicative of a child on the autism spectrum</td>
<td>Reaction of parent to the diagnosis: shock, disbelief, angry</td>
</tr>
<tr>
<td></td>
<td>Parents seek answers related to child’s diagnosis using the Internet</td>
</tr>
<tr>
<td>Treatment/diagnosis reactions</td>
<td>Commonality in services received by children as reported by parents includes speech, occupational therapy, applied behavioral analysis and physical therapy</td>
</tr>
</tbody>
</table>

Research question 3. How are treatment methods appropriately aligned when parents and pediatricians are better informed regarding a child’s diagnosis of ASD? The data analysis from the recorded interviews indicates that the majority of the children referenced in this study received applied behavioral analysis (ABA), which is a method used to support children’s cognitive, social and emotional development. The amount of
time ranged from an initially mandated 20%, at the onset of a diagnosis, to 10 hours per week down to 5 hours per week, but some children received no ABA at all. Only one parent identified the treatment and education of autistic and related communication handicapped children method (TEACCH) as a method used. Other details in the research chapters, such as floortime, natural environment teachings, and biomedical-based treatments were not mentioned by the parents. All of the parents interviewed stated that teachers were ill equipped and had not been retrained. Some parents reported that their school districts had been sanctioned for lack of services, and Parent 4 stated, “one therapist fell asleep while working with my son.” Parent 5 stated, “a free and appropriate education. My nonverbal child received speech once a week. That’s unfair.” One parent described early intervention as “a bombardment of services.”

With respect to parental supports, none of the parents reported attending any consistent support group or family therapy to assist them with their children’s diagnosis. Parent 2, an educator working in a school, attempted to provide a support group for parents, but the parents appeared burned out and just too overwhelmed to participate. Parent 1 began to attend a few Special Education Parent and Teacher Association (SEPTA) meetings once her child entered Pre-K. The goal of SEPTA meetings is to link parents of children with diverse developmental disabilities with resources to help their children. The meetings focus on identifying available resources for children and families, advocacy initiatives, rules and rights of parents, linking parents to other supportive services, such as help with toilet training or additional help at home, as well as transitioning to other grades. Parent 5 stated that she had gone to quite a few parent support meetings, guided by a close friend, who steered her in the right direction for the
purpose of gathering information for an out-of-school district placement and to understand special education law. She stated that the parent groups did not specifically meet her needs as a parent. The meetings covered a range of topics, which were not necessarily aligned with the needs of her 6-year-old child. The bulk of the trainings, she stated, focused on specific topics, and they did not pertain to many of the parents in the audience. Those parents were at a loss. She stated that her focus was just attending trainings of the advocates she was most familiar with as well as working to ensure her son remained in his current placement.

Table 4.7 describes the themes and sub-themes that emerged from Research Question 3, and it includes the parents’ perspective of their children’s behavior, their diagnosis, and the onset of symptoms as indicators of the disorder. Table 4.8 describes the themes that emerged from Research Question 3 from the pediatricians’ perspectives, and Table 4.9 lists the themes and sub-themes relating to the pediatricians’ knowledge about the services available to assist children diagnosed with autism.
<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limited Knowledge</td>
<td></td>
</tr>
<tr>
<td>Parent 1</td>
<td>Internet searches.</td>
</tr>
<tr>
<td></td>
<td>I had no idea.</td>
</tr>
<tr>
<td></td>
<td>The pediatrician really didn’t explain what autism was.</td>
</tr>
<tr>
<td></td>
<td>They kind of explained it in a broad way.</td>
</tr>
<tr>
<td>Parent 2</td>
<td>I went straight to blaming myself, I googled, there was so much research.</td>
</tr>
<tr>
<td>Parent 3</td>
<td>I really had no clue.</td>
</tr>
<tr>
<td></td>
<td>My own research.</td>
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<tr>
<td></td>
<td>That’s all the information I got.</td>
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<tr>
<td></td>
<td>ABA, I didn’t even know what that stands for.</td>
</tr>
<tr>
<td>Parent 4</td>
<td>I had no clue, I had no suspicion. I started to do a lot of research.</td>
</tr>
<tr>
<td></td>
<td>I did a lot of Internet searchers; took my cue from an article.</td>
</tr>
<tr>
<td></td>
<td>I had no knowledge; I was scared to talk to the school about it.</td>
</tr>
<tr>
<td>Parent 5</td>
<td>Certain things I thought were normal for him.</td>
</tr>
<tr>
<td></td>
<td>She’s not really telling me; she’s not qualified to tell me he has autism.</td>
</tr>
<tr>
<td>Symptoms</td>
<td></td>
</tr>
<tr>
<td>Parent 1</td>
<td>Did not respond to his name; was not typically developing.</td>
</tr>
<tr>
<td>Parent 2</td>
<td>Constant drawing all the time.</td>
</tr>
<tr>
<td></td>
<td>She didn’t eat, didn’t socialize.</td>
</tr>
<tr>
<td></td>
<td>He never looked at the speaker.</td>
</tr>
<tr>
<td></td>
<td>Poor social skills.</td>
</tr>
<tr>
<td></td>
<td>He was very verbal.</td>
</tr>
<tr>
<td></td>
<td>He was very self-directed.</td>
</tr>
<tr>
<td>Parent 3</td>
<td>Not typically developing.</td>
</tr>
<tr>
<td></td>
<td>Not developing like my other two children.</td>
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<tr>
<td></td>
<td>Not giving me eye contact.</td>
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<tr>
<td></td>
<td>Not smiling; no emotional connection.</td>
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<tr>
<td></td>
<td>He was withdrawn.</td>
</tr>
<tr>
<td></td>
<td>He was not babbling; no speech.</td>
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<tr>
<td></td>
<td>He would not respond to me.</td>
</tr>
<tr>
<td></td>
<td>Lack of speech.</td>
</tr>
<tr>
<td>Parent 4</td>
<td>Poor eye contact.</td>
</tr>
<tr>
<td></td>
<td>Behavior issues.</td>
</tr>
<tr>
<td></td>
<td>Turn lights on.</td>
</tr>
<tr>
<td></td>
<td>Banging doors.</td>
</tr>
<tr>
<td></td>
<td>Lack of speech.</td>
</tr>
<tr>
<td>Parent 5</td>
<td>Lack of speech.</td>
</tr>
<tr>
<td></td>
<td>Poor fine motor skills.</td>
</tr>
</tbody>
</table>

Table 4.7

*Themes and Sub-Themes That Evolved from Research Question 3 from the Parents*
# Table 4.8

## Themes and Sub-Themes That Evolved from Research Question 3 from the Pediatricians

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-Themes</th>
</tr>
</thead>
</table>
| Evolution of Diagnosis | Majority of the pediatricians were familiar with Early Intervention.  
Referred parents for services. |
| Pediatrician 1 | Special schools.  
Diagnosis not so common when he started. |
| Pediatrician 2 | Developmental pediatricians usually get involved.  
Many years ago, diagnosis very different.  
We referred to Early Intervention (EI). |
| Pediatrician 3 | I don’t use any instruments.  
They come to me diagnosed and tested.  
I encountered a child with delays; repetitive behaviors and treated with strong psychopathological agents. |
| Pediatrician 4 | A Diagnosis can be simple based on observation. I rely on the developmentalists and neurologists for confirming my diagnosis and supporting me as well. I use the M-CHAT at 1 and 2 as a base for diagnosis then move forward to neuropsych testing. |
| Pediatrician 5 | Child with classic signs of Asperger’s diagnosed as mildly retarded.  
Diagnosis not so common.  
At the onset of the disorder, autism was not a well-known entity and most of the children he saw were very ill and had self-injuring behavior. |
Table 4.9

Themes and Sub-Themes That Evolved from Research Question 3 Relating to the Pediatricians’ Knowledge About the Services Available to Assist Children Diagnosed with Autism

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Services are more common along with diagnosis</td>
<td>Early Intervention available</td>
</tr>
<tr>
<td>Applied behavior analysis (ABA) used by all parents</td>
<td>Speech and occupational therapy are common</td>
</tr>
<tr>
<td></td>
<td>Special instruction and adaptive skills services</td>
</tr>
<tr>
<td>Test hearing</td>
<td>Rules out medical concerns through hearing test</td>
</tr>
<tr>
<td>M-CHAT used by several pediatricians</td>
<td>Several programs available at Board of Cooperative Educational Services (BOCES), North East Consortium, Westchester Jewish Community System, Center for Autism and the Developing Brain (CADB)</td>
</tr>
<tr>
<td>Testing or assessment instruments:</td>
<td></td>
</tr>
<tr>
<td>Language screen</td>
<td>Family history</td>
</tr>
<tr>
<td>Bright Futures</td>
<td>Early Intervention (EI)</td>
</tr>
<tr>
<td></td>
<td>Communication and Symbolic Behavior Checklist Development Profile (CSBCDP)</td>
</tr>
</tbody>
</table>

Research question 4. What are the treatment options available for children as it relates to the learning environment, and what treatments have been found to be the most effective and why? All of the parents interviewed reported that the Early Intervention service was the first step toward treatment options. Parents, as well as pediatricians, reported applied behavioral analysis (ABA) was an important resource. ABA helps
children with developing adaptive living skills. During the researcher’s data collection, this was the training methodology that was most referenced by parents. The majority of the pediatricians used screening tools in their initial evaluations for potential signs of autism.

The Modified Checklist for Autism in Toddlers (M-CHAT) was the most common screening used by three out of the five pediatricians. The M-CHAT is a standard screening tool used to exam traits in children’s behavior for possible signs of autism. It is used by pediatricians with young children in the toddler age. The questions are geared toward best practices in child development. The primary use of the M-CHAT is to determine whether or not the child displays behavior traits indicative of autism spectrum disorder. The structured questions used in the M-CHAT are related to the child’s hearing, affect, social interactions, and processing of sensory information. Pediatrician 5, as well as Pediatrician 4, referred children for hearing testing during their initial evaluation for autism. Pediatrician 5 noted, “its criminal to give a child a diagnosis of autism without doing a hearing test, because you know the great imposter is hearing loss.” Parent 1 stated, “then came a point where we would ask him questions, or especially, the red flag was to call him by his name, and he would just, like, it’s like he was deaf.” According to Kanner’s (1943) research, many children on the autism spectrum were misdiagnosed with hearing loss. Pediatricians 4 and 5 also noted the importance of further neurological testing to ensure that the diagnosis is the most accurate. Pediatrician 5 further asserted:

You get to know who has an interest in children with this disorder. It’s not like going to the dentist and every dentist knows how to fill a tooth. You have pediatric neurologists who are interested in seniors. You got neurologists who are
interested in muscle disease, and there are pediatric neurologists who are
interested in language disorders or autism. So, if you know who’s around and
where you are, that often is a good source.

Table 4.10 details the services parents obtained for their children as well as the
parents’ reactions upon learning of their children’s diagnosis. In addition, the table
specifies what prompted their concerns as well the services their children received.

Table 4.10

| Themes and Sub-Themes That Evolved from Research Question 4 from the Parents |
|---|---|
| Themes | Sub-Themes |
| Similarity in services received by children | Applied Behavior Analysis (ABA), speech, occupational therapy. The parents’ treatment options chosen were consistent with offerings through Early Intervention and committee on preschool special instruction and special education. |
| Speech delays | Expressive and language skills lacking. All parents stated their concerns for their children’s development resulting from their children’s lack of speech. |
| Parents in need of additional resources | Lack of parenting supports available. The majority of the parents did not note that parent training or parent support were factors in their decisions regarding treatment options. |
| Lack of knowledge | Parents are ill informed about the services that are available for their children, and they do not seek out as many supports as they should to obtain support. |
| Parents’ feelings | Parents were overwhelmed, numb, blamed themselves. They turned to the Internet for support and did not have family or parent training or other supports in place to assist them with treatment options. |

According to the data analysis and the coding for themes and sub-themes, parents noted that the majority of the children diagnosed with autism receive the follow services:
(a) speech therapy, as many experienced receptive and expressive delays in their speech; (b) applied behavioral analysis, to support their behavior management and to assist them with learning new skills; and (c) occupational therapy, to assist them with adaptive skills. Two children of the children had physiological challenges: adenoids removed, sleeping difficulty, poor eating, and flat feet.

Applied behavior analysis addresses issues such as perseverant drawing, turning lights on and off, behavioral challenges, lining up objects, poor eye contact, and social skills development. Pediatrician 1 stated, “I keep a database of social service providers and psychiatrists for my patients; otherwise, it’s very difficult to infiltrate the system, I find.” In reviewing further the comments of Pediatrician 1, the statement surmises that if pediatricians do not collect well-regarded resources they stumble upon during their interactions with other professionals and families, it’s difficult to ascertain what is best for families. He further stated that unless a resource is recommended by a reliable source or he had an opportunity to research further a resource referred, he would not place it on his list of resources for parents. He did not want to give parents misinformation. He also stated that he relied heavily on the state-supported system, Early Intervention.

As indicated in the Table 4.10, ABA was identified as the primary treatment utilized by the families to support their children’s diagnosis of autism. Lovaas’s (1987) contributions to the research of applied behavioral analysis has served as the catalyst for existing treatment methodologies supporting children on the autism spectrum in the learning environment (Sallows & Graupner, year). As indicated by his seminal research study, children diagnosed with autism spectrum disorder significantly improved developmentally, cognitively, and socially upon receiving the Lovaas (1987) model of
applied behavior analysis, in comparison to a control group. Lovaas’s study indicates more than half of the children who participated in ABA treatment achieved a normal IQ as well as increased adaptive and social skills. As it relates to this study, applied behavioral analysis was the primary treatment methodology implemented in the learning environment with the children of the parent participants. According to the research of Cooper et al. (2013), applied behavioral analysis has many benefits for children with autism spectrum disorder in the learning environment. As it relates to children’s learning environment, ABA focuses on children’s social, adaptive, and cognitive skills. ABA breaks down concepts and provides a smaller context for children to learn day-to-day skills. An example of this is teaching a child to tie his or her shoes. ABA would outline visually, or in writing, each step required to learn how to tie one’s shoes. This task analysis would be repeatedly used to support teaching the child this concept. Other examples of ABA in the learning environment are visual schedules with or without words and using positive reinforcement.

As it relates to the other treatment options discussed in this study, the parents who participated identified related services such as occupational therapy, physical therapy, special instruction, speech therapy, applied behavioral analysis, prompt speech, and the TEACCH methodology as methods of treatment implemented over time with their children.

Summary of Results

The summary of the results indicates that minimal information was available to the parents at the onset of their children’s diagnosis of autism. The parents overly relied upon web-based resources, upon hearing the term “autism.” As affirmed by this current
study, and the research of Rhoades et al. (2007), the parents received very little information beyond their children’s initial diagnosis. The majority of the parents interviewed utilized the services of Early Intervention, a state-funded resource for young children with disabilities, and the services of the Committee on Pre-School Special Instruction (CPSE) and the Committee on Special Education (CSE). The majority of the children obtained applied behavioral analysis to address cognitive and social deficits. The parents interviewed identified the primary age of diagnosis between 2 and 3 years of age. With regard to the pediatricians, they varied in their knowledge levels, training, and communication with parents about their children’s developmental disability.

As indicated in the research of Mack (2008) and Shyu et al. (2010), most pediatricians do not perform any advance testing of children for the disorder or provide additional information to parents. The pediatricians in this study primarily relied upon another developmental specialist and state-funded agencies. As it pertains to the training related to children with autism, some pediatricians participated in training several years previously, while for others it was ongoing. The research of Major et al. (2013) identifies a need for ongoing training of physicians working with children diagnosed with autism. Moreover, the research of de Wolfe (2013) indicates a need for parent resources, and the research of Beaudoni et al. (2014) and the Beaumont Health System (2017) references the important of training for pediatricians working with children diagnosed with autism. As it relates to the learning environment, the most widely researched and referenced treatment approach used in the learning environment for children diagnosed with autism is ABA. Applied behavior analysis is written about early in the research, and it is an early intensive behavioral intervention, which provides support for children on the autism
spectrum. Within the learning environment, it provides a structural approach for children with ASD to understand abstract concepts as well as support children’s social development (Dawson, 2013; Smith et al., 1993). Other state-mandated supports available to families, such as occupational, physical, and speech therapy, focus on physical, sensory, language, and tactile skill development. According to the research of Gray and Garland (1993), social stories, visual cues, and visual schedules are effective approaches to implement in the learning environment of children with autism. They state that children diagnosed with autism require opportunities for inclusion with typically developing children in the learning environment, with collaboration across classrooms being important, and alternative socialization approaches help children with autism adapt to social situations, and it strengthens their ability to learn overall.

Researchers Mack (2008) and Shore (2008) posited that there are a vast number of complementary and alternative treatment options marketed to families. These alternative treatment therapies include: horse, vitamin, and chelation therapy; augmented communication devices; the floortime approach; relationship development intervention (RDI); and the Denver model to support children within the learning environment. The parents interviewed as part of this study opted out of the use of these metaphysical, vitamin, horse, or non-conventional treatment approaches. The parents relied primarily on state-funded programs to meet the learning needs of their children. As indicated by the parent interviews, the state-funded programs support the use of the widely researched empirical model of applied behavioral analysis theory. Further, the parents did not seek out their pediatricians to assist with identifying the best treatment options (Schopler et al., 1982). The parents also used the treatment intervention, ABA, as well as other related
services including occupational, speech, and physical therapy. The parents did not reference other treatment approaches.

Similar to the research of Hall (2011), Mack (2008), and Mann (2013), this study’s parent participants were global in their perspective and ancestry. The first parent was born in Ecuador, the second parent emigrated from Ireland, the third was from Cameroon, the fourth had African American roots and was born in New York, and the fifth parent was from Bangladesh.

According to the research of Mann (2013), pediatricians play a significant role in the treatment, diagnosis, and care of children on the autism spectrum. The pediatricians who participated in this study were White, predominantly of Eastern European ancestry, and in their mid-to-late ’50s up to the early ’70s in age. Their ages are significant to the research because they were able to observe the transformation of diagnosis, treatment, and services over time. As noted by Pediatrician 5, “a lot has evolved in diagnosis from the time I began caring for children now identified as autistic.”

The data analysis supports the commonality among the pediatricians in relationship to their central location, Westchester, as well as their commitment to diverse patient populations and developmentally challenged children. As stated earlier by Pediatrician 3, his patient population is 100% atypically developing children.

According to the findings of this study, parents are in need of ongoing support to assist them with understanding their children’s diagnosis of autism and the implications for their children’s futures. The emerging themes indicated for the parents by this study were that they: (a) had no idea what autism was, (b) relied heavily upon the Internet to obtain information pertaining to the disorder, (c) had no input in the treatment
interventions chosen, and (d) had limited knowledge regarding services available to assist their children. As far as the pediatricians were concerned, the results indicate that:

(a) many received training related to autism spectrum disorder more than 20 years ago, (b) only one was involved in continuous training, and (c) several named services that may be available to parents, however, the majority referred the parents out to specialists, rather than completing any advanced testing. The research of Mann (2013) outlines that a diagnosis of autism in young children is complex, and pediatricians and patients’ parents require training to obtain an understanding of its impact on their child, themselves, and their families.

Chapter 5 details the implications of the findings, the limitations to the research, the recommendations, and the conclusions.
Chapter 5: Discussion

Introduction

In Chapter 5, the researcher discusses the implications of the findings related to the research, states the limitations, gives recommendations, and finalizes with the conclusions. The purpose of this study was to identify the impact of a diagnosis of autism spectrum disorder on treatment options available, within the learning environment, at the onset of a diagnosis of autism spectrum disorder (ASD) from the perspective of parents and pediatricians. The research was conducted to identify what parents know at the onset of a diagnosis as well as what pediatricians know about autism. A qualitative analysis design using open-ended interview questions was used to gather the perspective of the participants. The researcher interviewed five parents and five pediatricians to gain their perspectives on the impact of a diagnosis of autism spectrum disorder on their treatment methodology. The participants met individually with the researcher.

Implications of Findings

This study identified similarities in the themes of research highlighting the needs of families coping with a diagnosis of autism. First, as noted in the research of Beaudoni et al. (2014) and Hall (2011), parents are ill equipped to deal with a diagnosis of autism. Without proper research or training related to best practices about treatment options, parents lack the resources to appropriately participate in their children’s treatment interventions that are implemented in their learning communities (Feinstein, 2011; Green et al., 2006; Ślifirczyk et al., 2013). Second, the training of pediatricians has not evolved,
although the disorder has evolved considerably (Warren, 2017), and the training of pediatricians has remained stagnant while the disorder has evolved (Major et al., 2013).

As indicated by the research of Hall (2011), Igwe et al. (2011), Kamei (2013), Mack (2008), and Mann (2013), the importance of a timely diagnosis, the awareness of treatment interventions, and the support of parents’ knowledge helps not only to strengthen and foster relationships with parents and pediatricians, but these help also to build the foundation to a relationship that ultimately supports the children diagnosed with autism. These relationships are a critical foundation to the treatment options for children and pediatricians in support of their families. The existing research from the Centers for Disease Control and Prevention (2014) demonstrates the rate of autism diagnoses continues to rise. Furthermore, the research of Brentani et al. (2013) indicates that collaboration among parents and pediatricians provides the right opportunities for children to obtain an earlier diagnosis of autism and, therefore, start treatment earlier.

Limitations

The researcher randomly selected the order in which she chose to interview the participants. This was based upon the participants’ availability as well as her ability to secure the interviews. The process of scheduling, as well as securing the interviews, with the pediatricians proved to be a challenging process in the research. The researcher contacted more than 40 providers before she was able to secure the five participants. While eager to support, it was difficult for many to find the time to participate. This was due to the nature of pediatricians’ work, their patient caseloads, and the limited time constraints of their practices. As the research indicates, the size of the pediatricians’ practices varied from 30 up to 3,000 patients. Many of the doctors reached out to their
colleagues in support of the researcher, however, many were unable to commit. Two of
the pediatricians were able to refer their colleagues, and the researcher contacted the
Town Supervisor where she lives, which proved to be helpful.

A limitation in the study was the sample size. The researcher would have liked to
interview twice the number of participants, for a total of 10 pediatricians and 10
children’s parents. Increasing the sample size might have helped to support the emerging
themes and would have provided additional data. Similar to the diverse parent population
that was interviewed, the researcher would have liked to interview some pediatricians of
color, specifically those serving a ethnogeographically diverse parent population. The
researcher would have also liked to interview more female pediatricians as well as to
complete a comparison study of younger pediatricians’ experience and knowledge with
that of an older group of pediatricians’ experience and knowledge.

**Recommendations**

As indicated in tables, the parents were unaware of the types of treatment options
available. The parents stated they were overwhelmed and at a loss as to what to do next,
once they received their children’s diagnosis. The learning environment is a critical
aspect that supports children’s cognitive, social, emotional, and physical development.
Applied behavioral analysis has been entrenched in more than 30 years of empirical
research to support its approach with children on the autism spectrum. A
recommendation from the researcher is to provide additional hands-on training for
parents to increase their knowledge of ABA as well as the benefits of the treatment. In
addition, it is important to familiarize parents with empirically based approaches that
support their children’s learning within their school environments. With the exception of
parent-influenced programs, such as early intervention, treatment and the education of autistic and communication-related handicapped children (TEACCH), the relationship development intervention (RDI), the developmental individual-difference, and the relationship-based (DIR) models touted parent involvement, yet the parents were often excluded from many day-to-day treatment interventions with their children. The research of Lovaas (1987) indicates for an early intensive behavioral program to be effective, parent involvement is essential to the implementation and success of the program. In addition to behavioral-intensive approaches early in the diagnostic process, parents require support with service coordination and attending meetings related to their children’s service plans and needs. Parents are often unfamiliar with the language used by related service providers. Related service providers are identified as occupational, speech, special education, and physical therapists. Often too embarrassed to state their confusion, they struggle to find a commonality with the parents of typically developing children, and they struggle to find support that uniquely identifies their needs (Bennet, 2012). In support of the outcomes of this research, the researcher recommends that prior to evaluation and screening, and to reduce delays, parents should have training, as well as informational sessions, provided by health care professionals or organizations to support the parents with concerns about their child’s development. These actions would assist parents with their understanding of treatment options, the methods available, and the best approaches to use with their child. In addition to receiving services, parents could be proactively involved and participate in supporting their understanding of the treatment interventions.
Similar to the parent training utilized in the tenets of the TEACCH approach (Schopler & Reichler, 1971), as well Lovaas (1987) method, effective parent training models serve as a spring board for best-practices models to implement with young children diagnosed with autism, as well as to provide a way to implement early intensive behavior approaches that yield positive results. These approaches assist with ongoing parent training to bridge the gap between home and school. These approaches also provide motivation for parents to remain proactively involved in their children’s service planning (Autism Speaks, 2015; Beaumont, 2017).

Often, as noted by the data collection, parents are dealing with considerable shame and guilt related to their children’s diagnosis, so much so, that they isolate themselves. As identified by the research of de Wolfe (2013), networks for parents to obtain resources, as well as network with other families, is important. Parent training assist parents with service coordination meetings, decoding language used during service planning meetings, writing letters to the district, resources for applying for services, training to assist families with understanding what they are entitled to, and training on understanding the approaches implemented with their children. An example of this is applied behavior analysis (ABA), because it is an empirically based model that has more than 30 years of research to support its approach. Most parents have no idea about the importance of data collection when implementing ABA. Families have limited cognitive understanding of the process and or what families are entitled to as well as understanding of how this method works. Parent training and education programs are needed to assist families with children diagnosed with autism. Parents of children with autism must have some control over the narrative concerning their children by participating in research.
developments. For pediatricians, the research has indicated many rely too much on developmental pediatricians. It is important for general pediatricians to have training available to them through multiple avenues to enact changes that lend themselves to earlier identification, early intervention services, and parent resources. By doing so, this will allow pediatricians to work closer with families, increase their involvement in service planning for such a vulnerable population, and assist with recommendations where appropriate.

Training would also increase pediatricians’ knowledge as well as enable them to direct parents appropriately toward support groups and treatment approaches. The research has shown that the number of children diagnosed with autism spectrum disorder has expanded considerably (Autism Speaks, 2013). The research of Mack (2008) and Hall (2011) states that providing additional training for doctors is necessary. Moreover, the researcher’s interviews stipulated that the training these pediatricians received in residency was antiquated. Furthermore, their training did not meet the needs of a population of children that is vastly different intellectually. Last, autism is currently the number-one developmental disability, and the number of children diagnosed is expanding. The research of Saggu (2015) posits that parents must be actively involved in advocacy efforts to ensure their children’s needs are heard and met through state legislation and that those in office understand all of their constituents.

Conclusion

The major conclusion of this study is that parents and pediatricians must be in partnership to support children diagnosed with autism, one of the most vulnerable populations (Farrugia, 2009). Parents, as the research indicates, have worked tirelessly to
understand a disorder that has a lifelong impact on their children’s health, well-being, and future. It is important to provide the most relevant and available resources to families in this critical time in their children’s development.

Additionally, pediatricians must strengthen their existing work with families by obtaining as much information as possible for parents who come to them and who are vulnerable, unaware, and without an inclination of what to do or what their next steps should be. The research of Symon (2005) indicates that it is essential that parents receive the proper training and support to assist them in serving as an effective advocate in their children’s lifelong journey.

Another conclusion is that the parents were not aware of the types of treatment options available in the learning environment. During the parent interviews, parents discussed that they did not understand their children’s diagnosis and sought answers using the Internet. They were unaware of what treatment options were available. There are cultural and language barriers that impact parents’ ability to be advocates for their children (Ennis-Cole, Durodoye, & Harris, 2013; Fox, Aabe, Turner, Redwood, & Rai, 2017; Kuenzli, 2012).

A major conclusion of this study is that many parents who participated in this study had no idea what autism was, had no clue what to do next, were overwhelmed, and were in need of support. Another conclusion is that the parents relied too much on the Internet, which is filled with inaccurate information. These parents said that, over time, the most beneficial support came from the relationships they cultivated with their children’s teachers, their health care providers, and from other parents. Of the pediatricians interviewed, many participated in extensive training many years ago. The
pediatricians who participated in more recent training endeavors had a vested interest
either professionally or personally. They, too, like the parents, had become advocates for
a population that has been misunderstood, misdiagnosed, and misrepresented. Parent
training, as well as pediatric training, must be available to support the increased needs of
families impacted by the diagnosis of autism.

As previously discussed, the timing, treatment interventions, and information are
critical to the needs of families as well as pediatricians caring for children with autism.
For parents, it leads to less uncertainty, anxiety, and confusion. Pediatricians are in a
unique position to assist families of children diagnosed with autism and help families
increase their quality of life.

The treatment needs of individuals with autism are diverse and vast, with some
children receiving up to 40 hours of ABA in a one-on-one behavioral therapy. Most states
allow for insurance to reimburse or cover the cost ABA services. This is largely due to its
scientifically based research. Parents attempting to introduce lesser known models into
their children’s treatment interventions, such as sensory integration therapy, music
therapy, dietary therapy or equestrian therapy, must finance the cost. Further
recommendations of the researcher are to:

1. ensure treatment interventions are available to families. Insurance, as well as
   fiscal constraints, make treatments prohibitive for many families. This
   includes developmentally appropriate recreational activities that meet the
   needs of children with autism;
2. create an infrastructure that supports parent involvement and inclusion in their children’s treatment interventions, knowing that parents have multiple responsibilities and complicated lives;

3. provide family therapy;

4. provide a list of highly recommended research-based and parent-friendly articles that help parents navigate their new normal.

5. advocate for parents to work more proactively regarding their children’s diagnosis and become better advocates to assist them in raising a child with ASD.

6. conduct a study of pediatricians who are in the 30–40-year-old range to gain a broader perspective from their point of view.

As a researcher, I am also committed to the following next steps related to my research: (a) writing articles to support families of children diagnosed with autism; (b) conducting workshops and training to prospective teachers and for families; (c) starting a blog for parents of children with ASD; and (d) writing a grant to assist with further research in this area.

Since the initial research of Kanner (1943), well over 50 years ago, depicting 11 vastly different children exhibiting symptoms of autism, there have been tremendous gains in the research. This includes the development of parent advocacy groups, parents as researchers contributing significantly to the field, as well as increased resources available to families caring for children with autism. However, the research is vast as well as complicated. It is changing every day along with the needs of families. A well-known quote by Shore (2008) indicates that “if you have met a child with autism, you
have met one child diagnosed with autism” (92 Favorite Quotes About Autism, 2017, para. 1). Each child’s needs are very different, and parents, similar to their children, require resources, support, and training. Hall (2011) stated, “It takes a village to raise a child. It takes a child with autism to raise the consciousness of the village” (92 Favorite Quotes, 2017, para. 2). Last, Dr. Ivar Lovaas noted, “If a they can’t learn the way we teach, we must teach the way they can learn” (AZ Quotes, n.d., para. 1).
References


Begley, S., & Interlandi, W. J. (2009, March 3). Anatomy of a scare: When one study linked childhood vaccines to autism, it set off a panic. The research didn’t hold up, but some wounded families can’t move on. *Newsweek, 43.*


Hall, S. E. (2011). *Factors affecting parents’ decisions to treat their children with autism spectrum disorder with complementary and alternative treatments* (Unpublished doctoral dissertation). Texas A&M University, College Station, TX.


Sallows, G., & Graupner, G. (2001). *Replicating Lovaas: Results after three years.* Presented at the 27th Annual Convention of the Association for Behavior Analysis, New Orleans, LA.


Appendix A

Recruitment Script

Parent and Pediatrician Introductory Letter and Consent Form

<table>
<thead>
<tr>
<th>Introduction Key Component</th>
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<tbody>
<tr>
<td>My name is Cecilia Scott-Croff. I am the Executive Director of a Campus-Based Children’s Program at the Borough of Manhattan Community College, as well as an Adjunct Faculty Member. I am a doctoral student at St. John Fisher College, in Rochester, NY, at the College of New Rochelle campus. As part of my doctoral studies, I will be conducting research to identify the knowledge level and treatment option outcomes from the perspectives of parents and pediatricians, at the onset of a child’s diagnosis of autism. The research project is entitled: “The Impact of a Diagnosis of Autism Spectrum Disorder on Nonmedical Treatment Options from the Perspectives of Parents and Pediatricians.”</td>
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<tr>
<th>Questions</th>
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<tbody>
<tr>
<td>As a former parent who has attended the Borough of Manhattan Community College and has a child diagnosed with autism who is at least 18 years of age, and/or as a pediatrician who has worked with autistic children in his/her practice, your voluntary participation in this study is integral to its success in gaining a body of knowledge in this field. Therefore, this Introductory Letter and Consent Form is your invitation to participate in this study. Your participation is voluntary. For parents previously enrolled at the college, participation in this study will not influence your grade, impact your courses or your access to child-care, if required in the near</td>
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</table>
future. Your instructors will not have any knowledge of your participation. For pediatricians who volunteer to participate, your input is vital in addressing the needs of a growing population of children diagnosed with Autism Spectrum Disorder.

If you volunteer to participate, you will receive a $10-dollar gift certificate from Barnes and Noble bookstore and you may request a copy of the completed study.

If you choose to participate in this study, you will be asked to meet with this researcher at a mutually agreed upon time. All interviews will be recorded in order to transcribe the data and note emerging themes. No names or personal information will appear on any documents. All participants will be coded with pseudonyms in order to maintain confidentiality and anonymity. All data collected will be stored in a locked cabinet in the researcher’s home and will be destroyed after completion of the study. If at any time you wish to withdraw from this study, you are free to do so. There is no penalty for withdrawing.

Thank you for taking the time to consider being a part of this project. It may help us understand how to assist parents, as well as pediatricians, with gaining new knowledge in this field.
Appendix B

Inform Consent

PERMISSION FORM

FOR PARENTS/PEDIATRICIAN PARTICIPATION IN RESEARCH

**Project Title:** The Impact of a Diagnosis of Autism Spectrum Disorder on Nonmedical Treatment Options In the Learning Environment from the Perspectives of Parents and Pediatricians

**Principal Investigator:**
Cecilia Scott-Croff, M.S. Ed.
Doctoral Student

**Site where study will be conducted:**
Westchester County, New York

**Committee Chair:**
Dr. Jennifer Schulman

**Committee Member:**
Dr. Janet B. Lyons
Introduction/Purpose: You are invited to participate in a research study. The study is conducted under the direction of Cecilia Scott-Croff, Doctoral Candidate at St. John Fisher College, at the College of New Rochelle campus, in New York. The purpose of this research study is to better understand parents and pediatricians’ perspectives on information available at the onset of a child’s diagnosis of autism spectrum disorder (ASD), leading to effective nonmedical treatment options in the learning environment. The results of this study will provide parents and pediatricians with support and assistance for families with a child diagnosed with ASD so that they may be better equipped to collaborate about how to assist their ASD child.

Procedures: Each participant will complete a demographic questionnaire and a semi-structured interview. The time commitment of each participant is expected to be approximately 45-50 minutes. Interview sessions will be recorded in order to examine and gain in-depth perceptions of this phenomenon from the participants. Each session will take place at a mutually agreed upon location, such as a doctor’s office, parent’s home or local library.

Potential Benefits: Through your participation, research in this field will assist other parents and pediatricians in gaining an understanding of what information is available to families and to pediatricians, and how this impacts available nonmedical treatment options in the learning environment.

Possible Discomforts and Risks: The risks and discomfort associated with participation in this study are estimated to be no greater than those ordinarily encountered in daily life. This may include possible fatigue or frustration. To minimize these risks, participants who feel uncomfortable will be told that they may stop participating at any time. The study will be discontinued if they become uncomfortable.

Voluntary Participation: Your participation in this study is voluntary, and you may decide to withdraw from participation at any time without prejudice, penalty, or loss of benefits in which you are otherwise entitled. If you decide to remove yourself from the study, please contact the principal investigator, Cecilia Scott-Croff, ____________ to inform her of your decision. For your time, parent volunteers, as well as pediatricians, will be given a gift card worth $10 and access to all study results, if requested.

Confidentiality and Anonymity: The information obtained from the interviews, in addition to being recorded, will include written notes taken by the researcher. To protect the participants’ confidentiality, the records of this study will be kept strictly confidential. In order to ensure anonymity, data from the recordings will be coded so that no names will appear on any documents. This information will be stored at the researcher’s home so it is free of any identifying information. When the study is completed, these documents will be destroyed.

Contact Persons / Questions: If you have any questions about the research now or in the future, please contact the Institutional review board at St. John Fisher College at ____________. If you have questions about your rights as a research participant, or you
have comments or concerns that you would like to discuss with someone other than the researchers, please call the St. John Fisher College Institutional Review Board, (___) ________ or email at ____________. Alternately, you can write to:

St. John Fisher College
Attn: Research Compliance Administrator
St. John Fisher College
3690 East Avenue
Rochester New York 14618

Statement of Consent:
“I have read the above description of this research and I understand it. I have been informed of the risks and benefits involved, and all my questions have been answered to my satisfaction. Furthermore, I have been assured that any future questions that I may have will also be answered by the principal investigator of the research study. I voluntarily agree to participate in this study. By signing this form, I have not waived any of my legal rights to which I would otherwise be entitled. I will be given a copy of this statement.”

I, ________________ (name) agree to participate in this study. I understand that I can withdraw from the study at any time without penalty and that my personal information will be anonymous and confidential through the use of pseudonyms in place of any name or contact information.

I agree to have my interview session recorded for this study. All records are confidential. Please check one: ☐ Yes ☐ No

<table>
<thead>
<tr>
<th>Printed Name of Parent / Pediatrician</th>
<th>Signature of Parent/Pediatrician</th>
<th>Date Signed</th>
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<tr>
<th>Email Address of Parent / Pediatrician</th>
<th>Phone Number of Parent/Pediatrician</th>
<th>Date Signed</th>
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<tr>
<th>Printed Name of Researcher</th>
<th>Signature of Investigator</th>
<th>Date Signed</th>
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For more information,
Contact: Cecilia Scott-Croff, at ________________
Phone: ________________
Chair: Dr. Jennifer Schulman
IRB: ________________
Appendix C

Interview Protocol

Name: Cecilia Scott-Croff, Doctoral Candidate, St. John Fisher College

Chair: Dr. Jennifer Schulman

Purpose of the Study: To identify the perspectives of parents and pediatricians concerning nonmedical treatment options available in the learning environment at the onset of a child’s diagnosis of autism.

How the research will be used: To enhance the existing literature in the field concerning nonmedical treatment options in the learning environment at the onset of a diagnosis of autism.

Benefits or Risk: There is minimal risk to participants

Length of Interview: 45 to 50 minutes

Qualifications for Participation: Former attendees of Borough of Manhattan Community College with a child diagnosed with autism. Resident of Westchester County. Eighteen years or older. Pediatricians working with children and families or formerly working with families who have received a diagnosis of autism. Where interview will take place: At participants preferred location. For pediatricians, interviews may take place at their office or a mutually agreed upon location. For parents, interviews may take place in their home, library, or a mutually agreed upon location.
Appendix D

Interview Research Questions

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<tr>
<td>1.</td>
<td>What information is available to parents at the onset of their child’s diagnosis of autism?</td>
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<tr>
<td>2.</td>
<td>What are the current levels of knowledge of parents and pediatricians at the onset of a child’s diagnosis of ASD?</td>
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<tr>
<td>3.</td>
<td>How are treatment methods appropriately aligned when parents and pediatricians are better informed regarding a child’s diagnosis of ASD?</td>
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<tr>
<td>4.</td>
<td>What are the treatment options available for children as it relates to the learning environment and what treatments have been found to be the most effective and why?</td>
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Appendix E

Demographics Information (Parents)

For parents, this would consist of information such as the following:

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<tbody>
<tr>
<td>1.</td>
<td>Age range of parents. Put in the ranges</td>
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<tr>
<td>2.</td>
<td>Number of children</td>
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<tr>
<td>3.</td>
<td>Birth order of the child with ASD</td>
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<tr>
<td>4.</td>
<td>Type of treatment option currently chosen for ASD child</td>
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<tr>
<td>5.</td>
<td>Where participants live</td>
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<tr>
<td>6.</td>
<td>Levels of education of parents</td>
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<tr>
<td>7.</td>
<td>Ethnicity</td>
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<td>8.</td>
<td>Marital status</td>
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<td>9.</td>
<td>Parent occupation</td>
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<td>10.</td>
<td>Age when their child was diagnosed with ASD</td>
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<td>11.</td>
<td>School environment of their child – private/public</td>
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<tr>
<td>12.</td>
<td>Type of pediatrician</td>
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Appendix F

Demographics (Pediatricians)

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<tbody>
<tr>
<td>1.</td>
<td>Age, gender, and ethnicity</td>
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<tr>
<td>2.</td>
<td>Number of years they have been in practice and in this assignment</td>
</tr>
<tr>
<td>3.</td>
<td>Size and location of practice</td>
</tr>
<tr>
<td>4.</td>
<td>Ethnicity of parents served</td>
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<tr>
<td>5.</td>
<td>Number of courses taken or training completed in ASD</td>
</tr>
<tr>
<td>6.</td>
<td>Number of children in their practice identified with ASD</td>
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<tr>
<td>7.</td>
<td>Practice setting: hospital/private/urban/suburban</td>
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<td>8.</td>
<td>Hours open</td>
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<tr>
<td>9.</td>
<td>Best time for interview</td>
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Appendix G

Demographics (Pediatricians) (Repeated)

<table>
<thead>
<tr>
<th>1. Age, gender, and ethnicity</th>
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<tr>
<td>2. Number of years they have been in practice and in this assignment</td>
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<tr>
<td>3. Size and location of practice</td>
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<tr>
<td>4. Ethnicity of parents served</td>
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<tr>
<td>5. Number of courses taken or training completed in ASD</td>
</tr>
<tr>
<td>6. Number of children in their practice identified with ASD</td>
</tr>
<tr>
<td>7. Practice setting: hospital/private/urban/suburban</td>
</tr>
<tr>
<td>8. Hours open</td>
</tr>
<tr>
<td>9. Best time for interview</td>
</tr>
</tbody>
</table>
Appendix H

Interview Questions Parents

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1.</td>
<td>Please tell me a little about yourself and your family.</td>
</tr>
<tr>
<td>2.</td>
<td>Can you describe for me how you found out your child had autism?</td>
</tr>
<tr>
<td>3.</td>
<td>What was one of the first things you did upon finding out about your child’s diagnosis?</td>
</tr>
<tr>
<td>4.</td>
<td>Who did you seek support from?</td>
</tr>
<tr>
<td>5.</td>
<td>Have you participated in any parent support programs?</td>
</tr>
<tr>
<td>6.</td>
<td>Can you describe the treatment intervention programs your child has participated in?</td>
</tr>
</tbody>
</table>
### Appendix I

**Interview Questions Pediatricians**

<p>| | |</p>
<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>1.</td>
<td>Please tell me a little about yourself and your experience working with families of children with disabilities.</td>
</tr>
<tr>
<td>2.</td>
<td>Please describe your first experience caring for a child with autism.</td>
</tr>
<tr>
<td>3.</td>
<td>What resources are available for your families?</td>
</tr>
<tr>
<td>4.</td>
<td>Are you familiar with any programs to support parents caring for a child with autism?</td>
</tr>
<tr>
<td>5.</td>
<td>What is your process for diagnosing a child with autism?</td>
</tr>
<tr>
<td>6.</td>
<td>Can you tell me about any developmental screening instruments used with families to detect autism?</td>
</tr>
</tbody>
</table>