WHAT DO PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS THINK?

by

Catherine Creighton Thompson
A Dissertation
Submitted to the
Graduate Faculty
of
George Mason University
in Partial Fulfillment of
The Requirements for the Degree
of
Doctor of Philosophy
Education

Committee:

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Date: ____________________________ Spring Semester 2014
George Mason University
Fairfax, VA
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Doctor of Philosophy at George Mason University

by

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Master of Arts
George Mason University, 2010
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Spring Semester 2014
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DEDICATION

This dissertation is dedicated to all the parents who spend countless hours in waiting rooms with their child who has an autism spectrum disorder. Parents’ persistence, tenacity, and love motivate them to search for interventions and solutions. Parents change laws, creating inclusive communities for all. Most specifically, this dissertation is dedicated to one of my best friends, Betty Truscelli. I am blessed to have met Betty in the waiting room while our children received therapies. Without her friendship, which included countless telephone conversations sharing sorrow, fear, and triumph, I would not be in this position today. She encouraged me to follow my dreams to pursue a degree that will facilitate my ability to help other families and children with disabilities. She is an amazing mother, wife, friend, and advocate, and I am honored to have her friendship and loyalty.
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This dissertation would not be possible without the encouragement and guidance of many people. Six years ago, I had a vision of where I wanted my career to progress. My vision seemed improbable and insurmountable on many levels. However, I was blessed with family, friends, teachers, and mentors who helped make my dream a reality.

First, I want to thank my friends from New Jersey. Betty Truscelli, Betsy Braitwaite, Nancy Respher Mollis, and Patricia Lee endured many discussions regarding my choices. Their patience, guidance and support helped me make difficult decisions and follow my dreams.

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LIST OF ABBREVIATIONS

Applied Behavior Analysis .......................................................... ABA
Attention Deficit Hyperactivity Disorder ..................................... ADHD
Autism Spectrum Disorder .......................................................... ASD
Diagnostic Statistical Manuel ...................................................... DSM
Evidence-Based Practice ............................................................ EBP
Free and Appropriate Public Education ........................................ FAPE
Individuals With Disabilities in Education Act .............................. IDEA
Individualized Education Program .............................................. IEP
Least Restrictive Environment ..................................................... LRE
Pervasive Developmental Disorder – Not Otherwise Specified ......... PDD-NOS
ABSTRACT

WHAT DO PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS THINK?

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The purpose of this mixed methods study was to better understand the perspectives of parents with children who are diagnosed with autism spectrum disorders regarding the Individualized Education Program (IEP) process, and interventions implemented to help their child meet IEP goals. The web-based survey included both closed and open-ended items. Major findings revealed that although a majority of the parents responded negatively to the single item asking their overall perceptions of the IEP process, they responded positively when asked their perceptions concerning specific IEP aspects including (a) their participation as equal IEP team members with educators, (b) that their suggestions were integrated into the IEP, and (c) that their child’s IEP would meet their child’s educational needs. Parents provided suggestions for improving the IEP process and desired the best education possible for their children, but also expressed concerns that generic and not “individualized IEP goals” may compromise the quality of their children’s education. Parents believed their participation in the IEP process was
critical, and greatly enhanced the individualization of IEP goals. Knowledge of their rights, special education law, and autism enhanced parents’ abilities to participate in IEP meetings as equal partners with school personnel.

Major findings also revealed that most parents had not used a majority of evidence-based practices for children with autistic spectrum disorders which were predominantly weighted toward individuals with more severe disabilities. However, a majority of parents who had implemented evidence-based practices rated these practices as effective or very effective, and a majority of respondents reported having higher functioning children. Most parents learned about autism from the Internet or other parents. In addition, most parents learned their rights and special education law from the Internet, other parents, professional and parent associations, school districts, or Wrightslaw. Findings are discussed with respect to previous and future research and practice.
I. INTRODUCTION

Autism prevalence is increasing (Lord & Bishop, 2010). The Centers for Disease Control and Prevention (CDC) reports autism prevalence is approximately 1 in 88 persons (CDC, 2012a). This number represents a 25% increase over previously reported prevalence rates. Estimates of Autism Spectrum Disorders’ costs to the United States are between 35 and 90 billion dollars per year (M.L. Ganz, 2007; Lord & Bishop, 2010). These costs include health care, Medicaid, social security, lost wages, and education. The etiology of autism is unknown; presently there is no genetic or medical test to identify autism.

Individuals with autistic spectrum disorders (ASD) have impairments in communication, social interaction, and behaviors (American Psychiatric Association, 2000). There is tremendous heterogeneity within the intensity and levels of impairment throughout the autism spectrum. This heterogeneity makes identification and diagnosis complex. Diagnosis involves observations and reports of behavior (Lord & Bishop, 2010). Medical professionals, psychologists, and psychiatrists diagnose ASD using criteria from The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) (American Psychiatric Association, 2013). Parents of individuals with ASD indicate they often consult with multiple doctors before obtaining an accurate ASD diagnosis (Brogan & Knussen, 2003; Goin-Kochel et al., 2006; Heidgerken et al., 2005).
Once diagnosed, these parents face the daunting task of selecting and implementing treatments, interventions, and therapies to remediate behaviors and teach skills (Miller, Schreck, Mulick, & Butter, 2012). There are a variety of treatments, interventions, and therapies such as pharmacological and dietary treatments, behavioral and educational interventions, and speech and occupational therapies (Bowker, D’Angelo, Hicks, & Wells, 2010; Goin-Kochel, Mackintosh, & Myers, 2006; Mackintosh, Goin-Kochel, & Myers, 2012; Miller, Schreck, Mulick, & Butter, 2012) Parents coordinate and sometimes implement many of these treatments and interventions (Goin-Kochel et al., 2006; Miller et al., 2012).

Parents learn about ASD, treatments, and interventions from a variety of sources. Parents may consult with medical professionals, occupational therapists, speech therapists, behavior therapists, audiologists, dieticians and several other professionals who work with their child (Miller et al., 2012). Research indicates that most parents consult the Internet to learn about ASD, treatments, and interventions (Green, Pituch, Itchon, Choi, O’Reilly, & Sigafous, 2006; Jegatheesan, Fowler, & Miller, 2010; Mackintosh et al., 2012). Parents also consult with other parents who have experience implementing treatments, interventions, and therapies.

The Individuals With Disabilities in Education Act (IDEA) (2004) provides special education through local schools to children with disabilities whose disability adversely affects their education performance. Special education involves evaluations and assessments to develop instructional strategies specifically designed to meet the unique needs of a child with a disability. Instructional strategies are documented in an
Individualized Education Program (IEP), which acts like a blueprint for the delivery of special education and related services (Christle & Yell, 2010; Fish, 2008; Simon, 2006). Students eligible for special education are entitled to a free and appropriate public education (FAPE) that insures students receive meaningful educational benefit. IDEA (2004) specifies procedures schools follow to develop an IEP for students with disabilities. The IEP documents goals and objectives as well as ways in which progress toward meeting goals will be measured (Christle & Yell, 2010; IDEA, 2004). The process of developing, monitoring, and implementing an IEP is the IEP process. IDEA (2004) outlines parental rights to participate as equal partners in developing an IEP. That is, parents have the right to fully participate in the education programming of their child.

Teachers, administrators, psychologists, therapists, counselors, and parents collaborate to develop an IEP. An IEP documents a child’s present level of performance, learning or functional needs, IEP goals, and documentation used to assess progress toward meeting IEP goals (Christle & Yell, 2010). The IEP outlines accommodations, the amount of special education a child receives, as well as the frequency and duration of related therapies (Christle & Yell, 2010; Zirkel, 2011). The IEP process involves discussions between educators and parents regarding IEP goals, treatments, interventions, and related therapies. Most disagreements between parents and local school districts involve the type of treatment or intervention as well as frequency of treatments, intervention, or related therapies (Zirkel, 2011).

IDEA (2004) provides due process rights to parents who disagree with school districts. The high cost of ASD on families and school districts often results in litigation.
Zirkel, 2011), and FAPE is the most commonly argued aspect in autism litigation (Etschiedt, 2003). Parents with children who have ASD are 10 times more likely to sue than parents of children with other disabilities (Zirkel, 2011). ASD litigation is the most expensive litigation within education (Etscheidt, 2003).

Relevance of the Study

Given the range and severity of needs of children with autism, understanding parent perceptions of the IEP process is especially important. A greater understanding of parental perceptions of the IEP process provides information to schools and researchers about ways that potentially could enhance IEP team collaboration, improve educational programming for children with ASD, and minimize litigation. Research investigating parental perceptions of the IEP process with families of children with autism is limited. Eleven studies investigated perceptions of parents of children with autism spectrum disorders (Bitterman, Daley, Misra, Carlson, & Markowitz, 2008; Brandt, 2011; Fish, 2006; Hume, Bellini, & Pratt, 2005; Jegatheesan, Miller, & Fowler, 2010; Jimenez, 2011; Kohler, 1999; Lovelin, 2012; Nickels, 2010; Spann, Kohler, & Soenkensen, 2003; Stoner & Agnell, 2006). A majority of the studies examined parental perceptions of parents who have children younger than age nine. Only 5 of the 11 studies investigated perceptions of parents of multiple-aged children with ASD (Brandt, 2011; Fish, 2006; Lovelin, 2012; Nickels, 2010; Spann et al., 2003). Three of these studies are dissertations (Brandt, 2011; Lovelin, 2012; Nickels, 2010), and two are published studies (Fish, 2006; Spann et al., 2003). Overall, few studies investigate the perceptions of parents with multiple aged children with ASD regarding the IEP process. Across the four studies, a total of 110
parents with children who have autism have shared their perceptions of the IEP process through interviews or surveys.

Survey research is frequently utilized as a method to investigate parental perceptions of autism treatments used by parents (Bowker, D’Angelo, Hicks, & Wells; Mackintosh et al., 2012). Parents who have children with ASD indicated using the Internet to learn about autism and treatments for autism (Green, 2007). Consequently, Web-based surveys have potential to reach the target population, parents who have children with ASD.

To date, no research studies have examined the perceptions of parents with multiple aged children with ASD regarding the IEP process in conjunction with medical issues that include the autism diagnosis, and parent-implemented treatments and interventions. A greater knowledge of parental perceptions of the IEP process and evidence-based practices provides information to schools and researchers about ways that potentially could enhance IEP team collaboration, improve educational programming for children with ASD, and minimize litigation

**Study Purpose and Research Questions**

This study was designed to gain an understanding of the perceptions of parents of children with autism spectrum disorders regarding the IEP process. Participants included parents of school age children of multiple ages with ASD. Gaining an understanding of parental perceptions will provide information to educators, policymakers, and advocates regarding ways to improve and facilitate the IEP process for families with children who have autism spectrum disorders. Given the litigious nature of families who have children
with autism, coupled with the increased prevalence of autism spectrum disorders, finding ways to enhance the IEP process is paramount. The following research questions were used:

1. What are the perceptions of parents who have children with ASD regarding the IEP process?
2. Are there relationships between the demographic variables and overall parental perceptions of the IEP process?
3. What are the perceptions of parents who have children with ASD regarding evidence-based practices for children with ASD?
4. How did/do parents learn about ASD and special education law?

**Definition of Terms**

A number of terms are used to describe and characterize the diagnosis of autism spectrum disorders, treatments, legal issues, and the IEP process. The following section provides definitions of terms used throughout this study.

*Applied Behavior Analysis (ABA).* Applied Behavior Analysis is the manipulation of contingencies used to modify or change behaviors. ABA manipulates environmental variables to affect behaviors. Data is taken to track and identify variables that will impact behaviors. ABA is a research-validated strategy that is frequently used with children who have autism.

*Autistic Spectrum Disorders (ASD).* ASD is a neurobiological disorder of unknown etiology. Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age
3. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change, or change in daily routines, and unusual responses to sensory experiences (Code of Federal Regulations, 2008, 34 CFR @ 300.7 ©(1)). There are four subtypes of Autism Spectrum Disorders: Autistic Disorder, Asperger’s Syndrome, Childhood Disintegrative Disorder, and Rett Syndrome.

*Comorbidity.* Comorbidity is the existence of a second disability or illness in addition to a primary disability.

*Continuum of services.* Continuum of services, mandated by IDEA 2004, provides for the education of children with disabilities in multiple settings from least restrictive, inclusive classrooms to self-contained classrooms.

*Diagnostic and Statistical Manual of Mental Disorders (DSM).* The American Psychological Association publishes the DSM to provide diagnostic criteria for 297 mental disabilities. Physicians, psychologists, social workers, pharmaceutical and insurance companies, social workers, legislators, and policymakers reference the DSM.

*Discrete Trial Training (DTT).* DTT, which is based on the principles of ABA, provides direct teaching of independence, social, and academic skills. DTT elicits targeted behaviors through prompting and reinforcement (Prelock, 2006).

*Due Process.* IDEA (2004) and the IEP process specify parents’ rights to due process. Parents who are unable to settle or mediate disputes with school districts may sue school districts in federal court.
Eligibility. Eligibility for special education occurs after assessments. A child must have a
disability that adversely impacts his or her education in order to be eligible for
special education.

Evidence-Based Practices (EBPs). EBPs are treatments and interventions are high quality
interventions that are researched and results are documented in peer reviewed
scientific journals.

Functional Behavior Assessment (FBA). FBAs are a type of analysis of behavior
implemented to determine the function and purpose of a behavior. During
observations and interviews, behaviors and environmental variables are analyzed.

Generalization. Generalization is the ability to use skills across settings, time, and
behaviors.

Holistic Treatments. Holistic treatments are natural treatments that include vitamins,
minerals and natural substances that rid the body of toxins.

Individualized Education Program (IEP). An IEP is a legal document which acts as the
blueprint for the delivery of special education and related services to a child with
a disability. IDEA (2004) requires that IEPs have several components:
documentation of students’ present level of performance, measurable annual
goals, progress monitoring method for collecting and reporting students’ progress,
instruction strategies, and related services. The IEP includes a statement regarding
class placement and general education participation, state assessment
participation, as well as projected IEP start and end dates, and frequency and
duration of special education services (Christle & Yell, 2010). IEP teams must
follow procedural and substantive requirements to insure schools develop IEPs in accordance with the law (Drasgow, Yell, & Robinson, 2001).

_Individuals With Disabilities in Education Act IDEA (2004)._ IDEA (2004) provides students with disabilities a right to a free and appropriate public education (FAPE) in the least restrictive environment (LRE). IDEA (2004) outlines procedures and processes schools must follow to develop an IEP, a legally binding document that serves as a blueprint for the delivery of special education and related services (Christle & Yell, 2010; Fish, 2008; Simon, 2006).

_Mediation._ IDEA (2004) provides parents the rights to mediation throughout the IEP process. Parents who disagree with local education agencies can mediate contested claims with a third party.

_Medicaid._ Medicaid is the primary funding source for residential and health care services for individuals with disabilities. Federal funding requires Medicaid payment for health care services; however, state laws dictate therapies payable by Medicaid. Therapies include occupational, physical, and speech therapies. State laws vary in therapies covered by Medicaid (Eskow et al., 2011).

_Occupational Therapy._ Occupational therapy is a type of therapy related to developing skills necessary for independent living. Skills include, but are not limited to, eating skills, handwriting, and sensory integration.

_Paraprofessional._ A paraprofessional is also referred to as an instructional assistant. Paraprofessionals provide assistance to classroom teachers and often work with students who have disabilities.
Pharmacological Treatments. Pharmacological treatments are treatments provided to individuals through medications.

Pragmatic Language. Pragmatic language is the social use of language.

Progress Monitoring. Progress monitoring tracks students’ progress and provides useful data for IEP teams. Progress monitoring includes data derived from observations, assessments, and anecdotal notes (Etscheidt, 2006).

Sensory Integration. Sensory integration involves the senses and how the brain processes senses.

Social Skills. Social skills are skills necessary to communicate verbally and nonverbally with others.

Special Education Teacher. A special education teacher is a teacher who is trained to educate students with disabilities.

Speech Therapy. Speech therapy refers to therapy delivered by speech pathologists. Therapies can include social skills, pragmatic language, receptive and expressive language, as well as articulation.

Treatments. Treatments are interventions that are implemented to influence the behavior or functioning of a child with a disability.

The next chapter presents a review of the literature regarding the experiences of parents who have children with autism spectrum disorders (ASD), their perceptions of treatments, and the IEP process.
II. LITERATURE REVIEW

Chapter 2 presents a detailed, in-depth review of the literature regarding experiences of families of children who have autism spectrum disorders (ASDs). The following section reviews the literature on characteristics of students with ASD and their families, parental perceptions of treatments, and parental perceptions of the Individualized Education Program (IEP) process. Subsequent sections provide a review of IEP goals and progress monitoring. Finally, a summary of research culminates in a comprehensive review of student and family characteristics, interventions and treatments, and experiences in the IEP process.

Literature Search Procedures

Comprehensive searches of available literature provided studies. Searches on parents or families of students with ASD and treatments, interventions, and the IEP process were utilized. Key search terms included: autistic disorder, autism, autism spectrum, Asperger’s Syndrome, Pervasive Developmental Disorder, PDD, Pervasive Developmental Disorder – Not Otherwise Specified, PDD-NOS, Individualized Education Program, IEP, progress monitoring, parent, parental, family, familial, therapy, therapist, intervention, and treatment. The researcher conducted computer-assisted searches in the following databases: Dissertations Abstracts, Education Research Complete, ERIC, Google Scholar, PsycInfo, Sage, and Social Citation Index. Ancestry
searches of article reference sections provided additional studies. Studies examining parental perceptions of the IEP process included only studies documenting experiences of parents in the United States.

**Characteristics of Autism Spectrum Disorder**

Autism spectrum disorder (ASD), a neurobiological disorder without definitive etiology or cure, affects millions and the prevalence is increasing. On March 30, 2012, the Centers for Disease Control (CDC) reported that the prevalence of autism spectrum disorders is 1 in 88 persons. This figure represents a 25% increase over the CDC’s 2006 ASD prevalence figure and almost double the prevalence since 2002 (CDC, 2012a). The cost of ASD to United States society is estimated to be approximately 35 billion dollars per year (M. L. Ganz, 2007). Concerned about the increased prevalence, in 2011 Congress enacted the Combating Autism Act and created the Interagency Autism Coordinating Committee (IACC) to coordinate research into the causes of and treatments for ASD. Annually the IACC reports summaries of research related to causes, diagnosis, treatments, and services for individuals and families with ASD (Combating Autism Act, 2011).

Autism, which is also known as Pervasive Developmental Disorder, is a spectrum disorder; children identified with ASD exhibit a wide variety of symptoms (Heflin & Alaimo, 2007). Intelligence and functional behaviors delineate children’s placement on the spectrum. Children on the high functioning side of the spectrum have higher IQs and adaptive functional behaviors. Children on the low end of the spectrum have lower IQs and impaired functional behaviors.
The heterogeneity of ASD impacts diagnosis, interventions, and treatments, as well as prognosis. Research indicates multiple systemic issues impact ASD prevalence rates and severity (Interagency Autism Coordinating Committee [IACC], 2012). Children with ASD have unique developmental trajectories that make interventions complex. Some children are easily identified at birth. Others develop normally and then experience significant regressions around 18 months. Some are not identified until they are in school where social deficits become more apparent (IACC, 2012).

A primary characteristic shared by all individuals with ASD is the inability to maintain social interactions (Prelock, 2006). Eye contact is often limited, and children have difficulties interpreting nonverbal communication and perceiving how others feel. Empathy and theory of mind are skills often lacking. Maintaining self-control and regulating emotions are difficult. Identifying and regulating emotions within themselves may interfere with self-regulation. Consequently, some students with ASD have self-injurious or aggressive behaviors (Heflin & Alaimo, 2007; Prelock, 2006).

A second shared characteristic is poor verbal and nonverbal communication skills. Children can perseverate on restrictive interests, lacking social reciprocity and an inability to interpret social cues. Many children have receptive, expressive, and pragmatic language deficits. Furthermore, some children have echolalia where they repeat words or phrases constantly. Children with Autistic Disorder are sometimes nonverbal (Heflin & Alaimo, 2007; Prelock, 2006).

A third shared characteristic is restricted interests and behaviors. Many children with ASD obsessively perseverate on specific interests (Prelock, 2006). They can develop
subject matter expertise in an area of interest and perseverate regarding interests regardless of social context (Heflin & Alaimo, 2007). Many individuals with ASD prefer sameness in routines. Changes in routines can cause significant regression among children who prefer rigid, predictable routines. Some children line toys in meticulous lines and become angry when lines are destroyed. Some have self-stimulatory behaviors such as arm-flapping, spinning, and delayed echolalia (Heflin & Alaimo, 2007; Prelock, 2006).

Finally, multisensory processing difficulties challenge the sensory system of some individuals with ASD. There is a wide range of sensitivities among those with ASD. Maintaining eye contact while looking at someone can be difficult for children with ASD. Thus, many individuals have limited eye contact. Some have difficulties processing loud sounds, making trips to the movies and fire drills unbearable. Sensory distractions affect children’s abilities to attend to and maintain appropriate relationships. Sensory differences and abnormalities can affect coordination and motor planning as well (Heflin & Alaimo, 2007; Prelock, 2006).

**Diagnosing Autism and the Diagnostic Statistical Manual**

In May 2013, the American Psychological Association updated the DSM-IV to DSM-V. Significant changes for ASD included renaming the umbrella term Pervasive Developmental Disorder to Autism Spectrum Disorder. Three subtypes, Asperger’s Syndrome, PDD-NOS, and Autistic Disorder, collapsed into one ASD diagnosis (IACC, 2012). The following paragraphs discuss the DSM-V and DSM-VI.

**DSM-V.** According to the *Diagnostic Statistical Manual*, fifth edition (DSM-V) (American Psychiatric Association, 2013), Autism Spectrum Disorder (ASD) is an umbrella diagnosis used to classify individuals with low functioning autism to milder autism. Diagnostic criteria for Autism Spectrum Disorder include a dyad of deficits, which are commutative/pragmatic language deficits and social interaction deficits. First, individuals must have verbal and nonverbal communication difficulties that appear when individuals engage in social activities, such as activities requiring pragmatic language skills and the give-and-take necessary to have appropriate social interactions. Individuals with ASD have difficulties modulating communication and social skills to match the social context. Thus, individuals with ASD may use formal pragmatic language unnecessarily. Individuals with ASD misunderstand metaphors, inferences, and inexplicit language. Thus, the nuances of speech are illusive. These communication challenges affect individuals’ ability to communicate in their professional and academic careers as well as social relationships.

The second deficit is pervasive social communication and interaction difficulties across multiple contexts. Individuals have difficulties with pragmatic language and nonverbal communication. Modulation of behaviors to match social context is difficult.
Thus, developing and maintaining friendships is challenging. The aforementioned characteristics are rated by severity levels, which are divided based on social communication deficits as well as patterns of rigid behaviors (Table 1).

Finally, symptoms of ASD may be apparent early in life. However, symptoms may not be fully recognized until social issues are problematic. Individuals that have difficulties with social communication, but do not exhibit all noted deficits, may have a social pragmatic communication disorder (Autism Speaks, 2013).

Table 1

<table>
<thead>
<tr>
<th>Severity Level</th>
<th>Social Communication</th>
<th>Restricted, Repetitive Behaviors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1 Child needs significant supports</td>
<td>Significant impairments in verbal and nonverbal social communication skills that affect social interactions.</td>
<td>Prefers routines, intense behaviors resulting from change, inflexible, rigid, can exhibit extreme behaviors resulting from change.</td>
</tr>
<tr>
<td>Level 2 Child needs substantial supports</td>
<td>Impairments in both verbal and nonverbal social communication skills; supports do not improve verbal and nonverbal communication skills.</td>
<td>Prefers routines, difficulties coping with change. Exhibits inflexibility such that rigid behaviors are observable.</td>
</tr>
<tr>
<td>Level 3 Child needs supports</td>
<td>Supports are necessary to facilitate verbal and nonverbal social communication. Atypical social interactions that may appear odd.</td>
<td>Prefers routines and exhibits inflexibility in behavior and thought, has challenges transitioning to new activities.</td>
</tr>
</tbody>
</table>

Note. *Adapted from Table 2 of DSM-5 Diagnostic Criteria by Autism Speaks, http://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria.

**DSM-IV-TR.** Medical professionals used the *Diagnostic Statistical Manual, Fourth Edition – Text Revision* (DSM-IV-TR) (American Psychiatric Association, 2000) to identify individuals with an autism spectrum disorder prior to May 2013. The DSM-
IV-TR classifies autism spectrum disorders into five diverse subtypes that reflect the spectrum of the disorder, and lists the following diagnostic criteria for ASD.

1. Qualitative impairment in social interaction, as manifested by at least two of the following:
   a. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
   b. Failure to develop peer relationships appropriate to developmental level
   c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people
   d. Lack of social or emotional reciprocity

2. Qualitative impairments in communication as manifested by at least one of the following:
   a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gestures or mime)
   b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
   c. Stereotyped and repetitive use of language or idiosyncratic language
   d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
e. Restrictive repetitive and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following:

i. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

ii. Apparently inflexible adherence to specific, nonfunctional routines or rituals

iii. Stereotyped and repetitive motor mannerisms

iv. Persistent preoccupation with parts of objects. (American Psychiatric Association, 2000, p. 75)

Specific types of ASD as identified in the DSM-VI-TR are described in the following text.

**Autistic Disorder.** The DSM-VI-TR defines Autistic Disorder by the presence of at least six of the previously listed diagnostic criteria. Comorbidities of intellectual disabilities (Prelock, 2006) and epilepsy are common (IACC, 2012). Functional and adaptive behaviors are significantly impaired (Prelock, 2006).

**Asperger’s Syndrome.** The DSM-VI-TR defines Asperger’s Syndrome with the same criteria, except impairments in language and cognitive development (Prelock, 2006). Many children with Asperger’s Syndrome have normal to high IQs. Cognitive and language development are normal. However, children with Asperger’s Syndrome have significant impairments in social interactions. Pragmatic language and nonverbal
communication are unusual. Many perseverate on restricted interests, lacking social awareness.

**Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS).**
PDD-NOS is a catchall diagnosis which includes children who do not meet all criteria in the DSM-IV for specific subtypes, but still have ASD. For example, many children diagnosed with PDD-NOS have similar skill deficits to children with Asperger’s Syndrome. However, children with PDD-NOS have receptive or expressive language disorders that are apparent before age 3 (Heflin & Alaimo, 2007; Prelock, 2006).

**Rett Syndrome and Childhood Disintegrative Disorder (CDD).** Rett Syndrome is a single gene genetic disorder. Because behaviors are similar to behaviors identified in children with autism, the DSM-IV includes Rett Syndrome under the PDD umbrella. Childhood Disintegrative Disorder (CDD) occurs when children typically develop until the age of 2. After the age of 2, a child must lose communication or adaptive skills in order to be classified with CDD (Heflin & Alaimo, 2007; Prelock, 2006).

**Individuals With Disabilities Education Improvement Act of 2004**
Clinical diagnosis of an autism spectrum disorder does not automatically qualify students for special education services and protections under IDEA (Heflin & Alaimo, 2007; MacFarlane & Kanaya, 2009). The clinical definition of autism and IDEA’s definition of autism share many eligibility requirements. However, IDEA’s eligibility requirements have two prongs. First, the child must have a disability. Second, the child’s disability must cause educational impact (IDEA, 2004).
Autism was added to the Individuals With Disabilities Education Improvement Act (IDEA) eligibility classifications in 1990 (Heflin & Alaimo, 2007; MacFarlane & Kanaya, 2009). Prior to 1990, researchers speculate that a majority of students with ASD received special education under the categories of intellectual disability, other health impaired, or emotionally disturbed (MacFarlane & Kanaya, 2009). To be eligible special education under the autism category, IDEA (2004) states:

> Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three that adversely affects a child’s educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change, or change in daily routines, and unusual responses to sensory experiences. The term does not apply if a child’s education performance is adversely affected primarily because the child has an emotional disturbance. (Code of Federal Regulations, 2008, 34 CFR @ 300.7 ©(1))

Overall, the number of students eligible for IDEA and special education under autism is increasing. In January 2012 the U.S. Department of Education (U.S. DOE) released the *Thirtieth Annual Report to Congress on the Implementation of the Individuals With Disabilities Education Improvement Act* (IDEA). Autism trend data reveals increases in the percentage of population diagnosed with autism spectrum disorders, especially in students ages 6 through 21 (U.S. DOE, 2012). For students ages
Autism increased from 0.1% of the total population in 1997 to 0.3% of the total population in 2006 (U.S. DOE, 2012).

Regardless of increases in the number of students eligible to receive services under autism, some high functioning students with ASD do not qualify for special education because their disability does not have educational impact (MacFarlane & Kanaya, 2009). These students often excel academically, and their functional performance does not adversely affect their education. Consequently, autism numbers reported by the U.S. Department of Education, Office of Special Education (OSEP) are smaller than clinical numbers reported by the CDC (MacFarlane & Kanaya, 2009).

The Individuals With Disabilities Education Improvement Act 2004 (IDEA, 2004) classifies subtypes of pervasive developmental disorder/autism spectrum disorder under Autism. The Code of Federal Regulations specifically notes that a child’s educational performance must be adversely affected in order for a child diagnosed with an Autism Spectrum Disorder to qualify for special education services. To receive special education services under the disability of autism, the Code of Federal Regulations states that autism is:

a developmental disability significantly affecting verbal and nonverbal communication and social interaction, usually evident before age 3 that adversely affects a child’s educational performance. Other characteristics often associated with ASD are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term does not apply if a child’s educational
performance is adversely affected because the child has an emotional disturbance.

(34 C.F.R. 300.8(c)(1))

**State Eligibility**

The federal government permits states to establish special education eligibility criteria in accordance with Code of Federal Regulations (CFR). Consequently, interstate variability regarding autism eligibility exists throughout the country (MacFarlane & Kanaya, 2009). Some states mandate medical diagnosis by a qualified medical professional; others do not require medical diagnosis (Etscheidt, 2003).

**School Special Education Eligibility**

Local education agencies conduct interdisciplinary evaluations to determine eligibility for special education (Heflin & Alaimo, 2007). Educational evaluation for special education is comprehensive and conducted by a team of professionals that includes general education teachers, special education teachers, school psychologists, counselors, speech therapists, physical therapists, occupational therapists, administrators, and parents (Mastropieri & Scruggs, 2010). Evaluation teams assess students to determine whether a child has a disability, and whether the child’s disability adversely affects educational performance. If a child is eligible for special education, then evaluations will be used to create specifically designed instructional strategies, which are outlined in an Individualized Education Program (IEP).

**Autism Spectrum Disorder Identification**

The median age of ASD diagnosis is 4 years 6 months (CDC, 2012b). Boys are five times more likely identified with an ASD than girls (CDC, 2012b). Of girls
identified, on average they are diagnosed at later ages than boys (Giarelli et al., 2010). In 2012, Pringle et al. conducted research for the Centers for Disease Control at the U.S. Department of Health and Human Services. Researchers surveyed families with children who had ASD ages 6-17 throughout the United States to learn about the autism identification process. Findings revealed that less than 20% of children were diagnosed before age 3, and 40% were diagnosed after age 6. Neurologists, multidisciplinary teams, and pediatric specialists most frequently diagnosed children with autism before age 5. After age 5, psychologists and psychiatrists identified students with ASD (Pringle et al., 2012).

Autism’s symptoms are apparent before the age of 3. Family doctors and pediatricians are usually the first to identify children with autism. During well visits, pediatricians screen for multiple disabilities. Families share developmental concerns with doctors during these visits (Heidgerken et al., 2005). Some pediatricians recommend consultation with specialists such as pediatric developmental specialists, psychologists, psychiatrists, or neurologists. Comorbid conditions such as epilepsy, anxiety, and behavior problems often necessitate specialized care (Heidgerken et al., 2005). Heidgerken et al. (2005) investigated autism knowledge among primary medical professionals, psychologists, psychiatrists, speech language pathologists, and pediatric developmental specialists and knowledge possessed by medical professionals working at the Center of Autism and Related Disabilities through a survey. Survey responses from the two groups were compared and data analyzed. Results showed that primary medical professionals not associated with the Center of Autism and Related Disabilities
maintained outdated beliefs regarding autism research. Many inaccurately assumed that autism is more prevalent in high-income families. Some medical professionals did not refer children to Child Find or recommend special education in school, despite evidence of positive outcomes for early intervention (American Academy of Pediatrics, 2001; Heidgerken et al., 2005).

Knowledgeable medical professionals identify ASD and recommend treatment plans and interventions. Recommendations for school special education services, class placements, and related services are outlined in reports. Sometimes, medical professionals recommend private and group therapies that augment services provided by schools.

**Comorbidity**

Comorbidity among children with ASD is common. Some studies estimate more than 75% of children diagnosed with ASD have comorbid disabilities such as Attention Deficit Hyperactivity Disorder (ADHD), anxiety disorders, depression, and other psychiatric disabilities (Brereton, Tonge, & Einfeld, 2006; MacFarlane & Kanaya, 2010). Autism Speaks (2012a) reports that 50% of children with ASD have gastrointestinal problems and 65% experience disruptions in sleep. Approximately 22-38% of children with ASD suffer from petite mal or grand mal seizures (Danielsson, Gillberg, Billstedt, Gillberg, & Olsson, 2005). The majority of children who have epilepsy and ASD also have intellectual disabilities (IACC, 2012). Parents report frustrations working with medical professionals and educators who often do not acknowledge and remediate comorbid disabilities (MacFarlane & Kanaya, 2010).
Etiology

The causes of autism are unknown. The National Institutes of Health’s Interagency Autism Coordinating Committee (IACC) plans autism research activities and publishes quality studies and evidence-based practices. IACC’s reports suggest genetic causes (McAdoo & Demyer, 2012; Ozonoff et al., 2011; Van Meter et al., 2010) and environmental triggers (McPheeters et al., 2011). Researchers found brain growth abnormalities involving brain structure and connectivity. Researchers are also investigating environmental factors that contribute to genetic changes that influence brain and central nervous system development (IACC, 2012).

Previous research linked the Mumps Measles Rubella (MMR) shot to increased susceptibility to ASD. In 1998, Wakefield et al. published a paper suggesting a correlation between the MMR shot and ASD (Langan, 2011; Wakefield et al., 1998). Although this research proved invalid and has now been retracted (The Editors of The Lancet, 2010), many parents continue to reject the MMR shot for their children and lobby for additional research funding to investigate vaccination correlations with ASD (Langan, 2011).

The Autism Research Institute (AIR), a nonprofit founded in 1967, investigates cases of ASD and treatments (Downing, 2007). AIR believes that vaccinations, environmental toxins, or biological reactions, which result in adverse chemical reactions within the body, cause ASD. AIR has a network of doctors called the Defeat Autism Now doctors, who recommend chelation therapy to rid the body of heavy metals, and special vitamins, and gluten/casein free diets (Autism Research Institute, 2012; Langan, 2011).
They also recommend caution when vaccinating children (Wakefield & McCarthy, 2010). These groups firmly believe that ridding the body of toxins cures ASD.

On April 5, 2012, researchers at the University of Southern California located the MSNP1AS gene, which may cause autism. Additional studies are necessary to determine causation. However, if MSNP1AS is linked to autism, medication can be developed to mitigate autism symptoms (Autism Speaks, 2012b).

The IACC claims that the heterogeneity within ASD impacts research methods and priorities. ASD symptoms and developmental trajectories are different. Thus, research encompasses a spectrum of disabilities. These factors complicate research priorities (IACC, 2012). Also, parents hold multiple beliefs about autism’s causes and advocate for research to investigate these causes. Consequently, multiple groups of parents advocate for different research priorities.

**Early Intervention Recommendations by Medical Professionals**

The American Academy of Pediatrics recommends intense early interventions for children diagnosed with ASD as positive outcomes are associated with early interventions (American Academy of Pediatrics, 2001; Pringle et al., 2012; Reichow, 2012). A delay in diagnosis or misunderstanding of autism dramatically affects outcomes. Interventions that start when children are older are less effective (Rogers, 1998). There are many treatments and interventions available to remediate symptoms associated with ASD. Speech therapy enhances receptive, expressive, and pragmatic language. Occupational therapy facilitates independent life skills such as eating, writing, and sensory integration. Assistive technology improves communication of nonverbal
individuals. Interventions such as Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH) and ABA have evidence of improved performance of some children. However, research shows a wide range of improvement among children with ASD. Some children improve significantly, whereas others show no improvements. Unfortunately, scientific evidence from randomized control trials supporting the efficacy of interventions is sparse (IACC, 2012).

Parents are an important component of early intervention because they provide wraparound services, streamlining interventions between home and school. Family and parental involvement has potential to significantly improve outcomes (Stoner & Angell, 2006). Autism Speaks (2008) reports that between 20% and 50% of children who receive appropriate early intervention will be able to attend inclusive kindergarten classes with typically developing peers.

Research investigating parental opinions of early interventions supports Autism Speak’s 2008 statement. Hume et al. (2005) investigated 195 parents’ perceptions regarding early intervention special education programs on the outcomes of children with ASD. Findings showed that 70% of parents felt that early interventions improved outcomes of their child. Parents reported the greatest improvements in speech and language development (43.4%), cognitive development (40.8%) adaptive skills (21.4%) and emotional development (19.9%).

Parent training programs are critical components of early intervention. Parents enhance outcomes when they implement therapies and provide wraparound instruction for their child with ASD. Children generalize skills to environments at home and in the
community. Research indicates that parents feel parent training is the most important program that enhances outcomes (Hume et al., 2005; Kogel, Bimbela, & Schareibman, 1996).

**Expensive to Educate**

ASD’s cost to society is estimated to be 35 billion to 90 billion dollars annually (M. L. Ganz, 2007). Although autism is a low-incidence disability with a small percentage of the student body diagnosed, it is one of the most costly disabilities (Chasson, Harris, & Neely, 2007; International Center for Autism Research and Education, 2012) In 2003, the Special Education Expenditure project reported that autism was one of the most expensive disabilities to educate: Expenses average $18,790 per year (MacFarlane & Kanaya, 2009).

The heterogeneity and complexity of autism necessitates individualized treatments among multiple professionals, which is costly (Heflin & Alaimo, 2007). A U.S. General Accountability Office (U.S. GAO) report indicated that students with autism receive a variety of services, including speech, occupational, physical, and behavior therapies (2005). CDC (2012a) survey data showed that approximately 40% of children ages 6-17 received behavioral interventions. The most popular related services include social skills training and speech language therapy. Younger children received speech language and occupational therapies more frequently than older children (Pringle et al., 2012).

Furthermore, paraprofessionals are often hired to facilitate students’ education in the least restrictive environment (Giangreco & Broer, 2005; Mazurik-Charles &
Stefanou, 2010). Some students with autism receive one-on-one paraprofessional instruction and support (Etscheidt, 2005). Qualified special education teachers oversee paraprofessionals. All in all, teams of educators collaborate to teach students with ASD, making autism one of the most expensive disabilities to educate.

**Parental Experiences in Diagnosis**

Identifying children with autism is often a long process. Sometimes, parents who voice concerns about their child’s development are told not to worry. Many parents consult with multiple doctors before obtaining a diagnosis (Goin-Kochel et al., 2006). Thus, diagnosis is sometimes delayed (Heidgerken et al., 2005). Parents feel frustrated by lengthy diagnosis processes (Brogan & Knussen, 2003).

Medical professionals’ knowledge of autism and autism services is an important aspect. Parents who receive a quick and accurate diagnosis of autism have more positive perceptions of the medical diagnostic process than parents who consult with multiple doctors before obtaining a diagnosis of autism (Goin-Kochel et al., 2006). Medical professionals who connect parents with therapists and support services improve parental diagnostic experiences (Brogan & Knussen, 2003). Parents who received information about services from medical professionals understand where to go for services.

**Families of Children With Autism Spectrum Disorder**

Many children with autism have significant sensory and behavior challenges that affect family life. Children with autism have difficulties communicating, frequent tantrums, and unusual repetitive habits (Heflin & Alaimo, 2007). These traits can make family life difficult (White, McMorris, Weiss, & Lunsky, 2012). Parents feel enormous
pressures raising a child with autism. They spend hours managing therapies and education plans. In the back of their minds, they are always concerned about their children’s future, and what will happen to their children when they die (White et al., 2012). The following paragraphs discuss parental stress, demographic characteristics of families who have children with autistic spectrum disorders, high costs of autism treatments and interventions, and employment issues.

**Parental Stress**

Overall, research indicates that parents with children who have ASD experience more stress than parents of typically developing children (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005), and more stress than parents of children who have other types of disabilities (Perry, Harris, & Minnes, 2005). Parents feel significant stress associated with managing ASD throughout their child’s life (White et al., 2012). The types of issues and stress also change throughout a child’s life. Parents with young children struggle to accept the autism diagnosis and life changes associated with the disability. White et al. (2012) found that many parents expressed dissatisfaction with medical professionals and their lack of knowledge on ways to manage severe and challenging behaviors. Parents feel alone, and frustrated with a lack of understanding within the medical community and beyond.

School and childcare are additional sources of stress (Fish, 2008). Challenging behaviors and comorbid child emotional disabilities such as anxiety and depression are significant causes of stress (White et al., 2012). Parents of children with lower
functioning autism experience even greater stress than parents of children with milder autism (Lyons & Leon, 2010).

The high cost of private therapies, many of which are not covered by insurance, causes additional parental stress (Parish, Thomas, Rose, Kilany, & McConville, 2012; Wang & Leslie, 2010). On average parents spend more than 10 hours per week coordinating and managing autism therapies (Kogan et al., 2008). These therapies are in addition to therapies provided by schools. Many private therapies are not covered by private insurance or Medicaid (Parish et al., 2012; Wang & Leslie, 2010).

**Family Demographic Characteristics**

Studies examining autism prevalence consistently correlate education and income levels with higher rates of autism (Bhasin & Schendel, 2007; McAdoo & Demyer, 2012; Van Meter et al., 2010). Bhasin and Schendel’s (2007) research showed that families who have high incomes and high maternal education levels are significantly associated with increased autism identification rates, especially students identified as having autism without intellectual disability. McAdoo and Demyer (2012) showed that families who had higher incomes and education levels also had higher rates of children with autism.

Similarly, Van Meter et al. (2010) investigated 10 autism clusters in California, which included 9,900 autism cases. Findings revealed that the majority of families living in clusters had high education levels and live near autism centers. Researchers speculated that families relocated near autism centers in order to receive treatments. Thus, more highly educated families with higher incomes may be more aware of autism and have economic means to pay for treatments (Van Meter et al., 2010).
Autism prevalence among children who are Black and Hispanic is low relative to population percentages (Mandell, Listerud, Levy, & Pinto-Martin, 2009). Most students who are Black or Hispanic receive diagnoses at ages later than peers of other races. Researchers postulate that factors such as the cost of obtaining a diagnosis, insurance issues, and location distance to autism treatment facilities are factors that affect families who are Black or Hispanic from obtaining early diagnoses. Also, medical professionals may inappropriately label these students as emotionally disturbed. More research is necessary to investigate the underrepresentation of students who are Black and Hispanic (Mandell et al., 2009).

**High Cost to Families**

As noted earlier, autism is also very costly to parents. Parents of children with autism spend more money on health care and therapies than parents of any other disability group (Parish et al., 2012; Wang & Leslie, 2010). Many private insurance companies will not pay for recommended educational treatments such as speech therapy, behavior therapy, and social skills. Many parents supplement educational treatments with private therapies to increase the frequency and intensity of treatments (Bitterman et al., 2008; Nickels, 2010). Subsequently, many families have unreimbursed medical expenses and struggle to pay for recommended private therapies (Sharpe & Baker, 2007). Some families go bankrupt in order to pay for private therapies (Sharpe & Baker, 2007).

Disability advocates have promoted state insurance parity legislation that requires insurance companies to pay for autism treatments. As of 2012, 26 states had enacted parity legislation for autism services (Parish et al., 2012). Preliminary analysis of state
and individual health care data in states that enacted parity laws provides tentative proof that parity legislation reduces families’ financial burdens (Parish et al., 2012).

Medicaid, the primary funding source for residential and health care services for individuals with disabilities, receives federal and state funding. Federal funding requires Medicaid payment for health care services; however, state laws dictate therapies payable by Medicaid, which include occupational, physical, and speech therapies. There is great variability among states regarding therapies covered (Eskow et al., 2011). Consequently, some states mandate coverage of specific therapies whereas other states do not. Only a few states have autism Medicaid waivers (Eskow et al., 2011).

**Employment Problems**

Managing and coordinating treatments requires significant amounts of time. As noted earlier, families report spending over 10 hours per week coordinating treatments (Kogan et al., 2008). Parents of children with autism were more likely to quit work or work part-time in order to manage therapies (Eskow et al., 2011; Kogan et al., 2008; Montes & Halterman, 2008).

Respite and Medicaid waivers may facilitate parental employment. Eskow et al. (2011) investigated the effects of Maryland’s autism waiver on families of children with ASD. Maryland’s autism waiver, a $40,000 per child taxpayer expense, provides respite, health care, and funds for private therapies. Of parents in the study, 38% stated that the waiver allowed them to return to work at least part-time (Eskow et al., 2011).

Finding appropriate childcare is a significant barrier to employment and contributor to parental stress. Parents frequently report having difficulties finding
qualified persons to care for their child. Haney (2012) surveyed parents of children with ASD regarding after-school programs. Of respondents, 59% reported they tried after-school care. However, only 33% of parents felt after-school care was positive. In fact, some parents stated they were told that their child’s after-school care program was not appropriate for their child. Other parents claimed the school called them at work to pick up their child from after care (Haney, 2012).

In summary, parents and families are required enter the special education world where they search for treatments to improve their child’s prognosis and family life. Treatments and interventions have potential to enhance functional behaviors and skills. Media coverage of autism and multiple “cures” put pressure on families to find the right cure for their child. Families participating in early intervention programs indicate that they feel enormous pressure and the clock ticking to find a cure for their child’s autism (Hume et al., 2005).

**Evidence-Based Treatments/Interventions**

The heterogeneity of autism necessitates individualized treatments, making autism treatment complex. In 2010, the International Autism Coordinating Committee (IACC) funded approximately 68 million dollars for autism treatments and interventions research. The IACC divides treatments and interventions into seven subcategories: behavioral interventions; complementary; dietary and alternative treatments; educational interventions; medical and pharmacologic treatments; model systems and therapeutic targets research; and occupational, physical, and sensory-based therapies (IACC, 2012). Research funding subcategories are: 35% for model systems and therapeutic targets,
which include animal research; 29% behavioral treatments; 16% medical treatments; 9% educational treatments; 7% technology-based interventions and supports; 2% occupational, physical, and sensory-based interventions; 1% complementary, dietary, alternative treatments (IACC, 2012). Some treatments are school based, while others are implemented in the home or private therapist’s office (Mackintosh et al., 2012; Thomas, Morrissey, & McLaurin, 2007).

In 2007, the U.S. Department of Education, Office of Special Education (OSEP) created the National Professional Development Center for Autism Spectrum Disorders (NPDC) at the University of North Carolina (UNC) Chapel Hill to research evidence-based treatments for children with ASD. An evidence-based treatment/practice is a practice that has documented and high quality research, which is peer reviewed and published in scientific journals. The NPDC conducted extensive reviews of the literature, identifying experimental and single-subject designed studies that were high quality. The NPDC established criteria specifying the number of studies necessary to qualify a practice as evidence based and identified 24 treatments that have sufficient support to warrant the designation of evidence-based practices (NPDC, 2013). The following paragraphs share these evidence-based practices.

**Antecedent-Based Interventions**

Antecedents are incidents that occur before a behavior. Some students with autism have antecedents that occur prior to behaviors that trigger behaviors. Thus, managing antecedents can be an effective method to control behaviors. Schools use functional behavior assessments (FBA), a formal process to evaluate and examine behaviors.
Through the FBA process, antecedents to behaviors are also identified. Antecedent-based interventions manage behavioral antecedents to facilitate appropriate behaviors. Research regarding antecedent-based interventions includes three single-subject and two group design studies, which were effective in reducing self-injurious and self-stimulating behaviors resulting from antecedent interventions (NPDC, 2013).

Preferential seating is an antecedent-based intervention. Since children with autism exhibit unusual sensory processing issues (Prelock, 2006), preferential seating can include seating that provides tactile input. In one study, Schilling and Schwartz (2004) investigated the effects of therapy balls on attentive and in-seat behaviors of young children with ASD. Researchers postulated that therapy balls may provide sensory tactile input that helps students’ self-regulate behaviors. Four preschool-aged children who attended a full day university inclusive preschool program participated in the single-subject withdrawal design study. Social validity was measured through teacher evaluations of the intervention. Results indicated that participants’ attention and seating behavior improved while sitting on therapy balls. Furthermore, teachers indicated that students preferred and enjoyed sitting on the therapy balls.

**Differential Reinforcement**

Differential reinforcement is the process of giving and modulating reinforcement for various behaviors. Reinforcement is a principle of applied behavior analysis that is used to teach behaviors. Students are rewarded for appropriate behaviors and not rewarded for inappropriate behaviors. There are various ways to measure behavior based on specific skills taught.
Research supports reinforcement as evidence-based practice. Six single-subject research designs examined differential reinforcements’ effects and met criteria as an evidence-based practice. Differential reinforcement provides positive reinforcement for appropriate behaviors while ignoring inappropriate behaviors. Differential reinforcement can be effective in reducing tantrums, aggression, self-injury, and stereotypic behaviors. Research indicates that differential reinforcement can be self-managed once a child reaches middle school (NPDC, 2013).

In one study, Piazza, Moes, and Fisher (1996) decreased the self-injurious and escape behaviors of an 11-year-old boy who was diagnosed with autism and mild intellectual disabilities through a single-subject intervention that utilized differential reinforcement. The treatment included differential reinforcement of compliance and continuous prompting, as well as demand fading every 10 minutes. Results indicated that the participant’s self-injurious behaviors decreased to near zero post intervention.

**Discrete Trial Training (DTT)**

DTT is a systematic one-on-one Applied Behavior Analysis (ABA) instructional approach used to teach joint attention, cognitive, functional, and social skills to preschool- and elementary-aged children with ASD. DTT utilizes the principles of ABA to analyze antecedents and manage consequences through discrete instructional trials. DTT is best performed in small classrooms and controlled environments, but can also be effective in home and school environments (NPDC, 2013; Prelock, 2006).

Research suggests that DTT can be effective in teaching young children with ASD (NPDC, 2013). DTT’s systematic instruction, which includes maintenance of joint
attention, and rewards for appropriate behaviors, facilitates skills development. In one study, Remington et al. (2007) compared the effects of preschool programs that utilized DTT for 25.6 hours of intensive 1:1 behavior therapy with standard preschool programs for children with disabilities. The researchers compared outcomes of the two programs on children’s social skills, IQ, and functional behaviors after two years of preschool attendance. Findings revealed that children who attended the DTT intensive behavior therapy preschool achieved higher IQ gains and improved social and pragmatic language skills. The NPDC (2013) claims that DTT is an evidence-based practice.

**Extinction**

Some children with autism exhibit significantly challenging behaviors. To be able to function in society, extinction of inappropriate behaviors is critical. Extinction is an ABA-based strategy that is used after other strategies have failed to extinguish inappropriate behaviors. Extinction involves analyzing a child’s behaviors to determine the purpose of the behavior. Once the purpose is determined, behavior reinforcements can be manipulated to change behaviors. Inappropriate behaviors may escalate prior to the extinction of inappropriate behaviors. Extinction strategies should be appropriately planned and implemented by persons familiar with the child (Prelock, 2006). Four single-subject studies and one group design study provide evidence for the extinction treatment as an evidence-based practice (NPDC, 2013).

In one study, Aiken and Saltzberg (1984) examined the effects of a sensory extinction intervention on the verbiage initiated by two children with autism spectrum disorders. These children made inappropriate noises by vocalizing, clapping hands, and
dropping objects. The single-subject reversal design utilized an intervention which consisted of headphones with white noise. The children wore white noise headphones, which inhibited their ability to hear sounds resulting from children’s actions. Thus, the headphones interrupted the audible feedback they received through vocalizations, hand clapping, and dropping objects. Findings revealed that the intervention reduced vocalizations. However, handclapping and object dropping continued. Researchers surmised that the children received another type of feedback from handclapping and object dropping and another intervention targeted toward the extinction of sensory feedback resulting from handclapping and object dropping could affect those behaviors.

**Functional Behavior Assessment (FBA)**

IDEA (2004) mandates functional behavior assessments for children demonstrating behavioral problems that interfere with their learning or the learning of others. Children with ASD typically have a multitude of behavior problems, including sensory abnormalities, verbal and physical aggression, tantrums, self-injurious behaviors, and rigidity. To remediate known behavior problems, schools and therapists conduct functional behavior assessments, which are formal assessments that analyze behaviors to determine functions of behaviors. Through the FBA process, behavior antecedents and consequences are identified across settings. Functional behavior assessments provide data to develop plans to reduce and mitigate problem behaviors. This data is part of a behavior intervention plan. Five single-subject studies and one group design study of individuals with multiple ages in school, community, and home settings provide evidence for FBA as an evidence-based instructional practice (NPDC, 2013).
In one of these studies, Butler and Luiselli (2007) performed a functional behavior assessment with a 13-year-old girl who was diagnosed with ASD. The girl exhibited extreme behaviors: She was self-injurious, banging her head, pulling hair, and hitting herself. She also was aggressive: hitting, biting, and kicking others. Finally, the girl cried, screamed, and had tantrums in class. The researchers conducted an FBA, determining that the function of these behaviors was to escape academic tasks. Types of academic tasks and instructors affected her responses. Researchers implemented an ABAB reversal design. Results demonstrated that the intervention successfully analyzed behaviors, establishing appropriate contingencies to change behaviors as well as identifying antecedents. All in all, the combination of noncontingent escape and instructional fading achieved a reduction in inappropriate behaviors.

**Functional Communication Training (FCT)**

Carr and Durand (1985) introduced functional communication training in 1985 as a strategy to modify and change severe and challenging behaviors. FCT is currently one of the most effective interventions for severe and challenging behaviors (Tiger, Hanley, & Bruzek, 2008). FCT uses a differential reinforcement procedure whereby a child learns an alternative response to replace the problem behavior. Functional behavior assessments identify behaviors and functions of those behaviors. The functions of behaviors are carefully examined and replacement behaviors are suggested which serve the same purpose of the original behaviors. However, the replacement behaviors are appropriate. Research indicates that FCT is an evidence-based practice. Five single-subject studies
with preschool- and elementary-aged children support FCT as evidence-based practice (NPDC, 2013).

In one of these studies, Casey and Merical (2006) implemented FCT with an 11-year-old boy with ASD who exhibited self-injurious behaviors within the inclusive classroom. The child hit himself in the head, sometimes until he bled. Through functional analysis, researchers determined that the child exhibited these behaviors to escape or avoid academic demands. The intervention consisted of the child using gestural requests to escape instruction instead of self-injurious behaviors, which had previously resulted in escape from academic demands. Results indicated that the child’s self-injurious behaviors decreased to zero in response to the intervention, and the child used gestures to escape academic demands.

**Pivotal Response Training (PRT)**

Pivotal Response Training utilizes the principles of ABA to teach young children with ASD communication and social skills (Prelock, 2006). PRT incorporates the child’s interests into instruction in order to expand social and communication skills. PRT is effective across home and school settings. Nine single-subject studies provide evidence of PRT for children with ASD (NPDC, 2013).

Minjarez, Mercier, Williams, and Hardan (2013) implemented a study to investigate the effects of a PRT communication skills training program with 17 families to examine family stress levels and feelings of empowerment preintervention and postintervention. The intervention consisted of group instruction of PRT for families to teach their child communication skills over 10 weeks. Dependent measures included the
Parent Stress Index/Short Form and Family Empowerment Scale. Preintervention, 75% of families indicated they had stress at significant levels. They reported not feeling empowered. Postintervention, over 50% of families still felt significant stress. Researchers postulated that the intervention may have been too short and families needed longer times before stress levels could reduce. However, findings showed that families felt more empowered and capable of improving their child’s skills.

**Prompting**

Prompting is introduced systematically to teach new skills. There are several types of prompting: verbal prompts, gestural prompts, model prompts, and physical prompts. The frequency of prompting is manipulated until children perform the new skill or behavior independently. Five single-subject studies across multiple ages provide evidence of prompting’s effects on skill acquisition. Prompting is often used in one-on-one instruction in clinic or home settings. However, prompting can also occur in school settings (NPDC, 2013).

Taylor and Harris (1995) investigated the effects of a time-delayed prompting multiple-baseline single-subject design intervention with three students who had ASD. The intervention taught students to ask questions when they wanted to learn something new. Specifically, the children were taught to ask “What’s that?” Results showed that students learned to ask questions and generalized this skill across settings.

**Time Delay**

Time delay is a specific type of prompting strategy that helps reduce prompting so that a child performs a behavior or skill independently. Once children master a skill,
prompts are faded according to skill mastery or faded according to a specific preestablished time frame. Prompts are faded until skills are generalized. Time delay can be used for multiple skills, including academic, behavioral, communication, and social skills. Five single-subject research studies show that time delay is most effective with children ages 6-11 (NPDC, 2013). In one study, Matson, Sevin, Box, Francis, and Sevin (1993) examined the effects of a self-initiated speech intervention with a multiple-baseline single-subject design with three children who had autism and intellectual disabilities. The intervention included visual cue fading with a time-delay procedure. Findings revealed that self-initiated verbalizations improved postintervention.

**Reinforcement**

Applied behavior analysis (ABA) is a systematic procedure that analyzes and manipulates behavior. Reinforcement, which is frequently used in ABA, is a form of operant conditioning that provides a response to a stimulus. There are positive reinforcements and negative reinforcements. Positive reinforcement is motivating rewards such as token economies and verbal praises. Positive reinforcement increases the likelihood that a behavior will occur. When a behavior occurs, a child receives reinforcement, which encourages the behavior. Alternatively, negative reinforcement occurs after an adverse behavior. The negative reinforcement decreases the likelihood of the behavior occurring if provided similar circumstances (NPDC, 2013; Prelock, 2006).

In one study, Todd and Reid (2006) investigated the effects of reinforcement on the physical activity of three high school-aged children with ASD with a single-subject changing conditions design study. Physical activity included snowshoeing and
walking/jogging. The intervention took place over 6 months and consisted of six phases, which were divided according to the number of edible reinforcers provided during each stage. The number of miles snowshoed, walked, and jogged increased while the number of edible and verbal reinforcements decreased. Findings revealed that the reinforcers improved the physical activity of participants. Visual inspection of the data showed that all participants’ physical activity improved during the intervention.

**Response Interruption and Redirection (RIR)**

Response interruption redirection (RIR) is a behavior management strategy utilizing the principles of ABA to interrupt and redirect challenging behaviors such as self-injurious and repetitive behaviors. RIR is particularly effective in interrupting behaviors that are sensory based where the reinforcement is also sensory based. Typically, a functional behavior assessment is performed to observe the behavior in order to understand the behavior’s purpose and reinforcement. A majority of research occurred in clinics. However, RIR has potential to be successful in home and school settings. There are five single-subject studies that provide evidence of RIR with participants ages 3-21 (NPDC, 2013).

In one of these studies, Hagopian, Bruzek, Bowman, and Jennett (2007) investigated the effects of response redirection and interruption intervention on the behavior of three children with ASD. The intervention consisted of differential and noncontingent reinforcement without interruption. The intervention was modified for sustainability within the natural environment by adding a schedule arrangement that was utilized to increase time between activities and interruptions. During the generalization
phase, a two-component multiple-schedule arrangement was used to progressively increase the period of time in which ongoing activities would be interrupted. Results demonstrated that the intervention improved behaviors.

**Instructional Strategies**

The National Professional Development Center for Autism Spectrum Disorders (NPDC) at the University of North Carolina Chapel Hill designated the treatments listed above as evidence-based practices. These practices meet mandates outlined by IDEA (2004), which also states that instructional methodologies within IEPs are based on peer-reviewed research to the maximum extent possible (Yell, Shriner & Katsiyannis, 2006).

There are several evidence-based instructional strategies for students with autism spectrum disorders which can be used at school, home, or private therapists’ offices. The U.S. Department of Education funds the National Professional Development Center on Autism Spectrum Disorders to support the use of evidence-based practices for autism. The University of North Carolina examines published and peer-reviewed research to determine interventions, treatments, and instructional strategies that qualify as evidence based. The NPDC at the University of North Carolina then shares these evidence-based practices by posting them to a website (NPDC, 2013). Outlined below are 13 evidence-based instructional strategies which were listed and reviewed on the NPDC website.

**Computer-Aided Instruction**

Computer-Aided Instruction (CAI) includes computerized tutors and computer instruction. Computer instruction is effective for academic as well as social skill development. Research indicates that children from preschool to age 18 improve
academic and social skills through CAI. Research effects are shown for classroom instruction, but no studies examined the use of CAI in the home (NPDC, 2013).

In one of these studies, Silver and Oakes (2001) implemented a randomized control trial to investigate the effects of a computer program on the emotional recognition skills of individuals with ASD. The computer program instructed individuals with ASD to recognize emotions. Participants included children ages 12 to 18 who were diagnosed with ASD. Researchers divided participants into two groups of 11 children. The experimental group received the computer-based intervention for 2 weeks for a total of 10 30-minute interventions. Dependent measures included facial expression recognition from photographs and cartoons as well as nonliteral stories. Findings revealed positive effects. The experimental group made gains relative to the control group in recognizing facial expressions from photographs and cartoons as well as nonliteral stories. However, statistical significance was only achieved for the recognition of facial expressions from cartoons ($F = 4.785, p = 0.041$) and nonliteral stories ($F = 6.881, p = 0.016$). Participants in the experimental group improved their ability to recognize facial expressions from photographs over the control group, but statistical significance was not achieved ($F = 5.571, p = 0.029$).

**Naturalistic Interventions**

Naturalistic interventions utilize an individual’s natural interests to encourage on-task behaviors and appropriate interactions. These interventions can be highly effective for children with autism because these children often have unique and specific areas of interest. They become experts in their chosen area of interest, perseverating on their...
interest. Many individuals with autism are fascinated with science, trains, fashion, history, or mathematics. Naturalistic interventions take advantage of natural interests to enhance generalization of skills. There are seven steps to implementing naturalistic interventions: identify target behavior, collect baseline data, identify contexts for intervention, provide training to team members, arrange environment to facilitate target behavior, use ABA to reinforce behavior, and collect data to monitor progress.

Naturalistic training is systematic, using the natural environment as a training tool. Eight single-subject studies and two group design studies provide evidence that naturalistic strategies are evidence-based instructional practices for individuals of all ages across school, community, and home settings (NPDC, 2013).

In one of these studies, Laski, Charlop, and Schreibman (1988) examined the effects of a parent-implemented Natural Language Paradigm (NLP) intervention with eight children who had ASD to increase communication skills. Parents were trained in NLP at a clinic. They implemented the NLP intervention at home, using toys and the natural environment to teach pragmatic language skills. Findings revealed that the intervention, which was implemented in the natural environment, facilitated language skill development. Furthermore, children generalized language skills, improving communication with siblings and other family members. Noteworthy in this study, episodes of echolalia did not increase as a result of the intervention. Thus, children’s social communication skills improved without increases in echolalia.
Parent-Implemented Interventions

Parents spend more time in a day with their child than anyone else. Research indicates that parents are effective in improving communication and social skills (McGee, Morrier, & Daly, 1999; Sofronoff, Leslie, & Brown, 2004), increasing joint attention (Kasari, Gulsrud, Wong, Kwon, & Locke, 2010), reducing challenging behaviors (Prelock, 2006), increasing functional self-help skills (Kroger & Sorensen, 2010), and improving self-determination skills (Suk-Hyang, Palmer, Turnbull, & Whemeyer, 2006) with their children. Parental instruction provides wraparound services for students with ASD, increasing skill generalization and improving student outcomes. Parents are able to partner with schools, creating consistency of rules and communication between home and school.

Nine studies of preschool children and one study of high school children indicate that parent-implemented interventions, which are individualized interventions that are implemented by parents after parental training, are effective in improving behaviors. Parents attend training sessions and learn how to implement treatments with their children. Studies examining effects demonstrate that parent-implemented interventions are an evidence-based instructional practice (NPDC, 2013).

In one of these studies, Gentry and Luiselli (2008) conducted a single-subject parent-implemented feeding intervention with one child who had ASD. The researchers instructed a child’s mother to implement an intervention within the home. Instruction included directions and practice to insure fidelity of treatment was achieved. The intervention combined both antecedent and positive reinforcement. During the
intervention’s first phase, the child was given two preferred and one nonpreferred foods. The child spun a Mystery Motivator, which was a spinner that had several colored sections indicating the number of bites from each food the child must consumer. When the child spun the Mystery Motivator, the mother instructed the child regarding how many bites the Mystery Motivator required eaten. After eating the required bites, the child was able to chart his successes and select a reward. During the second phase of the intervention, the Mystery Motivator was removed and the child continued to eat the required bites with verbal instructions from the mother. After eating the required bites, the child received a reward. Results of this study showed that the child continued to eat nonpreferred food with verbal requests from his mother and rewards. Implications for the study demonstrate that parent-implemented interventions have potential to improve eating habits of children with ASD.

**Peer-Mediated Instruction**

Children with autism spectrum disorders have difficulties relating to and communicating with peers. Adult-mediated interventions in which therapists, parents, or teachers prompt and facilitate interactions with peers can be effective strategies for students with ASD (Prelock, 2006). Parents, teachers, and therapists can implement peer-mediated interventions in a variety of settings; it is an inclusive instructional strategy used with peers from preschool to adult to teach peers how to engage with children who have ASD. Parents, teachers, and therapists instruct peers on ways to interact with children who have ASD. In turn, students with ASD learn social, academic, and behavioral skills from peers (NPDC, 2013).
Harper, Symon, and Frea (2008) implemented a peer-mediated instruction intervention with elementary school-aged students. Researchers instructed peers on ways to facilitate the inclusion of two students with autism during recess. Findings showed that both children with autism improved both social and pragmatic language skills.

**Picture Exchange Communication System (PECS)**

PECS is a program that teaches young children with autism communication and social skills through the use of picture exchange. Children with autism do not need verbal language to use PECS because it utilizes behavioral strategies of prompting and reinforcement within instruction (Ogletree, Oren, & Fischer, 2007). PECS has six instructional phases: picture exchange, spontaneous picture exchange, picture discrimination, developing sentences for communication, answering “what” questions, and responding to questions. Positive reinforcement is given for appropriate behaviors and skills. The first three phases involve learning to share and communicate with pictures. The final three phases of PECS teach language and pragmatic skills.

Lancioni et al.’s (2007) meta-analysis investigating the effects of PECS on basic communication skills of children with developmental disorders showed that 98% of children’s language skills improved. Furthermore, there are two single-subject studies and three randomized control studies providing evidence that PECS in an evidence-based instructional practice. PECS can be used across multiple settings, including school and home (NPDC, 2013).

Charlop-Christy, Carpenter, and Le, LeBlanc, and Kellet (2002) conducted the multiple-baseline single-subject study that examined the effects of a PECS intervention
on the speech, pragmatic language, and behaviors of three elementary-aged students with ASD. Results indicated that all children’s speech and communication skills improved after the intervention. One student’s speech skills improved from a baseline of 0% to 83%; another improved from 2% to 68%; a third improved from 28% to 100%. Furthermore, students’ pragmatic language and behaviors improved.

**Self-Management**

Self-management strategies increase an individual’s capacity to manage, monitor, and control himself or herself. Self-management includes a range of skills such as self-monitoring, self-assessment, self-observation, and self-evaluation. Self-determination, which is a term used to describe individuals’ abilities to advocate for themselves and determine their own lives, requires self-management skills. To effectively manage behaviors, individuals need to be able to assess skills, monitor progress, and develop goals (Lee, Simpson, & Shogren, 2007).

Research indicates that self-management strategies are effective across home and school settings (NPDC, 2013). Lee et al.’s (2007) meta-analysis analyzed the effects of 11 single-subject research investigations on self-management skills of individuals with autism, using percent of nonoverlapping data (PND) to describe effects. Across the 11 studies, 34 participants received intervention. Overall, the mean PND reported was 81.9% (SD = 30.5%). Furthermore, both younger and older children with autism improved self-management skills (Lee et al., 2007).
Social Narratives

Social narratives are brief stories shared with children ages preschool to middle school prior to a social event or change in routine. Social narratives inform children of upcoming changes and appropriate responses and behaviors expected during social events or new routines. Social narratives are individualized to address specific needs (NPDC, 2013).

In one study, Ivey, Heflin, and Alberto (2004) investigated the effects of a social stories intervention with children who had PDD-NOS who were experiencing a change in routine. Researchers prepared children for the change by reading social stories prior to the novel situation. Results showed that behaviors during novel situations improved with the intervention.

Social Skills Groups

DSM-V (2013) criteria specifies deficits in social communication as qualifying criteria for an autism spectrum disorder. Individuals with ASD have difficulties with pragmatic language, nonverbal communication, and conversation reciprocity, which greatly impair social skills. Social skills programs may take place in self-contained environments where direct instruction occurs. Later, skills can be generalized in inclusive environments. Two experimental and six single-subject studies support the use of social skills to improve the social and pragmatic language skills of multiple ages of individuals with ASD (NPDC, 2013).

In one experimental study, Solomon, Goodlin-Jones, and Anders (2004) investigated the effects of a social skills intervention on the theory of mind, emotional
awareness and recognition, and executive functioning skills of nine boys diagnosed with high functioning autism, including children with Asperger’s Syndrome and PDD-NOS. Researchers selected 18 boys who were between the ages of 8 and 12 to participate in the study and equitably divided participants into two groups through random assignment and matching of abilities. The first group, the intervention group, received the intervention first. The second group, the control group, received intervention second. Participants attended the M.I.N.D. Institute at the University of California Davis Medical Center for 1.5-hour intervention sessions weekly for 20 weeks. Results showed that the intervention significantly improved the theory of mind, emotional awareness and recognition, and executive functioning skills. Thus, this study adds to the evidence base that social skills interventions are evidence-based practices.

**Speech Generating Devices (SGDs)**

Speech generating devices are also called voice output communication aids (VOCA). They are portable assistive technology devices that generate electronic speech via key strokes. SGDs facilitate communication, especially for nonverbal children. Because children press keys to generate words and sentences, SGDs facilitate joint attention and pragmatics as well. There is some evidence suggesting that SGDs enhance math skills. Lancioni et al.’s (2007) meta-analysis found that 92% of children using VOCA communicated successfully. Five single-subject studies show that SGDs improve communication (NPDC, 2013).

Schepis, Reid, Behrmann, and Sutton (1998) implemented a multiple-probe single-subject study examining the effects of VOCA in naturalistic teaching
environments on the communication skills of four children with Autistic Disorder. The four children had functional skill levels between 18 and 24 months. The researchers trained teachers in naturalistic teaching as well as VOCA. Researchers examined communication behaviors of children during snack and play time through observations. Dependent variables were the number of communication interactions per minute, which included gestures, vocalizations, and the number of communication interactions per minute with naturalistic teaching and VOCA. Results showed that all four children achieved 100% PND for the number of communication interactions per minute during both snack and play time. Furthermore, all students’ communication interactions improved resultant to naturalistic teaching and VOCA. Children improved communication interactions with 100% PND. All in all, the combination of naturalistic teaching and VOCA improved the communication interactions of four young children with ASD.

**Structured Work Systems**

Structured work systems are visually organized work spaces where individuals with autism work. They take advantage of the highly visual strengths of autism and the need for routine. Structured work systems facilitate the development of independent skills by outlining expectations and tasks for completion, and can be utilized in schools, home, and workplace. There are five single-subject studies that document the effect of structured work systems on the independent skills development of individuals with ASD (NPDC, 2013).
In one of these studies, Hume and Odom (2007) investigated the effects of individual work systems on the individual functioning of three children with ASD with an ABA single-subject research study. The intervention consisted of individual work systems. Dependent measures included on-task behavior, work completion, and number of play items. Findings revealed that the work systems increased task behaviors, work completion, and number of play items during intervention. When the intervention was withdrawn, these behaviors decreased. When the intervention was reintroduced, task behavior, work completion, and number of play items increased again. Maintenance was achieved as well. Researchers conducted assessments 1 month postintervention and children maintained skills.

**Task Analysis**

Task analysis is the process by which an individual breaks down tasks into manageable steps. Task analysis involves a list of steps required to complete a task, and is used to improve project completions as well as social skills. Tasks can be visual cues, written language, or social scripts. Research indicates that task analysis is effective across school, home, and community settings (NPDC, 2013). Task analysis is also used as a self-monitoring tool (Parker & Kamps, 2010).

In one study, Haring, Kennedy, Adams, and Pitts-Conway (1987) implemented a multiple-baseline single-subject study with three young adults who were diagnosed with Autistic Disorder. The young adults’ functional levels were between four and five years old. Researchers examined the effects of using task analysis on the social and operational responses of the participants who went to the store independently. Intervention included
training participants with task analysis and well as combining task analysis with videotape training. Results indicated that all participants’ social and operational responses improved postintervention. Visual inspection of the data showed that task analysis combined with videotapes was especially powerful in generalization of skills across settings.

**Video Modeling**

Children with ASD are visual learners who lack theory of mind, which is the ability to empathize with others to predict how others would feel. Children with autism have difficulties understanding others’ perspectives due to difficulties processing how others would feel. Concurrently, children with autism are visual learners who have strong visual memories. Video modeling is an intervention that uses video to model behaviors, communication, social skills, and play. Children watch videos to learn appropriate and inappropriate skills. Through video and observations, children learn empathy skills and theory of mind. Video, coupled with contingent reinforcement of behavior, is an effective instructional strategy (Prelock, 2006).

Other forms of video modeling have proven effective. Self-modeling is a form of video modeling that videotapes the child with ASD engaging in behaviors and skills. Children watch themselves on video to see how others may perceive them. Video prompting breaks skills into manageable steps which are narrated and paused for discussion. Children learn social and behavior skills through this form of video modeling. Video modeling is an evidence-based instructional strategy supported by eight single-subject studies (NPDC, 2013).
In one study, Nikopoulous and Keenan (2004) implemented a multiple-baseline across participants study with three children who had mild to moderate autism. Researchers examined the effects of video modeling on the social initiation and play skills. Results indicated that all students’ social initiation and play skills improved postintervention, as well as one to three months post intervention. Thus, students maintained these skills 3 months after the intervention.

Visual Supports

Children with autism spectrum disorders usually have superior visual memories and skills (Prelock, 2006). Visual supports such as schedules, agendas, maps, pictures, and charts enhance understanding, minimizing anxiety and stress (J. B. Ganz, 2007; Prelock, 2006). Additionally, many children with autism have difficulties processing auditory, sensory, and social information. Visual supports enhance understandings of both social and academic expectations.

In one study, Dettmer, Simpson, Myles, and Ganz (2000) investigated the effects of visual supports to help children with autism transition to novel situations. Findings showed that visual supports enhanced the transitions, minimizing behavioral challenges. The NPDC indicates that visual supports are an evidence-based instructional strategy (2013).

Summary

All in all, research indicates that evidence-based instructional interventions can make a significant positive impact on a child’s level of functioning validity (Goin-Kochel et al., 2006; Green et al., 2006; Mackintosh et al., 2012). The NPDC identified several
effective evidence-based instructional interventions (2013). However, additional research is necessary in order to identify evidence-based practices specifically for individuals with autism spectrum disorders. Medical professionals, educators, and parents need access to interventions and treatments that have experimental validity.

**Treatments Implemented by Parents**

Parents use multiple approaches to treat their child’s autism and little is known about the decision process families make when selecting approaches (Thomas et al., 2007). Parents consult with multiple professionals, including doctors, psychologists, behaviorists, occupational therapists, speech therapists, dieticians, and school-based IEP teams to learn about autism treatments (Miller et al., 2012). Research indicates that many parents implement treatments that lack experimental validity (Goin-Kochel, Myers, & Mackintosh, 2007; Green et al., 2006; Mackintosh et al., 2012; Miller et al., 2012; Miller, Stephenson et al., 2001), and many of these treatments were recommended by the professionals they consulted (Miller et al., 2012).

Carlon, Carter, and Stephenson (2013) reviewed 16 published studies to examine the sources parents consulted to learn about autism treatments. Across studies, parents indicated they researched autism on the Internet. Parents stated that they looked for treatments and interventions that had evidence. However, there is no research investigating the criteria parents use to determine whether research is evidence-based (Carlon et al., 2013). The following paragraphs discuss the two most common resources for parents: the Internet and other parents, followed by parents’ approaches to treatment, treatment frequency, and their perspectives of treatments.
Internet

A majority of parents of children with ASD receive information about treatments and interventions from the Internet (Goin-Kochel et al., 2006; Green et al., 2006; Jegatheesan et al., 2010; Mackintosh et al., 2012). There is a multitude of information about treatments and cures available on the Internet and in mass media—yet there are no formal studies that investigate the quality of such information available on the Internet. Stephenson, Carter, and Kemp (2012) postulated that parents believe that autism associations are reputable sources for information. Therefore, Stephenson et al. (2012) studied the quality of information regarding autism treatments and interventions on national autism association websites. They researched web pages from large autism associations, examining their websites for information about evidence-based practices. Findings revealed that a majority of associations do not post information about treatments supported by evidence. Furthermore, associations did not provide links to sites that documented scientifically based treatments (Stephenson et al., 2012).

Other Parents

The second largest source of information about treatments is other parents (Goin-Kochel et al., 2006; Green, 2007). Parents interact and consult with other parents in waiting rooms, communities, associations, and schools. They share experiences regarding treatments and outcomes. Parents learn about treatments and interventions from one another, and parents view other parents as credible resources.
Approach to Treatment

Parents’ approach to treatment is often related to their belief(s) about the cause of autism (Levy & Hyman, 2005; Thomas et al., 2007). Levy and Hyman (2005) suggest that parents select treatments and interventions that are in alignment with their beliefs about autism’s cause. For example, if parents feel that environment, diet, or immunizations cause autism, then they will implement treatments and interventions that rid the body of toxins in order to cure autism (Levy & Hyman, 2005). Approaches to treatment include behavior-based approaches, relationship approaches, dietary approaches, and approaches that integrate multiple approaches (Thomas et al., 2007).

Treatment Frequency

The Centers for Disease Control and Prevention’s (2012a) data brief reported that 90% of children ages 6-17 with special health care needs and ASD receive at least one treatment. Reported treatments include school-based treatments and private treatments. A majority of children with ASD receive a multitude of treatments and some receive treatments simultaneously (Goin-Kochel et al., 2007; Green, 2007; Green et al., 2006; Mackintosh et al., 2012). Studies show that the average number of treatments implemented per child is 8 (Goin-Kochel et al., 2007; Green et al., 2006), but treatment numbers range from 7 to 15 (Goin-Kochel et al., 2007). There are a number of factors that affect the number of treatments, such as age and severity of autism (Bowkler et al., 2010; CDC, 2012b; Green et al., 2006).

Younger children receive a greater number of treatments than older children and adults. The Center for Disease Control and Prevention’s (2012a) report indicated that
families of younger children implement a greater number of treatments than families who have older children with autism. Treatment choices change as students age (Bowker et al., 2010; CDC, 2012b; Green et al., 2006). Not only do the numbers of treatments decrease, but the type of treatment differs. More parents report using speech language, floor time, ABA, and occupational therapy with younger children. Parents who have older children report using skill-based treatments and medications more frequently (Bowker et al., 2010; Goin-Kochel, Mackintosh, & Myers, 2009; Green et al., 2006).

Parents who have children with more severe autism implement a greater number of treatments than parents with children with high functioning autism and Asperger’s (Bowker et al., 2010; Goin-Kochel, et al., 2006; Green et al., 2006; Mackintosh et al., 2012). Researchers speculate that severe behavior, communication, and lifestyle issues motivate parents to seek a greater number of treatments. Bowker et al. (2010) conducted an Internet survey of 970 parents from around the world regarding the effectiveness of autism treatments. The survey consisted of 72 questions, many of which were open-ended. Results indicated that parents of children who have higher functioning ASD reported that social skills and behavior interventions most improved their child’s functioning. On the other hand, parents who have children with lower functioning ASD reported limited success with social skills interventions. These parents felt that linguistic, behavior treatments, pharmacological treatments, vitamin supplements, and detoxification treatments were more effective. Universally, parents indicated that they terminate treatments when their child’s skills do not improve. Medications and alternative diets were the most frequent treatments discontinued by parents (Bowker et al., 2010).
Parental Perspectives of Treatments

Several studies investigate the perceptions of parents regarding treatments and interventions. A majority of these studies investigated the number and type of interventions implemented by parents. Some studies investigated parental perceptions of treatments/interventions. However, there is a gap in the literature regarding parental perspectives of evidence-based practices for children with ASD or the educational interventions implemented in schools. Table 2 illustrates studies that investigate parental perceptions of treatments and interventions. The following paragraphs share details on that research regarding the perspectives of parents and treatments/interventions.

Table 2

Studies on Parental Perspectives of Autism Spectrum Disorder Treatments/Interventions

<table>
<thead>
<tr>
<th>Study</th>
<th>Participants</th>
<th>Method</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Green et al. (2006)</td>
<td>522 parents who had children with Autistic Disorder and Asperger’s</td>
<td>Online survey</td>
<td>Identify the number and types of interventions, programs and therapies implemented by parents</td>
</tr>
<tr>
<td>Green (2007)</td>
<td>19 parents who participated in the online survey</td>
<td>Telephone interviews</td>
<td>Understand parental experiences with Applied Behavior Analysis, sensory integration, and B6- magnesium treatments</td>
</tr>
<tr>
<td>Thomas et al. (2007)</td>
<td>301 families who participated in autism associations in North Carolina</td>
<td>Telephone and self-administered survey</td>
<td>Identify the number, types, and social validity of the interventions they implemented</td>
</tr>
<tr>
<td>Goin-Kochel et al.</td>
<td>479 parents with</td>
<td>Online questionnaire</td>
<td>Identify the number and</td>
</tr>
</tbody>
</table>
(2009) | children who had any diagnosis on the Autism Spectrum | types of treatments implemented by families |
---|---|---|
Bowker et al. (2010) | 1,034 parents | Online survey | Identify the number and types of treatments implemented by families and reasons for discontinuing treatments |
Nickels (2010) | 6 families with children diagnosed with Autism Spectrum Disorders from a Northeast Tennessee public school system | Interviews | Investigate the perceptions of parents, special education teachers, and general education teachers regarding educational interventions |
Mackintosh et al. (2012) | 486 parents | Qualitative questionnaire | Understand parental experiences regarding treatments they implemented |

**Parent-implemented interventions.** Parents implement a myriad of treatments/interventions. To gain a greater understanding of autism treatments used by parents, Green et al. (2006) created a survey of 111 treatments, which were divided into seven categories: medications, vitamin supplements, special diets, medical procedures, educational and therapy, alternative medicine, and combined programs. The survey had 115 items in three sections: demographics, child characteristics, and treatments. The researchers sent surveys to autism associations throughout the world, obtaining 552 respondents. A majority of respondents were from the United States. However, there were also respondents from Canada, the United Kingdom, Australia, New Zealand, Iceland, the Philippines, Denmark, Afghanistan, Albania, Egypt, Algeria, Israel, India, Malaysia, and South Africa. Finders were that many parents used treatments that did not
have evidence supporting their effectiveness. They implemented interventions based on
the severity of their child’s autism, often implementing multiple interventions
simultaneously. Green et al. (2006) stated that parents need “access to objective and data-
based yet consumer-friendly information on a range of specific treatments; depending on
the age and type/severity of the child’s disability” (p. 83).

In a follow-up study, Green (2007) telephone interviewed 19 parents who were
randomly selected from the Green et al. 2006 Internet survey participants to gain a
greater understating of their experiences with ABA, sensory integration, and B6-
magnesium treatments. A majority of respondents stated that their children’s behavior
improved with ABA. There was some variability among parental responses, though. A
few parents indicated that they did not feel ABA was effective, and these parents
typically had children who were higher functioning on the autism spectrum.
Approximately 80% of parents felt their child’s sensory processing improved with
intense occupational therapy. Sensory Integration therapies improved their child’s
behaviors as well. Finally, most parents reported that B6 and magnesium supplements
were ineffective. A majority of parents reported learning about treatments and
interventions from the Internet and other parents. Accordingly, Green felt parents needed
access to evidence-based practices in order to provide them with information about
empirical interventions (2007).

Goin-Kochel et al. (2009) surveyed 479 parents to understand the type and
frequencies of treatments implemented by parents and their perspectives of biological,
educational, and behavioral interventions. A majority of parents felt pharmacological and
behavior interventions improved their child’s functioning. Of respondents, 50% to 80% indicated improved skills resulting from pharmacological treatments, and 70% felt that behavioral interventions were effective. Approximately half of the surveyed parents believed that dietary interventions such as gluten-free or casein-free diets improved their child’s functioning. However, approximately a quarter of parents felt gluten-free or casein-free diets were ineffective (Goin-Kochel et al., 2009).

Thomas et al. (2007) conducted telephone interviews and self-administered surveys to investigate the perceptions of parents regarding TEACCH, ABA, floor time, Defeat Autism Now, and Lovaas (Lovaas, Schreibman, & Koegel, 1976), which are treatments provided by schools and private therapists. Participants were recruited through autism associations in North Carolina. The self-administered survey contained three main sections: demographic information, treatments implemented, and parental satisfaction with treatments. Findings revealed that parents most frequently used school-based services for autism treatments. They felt speech therapy provided by the school was most often the best therapy. Also, they felt private occupational therapy and speech therapy were effective (Thomas et al., 2007).

Educational interventions/evidence-based practices. Nickels (2010) interviewed the parents of six children diagnosed with ASD, eight special education teachers, and six general education teachers in a Northeast Tennessee school system to understand their perceptions of educational interventions they perceived effective, barriers to implementing educational interventions, and relationships between parents and teachers. Findings revealed that parents perceived the following interventions effective:
early interventions with multiple approaches, structured learning environments, adult-mediated interventions as well as peer-mediated interventions for social and communication skills, inclusion with a balance of services in general education and special education, paraprofessional support to facilitate inclusion, functional approaches to behavior management, alternative and augmentative communication system interventions, and sensory integration interventions. Barriers to implementation included lack of knowledge of ASD, lack of time, heterogeneity of characteristics and needs displayed by children with ASD, teacher attitudes, parent attitudes, transition issues, and the need for other types of therapies and services provided by schools.

In conclusion, parents are often heavily involved in treatments, and they learn about autism and interventions. They spend time negotiating with schools, and time in private therapists’ offices. Insurance often does not pay for autism treatments. Parents indicate they are always searching for a cure, and feel the pressure of time.

School is a key ingredient to their child’s success. Parents collaborate with schools and educators to develop an IEP for their child, and negotiate for educational interventions and treatments through related services. Parents mostly negotiate with schools at the formal Individualized Education Program meeting. At this meeting, parents collaboratively develop an Individualized Education Program (IEP) which documents educational strategies specifically designed for their child. The IEP provides for all of the special education services their child receives through school.
Legal Issues

IDEA (2004) provides students with disabilities a right to a free and appropriate public education (FAPE) in the least restrictive environment (LRE). IDEA (2004) outlines procedures and processes schools must follow to develop an IEP, a legally binding document that serves as a blueprint to deliver special education and related services (Christle & Yell, 2010; Fish, 2008; Simon, 2006). Teams of professionals develop an IEP. Professionals include a special education teacher, general education teacher, psychologist, administrator, related service professionals, parents, and sometimes the student (Mastropieri & Scruggs, 2010).

IDEA (2004) requires that IEPs have several components: documentation of student’s present level of performance, measurable annual goals, progress monitoring method for collecting and reporting student’s progress, instruction strategies, and related services. The IEP includes a statement regarding class placement and general education participation, state assessment participation, as well as projected IEP start and end dates, and frequency and duration of special education services (Christle & Yell, 2010).

IEP teams must follow procedural and substantive requirements to insure schools develop IEPs in accordance with the law (Drasgow et al., 2001). Procedural requirements involve the process of developing an IEP. Schools districts must adhere to these processes established by IDEA (2004) and state regulations to avoid procedural errors. Examples of procedural requirements are: including parents in the IEP process, establishing deadlines, and evaluation requirements. The most serious procedural errors involve actions that interfere with a student’s access to FAPE (Christle & Yell, 2010).
Substantive requirements refers to the IEP and whether the IEP provides meaningful educational benefit (Drasgow et al., 2001).

IDEA (2004) specifies procedural rights afforded to parents, including parental notification of meetings and access to data. IDEA (2004) and state regulations specify time frames for notification and school districts must follow these procedures to insure compliance. Not including parents as equal partners in the IEP process is one of the most common and serious procedural errors (Christle & Yell, 2010; Drasgow et al., 2001). School districts lose significant amounts of money when they do not include parents in the process. Yell and Drasgow (2000) analyzed due process cases of 45 public school districts. Findings revealed that many school districts made procedural errors and subsequently lost court cases because parents were not included as equal partners in the IEP process (Yell & Drasgow, 2000).

Furthermore, Hill (2009) analyzed 127 due process cases to investigate reasons why cases proceeded to due process. Investigations showed that over half of the cases involved procedural errors—a majority of which occurred because school districts did not include parents as equal partners in the IEP process. IDEA is very clear in mandating equal participation of parents in the special education of their child, and schools pay dearly for not adhering to IDEA’s (2004) procedural requirements.

The IEP is a legally binding document that directs and monitors students’ special education programs (Christle & Yell, 2010). IDEA (2004) stipulates substantive requirements to insure IEPs are developed in a way that students derive meaningful educational benefit. IEPs document students’ present level of performance, annual goals,
instruction strategies, and progress monitoring. Substantive errors occur when teams do not accurately identify annual measurable goals, create education plans designed to meet those goals, monitor progress, and appropriately place students in classrooms that enhance their ability to derive educational benefit (Christle & Yell, 2010; Zirkel, 2011).

**Individualized Education Program Goals and Instruction Methodologies**

Specifically designed instruction strategies, created for students to derive meaningful educational benefit, are at the heart of the IEP. In order to develop measurable goals, IEP teams must assess students’ needs and present levels of academic and functional performance. Assessments should be appropriately chosen based on individual student needs. Parents are able to provide independent evaluations and assessments as well. IEP team members use information from assessments and observations to collaboratively develop specifically designed instruction strategy goals (Stroggilos & Xanthacou, 2006).

In order to develop programs that have meaningful educational benefit, schools need to insure that student needs, identified through assessments, accurately reflect documented needs in the IEP. Team members must be qualified to develop IEP goals, and instructional methodologies designed to meet these IEP goals (Etscheidt, 2003). Finally, instructional methodologies must be based on evidence-based practice to the maximum extent possible (Zirkel, 2011). The school’s selection of instructional programming must be relevant to student needs (Etscheidt, 2003).

FAPE is the most commonly argued aspect in autism litigation, and the IEP is a critical component of FAPE. Developing meaningful goals, appropriate instruction
methods, and monitoring progress are parts of the IEP. To gain a greater understanding of autism litigation, Etscheidt (2003) analyzed 68 cases involving students with ASD between 1997 and 2002. Findings revealed that schools lost cases when they inappropriately developed IEP goals that did not reflect student needs, identified through assessments. Assessments must be valid and considerate of parental independent evaluator assessments (Etscheidt, 2003).

Instructional strategies designed to meet the unique needs of a child individualize the education plan. Reasonable calculation and selection of instructional methodology is critical. Schools comply with FAPE when they select individualized methodologies that are appropriate to meet students’ unique learning needs, and instructional methodologies that facilitate students’ abilities to meet IEP goals (Etscheidt, 2003).

Instructional strategies must rely on peer-reviewed research to the maximum extent possible. However, quality research regarding evidence-based practices for students with ASD is limited (Ryan, Hughes, Katsiyannis, McDaniel, & Sprinkle, 2011). Thus, school districts that provide sound documentation regarding the process for selecting appropriate instructional strategies prevail in court. IDEA (2004) only requires schools to utilize evidence-based practices to the maximum extent possible (Zirkel, 2011). If selected instructional strategies are consistent with evaluations and designed for students to derive academic benefit, courts rule in favor of school districts (Christle & Yell, 2010; Etscheidt, 2003; Zirkel, 2011).

Two of the most litigated instructional strategies for students with ASD are Applied Behavior Analysis (ABA) and Treatment and Education of Autistic and Related
Communication-Handicapped Children (TEACCH). Both strategies create predictable routines, provide supportive teaching, and facilitate family participation. TEACCH, which was developed at the University of North Carolina Chapel Hill, utilizes the environment and classroom to facilitate behaviors and independent skills (Prelock, 2006). On the other hand, ABA examines behaviors, manipulating contingencies to facilitate or extinguish specific behaviors (Choutka, Doloughty, & Zirkel, 2004; Prelock, 2006). ABA is often intense, requiring one-on-one instruction. Discrete Trial Training (DTT) is based on the principles of ABA, but to delivers 1:1 instruction through four phases: task presentation, student response, contingency reward/response, and pause (Prelock, 2006).

Parents litigate regarding the appropriateness of instructional strategy as well as the intensity and number of hours of intervention (Choutka et al., 2004).

**Progress Monitoring**

Monitoring student progress is essential to determine the appropriateness of the instructional methodology selected. Progress monitoring tracks students’ progress and provides useful data for IEP teams. Progress monitoring includes data derived from observations, assessments, and anecdotal notes (Etscheidt, 2006). IDEA (2004) mandates that teachers track progress, and that parents are notified of progress toward meeting IEP goals. The IEP must specify the progress monitoring method and frequency of reports (Etscheidt, 2006). IEPs identify not only the method to monitor progress, but who monitors progress, and where progress monitoring occurs (Etscheidt, 2006). Data from progress monitoring helps IEP teams adapt instructional methodologies if students are not making progress toward meeting IEP goals (Crockett & Yell, 2008; Etscheidt, 2003).
However, research indicates that schools frequently do not specify the method of monitoring student progress or collect data (Etscheidt, 2006; Kurth & Mastergeorge, 2010; Yell, Rogers, & Rogers, 1998; Zirkel, 2011). Yell et al. (1998) stated that schools comply less with progress monitoring mandates than any other mandate. Furthermore, many school districts do not meaningfully monitor academic, behavior, or functional life goals (Etscheidt, 2012). Consequently, there is limited data available to assist IEP teams in adapting instructional methodologies when students are not making gains toward meeting IEP goals. Courts rule in favor of parents when schools cannot provide adequate data regarding progress (Yell et al., 2006; Zirkel, 2011).

Tracking progress requires time and attention. Research indicates that teachers have difficulties monitoring progress when there are too many IEP goals. Kurth and Mastergeorge (2010) reviewed IEPs and examined goals of 15 adolescent students who had ASD. Findings revealed that students had an average of 19 goals on their IEP, and achieved less than 70% of their IEP goals. Furthermore, a large number of teachers never reported progress toward meeting IEP goals. Younger students had more goals than older students. Students attending self-contained classes had a greater number of IEP goals than students in inclusive classrooms (Kurth & Mastergeorge, 2010).

**Educational Placement**

The least restrictive environment provision (LRE) in IDEA (2004) mandates that students with disabilities are educated in the general education environment to the maximum extent possible. Data from the U.S. Department of Education shows that a majority of students with ASD are educated in general education classrooms. In 2006,
32.2% of students with ASD were educated in general education classrooms. Of total students with ASD, 38.7% were educated for less than 40% of the day in general education classes, and 9% were educated in self-contained classes or schools (U.S. DOE, 2012).

The heterogeneity of ASD necessitates individualized treatments and interventions. Developing appropriate education programs to meet complex needs is difficult. Some interventions require self-contained settings. Applied Behavior Analysis, an intervention with the most evidence base, is individualized and often implemented in self-contained classrooms. Lovaas (1987) researched the effects of Applied Behavior Analysis instruction on students with ASD and found ABA successfully enhanced students’ abilities to learn academically and socially. Resultantly, many parents request one-on-one ABA instruction in separate, self-contained classes (Simpson, Mundschenk, & Heflin, 2011).

To meet the least restrictive environment mandate, schools often employ paraprofessionals to work with students who have ASD (Giangreco & Broer, 2005; Mazurik-Charles & Stefanou, 2010). Some paraprofessionals work one-on-one with students, while others support groups of students. Yet, research indicates that many teachers and paraprofessionals lack an understanding of ASD and interventions that facilitate behaviors and their ability to participate in general education environments (Volkmar, Lord, Bailey, Schultz, & Klin, 2004). Some argue that the use of paraprofessionals in the general education classroom is actually the most restrictive education (Giangreco & Broer, 2005). Many students with ASD develop an overreliance
on paraprofessionals, inhibiting the development of self-determination skills that are necessary to live independently (Prelock, 2006).

**High Litigation Costs**

IDEA (2004) provides parents with rights to due process and mediation. Since its inception, IDEA was wrought with areas of disagreement that would later be decided by courts. IDEA does not define an appropriate education program, or meaningful education benefit. Schools need only provide appropriate educations. However, parents want the best education for their child. Also, issues involving assessments, evidence-based practices, progress monitoring, and class placement contribute to increased litigation. Furthermore, there is limited research available regarding IEP efficacy for students with ASD (Wilczynski, Monousek, Hunger, & Mudgal, 2007).

Litigation involving students with ASD is the most expensive area of education litigation (Etscheidt, 2003). Parents of children with ASD are 10 times more likely to sue than parents of children with other disabilities (Zirkel, 2011). Two areas most frequently litigated are FAPE and LRE (Zirkel, 2011). Zirkel (2011) examined 201 court decisions involving students with multiple types of disabilities between 1993 and 2008. Of the 201 cases, 32% involved students with ASD and FAPE or LRE.

Zirkel (2011) speculated several factors that inspire litigation. First, autism treatments are expensive for both families and school districts. Second, many behavioral, social, and academic interventions lack evidence. Third, the Internet provides information to parents regarding treatments, and parents who believe claims documented on websites sue districts to provide advertised treatments (Heflin & Simpson, 1998; Zirkel, 2011).
Parental Perceptions of the Individualized Education Program Process

IDEA (2004) recognizes and protects the rights of parents to participate in the IEP planning process. The development of an IEP document requires collaboration among teachers, therapists, psychologists, administrators, and parents (Stroggilos & Xanthacou, 2006). IDEA (2004) states the following:

Almost 30 years of research and experience has demonstrated that the education of children with disabilities can be made more effective by strengthening the role and responsibility of parents and ensuring that families of such children have meaningful opportunities to participate in the education of their children at school and at home. (20 U.S.C. § 1400(C)(5)(b))

Research shows that parental involvement in education positively impacts students (Stoner & Angell, 2006). Parents are influential partners who have potential to enhance the education performance of students with disabilities. Successful parent–teacher collaboration is essential to develop appropriate instruction strategies that meet the educational needs of students with disabilities (Fish, 2008). Given the critical role parents have in the IEP process, the following section reviews published literature and dissertations regarding parental perceptions of the IEP process.

There are 24 studies that investigate the experiences and perceptions of parents who have children with multiple types of disabilities regarding the IEP process (Angell, Stoner, & Shelden, 2009; Bitterman et al., 2008; Brandt, 2011; Cho & Gannotti, 2005; Fish, 2006, 2008; Hotchkiss, 2012; Hume et al., 2005; Jensen-McNiff, 2012; Jimenez, 2011; Kohler, 1999; Lo, 2008, 2009; Lovelin, 2012; Lynch & Stein, 1987; Nickels, 2010;
Salas, 2004; Sheehey, 2006; Sheldon, Angell, Stoner, & Roseland, 2010; Simon, 2006; Spann et al., 2003; Stoner & Angell, 2006; Stoner et al., 2005; Stroggilos and Xanthacou, 2006). Of these studies, 11 examine perceptions of parents of children with autism spectrum disorders (Bitterman et al., 2008; Brandt, 2011; Fish, 2006; Hume et al., 2005; Jimenez, 2011; Kohler, 1999; Lovelin, 2012; Nickels, 2010; Spann et al., 2003; Stoner & Agnell, 2006; Stoner et al., 2005). A majority of these studies investigate the perceptions of parents who have young children. Six of these 11 studies investigate perceptions of families who have children with ASD who are younger than 9 years (Bitterman et al., 2008; Brandt, 2011; Hume et al., 2005; Kohler, 1999; Stoner & Angell, 2006; Stoner et al., 2005). Five studies investigate perceptions of parents of multiple-aged children with ASD (Brandt, 2011; Fish, 2006; Lovelin, 2012; Nickels, 2010; Spann et al., 2003). Three of these studies are dissertations (Brandt, 2011; Lovelin, 2012 Nickels, 2010). Thus, as shown in Figure 1, there are only two published studies examining the perceptions of parents who have multiple-aged children with ASD and the IEP process (Fish, 2006; Spann et al., 2003).
The following paragraphs share current research regarding experiences and perceptions of parents in the IEP process. The first section includes results of studies that investigate perceptions of parents who have children with multiple types of disabilities through qualitative and survey methodologies. The second section shares results of studies that investigate the experiences of families with children who are culturally and linguistically diverse. Finally, the third section includes results of studies that investigate perceptions of parents of children with ASD and the IEP process.
Perceptions of Parents With Children With Multiple Disabilities

Studies examining the perceptions of parents who have children with multiple types of disabilities have equivocal findings regarding their perceptions of the IEP process. Findings from some studies show parents have positive perceptions of the IEP process, while other studies’ findings show parents have negative perceptions of the IEP process. The following paragraphs share results of studies that investigate parental perceptions of the IEP process of families who have children with multiple types of disabilities, including Autism Spectrum Disorders.

Fish (2008) implemented a mixed methods survey of 51 parents who were members of one family support agency in Texas. Participants’ children had multiple types of disabilities, including autism spectrum disorders. The survey had items that questioned participants about demographic information, IEP meeting experiences, educator knowledge of the IEP process and special education law, relations with educators, and IEP outcomes. Participants rated items with ratings on a 5-point Likert scale. At the end of the survey, there were two open-ended questions asking parents their recommendations for improving the IEP process. Fish analyzed survey data by reporting frequencies and percentages for survey questions and Likert scale responses. Fish aggregated positive and negative frequency counts to determine the total number of parents agreeing and disagreeing with survey questions, then divided this number by the total number of item responses and multiplied this number by 100 to have a percentage.

Results showed that a majority of parents reported positive IEP experiences. Parents felt educators were knowledgeable about special education law and the IEP
process. Parents had good relationships with educators, and believed that the outcomes for their child were appropriate. Parents felt confident in their abilities to negotiate IEPs with educators. Their recommendation for improving the IEP process was to improve communication prior to IEP meetings. They wanted to communication and collaboration prior to IEP meetings in order to individualize IEP goals for their child. They felt educators too frequently recommended generic goals that were predetermined prior to meetings without their input.

Alternatively, Jensen-McNiff (2012) interviewed 15 rural Nebraskan parents who had children diagnosed with ASD, emotional disabilities, and other health impairments to gain an understanding of their experiences during the IEP process. Parents reported they felt the IEP meeting was not collaborative, and they wanted greater communication with teachers prior to IEP meetings. Parents reported they believed teachers recommended not individually tailored IEPs, but rather what they referred to as “cookie-cutter” or highly similar IEPs, for all children with ASD. They felt IEP meetings were legal formalities where parents were encouraged to agree to prescribed plans. When parents made suggestions at meetings, they felt educators did not integrate their suggestions into the IEP. Some parents felt teachers did not understand their child’s disability and resultant behaviors, and blamed them for improper parenting. Finally, parents felt teachers did not fully understand how to implement accommodations necessary for their child’s success in the general education classroom. When asked what parents would like to do to change the IEP process, parents indicated they wished for more collaborative and conversational
IEPs. They felt IEP teams rigidly adhered to IEP rules, standards, and procedures in lieu of true collaboration.

To be true partners in the IEP process, parents also felt they needed a better understanding of their rights and special education law. They wanted to learn their rights and communication skills to collaborate more effectively with teachers and administrators. Some parents invited advocates and friends to IEP meetings with them to insure their rights were protected. They felt their advocate’s presence enhanced their ability to advocate and lessened their emotional responses (Jensen-McNiff, 2012).

Stroggilos and Xanthacou (2006) conducted case studies which consisted of interviews of IEP members for 10 children with profound and multiple disabilities, exclusive of ASD. Researchers interviewed parents and teachers about their experiences and perceptions as to whether the IEP process promoted collaboration among IEP participants in educating students with profound and multiple disabilities. Findings showed that parents felt teachers created IEP goals without their input and suggestions.

Teachers in this study were aware they did not include parents in the IEP goal setting process. They felt they needed to improve collaboration and communication with parents prior to IEP meetings. However, teachers said they did not have enough time to communicate and collaborate with parents before IEP meetings. This lack of time inhibited their ability to include parents in IEP goal setting.

School administrators are also IEP team members and have the authority to commit resources required by the IEP (Pacer Center, 2013). School administrators understand class and placement options available for students. Shelden et al. (2010)
interviewed 16 parents of children with disabilities regarding their perceptions of interactions with school administrators and attributes that they felt facilitated collaboration. Parents reported that principals who were warm, respectful, and caring enhanced their trust in the education system. Professional attributes such as accessibility, knowledge of disability, and approachability were cited as attributes that parents felt enhanced collaboration (Shelden et al., 2010).

Overall, studies that investigated the perceptions of parents who had children with multiple types of disabilities indicated that parents had negative opinions of the IEP process. Parents felt teachers created IEP goals without their input, and many parents desired communication with prior to IEP meetings. Furthermore, they believed teachers created generic IEP goals common among many children with ASD unless they contributed to conversations regarding IEP goals. Parents felt knowledge of their rights and special education law enhanced their ability to advocate for their child and participate meaningfully in meetings to develop individualized IEPs for their child.

**Demographic Characteristics’ Effect on Parental Perceptions**

Some researchers have postulated that demographic characteristics such as socioeconomic status, ethnicity, or location could affect parental perceptions and experiences. Several studies investigated this relationship. The following paragraphs discuss these studies.

Kemp (2011) investigated the relationship between specific population demographic characteristics of 51 parents and their perceptions of the IEP process through a survey. Characteristics examined included education, marital status,
socioeconomic status, number of years in special education, and disability categories. Results showed that there is no statistical difference between parental education and satisfaction with the IEP process. Furthermore, socioeconomic status did not impact parental satisfaction with the IEP process nor did a child’s disability classification. However, some parental demographic characteristics demonstrated a relationship between satisfaction with the IEP process. Parents who were married were less satisfied with the IEP process than parents who were divorced. Also, experienced parents—those who were involved in the IEP process for five years or more—were less satisfied with the process than parents who had children in special education for less than five years.

Very few studies examine perceptions of low-income parents or at-risk families. Lynch and Stein (1987), one of the few studies to investigate perceptions of low-income families, interviewed 100 Hispanic, Black, and Caucasian families of children with multiple types of disabilities regarding their experiences in special education. Findings revealed that 85% of 63 Hispanic parents felt the school appropriately identified their child’s disability and 89% were satisfied with special education programs. However, many parents were unaware of their child’s IEP goals: Only 55% of parents were able to identify their child’s IEP goals. Furthermore, 29% were unaware of progress toward meeting IEP goals. Parents cited barriers to participating in the IEP process which included work, time conflicts, transportation problems, and childcare. Of parents, 54% were unable to attend IEP meetings or other school meetings due to these barriers (Lynch & Stein, 1987).
These barriers to meaningful participation in IEP process were echoed by 10 African American participants in Hotchkiss’s (2012) dissertation. Hotchkiss investigated obstacles that prevented full participation in the IEP process of parents and guardians of African American males in special education. Participants’ children had a range of disabilities. Hotchkiss interviewed 10 parents and guardians of children in grades 9-12 in two counties in California. Findings revealed five major themes. First, parents wanted improved communication between home and school. They did not feel respected by the IEP team. Second, they felt a greater need for knowledge of special education. A majority of participants stated they had to learn about the IEP process and their rights from sources outside the school. Third, participants did not feel confident in their ability to contribute meaningfully at the IEP meeting. Their lack of confidence about and understanding of their rights and special education law affected their ability to collaborate. Fourth, 60% of participants felt that teachers were not always able to implement their child’s IEP. They felt that teachers were too busy to follow through to advocate for their child. Parents stated that family and work issues were barriers in their ability to advocate for their child. They wished that teachers had smaller classes, which would enable them to advocate for their child on their behalf. Finally, 60% of participants felt that educators did not understand African American culture. They felt that teachers who were Black had a greater ability to empathize with the Black experience. They also felt that Black teachers were positive role models for their children.

In another study, Simon (2006) surveyed 143 parents and 98 teachers regarding their perceptions of the IEP process. Participants’ demographics included a larger
percentage of African American and Hispanic/Latino parents than found in the general population of parents who had children with disabilities. Of participants, 53% were African American and 4% were Hispanic/Latino. Perceptions regarding special education services and IEP team collaboration were measured on a 5-point Likert scale survey that had 29 items. Results showed parents did not feel they were collaborative partners in the IEP process. Teachers in Simon (2006) had more favorable opinions of the IEP process. The researcher provided three strategies that would improve the IEP process. First, Simon recommended having well-organized meetings that include agendas. Second, parents want ongoing communication with teachers in order to assess their child’s progress. Ongoing communication helps parents understand their child’s needs in order to assess skills to collaborate more effectively when creating IEP goals. Finally, Simon recommended surveying IEP team participants after meetings to evaluate meetings’ effectiveness and to more fully meet the needs of families and teachers.

**Culturally and Linguistically Diverse Families**

Several studies investigated the experiences and perceptions of culturally and linguistically diverse families who had children with multiple types of disabilities regarding special education. All studies utilized qualitative research methodology to fully examine experiences at a personal level. All families reported difficulties with translators, lack of knowledge about IEPs and the IEP process, and feelings of disrespect by IEP team members. Results from Jegatheesan et al. (2010) study are reported in the section that discusses perceptions of parents with children who have ASD.
Cho and Gannotti (2005) interviewed 20 Korean American mothers of children with disabilities regarding experiences in the IEP process. Participants reported an insufficient number of translators qualified to translate between English and Korean. Translators had difficulties finding words in Korean that meant the same thing as words in English. They also felt that translators’ lack of knowledge of the IEP process affected their ability to participate fully in IEP meetings. Participants felt that translators who attend meetings need an understanding of the IEP process and special education law.

Language translator issues are complaints echoed by participants in two other studies. Lo (2008) conducted a qualitative investigation into the experiences of five Chinese families and their perceptions of the IEP process. Families had children with multiple types of disabilities including autism, cerebral palsy, Hunter syndrome, and attention deficit disorder. Lo observed families’ IEP meetings and interviewed parents after IEP meetings. Findings revealed that language barriers impeded communication during IEP meetings. Translators often did not fully understand the IEP process or have words in Chinese to approximate the English translation. Furthermore, Chinese parents felt disrespected by educators. Parents did not feel like equal partners in collaboration to develop the IEP. In another study, Lo (2009) investigated the experiences of two Chinese families during the IEP process. Families also expressed difficulties understanding the translators who communicated in Chinese to them during meetings. Again, the translators may not have understood the IEP process, or have knowledge of a comparable word in Chinese to describe concepts discussed at meetings.
In another study, Salas (2004) interviewed 10 Mexican American women regarding their perceptions of the IEP process. Interviews took place throughout the entire school year, so IEP issues could be discussed as they arose. Findings revealed that the Mexican American women did not feel respected by education professionals. They felt that their suggestions and input were not integrated into IEP goals.

Across studies, culturally diverse families reported that they did not understand special education practices and the IEP process. Parents felt their ignorance regarding special education law and the IEP process inhibited their ability to collaborate with education professionals (Hochkiss, 2012; Jegatheesan et al., 2010; Lo, 2008; Sheehey, 2006). Some English language terms do not translate to terms in other languages. Therefore, parents have no point of reference for definition of terms (Jegatheesen et al., 2010; Lo, 2009, 2008).

Other families felt cultural differences inhibited collaboration. The IEP process and language used in meetings were completely foreign. In one study, Sheehey (2006) used qualitative case study methodology to investigate parental involvement in the educational decision making of three Hawaiian families who had children with intellectual and developmental disabilities. Findings showed that parents felt uncomfortable during meetings. They felt cultural barriers between home and school. Parents did not understand special education terms, or the IEP process. All in all, research indicates that culturally diverse families can have language and cultural barriers that inhibit collaboration.
Perceptions of Parents of Children With Autism Spectrum Disorders and the Individualized Education Program Process

The heterogeneity of autism complicates diagnosis and treatment. Parents sometimes consult with multiple doctors to get an accurate diagnosis of autism. Delays in identification delay services and treatments. Several studies noted frustration regarding the long diagnosis process and delay in services (Bitterman et al., 2008; Kohler, 1999; Stoner et al., 2005). Treatments and interventions are individualized to meet the unique needs of a child with ASD. The following paragraphs share research that examines the perceptions of parents who have children with ASD and the IEP process. Table 3 illustrates these studies.

Table 3

Studies Investigating the Perceptions of Parents With Children With Autism Spectrum Disorders and the Individualized Education Program Process
### Study Participants Method

<table>
<thead>
<tr>
<th>Study</th>
<th>Participants</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kohler (1999)</td>
<td>25 families with children ages 3 to 9</td>
<td>Telephone interviews</td>
</tr>
<tr>
<td>Spann et al. (2003)</td>
<td>45 parents with children ages 4 to 18 who participated in a Midwestern autism family support group</td>
<td>Telephone survey</td>
</tr>
<tr>
<td>Hume et al. (2005)</td>
<td>195 parents with children ages 2 to 8</td>
<td>Mail survey</td>
</tr>
<tr>
<td>Stoner et al. (2005)</td>
<td>4 families with preschool- and early elementary-aged children</td>
<td>Interviews</td>
</tr>
<tr>
<td>Stoner and Angell (2006)</td>
<td>4 families with preschool-and early elementary-aged children</td>
<td>Interviews</td>
</tr>
<tr>
<td>Fish (2006)</td>
<td>7 parents who participate in a family support group in North Texas</td>
<td>Interviews</td>
</tr>
<tr>
<td>Bitterman et al. (2008)</td>
<td>186 parents with children ages 3 to 5</td>
<td>Telephone interviews</td>
</tr>
<tr>
<td>Jimenez (2011) dissertation</td>
<td>9 Mexican families with children of multiple ages</td>
<td>Interviews</td>
</tr>
<tr>
<td>Nickels (2010) dissertation</td>
<td>6 families with multiple-aged children who attended a North Tennessee school district</td>
<td>Interviews</td>
</tr>
<tr>
<td>Brandt (2011) dissertation</td>
<td>30 parents with children of multiple ages who participated in a Midwestern autism family support group</td>
<td>Online survey</td>
</tr>
<tr>
<td>Lovelin (2012) dissertation</td>
<td>22 parents who participated in the SUCCESS program in the Oaks View School District</td>
<td>Mixed methods with questionnaire and interviews</td>
</tr>
</tbody>
</table>

**Positive perceptions.** Spann et al. (2003) telephone interviewed 45 parents to investigate parental perceptions of special education services and the communication they had with educators. Participants were members of one Midwestern autism support group,
and parents’ children’s ages ranged from 4 -18. The telephone survey consisted of 15 questions, which included questions about educational placement, special education services, communication with educators, parental knowledge of the IEP process, and overall satisfaction with the IEP process. Parents responded to survey questions with three responses: low, medium, or high satisfaction. Results indicated that a majority of parents’ children were educated in general education classes for most of the day. Parents felt knowledgeable about the IEP process and communicated with educators frequently regarding a multitude of issues. Furthermore, a majority of parents had positive perceptions with the IEP process. Of parents, 79% felt that they were moderately satisfied with the IEP process and 13% had high satisfaction with the IEP process. Parents also indicated they were satisfied with communication they had with educators. Parents who had younger children stated they were more satisfied with communication with educators than parents who had older children.

In a three-phase mixed methods study, Lovelin (2012) investigated the IEP experiences of parents, educators, and students in a small school district to gain an understanding of multiple stakeholder perceptions. During the first phase, Lovelin surveyed 22 parents regarding their perceptions of the IEP process. In the second phase, 17 parents participated in researcher/parent semistructured interviews that explored IEP experiences in further detail. Finally, during the third phase, 8 parents analyzed interview transcripts from students and parents to develop questions and responses. Results of this study showed that 73% of respondents understood the IEP process and had positive perceptions regarding their involvement. Parents articulated suggestions that would
improve the IEP process. First, parents wanted communication with teachers prior to IEP meetings. Parents perceived that teachers did not have time to collaborate with them.

Teachers’ lack of time inhibited communication and their participation in drafting IEP goals before meetings. Parents felt they had to negotiate for accommodations and wished accommodations were more explicitly stated on the IEP instead of negotiated. They felt they had to ask for services and continually advocate for their child. If they did not ask for services, their child would not receive them, even if their child needed the services.

Finally, parents perceived that teachers needed more training and support to teach students with autism. They felt teachers did not understand their child’s behaviors and therefore had difficulties creating IEPs with meaningful strategies to facilitate behaviors and learning.

Nickels (2010) interviewed the parents of six children diagnosed with ASD who attended a Northeast Tennessee school system. Nickels wanted to gain an understanding of parental perceptions regarding educational interventions they perceived effective, barriers to implementing educational interventions, and relationships between parents and teachers. Findings demonstrated that parents had positive perceptions regarding their participation in the IEP process. They felt their suggestions were integrated into the IEP and that they were respected IEP team members. However, they felt teachers’ lack of time inhibited collaboration prior to IEP meetings. Resultantly, teachers created generic IEP goals without their suggestions and input.

In another study, Bitterman et al. (2008) examined a subsample of 186 respondents who had children with ASD in preschool and elementary school. Data was
obtained from telephone interviews with children’s parents, questionnaires mailed to teachers, and evaluations. Findings revealed that most parents had positive overall perceptions of the services their child received. Between 91% and 96% of parents had positive perceptions of their child’s program, special education teachers, and services. Approximately 25% of parents felt their child needed more frequent services than were provided by the school and 25% felt their child was not receiving services that should be provided by the school. Approximately 25% felt their child spent too much time in a self-contained class, and needed to be educated with children who did not have disabilities.

Hume et al. (2005) surveyed 195 parents of young children ages 2-8 with ASD in Indiana regarding their perceptions of services for their child and resultant outcomes. The Indiana Autism Resource Center contacted parents regarding participation. The survey had six sections that included demographics, types and amounts of interventions, strategies, settings of services, evaluation of services, evaluation of service delivery, and outcomes of interventions. The evaluation of services sections required parents to rate progress on a 4-point Likert scale. A total of 586 surveys were distributed, and 198 were returned (33.7% response rate). Results indicated that a majority of parents, 59%, stated that parental participation and collaboration were important and 47.7% received progress reports documenting educational progress toward meeting IEP goals. A majority of parents felt that parent training in special education law contributed to the best outcomes for their child. Parents also felt their child needed more frequent related services. Their child received services that were less than services recommended by medical professionals or other professionals. Parents felt related services improved their child’s
skills and functioning. Finally, parents wanted more inclusion opportunities for their child.

**Negative perceptions.** Brandt (2011) surveyed 30 parents who had children with autism from one upper Midwestern autism support group regarding their perceptions of the IEP process. A majority of respondents’ children were between the ages of 7 and 12. The online survey included two main sections: demographic questions and 55 questions about perceptions of the IEP process, which was further divided into seven sections. These seven sections were: parental perspective of priorities for their child, IEP content, parental experiences, IEP meeting attendance, comfort with IEP meetings, parental involvement, and parental participation in meetings. Participants rated survey items with a 5-point Likert scale. Unfortunately, the study’s small sample size inhibited statistical analysis except frequency reporting. There were several major findings. First, parents felt that functional life skills such as communication and social skills were not prioritized by IEP teams. Parents felt IEP teams focused too much on academic skills. Next, when parents felt like they were equal members of the IEP team, they felt more comfortable participating in meetings. Finally, parents felt more comfortable collaborating and contributing their suggestions when teachers communicated frequently with parents. Communication enhanced parents’ level of trust which in turn made them feel more comfortable at IEP meetings.

Fish (2006) interviewed seven parents who participated in one family support agency in North Texas. Participants’ children’s ages were not reported, but Fish noted that one student was in high school and all participants had experience with IEP
meetings. Parents were asked questions regarding the quality of services provided in the IEP, perceptions of being treated as equal IEP team members, changes they desired for their child’s IEP, and what districts and parents can do to improve the IEP process. Findings revealed that parents did not perceive themselves as being treated like equal members of the IEP team. They felt IEP goals were created prior to IEP meetings without their input or suggestions. Furthermore, they perceived IEP goals were not implemented in classrooms or prioritized by teachers. To improve the IEP process and more fully engage parents, parents believed school districts needed to improve education programs that teach parents their rights and special education law.

Stoner and Angell (2006) interviewed the families of four young children who were diagnosed with autism spectrum disorders. Two families had children in elementary school and two families had children in preschool. All parents participated in a parent support group for children with ASD. Over a period of 9 months, researchers interviewed participants three times about their experiences with special education professionals. Cross-case analysis was used to obtain themes and validate findings. Themes revealed that parents engaged in several roles throughout the IEP process. Their relationships with educators and levels of trust dictated when and how long they remained in these roles. The first role parents engaged in was a negotiator: a person who negotiates and compromises to obtain a desired outcome. Parents in this study hired advocates to negotiate for them and their child during IEP meetings. They had positive perceptions of advocates, whom they felt enhanced collaboration. A second role parents engaged in was monitor. In the monitor role, a parent communicated with teachers and monitored their
child’s progress with IEP progress reports, and informal, ongoing communication with teachers. Two final roles were supporter and advocate. In the supporter role, parents helped teachers by providing materials and sharing positive encouragement. In the advocate role, parents advocated for children and families with disabilities within the community. Parents shared the experiences they had during their child’s diagnosis.

Parents had a difficult time obtaining a medical diagnosis of ASD. Once parents received the diagnosis, they educated themselves on autism and services for their child. Parents reported feeling frustrated during the IEP process when they could not agree on services for their child. Once the school lost credibility and trust, parents were more adversarial during the IEP process. Parents felt that knowledge of special education law was necessary in order to be an equal IEP team member.

In another study, Stoner et al. (2005) interviewed four married couples who had preschool- or early elementary-aged children with ASD regarding their relationships and experiences with education professionals. Three of the four children in the study were nonverbal. The researchers used a collective case study method and cross-case analysis to identify themes to uncover how parents described their experiences interacting with education professionals, their roles, relationship, and influencers on their interactions. Findings revealed that parents had difficulties obtaining an accurate diagnosis, which caused extreme frustration. Parents wanted a diagnosis to be able to provide treatments to remediate symptoms. Once they received a diagnosis of autism, they distrusted medical professionals’ ability to recognize and understand autism. They learned to trust their own instincts over medical professionals’ opinions. The authors speculated that the level of
distrust, learned during the diagnosis process, may project their poor experiences with medical professionals to relationships with education professionals. After parents received an autism diagnosis, they researched autism by consulting with multiple professionals to learn about their child’s disability. Parents had positive perceptions of preschool education programs. They felt preschool teachers and therapists worked well with their child, and educated them on their child’s disability. In contrast, transitioning from preschool programs to school-based programs was traumatic. Parents felt the IEP process was more rigid, and communication decreased. Consequently, they relied on their child’s behavior to assess their child’s progress and success at school. Positive interactions with educators enhanced trust and communication between home and school. Negative interactions adversely affected parents’ trust levels. Parents wanted honest and frequent communication with teachers. Finally, parents felt administrators who made an effort to form relationships with them and their child enhanced their trust and facilitated the IEP process. However, fathers indicated they were always skeptical that their child would not receive services because of limited school budgets. Consequently, they were cautious regarding interactions with school administrators.

In another telephone survey, Kohler (1999) interviewed 25 families who had children ages 3 to 9 diagnosed with ASD. Researchers conducted 45- to 90-minute telephone interviews with parents regarding the type and amount of services received, accessibility of services, family involvement, continuity of services, and satisfaction. Families were members of four agencies that worked with families in Pennsylvania. Researchers used independent t tests to analyze differences between responses provided
by parents of children with preschool children and parents of school-aged students. Findings revealed significant differences between the numbers of hours of intervention per week: Children in school-age grades received a greater number of hours of intervention than children in preschool. Findings also revealed that all families received services from multiple agencies and providers, making coordination of services difficult. All families were minimally involved in planning treatments.

Jimenez (2011) conducted a series of semistructured interviews with nine Mexican families who had a child diagnosed with ASD to learn about their experiences during the IEP process. Family education levels ranged from elementary school to two years of college. Families resided within the United States from 5 to 25 years. Parents shared they wanted more communication with teachers as well as education regarding the IEP process and their rights. Several parents felt insecure about contributing to conversations in IEP meetings because they did not fully understand their rights to participate, or lacked assertiveness skills. Relationships with teachers and other IEP team members improved parental participation in meetings. When parents felt their child’s teacher truly cared, they participated collaborated more with teachers, making suggestions on IEP goals. Jimenez noted the Latino culture values personal connection with others. When teachers and IEP team members established a personal connection, collaboration with families who are Mexican improved.

In another study, Jegatheesan et al. (2010) interviewed three South Asian Muslim immigrant families regarding their experiences raising children with ASD. Findings showed that many parents were unaware of their rights as mandated by IDEA (2004).
This lack of knowledge affected families’ abilities to advocate and access services (Jegatheesan et al., 2010).

**Summary of Parental Perspectives**

Autism is a spectrum. Children diagnosed with autism spectrum disorder exhibit a wide range of symptoms. Some children have milder pragmatic language issues and atypical social skills. Other children are nonverbal and have significant behavior challenges. This heterogeneity complicates diagnosis and treatment. Consequently, parents often consult with multiple doctors prior to diagnosis. Parents begin the education and treatment journey with skepticism regarding the knowledge of medical professionals.

Furthermore, there is no “cure” to autism. Multiple treatments remediate symptoms, but there is still no cure. Schools provide services and treatments to remediate symptoms of autism. The following paragraphs synthesize and summarize research regarding perceptions of parents and the IEP process in the following sections: overall perceptions, equal partners in the IEP process, educator knowledge of ASD and special education law, and class placement.

**Overall perceptions.** Eleven studies investigated the perceptions and experiences of parents of children who have autism spectrum disorders and the IEP process, two of which are dissertations. A majority of studies examine perceptions of parents who have children younger than age 9 (Bitterman et al., 2005; Hume et al., 2005; Kohler, 1999; Spann et al., 2005; Stoner & Angell, 2006; Stoner et al., 2005). Thus, there is limited research regarding the perceptions of parents who have children older than elementary school (Brandt, 2011; Fish, 2006, 2008; Lovelin, 2012; Nickels, 2010).
Findings were equivocal. In some studies, parents felt positively about the IEP process (Bitterman et al., 2005; Fish, 2006; Hume et al., 2005; Lovelin, 2012; Nickels, 2010; Spann et al., 2005). In other studies, parents had negative perceptions (Brandt, 2011; Fish, 2006; Kohler, 1999; Stoner & Angell, 2006; Stoner et al., 2005). Figure 2 outlines the studies that illustrate positive as well as negative perceptions of the IEP process.

**Figure 2.** Perceptions of parents with children who have Autism Spectrum Disorders regarding the Individualized Education Program (IEP) process.

**Equal partners in the IEP process.** The most contentious aspect of the IEP process involves FAPE. A key component of FAPE is the IEP. IDEA (2004) provides parents the right to be equal partners with educators in the IEP process. In order to
collaborate with teachers to develop IEPs, parents want and need frequent
communication with teachers. They feel that teachers who understand their child and
family will create instructional strategies that are specifically designed for their child.

*Communication and trust.* Many parents believed that positive relationships and
communication with teachers improved teachers’ disposition and understanding of their
child (Fish, 2006; Stoner et al., 2005). Parents reported that positive communication
helped teachers develop empathy for families, and in turn understand their child’s needs
(Fish, 2006; Stoner et al., 2005). A greater understanding of their child’s needs translated
to more effective education practices and behavior management. Parents wanted
increased communication with teachers (Fish, 2006; Lovelin, 2012; Stoner et al., 2005).
Parents who had children who were nonverbal especially wanted more frequent school–
home communication. Parents felt that frequent communication developed trust. They
also felt they were better able to coordinate behavioral management strategies between
home and school (Spann et al., 2003; Stoner & Angell, 2006).

*Communication prior to IEP meetings.* In a majority of studies, parents felt
teachers did not communicate with them prior to IEP meetings regarding goals for their
child (Brandt, 2010; Fish, 2006; Lovelin, 2012; Nickels, 2010). Parents felt teachers did
not have enough time to collaborate with them before meetings (Fish, 2006; Lovelin,
2012; Nickels, 2010). Consequently, they felt teachers’ lack of time inhibited their ability
to individualize IEP goals (Brandt, 2010; Fish, 2006; Lovelin, 2012; Stoner & Angell,
2006; Stoner et al., 2005).
Furthermore, some parents perceived that teachers never read their child’s IEP. Some parents believed that IEP meetings and goals were legal formalities and teachers never implemented IEPs (Fish, 2006; Stoner et al., 2005). Others parents indicated they thought teachers never read IEPs (Fish, 2006).

**Parental knowledge of special education law.** Gaining knowledge of ASD and special education law empowered parents to feel like equal participants in the IEP process (Brandt, 2011; Fish, 2006; Spann et al., 2003). Parents consistently felt that having knowledge their rights and special education law is essential in order to collaborate with teachers (Fish, 2006; Hume et al., 2005; Lovelin, 2012; Nickels, 2010). Developing knowledge of rights under IDEA was essential to be treated as equal, respected IEP team members. Parents who wanted assistance negotiating IEPs hired advocates to attend IEP meetings with them (Fish, 2006; Lovelin, 2012; Stoner & Angell, 2006). These parents reported that the presence of advocates facilitated IEP team collaboration. They also felt their opinions were valued more when advocates were present (Fish, 2006). A majority of parents felt knowledgeable about ASD and special education law (Brandt, 2011; Fish, 2006; Spann et al., 2003).

**Culturally and linguistically diverse families.** Culturally and linguistically diverse (CLD) families who did not speak English expressed concern regarding language barriers that inhibited parental advocacy, which subsequently adversely affected their children’s education programming (Cho & Gannotti, 2005; Jimenez, 2011; Lo, 2008, 2009; Salas, 2004). Culturally and linguistically diverse families indicated that they did not understand the IEP process. Some did not know how to get services, or where to go to
learn about them. In another study, Jegatheesan et al. (2010) interviewed three South Asian Muslim immigrant families regarding their experiences raising children with ASD. Findings showed that many parents were unaware of their rights as mandated by IDEA (2004). This lack of knowledge affected families’ abilities to advocate and access services (Jegatheesan et al., 2010). Parents living in rural areas also expressed difficulties with the IEP process and advocating for services (Sheehy, 2006). All in all, knowledge of parental rights, special education law, and ASD helped parents develop the confidence and knowledge necessary to advocate for services (Cho & Gannotti, 2005; Fish, 2006; Jimenez, 2011; Lo, 2008, 2009; Lynch & Stein, 1987; Salas, 2004).

**Frequency of Related Services.** Disagreements regarding the type of related service/intervention, and intensity/frequency of behavior management, are often litigated (Etscheidt, 2003). Many parents felt their child received an insufficient amount of related therapies (Bitterman et al., 2008; Hume et al., 2005; Lovelin, 2012). Parents perceived that educators thought they were unreasonable in their expectation of services provided by schools (Bitterman et al., 2008). Parents who wanted different programs or increased intensity and frequency of programs felt pushback by schools, and their opinions marginalized (Fish, 2006; Spann, 2003; Stoner et al., 2006).

**Teacher knowledge of ASD.** Many parents felt that teachers did not fully understand autism or how to manage behaviors (Brandt, 2011; Fish, 2006; Spann et al., 2003). Parents indicated that teachers’ lack of understanding of ASD and behavior management inhibited collaboration, adversely affecting their child’s education (Brandt, 2011; Fish, 2006; Jimenez, 2011; Spann et al., 2003). Teachers’ reliance on punitive
behavior management strategies and misunderstanding of ASD interfered with their children’s class participation and education (Fish, 2008).

**Class placement.** Many parents indicated they wanted their child to participate more frequently in general education classes. Reasons cited included social skill generalization with typically developing peers who served as social models (Bitterman et al., 2008; Fish, 2006; Stoner et al., 2006). Paraprofessionals often support the inclusion of students with ASD. Although many parents had positive perceptions of paraprofessionals, some parents felt paraprofessional support inhibited their child’s independence and development of self-determination skills (Hume et al., 2005). Thus, paraprofessionals who were used to enhance the inclusion of disabilities should be trained to teach students’ self-regulatory skills that enable them to meaningfully participate independently.

**Chapter Summary**

This review of the literature described the characteristics of children with ASD; information about autism’s prevalence, diagnosis, and etiology; and special education eligibility. Information regarding family characteristics, and issues related to managing ASD such as employment, insurance coverage, childcare, and cost contribute to considerable family stress. Through the medical diagnosis process, which is often lengthy, parents learn to advocate and persevere. The complexities and challenges of autism propel parents to look for interventions and treatments to remediate autism’s symptoms. Parents reported searching the Internet; however, little is known about where they search and how parents identify treatments/interventions given the plethora of information available on the Internet. Little is also known about how they evaluate the
effects of these treatments/interventions. Prior to their child even entering school, parents endure considerable stress as they search for a diagnosis and treatments concurrent to accepting their child’s disability of autism.

Negotiating for services from schools is paramount. Schools provide for the education and treatment of autism. Insurance companies sometimes will not pay for services that are provided for free by local school districts. The high cost of private services serves as incentive to get the most services from school districts. Given this financial reality, parents negotiate for services and treatments with school districts in the IEP meetings.

In the IEP meeting, parents and teachers collaborate to develop an IEP, which outlines specifically designed strategies appropriate for each child. The IEP acts like a blueprint to deliver special education services, outlining strategies, treatments and therapies, and number of hours of treatment. A majority of studies investigating the parental perceptions of the IEP process with parents who had children with ASD were with parents who had early elementary- and preschool-aged children. Participants in these studies were dissatisfied with educators’ knowledge of ASD. They were particularly dissatisfied with teachers’ behavior management practices. Many parents were dissatisfied with the level and intensity of treatments and therapies. Subsequently, they supplemented these therapies with private therapy, which is often expensive.

Parents wanted frequent communication with teachers. They felt they needed data to effectively monitor behavior management strategies and monitor progress toward meeting IEP goals. Additionally, they were empowered when they became
knowledgeable about special education law. In order to co-plan and collaborate to develop an IEP, parents felt they need to understand ASD and special education law.

All in all, the review of the literature revealed that parents who had children with ASD reported they wanted to collaborate with teachers to develop an IEP for their child. Parents reported they felt they needed knowledge of ASD, treatments and interventions, and special education law in order to effectively collaborate. Studies investigating the resources parents use to learn about autism and special education law are limited. Given that many parents implement multiple private treatments and collaborate with schools to develop IEPs, there is a need to gain a greater understanding of the resources parents use to learn about autism and special education law.

The review of the literature also revealed a very limited number of studies investigating the perceptions of parents who had children of multiple ages with autism spectrum disorders and the IEP process. Thus there is a need for more research on the parent perceptions of multiple-aged children with autism in order to understand their views of the IEP process. Gaining a clearer understanding of their perspective may provide information that will enhance the IEP process to become more collaborative.
III. METHODOLOGY

Design

This study utilized a mixed-methods Web-based survey research design to investigate the perceptions of parents of children with ASD regarding the IEP process. Mixed-methods designs enhance the understanding of research problems and questions by providing multiple ways of exploring phenomena (Creswell, 2008). In this study, the mixed-methods survey research design included both closed and open-ended survey items. This method allowed for participants to share their perceptions of the IEP process in one way through closed response items that required participants to rate responses from 1 to 5 on a Likert scale. Additionally, participants responded to several open-ended questions. For example, in one open-ended item, participants shared ways in which they educated themselves about autism spectrum disorders.

After evaluating the research questions and the advantages and disadvantages of the variety of research methods, a mixed-methods Web-based survey design with closed and open-ended items was selected. A Web-based survey design was selected for several reasons. First, participants are able to complete surveys at their convenience. Self-administered surveys are less expensive and time intensive as telephone surveys and interviews (Nardi, 2003). They also reduce the effects of researcher bias, which is sometimes seen in other survey methods (Fowler, 2009). Nardi (2003) states that self-
administered surveys “are more efficient tools for surveying large samples of respondents in short periods of time than interviews or other research methods, with less expense than interviews or telephone surveys” (p. 59).

Couper et al. (1998) recommend that researchers follow a distinct process to properly develop Web-based surveys. First, the authors recommend conducting extensive literature reviews to develop survey questions. Item order and verbiage are critical. Positive tone and duplicity of items enhance reliability. In this study, a three-stage process to develop the survey was implemented. In the first stage, extensive research regarding survey items was conducted. Demographic questions were created to be mutually exclusive and exhaustive in order to capture characteristics of participants. Closed responses, which necessitated a scaled answer on a 5-point Likert scale, were developed. Couper et al. (1998) recommend carefully wording survey items to insure respondents accurately answer questions as self-reported responses to items necessitate recall of opinion. de Leeuw, Hox, and Dillman (2008) concur that frequency scales force participants to recall and rate their perceptions. These perceptions may not always be accurate; however, accuracy can be improved when participants respond to a large number of items with similar responses in greater frequency. Thus, frequency of responses to similarly worded items improves the accuracy of perception recall (de Leeuw, 2008). Additionally, the survey included open-ended questions to allow participants to share experiences in their own words.

In the second stage, the manner and type of survey were determined. Because the study’s target population, parents who have children with ASD, had previously reported
using the Internet to research autism (Green et al., 2006; Jegatheesan et al., 2010; Mackintosh et al., 2012), a Web-based survey was determined to be appropriate. Couper et al. (1998) recommend selecting survey software carefully. Browser compatibility issues and ease of use are paramount. This survey used propriety survey software from George Mason University. The software was selected for several reasons. First, the software was supported by George Mason University and the university server allowed for confidentiality within item responses. Also, the software was easy for respondents to use.

In the third stage, multiple drafts of the survey were created and examined to improve item comprehension, reliability, and redundancy (Nardi, 2003; de Leeuw et al., 2008). Question order and survey layout were revised through multiple drafts. Couper et al. (1998) recommend piloting the survey to refine items and streamline the survey for item redundancy. Feedback from pilot participants enhances the comprehension and accuracy of item wording for survey items (Nardi, 2003). In this study, the final electronic Web-based survey was created and piloted under authentic conditions with four participants who have children with autism spectrum disorders. The mean age of pilot participants’ children was 14 ($SD = 2$), with ages ranging from 10 to 17. Pilot participants’ children represented the range of the autism spectrum with children with low functioning and high functioning autism spectrum disorders. Pilot participants shared feedback that was used to further refine the survey.

There were several noted limitations in utilizing a Web-based survey. First, participants need access to the computer to take the survey. Some demographic
subgroups may not have access to computers (Nardi, 2003). However, de Leeuw et al. (2008) note that the issue of accessibility to demographic subgroups is “less critical for web surveys aimed at…special populations where all or most of the members have Internet access” (p. 269). As such, the target audience in this survey was a special population that had Internet access. Additionally, research indicates that families who have children with ASD have higher incomes (Bhasin & Schendel, 2007; McAdoo & Demyer, 2012; Van Meter et al., 2010), so these families are more likely have access to a computer and the Internet (McAdoo & Demyer, 2012).

A final limitation of Web-based surveys is the difficulty of generalizing the sample’s response rate to the total population. When the total population number is unknown, then it is difficult to generate response rates (Fowler, 2009). Without a response rate, it is hard to assess whether the sample represents opinions of the total population. Yet, despite limitations of Web-based surveys, a majority of studies investigating perceptions of parents of children with autism regarding treatments are Web-based (Bowkler et al., 2010; Goin-Kochel et al., 2007; Green et al., 2006; Mackintosh et al., 2012). The unique characteristics of the population of parents who have children with autism dovetail well with survey research design.

**Sample**

Obtaining the perceptions of the total population of parents who have children with autism spectrum disorders is unlikely. “Researchers do not always study an entire population, either because they cannot identify individuals or they cannot obtain lists of names” (Creswell, 2008, p. 393). Creswell suggests that researchers choose a sample
from a population and generalize the results from the sample to the opinions and perceptions of the total population. Thus, the population sample can be used to predict the opinions and perceptions of the total population, who

is the group of individuals having one characteristic that distinguishes them from other groups. The target population or sampling frame is the actual list of sampling units from which the sample is selected. The sample is the group of participants in the study selected from the target population from which the researcher generalizes to the target population. (Creswell, 2008, p. 393)

This study’s target population was parents of children with autism spectrum disorders. Six parent associations and disability groups which targeted members who were parents of children with ASD, or had contact with parents who had children with ASD, were invited to participate in the study. The following sections describe the participating associations and disability organizations: Autism Society of America of Northern Virginia (ASANV), Fairfax Alliance for Appropriate Public Education (FAAPE), Partners in Policymaking (PIP), Parents of Autistic Children (POAC), Statewide Parent Advocacy Network (SPAN), and Parent Education Advocacy and Training Center (PEATC).

**Autism Society of America of Northern Virginia (ASANV)**

ASANV, a nonprofit chapter of the Autism Society of America, advocates for individuals with ASD and their families by providing information about community resources, housing, education, employment, and respite. ASANV lobbies for state regulations and laws that enhance the lives of individuals with ASD and their families.
ASANV serves individuals and families of individuals with ASD within a geographic area on the east coast of the United States (Autism Society of America, Northern Virginia, 2014). ASANV uses Facebook to inform the community about participation in survey research studies.

**Fairfax Alliance for Appropriate Public Education (FAAPE)**

FAAPE is a nonprofit advocacy group located in the eastern United States whose members are families with children who have multiple types of disabilities including ASD. FAAPE members include educators and community members as well as parents. FAAPE advocates for policies and programs that promote effective education programs and instructional practices for children with disabilities (Fairfax Alliance for Appropriate Public Education, 2014). FAAPE uses a listserv and Facebook to inform the community about participation in survey research studies.

**Partners in Policymaking (PIP)**

PIP is a federally funded advocacy training program for individuals and families who have children with intellectual and developmental disabilities, including ASD. A participant in PIP is either an individual with a disability or a parent of a child with a disability. PIP participants learn about Medicaid, housing, education, and community services (Partners in Policymaking, 2014). PIP emails current PIP students and graduates to inform them about participation in survey research studies.

**Parents of Autistic Children (POAC)**

POAC is a nonprofit organization that provides training, education, and information about recreational activities and services for families with children who have
ASD. POAC members are parents or caregivers who have children with ASD. At the time of this study POAC had 669 members who received emails regarding their programs and services (Parents of Autistic Children, 2014). POAC informs members about participation in survey research studies by emailing members.

**Statewide Parent Advocacy Network (SPAN)**

SPAN is a nonprofit organization that serves as a parent training and information center in the northeastern United States. SPAN provides information to parents who have children with disabilities regarding special education law, disabilities, and community services. Its members are parents or caregivers who have children with multiple types of disabilities, including ASD (Statewide Parent Advocacy Network, 2014). SPAN informs the community about participation in survey research studies through Facebook.

**Parent Educational Advocacy Training Center (PEATC)**

PEATC is a nonprofit organization that serves as a parent training and information center in the eastern United States. PEATC provides information to parents who have children with disabilities regarding special education law, disabilities, and community services. PEATC members are parents or caregivers who have children with multiple types of disabilities, including ASD (Parent Educational Advocacy Training Center, 2014). PEATC informs the community about participation in survey research studies through their listserv.

**Inclusion and Exclusion Criteria**

To be included in this study, participants must have had a child with an ASD diagnosis. Their child must have been receiving or have received special education
services and have had an IEP at some point. Parents who did not meet these criteria were excluded. Included participants were members of associations and disability advocacy groups. There was the possibility that a snowball sample occurred and that the survey was forwarded to others beyond members of these groups. Thus, this survey may have reached participants who were not members of associations or disability advocacy groups.

**Instrumentation**

All participants completed the Web-based electronic survey (Appendix A). The survey items were constructed based on extensive research reported in this literature review. Survey items were concise and carefully designed. Creswell (2008) recommends that survey items are clearly and concisely written. Positive words for question items and researcher bias were closely examined during survey design iterations. Negatively worded survey items could confuse participants regarding the question meaning and could introduce researcher bias (Creswell, 2008).

Earlier versions of the survey included closed and open-ended demographic data items as well as items that asked participants their perspectives of treatments, the IEP process, and legal process. After analyzing the pilot survey results with a professor who worked in special education research for over twenty years, additional treatments were deemed necessary. For example, the first survey did not include items that were noted evidence-based practices, so the survey was revised to include these evidence-based practices. There were a total of 35 items in the final survey which requested parents’ perspectives of autism treatments and evidence-based practices.
The final survey had a total of 99 items that included both closed and open-ended items. The amount of time to complete the survey was approximately 20 minutes. Informed consent was presented at the beginning of the survey. All participants were informed regarding research procedures, risks, benefits, confidentiality, and voluntary participation. Participants were provided the researcher’s name and contact information. Informed consent is discussed in greater detail in a subsequent survey section.

The 99 survey items were divided into four sections. The first section obtained information about participants’ demographics. The second section gathered information about participants’ perceptions of treatments, interventions, and evidence-based practices for children with ASD. The third section obtained information about parents’ perceptions of the IEP process. The fourth section gathered information about participants’ perceptions of the legal process.

The second, third, and fourth sections asked participants to rate items using ratings from a Likert scale. The second section of the survey asked participants to rate their satisfaction with evidence-based practices with a Likert scale with ratings from 0 to 5. Responses were assigned the following numeric values: 0 - Never Used or Uncertain, 1 - Very Poor, 2 - Poor, 3 - Neutral, 4 - Good, and 5 - Excellent. If a participant’s child never received a listed treatment/evidence-based practice or the participant was uncertain as to whether his or her child received the treatment/evidence-based practice, then that participant could select 0 - Never Used/Uncertain. If a participant had no opinion regarding the evidence-based practice, then the participant could select 3 - Neutral.
The third section of the survey had Likert scale ratings with numeric values that ranged from 1 to 5. Responses were assigned the following numeric values: 1 - Strongly Disagree, 2 - Disagree, 3 - Neutral, 4 - Agree, 5 - Strongly Agree. If a participant had no opinion regarding the item, then the participant could select 3 - Neutral.

The fourth section of the survey asked participants to rate experiences with the legal system and special education law with Likert scale ratings that were assigned numeric values that ranged from 0 to 5. Ratings were assigned the following numeric values: 0 - Not Applicable, 1 - Strongly Disagree, 2 - Disagree, 3 - Neutral, 4 - Agree, 5 - Strongly Agree. If a participant did not have experience with the item in question, then the participant could select 0 - Not Applicable.

A total subscale for each section was calculated by adding every item’s numeric value for a total subscale score. Subscales were calculated for the second, third, and fourth sections of the survey. The first subscale represented the second survey section, the second subscale represented the third survey section, and the third subscale represented the fourth survey section. The following paragraphs discuss the survey sections.

**Section 1**

The first section included a total of 10 demographic questions that investigated demographic characteristics. The majority of these questions were closed questions, which are “useful for sensitive questions because participants might feel more comfortable knowing the parameters of response options” (Creswell, 2008, p. 398). Questions investigated income, ethnicity, and ASD diagnosis, to name a few. This section
also included questions about the medical diagnostic process, school and class placement, special education therapies, and behavior characteristics. A majority of these questions were also close-ended questions.

The section concluded with two open-ended questions regarding school-based related therapies. The first question asked participants their satisfaction with related therapies provided by the school district. The second question asked participants whether related therapies changed over time, and if so how. Thus, the open-ended questions asked parents their satisfaction with related therapies, and their experiences with related therapies as their child progressed through school.

Section 2

The second section examined parents’ experiences and perceptions of treatments and interventions as well as evidence-based practices that are implemented with children who have autism spectrum disorders. The first part of this section asked participants to rate their satisfaction with the private therapies they implemented. The 12 private treatments listed in this survey were selected from extensive review of the literature, especially the treatments Bowker et al.’s (2010) study used to assess the perceptions parents have regarding autism treatments. The treatments, which included alternative diets, applied behavior analysis (ABA), auditory integration training (AIT), detoxification treatments, Fastforward (Earobics), medications, occupational therapy, relationship-based therapies, sensory integration therapies, social skills, and speech, were treatments parents frequently implemented through private therapists (Bowker et al., 2010). Item responses were close-ended responses that had Likert scale responses from 1 - Very Poor to 5 -
Excellent. If a participant’s child never received the listed private treatment/intervention or the participant was uncertain as to whether his or her child received the treatment/intervention, then participants selected 0 - Never Used/Uncertain. If a participant had no opinion regarding the treatment or intervention, then the participant selected 3 - Neutral. A sample of a parent-implemented treatment item is illustrated in Figure 3.

<table>
<thead>
<tr>
<th>Sensory Integration Therapies</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - Never Used</td>
</tr>
</tbody>
</table>

*Figure 3. Sample of a parent-implemented treatment survey item.*

In the second part of this section, participants rated their satisfaction with evidence-based practices for youth and children with autism spectrum disorders in school or at home. The National Professional Development Center for Autism Spectrum Disorders (NPDC) at the University of North Carolina Chapel Hill (2013) designated the treatments listed as evidence-based practices and these treatments were used to develop survey items. Participants rated their satisfaction with evidence-based practices on a Likert scale with responses from 1 - Very Poor to 5 - Excellent. If a participant’s child never received the listed evidence-based practice or the participant was uncertain as to whether his or her child received the evidence-based practice, then participants selected 0 - Never Used/Uncertain. If a participant had no opinion regarding the evidence-based
practice, then the participant selected Neutral. This section’s Likert scale items represented the first subscale. Figure 4 illustrates a sample of an evidence-based practices survey item.

**Antecedent-Based Interventions**

<table>
<thead>
<tr>
<th></th>
<th>0 - Never Used or Uncertain</th>
<th>1 - Very Poor</th>
<th>2 - Poor</th>
<th>3 - Neutral</th>
<th>4 - Good</th>
<th>5 - Excellent</th>
</tr>
</thead>
</table>

*Figure 4. Sample of an evidence-based practices survey item.*

This section concluded with one multiple choice item and one open-ended item. The first multiple choice item asked parents to select the sources they used to learn about autism treatments and evidence-based practices. Extensive review of the literature provided these choice selections: Internet, conference, clinic/institute, school/teachers, occupational therapist, medical doctor, neurologist, parents who have children with autism spectrum disorders, and an open-ended item where parents could provide another source. Parents could select multiple sources from this list. The other source choice selection option allowed parents to share another source, other than sources provided, in less than three words. The second item was an open-ended item that asked parents which sources they found most helpful in learning about autism, autism therapies, treatments, and evidence-based practices.

**Section 3**

The third section investigated participants’ perceptions of the IEP process with 16 Likert scale items and one open-ended question. Participants rated the 16 items using a 5-
point Likert scale which ranged from 1 - Strongly Disagree to 5 - Strongly Agree. If a participant had no opinion regarding the treatment or intervention, then the participant selected 3 - Neutral. The Likert scale items in this section represented the second subscale. An example of a Likert scale item is illustrated in Figure 5. The section concluded with one open-ended question that asked parents how they learned about the IEP process and their legal rights.

<table>
<thead>
<tr>
<th>Overall, I have positive perceptions of the IEP process.</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ 1 - Strongly Disagree</td>
</tr>
</tbody>
</table>

*Figure 5. Sample IEP process survey item.*

**Section 4**

The fourth section investigated parental experiences with the legal system and special education law. This section had two parts. In the first part, the survey asked several questions regarding advocates and attorneys, and legal actions. The first item asked parents whether an attorney or advocate attended IEP meetings with them. The second item asked parents whether they had ever filed a formal complaint against the school district, negotiated a case through mediation, or litigated a case through due process. The second item included an “other” option, which allowed parents to provide a short answer in an open-ended “other” response. For this item, parents were able to select more than one response. Figure 6 illustrates the second item.
Have you ever done the following? Please check all that apply.

☐ Not Applicable
☐ Filed a formal complaint against the school district
☐ Negotiated a case through mediation
☐ Litigated a case through due process

other: [Box for other answers]

Figure 6. Legal actions item.

In the second part, the survey had seven items that investigated parents’ opinions of attorneys and advocates with seven close-ended items that used a 5-point Likert scale that had ratings from 1 - Strongly Disagree to 5 - Strongly Agree. If a participant did not have experience with the item in question, then the participant could select 0 - Never Used. If a participant had no opinion regarding the treatment or intervention, then the participant selected 3 - Neutral. The Likert scale items in this section represented the third subscale.

I feel my child benefited from the outcome of the mediation process/due process hearing.

☐ 0 - Not Applicable ☐ 1 - Strongly Disagree ☐ 2 - Disagree ☐ 3 - Neutral ☐ 4 - Agree ☐ 5 - Strongly Agree

Figure 7. Sample legal Likert scale item.
The section concluded with two open-ended questions about the IEP process. The first item asked parents what they felt was effective about the IEP process. The second item asked parents what they would like to change about the IEP process. The entire survey is illustrated in Appendix A.

In summary, survey items within each section were developed after extensive review of research. The final survey had four sections. The first section included a total of 10 demographic questions to define characteristics of the population. These demographic questions were similar to demographic questions from other national surveys that surveyed parents who have children with autism spectrum disorders (CDC, 2012). The second section examined parents’ experiences and perceptions of treatments and interventions as well as evidence-based practices that are implemented with children who have autism spectrum disorders. The treatments in this section were the most popular treatments parents stated they implemented in Bowkler et al.’s (2010) study, which was a Web-based survey of 970 parents. In this study, researchers asked parents to rate the effectiveness of numerous autism treatments, and parents reported that the treatments listed in this study were the most frequent treatments implemented by parents (see Table 1). Also included in this section were items listing evidence-based practices for youth and children with autism spectrum disorders that the National Professional Development Center for Autism Spectrum Disorders (NPDC) at the University of North Carolina Chapel Hill (2013) designated as treatments that had enough evidence to support their effectiveness and credibility. These treatments were listed and participants rated their satisfaction with the evidence-based practices.
The third section included items where parents rated their perceptions of the IEP process. These items were similar to items that Fish (2008) used to survey 51 parents who had children with multiple types of disabilities. In this study, parents rated their perceptions on a 5-point Likert scale. Finally, in the fourth section of the survey, items investigating parental perceptions of the legal system and special education law were developed from extensive research.

** Procedures **

Consent and confidentiality protection issues were discussed prior to developing the survey. On May 7, 2013, an application to conduct research was submitted to the George Mason University Internal Review Board (IRB). Approval was granted on the original draft survey on May 8, 2013. Associations and disability advocacy groups were contacted via email and invited to participate in the study. The following paragraphs document correspondence with participant groups.

**Parents of Autistic Children (POAC)**

On March 21, 2013, the Parent Education and Advocacy Training Center (PEATC) was contacted regarding participation. On March 22, 2013, the director of PEATC declined to participate, but referred the researcher to another organization, Parents of Autistic Children (POAC). On March 22, 2013, the researcher emailed the director of POAC requesting participation. On March 23, 2013, the director agreed to present the dissertation to the board of POAC for approval, contingent on public dissemination of the survey results to members. On April 10, 2013, the POAC board agreed to support the dissertation study. On May 7, 2013, the researcher submitted signed
consent forms from POAC to George Mason University IRB, which granted the research exempt status on May 8, 2013.

On May 16, 2013, POAC emailed individual members copies of the survey, endorsing the research as one of the few dissertations POAC supported, and encouraging members to respond to the survey. This was likely effective as personalized invitations are “far more effective than general invitations” (de Leeuw et al., 2008, p. 270). The email (Appendix B) documented the purpose of the research and approximate time to complete the survey as well as the survey URL, which permitted participants to single-click on the URL listed in the e-mail to take the survey. Having the URL link available reduces the survey respondents’ time and effort by providing access to the survey with a single click (de Leeuw et al., 2008).

Emails reminding participants of surveys improve response rates (de Leeuw et al., 2008). On May 23, 2013, POAC emailed members to remind them to take the survey. In this email, the survey was mentioned, but an incomplete survey URL was provided, so members were not able to link directly to the survey from the letter. On June 9, 2013, the researcher emailed POAC again, requesting another email reminder of the survey. On June 17, the director emailed the researcher stating that board approval was required for a second posting. Over the summer the board did not meet. Finally, on September 3, 2013, the board approved the reminder email and POAC sent the email and survey URL link to members.
**Statewide Parent Advocacy Network (SPAN)**

The researcher contacted Statewide Parent Advocacy Network (SPAN) regarding participation on March 22, 2013. The director agreed to participate in the study on March 23, 2013, and emailed signed consent agreements on March 26, 2013. George Mason University IRB approved the research with exempt status on May 8, 2013. The researcher emailed Statewide Parent Advocacy Network the survey URL link on May, 16, 2013, and SPAN posted the survey to their Facebook page. On June 12, 2013, the researcher contacted SPAN about reposting the survey. The next day, SPAN reposted the survey to their Facebook page.

**Virginia Partners in Policymaking (VA-PIP)**

On March 22, 2013, the researcher contacted the Virginia Partners in Policymaking (VA-PIP) group regarding participation. The administrator agreed to participate in the study on March, 22, 2013, and emailed signed consent agreements on March 25, 2013. George Mason IRB approved the research with exempt status on May 8, 2013. The researcher emailed VA-PIP the survey URL link on May 16, 2013, and VA-PIP emailed members the survey URL on May 17, 2013. On June 12, 2013, the researcher contacted VA-PIP regarding another email to remind members about the survey. On June 19, 2013, a participant emailed the administrator at VA-PIP to notify her that the survey URL was not working. Participants had completed the survey, but the survey did not submit. The administrator contacted the researcher via email on June 19, 2013, and the researcher notified George Mason University (GMU) technical support. GMU technical support stated that the server was having problems with the survey, fixed
the problem on the server on June 20, 2013, and the researcher was notified that the
problem on the server had been fixed. The researcher contacted VA-PIP that the survey
was fixed and ready. Unfortunately, participants were lost due to the problem with the
survey URL.

**Autism Society of America, Northern Virginia (NVASA)**

On March 22, 2013, the researcher contacted the Autism Society of America,
Northern Virginia (NVASA) regarding participation in the study. The director had
numerous questions, and the researcher had a telephone conversation with the director on
March 25, 2013. In this conversation, the researcher also discussed the IRB process so
that the director understood how IRB approves research. After the phone conversation,
the director agreed to participate in the study. On May 7, 2013, the researcher submitted
documents to GMU IRB for approval. On May 8, 2013, GMU IRB approved the research
with exempt status. On May 9, NVASA posted the survey to their Facebook page.

**Fairfax Alliance for an Appropriate Public Education (FAAPE)**

On March 22, 2013, the researcher contacted the Fairfax Alliance for an
Appropriate Public Education (FAAPE) regarding participation. On March 22, 2013, the
director agreed to participate and sent a signed consent agreement. The researcher
submitted the research documentation on May 7, 2013, to GMU IRB. On May 8, 2013,
GMU IRB deemed the research exempt. Fairfax Alliance for an Appropriate Public
Education emailed members on May 9, 2013. On May 18, 2013, the director emailed the
researcher about a mistype on the survey regarding the Fairfax Alliance for an
Appropriate Public Education’s name, which was mistyped on the survey as Parents for a
Free and Appropriate Public Education. The researcher informed the director on May 18, 2013, that members could select “other” when choosing how participants learned about the survey. The researcher contacted the director on June 11, 2013, regarding another email with the survey URL; that same day the director emailed members the survey URL.

**Parent Education and Advocacy Training Center (PEATC)**

As noted previously, on March 21, 2013, the Parent Education and Advocacy Training Center (PEATC) was contacted regarding participation. On March 22, 2013, the director of PEATC declined to participate. The researcher recontacted PEATC on August 28, 2013, regarding participation in the study. PEATC agreed, sending a consent letter to the researcher on September 3, 2013. George Mason University IRB granted approval on September 4, 2013 and the survey was emailed to PEATC that same day. No one responded to the survey. On September 26, 2013, the researcher sent PEATC an email inquiring about the status of the research since no one had responded to the survey. PEATC stated that they would repost the survey. On October 3, 2013, the researcher emailed PEATC to learn the date when they posted the survey to their listserv. On October 8, 2013, the director replied to the email stating that PEATC did not post the survey to their listserv in September, and said that PEATC was migrating to a new listserv and the survey must have been lost on the old listserv. The director said they posted the survey to their listserv on October 1, 2013. However, no one responded to the survey.
Survey

An electronic survey (Appendix A) was created using the GMU Web-based software program. The researcher emailed associations (Appendix B) with an introductory letter and survey URL. Individual participant consent to participate in the survey was obtained before participants completed the survey. The first page of the survey contained a statement of consent and agreement with research procedures. The consent page listed researcher contact data, which allowed participants to email or call the researcher with questions. Confidentiality procedures were also outlined on the consent page. All responses were confidential. Nothing was provided to participants in exchange for completing the survey.

The survey was posted from May 9, 2013 until December 3, 2013. The survey was originally scheduled to remain open until the end of August, 2013. However, a low response rate after two months necessitated keeping the survey open to maximize the number of participants. On October 10, 2013, the researcher reviewed the survey data that had been collected. There were several duplicate entries within the data and some open-ended responses contained letters and sentences that did not make sense. The researcher contacted GMU technical support on October 10, 2013, regarding the issue. On October 11, 2013, GMU technical support emailed the researcher to notify her that the nonsensical responses were spam. On October 11, 2013 there were 42 SPAM entries. The researcher and a professor at GMU who had over 20 years of research experience independently reviewed the data, documenting spam entries. On October 22, 2013, the researcher and professor met to discuss the data in order to obtain an agreement score.
regarding the number of entries that were legitimate and the number of entries that were spam, and achieved 100% agreement. The spam entries were deleted from the data on October 26, 2013. There were a total of 102 SPAM entries, which left a total of 87 legitimate entries.

**Validity**

The initial survey was first reviewed by a professor and two doctoral graduate research assistants at George Mason University. The professional reviewers had extensive experience working with children with autism as well as researching education issues related to students with autism spectrum disorders. Revisions, which included rewording items and changing survey layout, occurred after their review. The researcher revised the survey, and had a friend who is a parent of a child with autism take the survey. The parent recommended further revisions to clarify several items. A final draft of the survey was presented to the professor and two doctoral graduate research assistants for approval.

The researcher entered the final survey into the GMU survey software to create a Web-based survey. The researcher then developed a letter to send to associations which included the survey URL that allowed participants to click on the URL to link to the survey. The survey was then piloted with four parents of children who had been diagnosed with autism spectrum disorders. Two of the parents had children with high functioning autism and two of the parents had children with low functioning autism. The mean age of the children whose parents participated in the pilot study was 14 ($SD = 2$). All parents were experienced with the IEP process, having participated in IEP meetings.
for over five years. All parents also utilized private and school-based treatments. The researcher forwarded the email letter with the survey URL to pilot participants.

**Data Analysis**

SPSS Statistics version 21.0 (IBM Corporation, 2012) was used for quantitative analysis. NVivo10 (QSR International, 2012) qualitative data analysis software was used for analysis and validation of themes and concepts of qualitative items. Word clouds that were generated by the data entered into NVivo illustrated the most frequently used words, closely related words, and synonyms, with words used more frequently in increasingly larger fonts. The selection criteria for word clouds included synonyms, closely related words, and exact word matches.
IV. ANALYSIS

The purpose of this mixed-methods survey design study was to understand the perceptions of parents who have children with autism spectrum disorders regarding their experiences and the IEP process. This chapter presents the study’s results. The first section of this chapter describes the survey instrument and participant description. The second section presents results from research questions, which were obtained through quantitative and qualitative data analysis.

Survey Instrument

The survey had a total of 99 questions, which were divided into four sections. The first section included 10 demographic questions that were primarily closed-ended items which asked about ethnicity, income, and marital status to name a few. This section also included questions about autism diagnosis, the medical diagnostic process, school and class placement, special education therapies, and behavior characteristics. The section concluded with two open-ended questions regarding school-based related therapies.

The second section of the survey instrument investigated parents’ experiences and perceptions of treatments and interventions as well as evidence-based practices that are implemented with children who have autism spectrum disorders. A total of 35 treatments and evidence-based practices were identified, with each item representing a single treatment or evidence-based practice. Participants rated their satisfaction with these
treatments and evidence-based practices with a Likert scale that had responses from 1 - very poor to 5 - excellent. If a participant’s child never received the listed evidence-based practice or the participant was uncertain as to whether his or her child received the evidence-based practice, then participants selected 0 - never used/uncertain. Section two concluded with two open-ended items about the resources parents consulted to learn about autism spectrum disorders and treatments.

The third section of the survey instrument included 17 items that investigated parental perceptions of the IEP process using statements regarding the process. Participants rated their level of agreement with the item statement using a 5-point Likert scale rating, which ranged from 1 - strongly disagree to 5 - strongly agree. The section concluded with an open-ended question that asked participants how they learned about the IEP process and special education law.

The fourth section of the survey instrument investigated parental experiences with the legal system and special education law. The section included 7 items where participants rated their level of agreement to statements with responses that required ratings that were on a 5-point Likert scale. These ratings ranged from 1 - strongly disagree to 5 - strongly agree. The section concluded with two open-ended questions about what participants liked about the IEP process, and what they would like to change about the IEP process.

Three subscales represented the second, third, and fourth sections of the survey. The first subscale, section two, investigated parents’ perceptions of treatments and evidence-based practices. There were 35 items within this subscale. The second subscale
represented the third survey section, which investigated parents’ perceptions of the IEP process. In this subscale, there were 16 items. Finally, the third subscale comprised perceptions of the legal system. In this subscale there were 7 items.

**Reliability**

Analysis of internal consistency was completed for the entire survey instrument as well as the three subscales. The entire survey instrument had a Cronbach’s alpha of .86. Cronbach’s alpha for subscale one, parental perceptions of treatments and evidence-based practices was .88. Cronbach’s alpha for the second subscale, parental perceptions of the IEP process, was .94. The third subscale had a Cronbach’s alpha of .88. All of the Cronbach’s alpha scores indicate high internal consistency.

**Response Rate**

Surveys were distributed to Autism Society of America, Northern Virginia (NVASA), Fairfax Alliance for an Appropriate Public Education (FAAPE), Parents of Autistic Children (POAC), Virginia Partners in Policymaking (VA-PIP), Parent Education and Advocacy Training Center (PEATC), and Statewide Parent Advocacy Network (SPAN). A total of 87 persons completed the survey, excluding spam entries. Respondents completed a majority of the survey; however, some respondents did not answer every item.

POAC was the only organization that distributed the survey by emailing members directly. The email included a personal note from the POAC director, encouraging members to participate. POAC had 669 members, but it is not known how many members actually received or opened the email. Furthermore, it is not known how many
members clicked on the survey link. Notwithstanding, a total of 33 POAC members responded to the survey, culminating in a response rate of 4.9% (calculated by dividing the number of respondents by the total number of POAC members).

NVASA and SPAN posted the survey to their Facebook pages. SPAN posted the survey twice and NVASA posted the survey once. It is not known how many people viewed their Facebook pages. A total of four persons responded to the NVASA survey and five persons responded to the SPAN survey.

Virginia Partners in Policymaking (VA-PIP) is a parent advocacy group whose members are parents with children who have multiple types of disabilities and reside in Virginia. PIP emailed members the survey with the intention that members would share the survey with other disability groups. It is not known how many VA-PIP members have children with ASD or received the PIP email with the survey link.

With FAAPE, Parents for a Free and Appropriate Public Education was incorrectly written on the survey, while the actual association name was Fairfax Alliance for Appropriate Public Education (FAAPE). The survey was posted on their Facebook page. The number of members is unknown. Only one person responded to the survey from this group. However, several members noted in the response to “other item” question that they learned about the survey from Sheree Brown Kaplan, FAAPE president. A total of 26 participants, which represents 30% of respondents, indicated that they learned about the survey from other sources.
Adequacy of the Sample

The associations sent the web-based survey through emails to members or posted the survey to their Facebook pages. A total of 66 persons responded to the survey by July 1, 2013. To increase the number of participants, the researcher asked associations to send the survey link to members a second time. POAC, FAAPE, and VA-PIP emailed members the survey. SPAN reposted the survey to their Facebook page. A total of 17 persons responded to the second posting of the survey.

This survey resulted in two waves of participants: early respondents who took the survey before July 1, 2013 and late respondents who took the survey after July 1, 2013. The first 66 responses occurred during the first wave in May and June, 2013. The remaining 17 responses occurred after July 1, 2013.

Analysis was performed to determine whether there were statistically significant differences in responses between first and second wave respondents on the survey’s three subsections. Total responses in each subsection were combined to form total subscale scores. Independent t-tests were conducted to compare the total subscale responses between the first and second wave responders. Results indicated there were no significant differences between early and late responders for subscale 1 (parents’ perceptions of treatments/interventions and evidence-based practices) \( t(49) = 1.67, p = .10 \), subscale 2 (parents’ perceptions of the IEP process) \( t(73) = .059, p = .953 \); or subscale 3 (parents’ perceptions of the legal system and special education law) \( t(54) = 1.248, p = .217 \). Since there were no significant differences between responses of the early and late responders, data from both waves were combined for all subsequent analyses.
Since online surveys are relatively new, limited research on their merits exists. Fowler (2009) postulated that online surveys are similar to mail surveys. Gosling, Vazire, Srivastava, and John (2004) evaluated the reliability of Internet survey research relative to traditional methods, and found that Internet survey research is a reliable method, comparable to mail or in-person survey methods. Furthermore, Internet survey methods can reach populations that are hard to reach such as individuals with disabilities or parents who have children with disabilities (Gosling et al., 2004). Sue and Ritter (2007) indicated that web-based surveys should have a response rate of approximately 30%.

Many studies that investigate the perceptions of parents who have children with ASD use online surveys (Goin-Kochel et al., 2007; Green et al., 2006; Mackintosh et al., 2012). In these studies, surveys were posted to websites and forwarded by participants to other parents, creating a snowball sample—both factors that inhibited a response rate calculation. Other research investigating perceptions of parents regarding the IEP process with surveys also does not report response rates (Brandt, 2011; Fish, 2008).

Mackintosh et al. (2012) recruited 486 participants by emailing 220 autism associations advertisements that publicized their survey, which investigated treatments parents implemented with their children. There was no way to track the number of participants who saw the survey, so a response rate was not published. In another study, Goin-Kochel et al. (2007) contacted 220 autism associations through email and postal mail regarding participation in a study that examined treatments implemented by parents with an online survey. The authors did not report the number of associations that agreed to participate in the study, but indicated that participating associations emailed members
and advertised the survey on their website. A total of 479 parents responded to the survey, but a response rate was not reported. The Autism Society of America (ASA) and worldwide autism associations participated in Green et al.’s (2006) study that utilized an online survey to investigate treatments implemented by parents. Over three months, 552 parents responded to the survey; again, a response rate was not calculated or reported.

Brant (2011) and Fish (2008) examined the perceptions of parents regarding the IEP process utilized survey methodologies. In these studies, one support agency was contacted regarding participation. Fish (2008) mailed surveys to parents who were members of one family support agency in Texas. A total of 51 participants responded to the survey. Fish did not report a response rate or indicate the percentage of support agency members who responded to the mailed survey.

Brandt (2011) investigated the perceptions parents who had children with autistic spectrum disorders regarding the IEP process with an online survey. Participants were parents with children who received special education services from an upper Midwestern school district. Parents attended support groups provided by the school district’s parent resource center. A total of 30 parents responded to the survey. Brandt did not share the number families who received the survey, or the number of families who could have responded to the survey. No response rate was provided.

One of the few relevant studies to provide a response rate for a survey was Hume et al. (2005), who used a mail questionnaire to survey parents about autism services and outcomes. A total of 195 parents who had young children with autism responded to the mail questionnaire. Participants were recruited through the Indiana state autism resource
center. A total of 586 surveys were distributed to parents, and 198 parents responded to the survey for a 33.7% response rate.

As noted earlier, this current study’s survey’s response rate could only be determined for one group, POAC, as it was the only group that sent a personalized recruiting email to members. It is also the only group that knew the total number of persons who were on their email distribution list. However, there is no way to know how many of the 669 members received the recruiting email or clicked on the survey. A total of 87 persons responded to the survey, and 44 of the respondents were POAC members. The response rate for POAC was 4.9%, which is below the 30% response rate recommended by Sue and Ritter (2007). Also as noted earlier, response rates for the other associations could not be calculated because associations posted the survey to Facebook or forward the survey through email, creating a snowball sample.

Given the recommendations of Sue and Ritter (2007), the low response rate for the only organization for which the calculation was possible suggests caution when generalizing the survey results. However, there are several other reasons this research is credible. Notably, the characteristics of the sample are similar to characteristics of parents who have children with autism, and nonresponse bias did not exist. The following paragraphs discuss these two factors.

Characteristics of the Sample

The sample of parents who responded to the survey have characteristics that are similar to characteristics of parents who have children with autism that are reported in the literature (Goin-Kochel et al., 2007; Green et al., 2006; Mackintosh et al., 2012). In this
current study, 93% of participants reported that they attained education levels beyond high school and 78.6% reported they earned more than $80,000. Research suggests that parents who have children with ASD have high education and income levels (Bhasin & Schendel, 2007; McAdoo & Demyer, 2012; Van Meter et al., 2010). Mackintosh et al. (2012) indicated that 77.7% of respondents furthered their education levels beyond high school, and 35% earned incomes over $70,000. Similarly, Green et al. (2006) reported that 88% of participants furthered their education levels beyond high school. Finally, Goin-Kochel et al. (2007) reported that 51.8% of respondents earned incomes at or above $55,000, and the average level of education was 15.2 years ($SD = 2.4$, range = 9-26).

**Survey Results**

For every Likert scaled and forced-choice item, descriptive statistics were calculated which included both frequency of response number and/or percentages of responses. Means and standard deviations were used to analyze and report continuous variables such as age and child grade level. Group comparisons were analyzed using parametric and nonparametric tests.

**Section 1. Demographic Information**

A total of 87 parents responded to the survey. Of the 87 respondents, 4.6% learned about the survey from the Autism Society of America, 1.1% from Parents for a Free and Appropriate Public Education, 20.7% from Partners in Policymaking, 37.9% from Parents of Autistic Children, 5.7% from Statewide Parent Advocacy Network, and 29.9% from other sources. Other sources included a variety of school and association
listservs. Respondents also indicated they learned about the survey from Facebook and individuals who forwarded them the survey.

A majority of respondents lived in suburban or urban areas. Of respondents, 92% resided in suburban (72%) and urban (20%) locales. Approximately 7% of respondents indicated they lived in rural areas. A predominant percentage of respondents were Caucasian, White, or Non-Hispanic (86.2%). Of respondents, 5.7% were Asian or Asian American, 2.3% were African American or Black, 1.1% were American Indian or Alaska Native, and 1% were Hispanic or Latino. Most respondents were well educated (Table 4), and 40.2% worked full time. Many did not work (31%) or worked part time (23%).

Table 4

*Education Levels*

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>High School</td>
<td>6</td>
<td>6.9</td>
</tr>
<tr>
<td>Some College</td>
<td>6</td>
<td>6.9</td>
</tr>
<tr>
<td>College</td>
<td>62</td>
<td>71.3</td>
</tr>
<tr>
<td>Advanced Degree</td>
<td>13</td>
<td>14.9</td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Most families earned over $100,000 annually (Table 5), and had private health insurance (79.3%), which were either employer-sponsored or self-paid. Some families indicated they had both private health plans and Medicaid (13.8%) and only a few responded that they only had Medicaid (2.3%) or did not have health insurance (2.3%). Most respondents were married (89.7%), but some were divorced (5.8%), single (1.1%), or living with a partner or relative (2.3%). Over 90% of respondents were birth parents,
and 9.2% adopted their child. A majority of families had one child with a disability (82.8%), but some families indicated they had two children with disabilities (17.2%).

Table 5

Income Levels

<table>
<thead>
<tr>
<th>Income Level</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>$100,000 or more</td>
<td>47</td>
<td>54.0</td>
</tr>
<tr>
<td>$80,000 - 99,000</td>
<td>19</td>
<td>21.8</td>
</tr>
<tr>
<td>$60,000 - 79,000</td>
<td>11</td>
<td>12.6</td>
</tr>
<tr>
<td>$40,000 - 59,000</td>
<td>4</td>
<td>4.6</td>
</tr>
<tr>
<td>Less than $40,000</td>
<td>3</td>
<td>3.4</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>3.4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>87</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

Parents provided information about their children with autism. Of parents, 75.9% had a male child and 24.1% had a female child. Ages ranged from 3 to 26. The mean age was 11 ($SD = 5$), and the median age 10. Pediatric Developmental Specialists diagnosed a majority of participants’ children (49.4%). However, Neurologists (21.8%), psychologists (9.2%), psychiatrists (3.4%), school (3.4%), and pediatricians (3.4%) also diagnosed children. Some parents (9.2%) stated that other doctors diagnosed their child’s autism. Other doctors included multidisciplinary teams at medical centers, as well as autism medical centers and hospitals. The mean number of doctors consulted prior to getting an autism diagnosis ranged from 1 to 17. The mean number of doctors consulted was 5.3 ($SD = 5.9$), and the median number of doctors consulted was 2.5. The mean age diagnosed was four ($SD = 2.1$). When asked the type of autism diagnosis, 37.9% indicated their child had Autistic Disorder, 36.8% PDD-NOS, 19.5% Asperger’s, 1.1%
Rett Syndrome, 1.1% Childhood Disintegrative Disorder, and 3.4% were not sure of their child’s diagnosis (Table 6).

Table 6

Child’s Autism Spectrum Disorder Diagnosis

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asperger’s</td>
<td>17</td>
<td>19.5</td>
</tr>
<tr>
<td>Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)</td>
<td>32</td>
<td>36.8</td>
</tr>
<tr>
<td>Autistic Disorder</td>
<td>33</td>
<td>37.9</td>
</tr>
<tr>
<td>Rett Syndrome</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td>Childhood Disintegrative Disorder</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td>Not Sure</td>
<td>3</td>
<td>3.4</td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>100.0</td>
</tr>
</tbody>
</table>

The number of parents who stated their children were diagnosed with Autistic Disorder (33) was almost the same as the number of parents who stated their child was diagnosed with PDD-NOS (32). Only one parent reported his or her child was diagnosed with Childhood Disintegrative Disorder and Rett Syndrome. A total of three parents did not know their child’s specific autistic spectrum disorder diagnosis. Figure 8 illustrates the frequency of ASD diagnoses.
Parents indicated whether their child had other diagnosed disabilities or medical conditions. Of parents, 54% stated their child had another disability and 43.7% said their child did not have another disability. The survey item that asked parents about comorbid disabilities had closed responses, which included Attention Deficit Hyperactivity Disorder (ADHD), Emotional Disability, Intellectual Disability, Physical Disability, and Other. The researcher recoded the responses of Anxiety Disorder and Oppositional Defiant Disorder as emotional disabilities. Results indicated that Attention Deficit Hyperactivity Disorder (ADHD) was the most frequent comorbid disability (37.9%), and Emotional Disability was the second most frequent disability (13.4%). Other disabilities reported were Intellectual Disability (12.6%), Learning Disability (10.3%), and Physical Disability (3.4%) (Figure 9). A small percentage of parents reported that their child had
Tourette’s Syndrome (3.4%) and Cerebral Palsy (1.1%) in the open-ended “other” response.

![Bar graph showing frequency of comorbidities including ADHD, Emotional Disability, Intellectual Disability, Learning Disability, Physical Disability, and ADHD.]

*Figure 9. Comorbidities.*

Note: ADHD = Attention Deficit Hyperactivity Disorder.

One survey item asked parents if their child had any other diagnosed medical disabilities. Of parents, 65.5% said their child did not have another medical disability. Of those responding yes, 8% of parents indicated their child had dietary sensitivities that required medical care, 5.7% stated their child had gastrointestinal issues that required medical care, 5.7% said that child had Epilepsy, and 4.6% indicated another medical disability. Other responses included allergies, asthma, tremors, gastrointestinal issues that do not require medical care, Lyme disease, Trisomy 11p, Agenesis of the Corpus Callosum, Atrial Septal Defect, mild astigmatism, and subclinical seizures.
The survey asked parents to rate their child’s behaviors on the following scale: minimally challenging behaviors, some challenging behaviors, and significant challenging behaviors. Of parents, 29.2% reported their child had minimally challenging behaviors at home, and 34.5% reported their child had minimally challenging behaviors at school. The greatest number of parents reported that they had some challenging behaviors in the home (55.2%), and some challenging behaviors in school (43.7%). Some parents reported their child had significant challenging behaviors in the home (13.8%), and significant challenging behaviors in school (20.7%) (Figure 10).

![Figure 10. Parents’ ratings of child’s behaviors at home and school.](image)

Parents provided information about their child’s schooling. The mean grade level was 7.6 (SD = 4.8). Grade levels ranged from preschool to post high school, with a majority of respondents having children in 1st through 12th grades (Table 7). Third and
Eighth grades were the most frequently reported grade levels, with 10 parents indicating their child was in either grade 3 or 8. Most children participated in either general education classes with a co-teacher or general education classes with a resource room (32.2%). However, 29.9% of parents reported their child attended only self-contained classes or a self-contained school (Figure 11).

Table 7

*Child’s Grade Level*

<table>
<thead>
<tr>
<th>Grade Level</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grade 1</td>
<td>8</td>
<td>9.2</td>
</tr>
<tr>
<td>Grade 2</td>
<td>6</td>
<td>6.9</td>
</tr>
<tr>
<td>Grade 3</td>
<td>10</td>
<td>11.5</td>
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<tr>
<td>Grade 4</td>
<td>6</td>
<td>6.9</td>
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<tr>
<td>Grade 5</td>
<td>4</td>
<td>4.6</td>
</tr>
<tr>
<td>Grade 6</td>
<td>7</td>
<td>8.0</td>
</tr>
<tr>
<td>Grade 7</td>
<td>3</td>
<td>3.4</td>
</tr>
<tr>
<td>Grade 8</td>
<td>10</td>
<td>11.5</td>
</tr>
<tr>
<td>Grade 9</td>
<td>4</td>
<td>4.6</td>
</tr>
<tr>
<td>Grade 10</td>
<td>5</td>
<td>5.7</td>
</tr>
<tr>
<td>Grade 11</td>
<td>2</td>
<td>2.3</td>
</tr>
<tr>
<td>Grade 12</td>
<td>2</td>
<td>2.3</td>
</tr>
<tr>
<td>Before Preschool</td>
<td>2</td>
<td>2.3</td>
</tr>
<tr>
<td>Preschool</td>
<td>5</td>
<td>5.7</td>
</tr>
<tr>
<td>Kindergarten</td>
<td>6</td>
<td>6.9</td>
</tr>
<tr>
<td>Post High School</td>
<td>6</td>
<td>6.9</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>87</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

A large percentage of parents reported that their child received shared paraprofessional support (37.9%). Shared paraprofessionals are paraprofessionals that supported multiple students. A total of 25 parents indicated their child received no paraprofessional support (28.7%), and 18 parents indicated their child received one-on-one paraprofessional support (20.7%). Nine parents were not sure whether their child
received any paraprofessional support (10.3%). Of parents who said their child received paraprofessional support, 20.7% of parents said their child often received these support, while equivocally 20.7% said their child always had paraprofessional support. Seven parents said their child sometimes received paraprofessional support (8%), and 4 said they infrequently received paraprofessional support (4.6%).

*Figure 11*. Class placement.
The survey asked several questions about school-provided related services. First, parents were asked what related services their child received, with multiple choice options of occupational therapy, physical therapy, psychological services, speech therapy, social skills groups, none, and other. If their child received related services that were not listed, respondents typed the related service in the space for other. Finally, parents were asked two qualitative questions. First, they were asked how satisfied they were with the related services. Second, they were asked if their experiences with related services changed over time and if so, how.

Speech therapy was the most popular related therapy. Of respondents, 72.4% received speech therapy at school. Forty-five parents reported their child received occupational therapy at school (51.7%), and 33 reported their child received social skills (37.9%). Only 9.2% received psychological services, and 6.9% received physical therapy (Figure 12). Other related therapies included assistive technology, Applied Behavior Analysis therapy, and adapted physical education.
Related Therapies Open-Ended Items

Finally, Section 1 of the survey asked participants two open-ended questions regarding related therapies. The first item asked participants about their satisfaction with related therapies, and the second item asked participants whether their experiences with related services changed over time. For both items, a strategy was used to categorize and analyze responses to open-ended items (Maxwell, 1996). Every parent response was coded, categorized, and analyzed into themes. Codes were then analyzed to identify themes and concepts among responses. NVivo10 (QSR International, 2012) qualitative data analysis software was used for analysis and validation of themes and concepts. Word clouds that were generated by the data entered into NVivo illustrated the most frequently used words, closely related words, and synonyms, with words used more frequently in increasingly larger fonts. The selection criteria for word clouds included synonyms,
closely related words, and exact word matches. Three major themes emerged: satisfaction with services, infrequent services, and lack of therapist knowledge of autism spectrum disorders.

**Satisfaction with related therapies.** Of the 87 participants, a total of 76 parents (87%) shared their satisfaction with related therapies. Twenty-seven (36%) parents indicated they were satisfied with related therapies. Parents, who had preschool children, stated more frequently than parents, who had over-elementary-aged children that they thought therapists and teachers collaborated and worked well with their child. One parent shared,

> Overall, I am very satisfied with the services my son receives at his school. We were admitted into special education pre-school [sic] and had a fantastic experience (in two counties). We have three different schools and service at all of them has [sic] been good. I feel he gets what he needs.

Another said, “We are very satisfied with the pre-school [sic] autism class.” None of the respondents who had children in elementary, middle, or high school indicated their satisfaction regarding collaboration among therapies and overall positive perceptions of related therapies.

Several parents supplemented related therapies with private therapies, for several reasons. Parents noted they do not want their children to miss instructional time when they are pulled from class for therapies. Also, parents reported the intensity of therapy necessary to meet their child’s needs cannot be achieved during school. One parent stated,
Overall we are satisfied based on the fact that our child continues to improve, however we also supplement the school’s services with private speech, occupational therapy, and ABA. We do private speech because that has always been his greatest weakness and source of frustration. We just recently started ABA to tackle some challenges/behaviors we see at home and sometimes at school that OT [occupational therapy] was not able to address.

Supplementation of school therapies with private therapy was a theme echoed by several parents. Another parent stated, “Therapies are fine. They meet his needs, but we also get private services to cover what the school does not.” A third parent stated,

Things are going well at my son’s school, plus he has a ton of therapies at home. I choose for most of his therapies to be after school, so he does not miss instruction in school. Plus, there is only so much the school can do for children in school. Parents have to participate in caring for their child.

The second major theme involved the infrequency of therapies and services.

Nineteen (25%) parents reported that their child needed more frequent therapies than the school system provided. One parent said,

Speech is helpful, but does not happen often enough to make a full impact. We have also received reports of successfully completing at least one speech goal when it did not match our experience and observations at all. Unstuck and On Target seems to be working well. It appears it was not done as regularly as it was supposed to be at the beginning of the year, so it is now being crammed in a bit.
Another parent said, “We are somewhat satisfied with related therapies. The occupational therapist works wonders but sees him for only a couple hours a month. At this rate, we will have him tying his own shoes by age 30.” Some supplemented school therapies with private therapies, if they were able. One parent said,

We are not very satisfied with related therapies at school. We feel he could use more speech therapy than just an hour a week, but the school system refuses to provide, and we can’t get him private speech therapy until his insurance goes thru.

Finally, three parents reported the infrequency of services was due to a lack of school-based qualified therapists. One of these parents said,

When he was attending public school, speech services in particular could be hit or miss, because they didn’t have enough therapists. Often we only found out about this when he had gone 6 weeks or more without the services specified in his IEP. Two other parents had similar perspectives regarding a lack of services due to a deficiency in therapists.

The final theme was therapist knowledge of autism and autism interventions. Eleven parents (14.4%) reported that therapists who understood interventions for children with autism provided effective therapies. These parents spoke most frequently about speech and occupational therapies. One parent stated,

I think these therapies are great as long as the therapist understands and has experiences working with children who have autism. I found some speech therapists to understand either pragmatics or articulation well.... When a therapist does not fully understand autism, then they are far less effective. Occupational
therapists work the same way. They may not understand sensory processing
deficits. When this is the case, occupational therapy is useless.

Another parent said, “We are very dissatisfied because the speech therapist is not familiar
with the concept of social stories.” A final parent stated,

Happy to have daily social skills lesson, though wish it were more “Social
Thinking” in content. Counseling seems to help minimally (refusal to
participate/directs activity). Support room varies—nice to have place to go for
“student referral.” Sometimes staff engages in power struggles, which is not
helpful.

All in all, these parents reported that knowledge of autism and treatments and
interventions were important qualifiers for therapists.

NVivo 10 (QSR International, 2012) was used to analyze concept frequencies and
validate themes. Figure 13 presents a word cloud that illustrates word concept
frequencies related to satisfaction with related therapies. Words that were generated by
the data entered into NVivo illustrated the most frequently used words, closely related
words, and synonyms, with words used more frequently in increasingly larger fonts. The
selection criteria for word clouds included synonyms, closely related words, and exact
word matches. The most frequent five word concepts were: measurable (3.01%), content
(2.96%), communication (2.47%), satisfied (2.01%), and activity (.71%). Similar words
were included within these concepts. For example, words similar to measurable included
hours, minimum, and time to name a few. Concurrently, words similar to content include
goal, instruction, and schedule.
Figure 13. Satisfaction with related therapies word cloud.

Related services change over time. Sixty-four participants (74%) shared their perceptions of whether they reported related services their child receives changed over time. Every response was coded, categorized, and analyzed into themes. Findings revealed three themes: quantities, organization issues, and communication.

The quantities theme related to the amount of related services a child received. Twenty-seven respondents (42%) shared that the amount of related services their child received changed over time, with the primary reason respondents cited being their child’s changing needs and skills. Parents indicated that their child’s related therapies evolved in
response to their child’s changing needs. Once skills were mastered, goals and therapies evolved to meet their child’s learning needs. One parent stated, “They have evolved with my child’s maturity level. Different social/learning issues have required new strategies and teaching styles over the last yes-no years.” Another parent reported that instructional time was critical: “Over time his need for services has decreased so the time with specialists out of the classroom has decreased. This has helped as he has gotten older in missing out on instructional time in his regular education classroom.” One parent expressed concern over exiting services: “We had speech and he was exited out because he met his goals. The developmental pediatrician still thinks he needs some speech instruction.” Finally, children age out of services. One parent stated that related therapies change because of “aging out of services and time decreases.” All in all, parents reported that the amount and frequency of related therapies evolved in response to their child’s needs.

The second largest theme involved organizational issues, which encompassed school district issues and therapist/organizational knowledge of autism spectrum disorders and interventions. Nineteen parents (29.6%) shared their perspectives regarding organizational issues. First, several parents they reported that their school wanted to reduce or not provide services. One parent said, “Every year they try and reduce services, and every year I say no.” Other parents claimed they had to fight for services: “We were denied speech therapy for three years. We requested speech therapy again this year and were able to justify the need based on a private ABA therapist’s recommendation and a medical evaluation.” Another parent shared, “Once I figured out what would best help
my own child I was able to get her the services she needed. I have had to be involved every step of the way.” Advocating for services was frequently mentioned; as another parent added, “once we got the school district to approve it [related therapies], it was great. Getting them to approve anything is hard.”

Several parents mentioned inequities among school districts and states and their resultant advocacy efforts. One parent said,

When we lived in Massachusetts, the district provided services to meet the needs of my child including social thinking. I feel Virginia does not understand the needs of a child with autism and tries to mainstream even though it might not be the best choice.

Another parent said,

When we were still in ------ County, I was somehow satisfied with the speech therapy services for my son given the attention, time and progress reporting afforded to him. Now that we moved to ------ County, I needed to push harder for these services to be provided to my son at school.

Many parents indicated that therapist and school district knowledge of autism was critical, specifically that the therapist’s knowledge of autism and autism interventions affected the therapies provided. One parent said, “My impression of how little time is offered by the schools has not changed over time, but each therapist’s competency levels change from year to year or school to school.” Knowledge was an inconsistency echoed by several parents. One stated, “It all depends on the therapist. Some have been awesome, others lack experience. We currently have great ones.” Another parent said, “We get new
people every year who are either incompetent or insufficiently trained.” One parent mentioned programming for children who are high functioning: “Schools do not understand the needs of higher functioning kids and once kids have basic pragmatic language skills they do not have programs that are high enough to help them.” Another parent stated that schools lack knowledge of autism interventions:

School is providing less support, because of reduced behavioral problems, but now he is beginning to struggle academically. . . . [He is] just receiving typical interventions for struggling students, not geared toward ASD students learning challenges (focus, attention, organization of thoughts for oral retelling of stories).

Communication with therapists was a third theme mentioned by respondents. Eight parents (12.5%) stated that therapist communication changed as their child progressed through school. One parent said,

As the years go on and my son started elementary school, the communication has deceased. The decrease in communication, especially when one has a nonverbal child, is very difficult for parents. You don’t want to become the “problem” parent; however, you need to know what is going on during your child’s day. Another parent stated, “There was more communication with the therapists when my son was in elementary school. At the middle school level, there is less interaction with the therapists—but significant interaction with his main teacher.”

Alternatively, another respondent reported always having good communication with therapists. “They [related therapies] haven’t really changed. We are, generally, satisfied with some moments of reservation and disconnect. We have always had very
good communication with the related services providers though.” All in all, most people mentioned that communication with related therapists changed as their child progressed through school.

NVivo 10 (QSR International, 2012) was used to analyze concept frequencies and validate themes. Figure 14 illustrates a word cloud with these concept frequencies. Participants’ most frequently used words are larger in font. NVivo 10 (QSR International, 2012) processes words similar to actual words, and these words are illustrated in the word cloud as well. The top words used were: quantities (3.55%), change (3.52%), organization (2.83%), communication (2.37%), and needs (2.10%).
Figure 14. Related therapies change over time word cloud.
Section 2. Parental Perceptions of Private Therapies/Treatments and Evidence-Based Practices

Parents shared their perceptions of 12 private therapies/treatments as well as 22 evidence-based practices for students with autism spectrum disorders using the following Likert scale: very poor, poor, neutral, good, and excellent. Parents had the option to select never used if they had never implemented the private therapy/treatment or evidence-based practice with their child. Likert scale ratings were given numerical values and calculated into means and standard deviations. Calculations were as follows: Never Used = 0, Very Poor = 1, Poor = 2, Neutral = 3, Good = 4, Excellent = 5.

Private therapies/treatments. Parents were most satisfied with the following 5 of 12 private therapies/treatments: occupational therapy, speech therapy, social skills, sensory integration, and relationship-based therapies. Alternatively, parents rated the following 4 therapies/treatments the lowest: detoxification, Fastforward/Earobics, alternative diets, and vitamin therapy. The frequencies of responses are illustrated in Table 8, which details the frequency of responses as well as the mean and standard deviation for every private therapy/treatment.
Table 8

*Means and Standard Deviations of Private Therapies/Treatments*

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Frequency</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alternative Diets</td>
<td>85/87</td>
<td>1.00</td>
<td>1.6</td>
</tr>
<tr>
<td>Applied Behavior Analysis</td>
<td>86/87</td>
<td>2.56</td>
<td>2.2</td>
</tr>
<tr>
<td>AIT-Listening Program</td>
<td>84/87</td>
<td>1.10</td>
<td>1.5</td>
</tr>
<tr>
<td>Detoxification</td>
<td>85/87</td>
<td>.35</td>
<td>1.0</td>
</tr>
<tr>
<td>Fastforward/Earobics</td>
<td>83/87</td>
<td>.48</td>
<td>1.3</td>
</tr>
<tr>
<td>Medications</td>
<td>85/87</td>
<td>2.00</td>
<td>2.0</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>85/87</td>
<td>3.50</td>
<td>1.5</td>
</tr>
<tr>
<td>Relationship-Based Therapy</td>
<td>85/87</td>
<td>2.10</td>
<td>2.1</td>
</tr>
<tr>
<td>Sensory Integration</td>
<td>83/87</td>
<td>2.60</td>
<td>1.9</td>
</tr>
<tr>
<td>Social Skills</td>
<td>84/87</td>
<td>2.70</td>
<td>1.8</td>
</tr>
<tr>
<td>Speech Therapy</td>
<td>86/87</td>
<td>3.30</td>
<td>1.7</td>
</tr>
<tr>
<td>Vitamin Therapy</td>
<td>83/87</td>
<td>1.07</td>
<td>1.8</td>
</tr>
</tbody>
</table>

*Note. AIT = Auditory Integration Training.*

Parents rated the 12 private therapies with the following Likert scale: very poor, poor, neutral, good, and excellent. High agreement scores were combined to include ratings of good and excellent. Low agreement scores were combined to include ratings of poor and very poor. Figure 15 illustrates parental perceptions of private therapies/treatments with the combined Likert scale ratings of good/excellent, neutral, and poor/very poor.
Figure 15. Parental perceptions of private therapies/treatments.
Table 9 illustrates parental perceptions with ratings: Good/Excellent, Neutral, Poor/Very Poor, Never Used, and Missing. Results (Table 8) indicated that parents rated occupational therapy the highest with a mean of 3.5 ($SD = 1.5$). Of 85 parents, 66.6% rated occupational therapy excellent or good, 16.1% rated occupational therapy neutral, 3.4% rated occupational therapy as poor or very poor, and 11.5% never used private occupational therapy. The second highest rated therapy was speech therapy, which received a mean of 3.3 ($SD = 1.7$). Of parents, 63.8% rated speech therapy as excellent or good, 12.6% rated speech as neutral, 6.8% rated speech as poor or very poor. Social Skills was rated third by parents with a mean of 2.7 ($SD = 1.8$). Of parents, 47.3% rated social skills as good or excellent, 14.9% as neutral, 14.9% as poor or very poor, and 23% never used social skills treatments while 3.4% did not rate this item. Sensory integration therapies were rated fourth with a mean of 2.6 ($SD = 1.9$). Of parents, 43.7% rated sensory integration as excellent or good, 21% neutral, 11.5% as poor or very poor, and 27.6% never used sensory integration therapies while 4.6% did not rate sensory integration. The fifth rated therapy/treatment was relationship-based therapies such as floor time. Approximately 46% of participants never implemented a relationship-based treatment/therapy and 2.3% did not rate the treatment/therapy. Of participants who rated, 40.2% rated relationship-based therapies as good or excellent, 6.9% were neutral, and 4.5% rated it poor or very poor.

Applied Behavior Analysis (ABA) received high ratings from parents who implemented ABA; however, approximately 37% of participants had never used ABA. Of participants who implemented ABA, 50.6% reported ABA was good or excellent, and
only 6.9% reported ABA was poor or very poor. Medications received high ratings from participants who used them with their children, although approximately 44% of participants did not implement pharmacological treatments. Of parents who used pharmacological treatments, 33.3% of parents rated these treatments as good or excellent, and only 6.8% of parents rated pharmacological treatments as poor or very poor. The lowest rated treatment was detoxification, which received a mean score of .34 ($SD = 1$). Only 1.1% of parents rated detoxification treatments as good, 1.1% rated detoxification treatments as excellent, and approximately 82% of participants never implemented detoxification treatments.

Table 9

Perceptions of Private Therapies/Treatments

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Missing</th>
<th>Never Used</th>
<th>Poor/Very Poor</th>
<th>Neutral</th>
<th>Good/Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alternative Diets</td>
<td>2.30%</td>
<td>46.00%</td>
<td>27.60%</td>
<td>5.70%</td>
<td>10.30%</td>
</tr>
<tr>
<td>Applied Behavior Analysis</td>
<td>1.10%</td>
<td>37.00%</td>
<td>6.90%</td>
<td>4.60%</td>
<td>50.60%</td>
</tr>
<tr>
<td>Auditory Integration Training –</td>
<td>3.40%</td>
<td>59.80%</td>
<td>13.70%</td>
<td>12.60%</td>
<td>10.30%</td>
</tr>
<tr>
<td>Listening Program</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Detoxification Treatments</td>
<td>2.30%</td>
<td>86.20%</td>
<td>3.40%</td>
<td>5.70%</td>
<td>2.20%</td>
</tr>
<tr>
<td>Fastforward/Earobics</td>
<td>4.60%</td>
<td>81.60%</td>
<td>3.40%</td>
<td>3.40%</td>
<td>6.80%</td>
</tr>
<tr>
<td>Medications</td>
<td>2.30%</td>
<td>43.70%</td>
<td>6.80%</td>
<td>13.80%</td>
<td>33.30%</td>
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<tr>
<td>Occupational Therapy</td>
<td>2.30%</td>
<td>11.50%</td>
<td>3.40%</td>
<td>16.10%</td>
<td>66.60%</td>
</tr>
<tr>
<td>Relationship-Based Therapies</td>
<td>2.30%</td>
<td>46.00%</td>
<td>4.50%</td>
<td>6.90%</td>
<td>40.20%</td>
</tr>
<tr>
<td>Sensory Integration Therapies</td>
<td>4.60%</td>
<td>27.60%</td>
<td>11.50%</td>
<td>12.60%</td>
<td>43.70%</td>
</tr>
<tr>
<td>Social Skills Therapy</td>
<td>3.40%</td>
<td>23.00%</td>
<td>14.90%</td>
<td>14.90%</td>
<td>43.70%</td>
</tr>
<tr>
<td>Speech Therapy</td>
<td>1.10%</td>
<td>16.10%</td>
<td>6.80%</td>
<td>12.60%</td>
<td>63.20%</td>
</tr>
<tr>
<td>Vitamin Therapy</td>
<td>4.60%</td>
<td>64.40%</td>
<td>10.30%</td>
<td>4.60%</td>
<td>16.10%</td>
</tr>
</tbody>
</table>

Evidence-based practices. Parental perceptions of evidence-based practices for youth and children with Autism Spectrum Disorders in school or at home are illustrated
in Table 10, which details the frequency of responses as well as the mean and standard deviation for every evidence-based practice. Reinforcement ($M = 3.5$, $SD = 1.7$), Visual Supports ($M = 3.3$, $SD = 1.8$), Prompting ($M = 3.3$, $SD = 1.7$), Response Interruption and Redirection ($M = 2.6$, $SD = 1.9$), and Social Skills ($M = 2.5$, $SD = 1.7$) achieved the highest mean ratings.

Table 10

*Means and Standard Deviations of Evidence-Based Practices*

<table>
<thead>
<tr>
<th>Evidence-Based Practice</th>
<th>Frequency</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antecedent-Based Interventions</td>
<td>86/87</td>
<td>1.40</td>
<td>2.00</td>
</tr>
<tr>
<td>Computer Aided Instruction</td>
<td>86/87</td>
<td>2.00</td>
<td>2.10</td>
</tr>
<tr>
<td>Differential Reinforcement</td>
<td>85/87</td>
<td>1.20</td>
<td>1.90</td>
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<tr>
<td>Discrete Trial Training</td>
<td>83/87</td>
<td>1.30</td>
<td>2.00</td>
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<tr>
<td>Extinction</td>
<td>84/87</td>
<td>1.30</td>
<td>1.90</td>
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<td>Functional Behavior Assessment</td>
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<td>1.70</td>
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<td>Functional Communication Training</td>
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<td>.72</td>
<td>1.50</td>
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<td>Naturalistic Intervention</td>
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<td>.73</td>
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<td>Peer-Mediated Instruction and Intervention</td>
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<td>1.20</td>
<td>1.80</td>
</tr>
<tr>
<td>Picture Exchange Communication System</td>
<td>85/87</td>
<td>2.00</td>
<td>2.00</td>
</tr>
<tr>
<td>Pivotal Response Training</td>
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<td>.40</td>
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*Note.* VOCA = Voice Output Communication Aid.
Parental perceptions of evidence-based practices. Parents rated evidence-based practices with ratings from a 5-point Likert scale with ratings of very poor, poor, neutral, good, and excellent. The following paragraphs illustrate findings and the frequencies of parents’ responses for the evidence-based practices. Ratings of poor and very poor were combined into one rating of poor/very poor, and ratings of good and excellent were combined into one rating of good/excellent. A large number of respondents reported they had never used many of the evidence-based practices. Analysis was conducted to evaluate respondents who rated the evidence-based practices. The following paragraphs share findings from respondents who answered items regarding the effectiveness of evidence-based practices for children with Autism Spectrum Disorders.

Antecedent-based interventions. Of 87 participants, 32 parents (37%) rated antecedent-based interventions as poor/very poor, neutral, or good/excellent. For this item, 21 (65.6%) parents rated antecedent-based interventions as good or excellent, 5 (15.6%) rated antecedent-based interventions as neutral, and 6 (18.8%) rated antecedent-based interventions as poor or very poor. Figure 1 illustrates frequency of responses for this item. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses, which included responses of good or excellent, neutral, or poor or very poor. Results of the test were significant with $\chi^2 (2, N = 32) = 15.06, p = .001$, indicating that more parents reported antecedent-based interventions a valid evidence-based practice. A follow-up test demonstrated that the proportion of parents who rated antecedent-based interventions as good or excellent differed significantly from the proportion of persons who rated the
intervention as poor/very poor, $\chi^2 (1, N = 27) = 8.333, p = .004$. Overall, these results demonstrate that parents reported antecedent-based interventions were acceptable evidence-based practices.

Figure 16. Antecedent-based interventions frequency of responses.

*Computer aided instruction.* Of the 87 participants, 44 parents (51%) rated computer aided instruction, with the ratings of poor/very poor, neutral, or good/excellent. Figure 17 illustrates the frequency of responses. For this item, 32 (72.7%) parents rated
computer aided instruction as good or excellent, 10 (22.7%) rated computer aided instruction as neutral, and 2 (4.5%) rated computer aided instruction as poor or very poor. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses, which included responses of good or excellent, neutral, or poor or very poor. Results of the test were significant with $\chi^2 (2, N = 44) = 32.909, p = .000$, indicating that more parents reported computer aided instruction a valid evidence-based practice. A follow-up test demonstrated that the proportion of parents who rated computer aided instruction as good or excellent differed significantly from the proportion of parents who rated the intervention as poor/very poor, with $\chi^2 (1, N = 27) = 8.333, p = .004$. Overall, these results suggest that parents reported computer aided instruction an acceptable evidence-based practice.
Differential reinforcement. Of 87 participants, 27 parents (31%) rated differential reinforcement poor/very poor, neutral, or good/excellent. For this item, 19 parents (70.3%) rated differential reinforcement as good or excellent, 3 (15.78%) rated differential reinforcement as neutral, and 5 (26.3%) rated differential reinforcement as poor or very poor. Figure 18 illustrates the frequency of responses. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses, which included responses of good or excellent,
neutral, or poor or very poor. Results of the test were significant, with \( \chi^2 (2, N = 27) = 16.889, p = .000 \), indicating that more parents reported differential reinforcement a valid evidence-based practice. A follow-up test demonstrated that the proportion of parents who rated differential reinforcement as good or excellent differed significantly from the proportion of persons who rated the intervention as poor/very poor, \( \chi^2 (1, N = 24) = 8.167, p = .004 \). Overall, these results suggest that parents reported differential reinforcement an acceptable evidence-based practice.

Figure 18. Differential reinforcement response frequencies.
Discrete trial training. Of 87 participants, 28 parents (32%) rated discrete trial training poor/very poor, neutral, or good/excellent. For this item, 21 parents (75%) gave ratings of good or excellent, 4 parents (14.28%) of neutral, and 3 parents (10.71%) of poor or very poor. Figure 19 illustrates frequency of responses. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses. Results of the test were significant, with \( \chi^2 (2, N = 28) = 21.929, p = .000 \), indicating that parents reported discrete trial training was a valid evidence-based practice. A follow-up test demonstrated that the proportion of parents who rated discrete trial training as good or excellent differed significantly from the proportion of persons who rated the intervention as poor/very poor, \( \chi^2 (1, N = 24) = 13.5, p = .000 \). Overall, these results suggest that parents reported discrete trial training an acceptable evidence-based practice.
Extinction. Of 87 participants, 30 parents (34.5%) rated extinction poor/very poor, neutral, or good/excellent. For this item, 17 parents (56.67%) gave ratings of good or excellent, 7 parents (23.3%) of neutral, and 6 parents (20%) of poor or very poor. Figure 20 illustrates frequency of responses. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses. Results of the test were significant, $\chi^2(2, N = 30) = 7.4, p = .025$, indicating that parents reported extinction a valid evidence-based practice. A follow-up test
demonstrated that the proportion of parents who rated extinction as good or excellent differed significantly from the proportion of parents who rated the intervention as poor/very poor, $\chi^2 (1, N = 23) = 5.261, p = .022$. Overall, these results suggest that parents reported extinction to be an acceptable evidence-based practice.

![Figure 20. Extinction frequency of responses.](image)

*Functional behavior assessment.* Of 87 participants, 42 parents (48%) rated functional behavior assessment poor/very poor, neutral, or good/excellent. For this item,
22 parents (52.3%) gave ratings of good or excellent, 11 parents (26.2%) of neutral, and 9 parents (21.4%) of poor or very poor. Figure 21 illustrates the frequency of responses. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses, which included the responses of good or excellent, neutral, and poor or very poor. Results of the test were significant, with \( \chi^2 (2, N = 42) = 7, p = .030 \), indicating that parents reported functional behavior assessment valid evidence-based practice. A follow-up test demonstrated that the proportion of parents who rated functional behavior assessment as good or excellent differed significantly from the proportion of parents who rated the intervention as poor/very poor, \( \chi^2 (1, N = 31) = 5.452, p = .020 \). Overall, these results suggest that parents indicated functional behavior assessments an acceptable evidence-based practice.
Figure 21. Functional behavior assessment response frequencies.

**Functional communication training.** Of 87 participants, 17 parents (20%) rated functional communication training poor/very poor, neutral, or good/excellent. For this item, 8 parents (47%) gave ratings of good or excellent, 7 parents (41.1%) of neutral, and 2 parents (11.8%) of poor or very poor. Figure 22 illustrates the frequency of responses, which included the responses of good or excellent, neutral, and poor or very poor. A chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses in their perceptions of functional communication.
training. Results of the test were not significant, $\chi^2 (2, N = 17) = 3.647, p = .161$, indicating that the proportion of parents rating functional communication training as good or excellent was not statistically significant. A follow-up test demonstrated that the proportion of parents who rated functional communication training as good or excellent did not differ significantly from the proportion of parents who rated the intervention as poor/very poor, $\chi^2 (1, N = 17) = 3.6, p = .058$.

![Bar chart showing functional communication training frequencies of responses.](chart.png)

*Figure 22. Functional communication training frequencies of responses.*
Naturalistic intervention. Of 87 participants, 17 parents (20%) rated naturalistic intervention poor/very poor, neutral, or good/excellent. For this item, 11 parents (64.7%) gave ratings of good or excellent, 4 parents (23.5%) of neutral, and 2 parents (11.8%) of poor or very poor. Figure 23 illustrates the frequency of responses, which included the responses of good or excellent, neutral, and poor or very poor. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses. Results of the test were significant, \( \chi^2 (2, N = 17) = 7.882, p = .019 \), indicating that parents reported naturalistic intervention was a valid evidence-based practice. A follow-up test demonstrated that the proportion of parents who rated naturalistic intervention as good or excellent differed significantly from the proportion of parents who rated the intervention as poor/very poor, \( \chi^2 (1, N = 13) = 6.231, p = .013 \). Overall, these results suggest that parents indicated naturalistic intervention an acceptable evidence-based practice.
Peer-mediated instruction and intervention. Of 87 participants, 27 parents (34%) rated peer-mediated instruction and intervention poor/very poor, neutral, or good/excellent. For this item, 15 parents (55.56%) gave ratings of good or excellent, 6 parents (20%) of neutral, and 6 parents (20%) of poor or very poor. Figure 24 illustrates the frequency of responses, which included responses of good and excellent, neutral, and poor or very poor. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses. Results of the
test were significant, with $\chi^2 (2, N = 27) = 6, \ p = .05$, indicating that parents reported peer mediated instruction and intervention a valid evidence-based practice. A follow-up test demonstrated that the proportion of parents who rated peer-mediated instruction and intervention as good or excellent differed significantly from the proportion of persons who rated the intervention as poor/very poor, $\chi^2 (1, N = 21) = 3.857, \ p = .05$. Overall, these results suggest that parents indicated peer mediated instruction and intervention an acceptable evidence-based practice.

![Figure 24. Peer-mediated instruction and intervention frequency of responses.](image-url)
Picture Exchange Communication System (PECS). Of 87 participants, 40 parents (46%) rated PECS poor/very poor, neutral, or good/excellent. For this item, 25 parents (62.5%) gave ratings of good or excellent, 7 parents (17.5%) of neutral, and 8 parents (20%) of poor or very poor. Figure 25 illustrates the frequency of responses, which included responses of good or excellent, neutral, and poor or very poor. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses. Results of the test were significant, with $\chi^2 (2, N = 40) = 15.35, p = .000$, indicating that parents reported PECS a valid evidence-based practice. A follow-up test demonstrated that the proportion of parents who rated PECS as good or excellent differed significantly from the proportion of parents who rated the intervention as poor/very poor, $\chi^2 (1, N = 33) = 8.758, p = .003$. Overall, these results suggest that parents reported PECS an acceptable evidence-based practice.
**Figure 25.** Parent response frequencies for Picture Exchange Communication System (PECS).

**Pivotal response training.** Of 87 participants, 10 parents (11.4%) rated pivotal response training poor/very poor, neutral, or good/excellent. Figure 26 illustrates frequency of responses for this item. The small number of respondents inhibited data analysis. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses, which included responses of good or excellent, neutral, and poor or very poor. Results of the test were not
significant, $\chi^2 (2, N = 10) = 3.8, p = .15$. However, three of the cells had expected frequencies which were less than 5, violating an assumption of the chi-square analysis. Therefore, chi-square analysis is not recommended.

Figure 26. Pivotal response training (PRT) response frequencies.

Prompting. Of 87 participants, 71 parents (82%) rated prompting poor/very poor, neutral, or good/excellent. For this item, 56 parents (78.9%) gave ratings of good or excellent, 11 parents (15.5%) of neutral, and 4 parents (5.6%) of poor or very poor. Figure
27 illustrates the frequency of responses, which included responses of good or excellent, neutral, and poor or very poor. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses. Results of the test were significant, with $\chi^2 (2, N = 71) = 67.296, p = .000$, indicating that parents reported prompting to be a valid evidence-based practice. A follow-up test demonstrated that the proportion of parents who rated prompting as good or excellent differed significantly from the proportion of persons who rated the intervention as poor/very poor, $\chi^2 (1, N = 60) = 45.067, p = .000$. Overall, these results suggest that parents reported prompting to be acceptable evidence-based practice.
Figure 27. Prompting response frequencies.

Reinforcement. Of 87 participants, 72 parents (83%) rated reinforcement poor/very poor, neutral, or good/excellent. For this item, 57 parents (79%) gave ratings of good or excellent, 10 parents (13.89%) of neutral, and 5 parents (6.94%) of poor or very poor. Figure 28 illustrates the frequency of responses, which included responses of good or excellent, neutral, and poor or very poor. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses. Results of the test were significant, with $\chi^2 (2, N = 72) = 68.583$, $p = .000$, indicating that parents reported reinforcement effective valid evidence-based
practice. A follow-up test demonstrated that the proportion of parents who rated reinforcement as good or excellent differed significantly from the proportion of persons who rated the intervention as poor/very poor, $\chi^2 (1, N = 62) = 43.613, p = .003$. Overall, these results suggest that parents indicated reinforcement to be acceptable evidence-based practice.

Figure 28. Reinforcement response frequencies.
Response interruption/redirection (RIR). Of 87 participants, 58 parents (67%) rated response interruption/redirection poor/very poor, neutral, or good/excellent. For this item, 44 parents (75.9%) gave ratings of good or excellent, 7 parents (15.9%) of neutral, and 7 parents (15.9%) of poor or very poor. Figure 29 illustrates the frequency of responses. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses, which included responses of good or excellent, neutral, and poor or very poor. Results of the test were significant, with $\chi^2 (2, N = 58) = 47.207, p = .000$, indicating that parents reported response interruption and redirection to be a valid evidence-based practice. A follow-up test demonstrated that the proportion of parents who rated RIR as good or excellent differed significantly from the proportion of persons who rated the intervention as poor/very poor, $\chi^2 (1, N = 51) = 26.843, p = .000$. Overall, these suggest that parents indicated response interruption and redirection to be acceptable evidence-based practice.
Figure 29. Parental frequency responses to response intervention and redirection (RIR).

**Self-management.** Of 87 participants, 52 parents (60%) rated self-management poor/very poor, neutral, or good/excellent. Figure 30 illustrates the frequency of responses. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses. Results of the test were not significant, $\chi^2 (2, N = 52) = 5.115, p = .077$, indicating that the proportion of parents rating self-management as good or excellent was not statistically significant. A follow-up test demonstrated that the proportion of parents who rated self-management as
good or excellent did not differ significantly from the proportion of parents who rated the intervention as poor/very poor, $\chi^2 (1, N = 52) = 3.103, p = .078$. A second follow-up test demonstrated that the proportion of parents who rated self-management as good or excellent or poor/very poor differed significantly from the proportion of parents who rated the intervention as neutral, $\chi^2 (1, N = 52) = 13, p = .000$.

Figure 30. Parental response frequencies for self-management.
Social narratives. Of 87 participants, 65 parents (75%) rated social narratives poor/very poor, neutral, or good/excellent. For this item, 33 parents (50.8%) gave ratings of good or excellent, 19 parents (29%) of neutral, and 13 parents (20%) of poor or very poor. Figure 31 illustrates frequency of responses which included responses of good or excellent, neutral, and poor or very poor. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses. Results of the test were significant, with $\chi^2 (2, N = 65) = 9.723, p = .008$, indicating that parents reported social narratives to be a valid evidence-based practice. A follow-up test demonstrated that the proportion of parents who rated social narratives as good or excellent differed significantly from the proportion of parents who rated the intervention as poor/very poor, $\chi^2 (1, N = 46) = 8.696, p = .003$. Overall, these results suggest that parents indicated social narratives an acceptable evidence-based practice.
Social skills groups. Of 87 participants, 58 parents (67%) rated social skills groups poor/very poor, neutral, or good/excellent. For this item, 34 parents (58.6%) gave ratings of good or excellent, 13 parents (38.2%) of neutral, and 10 parents (29.4%) of poor or very poor. Figure 32 illustrates the frequency of responses. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses which included responses of good or excellent, neutral, and poor or very poor. Results of the test were significant, with $\chi^2 (2, N = 57) =$
18, $p = .000$, indicating that parents reported social skills groups a valid evidence-based practice. A follow-up test demonstrated that the proportion of parents who rated social skills groups as good or excellent differed significantly from the proportion of parents who rated the intervention as poor/very poor, $\chi^2(1, N = 44) = 13.091, p = .000$. Overall, these results suggest that parents reported social skills groups an acceptable evidence-based practice.

*Figure 32.* Parent response frequencies for social skills groups.
Speech generating devices. Of 87 respondents, 9 parents (10%) rated speech generating devices poor/very poor, neutral, or good/excellent. For this item, 2 parents (22%) gave ratings of good or excellent, 4 parents (44.4%) of neutral, and 3 parents (33.3%) of poor or very poor. Figure 33 illustrates frequency of responses. The small number of parents who responded to this item inhibited analysis. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses. Results of the test were not significant, $\chi^2 (2, N = 9) = .667, p = .717$. However, three cells had expected frequencies that were less than 5, violating the chi-square test assumption.
Structured work systems. Of 87 participants, 17 parents (20%) rated structured work systems poor/very poor, neutral, or good/excellent. For this item, 10 parents (58.8%) gave ratings of good or excellent, 2 parents (11.8%) of neutral, and 5 parents (29.4%) of poor or very poor. Figure 34 illustrates the frequency of responses. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses. Results of the test were not significant, $\chi^2 (2, N = 17) = 5.765, p = .056$, indicating that the proportion of parents
rating structured work systems as good or excellent was not statistically significant. A follow-up test demonstrated that the proportion of parents who rated structured work systems as good or excellent did not differ significantly from the proportion of parents who rated the intervention as neutral, \( \chi^2 (1, N = 15) = 1.667, p = .197 \). A second follow-up test demonstrated that the proportion of parents who rated structured work systems as good or excellent or poor/very poor differed significantly from the proportion of parents who rated the intervention as neutral, \( \chi^2 (1, N = 17) = 9.941, p = .002 \).
Figure 34. Parent response frequencies for structured work systems.

Task analysis. Of 87 participants, 28 parents (32%) rated task analysis poor/very poor, neutral, or good/excellent. Figure 35 illustrates the frequency of responses. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses, which included responses of good or excellent, neutral, and poor or very poor. Results of the test were significant, with $\chi^2 (2, N = 28) = 12.071, p = .002$, indicating parents reported task analysis to be a valid evidence-based practice. A follow-up test demonstrated that the proportion of parents who rated
task analysis groups as good or excellent differed significantly from the proportion of parents who rated the intervention as poor/very poor, $\chi^2(1, N = 23) = 7.348, p = .007$. Overall, these results suggest that parents indicated task analysis an acceptable evidence-based practice.

![Figure 35. Parent frequency responses for task analysis.](image)

*Time delay.* Twenty-four respondents out of 87 participants (28%) rated time delay poor/very poor, neutral, or good/excellent. For this item, 14 parents (58.3%) gave
ratings of good or excellent, 4 parents (16.7%) of neutral, and 6 parents (25%) of poor or very poor. Figure 36 illustrates the frequency of responses. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses, which included responses of good or excellent, neutral, and poor or very poor. Results of the test were significant, with $\chi^2 (2, N = 24) = 7, p = .03$, indicating that parents reported time delay a valid evidence-based practice.

Figure 36. Parent response frequencies for time delay.
Video modeling. Of 87 participants, 31 parents (36%) rated video modeling poor/very poor, neutral, or good/excellent. For this item, 19 parents (61.3%) gave ratings of good or excellent, 6 parents (19.4%) of neutral, and 6 parents (19.4%) of poor or very poor. Figure 37 illustrates the frequency of responses. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses, which included responses of good or excellent, neutral, and poor or very poor. Results of the test were significant, with $\chi^2 (2, N = 31) = 10.903, p = .004$, indicating that parents reported video modeling a valid evidence-based practice. Overall, these results suggest that parents reported video modeling an acceptable evidence-based practice.
Visual supports. Of 87 participants, 68 parents (78%) rated visual supports poor/very poor, neutral, or good/excellent. For this item, 55 parents (80.9%) gave ratings of good or excellent, 7 parents (10.3%) of neutral, and 6 parents (8.8%) of poor or very poor. Figure 38 illustrates the frequency of responses. A one-sample chi-square analysis was performed to evaluate whether there were significant differences in the frequencies of parents’ responses, which included responses of good or excellent, neutral, and poor or very poor. Results of the test were significant, with $\chi^2 (2, N = 68) = 69.206, p = .000,$
indicating that parents reported visual supports a valid evidence-based practice. Overall, these results suggest that parents reported visual supports an acceptable evidence-based practice.

**Figure 38.** Parent response frequencies for visual supports.

**Summary of evidence-based practices.** In conclusion, a majority of parents indicated they had never used most of the evidence-based practices. Of parents who
implemented evidence-based practices, most parents reported they were effective. Table 11 illustrates evidence-based practices and corresponding frequencies of responses.

Reinforcement achieved the highest mean score of 3.5 ($SD = 1.7$). Of parents, 65.5% of parents rated reinforcement as excellent or good, 11.5% as neutral, and 5.7% as poor. Approximately 14% of parents indicated that they had never used reinforcement.

Two evidence-based practices achieved the second highest mean scores. Prompting had a mean of 3.3 ($SD=1.7$), and visual supports had a mean score of 3.3 ($SD=1.8$). Eighty Six parents rated the evidence-based practice of prompting. Of respondents 64.3% rated prompting as excellent or good, 12.6% rated prompting as neutral, and 4.6% rated prompting as poor or very poor. Approximately 17% of parents indicated they had never used prompting. Alternatively, 85 parents rated the evidence-based practice of visual supports. Of respondents, 63.2% rated visual supports as excellent or good, 8% as neutral, and 8.9% as poor or very poor. Approximately 17% of respondents reported they had never used visual supports.

Parents rated Response Interruption and Redirection (RIR) with the fourth highest mean score of 2.6 ($SD = 1.7$). Of 85 participants who responded to this question, 50.5% rated RIR as excellent or good, 8% as neutral, and 8% as poor or very poor. Approximately 31% never used RIR. Finally, the fifth most highly rated evidence-based practice was social skills with a mean of 2.5 ($SD = 1.7$). Of participants, 38.9% rated social skills as excellent or good, 14.9% as neutral, and 12.4% as poor or very poor. Approximately 28.7% did not implement RIR. Speech generating devices/VOCA achieved the lowest mean rating of .32 ($SD = .99$). Only 1.1% of parents rated speech
generating devices/VOCA as excellent and good. A large percentage of parents, 82.8% indicated that they had never used speech generating devices/VOCA. Table 11 details parental perceptions of evidence-based practices with the 5-point Likert scale ratings.

Findings showed that a significant percentage of parents had never used a majority of evidence-based practices (Table 11). Over 50% of parents stated they had never used 14 of the 23 listed evidence-based practices. Thus, a majority of parents in this study never used 63% of the evidence-based practices listed. Only 9 of the 23 practices achieved parent ratings for never used that were under 50%. These practices were: prompting (17.2%), reinforcement (13.8%), visual supports (17.2%), social narratives (20.7%), social skills groups (28.7%), response interruption/redirection (31%), self-management (36.8%), computer aided instruction (43.3%), and functional behavior assessment (49.4%).
Table 11

Perceptions of Evidence-Based Practices

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<th>Evidence-Based Practice</th>
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<th>Neutral</th>
<th>Good/ Excellent</th>
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<tr>
<td>Response Interruption/Redirection</td>
<td>2.3%</td>
<td>31.0%</td>
<td>8.0%</td>
<td>8.0%</td>
<td>50.5%</td>
</tr>
<tr>
<td>Self-Management</td>
<td>3.4%</td>
<td>36.8%</td>
<td>16.1%</td>
<td>14.9%</td>
<td>28.7%</td>
</tr>
<tr>
<td>Social Narratives</td>
<td>4.6%</td>
<td>20.7%</td>
<td>14.9%</td>
<td>21.8%</td>
<td>37.9%</td>
</tr>
<tr>
<td>Social Skills Groups</td>
<td>5.7%</td>
<td>28.7%</td>
<td>11.4%</td>
<td>14.9%</td>
<td>38.9%</td>
</tr>
<tr>
<td>Speech Generating Devices</td>
<td>6.9%</td>
<td>82.8%</td>
<td>3.4%</td>
<td>4.6%</td>
<td>2.2%</td>
</tr>
<tr>
<td>Structured Work Systems</td>
<td>8.0%</td>
<td>72.4%</td>
<td>5.7%</td>
<td>2.3%</td>
<td>11.5%</td>
</tr>
<tr>
<td>Task Analysis</td>
<td>4.6%</td>
<td>63.2%</td>
<td>5.7%</td>
<td>5.7%</td>
<td>20.6%</td>
</tr>
<tr>
<td>Time Delay</td>
<td>2.3%</td>
<td>62.1%</td>
<td>6.8%</td>
<td>6.9%</td>
<td>21.8%</td>
</tr>
<tr>
<td>Video Modeling</td>
<td>2.3%</td>
<td>62.1%</td>
<td>6.8%</td>
<td>6.9%</td>
<td>21.8%</td>
</tr>
<tr>
<td>Visual Supports</td>
<td>4.6%</td>
<td>17.2%</td>
<td>6.9%</td>
<td>8.0%</td>
<td>63.2%</td>
</tr>
</tbody>
</table>

How Parents Learned About Autism Spectrum Disorders

The second part of the survey’s Section 2 investigated how parents learned about autism spectrum disorders. Participants answered three items regarding the sources they consulted and methods they used to learn about autism spectrum disorders and special education law.

Sources of information about autism treatments and evidence-based practices. The first item was a multiple choice question that inquired into the sources parents consulted to learn about autism treatments and evidence-based practices. Parents
had the option to select from seven multiple choices: Internet, conference, clinic/institute, school teachers, occupational therapist, medical doctor/Neurologist, and parents who have children with autism spectrum disorders. Parents were also able to share other sources consulted in an open-ended selection box. Thus, parents were able to share a source they consulted if that choice was not listed among the seven multiple choice options.

Figure 39 illustrates the frequencies of participants’ responses for the seven multiple choice options. Participants most frequently consulted the Internet (85.1%), other parents (67.8%), doctor/Neurologist (63.2%), school (58.6%), occupational therapist (55.2%), conference (48.3%), and clinic (39.1%). A majority of participants, 74, consulted the Internet to learn about autism spectrum disorders and evidence-based practices. The second source most frequently consulted was other parents with 59 participants, and only 18 participants indicated they did not consult with other parents. The third largest source of information was doctor/Neurologist. Of 80 respondents, 55 indicated they learned about autism from a doctor/Neurologist, and 25 reported they did not.
Ten participants shared other resources they consulted to learn about autism spectrum disorders and evidence-based practices. Three of these participants read books and peer-reviewed journals. Two participants learned about autism and evidence-based practices from Parent Resource Centers. One parent reported learning about autism and evidence-based practices from multiple sources, which included speech therapist, nutritionist, autism association, private therapist, and personal expertise. One parent stated he or she was employed as a special education teacher and had personal expertise. Figure 40 illustrates the open-ended responses to the item inquiring into sources consulted to learn about autism spectrum disorders and evidence-based practices.
Most helpful sources of information about autism, autism therapies, treatments, and evidence-based practices. The second item asked parents which sources were most helpful in learning about autism, autism therapies, treatments, and evidence-based practices. Seventy-four participants responded to this item. Most responses were short answers, which were analyzed by counting word frequencies and then coded into 15 categories and then themes. Figure 41 illustrates the frequencies of responses and 15 categories.

A majority of parents reported other parents were most helpful. One parent noted requisitioning advice from parents who shared resources and information that was supported by empirical evidence. Numerous parents stated they learned about autism through parent listservs which were available through associations, organizations, and parent resource centers.

Figure 40. Other sources consulted to learn about autism spectrum disorders and evidence-based practices.
Parents mentioned that they examined a plethora of information to learn about autism. They used the Internet, books, read peer-reviewed journal articles, and attended conferences. Several parents noted criteria they used to determine the reliability and trustworthiness of the information they processed. Some parents reported that autism associations shared information that was trustworthy and therefore were a reliable source. Other parents discerned information shared from other parents, doctors, and Internet sites based on their prior knowledge as to what they reported was empirically valid information. Some parents indicated that information from doctors, occupational therapists, speech therapists, ABA therapists, Cognitive Behavior Therapists, and special education teachers were most helpful. A majority of these parents stated the aforementioned professionals’ knowledge of autism spectrum disorders prerequisite to considering their information reliable and valid. In conclusion, one parent stated, “It has been an ongoing process and I can’t say one resource has been more helpful than others. Every therapist, teacher, book, listserv, blog, etc. has helped.”
NVivo 10 (QSR International, 2012) was used to analyze concept frequencies and validate themes. Word clouds that were generated by the data entered into NVivo illustrated the most frequently used words, closely related words, and synonyms, with words used more frequently in increasingly larger fonts. The selection criteria for word clouds included synonyms, closely related words, and exact word matches. The top words used were: parents (6.29%), Internet (5.26%), organizations (4.07%), ground (3.32%), and conferences (3.02%). Figure 42 illustrates a word cloud with these concept frequencies.
Figure 42. Concept frequencies for most helpful resources word cloud.
Sources of information about the IEP process and parents’ legal rights. The final item asked parents how they learned about the IEP process and their legal rights. Eighty participants (92%) answered this item. A majority of responses were one- or two-word listings of sources parents accessed to learn about the IEP process and legal rights. Every response was coded in Excel and then imported from Excel into SPSS for analysis. Results indicated that parents most frequently learned about the IEP process from Wrightslaw, other parents, self-study, the school district, the Internet, and experience participating in meetings. Figure 43 illustrates the frequencies of sources parents consulted to learn about the IEP process and legal rights.
Figure 43. Resources parents consulted to learn about Individualized Education Program (IEP) process and legal rights.

NVivo 10 (QSR International, 2012) was used to analyze concept frequencies and validate themes. Word clouds that were generated by the data entered into NVivo illustrated the most frequently used words, closely related words, and synonyms, with words used more frequently in increasingly larger font. The selection criteria for word clouds included synonyms, closely related words, and exact word matches. The most frequently used words used were: organizations (3.99%), IEP (2.68%), groups (2.46%), system (2.45), and communication (2.43%). Figure 44 is a word cloud with these concept frequencies.
NVivo 10 (QSR International, 2012) coded information from other parents, associations, and Wrightslaw seminars under the code organization. Approximately 20% of respondents indicated they learned about their rights through networking with other parents through associations and listservs. Additionally, parents reported they learned about their legal rights and the IEP process through organizations. Some parents shared specific names of organizations, which included Parent Education and Training Centers such as Statewide Parent Advocacy Network (SPAN) and Partners in Policymaking (PIP). These organizations sometimes sponsored workshops and seminars with Wrightslaw. Subsequently, Wrightslaw is part of the word cloud as well as being one of the most frequent words mentioned through coding. Approximately 21% of the 80 parents who responded to this question attended Wrightslaw classes to learn about their legal rights.

Some parents said they learned about the IEP process through experience participating in IEP meetings. Every year these parents acquired more knowledge of the legal process by participating in meetings. Accordingly, schools provided information about the IEP process and special education law. Many parents mentioned they obtained special education law pamphlets from schools which outlined rights afforded to parents and steps in the IEP process. Approximately 18% of participants indicated they studied pamphlets to learn about their rights. NVivo 10 (QSR International, 2012) coded IEP experience under the code IEP.

Many parents researched the Internet to learn about their legal rights and the IEP process. NVivo 10 (QSR International, 2012) coded Internet research under the code
system, which is denoted in Figure 47. The Internet was used to access information from organizations, associations, Wrightslaw, parent listservs, and state websites.

Finally, parents learned about the IEP process and their legal rights through self-study, which included reading books, research, and consultations with attorneys and advocates. Approximately 20% of participants indicated they learned their legal rights through self-study. NVivo 10 (QSR International, 2012) coded self-study within the communication code, which is illustrated in Figure 47.

Of note, six parents learned about the IEP process and special education law through their jobs. Four of the six participants indicated they were special education teachers, and two of the participants were attorneys. The attorneys mentioned they studied special education law in order to become knowledgeable. Some parents mentioned consulting the code, while others mentioned referencing material provided by school districts.
Figure 44. Where parents learned about the Individualized Education Program (IEP) process word cloud.
Section 3. Parents’ Perceptions of the Individualized Education Program (IEP) Process

Section 3 of the survey investigated parents’ perceptions of the IEP process with 17 items that required responses that were limited to ratings on a 5-point Likert scale of strongly disagree, disagree, neutral, agree and strongly agree. For purposes of analysis, numerical values were assigned to each rating: Strongly disagree was a 1, disagree was a 2, neutral was a 3, agree was a 4, and strongly agree was a 5. Thus, the range of scores possible was between 1 and 5. Means and standard deviations for each item were calculated using the aforementioned numerical values. Table 1 illustrates frequency of responses, means, and standard deviations for the 17 statements regarding the IEP process.

Results indicated that respondents reported they understood their rights as an IEP team member and knew the steps they would take if they disagreed with the school district. The statement, “I understand my rights as an IEP team member,” achieved a mean of 4.2 (SD = .81), which was the highest mean score reported. The statement, “I understand the steps I would take if I disagreed with the school district,” received the second highest mean, 3.7 (SD = 1). Similarly, a majority of parents reported their input was valuable (M = 3.6, SD = 1.3), and that educators integrated their suggestions into the IEP (M = 3.5, SD = 1.2). Many parents reported they were treated with respect (M = 3.5, SD = 1.2).

Alternatively, many parents felt that school administrators were knowledgeable about the IEP process and law (M = 3.4, SD = 1.2), more so than school administrators’ knowledge about their child’s disability (M = 2.8, SD = 1.3). Mean ratings for teachers’
understanding and knowledge of their child’s disability ($M = 2.9$, $SD = 1.3$) was similar to the mean of 2.8 ($SD = 1.3$) reported for school administrators’ knowledge of disability.

The lowest mean reported was for the statement, “Overall I have positive perceptions of the IEP process.” For this statement, the mean was 2.7 ($SD = 1.2$). Similarly, the mean reported for the statement, “I feel my child’s IEP will meet my child’s education needs” was almost as low at 3 ($SD = 1.2$).

Table 12

*The Individualized Education Program (IEP) Process: Perceptions of Parents*

<table>
<thead>
<tr>
<th>Perception</th>
<th>$N$</th>
<th>$M$</th>
<th>$SD$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall, I have positive perceptions of the IEP process</td>
<td>86/87</td>
<td>2.7</td>
<td>1.20</td>
</tr>
<tr>
<td>I feel as an equal team member in IEP process</td>
<td>86/87</td>
<td>3.1</td>
<td>1.30</td>
</tr>
<tr>
<td>I feel I am treated with respect</td>
<td>86/87</td>
<td>3.5</td>
<td>1.20</td>
</tr>
<tr>
<td>I feel my input is valuable</td>
<td>86/87</td>
<td>3.6</td>
<td>1.30</td>
</tr>
<tr>
<td>Educators integrate my suggestions into IEP</td>
<td>86/87</td>
<td>3.5</td>
<td>1.20</td>
</tr>
<tr>
<td>Select appropriate evaluations to determine learning and behavior needs</td>
<td>86/87</td>
<td>2.9</td>
<td>1.10</td>
</tr>
<tr>
<td>Teachers et al. discuss alternative placements</td>
<td>86/87</td>
<td>2.9</td>
<td>1.20</td>
</tr>
<tr>
<td>Education professionals create individualized IEP goals designed to meet child’s needs</td>
<td>85/87</td>
<td>3.2</td>
<td>1.20</td>
</tr>
<tr>
<td>Education professionals create generic goals</td>
<td>86/87</td>
<td>3.2</td>
<td>1.12</td>
</tr>
<tr>
<td>I feel my child’s IEP will meet my child’s education needs</td>
<td>85/87</td>
<td>3.0</td>
<td>1.20</td>
</tr>
<tr>
<td>Educators provide adequate feedback to me regarding my child’s progress toward meeting IEP goals</td>
<td>84/87</td>
<td>2.9</td>
<td>1.20</td>
</tr>
<tr>
<td>Everyone communicates and collaborates regarding issues with my child</td>
<td>86/87</td>
<td>2.8</td>
<td>1.30</td>
</tr>
<tr>
<td>I feel teachers are knowledgeable about my child’s disability</td>
<td>86/87</td>
<td>2.9</td>
<td>1.30</td>
</tr>
<tr>
<td>I feel school administrators are knowledgeable about my child’s disability</td>
<td>84/87</td>
<td>2.8</td>
<td>1.30</td>
</tr>
<tr>
<td>I feel school administrators are knowledgeable about IEP process and law</td>
<td>85/87</td>
<td>3.4</td>
<td>1.20</td>
</tr>
<tr>
<td>I understand my rights as an IEP team member</td>
<td>84/87</td>
<td>4.2</td>
<td>.81</td>
</tr>
<tr>
<td>I understand the steps I would take if I disagreed with the school district</td>
<td>84/87</td>
<td>3.7</td>
<td>1.10</td>
</tr>
</tbody>
</table>

Descriptive statistics were reported for the 17 statements regarding the IEP process. Frequency of responses utilized the 5-point Likert scale ratings from strongly disagree to strongly agree (see Table 12). For purposes of analysis, responses were
combined to include the following scale: Disagree/Strongly Disagree, Neutral, Agree/Strongly Agree, and Missing. Responses to these items are illustrated in Figure 45.

The following paragraphs provide analysis for every item.

**Figure 45.** Parental responses regarding the Individualized Education Program (IEP) process: Percentage responses to Likert scale items.
Overall perceptions of IEP process. The first item asked parents their overall perceptions of the IEP process. Most parents reported they did not have positive perceptions of the IEP process: Of 84 parents who responded to this item, 50% either disagreed or strongly disagreed with this item, 14% were neutral, and 34.9% agreed or strongly agreed (Figure 46).

![Bar chart](image)

*Figure 46. Overall, I have positive perceptions of the IEP process.*

Equal team members in the IEP process. Parents were asked whether they felt they were treated as an equal team member in the IEP process (Figure 47). Results
showed that a majority of parents reported they were treated as equal team members in the IEP process. Of respondents, 43% stated they agreed or strongly agreed, 30% disagreed or strongly disagreed, and 13% were neutral in their opinion.

Figure 47. I feel that I am treated as an equal team member in the IEP process.

**Treated with respect by the IEP team.** Similarly, most parents reported they were treated with respect by the IEP team (Figure 48). Of 84 respondents, 52% agreed or strongly agreed they were treated with respect, 14% were neutral, and 20% disagreed or
strongly disagreed. All in all, most parents reported they were treated with respect and as though they were equal IEP team members.

![Bar chart](image.png)

*Figure 48.* I feel that I am treated with respect by the IEP team.

**Suggestions are valuable and educators integrated suggestions into IEP.**

More than half of 86 respondents to this item reported their input was valuable (65.1%), as noted by stating they agreed or strongly agreed with the item that asked whether respondents reported their input was valuable during the IEP process. However, 24.4%
indicated they did not feel their input was valuable, and 10.5% stated they were neutral.

Concurrently, most (60.9%) of the 86 respondents to this item reported that educators listened to their suggestions and integrated suggestions into the IEP. Of respondents, 60.9% agreed or strongly agreed, 10.3% were neutral, and 26.4% disagreed or strongly disagreed. Figure 49 illustrates the frequencies of responses to these two items.

![Bar chart](image-url)

*Figure 49. I feel that educators integrate my suggestions into the IEP and my input is valuable during the IEP process.*
Educators select and administer appropriate evaluations to determine my child’s learning and behavior needs. The next item asked parents whether they reported counselors, teachers, and school therapists selected and administered appropriate evaluations to determine their child’s learning and behavior needs. Parents were divided:

Of 86 respondents to this item, 35.6% agreed or strongly agreed with this statement, and 36.8% disagreed or strongly disagreed, and 26.4.5% reported they were neutral (Figure 50).
Counselors, teachers, and school therapists select and administer appropriate evaluations to determine my child’s learning and behavior needs.

A one-sample chi-square was conducted to determine whether all parents reported counselors, teachers, and school therapists selected and administered appropriate evaluations to determine their child’s learning and behavior needs. The results of the test were not significant, $\chi^2(2, N=86) = 1.698$, $p = .428$, indicating that observed frequencies were similar to expected frequencies. Thus, respondents’ perceptions were similar.
A two-way contingency table analysis test was conducted to evaluate whether parents who have children with different types of autism had similar perceptions on whether counselors, teachers, and school therapists selected and administered appropriate evaluations to determine their child’s learning and behavior needs. Both the chi-square and two-way contingency analysis have assumptions that require 5 frequencies or more per category. To meet the assumption requirements, the disability categories of Asperger’s Syndrome and PDD-NOS were combined into one. Autistic Disorder, Rett Syndrome, and Childhood Disintegrative Disorder (CDD) were also combined into one in order to meet the assumption requirement. These broader categories represented the higher and lower functioning disabilities classifications on the autism spectrum with Asperger’s and PDD-NOS reflecting higher functioning autism, and Autistic Disorder, Rett Syndrome, and CDD representing lower functioning autism. Thus, there were two disability categories.

The first two-way contingency table analysis was performed to evaluate whether there were significant differences in the frequency of responses regarding whether parents reported counselors, teachers, and school therapists select and administer appropriate evaluations to determine their child’s learning needs by disability among parents who had children diagnosed with the two broader disability categories of Asperger’s Syndrome and PDD-NOS, and Autistic Disorder, Rett Syndrome, and CDD. Results demonstrated that there were no significant differences between the disability categories of Asperger’s and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), and Autistic Disorder, Rett Syndrome, and CDD, $\chi^2 (2, N=84) =$
3.252, p = .197. Of parents who had children with Asperger’s and PDD-NOS, 71% disagreed or strongly disagreed that educators selected and administered appropriate evaluations to determine learning needs, 52.2% were neutral, and 50% agreed or strongly agreed. Alternatively, of parents who had children with autistic disorder, Rett Syndrome or CDD, 36.9% of parents disagreed or strongly disagreed that educators selected and administered appropriate evaluations to determine learning needs, 27.4% were neutral, and 35.7% agreed or strongly agreed. These results suggest that disability type has an impact on the perceptions parents regarding whether counselors, teachers, and school administrators selected and administered appropriate evaluations to determine their child’s learning needs (Figure 51).
Figure 51. Counselors, teachers, and school therapists select and administer appropriate evaluations to determine my child's learning and behavior needs, by disability category. Note. PDD-NOS = Pervasive Developmental Disorder – Not Otherwise Specified, CDD = Childhood Disintegrative Disorder.

Closer inspection of the frequencies of responses among parents who had children with Asperger’s, PDD-NOS, and Autistic Disorder reveals differences. Of respondents, there were 47.1% with children who had Asperger’s, 43.8% with children who had PDD-NOS, and 24.2% with children who had autistic disorder reported they believed counselors, teachers, and school therapists did not select and administer appropriate evaluations to determine their child’s needs. Alternatively, of respondents, 29.4% with
children who had Asperger’s, 31.3% with children who had PDD-NOS, and 45.5% of parents who had children with autistic disorder agreed that counselors, teachers, and school therapists selected and administered appropriate evaluations to determine their child’s needs.

A second two-way contingency analysis was conducted to evaluate parental perceptions regarding whether counselors, teachers, and school therapists select and administer appropriate evaluations to determine learning and behavior needs by parental income category. To meet the chi-square assumption requiring categories with 5 frequencies or more, incomes were combined into respondents with family incomes $100,000 and more per year and respondents with family incomes under $100,000 per year. A two-way contingency analysis was performed to evaluate whether respondents who had annual family incomes of $100,000 or more were similar or dissimilar in their perceptions from respondents who had annual family incomes under $100,000 regarding the item: Counselors, teachers, and school therapists select and administer appropriate evaluations to determine my child’s learning and behavior needs. Results of the two-way contingency analysis indicated that there were no significant differences by income category, $\chi^2 (2, N = 83) = 5.358, p = .069$, indicating that annual family income level did not seem to affect parents’ perceptions on whether counselors, teachers, and school therapists select and administer appropriate evaluations to determine their child’s learning and behavior needs (Figure 52).
Counselors, teachers, and school therapists select and administer appropriate evaluations to determine my child's learning and behavior needs, by income category. A final two-way contingency analysis analyzed the differences in frequencies regarding the number of doctors parents consulted to obtain an ASD diagnosis and educators’ selection and administration of appropriate evaluations to determine learning and behavior needs. For purposes of analysis to meet the two-way contingency analysis assumption requiring 5 frequencies or more per category, the number of doctors consulted was combined into the following categories: less than three doctors, and three doctors or more. Results of the two-way contingency analysis indicated that there were...
no significant differences between parents who consulted less than three doctors to obtain an ASD diagnosis, and parents who visited three or more doctors to obtain an ASD diagnosis, $\chi^2 (2, N = 84) = .491, p = .782$. Thus, the number of doctors that parents consulted did not seem to affect their perception on whether counselors, teachers, and school therapists select and administer appropriate evaluations to determine their child’s learning and behavior needs (Figure 53).

Figure 53. Counselors, teachers, and school therapists select and administer appropriate evaluations to determine learning and behavior needs, by number of doctors consulted.
Teachers, school therapists, or other education professionals discussed alternative placements. The next item asked parents whether teachers, school therapists, or other education professionals discussed alternative placements with them, which included a range of class options from honors classes to self-contained classes. Placement options also included public/private self-contained schools. Responses to this item were polarized. A slight majority of the 86 respondents to this item agreed or strongly agreed with this statement (41.4%); however, 40.2% disagreed or strongly disagreed with this statement. Many parents were neutral (17.2%), and one did not answer this item (Figure 54).
A one-sample chi-square analysis was performed to assess parental perceptions regarding whether teachers, school administrators, and counselors took time to discuss alternative school and class placements. Results were significant: $\chi^2 (2, N = 86) = 9.791$, $p = .007$. The proportion of parents who disagreed/strongly disagreed ($P = .41$), and the proportion of parents who agreed/strongly agreed ($P = .42$), was greater than the
hypothesized proportion of .33. The proportion of parents who were neutral \((P = .17)\) was less than the hypothesized proportion of .33.

A two-way contingency analysis was conducted to assess whether there were significant differences in parental responses by disability type, which were Asperger’s and PDD-NOS, and Autistic Disorder, Rett Syndrome, and CDD. Results indicated that there were no significant differences between disability type, \(\chi^2 (2, N= 84) = .041, p = .980\). Thus, type of disability did not seem to impact parents’ perceptions on whether parents reported teachers, school administrators, and counselors took time to discuss alternative placements with them. Figure 55 illustrates frequencies.
Another two-way contingency test was conducted to evaluate whether there were any significant differences among income categories. Results demonstrated that there were no significant differences among income levels, $\chi^2 (2, N = 83) = 2.652, p = .266$, indicating that income level does not seem to impact parental perceptions of whether teachers, school administrators, and counselors take time to discuss alternative placements with them. Figure 56 illustrates frequencies by income categories.
A final two-way contingency table analysis was performed to analyze differences between parental perceptions regarding whether teachers, school administrators, and counselors took time to discuss alternative school and class placements between parents who consulted with three doctors or more, or less than three doctors, to obtain an ASD diagnosis. Results were significant, $\chi^2 (2, N = 84) = 6.127, p = .047$, indicating that the number of doctors consulted impacted parental perceptions on whether they reported
educators took time to discuss alternative school and class placements. Note that the number of respondents who reported consulting with three doctors or more was less than five. The chi-square and two-way contingency table analysis assumptions requires five or more. Thus, this test violated the two-way contingency analysis assumption.

A follow-up pairwise comparison using the two-way contingency analysis was conducted to assess perception differences between parents who agreed/strongly agreed and parents who disagreed/strongly disagreed. Results were significant, $\chi^2 (1, N = 70) = 5.245, p = .022$, indicating that the number of doctors consulted being greater than or equal to three, or less than three, was significantly related to parents’ perceptions about whether educators took time to discuss alternative school and class placements with them (Figure 57).
A second follow-up analysis was a pairwise comparison which examined perceptions of parents who agreed/strongly agreed and parents who disagreed/strongly disagreed with parents who had neutral perceptions, was not significant, $\chi^2(1, N = 84) = .713, p = .398$. Of note, there were a total of three neutral perceptions for parents who consulted less than three doctors. The low number of three neutral perceptions was less
than five, violating the two-way contingency table analysis assumption of five or more frequencies per category.

**Teachers, school therapists, and other education professionals create and recommend individualized IEP goals.** The next item asked parents whether teachers, school therapists, and other education professionals create and recommend individualized IEP goals designed to meet their child’s needs. A majority of parents reported that education professionals created and recommended individualized IEP goals. Of 85 parents who responded to this item, 49% agreed or strongly agreed, 49.4% agreed, 14.9% were neutral, 27.6% disagreed or strongly disagreed (Figure 58).
Teachers, therapists, and other education professionals create and recommend individualized IEP goals that are designed to meet my child's needs. A similar item asked parents whether teachers, therapists, and counselors created and recommended generic IEP goals common to many students with autism spectrum disorders. For this item, a majority of parents agreed or strongly agreed (49.5%). However, 27.6% reported that teachers, therapists, and counselors did not recommend generic IEP goals. A large
percentage of parents (21.8%) reported neutral regarding this item. Only one person did not respond to this question (Figure 59).

Figure 59. Teachers, therapists, and counselors create and recommend generic IEP goals that are common to many students with autism spectrum disorders.

**Child’s IEP would meet education needs.** The next item asked parents whether they reported their child’s IEP would meet their child’s education needs (Figure 60).
Almost 50% of parents agreed or strongly agreed. Conversely, approximately 42% of parents disagreed. Almost a quarter of the parents selected neutral for this item (24.1%).

A chi-square analysis was conducted to examine parental perceptions on whether they reported their child’s IEP would meet their child’s education needs. Results were not significant, $\chi^2 (2, N = 85) = 3.976, p = .137$, indicating that observed values, which were
disagree/strongly disagree ($P = .33$), neutral ($P = .25$), and agree/strongly agree ($P = .42$) were not different from hypothesized values of .33.

A two-way contingency table analysis was performed to evaluate whether there were significant differences in perceptions for the frequency of responses by two disability categories: Asperger’s and PDD-NOS, and Autistic Disorder, Rett Syndrome, and CDD. Results demonstrated that there were no significant differences between frequencies of responses by the disability type, $\chi^2 (2, N = 83) = 1.301, p = .522$, indicating that the type of disability did not seem to impact parental perceptions on how they reported their child’s IEP would meet their child’s learning needs. Figure 61 illustrates frequencies of responses by disability type.
Another two-way contingency table analysis was performed to evaluate whether there were significant differences in the frequency of responses by the number of doctors parents consulted, which included the following categories: less than three doctors, and three or more doctors. Results demonstrated that there were no significant differences between frequencies of responses by the number of doctors parents consulted categories, $\chi^2 (2, N = 83) = 4.286, p = .117$, indicating that the number of doctors parents consulted to obtain an ASD diagnosis did not seem to impact their perceptions on whether they
reported their child’s IEP would meet their child’s learning needs. Figure 62 illustrates frequencies by number of doctors consulted.

![Bar chart showing frequencies by number of doctors consulted.](image)

**Figure 62.** I feel my child’s IEP will meet my child’s education needs, by number of doctors consulted.

A final two-way contingency table analysis was performed to evaluate whether there were significant differences in the frequency of responses by income categories, which were $100,000 or more and less than $100,000. Results demonstrated that there
were no significant differences between frequencies of responses by income category, $\chi^2(2, N = 82) = 1.008, p = .604$, indicating that income does not seem to impact parents’ perceptions on whether their child’s IEP will meet their child’s education needs. Figure 63 illustrates frequencies by income category.

Figure 63. I feel my child's IEP will meet my child's education needs, by income category.
Educators provide adequate feedback to me regarding my child’s progress toward meeting IEP goals. For the next item, parents indicated their agreement level on whether educators provided adequate feedback on progress toward meeting IEP goals. Of 84 respondents to this item, a majority of parents agreed or strongly agreed (37.9%). Alternatively, 33.3% disagreed or strongly disagreed. Approximately 25% of parents reported neutral regarding this item. Three respondents did not answer this item (Figure 64).
A chi-square analysis was performed to assess whether there were statistically significant differences in all parents’ perceptions on whether educators provided adequate feedback regarding their child’s progress toward meeting IEP goals. Results were not significant, $\chi^2 (2, N = 84) = 2.214, p = .331$, indicating parents’ perceptions were not different from hypothesized perceptions proportions (Disagree/Strongly Disagree, $P = .35$; Neutral, $P = .26$; Agree/Strongly Agree, $P = .39$).
A two-way contingency analysis was performed to evaluate whether there were significant differences in the perception frequency of responses by two disability categories: Asperger’s and PDD-NOS, and Autistic Disorder, Rett Syndrome, and CDD. Results demonstrated that there were no significant differences between frequencies of responses by disability category, $\chi^2 (2, N = 83) = .194, p = .908$, indicating that disability type does not seem to impact parental perceptions on whether they reported educators provided adequate feedback regarding their child’s progress toward meeting IEP goals. Figure 65 illustrates frequencies by disability category for the item: Educators provide adequate feedback to me regarding my child’s progress toward meeting IEP goals.
Figure 65. Educators provide adequate feedback to me regarding my child's progress toward meeting IEP goals, by disability type.

A two-way contingency analysis was performed to evaluate whether there were significant differences in the perception frequency of responses by income categories. Results demonstrated that there were no significant differences between frequencies of responses by income category, $\chi^2(2, N = 81) = 2.034, p = .362$, indicating that income does not seem to impact parental perceptions regarding educators providing adequate
feedback. Figure 66 illustrates frequencies by income category for the item: Educators provide adequate feedback regarding my child’s progress toward meeting IEP goals.

![Bar chart showing frequency by income category](chart.png)

*Figure 66. Educators provide adequate feedback to me regarding my child's progress toward meeting IEP goals, by income.*

**Number of doctors consulted.** A two-way contingency table analysis was performed to evaluate whether there were significant differences in the perceptions frequency of responses by number of doctors consulted categories. The categories were
number of doctors consulted less than three, and number of doctors greater than or equal to three. Findings revealed that there were significant differences between frequencies of responses by the number of doctors parents consulted to obtain a diagnosis, $\chi^2 (2, N = 82) = 10.034, p = .007$. Figure 67 illustrates frequencies by number of doctors consulted with the item: Educators provide adequate feedback regarding my child’s progress toward meeting IEP goals.

Figure 67. Educators provide adequate feedback to me regarding my child’s education needs, by consultation with number of doctors.
Two pairwise two-way contingency analysis tests were performed to confirm findings of the initial two-way contingency test. The first test analyzed whether the proportion of respondents who agreed/strongly agreed differed from the proportion of respondents who disagreed/strongly disagreed. The Holm’s sequential Bonferroni method was used to control for Type I error at the .05 level across comparisons. Findings revealed that the two-way contingency analysis was significant, $\chi^2 (1, N = 60) = 5.480$, $p = .019$. The proportions of respondents who agreed/strongly agreed and the proportion of respondents who disagreed/strongly disagreed were not similar for respondents who consulted less than three doctors and respondents who consulted with three doctors or more. Approximately 77% of parents who consulted with less than three doctors agreed/strongly agreed. Alternatively, approximately 23% of parents who consulted with three doctors or more agreed/strongly agreed. Figure 68 illustrates frequencies.
Educators provide adequate feedback to me regarding my child’s progress toward meeting IEP goals, by number of doctors, pairwise tests. The second two-way contingency table analysis was performed to evaluate whether there was a significant difference from respondents who selected neutral and the combined categories representing respondents who selected agreed/strongly agreed and disagreed/strongly disagreed. The Holm’s sequential Bonferroni method was used to control for Type I error at the .05 level across comparisons. Findings revealed that the chi-square test was also significant, $\chi^2 (1, N = 82) = 4.029, p = .045$. Thus, the

Figure 68. Educators provide adequate feedback to me regarding my child’s progress toward meeting IEP goals, by number of doctors, pairwise tests.
proportions of respondents who agreed/strongly agreed and disagreed/strongly disagreed were not similar to proportions of respondents who were neutral. Figure 69 illustrates response frequencies. All in all, results of these tests indicate that the number of doctors parents consulted to diagnose ASD impacted their perceptions on whether educators provided adequate feedback on their child’s progress toward meeting IEP goals.

Figure 69. Educators provide adequate feedback to me regarding my child’s progress toward meeting IEP goals, by number of doctors consulted, second contingency analysis.
**Perceptions of educator collaboration.** For the next item, parents were asked whether they reported general education teachers, special education teachers, administrators, and therapists collaborated and communicated well regarding issues with their child. Of 86 respondents to this item, 36 parents (46%) disagreed or strongly disagreed. A total of 32 parents (36.7%) agreed or strongly disagreed, and 14 parents (16.1%) were neutral (Figure 70).

*Figure 70. Educators communicate and collaborate regarding issues with my child.*
Teacher knowledge. The next item asked parents whether they thought teachers were knowledgeable about autism spectrum disorders. For this item, opinions were almost evenly split with 41.4% of parents indicating they disagreed or strongly disagreed, and 41.3% of parents indicating they agreed or strongly agreed. Of 86 respondents to this item, 20.7% strongly disagreed, 20.7% disagreed, 16.1% were neutral, 31% agreed, and 10.3% strongly agreed. Figure 71 illustrates response frequencies.

Figure 71. Teachers are knowledgeable about my child’s disability.
A one-sample chi-square analysis was conducted to examine whether there were significant differences in parental perceptions regarding teachers’ knowledge of their child’s disability. Results were significant, $\chi^2 (2, N = 86) = 11.256, p = .004$. The proportion of parents who disagreed/strongly disagreed ($P = .42$), were neutral ($P = .16$), and agreed/strongly agreed ($P = .42$) were different from hypothesized proportions of .33.

A two-way contingency analysis was performed to evaluate whether there were significant differences in the frequency of responses by two disability categories: Asperger’s and PDD-NOS, and Autistic Disorder, Rett Syndrome, and CDD. Results demonstrated that there were no significant differences between frequencies of responses by disability category, $\chi^2 (2, N = 84) = .480, p = .787$, indicating that disability type did not seem to impact parental perceptions on whether they reported teachers were knowledgeable about their child’s disability. Figure 72 illustrates frequencies by disability category for the item: I feel that my child’s IEP will meet my child’s education needs.
A second two-way contingency table analysis was performed to evaluate whether there were significant differences in the frequency of responses by income categories of $100,000 or more and less than $100,000. Results demonstrated that there were significant differences between frequencies of responses by income category, $\chi^2 (2, N = 83) = 6.355, p = .042$. Figure 73 illustrates frequencies by income category for this item.
Two follow-up two-way contingency analysis tests were performed to confirm findings of the initial two-way contingency analysis. The first test analyzed whether the proportion of respondents who agreed/strongly agreed differed from the proportion of respondents who disagreed/strongly disagreed. The Holm’s sequential Bonferroni method was used to control for Type I error at the .05 level across comparisons. Findings revealed that the two-way contingency test was not significant, $\chi^2 (1, N = 70) = 1.415, p = .234$. The proportions of respondents who agreed/strongly agreed and the proportion of
respondents who disagreed/strongly disagreed were similar for respondents who had incomes of $100,000 or more and respondents who had incomes less than $100,000. Thus, the aforementioned income levels did not seem to impact parents’ perceptions of whether they reported teachers were knowledgeable about their child’s disability for parents who agreed/strongly agreed and parents who disagreed/strongly disagreed.

The second follow-up two-way contingency analysis test was performed to evaluate whether there was a significant difference from respondents who selected neutral and the combined categories of respondents who selected agreed/strongly agreed and disagreed/strongly disagreed. The Holm’s sequential Bonferroni method was used to control for Type I error at the .05 level across comparisons. Findings revealed that the two-way contingency analysis was significant, \( \chi^2 (1, N = 83) = 4.916, p = .027 \). Thus, the proportions of respondents who agreed/strongly agreed and disagreed/strongly disagreed were dissimilar to proportions of respondents who were neutral for respondents who had incomes of $100,000 or more and respondents who had incomes less than $100,000 (Figure 74).
A final two-way contingency analysis was performed to evaluate whether there were significant differences in the frequency of responses by number of doctors consulted in two categories: respondents who consulted with less than three doctors, and respondents who consulted three doctors or more. Results demonstrated that there were no significant differences between frequencies of responses by number of doctors consulted, $\chi^2 (2, N = 84) = 1.315, p = .518$, indicating that the number of doctors
consulted did not seem to impact parental perceptions of teacher knowledge about their child’s disability. Figure 75 illustrates frequencies by number of doctors consulted with the item: I feel teachers are knowledgeable about my child’s disability.

Figure 75. Teachers are knowledgeable about my child’s disability, by number of doctors consulted.

**School administrator knowledge.** The next two items asked parents their perceptions of school administrators. The first item asked parents about school
administrators’ knowledge of ASD, and the second item asked parents about school administrators’ knowledge of the IEP process and special education law. Results showed that a majority of parents did not feel school administrators were knowledgeable about ASD (42.5%). Of parents, 19.5% disagreed and 23% strongly disagreed. Approximately 29% of parents reported school administrators were knowledgeable about ASD, and approximately 25% were neutral. Figure 76 illustrates the 84 participant responses to this item.
Conversely, a majority of parents reported that school administrators were knowledgeable about special education law (60%). Figure 77 illustrates the 85 responses to this item. Of respondents, 21.8% of parents did not feel school administrators were knowledgeable about special education law or the IEP process.
Figure 77. Parental perceptions of school administrators’ knowledge of special education law.

Parental knowledge of special education law and the IEP process. Two final Likert-style items asked parents their perceptions regarding their knowledge of special education law and knowledge of the IEP process. The first item asked parents whether they reported they understood their rights as an IEP team member. A total of 84 parents responded to this item; of those, almost 71% agreed or strongly agreed that they
understood their rights as an IEP team member (Figure 78). Only 3% of parents disagreed or strongly disagreed with this statement, and 10% indicated they were neutral.

Figure 78. I understand my rights as an IEP team member.

The second item asked parents whether they understood the steps they would take if they disagreed with the school district. Eighty-four participants responded to this item, and a majority of these (64.4%) reported they understood the steps they would take if they disagreed with the school district (Figure 79). Approximately 16% of parents...
disagreed or strongly disagreed with this item and approximately 16% reported neutral.

All in all, respondents reported knowledgeable about their rights and the steps they would take if they disagreed with the school district.

Figure 79. I understand the steps I would take if I disagreed with the school district.
Section 4. Legal issues

The final section of the survey asked participants about their experiences with the legal system and special education law. Descriptive statistics were used to analyze item frequencies.

**Attorney or advocate attends IEP meetings.** The first item in this section asked parents whether an attorney or advocate attended IEP meetings with them. A majority of respondents, 71 (80.5%) reported they did not attend meetings with an attorney or advocate. Of respondents, 13% reported they attended meetings with an advocate, and only two (2.3%) attended IEP meetings with an attorney. Figure 80 illustrates response frequencies.
Figure 80. Frequencies of responses to the item: Does an attorney or advocate attend IEP meetings with you?

Legal action taken. The second item asked parents if they had ever filed a formal complaint against the school district, negotiated a case through mediation, litigated a case through due process, or other. A majority of participants, 63 (72.4%), were not involved in the aforementioned legal actions. However, 21 parents (24%), were involved in some sort of legal action. Eleven respondents (12.6%) filed a complaint against the school district. Two respondents negotiated a case through mediation (2.3%), and three
respondents filed a complaint against the school district and negotiated a case through mediation (3.4%). One parent indicated filing a complaint and other (1.1%). Finally, one respondent litigated a case through due process (1.1%). Four parents reported that they were involved in other legal proceedings, including inviting the special education director to attend an IEP meeting prior to filing a complaint, hiring attorneys for independent educational evaluations, and two were planning to file complaints. Figure 81 illustrates frequencies of responses.

*Figure 81. Frequencies of reported legal actions.*
**Fairness of mediation and/or due process.** The next seven questions asked participants about mediation and/or due process. The first item asked parents whether they reported the mediation process and/or due process was fair. Only 10 parents responded to this item (11.5%), and a majority did not feel the processes were fair. Of respondents, 70% disagreed or strongly disagreed, 1% was neutral, and 2% agreed or strongly agreed. Figure 82 illustrates response frequencies.

*Figure 82. I feel the mediation process/due process was fair.*
Helpfulness of mediation and/or due process. The second of these seven items asked parents whether they reported the mediation process or due process helped their child receive the services they needed. Only 10 parents responded to this item (11.5%). Of respondents, approximately 70% did not feel the outcome of mediation or due process benefited their child. Only 30% agreed or strongly agreed. Figure 83 illustrates frequency responses.

![Histogram showing frequency responses to the question: I feel the mediation process/due process helped my child receive the services they need.](image)

*Figure 83. I feel the mediation process/due process helped my child receive the services they need.*
Benefit of mediation and/or due process. Concurrently, for the third of these seven items, a majority of respondents who answered this item reported that they did not feel their child benefited from the outcome of the mediation or due process hearing (Figure 84). Only 9 parents responded (10%). Of these respondents, approximately 56% disagreed or strongly disagreed, 33% agreed or strongly agreed, and 11% were neutral.

Figure 84. I feel my child benefited from the outcome of the mediation/due process hearing.
Mediation and/or due process improved IEP team collaboration. The fourth of these seven items asked parents to rate their perceptions on whether they reported the IEP team collaboration improved after going through mediation or due process. Only 9 participants responded to this item (10%). Of respondents, a majority disagreed (55%), 10% were neutral, and 33% agreed or strongly agreed. All in all, a majority of respondents reported that the IEP team collaboration did not improve after going through mediation or due process. Figure 85 illustrates response frequencies.
Attorney/advocate facilitates IEP team collaboration. Alternatively, most respondents reported that attorneys and advocates facilitated IEP team collaboration. Twenty parents (23%) responded to this item. Of respondents, 70% agreed or strongly agreed, 10% disagreed or strongly disagreed, and 20% were neutral. Figure 86 illustrates response frequencies for this fifth of the seven items.
Attorney/advocate protects the child’s rights. The sixth of these seven items asked parents whether they reported their attorney or advocate was effective in protecting the rights of their child. A total of 22 participants responded (25%). A majority of these respondents reported their attorney or advocate effectively protected the rights of their child. Of the 22 respondents, 77% agreed or strongly agreed, 18% said they were neutral, and 4.5% disagreed or strongly disagreed. Figure 87 illustrates frequencies of responses to this item.
Attorney/advocate is expensive. Finally, the seventh item in this part asked parents whether their attorney or advocate was expensive. Eighteen parents (20.6%) responded. Approximately 56% of these respondents agreed or disagreed that their attorney or advocate was expensive. However, not all parents reported their attorney or advocate was expensive. Of respondents, 28% disagreed or strongly disagreed, and 17% were neutral (Figure 88).
Summary of legal issues. In summary, 21 of the 87 participants (24%) were involved in some form of legal action. Legal actions include filing a complaint, mediation, or due process. Only a small number of respondents actually mediated or litigated a case. Nine parents consistently responded to the items specifically related to mediation and due process. These items were: I feel the mediation process/due process was fair. I feel the mediation process/due process helped my child receive the services they need. I feel that IEP team collaboration improved after going through the mediation
process/due process hearing. I feel my child benefited from the outcome of the mediation process/due process hearing. Overall, responses to these items indicated that a majority of parents reported that the mediation process and due process was unfair. Furthermore, they reported IEP collaboration did not improve after going through mediation or due process, and their child did not benefit from the outcome of mediation or due process.

Although a majority of respondents did not feel that the outcome of mediation or due process improved IEP team collaboration nor benefited their child, a majority of parents reported that their attorney or advocate facilitated IEP team collaboration. Most reported their attorney or advocate was expensive, but almost a quarter of respondents reported their attorney or advocate was not expensive. Furthermore, most respondents believed that their attorney or advocate was effective in protecting the rights of their child.

Open-Ended Responses About the Individualized Education Program Process

The final three items were open-ended questions that asked parents about of the IEP process. The first item asked parents what they reported was effective about the IEP process, the second item asked parents what they would like to change about the IEP process, and the final item asked parents to share any IEP meeting experiences. The following paragraphs share the results.

Effective parts of the IEP process. Seventy-three participants (84%) shared their perceptions of what they reported was effective about the IEP process. Every response was coded, categorized, and analyzed into themes. Findings revealed three themes: communication and collaboration, individualization of education, and nothing.
Communication and collaboration. A majority of respondents reported that communication and collaboration were the qualities they liked most about the IEP process. One parent stated,

A good IEP process requires a collaborative open relationship with your child’s teacher. Ongoing communication is the key. I understand that the IEP process is stressful and anxiety provoking and can easily be disrupted by multiple variables. I think it is important to remind yourself that you as the parent and the school are trying to work together to meet the needs of your child.

Another parent reported that parental and school knowledge of autism, autism treatments, and the IEP process were critical in creating a collaborative team:

I feel the effectiveness of the IEP process is directly proportional to the amount of knowledge a parent has of the special education system/cycle, as well as the amount of knowledge the school staff has of a child’s strengths and not just a child’s challenges.

One other parent discussed the importance of home/school collaboration:

The IEP can be truly effective if it is a true partnership between school and home, with each supporting the other. The teachers have a load on them, so it is difficult to do if the teacher isn’t an expert in his or her field. The learning curve, along with the paperwork, makes it difficult for the teacher plan for that partnership.

Individualization of education. The second largest theme shared was individualized needs. Parents reported the IEP process allowed educators to customize education plans specifically for their child. One parent said, “It forces those involved in a
child’s education to go through a specific process and steps to plan for that child’s needs. It documents what should be done (which doesn’t mean it will always work out as written).” Parents like how “various areas of instruction seem targeted to various areas of needs.” One parent noted that the IEP process facilitated his or her child’s ability to attend regular education classrooms while still receiving special education. However, several parents noted difficulties with general education teachers and reported the IEP process was an opportunity to educate general education teachers about the needs of their child and autism. Some parents reported frustrated by the lack of communication with general education teachers regarding their child’s IEP and disability. One parent said, “IEPs are not discussed with General Ed teachers, procedures are not implemented in General Ed classrooms unless the parent takes it upon himself/herself to fight it out.”

**Nothing beneficial about the IEP process.** Frustration was apparent in several responses from parents who stated that there was nothing beneficial about the IEP process. One parent said, “It is just a document that drives the special needs teachers to provide special attention.” Another stated, “It’s a painful, annual battle where we often spend hours and hours go over things to have it ignored during implementation.” Some parents expressed frustration over the length of time the IEP takes to implement. A parent said, “it’s a waste of time, the teachers administrators and the school districts take so long to get an IEP going that the child is going a whole school year without services. “

**NVivo 10 (QSR International, 2012) was used to analyze concept frequencies and validate themes. Figure 89 is a word cloud with these concept frequencies regarding parent perceptions about what is effective about the IEP process. Participants’ most**
frequently used responses are larger in font. NVivo 10 (QSR International, 2012) processes words similar to actual words, and these words are illustrated in the word cloud as well. The top words used were: IEP (3.61%), organizing (3.06%), person (2.79%), events (2.13%), and issues (1.88%). NVivo 10 (QSR International, 2012) processed similar words within frequency counts. For example, NVivo 10 counted therapist, partnership, and volunteer as words similar to organizing.
Figure 89. Parental perceptions of what they reported was effective about the IEP process word cloud.
**What to change about the IEP process.** Sixty-two participants (71%) shared their perceptions of what they reported would like to change about the IEP process. Every response was coded, categorized, and analyzed into themes. Findings revealed six themes: systemic changes, less contentious, collaboration and communication before meetings, time, IEP issues, and teacher issues.

**Systemic changes.** Fourteen respondents reported that the IEP process needed systemic change which involved laws and legal issues that impact collaboration necessary to develop an IEP. One parent said,

Systemic change needs to occur for the IEP process to do what it is supposed to do. Currently, the school system administrators use the IEP process to segregate children—if parents disagree, they are forced to go to due process and there are not even any legitimate low-cost legal services listed (as there should be) on the parent rights booklet.

Several parents reported that they needed advocates to facilitate the process. Advocates included persons attending meetings as well as nonprofit groups that protected their legal rights. One parent said,

I would like to change the IEP process where every parent/guardian is appointed a qualified, vetted advocate (non-attorney) for FREE to assist with the first three IEP sessions, and then available to the parent on a sliding scale for any further IEP meetings. Also, I would expand that to be that the advocate is available two IEP meetings during the transitional times of an IEP (preschool to kindergarten [sic], elementary to middle school, middle school to high school, and high school
to post-secondary life). By the time a parent starts to learn the meanings of the acronyms, and the power of knowing something as simple as “prior written notice,” the student may have been serviced by an ineffective IEP for three, five or seven years. The other change I would like to make about the IEP process is to find a way/make a way to REALLY have it child-focused.

Similarly, a parent reported a nonprofit agency was needed to help advocate for their child’s rights. The person said,

I believe schools should be held accountable for being in non-compliance. My son’s LEA [Legal Education Agency] was found to be in non-compliance of FAPE. They were issued a corrective action plan (CAP) by ODRAS [Office of Dispute Resolution and Administrative Services] of the ------ [State Department of Education]. The LEA refused to follow the CAP—as weak as it was. They argued that ODRAS does not have the authority to regulate LEAs and that ODRAS has no constitutional authority to enforce compliance. The LEA is correct. Legally, ODRAS cannot force an LEA to comply with their directives, even if they are found in non-compliance. The best VDOE can do is make an appeal to Virginia Board of Ed and request that some funding be withheld. When the composite index of an LEA is so great, they don’t get as much State funding as other LEAs...therefore, they take the gamble. In our case, we could file a Due Process, but what’s the point. Our family income can’t support the level of services that my son needs, much less pay for an attorney. Even if we did win a due process, we’re looking at $10k in fees to get compensatory services for FAPE
that would be poorly delivered. We need more agencies like VOPA. We need more agencies to assist families in making LEAs do their jobs and follow the law.

One parent expressed frustration with interstate variability in special education laws and services. The parent said, “Eliminate the individual State ‘interpretation’ of IDEA. The IEP process is so inconsistent from state to state.” Several respondents noted inconsistencies between and within states, including county school systems. Parents said that all states and counties do not provide the same services. Thus, one county may provide a service, and another county may not. Therefore, these parents said they needed to advocate exceptionally hard-to-get the services their child would receive in another county.

Finally, many parents reported the system needed to change in order to meet their child’s unique exceptional learning and behavior needs. A parent stated,

I feel like am lucky since I have friends with similar experiences who have been able to help me. I also had the time and money to seek out many doctors (over 15) to help me arrive at diagnosis and spend time to get him the services he needs. I worry about single mothers (or fathers) who don’t have the time, money or education to educate themselves on the process. I don’t know how to fix it, but know it must be hard for so many parents.

Less contentiousness. The second theme was less contentious IEP meetings. Eight parents wanted less contentious IEP meetings that focused on the needs of their child. When asked what they would like to change about the IEP process, a parent said, “I
would like to see it be less contentious in general.” Another parent noted the aggressive tone of meetings and computer systems used by their school district:

I don’t like the computer programs with written accommodations. I would also change the intimidation factor. I don’t like that it feels like the parents vs [sic] the school. You walk into a room with the school team on one side of a table or around a conference table and you at the other end or across the table from them. [It] feels very aggressive.

Some parents reported that limited resources and school budgets were factors that made IEP meetings more contentious. Several reported school administrators were gatekeepers to funding services. Consequently, parents reported effective advocacy facilitated opening gates toward funding services for their child. A parent said,

Another thing I would change is the Educators and the family being on the same side and working towards the goal of addressing the child’s unique needs. It seems that they hold back services as much as they can and they hold back accommodations as much as they can. Too much work for them.

Another parent said,

Parents should have [a] greater role. [They] should know more about what is possible at school. [I] Always feel [the] school intentionally leaves us in the dark because they do not have enough resources for all the children. If you ask, you may get. But if you don’t ask, you definitely do not get it even if your child needs it.

The contentious feel was echoed by many. Another parent said,
I wish that it didn’t come across as such an “us against them” process. It seems that there are so many stories about the nightmare that it becomes. I’ve been to a couple of parents meetings—many years ago. And I totally get advocating for your child. Resources are scarce for this huge population, & [sic] everyone is just doing what’s best for their child. But I feel like things can get blown out of proportion, team members on both sides can stop listening, and then the whole thing can devolve & [sic] no one is happy. Negative energy, everyone looking for problems. It is a scary thing, but maybe the teachers/administration need to be flexible. Show the parents that it isn’t always black/white, & [sic] that they are able to work together for the best of the child.

One parent summed up opinions:

I feel that the school system is always watching what they say and they don’t offer services to your child. On the contrary, you have to PUSH as a parent to get any related services. Also, they lie and tell you there is a max [maximum] number of hours of related services. When pushed on this number, they balk, but it takes a persistent and well-informed parent to get through the clutter. I have compared IEP stories with other parents and all administrators tell you what they think they can get away with. Clearly I am not a huge fan, even though the majority of my IEP meetings have been incident-free.

Collaboration and communication before meetings. A third theme noted by 11 parents was the need for collaboration and communication with teachers prior to IEP meetings. The communication included more frequent informal discussions regarding
progress toward meeting IEP goals, as well as parental input into IEP goals prior to IEP meetings. A parent said, “It should be more collaborative before the actual meeting. If we went back and forth discussing goals and present level then the actual meeting would not take so long.” Another parent said,

Parents and professionals should meet BEFORE an IEP is written. Schools should offer parents a chance to learn about how the IEP process works so they are not in the dark about what is going on. Professionals should realize that they don’t own the child, and that the parents are just as important to the learning and development of the child as the school. Respect, information, and cooperation are essential if the child is to get what s/he needs and achieves at the highest level possible given their challenges. Too many times, it felt like we were enemies meeting on a battlefield, and not adults trying to help a child with special needs.

Another parent stated, “I’d like the actual goals to be agreed upon BEFORE the meeting with parent and school input. It has been difficult to have my suggestions put anywhere other than the PLOP [Present Level of Performance] page.”

The need for updates on progress toward meeting IEP goals was echoed by several parents. These parents reported that informal meetings on progress toward meeting IEP goals would provide critical information necessary to create IEP goals. One parent said, “More frequent communication about his performance/status at school would be helpful.” Another parent said,

[We] would like short quarterly meetings to be the norm to review progress as a team. (I understand I can request a meeting at any time). There is so much
“legalize” [legalese], percentages of time spent where, etc. which can be distracting and confusing. I hate the pre-IEP meeting that sometimes leads to a wait in the school office. It is very uncomfortable to know that there is a discussion happening about your child behind closed doors.

**Time.** Time was a fourth theme mentioned by nine parents who reported that teachers did not have enough time to attend meetings and manage classes. Teacher balance between instructing classes and managing IEPs was reported by several, who reported that this lack of time affected IEP team collaboration and goal development. One parent said,

I also don’t like how much time it takes the classroom teacher out of the classroom. On average, IEPs take two hours per student. Multiply that by the number of students in the self-contained classroom and that’s a huge amount of time away from teaching. If draft IEP can be emailed back and forth, then it would save a lot of time and perhaps angst in the school conference room.

Another parent said, “It seems like the teachers don’t have enough time to talk about my child. I don’t feel they collaborate.” A final parent said, “[Make] time for meetings. Meetings are often rushed and everything is written and decided prior to the meeting.”

All in all, parents reported the lack of time impacted the IEP process. A parent said,

It is too rushed, it would be helpful if parents could share effective goals with each other in a more systematic way that would still ensure privacy, you may write the greatest IEP, but if it’s not implemented well, it doesn’t matter, there...
should be more or as much focus on the PLOPs and accommodations, each IEP meeting should be broken into two parts so that you can write it, take a break, and return to review it, alter it, and sign it.

**IEP issues.** The sixth theme was IEP issues. Parents reported that IEP goals should focus more on student strengths as well as transition issues. One parent said, “It might be helpful to have more discussion about possible future goals so everyone is on the same page and, hopefully, will have the same goal in mind when making recommendations.” The individualized need of goals that would enhance outcomes was mentioned by some. Another parent said, “More emphasis on skills necessary for success in life and not just a state[-]mandated test.” Several parents expressed concern that IEP goals were never implemented. One parent said,

> It should be student[-]centered and oriented in reality. Most of the services that are actually required for the student are never provided. Always accommodations are made to see how one teacher/therapist can handle the workload of three teacher/therapists. The quality of therapy provided as a result of this is significantly deteriorated.

**Teacher issues.** The final theme was teacher issues. A few parents mentioned that teacher education and understanding of autism was critical to having an effective IEP process. One parent said, “Speed up the time, train teachers admins etc. on ASD children. Make it a mandatory training.” Another parent reported that schools needed to facilitate school year transitions for children with autism by developing a program that acquisitions them to school prior to the start of school. One parent said, “There needs to be greater
collaboration and thought into things that set off my child’s behaviors before school starts. There is not enough true understanding of autism and expectations among teachers is often unclear.” Teacher education and systemic reform to facilitate school year transitions for children with autism was also mentioned by parents.

NVivo 10 (QSR International, 2012) was used to analyze concept frequencies and validate themes. Figure 90 is a word cloud with these concept frequencies of parental perceptions of what they reported was effective about the IEP process. Participants’ most frequently used words are larger in font. NVivo 10 (QSR International, 2012) processes words similar to actual words, and these words are illustrated in the word cloud as well. The top words used were: IEP (2.64%), parent (2.31%), change (2.15%), individual (1.86%), and period (1.72%). NVivo 10 (QSR International, 2012) processed similar words within frequency counts. For example, NVivo 10 counted day, quarterly, and review as words similar to the word *period*. 
Share your experiences of the IEP process. For the final open-ended item, parents were asked to share experiences. Fifty-four participants (62%) had responses diverse and unique—concordant with their unique experiences throughout the IEP process. Every response was coded, categorized, and analyzed into themes. Findings revealed four themes: equal partner and respect, the IEP (which included evidence-based practices and progress/data), continuum of services, and teachers.
**Equal partnership and respect.** The first theme was equal partner and respect.

Many of these parents reported they felt the IEP process was adversarial. They reported they believed the school did not share information about services provided. Some reported the only way their child could get services was for the parents to ask for them. Consequently, these parents lack of trust inhibited true partnership. One parent wrote, “They like to say no a lot and want parents to fight for their kids. The schools don’t tell you everything and make it hard on parents.” Another parent wrote,

I had a principle lie to me throughout an IEP meeting. How can I prove such an allegation? I can. The tape recordings (both mine and [the school’s] machine) were left running on when the family left the room for a side bar. During that time, the school officials talked about how they were hood winking [sic] us with their predetermined plans, and then, when [the school] discovered (to their horror) that the recorders were still running, they turned off the family’s recorder without telling us. As a consequence, I missed recording the rest of the IEP meeting. True story. At another school, I had to wait in the front office while the principal went into the conference room and closed the door so that [the school] could get its “predetermination” story straight with all their team members before they would let the family into the meeting. This was their regular M.O. So much for the family being an equal partner in the process. When I hear about families in southern [state name] speak about how lucky we are to live in County, I can’t help but LOL. If you [researcher] want to do something to really help our families. Take a copy of your Doctoral Dissertation
to Congressman ------ and ask him about introducing legislation for Federal regulatory enforcement of their own special education laws.

Some parents reported the school did not respect their perspective. Parents reported that teachers and administrators did not think they were knowledgeable about their child’s disability or needs. One parent wrote, “Many times the schools do not see the parents as a knowledgeable team member and often make the parent feel unsecured [insecure] to intimidate them to agree to terms that don’t always meet the needs of the child.” Another parent discussed the condescending tone:

I just got done with my son’s IEP (he’s going to be 4 and is high functioning autistic), and I was made to feel stupid and like I had no valid input about my son. Overall it went well, but I reported like they were talking AT me until I said I had a degree and went to college also. Then it changed, and they spoke to me in “adult language” instead of treating me like I was stupid. I got what I wanted for my son, but it could’ve gone better.

Several parents mentioned the IEP process when their child first entered special education and steps they took to feel empowered. One parent wrote,

Early years were awful, with condescending professionals and some loud fights. I even took my mother, a professional social worker specializing in child protection services, to a meeting with us, and she left disgusted at the attitudes displayed toward my husband and me by the staff. After Wright’s Law [sic] training, and with a change to a special education school, things became less contentious as I learned ways to work more smoothly with the staff, and they were more
knowledgeable and willing to talk things over with us and incorporate our concerns in the IEP. Having a school where every child had an IEP or 504 plan really made a difference. But in most general education schools, the special education students were regarded as a nuisance and a drag on the “regular” kids, and many school administrators seem to resent any time or money spent on our children. This is not just my experience with my child, but also what I found when visiting schools as a member of the Special Education Advisory Committee, very sad to find this attitude in so many schools. That made it very exciting when we found an engaged principal who wanted ALL the students to get what they needed, including special needs classes.

Learning about legal rights and attending classes helped parents feel more empowered, enabling them to be equal partners in the IEP process. Another parent shared what the enhanced their ability to participate in IEP meetings:

Too many frustrations to count! Snotty, condescending special ed administrators, not enough time to talk about issues, lack of information about options, paperwork being rushed to meet a deadline, services promised but not delivered, battles to get summer services included, lack of coordination among various education providers, failure of outside agencies to follow up with the school, etc. After attending a Wrightslaw boot camp, I was able to manage things better, and reported stronger about confronting administrators in a polite but forceful way to get my views about my son’s needs incorporated into his education. Attending Partners in Policymaking truly made a difference, too. I discovered many people
in our community have similar issues with schools and the mysterious IEP process and was able to assist them as I wish someone had done with me when we started out. Parents feel they are on their own when it comes to understanding their rights and responsibilities, and the schools for the most part keep quiet because it is easier to deal with ignorant rather than informed parents.

**The IEP.** The second theme incorporated components of the IEP such as IEP goals and progress monitoring. Thus, this theme encompassed and included data necessary to create IEP goals and track progress toward meeting these goals, as well as evidence-based practices.

Some parents reported that the focus of IEP goals was predetermined, and too academic. A few parents mentioned they reported that passing state-mandated assessments were more important than functional life and social skills. Sometimes, parents reported the IEP goals did not match their children’s needs. A parent said,

> We routinely share goals we would like to see in the IEP prior to the meeting. Almost universally, we are told our goals are not appropriate, even when they were recommended by other special education teachers—for example, we thought toilet training/ability to use school restroom was a worthwhile goal and were told it could not be a goal. Safety considerations are easily ignored—we requested, for instance, that they help us keep him from breaking any more teeth at school. At home, I watch him to keep him from chewing inappropriate objects. At school, he eats rocks and breaks his teeth. But this cannot be a goal. When our goals are agreed to, they disappear from the final document. By the end, if our child can
touch his nose on command and not act out more than occasionally, he has miraculously achieved all of his goals.

Several parents wrote about difficulties with collection of the data which is used to create IEP goals and track progress toward meeting goals. One parent wrote,

Hate the process of IEP data collection, too random, too subjective. Cannot really analyze the data to find trends and change interventions in a timely manner. Never yet seen any data analysis conducted by the teachers. They are really putting out fires, reactionary. Don’t think they really plan for continued improvement in any strategic manner. Just following the typical academic curricula for no interventions to help my son with focus, attention, executive functioning challenges, etc. We supplement the school with private therapists providing speech and social skills three times a week. We support intensively at home with skills learned through conferences and self-study. School feels satisfied with my son’s progress, but they are not responsible for a significant amount of it.

Another parent was frustrated that the school would not accept evaluations and reviews by private experts. The parent wrote,

My son’s LEA [Local Education Agency] is apathetic. We have brought and pulled reports from highly regarded experts—Dr. ----- with ----- [name of university], Dr. ----- of [name of another university], Dr. -----, Faison [The Faison School of Autism], the Region 1 Autism Consortium, T/TAC [a university training and assistance center], and ----- [a well-known occupational therapist].
The LEA dismissed me each report/evaluation and refused to follow any recommendations.

Some parents were knowledgeable about evidence-based practices, and reported frustrated when schools did not implement them. A parent wrote,

I have always pushed for measurable goals and ABA techniques in IEP meetings. Early on, our school system, ------, was anti-ABA so the meetings were contentious. Later, due to parent pressure, ------ adopted ABA and the meetings became easy. They still always have a great shortfall of properly trained staff so IEPs are rarely implemented well, but that is another issue.

Several parents reported that teachers were inadequately trained in creating measurable IEP goals. A parent shared,

After Partners [Partners in Policymaking Program], I became very active in advocacy work, and served as a child advocate for many years. It was appalling to see the IEPs written by our public school system staff. Teachers certainly need more training, as goals are not written in measurable terms, they are too generic...in general, IEPs are just written poorly. I have also had several instances where the LEA [Local Education Agency] reps do not know the law concerning particular points. I once had the head of Special Ed. tell me in a meeting that they couldn’t afford ESY [Extended School Year] services for my son, and when I insisted they must legally provide them since the IEP team found it necessary, was told, “You can’t get blood from a turnip.’ !!!!!!! Thanks to learning the state regulations, we did indeed get blood from a turnip! I have met so many parents
who don’t know their children’s’ [sic] rights, and simply accept what the IEP team tells them. Unfortunately, many special ed. teachers just aren’t trained in properly writing IEPs. Even more frustrating is that it takes an advocate to point out the problems, instead of the LEA.

To effectively develop IEP goals and education plans, some parents hired advocates and consulted with disability specialists. One parent said, “Although my advocate has not attended meetings with me, she has been an invaluable resource with helping me learn the law, composing correspondence, suggesting evaluations and goals, etc.” Other parents reported they were successful through independent study where they enrolled in classes, read books, or spoke with experts in autism. A parent wrote,

Over the years we’ve had to argue for what should have been routine assessments for our child. And after having our own assessments completed, arguments with educators over recommendations made by top[-]level autism specialists. It was a back[-]and[-]forth negotiation and in the end a compromise reached but reported that the school was more worried about the school budget/time constraints than getting my child what was in her best interest.

Once the IEP was created, some parents reported the IEP was never implemented and IEP goals were ignored. One parent wrote,

In our school system, it’s NOT a team, no matter how many times they call it an “IEP Team.” It’s parents against school staff. I’ve never had this problem in years of attending IEP meetings until this particular school. Most of the IEP “team” will listen and we do work well together even with the “us vs [sic] them” mentality but
it’s at the teacher level that is the problem in our school. The only successful year my son has had (2\textsuperscript{nd}-4\textsuperscript{th} grade) was the 3\textsuperscript{rd} grade. The 2\textsuperscript{nd} grade teacher and the 4\textsuperscript{th} grade teacher don’t even KNOW what his IEP says most of the time, when I asked them. They don’t follow protocol and they don’t apply the IEP in the classroom unless someone (my son’s case manager) is in the room. My son’s case manager is PHENOMENAL but her hands are tied because administration won’t entertain the idea that teachers are dismissing the IEP, even though my son’s lack of progress (both anecdotal and from data) is apparent. We’ve rewritten the IEP goals at least 4 or 5 times this year but it’s NOT the goals that are the problem. The goals only work if they are actually WORKED on.

Another parent wrote, “This year the school did not follow the IEP and did their own thing. It had to do with testing accommodations. Our son is in team taught and one self-contained.”

*Continuum of services.* A third theme was continuum of services. Several parents mentioned that self-contained classes and schools enhanced their child’s education performance. One parent wrote,

My son’s base school did all they could to help him succeed, but they did not have the supports to help him with his emotional liability in the general ed classroom. He transferred to a CEDS [Center for Excellence in Disabilities] program within County that has a support room, weekly psychologist appointments, social worker if needed, art therapy and music therapy. He currently is in a contained class of 9 and can have the opportunity to be taught in the general education class
with support of an IA [instructional assistant] for some or all of his subjects. Although he isn’t at this level yet, I believe he will be able to handle a gen ed classroom setting for science and social studies next year. He needs a lot of support for writing and reading. I have heard horrible stories about IEPs, so I feel lucky that we have had two great schools for my son that truly want him to succeed and do well in school and in life.

Other parents noted difficulties during the transition years, which include transitioning from kindergarten to elementary school, elementary to middle school, middle to high school, and high school to post school. Sometimes services provided in self-contained settings are not available in other settings. One parent remarked,

Overall, my IEP experiences thus far have been very positive. My son’s PAC [Preschool Autism Class] teacher is an amazing teacher and is just as willing to fight for him as I am. We have just held his transitional IEP for Kindergarten and the IEP meeting was a bit more of a challenge. There has been more push back on requesting evaluations for services than there was in the preschool setting.

**Teachers.** The fourth theme was teachers, who were noted as critical players in developing appropriate IEP goals and implementation of IEPs. One parent wrote, “Both of my IEP experiences were productive and useful. I know that this is not often the case. I think a strong relationship with the teacher helps a lot.” Another parent summed up comments, writing,

I remember a few times being overwhelmed and reported it was hard since everyone else in the room had their master’s degrees with special ed or education
(principal and therapists) and I didn’t understand all the terminology being used. A few times I brought my behavior therapist with me (who I paid $100 an hour) to attend with me to be my advocate. Overall, the teachers and specialists who I have worked with for the last 9 years have been very good and there was always at least one person who really seemed to care about my son on a personal level. I think the special ed teachers seem to be the key in the process.

Many parents reported they wanted teachers to truly care for their child.

One parent shared how he or she effectively collaborated and communicated with teachers to develop IEP goals:

Once I learned what comprises a “good” IEP, I make sure to write the goals myself and give them to the teacher to add to. I insist that I am part of the process in this way and I have gotten the goals I want/need and the amount of reporting back to me about progress. I have learned how to write IEP goals to get what I think my child needs, but what about parents who can’t put this effort into it?

It was clear that collaboration required time and effort on behalf of parents.

Effective parent/teacher communication was noted as important to developing IEP goals. However, children do not have teachers for multiple years, and the transition of teachers was noted by one parent as being an issue:

The teacher administering the IEP meeting isn’t necessarily the teacher your child will have that next year. So he/she will say “I’ll do this or that,” then you don’t have that teacher so it doesn’t always get followed through. I also feel they try and speed through time and get it down and don’t like to discuss it. Maybe they
[IEP meetings] should be held on teacher work days so they don’t worry about subs and getting back to their classroom.

Teacher knowledge and school acceptance of diversity and disability were noted as important. One parent shared,

Our daughter has been ridiculed by both teachers and students. She has been excluded from many classroom activities and celebrations when she has not been able to finish homework. She has been called stupid and a faker by teachers. There really isn’t any reason to bore you any longer—it was/is hell. She deserved and deserves to be treated better and deserved a FAPE :( - Our school district is small and a lot of wealthy people live out here and most of the kids with disabilities leave the district for another school or just drop out.

NVivo 10 (QSR International, 2012) was used to analyze concept frequencies and validate themes. Figure 91 is a word cloud with these concept frequencies representing IEP experiences. Participants’ most frequently used words are larger in font. NVivo 10 (QSR International, 2012) processes words similar to actual words, and these words are illustrated in the word cloud as well. The top words used were: IEP (3.15%), act (1.72%), issues (1.58%), communication (1.46%), and change (1.35%). NVivo 10 (QSR International, 2012) processed similar words within frequency counts. For example, NVivo 10 counted accommodation, complaint, evaluation, liaison, and collaboration as words similar to the word act.
Figure 91. Parents' shared IEP experiences word cloud.
V. CONCLUSIONS

This study’s purpose was to better understand the perceptions of parents who have children with ASD regarding the IEP process. The study used a web-based mixed methods survey with quantitative and qualitative items that gathered data from participants to answer research questions. The survey included items that asked participants about the IEP process as well as their perceptions of evidence-based practices for children with autistic spectrum disorders. Several parent groups and associations, POAC, SPAN, VA-PIP, ASA-NV, and FAAPE, participated in the study. The final sample included 87 parents who parented children of multiple ages with autism spectrum disorders. Participants’ children’s ages ranged from 3 to 26, with a mean age of 11 ($SD = 5$). The sample’s children were low and high functioning on the autism spectrum. Of participants, 37.9% indicated their child had Autistic Disorder, 36.8% indicated their child had PDD-NOS, and 19.5% stated their child had Asperger’s Syndrome. Only one parent said his or her child was diagnosed with Rett Syndrome, and one had Childhood Disintegrative Disorder. Approximately 3.4% of parents were unsure of their child’s diagnosis.

The small number of respondents prohibited analysis of items by several demographic characteristics. For example, the small number of culturally diverse parent respondents (two African American/Black, one American Indian or Native American,
five Asian or Asian American, and one Hispanic or Latino parents), the small number of rural respondents \((n = 6)\), and the a small number of respondents who indicated they were not married \((n = 1\) single, and \(n = 5\) divorced) prohibited the use of these demographic characteristics in meaningful analyses. All in all, the small number of participants limited analysis.

Findings were reported by research questions and corresponding survey subscales. The research questions were:

- What are the perceptions of parents who have children with ASD regarding the IEP process?
- Are there relationships between demographic variables and overall parental perceptions of the IEP process?
- Is there a relationship between the length of time to medically diagnose autism and participants’ overall perceptions of the IEP process?
- What are the perceptions of parents who have children with ASD regarding evidence-based practices?
- Where did parents learn about autism, autism treatments, and interventions, and their legal rights?

This chapter discusses the study’s major findings, educational implications, limitations of the research, and recommendations for future research.

**Major Findings**

The study’s major findings demonstrated that: (a) a majority of parents reported overall negative perceptions of the IEP process on a single item, but conversely reported
they felt respected and treated as equal members of the IEP team; (b) most parents reported they understood their legal rights; (c) a majority of parents indicated their child’s IEP would meet their child’s needs; (d) significant differences existed regarding parents’ perspectives of teachers’ knowledge of ASD; (e) most parents had never used evidence-based practices (EPBs) for children with ASD, but parents who implemented EPBs reported the interventions were effective; and (f) parents consulted a multitude of sources to learn about autism spectrum disorders, treatments, and interventions; the most credible source, as deemed by these parents, was other parents. A discussion each of these major findings follows.

**Overall Perceptions of the Individualized Education Program Process**

Findings from this study indicated that 50% of parents reported overall negative perceptions of the IEP process on a single item, but conversely reported positive perceptions regarding their participation in the IEP process on five related items and offered many suggestions for improving the process. A majority of parents reported they felt they were equal members of the IEP team (49.4%) whose suggestions and opinions were integrated into their child’s IEP (64.4%). Accordingly, most parents reported they felt they were respected members of the IEP team (59.8%). A majority of parents indicated their child’s IEP would meet their child’s learning needs (50%), and a small majority (37.9%) reported they received adequate feedback regarding their child’s progress toward meeting IEP goals.

Overall perceptions of the IEP process were garnered from one Likert scale item that asked parents their overall perceptions of the IEP process. For this item, 86 parents
responded (99%). Approximately 50% of these parents reported they did not have positive overall perceptions of the IEP process. Of parents responding to the item, “Overall I have positive perceptions of the IEP process,” approximately 20% strongly disagreed, 30% disagreed, 15% were neutral, 29% agreed, and 6% strongly agreed.

Among all items that asked parents their perceptions of the IEP process, the lowest mean score reported was for the item, “Overall I have positive perceptions of the IEP process” \((M = 2.7, SD = 1.2)\). Since parents reported positive perceptions among five related items, factors other than these five related items must have influenced a majority of respondents’ negative overall perceptions of the IEP process. Parents’ desires to have the best possible educational plan for their children, coupled with their fears that this may not be realized, may have impacted the overall negative response.

Additional information about parents’ overall perceptions of the IEP process was garnered from information parents wrote in responses to five open-ended items that asked parents about related services and the IEP process. The first open-ended item asked parents how satisfied they were with related services, and 76 participants (87%) responded to this item. Many of these respondents indicated they were satisfied with related services, but felt related services occurred too infrequently. The second open-ended item asked parents about their experiences with related services changing over time, and 64 participants (74%) responded to this item. Most of these respondents indicated that related services changed as their child’s needs changed, and communication with therapists decreased as their child matured. The third open-ended item asked parents what they felt was effective about the IEP process, and 73 parents
(84%) responded to this item. Most of these respondents reported that they felt communication and collaboration during IEP meetings was effective. Some parents indicated that they believed that their contributions and suggestions, which were integrated into their child’s IEP, individualized the IEP for their child. The fourth open-ended item asked parents what they would like to change about the IEP process, and 62 parents (71%) responded to this item. A majority of these respondents indicated that the IEP process was contentious, and needed systemic changes in order to become collaborative. Finally, the fifth open-ended item asked parents to share any experiences during the IEP process, and 54 parents (64%) responded to this item. Many respondents wrote that they felt school budgets affected services available to their child, and parental advocacy was necessary to secure services they felt their child needed.

Responses to these five open-ended items revealed that most parents felt positive overall about their participation in IEP meetings. They reported that the IEP process helped individualize their child’s education, and communication within meetings was collaborative and effective. However, some respondents also reported that they felt meetings had a contentious tone, and schools were not always forthright regarding services available for their child. This lack of transparency created a sense of doubt and mistrust. While parents reported they felt positively about many aspects of the IEP process, perhaps the contentious tone and perception regarding transparency of services affected their overall perceptions of the IEP process. The following paragraphs discuss these parents’ responses in relation to overall perceptions of the IEP process. Systemic changes and related services are discussed.
**Systemic changes.** Many parents reported the IEP process needed legal overhaul and systemic changes in order to become a collaborative process that focused on their child’s needs instead of legal mandates. The contentious tone in meetings was “stressful and anxiety provoking,” a tone that could “easily be disrupted by multiple variables.” A parent wrote, “Parents feel they are on their own when it comes to understanding their rights and responsibilities, and the schools for the most part keep quiet because it is easier to deal with ignorant rather than informed parents.”

Parents reported they believed a limited amount of school resources and budgets pressured school personal to offer the least amount of services possible. Consequently, they reported schools may not provide services for their child, even if their child needed them. One parent wrote that she “would like educators to be more open with available options.” Parents indicated that limited budgets and reduced services made them insecure regarding services their child needed were not provided or recommended. A parent said, Parents should have [a] greater role. [They] should know more about what is possible at school. [I] always feel [the] school intentionally leaves us in the dark because they do not have enough resources for all the children. If you ask, you may get. But if you don’t ask, you definitely do not get it even if your child needs it.

Parents reported fear regarding losing services for their children. For example, some indicated that limited budgets and resources fueled insecurities among those who wrote that their child would not receive services, and parental fears that the squeaky wheel gets the grease. A parent summed it up, saying, “Resources are scarce for this huge
population and everyone is just doing what’s best for their child.” Parents reported they believed that limited school resources pressured schools to provide the least amount of services, rather than the greatest amount possible. This perception appeared to create distrust among parents that their child may not receive needed services.

This is not the first time parents have differed from schools on what is considered Free and Appropriate Public Education (Hendrick Hudson District Board of Education, 1982). The need for systemic change and an updated definition of FAPE are mentioned in the literature (Zirkel, 2013). IDEA (2004) provides students with disabilities a right to a free and appropriate public education (FAPE), such that students with disabilities derive meaningful educational benefit. Appropriate is a gray term inherent in the law and not clearly defined by the law (Etschiedt, 2003; Zirkel, 2011, 2013). Parents want the best services for their child (Fish, 2006), and school districts are legally responsible to provide appropriate services for students with disabilities (Etschiedt, 2003; Zirkel, 2011, 2013). Disagreements occur when parents and school districts do not agree regarding services that are appropriate (Etschiedt, 2003; Zirkel, 2011). Zirkel (2013) argues that Congress needs to develop an updated definition of FAPE to clarify rights afforded to a child with a disability, and school district obligations. The new definition of FAPE should account for evidence-based practices, the high costs of special education, limited fiscal congressional budgets, and unfunded special education mandates (Zirkel, 2013).

Special education is expensive, and autism is one of the most costly disabilities for school districts (Chasson et al., 2007; International Center for Autism Research and Education, 2012; Yell, 2006) and families (Mackintosh et al., 2012; Parish et al., 2012;
Wang & Leslie, 2010). Yet the federal government continues to fund only 15% of the cost of special education—despite promises to fund 40% of the cost (Sherman, 2013). Federal funding mandates then become the responsibilities of state and local school districts, which struggle to provide services for children with disabilities while meeting the learning needs of all students in the school district (Kusler, 2003).

In this study, parents reported they believed the school would not provide an appropriate level of services for their child without parental advocacy. Findings from this study are consistent with findings from other studies (Brandt, 2011; Fish, 2006; Lovelin, 2012; Stoner & Angell, 2006; Stoner et al., 2005). Fish (2006) interviewed eight parents regarding their perceptions of the IEP process. Findings revealed that parents felt the school district was not open regarding services available for their child. Fathers reported they believed that school administrators did not want to commit financial resources for recommended therapies unless parents advocated for these therapies. Furthermore, fathers reported they felt limited school budgets impacted services for their child.

Distrust regarding services was a theme echoed by parents in another study. Lovelin (2012) interviewed 22 parents who participated in the SUCCESS program, a program for children with ASD in Oregon, regarding parents’ experiences during the IEP process. Parents reported they believed the school district withheld information about services available for their child, unless parents requested these services. Parents reported they believed their child would not receive services unless they had knowledge of the services and the communication skills to request them. All in all, parents reported they
felt services were not always visible, and the invisibility of services created distrust in the system (Lovelin, 2012).

Although some studies suggest parents distrust school districts regarding the visibility of services, research is unclear regarding the perceptions of all parents who have children with ASD. Findings from this study are inconsistent with some other studies’ findings which indicated parents believed services were provided if their child needed them (Bitterman et al., 2008; Fish, 2008; Hume et al., 2005; Spann et al., 2003). It is noteworthy that a majority of these studies examined the perceptions of parents who had children younger than age nine (Bitterman et al., 2008; Hume et al., 2005; Spann et al., 2003), and the perceptions of parents who had children in preschool programs (Bitterman et al., 2008; Hume et al., 2005). Thus, this study’s sample, which included parents who had children with multiple ages and the mean age was 11 ($SD = 5$), is not similar to the sample of parents investigated in these previous studies.

**Duration and frequency of related services.** In this study, many parents indicated the duration and frequency of related therapies provided was inadequate. One parent wrote, “I feel that the school system is always watching what they say and they don’t offer services to your child. On the contrary, you have to PUSH as a parent to get any related services.” Parents also reported they believed their child needed more frequent therapies than provided by the school. A parent wrote, “Speech [therapy] is helpful, but does not happen often enough to make a full impact.” Another parent wrote, “The occupational therapist works wonders but sees [my child] for only a couple hours a
“Consequently, many parents supplemented school therapies with private related therapies to increase the frequency of intervention they reported met their child’s needs.

Findings from this study are consistent with findings from other studies where parents reported they felt related therapies occurred too infrequently (Bitterman et al., 2008; Nickels, 2010). Participants in both earlier studies indicated that their child needed more frequent and intense related therapies than recommended by the school. Consequently, parents supplemented school therapies with private therapies.

**Respected and Equal Individualized Education Program Team Members**

A majority of parents (59.8%) in this study perceived themselves as respected IEP team members, who participated equally in team meetings with educators. Parents reported they understood their child’s needs and interventions that develop skills to remediate weaknesses. Accordingly, most parents (64.4%) reported their suggestions were valuable and integrated into the IEP, and their child’s IEP would meet their child’s needs.

Findings from this study conflict with findings from other studies (Fish, 2006; Jensen-McNiff, 2012). Fish (2006) interviewed eight parents who had children with ASD regarding their experiences during IEP meetings. Findings revealed that parents did not feel like equal participants during the IEP process. Furthermore, they reported their suggestions were not integrated into the IEP. Subsequently, parents hired advocates to help them collaborate more effectively with educators (Fish, 2006). In another study, Jensen-McNiff (2012) interviewed 15 rural Nebraskan parents who had children diagnosed with autistic spectrum disorders, emotional disabilities, and other health
impairments to gain an understanding of their experiences during the IEP process. Parents reported that educators did not listen to their suggestions nor integrate suggestions into the IEP.

In this study, a large majority of parents (71%) reported they understood their rights and steps they would take if they disagreed with the school district. Only 3% of parents reported they did not understand their rights and steps they would take if they disagreed with the school district. Parents reported their knowledge of autism, autism treatments, and special education law empowered advocacy efforts, helping them achieve confidence necessary to fully participate in IEP meetings as an equal team member. One parent wrote,

After Wright’s Law [sic] training, and with a change to a special education school, things became less contentious as I learned ways to work more smoothly with the staff, and they were more knowledgeable and willing to talk things over with us and incorporate our concerns in the IEP.

Another parent wrote, “After attending a Wright’s Law [sic] boot camp, I was able to manage things better, and felt stronger about confronting administrators in a polite but forceful way to get my views about my son’s needs incorporated into his education.”

The findings from this study are consistent with findings from numerous other studies that show the acquisition of knowledge of ASD and special education law empowers parental advocacy and confidence, enhancing parental participation in IEP meetings (Brandt, 2011; Cho & Gannotti, 2005; Fish, 2006; Jegatheesan et al., 2010; Jimenez, 2011; Lo, 2008, 2009; Lynch & Stein, 1987; Salas, 2004). Parents reported that
knowledge of their child’s disability, their rights, and their child’s rights helps them become an informed consumer. This knowledge facilitates their ability to discern what services schools are required to provide, and their ability to request them. Having an understanding of their child’s needs, interventions and strategies, and services the school can provide enhances IEP team collaboration and their child’s progress.

A majority of parents (80.5%) in this study did not hire attorneys or advocates to attend IEP meetings with them. Of the parents who hired attorneys or advocates, most (77%) reported attorneys or advocates facilitated IEP team collaboration. A parent wrote, “Although my advocate has not attended meetings with me, she has been an invaluable resource with helping me learn the law, composing correspondence, suggesting evaluations and goals, etc.” Advocates advised parents regarding services and instructional strategies the school may be able to provide their child. One parent wrote, Meeting in the same room and discussing the specific needs of my son are important parts of the IEP process. We have an ABA therapist who attends the IEP with us as my son’s advocate. Having an advocate is a critical part of the process.

Parents reported they believed advocates understood instructional strategies that would help their child. They also indicated that they believed advocates understood laws and services that were not offered unless specifically requested. A parent wrote, We had to hire an advocate to get our district to take my son’s needs seriously. He was placed in an ED class and was being restrained on a regular basis. He is now in a private placement which is much better.
The overwhelming feeling of distrust regarding services not being provided unless requested was apparent in many parents’ responses. One parent wrote that the IEP process is only effective when “you have an advocate who knows the process and laws otherwise I feel they try to slide things by you.”

Most parents (56%) in this study agreed that their advocates or attorneys were expensive. However, a majority of parents (77%) indicated the benefits of hiring an attorney or advocate outweighed the expense. A few parents reported that school districts should appoint advocates for free. One parent wrote,

I would like to change the IEP process where every parent/guardian is appointed a qualified, vetted advocate (non-attorney) for FREE to assist with the first three IEP sessions, and then available to the parent on a sliding scale for any further IEP meetings.

Parents reported they believed laws favored school districts, and litigation was an expense beyond the average family’s budget. Of parents who responded to this item, 77% felt the process was unfair and favored school districts. A parent wrote,

Our family income can’t support the level of services that my son needs, much less pay for an attorney. Even if we did win a due process, we’re looking at $10K in fees to get compensatory services for FAPE that would be poorly delivered.

Costly legal battles that settled disagreements between parents and schools inhibited families’ abilities to challenge school decisions. Schools’ legal budgets are larger than most families’ budgets and the inequity made due process unlikely for many families.
Findings from this study are consistent with Fish’s (2006) findings that revealed parents hired advocates to insure their child received needed services. There is limited research regarding parents’ perceptions of their advocates and their experiences with advocates and attorneys, even though extant research indicates that parents who have children with autism are 10 times more likely to sue than parents in any other disability group (Zirkel, 2011). Litigation involving students with ASD is the most expensive area of education litigation (Etscheidt, 2003).

Approximately 5% of the sample of parents in this study indicated they were involved in legal proceedings, which include filing a complaint, negotiating a case through mediation, and litigating a case through due process. Of the parents who were involved in legal proceedings, a majority (77%) reported the mediation process or due process was unfair. Only 33% of parents reported they believed mediation or due process helped their child receive the services they needed, and 33% of parents reported their child benefited from the outcome of the mediation or due process hearing. Furthermore, 33% of parents reported they did not believe mediation or due process improved IEP team collaboration.

**The Individualized Education Program Will Meet the Child’s Needs**

The IEP outlines children’s present level of academic and functional performance, academic and functional needs, and goals that are designed to facilitate skill development to meet these academic and functional needs. Educators select and develop instructional strategies that help children achieve their IEP goals. Instructional methodologies must be based on evidence-based practices to the maximum extent possible (Zirkel, 2011). IEP
goals are documented in an IEP, which acts like a blueprint to deliver special education services. The IEP outlines goals, as well as frequency and duration of related therapies and special education services.

In this study, a majority of parents reported their child’s IEP would meet their child’s education needs (50%). Notably, 42% of parents reported their child’s IEP would not meet their child’s education needs. The following sections and paragraphs discuss issues related to the IEP, IEP goals, and class placement in the least restrictive environment. Parental perceptions regarding evaluations and assessments that are used to determine student needs are examined. The individualization of IEP goals as well as generic IEP goals common among children diagnosed with ASD are discussed. Finally, parental perceptions of class placements are examined.

**Evaluations and assessments.** Selecting and administering appropriate evaluations and assessments to identify academic and functional needs is critical. Etscheidt (2003) analyzed 68 cases involving students with ASD between 1997 and 2002. Findings revealed that schools violated FAPE when they did not select or administer appropriate assessments to identify academic or functional needs. Counselors, teachers, and school therapists select and administer evaluations to identify academic and functional needs.

In this study, parents had bimodal responses regarding whether counselors, teachers, and school therapists selected and administered appropriate evaluations to determine their child’s needs. Of 86 respondents, 35.6% agreed or strongly agreed with this statement, and 36.8% disagreed or strongly disagreed. Unfortunately, the small
number of participants inhibited statistical analysis. Analysis that was performed combined autism disability subtypes, income levels, and number doctors consulted to facilitate analysis. There were no statistically significant differences in parental responses among demographic characteristics.

Parents reported they understood that evaluations were instrumental to understand their child’s needs. One parent wrote, “Good evaluations in ALL areas of need are the key to identifying specific needs and deciding on goals/accommodations.” Some parents hired advocates to recommend evaluations that would uncover academic or functional needs. A parent wrote that her advocate was helpful in “suggesting evaluations” that uncovered her child’s functional needs. Evaluations were a source of contention for some parents. A parent wrote, “We were denied speech therapy for three years. We requested speech therapy again this year and were able to justify the need based on a private ABA therapist’s recommendation and a medical evaluation.”

Closer inspection of this study’s data reveals that there are differences in parents’ perceptions by examining response frequencies and autism subtype. Approximately 47% of parents with children who had Asperger’s reported they believed counselors, teachers, and school therapists did not select and administer appropriate evaluations to determine their child’s needs. Similarly, approximately 44% of parents with children who had PDD-NOS reported they believed counselors, teachers, and school therapists did not select and administer appropriate evaluations to determine their child’s needs. Alternatively, approximately 24% of parents with children who had autistic disorder reported counselors, teachers, and school therapists did not select and administer appropriate
evaluations to determine their child’s needs. Concurrently, 29.4% of parents with children who had Asperger’s, and 31.3% of parents who had children with PDD-NOS agreed that counselors, teachers, and school therapists selected and administered appropriate evaluations to determine their child’s needs. A larger majority of parents (45.5%) who had children with autistic disorder agreed that counselors, teachers, and school therapists selected and administered appropriate evaluations to determine their child’s needs.

Although this study’s findings are limited because of the low number of participants, this study suggests that parents who have children with higher functioning ASD, which includes Asperger’s and PDD-NOS (Prelock, 2006), reported counselors, teachers, and school therapists did not select and administer appropriate evaluations to determine their child’s needs. Since a significant number of children newly identified with ASD are diagnosed with higher functioning ASD (CDC, 2012a), factors affecting parental perceptions should be examined to insure school districts are not violating FAPE for these children.

Once student needs are identified, a child’s IEP documents needs and his or her present level of academic and functional performance. Goals are designed and developed to meet these needs. IDEA (2004) stipulates that goals must be developed in a way such that students derive meaningful educational benefit. Substantive errors occur when IEP teams do not develop meaningful goals, or do not create education plans with instructional strategies that enable children to meet IEP goals (Christle & Yell, 2010; Zirkel, 2011).
**Individualized goals.** In this study, a majority of parents (49.4%) reported that teachers, school therapists, and other education professionals created and recommended individualized IEP goals that were designed to meet their child’s needs. Several parents commented that their favorite aspect of the IEP process was collaborating with educators to discuss their child’s needs and designing goals to meet these needs. A parent wrote that the collaboration was valuable for,

Bringing various people and their perspectives together to talk about your child as a whole person and to try to understand what works best for your child in different settings within the school. For me, it gives me a chance to write or help write goals for my child with input from the teachers/staff who work with him.

One parent shared her successes in developing IEP goals:

It takes weeks to prepare for the annual IEP process. Beginning in April, I request written progress reports from child’s private therapists and developmental pediatrician. I review the SOL documentation to determine what challenges my child will face with the next school year’s curriculum. I ask pointed questions to determine how [my] child is behaving in school. I review and comment on draft IEP goals. I review all materials with spouse so he is prepared to speak on issues as well. I always complete the parent progress report and make comments both on what is going well and what is not in the school environment. In the meeting, I try to stay calm at all times. When I disagree with the teacher’s or administrator’s point, I ask pointed questions to ensure that I understand their logic before
responding. So far, my spouse and I have been able to keep [our] child’s support levels at or close to desired levels.

Preparing for an IEP takes time. Another parent wrote,

Once I learned what comprises a “good” IEP, I make sure to write the goals myself and give them to the teacher to add to. I insist that I am part of the process in this way and I have gotten the goals I want/need and the amount of reporting back to me about progress. I have learned how to write IEP goals to get what I think my child needs, but what about parents who can’t put this effort into it?

The results of this study differ with findings from other studies that report parents feel educators do not individualize IEP goals (Fish, 2006, 2008; Jegatheesan et al., 2010; Jensen-McNiff, 2012; Lovelin, 2012; Stoner et al., 2005; Strooggilos & Xanthacou, 2006). Research is clear that parents who feel knowledgeable about autism, special education law, and the IEP process participate in IEP meetings, helping to individualize IEP goals (Fish, 2006, 2008; Jegatheesan et al., 2010; Lovelin, 2012; Stoner et al., 2005). Parents in this study reported they felt very knowledgeable about special education law and the IEP process. They understood their rights and indicated they were confident in their ability to suggest IEP goals in meetings. Accordingly, they reported they felt their suggestions were valuable and integrated into their child’s IEP. Consequently, they reported they believed their child’s IEP was individualized and would meet their child’s needs.

Approximately 28% of parents did not agree that IEP goals were individualized for their child. They felt goals were prescribed and generic. The following paragraphs discuss generic IEP goals common among children with ASD.
**Generic IEP goals.** A similar majority of parents (49.5%) reported that teachers, therapists, and counselors created and recommended generic IEP goals common to many students with ASD. Notably, approximately 28% of parents did not feel goals were generic, and approximately 22% were neutral in their opinion. Several parents expressed concern regarding IEP goals that were predetermined, and too academic. They reported every child with autism had the same goals as their child, regardless of the heterogeneity of the disability. A parent shared, “The IEP ‘process’ is pretty nakedly about working around us to write minimal, easily met goals and with an eye toward a placement predetermined by the school team. We are treated as ignorant window dressing.”

When parents understood their rights and participated more fully in the IEP process, they became engaged partners who helped individualize goals for their child. A parent shared,

> Early on, when my son was young, I would go into the IEP meeting feeling like everyone was doing me a great service. That they knew what was best for my son, and were doing the absolute best they could. After I educated myself on the IEP process and my rights as a parent, I realized that my son’s early IEPs were very cookie-cutter and not individualized for him at all. We have become full participants in my son’s IEPs and now attend IEPs with other parents to help them understand the process.

Parents’ perceptions regarding IEP goals that were generic and not individualized are well reported in the literature (Fish, 2006, 2008; Jegatheesan et al., 2010; Lovelin, 2012; Stoner et al., 2005), and findings from this study are consistent. Parents perceived
that knowledge of autism, the IEP process, and special education law enhanced their ability to collaborate with teachers to recommend individualized IEP goals for their child. Studies that investigated the perceptions of parents regarding the IEP process have similar findings in that knowledge of autism and the IEP process facilitated parental advocacy and collaboration necessary to create individualized IEP goals (Fish, 2006; Jegatheesan et al., 2010; Lovelin, 2012).

Although difficulties with transitions are common among children with ASD (Prelock, 2006), parents reported that IEP teams did not adequately plan for transitions that occur between elementary, middle, and high schools. Several parents shared their perspectives regarding the lack of transition planning and IEP goals in open-ended responses. The following paragraphs discuss parental perceptions of transition issues and IEP goals.

**Transitions.** Children with ASD have difficulties with changes in routines and transitioning to novel activities and situations (DSM-IV-TR, 2000; Prelock, 2006). Difficulties transitioning from kindergarten and preschool are well documented the literature (Denkyirah & Wilson, 2010; Forest, Horner, Lewis-Palmer, & Todd, 2004; Quintero & McIntyre, 2010). Change is inevitable in life, and many instructional strategies facilitate change for children with ASD (NPDC, 2013; Prelock, 2006). One such strategy is an evidence-based practice: antecedent-based interventions. Antecedent-based interventions include behavioral supports and strategies that are implemented prior to the occurrence of problem behaviors (NPDC, 2013). The NPDC states that, “antecedent-based interventions (ABI) include a variety of modifications that are made to
the environment/context in an attempt to change or shape a student’s behavior” (2013, p. ?).

Several parents in this study reported frustrations regarding their child’s transition to elementary, middle, or high schools. One parent wanted assistance from an advocate to help design IEP goals and strategies that facilitated transitions to new schools. When asked what the parent would change about the IEP process, the parent wrote, “I would expand that [an] advocate is available two IEP meetings during the transitional times of an IEP (preschool to kindergarten, elementary to middle school, middle school to high school, and high school to post-secondary life).” A parent of a younger child wrote,

Overall, my IEP experiences thus far have been very positive. My son’s PAC teacher is an amazing teacher and is just as willing to fight for him as I am. We have just held his transitional IEP for Kindergarten and the IEP meeting was a bit more of a challenge. There has been more push back on [resistance to] requesting evaluations for services than there was in the preschool setting.

Findings from this study are similar to findings from other studies (Nickels, 2010; Quintero & McIntyre, 2010). In one study, Quintero and McIntyre (2010) obtained teacher and parent reports regarding transition practices for children with ASD who were transitioning from preschool to elementary school. Findings revealed that parents reported elementary schools were less involved in the transition process than preschools.

There is a gap in research regarding strategies and antecedent-based interventions that enhance and facilitate transitions for children with ASD. Adreon and Stella’s (2001) article outlined two major strategies that facilitate transitions for children with ASD.
First, they recommended having transition planning meetings with both schools in attendance. Also, they recommended IEP teams create goals and plan strategies that facilitate the transition to new schools. These goals should incorporate antecedent-based intervention strategies that acquisition children to new routines, class changes, bus schedules, lockers, and unstructured time such as lunch and time between classes (Adreon & Stella, 2001).

**Communication and collaboration.** Communication among education professionals and parents is necessary in order to design and create individualized IEP goals such that children with disabilities derive meaningful educational benefit (Christle & Yell, 2010; Zirkel, 2011). Communication regarding IEP goals with multiple teachers and therapists is essential given the heterogeneity of ASD and lifestyles of these children, whose parents often consult with numerous education professionals and therapists (Goin-Kochel et al., 2007; Green et al., 2006; Mackintosh et al., 2012). Communication regarding progress toward meeting IEP goals insures parents are aware of their child’s progress toward meeting these goals. Progress monitoring of IEP goals reports the effectiveness of strategies and interventions designed to help children meet IEP goals. If there is little or no growth toward meeting IEP goals, then interventions and strategies are examined and analyzed.

The following sections and paragraphs discuss issues related to communication. The first section discusses teacher and parent communication which occurs prior to IEP meetings. The second section discusses communication necessary to implement the IEP and IEP goals. The third section examines the perceptions of parents regarding
communication among teachers, therapists, counselors and administrators. Finally, the fourth section discusses progress monitoring and communication of progress toward meeting IEP goals.

*Communication before meeting.* Parents reported that collaboration and communication prior to IEP meetings enhanced parental participation in IEP meetings and IEP team collaboration. A parent shared,

I meet with my child’s teacher before the IEP meeting. I request a draft of the IEP before the meeting, review it, send it back with questions or comments, re-review the new draft, and continue that cycle until most of the IEP is to my satisfaction before the formal meeting. It saves a lot of time!”

Many parents reported that communication prior to IEP meetings enhanced their ability to participate in the IEP process. A parent said, “I’d like the actual goals to be agreed upon BEFORE the meeting with parent and school input. It has been difficult to have my suggestions put anywhere other than the PLOP page.” Another parent echoed, “It should be more collaborative before the actual meeting. If we went back and forth discussing goals and present level then the actual meeting would not take so long.” All in all, communication with parents, sharing proposed IEP goals, and data regarding progress toward meeting those goals enhanced relationships with parents, improving IEP team collaboration and parental participation. These findings are consistent with findings from other studies, where participants reported that sharing proposed IEP goals prior to meetings enhanced parental participation and IEP team collaboration (Brandt, 2011; Fish, 2006, 2008; Jegatheesan et al., 2010, Lovelin, 2012; Stoner et al., 2005).
Implementation of goals. Numerous parents in this study reported that they perceived teachers did not implement their child’s IEP. Through open responses, parents shared concerns regarding IEP implementation. A parent wrote, “The issue is with implementation.” Parents were frustrated with IEP implementation. A parent shared that IEP teams can collaborate well and design the perfect IEP, “but if it’s not implemented well, it doesn’t matter.” Some parents reported that teachers did not understand autism well enough to implement goals. One parent wrote, “They still always have a great shortfall of properly trained staff so IEPs are rarely implemented well.” A few parents reported general education teachers were especially unprepared to implement and monitor IEP goals. A parent wrote, “IEPs are not discussed with General Ed teachers, procedures are not implemented in General Ed classrooms unless the parent takes it upon himself/herself to fight it out.”

Other research suggests that parents believe IEP documents are legal formalities that are rarely implemented in the classroom (Fish, 2006; Hotchkiss, 2012; Stoner et al., 2005; Stoner & Angell, 2006). Parents believed teachers did not fully implement IEP goals due to lack of time (Fish, 2006; Hotchkiss, 2012), or lack of understanding of autism (Fish, 2006). Some parents hired advocates and ABA therapists to assist them in monitoring progress and implementing IEP goals (Stoner & Agnell, 2006). Advocates and ABA therapists communicated with teachers to collaborate with them to implement goals.

Communication among therapists and teachers. A majority of parents (46%) in this study reported that they perceived general education teachers, special education
teachers, administrators, and specialists (speech therapists, occupational therapists, physical therapists, etc.) did not collaborate and communicate well regarding issues. One parent wrote, “It seems like the teachers don’t have enough time to talk about my child. I don’t feel they collaborate.” Several parents reported they felt discussions regarding their child’s needs only occurred during IEP meetings. A parent wrote, “I feel like this is sometimes the only place they share information about my child! I do not find they talk and collaborate much.” Some parents reported teachers did not have enough time to collaborate with therapists and other education professionals. A parent shared, “It seems like the teachers don’t have enough time to talk about my child.”

Findings from this study are similar to findings from other studies where parents indicated they believed teachers did not discuss issues regarding their child with each other (Fish, 2006; Nickels, 2010). Parents reported they were particularly concerned regarding communication surrounding interventions and strategies (Fish, 2006). When strategies were ineffectual, they felt educators did not communicate or collaborate to discuss alternative interventions (Fish, 2006).

**Progress monitoring.** Monitoring progress toward meeting IEP goals is essential to determine the appropriateness of the instructional methodology. If a child is not making meaningful progress toward meeting IEP goals, then instructional methodologies should be evaluated and altered (Christle & Yell, 2010). Data from progress reports is used to change instructional methodologies if necessary, and create IEP goals (IDEA, 2004). IDEA (2004) requires teachers to track children’s progress toward meeting IEP
goals through observations, assessments, and anecdotal notes (Etscheidt, 2006), and communicate progress toward meeting goals with parents (Christle & Yell, 2010).

In this study, a small majority of parents (37.9%) reported that educators provided adequate feedback on progress toward meeting IEP goals. Alternatively, approximately 33.3% of parents reported they were provided adequate feedback toward meeting IEP goals. There were no significant differences among parents and respective demographic characteristics. However, there were significant differences among respondents who consulted with less than three doctors and respondents who consulted with three doctors or more to obtain an ASD diagnosis. Parents who consulted with a greater number of doctors to obtain an ASD diagnosis reported that they were not provided adequate feedback toward meeting IEP goals. Approximately 23% of parents who consulted with three doctors or more to obtain an ASD diagnosis reported they were not provided adequate feedback toward meeting IEP goals. Alternatively, 77% of parents who consulted with less than three doctors to obtain an ASD diagnosis reported they were provided adequate feedback toward meeting IEP goals.

When parents were asked what they would like to change about the IEP process, many responded that they wanted meaningful information about their child’s progress toward meeting IEP goals. A parent wrote, “Periodic progress reports should be more elaborate and concrete rather than mechanical just so to say the school had complied.” Parents also reported there was no attempt to evaluate alternative strategies or instruction when their child was not making progress toward meeting IEP goals. One parent wrote,
Hate the process of IEP data collection, too random, too subjective. Cannot really analyze the data to find trends and change interventions in a timely manner. Never yet seen any data analysis conducted by the teachers. They are really putting out fires, reactionary. Don’t think they really plan for continued improvement in any strategic manner. Just following the typical academic curricula for no interventions to help my son with focus, attention, executive functioning challenges, etc. We supplement the school with private therapists providing speech and social skills three times a week. We support intensively at home with skills learned through conferences and self-study. School feels satisfied with my son’s progress, but they are not responsible for a significant amount of it.

Frustration regarding lack of progress toward meeting IEP goals was apparent in numerous responses. Parents reported there were no attempts to modify interventions or strategies as mandated by IDEA (2004). One parent shared,

With each year, the IEP experience has gotten more and more difficult, especially when my son hasn’t made any true progress at school for two years. At the moment, the team seems unwilling to be flexible on how data is gathered or how the programs reinforced. We’re still in the middle of this year’s IEP, so the jury is still out on how much they may incorporate parent comments/goals into my son’s new IEP. I have a feeling that I may be able to answer the attorney/advocate questions in about a year.

Findings from this study mirror findings from Fish’s (2006) study. Fish interviewed seven parents who had children with ASD regarding their experiences during
the IEP process. Parents reported that teachers did not monitor progress toward meeting IEP goals. Furthermore, parents reported teachers wrote progress reports without measuring true progress. They adhered to legal mandates to provide progress reports to comply with legal mandates. There was no true attempt by teachers to monitor progress or change interventions or treatments to find an intervention that would result in progress toward meeting IEP goals. Parents reported that teachers did not have time to adequately monitor IEP goals (Fish, 2006). They also reported teachers did not understand autism, interventions, or evidence-based practices in order to modify interventions and strategies (Brandt, 2011; Fish, 2006; Spann et al., 2003).

Research indicates that many school districts do not meaningfully monitor progress toward meeting IEP goals (Etscheidt, 2012). When school districts do not monitor progress toward meeting IEP goals, they are unable to track progress or collect data. Tracking progress requires teacher time and attention (Kurth & Mastergeorge, 2010). Evaluating strategies and interventions also requires teacher time and knowledge of evidence-based practices.

**Teachers’ Knowledge of Autism Spectrum Disorder, Lack of Time, and Alternative Placements**

IDEA (2004) mandates educators develop individualized IEP goals to meet the diverse needs of children with disabilities. The heterogeneity of ASD necessitates an understanding of autism to develop meaningful, measurable goals. Teachers select interventions and strategies that are designed to meet IEP goals. Clearly, developing
interventions and strategies requires teachers be knowledgeable about ASD and dedicate time to identify and develop effective interventions and strategies.

**Knowledge.** In this study, parents were evenly split regarding their perceptions of teachers’ knowledge of their child’s disability. Of 86 parents, 41.4% disagreed and 41.3% agreed that teachers were knowledgeable about their child’s disability. Further analysis revealed that there were no significant differences in parents’ perceptions by disability or number of doctors consulted to obtain an ASD diagnosis. However, significant differences in parental perceptions were found when data was analyzed by income level. Results demonstrated there were significant differences between frequencies of responses by incomes of $100,000 or more and less than $100,000. A greater percentage of parents who had incomes $100,000 or more reported teachers were knowledgeable about their child’s disability than parents who had annual family incomes less than $100,000.

Very few parents discussed teacher knowledge in open-ended response items. One parent wrote, “There is not enough true understanding of autism and expectations among teachers is often unclear.” Parents reported that related therapy therapists’ (speech, occupational therapy, etc.) knowledge was critical in order to have successful outcomes. One parent wrote,

> I think these therapies are great as long as the therapist understands and has experiences working with children who have autism. I found some speech therapists to understand either pragmatics or articulation well.... When a therapist does not fully understand Autism, then they are far less effective.
Another parent added, “It all depends on the therapist. Some have been awesome, others lack experience. We currently have great ones.”

In this study, 41.4% of parents reported they did not believe teachers were knowledgeable about ASD, and 41.3% reported they believed teachers were knowledgeable about ASD. Findings from this study are not only not consistent with findings reported in the literature, but this study’s equivocal findings actually contrast these studies (Brandt, 2011; Fish, 2006; Jegatheesan et al., 2010; Jimenez, 2011; Spann et al., 2003; Stoner et al., 2005), which had findings that indicated a majority of parents believed teachers are not knowledgeable about ASD. In some studies (Fish, 2006; Spann et al., 2003; Stoner et al., 2005), parents reported teachers’ lack of knowledge regarding their child’s disability adversely affected their child’s education through implementation of inappropriate behavior management strategies. In one study (Fish, 2006), parents reported teachers did not fully understand ASD, and they believed teachers interpreted idiosyncratic behaviors as oppositional instead of manifestations of ASD. Consequently, teachers implemented punitive behavior management strategies that resultantly escalated behaviors. This lack of understanding of the characteristics of ASD and appropriate behavior management strategies adversely affected their child’s education. In this current study, none of the participants discussed teachers’ lack of knowledge regarding the characteristics of autism and implementation of inappropriate behavior management strategies.

Lack of time. Parents in this study expressed concern regarding teachers’ ability to balance teaching and IEP case management. They reported that teachers did not have
time to communicate and collaborate with them on IEP goals. They also reported that teachers’ lack of time inhibited their ability to monitor progress toward meeting IEP goals. A parent wrote, “Time seems to be the great equalizer. The teachers are overworked and often giving up their lunch or planning to attend the IEP meeting so naturally they are in a hurry for the meeting to finish.”

Parents were concerned about teachers taking instructional time to attend IEP meetings. A parent wrote,

I also don’t like how much time it takes the classroom teacher out of the classroom. On average, IEPs take two hours per student. Multiple that by the number of students in the self-contained classroom and that’s a huge amount of time away from teaching.

Several parents reported rushed during IEP meetings. A parent added,

I also feel they try and speed through time and get it down and don’t like to discuss it. Maybe they [IEP meetings] should be held on teacher work days so they don’t worry about subs and getting back to their classroom.

Findings from this study are similar to findings from Nickels’ (2010) dissertation. Nickels (2010) interviewed seven parents regarding their perceptions of educational interventions and barriers to implementing those interventions. Parents perceived teachers’ caseloads and paperwork as reasons why teachers have a difficult time meeting divergent needs of children with autism. Some research from Fish’s (2006) study suggests that parents also held the perception that excessive paperwork took time from case management and individualization of instruction. Limited research exists
investigating the balancing special educator roles and parental perspectives of special education teachers’ effectiveness in these roles.

The next section discusses the class placement. IDEA (2004) mandates that children with disabilities have a right to a free and appropriate public education (FAPE) in the least restrictive environment. The least restrictive environment provision requires schools to educate students with disabilities in the general education environment to the maximum extent possible.

**Alternative placements.** In this study, a majority of children (38%) were educated in general education with a co-teacher or general education classes with resource room support. The U.S. Department of Education (2006) report indicated that nationally, approximately 32.2% of children with ASD were educated in general education classrooms. The children in the current study participated in general education classes more frequently than seen nationally, but not by a significant percentage. Most parents reported their child received shared paraprofessional support.

There were near equivocal parental perceptions of the item “Teachers, school therapists, or other education professionals discussed alternative placements with me.” Of 86 respondents, 41.4% agreed and 40.2% disagreed. The small number of participants inhibited analysis on many demographic characteristics. There were significant differences in perceptions regarding parents who consulted with three or more doctors to obtain an ASD diagnosis and parents who consulted with less than three doctors to obtain an ASD diagnosis. Interestingly, parents who consulted with less than three doctors were
more likely to indicate that education professionals discussed alternative placements with them than parents who consulted with three doctors or more.

**General education teachers.** Several parents in this study reported general education teachers did not understand ASD or their child’s needs. Lack of knowledge regarding characteristics of children with ASD and strategies that facilitate inclusion made inclusion more difficult. One parent wrote that she wanted to make, “general education teachers aware that my child was definitely going to behave differently than his typical peers.” Several parents expressed grief regarding general education teachers’ lack of knowledge regarding autism. One parent wrote,

> The services my child receives are adequate. The problem is the Gen Ed teacher refuses to implement the IEP when no one else is around. She is a much older “old school” teacher who feels my son just has “anger/emotional” issues (despite multiple experts diagnosing him with high functioning autism).

Lack of understanding of autism was apparent in many responses. Parents reported that general education teachers struggled managing their child’s behaviors. Parental perceptions of a lack of knowledge regarding behavior management strategies for children with ASD is well documented in the literature (Brandt, 2011; Fish, 2006; Jegatheesan et al., 2010; Jimenez, 2011; Spann et al., 2003; Stoner et al., 2005). Parents in this study had similar concerns when their child was placed in the general education classroom.

Sometimes, parents reported the school culture inhibited inclusion. A parent wrote,
But in most general education schools, the special education students were regarded as a nuisance and a drag on the “regular” kids, and many school administrators seem to resent any time or money spent on our children. This is not just my experience with my child, but also what I found when visiting schools as a member of the Special Education Advisory Committee, very sad to find this attitude in so many schools.

Approximately 28% of children in this study were educated in self-contained classes or self-contained schools. Several parents shared that self-contained placements helped their child develop skills necessary for success in general education classrooms. A parent shared,

My son's base school did all they could to help him succeed, but they did not have the supports to help him with his emotional liability in the general ed classroom. He transferred to a ------ program within ------ County that has a support room, weekly psychologist appointments, social worker if needed, art therapy and music therapy. He currently is in a contained class of 9 and can have the opportunity to be taught in the general education class with support of an IA [instructional assistant] for some or all of his subjects. Although he isn’t at this level yet, I believe he will be able to handle a gen ed classroom setting for science and social studies next year. He needs a lot of support for writing and reading. I have heard horrible stories about IEP’s, so I feel lucky that we have had two great schools for my son that truly want him to succeed and do well in school and in life.
Findings from this study mirrored findings from Nickels’ (2010) dissertation. Nickels (2010) interviewed teachers and seven parents with children who had ASD in a Tennessee school district. Parents reported inclusion in general education was essential for children with ASD in order to model appropriate behaviors, preferring inclusion for at least part of a day. However, parents also reported that their children required general education as well as special education services that targeted their child’s needs and skill deficits. Sometimes, interventions were only possible in self-contained settings, and parents were aware that targeted interventions necessitated a self-contained class setting.

**Evidence-Based Practices and Educational Interventions**

Instructional strategies and evidence-based practices (EBPs) are interventions that help students with disabilities develop skills to achieve IEP goals. IDEA (2004) mandates schools implement instructional methodologies that are evidence-based practices, or rely on peer-reviewed research to the maximum extent possible (Zirkel, 2011). The National Professional Development Center for Autism Spectrum Disorders (NPDC) at the University of North Carolina Chapel Hill designated treatments/interventions as EBPs for children with autism spectrum disorders, all of which are high-quality interventions that are documented in peer-reviewed scientific journals. In this study, 87 parents rated their perceptions of these EBPs on a 5-point Likert scale that had ratings that ranged from very poor to excellent. Parents who had never used an intervention were able to select “never used.”

Findings from this study illustrate that a significant percentage of parents never used a majority of the EBPs. However, a majority of participants had children with higher
functioning ASD. Only 37.9% of participants had children with Autistic Disorder, a lower functioning form of ASD, and many EBPs are implemented with children who have lower functioning ASD. Since most respondents had higher functioning children and most EPBs listed on this survey were for lower functioning students, it makes sense the percentage of parent use reported in this study was low.

Of the parents who had used the EBPs, most parents rated the practices effective with ratings of good or excellent. Parents in this study rated the following 22 interventions as good/excellent: (a) antecedent-based interventions, (b) computer aided instruction, (c) differential reinforcement, (d) discrete trial training, (e) extinction, (f) functional behavior assessments, (g) functional communication training, (h) naturalistic intervention, (i) peer-mediated instruction, (j) picture exchange communication, (k) pivotal response training, (l) prompting, (m) reinforcement, (n) response interruption/redirection, (o) self-management, (p) social narratives, (q) social skills groups, (r) structured work systems, (s) task analysis, (t) time delay, (u) video modeling, and (v) visual supports. Only speech generating devices/VOCA was rated neutral (44.4%) or poor (33.3%) more frequently than good/excellent. Notably, only 10 respondents rated their perceptions of speech generating devices/VOCA, and speech generating devices are used with individuals with lower functioning ASD. The small number of respondents to this item inhibits generalization of findings.

Findings from this study significantly add to the research base regarding the parents’ perceptions of evidence-based practices for children with ASD. There is a gap in research regarding evidence-based practices that parents perceive effective, and findings
from this study confirm findings in other studies (Callahan, Henson, & Cowan, 2008; Nickels, 2010). Callahan et al. (2008) surveyed teachers, parents, and school administrators about their perceptions of autism intervention components and their effectiveness with children who have ASD. A total of 95 respondents reported that functional behavior assessments, reinforcement, task analysis, naturalistic teaching strategies, peer-mediated interventions, pivotal response treatment, and time delay were effective practices.

Findings from this study are similar to findings from Nickels’ (2010) dissertation. Parents who used antecedent-based interventions, that is, behavior interventions such as differential reinforcement, discrete trial training, extinction, functional behavior assessment, pivotal response training, prompting, reinforcement, response interruption and redirection, video modeling, visual schedules, self-management, and social narratives rated these interventions as effective. Additional research that investigates the perceptions of parents regarding evidence-based practices for children with ASD is necessary to gain a greater understanding of the interventions and strategies parents perceive effective.

**Sources Parents Consult to Learn About Autism Spectrum Disorder and Special Education Law**

Parents implement a variety of interventions with their child (Bowkler et al., 2010; Goin-Kochel et al., 2006; Green et al., 2006; Mackintosh et al., 2012), and spend a significant amount of time and money on private therapies (Kogan et al., 2008). The following section discusses sources parents in this study reported consulting to learn
about ASD and special education law. Parental knowledge of ASD and special education law enhances parental participation in the education of their child.

**Autism spectrum disorders.** A majority of parents in this study consulted the Internet and other parents to learn about ASD. Findings from this study resemble findings from other studies that indicate parents most frequently consult the Internet (Carlon et al., 2013; Goin-Kochel et al., 2006; Green et al., 2007; Jegatheesan et al., 2010; Mackintosh et al., 2012), and other parents (Goin-Kochel et al., 2006; Green et al., 2007) to learn about ASD. Other sources parents consulted included doctors, neurologists, occupational therapists, schools, clinics, and conferences.

Most parents in this study reported that other parents were the most helpful sources they consulted to learn about autism, autism treatments, therapies, and evidence-based practices. They reported other parents were reliable sources because they directly experienced interventions’ effects and resultant outcomes. Numerous parents shared they learned about interventions through parent listservs that are available through associations, organizations, parent resource centers, and local school districts.

A few parents discussed the process they used to evaluate the credibility of information they received from other parents or the Internet. These parents evaluated information by comparing new recommendations with information they knew was valid from prior experience or readings. Parents indicated they trusted the reliability of information provided by doctors, neurologists, or trusted therapists or teachers. When a professional/other parent recommended a treatment or intervention that they perceived ineffective, parents questioned the reliability and validity of information provided from
that professional/other parent. Other sources parents reported facilitated their knowledge of ASD included programs and conferences, autism association and groups, books, the school, parent listservs, occupational therapists, medical professionals, peer-reviewed journals, speech therapist, adults with ASD, ABA therapist, private therapists, and DAN! doctors.

**Special education law.** A majority of parents in this study reported they were knowledgeable about their rights and understood the steps they would take if they disagreed with the school district. Parents learned about their rights and special education law from a multitude of sources, most frequently from other parents, associations, the school district and Wrightslaw workshops sponsored by associations, parent groups, and parent information centers. Several parents learned about the IEP process through experience participating in IEP meetings.

Parents consulted the Internet to learn about their legal rights. Wrightslaw provides a free website to parents with legal vignettes where parents learned about special education law and workshops. Parents consulted books and consulted with attorneys and advocates to understand their rights. Finally, parents mentioned they studied special education law through books and classes.

There is limited research regarding sources parents consult to learn about special education law and their legal rights. Murray’s (2013) dissertation investigated the effects of Wrightslaw workshops on the self-efficacy and stress levels of 135 parents who had children with autism through an online survey. Findings revealed that the Wrightslaw workshop had no effect on parental stress or self-efficacy. This current study did not
investigate parental stress or self-efficacy; however, parents reported that special education law workshops such as Wrightslaw enhanced their ability to advocate for their child.

**Limitations**

This study had several limitations, in particular the number of participants and the survey instrument, which are discussed in this section.

**Participants**

Participants in this study represented a sample of parents who were active in several parent advocacy groups. By nature of their affiliation with these groups, these parents may have a greater awareness of autism and services available to them than parents in the general population. A total of 87 parents responded to the survey. There were 22 spam entries, which were deleted. Deletion of spam entries required copious review of the data with the researcher and a professor. After agreement conferences, the spam entries were deleted. Unfortunately, the small sample size inhibited some statistical analysis.

The small number of respondents (87) represented a small sample of parents who have children with ASD. Yet, this study’s sample closely resembled many demographic characteristics of families with children who have ASD that are reported in the literature (Bhasin & Schendel, 2007; McAdoo & Demyer, 2012; Van Meter et al., 2010). A majority of participants in this study had family incomes over $100,000 per year. Of study participants, 93% attained education levels beyond high school. Research that examines characteristics of families with children who have ASD correlates autism
prevalence with high incomes and education levels (Bhasin & Schendel, 2007; McAdoo & Demyer, 2012; Van Meter et al., 2010).

The small sample included a majority of parents who reported their child had Asperger’s Syndrome or PDD-NOS, a higher functioning ASD. Only 33 participants (37.9%) indicated their child was diagnosed with Autistic Disorder. Many evidence-based practices are appropriate for individuals with lower functioning ASD and Autistic Disorder. Given the small sample size of children with lower functioning ASD, caution regarding generalization of findings is necessary.

**Survey Instrument**

Participants independently completed surveys and data was self-reported. Thus, reliability of the data is based on the perceptions of parents who completed the survey. Therefore, the sample’s perceptions may not represent all parents’ perceptions. The survey instrument was web-based, and participants needed access to a computer to complete the survey. Some parents may not have access to computers and thus their participation was improbable. Furthermore, the survey was written in English. Parents who were unable to read English were precluded from the study.

The amount of time estimated to complete the survey was 20 minutes. Some participants may have required more time to complete the survey, whereas others may have required less time. The survey had a total of 99 items. The large number of items and size of the survey may have reduced the response rate.
Implications for Future Research

Previously, only four studies investigated the perceptions or experiences of parents with multiple-aged children who had ASD and the IEP process (Brandt, 2011; Fish, 2006; Lovelin, 2012; Spann et al., 2003), and the total number of parents from all of those studies combined was 104. Findings from this study contribute to the literature base by sharing the perceptions of 87 parents with multiple ages of children with ASD. To gain a greater understanding of the perspectives of parents with children who have ASD, additional studies are necessary. Studies that investigate perceptions of families with low income levels are especially needed. The following paragraphs discuss additional research implications: time, transitions, and evidence-based practices.

Time

Parents in this study perceived that teachers did not have enough time to balance teaching responsibilities and case management. The lack of time inhibited teachers’ abilities to collaborate and communicate with other education professionals regarding their child’s needs, IEP goals, and progress toward meeting IEP goals. The heterogeneity of autism necessitates individualized instructional strategies. Parents reported teachers recommended generic IEP goals because they did not have time to individualize goals and assess their child’s learning needs. Findings from this study are consistent with findings from Lovelin’s (2012) dissertation where parents reported teachers’ lack of time inhibited their ability to collaborate and communicate with them to develop individualized IEP goals. Consequently, parents perceived they received generic IEP goals, common among children with ASD. Additional research is necessary to insure
special education teachers have time to perform both teaching and case management responsibilities and their lack of time does not affect IEP team collaboration.

**Transitions**

A few parents in this study reported that schools did not have programs that facilitated the transition from preschool to elementary school, elementary school to middle school, and middle school to high school. This study’s findings extend the research of Nickels’ (2010) dissertation, which reported that parents believed schools did not adequately prepare for their child’s transition from elementary school to middle school, and middle school to high school. Several studies examine ASD student transition issues and antecedent-based interventions related to transitioning from preschool to kindergarten (Denkyirah & Wilson, 2010; Forest et al., 2004; Quintero & McIntyre, 2010), but few studies investigate antecedent-based interventions that facilitate the transition from elementary school to middle school and middle school to high school (Quintero & McIntyre, 2012). There is a gap in research investigating transitions for students with ASD from elementary school to middle school and middle school to high school. Additional research is necessary to meet the needs of these children and their families.

**Evidence-Based Practices**

Research shows that parents with children who have ASD use the Internet to research autism treatments and interventions (Goin-Kochel et al., 2006; Green et al., 2007; Jegatheesan et al., 2010; Mackintosh et al., 2012). There is a plethora of information available regarding autism treatments and interventions on the Internet, yet
there are no formal studies that investigate the quality of information available on the Internet. Stephenson et al. (2012) studied the quality of information regarding autism treatments and interventions on national autism association websites. The researchers examined web pages from large autism associations for information about EBPs. Findings revealed that a majority of associations do not post information about treatments supported by evidence or provide links to sites that educate the public about EPBs for children with ASD (Stephenson et al., 2012).

Most parents in this study reported they researched autism on the Internet, and consulted with other parents to learn about treatments and interventions. Accordingly, a majority of parents reported they were well educated in special education law and autism. Yet a majority of these parents reported they did not use or implement most of the evidence-based practices for children with ASD.

Future research studies that investigate ways to educate parents regarding EBPs are necessary in order to facilitate the implementation of EBPs in school and home. Parents are equal partners with educators in the IEP process, and they collaborate to develop individualized IEP goals (IDEA, 2004; Zirkel, 2011). Instructional strategies are implemented to facilitate the development of skills identified necessary to master IEP goals (Zirkel, 2011). Parental knowledge of autism treatments and interventions enhances parents’ ability to collaborate with educators to create individualized IEP goals. Parental knowledge of EBPs facilitates the implementation of strategies that are proven effective.

There is a gap in research regarding evidence-based practices that parents perceive effective. The findings from this study confirm findings from two other studies.
(Callahan et al., 2008; Nickels, 2010). However, additional research that investigates the perceptions of parents regarding EBPs for children with ASD are necessary to gain a greater understanding of the interventions and strategies parents perceive effective. Research shows that parents consult with other parents to learn about treatments and interventions (Goin-Kochel et al., 2006; Green et al., 2007; Jegatheesan et al., 2010; Mackintosh et al., 2012), and participants in this study reported they consulted with other parents to learn about autism treatments and interventions too. Understanding parental perceptions of EBPs provides a generalized measure of social validity among individuals who are often heavily involved in implementing such interventions.

Parents in this study indicated they hired advocates to insure their child received the services they needed. Findings from this study are consistent with findings from Fish (2006) in which parents reported they hired advocates to insure appropriate services and therapies were provided. Some parents in this study reported they consulted with advocates to learn about strategies, and they felt advocates enhanced IEP team collaboration by sharing and suggesting strategies in IEP meetings.

Since parents hire advocates as consultants to recommend IEP goals, advocates serve as unofficial IEP team members. Advocates are consultants who have potential to facilitate the implementation of EBPs through discussions with parents and educators. There is limited research that examines the perceptions of advocates regarding evidence-based practices for children with ASD. Furthermore, little is known about the strategies that advocates recommend for families and children with ASD, and where advocates acquired their knowledge of evidence-based practices.
Implications for Practice

This study’s purpose was to gather data regarding parents’ perspectives of the IEP process and evidence-based practices in order to develop strategies that would facilitate IEP team collaboration and implementation of evidence-based practices. This study’s several implications for practice are discussed below.

Communication Prior to Individualized Education Program Meetings

Findings from this study suggest that school IEP teams should prioritize communication with parents prior to IEP meetings. Parents in this study desired increased communication with teachers prior to IEP meetings to develop individualized IEP goals for their child. These findings concur with findings from other studies that report parents want communication before meetings regarding IEP goals (Brandt, 2012; Fish, 2006, 2008; Lovelin, 2012; Jegatheesan et al., 2010, Stoner et al., 2005), and communication with parents prior to IEP meetings builds trust (Fish, 2006; Lovelin, 2012). Parents reported they believed communication before meetings would save time during meetings and facilitate the overall IEP process.

Implementation of Individualized Education Program Goals

Several parents reported they felt teachers did not implement their child’s IEP. Findings from this study are consistent with findings from other studies that report parents believe IEP documents are not implemented in the classroom (Fish, 2006; Hotchkiss, 2012; Stoner et al., 2005; Stoner & Angell, 2006). Research indicates that parents perceive teachers do not implement IEP goals due to a lack of time (Fish, 2006; Hotchkiss, 2012), or a lack understanding of their child’s disability (Fish, 2006).
districts may consider evaluating the implementation of IEP goals in their respective schools, and implementing goals across class settings and the general education classroom.

**Communication Within Schools**

Parents reported they felt teachers and therapists did not converse regarding issues with their child other than at the IEP meeting. Findings from this study are similar to findings from other studies where parents indicated they felt teachers did not discuss their child outside of IEP meetings (Fish, 2006; Nickels, 2010). Given these perspectives, school districts should evaluate collaboration time to insure teachers and therapists have adequate time to discuss issues related to children with ASD.

**Antecedent-Based Interventions for School Transitions**

Given that children with ASD have difficulties with transition and change, parents reported schools did a poor job developing transition plans between preschool and elementary school, elementary school and high school, and high school and postsecondary. Parents indicated that the lack of planning and implementation of antecedent-based interventions created to facilitate these transitions adversely affected their child. Results of this study are consistent with findings from Nickels’ (2010) dissertation where parents also reported difficulties with transitions. School districts need to take the unique needs of children with autism into consideration when developing plans to transition children within schools.
Parent Education and Evidence-Based Practices

A majority of parents in this study indicated they never used most EBPs. However, parents who implemented EBPs reported a majority of EBPs were effective. Programs that educate parents regarding EBPs could provide information about effective practices for children, and enhance IEP goal development that utilizes EBPs to help children acquire skills necessary to master IEP goals. Parents indicated they consulted the Internet and other parents to learn about autism and strategies that would help their child. As noted earlier, findings from this study are consistent with findings from other studies that show parents consult the Internet and other parents to learn about ASD, treatments, and interventions (Goin-Kochel et al., 2006; Green et al., 2007; Jegatheesan et al., 2010; Mackintosh et al., 2012). Programs within the community, schools, and associations that build awareness of EBPs are critical to insure parents have information necessary to evaluate interventions.

Teacher Preparation Programs

Information learned from this study can enhance educators’ understanding of the perspectives of parents who have children with ASD regarding the IEP process and EBPs. Understanding the perspectives of parents has potential to enhance collaboration and communication that facilitates and encourages parental participation in the IEP process. Knowledge of parents’ perspectives of EBPs can help educators find ways to gain a better understanding of interventions and treatments parents perceive to be effective. Also, educators have greater potential to educate parents about interventions that have experimental validity.
Summary and Conclusion

The purpose of this study was to gain a greater understanding of the perspectives of parents who have children with ASD regarding the IEP process and evidence-based practices. The study implemented a mixed methods web-based survey to gather information from parents. A total of 87 parents responded to the survey. The following paragraphs summarize findings.

A majority of parents in this study reported they were treated with respect and felt they were equal IEP team members. They indicated their suggestions were integrated into their child’s IEP, and they believed their child’s IEP would meet their child’s needs. Most parents reported they received adequate feedback regarding their child’s progress toward meeting IEP goals.

Conversely, approximately 50% responded to a single item that they had negative overall perceptions of the IEP process, whereas 35% had positive overall perceptions of the IEP process. The response to this item is inconsistent with other responses, but may be indicative of the highly emotionally charged nature of parents wanting the best education for their children with disabilities. Parents’ responses to open-ended questions suggested that many of these parents perceived the IEP process as adversarial. These parents wrote that services were not always apparent, and advocacy was required to obtain services. Some perceived limited budgets affected services school districts provided and those parents indicated they felt schools did not always provide services unless parents specifically requested them.
A large majority of parents reported they understood their rights, and the steps they would take if they disagreed with the school district. Parents indicated that knowledge of their rights and special education law facilitated their ability to participate equally in the IEP process. Parents hired advocates to insure their child received services they felt their child needed. Advocates were aware of services schools provided and were able to secure these services. Parents reported advocates were effective in enhancing IEP team collaboration and individualizing IEP goals to meet their child’s unique and heterogeneous needs.

Parents also reported that knowledge of their rights and special education law helped them individualize the IEP document for their child. A majority of parents reported they perceived school districts provided generic IEPs, containing similar goals and objectives for all students with ASD. When parents understood their legal rights to contribute equally in the IEP process, they reported they made recommendations and suggestions regarding IEP goals, and suggestions were integrated into their child’s IEP. These parents indicated they believed their suggestions helped individualize their child’s IEP.

Parents reported they perceived teachers’ lack of time affected communication and collaboration with them as well as other teachers and therapists. Some parents wrote they believed teachers recommended generic IEP goals that were predetermined because teachers did not have time to individualize goals. Other parents wrote the only time they believed teachers and therapists met to discuss their child’s needs and IEP was during IEP meetings.
Parents in this study were not aware of many EBPs, but this may have been an artifact of the sample because most parents reported having higher functioning children whereas the EBPs listed were more suitable for children with lower functioning abilities. Parents with children who have ASD are heavily involved in their child’s treatments and interventions (Goin-Kochel et al., 2009; Green et al., 2006; Green, 2007; Mackintosh et al., 2012), and therefore need to know which interventions enhance behavioral, functional, and academic skills. Thus, there is a need for programs that educate parents regarding interventions that are reliable and scientifically valid.

Parents’ knowledge of ASD and advocacy efforts improves the educational programming for their child (Brandt, 2012; Fish, 2006, 2008; Nickels, 2010). In this study a parent wrote,

I have always pushed for measurable goals and ABA techniques in IEP meetings. Early on, our school system, ------ County [acronym], was anti-ABA so the meetings were contentious. Later, due to parent pressure, [the school system] adopted ABA and the meetings became easy.

Increasing parental knowledge can help bridge the research-to-practice gap such that parents advocate for evidence-based practices within school districts for their autistic children.
## APPENDIX A. SURVEY

**Where did you learn about this survey?**

- [ ] Autism Society of America (ASA)
- [ ] Parents for a Free and Appropriate Public Education
- [ ] Partners in Policymaking
- [ ] POAC
- [ ] Statewide Parent Advocacy Network (SPAN)
- [ ] Other

**Short Answer**

- [ ] edit
- [ ] copy
- [ ] delete
- [ ] move up
- [ ] move down
- [ ] add question above
- [ ] add text above

If you selected other, then where did you hear about this survey?

**What is the population where you live?**

- [ ] Urban - City
- [ ] Suburban
- [ ] Rural
- [ ] Other
### What is your education level?
- High School
- Some College
- College
- Advanced Degrees (Masters, JD, MD, Ph. D)

### What is your family’s income level?
- $100,000 or more
- $80,000 – $99,000
- $60,000 - $79,000
- $40,000 - $59,000
- Less than $40,000

### What is your employment status?
- No paid employment
- Part-time employment
- Full-time employment
- More than full time employment
| Multiple choice - pick one | edit | copy | delete | move up | move down | add question above | add text above |

**What type of medical insurance do you have?**

- None
- Private plan (employer sponsored or self-paid)
- Medicaid
- Both private plan and Medicaid
- Other

| Multiple choice - pick one | edit | copy | delete | move up | move down | add question above | add text above |

**What is your ethnicity?**

- African American or Black
- American Indian or Alaska Native
- Arab American
- Asian or Asian American
- Caucasian, White, or Non-Hispanic
- Hawaiian or Other Pacific Islander
- Hispanic or Latino
- Other
Multiple choice - pick one

**What is your marital status?**
- Single
- Married
- Divorced
- Living with partner or relative

Short Answer - one line

**Please write the number of child/children you have with a disability?**

Text

The following questions pertain to your child

Multiple choice - pick one

**What is your child's gender?**
- Male
- Female
<table>
<thead>
<tr>
<th>Multiple choice - pick one</th>
<th>edit</th>
<th>copy</th>
<th>delete</th>
<th>move up</th>
<th>move down</th>
<th>add question above</th>
<th>add text above</th>
</tr>
</thead>
</table>

**What is your relation to your child?**

- Birth child
- Adopted child
- Foster child
- Grandchild
- Other

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<tr>
<th>Multiple choice - pick one</th>
<th>edit</th>
<th>copy</th>
<th>delete</th>
<th>move up</th>
<th>move down</th>
<th>add question above</th>
<th>add text above</th>
</tr>
</thead>
</table>

**What is your child’s Autism Spectrum Disorder diagnosis?**

- Not Sure
- Asperger’s Syndrome
- Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)
- Autistic Disorder
- Rett Syndrome
- Childhood Disintegrative Disorder
**Who diagnosed your child with an Autism Spectrum Disorder?**

- [ ] Neurologist
- [ ] Pediatric Developmental Specialist
- [ ] Psychiatrist
- [ ] Psychologist
- [ ] Primary Care Physician/Pediatrician
- [ ] School
- [ ] Other

**Short Answer - one line**

If you selected other, then who diagnosed your child with an Autism Spectrum Disorder?

**What age was your child diagnosed with an Autism Spectrum Disorder? Please write the number of your child's age.**
### What is your child's age? Please write the number of your child's age.

<table>
<thead>
<tr>
<th>Age</th>
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</table>

### Other than your child’s regular pediatrician, how many doctors did you visit prior to getting an Autism Spectrum Disorder diagnosis?

- [ ] None
- [1] 1
- [2] 2
- [3] 3
- [4] 4
- [5] 5
- [ ] More than 5 doctors

### Does your child have any other diagnosed disability?

- [ ] Yes
- [ ] No
If your child has another diagnosed disability, then what is/are your child's other disabilities? Please check all that apply.

- Attention Deficit Hyperactivity Disorder (ADHD)
- Emotional Disability
- Specific Learning Disability
- Intellectual Disability
- Physical Disability
- Other: 

Does your child have other diagnosed medical conditions? Please check all that apply.

- None
- Epilepsy
- Dietary sensitivities that require medical care
- Gastrointestinal issues that require medical care
- Other: 

other:
### How would you rate your child's behaviors at HOME?

- [ ] Minimal challenging behaviors
- [ ] Some challenging behaviors
- [ ] Significant challenging behaviors

### How would you rate your child's behaviors at SCHOOL?

- [ ] Minimal challenging behaviors
- [ ] Some challenging behaviors
- [ ] Significant challenging behaviors

### What is your child's grade level?

- [ ] Before pre-school
- [ ] Pre-school
- [ ] Kindergarten
- [ ] Grade 1
- [ ] Grade 2
- [ ] Grade 3
- [ ] Grade 4
- [ ] Grade 5
What is your child's educational placement? Please check all that apply

- Honors/Advance Placement/IB General Education classes (no special education teachers or paraprofessionals in room)
- General Education classes (no special education teachers or paraprofessionals in room)
- General Education with paraprofessionals in room
- General Education classes with special education teacher co-teaching
- General education classes and some resource room with special education teacher
- Self-contained class
- Self-contained school
- Home bound
- Hospital/Residential setting
- Post High School program
### Multiple choice - pick one

**Does your child receive supports from a paraprofessional? Please check all that apply.**

- [ ] Not sure
- [ ] No paraprofessional
- [ ] One on one paraprofessional
- [ ] Shared paraprofessional

### Multiple choice - pick one

**If your child receives paraprofessional support, how often does your child receive these support(s)? If your child does not receive paraprofessional supports, please select "no paraprofessional"**

- [ ] Not sure
- [ ] No paraprofessional
- [ ] Infrequently
- [ ] Sometimes
- [ ] Often
- [ ] Always
<table>
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<tr>
<th>Check all that apply</th>
<th>edit</th>
<th>copy</th>
<th>delete</th>
<th>move up</th>
<th>move down</th>
<th>add question above</th>
<th>add text above</th>
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What are the school related services your child uses(used)? Please check all that apply.

- [ ] None
- [ ] Occupational Therapy
- [ ] Physical Therapy
- [ ] Psychological Services
- [ ] Speech Therapy
- [ ] Social Skills Groups
- [ ] Other

If you selected other, then what other related services does your child receive/received?

Short Answer - one line

**Comment/Essay question**

How satisfied are you with these related services?
Have your experiences with related services changed over time? Please explain how they have changed or how they have not changed.

The following questions investigate your experiences and perceptions of private therapies/treatments and early.

If you have used (or are using) the following private therapies/treatments, please rate your satisfaction using the following scale: 1 - Very Poor, 2 - Poor, 3 - Neutral, 4 - Good, 5 - Excellent. If you have never used the private therapy/treatment, then please select 0 - Never Used.

Alternative Diets

- 0 - Never Used
- 1 - Very Poor
- 2 - Poor
- 3 - Neutral
- 4 - Good
- 5 - Excellent
### Applied Behavior Analysis

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<th>Rating</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>0</td>
<td>Never Used</td>
</tr>
<tr>
<td>1</td>
<td>Very Poor</td>
</tr>
<tr>
<td>2</td>
<td>Poor</td>
</tr>
<tr>
<td>3</td>
<td>Neutral</td>
</tr>
<tr>
<td>4</td>
<td>Good</td>
</tr>
<tr>
<td>5</td>
<td>Excellent</td>
</tr>
</tbody>
</table>

### Auditory Integration Training, Listening Program, etc.

<table>
<thead>
<tr>
<th>Rating</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Never Used</td>
</tr>
<tr>
<td>1</td>
<td>Very Poor</td>
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<tr>
<td>2</td>
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### Detoxification treatments

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### Fastforward, Earobics

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## Sensory Integration Therapies

- **Never Used**
- **Very Poor**
- **Poor**
- **Neutral**
- **Good**
- **Excellent**

## Social Skills Therapies

- **Never Used**
- **Very Poor**
- **Poor**
- **Neutral**
- **Good**
- **Excellent**

## Speech Therapy

- **Never Used**
- **Very Poor**
- **Poor**
- **Neutral**
- **Good**
- **Excellent**
If your child has received(s) the following evidenced based practices for youth and children with autism spectrum disorders in school or at home, please rate your satisfaction using the following scale: 1 - Very Poor, 2 - Poor, 3 - Neutral, 4 - Good, 5 - Excellent. If your child has NEVER received the listed evidence-based practice or you are UNCERTAIN whether your child has received the listed evidence-based practice, then please select 0 - Never Used/Uncertain.

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**Pivotal Response Training**

- 0 - Never Used or Uncertain
- 1 - Very Poor
- 2 - Poor
- 3 - Neutral
- 4 - Good
- 5 - Excellent

**Prompting**

- 0 - Never Used or Uncertain
- 1 - Very Poor
- 2 - Poor
- 3 - Neutral
- 4 - Good
- 5 - Excellent

**Reinforcement**

- 0 - Never Used or Uncertain
- 1 - Very Poor
- 2 - Poor
- 3 - Neutral
- 4 - Good
- 5 - Excellent
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**Self-Management**

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**Social Narratives**

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<td>5 - Excellent</td>
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</table>
What sources did you consult to learn about autism treatments and evidence-based practices? Please check all that you consulted.

- [ ] Internet
- [ ] Conference
- [ ] Clinic/Institute
- [ ] School/teachers
- [ ] Occupational Therapist
- [ ] Medical Doctor, Neurologist
- [ ] Parents who have children with autism spectrum disorders

Other Source: [ ]
What sources were most helpful in learning about autism, autism therapies, treatments, and evidence-based practices?

The following questions regard your perceptions of the Individualized Education Program (IEP) process. Please select whether you 1 - Strongly Disagree, 2 - Disagree, 3 - Neutral, 4 - Agree, or 5 - Strongly Agree with each statement.

Overall, I have positive perceptions of the IEP process.

- 1 - Strongly Disagree
- 2 - Disagree
- 3 - Neutral
- 4 - Agree
- 5 - Strongly Agree
<table>
<thead>
<tr>
<th>I feel that I am treated as an equal team member in the IEP process.</th>
<th>1 - Strongly Disagree</th>
<th>2 - Disagree</th>
<th>3 - Neutral</th>
<th>4 - Agree</th>
<th>5 - Strongly Agree</th>
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</thead>
</table>

<table>
<thead>
<tr>
<th>I feel that I am treated with respect by the IEP team.</th>
<th>1 - Strongly Disagree</th>
<th>2 - Disagree</th>
<th>3 - Neutral</th>
<th>4 - Agree</th>
<th>5 - Strongly Agree</th>
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</table>

<table>
<thead>
<tr>
<th>I feel that my input is valuable during the IEP process.</th>
<th>1 - Strongly Disagree</th>
<th>2 - Disagree</th>
<th>3 - Neutral</th>
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<tr>
<td>I feel that educators integrate my suggestions into the IEP.</td>
<td>1 - Strongly Disagree  2 - Disagree  3 - Neutral  4 - Agree  5 - Strongly Agree</td>
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<tr>
<td>Counselors, teachers, and school therapists select and administer appropriate evaluations to determine my child’s learning and behavior needs.</td>
<td>1 - Strongly Disagree  2 - Disagree  3 - Neutral  4 - Agree  5 - Strongly Agree</td>
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<tr>
<td>I feel teachers, school administrators, and counselors take time to discuss alternative school and class placements with me.</td>
<td>1 - Strongly Disagree  2 - Disagree  3 - Neutral  4 - Agree  5 - Strongly Agree</td>
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</table>
Multiple choice - pick one  

Teachers, school therapists, and other education professionals create and recommend individualized IEP goals that are designed to meet my child’s needs.

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<td>Strongly Agree</td>
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Multiple choice - pick one  

Teachers, therapists, and counselors create and recommend generic IEP goals that are common to many students with autism spectrum disorders.

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Multiple choice - pick one  

I feel that my child's IEP will meet my child's education needs.

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<td>Teachers are knowledgeable about my child's disability.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strongly Disagree</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disagree</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neutral</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agree</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strongly Agree</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
I feel school administrators understand my child’s disability.  

<table>
<thead>
<tr>
<th></th>
<th>1 - Strongly Disagree</th>
<th>2 - Disagree</th>
<th>3 - Neutral</th>
<th>4 - Agree</th>
<th>5 - Strongly Agree</th>
</tr>
</thead>
</table>

I feel school administrators are knowledgeable about the IEP process and special education law.  

<table>
<thead>
<tr>
<th></th>
<th>1 - Strongly Disagree</th>
<th>2 - Disagree</th>
<th>3 - Neutral</th>
<th>4 - Agree</th>
<th>5 - Strongly Agree</th>
</tr>
</thead>
</table>

I understand my rights as an IEP team member.  

<table>
<thead>
<tr>
<th></th>
<th>1 - Strongly Disagree</th>
<th>2 - Disagree</th>
<th>3 - Neutral</th>
<th>4 - Agree</th>
<th>5 - Strongly Agree</th>
</tr>
</thead>
</table>
How did you learn about the IEP process and your legal rights?

The following questions involve your experiences with the legal system and special education law.

I understand the steps I would take if I disagreed with the school district.

Does an attorney or advocate attend IEP meetings with you? Please check all that apply.

- No Attorney or Advocate
- Attorney
- Advocate
Have you ever done the following? Please check all that apply.

- [ ] Not Applicable
- [ ] Filed a formal complaint against the school district
- [ ] Negotiated a case through mediation
- [ ] Litigated a case through due process

Other: ________________

If you have been through mediation or due process, please rate your perceptions with the following rating scale 1 - Strongly Disagree, 2 - Disagree, 3 - Neutral, 4 - Agree, 5 - Strongly Agree. If you have not been through mediation or due process, please select 0 - Not Applicable.

I feel the mediation process/due process was fair.

- [ ] 0 - Not Applicable
- [ ] 1 - Strongly Disagree
- [ ] 2 - Disagree
- [ ] 3 - Neutral
- [ ] 4 - Agree
- [ ] 5 - Strongly Agree
<table>
<thead>
<tr>
<th>Question</th>
<th>Rating Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel the mediation process/due process helped my child receive the services they need.</td>
<td>0 - Not Applicable, 1 - Strongly Disagree, 2 - Disagree, 3 - Neutral, 4 - Agree, 5 - Strongly Agree</td>
</tr>
<tr>
<td>I feel that IEP team collaboration improved after going through the mediation process/due process hearing.</td>
<td>0 - Not Applicable, 1 - Strongly Disagree, 2 - Disagree, 3 - Neutral, 4 - Agree, 5 - Strongly Agree</td>
</tr>
<tr>
<td>I feel my child benefited from the outcome of the mediation process/due process hearing.</td>
<td>0 - Not Applicable, 1 - Strongly Disagree, 2 - Disagree, 3 - Neutral, 4 - Agree, 5 - Strongly Agree</td>
</tr>
</tbody>
</table>
If you have worked (work) with an attorney or advocate, please rate your perceptions with the following rating scale: 1 - Strongly Disagree, 2 - Disagree, 3 - Neutral, 4 - Agree, 5 - Strongly Agree. If you have not been through mediation or due process, please select 0 - Not Applicable.

<table>
<thead>
<tr>
<th>Question</th>
<th>Rating Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel that my attorney/advocate is effective in protecting the rights</td>
<td><img src="https://example.com/radio-buttons.png" alt="Radio Buttons" /></td>
</tr>
<tr>
<td>of my child.</td>
<td></td>
</tr>
<tr>
<td>My attorney/advocate is expensive.</td>
<td><img src="https://example.com/radio-buttons.png" alt="Radio Buttons" /></td>
</tr>
<tr>
<td>I feel that my attorney/advocate facilitates IEP team collaboration.</td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>0 - Not Applicable</td>
<td>1 - Strongly Disagree</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What do you feel is effective about the IEP process?</th>
</tr>
</thead>
<tbody>
<tr>
<td>[Question Box]</td>
</tr>
</tbody>
</table>

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What would you like to change about the IEP process?

Please share any IEP experiences in the space below.
APPENDIX B. RECRUITMENT PAPERWORK

Dear Parents,

The attached web based survey provides an opportunity to share your opinions and perceptions of the Individualized Education Program (IEP) process! I am a George Mason University special education doctoral student, who is conducting a research study whose purpose is to understand the perceptions of parents’ of children who have autism spectrum disorders regarding the IEP process. This area is of great interest because schools need to gain a better understanding of parents’ perceptions and experiences in order to engage parents as true partners in the IEP process. Through collaboration, educators are able to wrap services between home and school, extending learning and generalization of skills. I am currently recruiting participants and requesting your participation in an online survey.

The survey is web-based and is located at the following URL:
[URL to be pasted here]

If the hyperlink does not work, please try copying and pasting the URL into a new browser window.

This survey should take approximately 15 to 20 minutes to complete. I greatly appreciate the effort and time you invest in completing this survey. Your input is very important. Should you have questions, please feel free to contact me. Thank you for your time and attention.

Regards,
Catherine Creighton Thompson
REFERENCES


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Jensen-McNiff, B. K. (2012). If the goal is collaboration: Toward more satisfactory inclusion of parents in the individual education plan meetings (Doctoral dissertation). Available from ProQuest Dissertations and Theses Database. (UMI No. 3521951)


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Catherine Creighton Thompson graduated from Robert E. Lee High School, Springfield, Virginia, in 1985. She received her Bachelor of Science in Marketing from Virginia Polytechnic Institute and State University in 1989. She received her Master of Special Education from George Mason University in 2010.