A Qualitative Examination of Factors Influencing Parents' Decision Making Process When Choosing or Rejecting Recommended Services for Their Child Following a Diagnosis of Autism Spectrum Disorder

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A QUALITATIVE EXAMINATION OF FACTORS INFLUENCING PARENTS’ DECISION MAKING PROCESS WHEN CHOOSING OR REJECTING RECOMMENDED SERVICES FOR THEIR CHILD FOLLOWING A DIAGNOSIS OF AUTISM SPECTRUM DISORDER

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To Harrison.
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ABSTRACT

The drastic increase in the number of children identified with autism spectrum disorders has become a “public health concern.” Parents have increasingly been utilized as key components throughout the assessment and diagnostic process. Parents have also become a vital part of the development of interventions and their implementation in their children’s education; and with significant gains. Despite improvements in interventions and service delivery models targeting autism and the abundance of newly diagnosed individuals, services for children with developmental disabilities continue to be difficult for parents and caregivers to access and . A significant portion of parents and caregivers who seek help for their children do not follow through with recommended interventions for a variety of reasons. Closer examination is needed to understand the decision making processes associated with parents’ difficulties, inability, or refusal to access services necessary for their children’s treatment. Another under-researched factor in the treatment of ASDs that may inhibit or facilitate service utilization involves parents’ perception of service characteristics. The purpose of this study is to gain information regarding parents’ perceptions of the multiple factors that may affect their decision making process when deciding which recommended services to utilize for their children following a diagnosis of ASD. This study primarily aims to examine reasons why parents may voluntarily choose to decline recommended services for their child.

This project represents the first attempt to expand upon a previous model of help-seeking behaviors in order to create a model of help-seeking behaviors that explains the specific and unique experiences of parents of children diagnosed with ASD. The expanded theory proposes that, overall, parents’ perceptions of the severity of their children’s symptoms proved to have the
greatest impact on their ability to access and utilize services for their children following a diagnosis of ASD. Parents’ resourcefulness and ability to seek treatments and interventions for their children independently also greatly impacted their ability to access and utilize services. To a lesser extent, “outside influences,” such as family, social, and community support also affected parents’ ability to access and utilize services. Family, social, and community influence as well as pediatricians’ feedback appeared to have the biggest impact on parents’ decision making processes when initiating the diagnostic process. Service providers also had an impact at this stage in the diagnostic and treatment process. Many of the parents reported a desire for coordinated services before, during, following their children’s diagnosis as they had difficulties “navigating the system.” Following their children’s diagnosis, many parents had difficulties deciding which services to access first and which service providers accepted their insurance.
CHAPTER 1
INTRODUCTION

Today, approximately one in every 88 children is diagnosed with autism, with prevalence rates markedly higher for boys at an estimated one in every 54 boys (Centers for Disease Control and Prevention, 2012). These numbers indicate that more children are being diagnosed with autism spectrum disorders than pediatric AIDS, cancer, and juvenile diabetes collectively. In the United States, an estimated 1.5 million individuals are impacted by autism, with national data suggesting that new cases of autism are increasing annually at a rate of 10-17% (Centers for Disease Control and Prevention, 2011). The drastic increase in the amount of children identified with autism spectrum disorders enrolled in educational systems has become a “public health concern” (Levy et al, 2009).

The term “autism spectrum disorders” is used to describe a “spectrum of psychological conditions characterized by widespread abnormalities of social interactions, communication, interests, and behaviors” (World Health Organization, 2006). The Diagnostic and Statistical Manual of Mental Disorders, 4th edition (“DSM-IV”) and the International Classification of Diseases, 10th edition (“ICD-10”), include “autistic disorder,” “Asperger’s disorder,” “pervasive developmental disorder-not otherwise specified” (“PDD-NOS”), “Rett’s syndrome,” and “childhood disintegrative disorder” as “pervasive developmental disorders,” although most clinicians and researchers often use the term “autism spectrum disorders” to refer to autism, Asperger’s disorder, and PDD-NOS (Levy et al., 2009). For the current study, the term “autism
spectrum disorders” will also refer to autistic disorder (“autism”), Asperger’s disorder, and PDD-NOS.

Autism spectrum disorders (ASD) are developmental disabilities that negatively impact individuals’ overall intellectual, adaptive, communicative and social development. Compared to behaviors displayed by the general population, behavior displayed by those diagnosed with ASD is either excessive or in deficit, especially in regards to their social skills and communicative abilities (Dawson, Meltzoff, Osterling, Rinaldi, & Brown, 1998). Core symptoms of ASD affect domains of socialization, communication, and behavior. In order to meet DSM-IV criteria for the diagnosis of ASD, a marked discrepancy between social skills and overall developmental functioning must be observed (Filipek, Accardo, Ashwal, et al., 2000). In terms of socialization, children with autism often exhibit “impaired use of nonverbal behaviors to regulate interactions; delayed peer interactions; few or no friendships; little interaction; absence of seeking to share enjoyment and interests; delayed initiation of interactions; and, little or no reciprocity and absence of social judgment” (Lerman, Sansbury, Hованetz, Wollever, Garcia, O’Brien, & Adedipe, 2008). According to Lerman et al. (2008), their communication is often delayed in verbal language without nonverbal compensation and they often demonstrate “impairment in expressive language and conversation, disturbance in pragmatic language use, stereotyped, repetitive, or idiosyncratic language, and delayed imaginative and social imitative play” (Lerman et al., 2008). Lastly, children with ASD exhibit “restricted, stereotyped, and repetitive patterns of behavior, including preoccupations with stereotyped or restricted interests or topics, adherence to routines, rigidity, and perseverative behavior, stereotyped and repetitive motor mannerisms, and self-stimulatory behavior, preoccupation or fascination with parts of items, and unusual visual exploration” (Levy et al., 2009).
These characteristics of ASD place the individuals living with these disorders at risk for poor outcomes. Ramey and MacPhee (1986) recognized the individual as an “active participant in the developmental process” who learns to develop and adapt skills through varied interactions with the environment. Unfortunately, however, ASD’s often debilitating impact upon social and communication skills qualitatively and quantitatively limit ability of those diagnosed with ASD to serve as active participants in the developmental process thus often perpetuating their impairment (Symon, 2001).

Many studies have documented significant gains in multiple developmental domains for children with ASD when interventions are implemented. (Ben Itzchak & Zachor, 2009). Over the years, increasing evidence has indicated that the age of the child when intervention(s) begin is “predictive of outcome” for children with ASD. Substantial progress in specifically cognitive and educational functioning has been documented in about 47% of children who participated in early intensive behavioral interventions beginning by the age of 3. (Ben Itzchak & Zachor, 2009; Lovaas, 1987; McEachin, Smith, and Lovaas, 1993). Overall, these children display significantly better outcomes than children who began receiving services after the age of five (Woods & Wetherby, 2003; Fenske, Zalenski, Krantz, & McClannahan, 1985; Harris & Handleman, 2000). More recently, research is illustrating the “pressing need to identify and provide intervention for children with ASD as early as possible,” with research findings indicating a greater impact for children participating in interventions before the age of 3 (Woods & Wetherby, 2003).

Recently, parents have increasingly been utilized as key components throughout the assessment and diagnostic process. Parents have also become a vital part of the development of
interventions and their implementation in their children’s education; and with significant gains. Parent education programs, for example, have shown reductions in problem behaviors and improved family functioning for children and families living with disabilities (Koegel, Bimbela, & Schreibman, 1996; Symon, 2001). Many of these improvements have resulted from increasing collaborations between “professionals, schools, agencies, and families in designing intervention programs for children with special needs” to focus on the individual, the family, and “the larger system variables that influence behaviors,” and then “target the development of comprehensive support interventions” (Sheridan, 1997; Symon, 2001).

1.1 Statement of the Problem

At the family and community levels, researchers are identifying the barriers and facilitators of service utilization for children diagnosed with disabilities and their parents (Dunst, Trivette, & Deal, 1993; Fine & Gardner, 1994; Singer & Powers, 1993; Symon, 2001). Despite improvements in interventions and service delivery models targeting autism and the abundance of newly diagnosed individuals, services for children with developmental disabilities continue to be difficult for parents and caregivers to access and navigate (Silver, 2010; Symon, 2001). A significant portion of parents and caregivers who seek help for their children do not follow through with recommended interventions for a variety of reasons. Corsello (2005) reported that while many programs for preschool aged children with ASD exist, not all are widely known or available. In a recent poll conducted by Autism Speaks, three-fourths of parents reported that they are unable to access necessary medical, educational, and recreational services for their child with ASD (Goodwin, 2011). Besides reporting a lack of services, 83% of respondents said they had difficulty finding “appropriate” recreational activities and programs for their child with
ASD. Only 55% of parents polled reported that their employers had flexible work schedule policies that enabled them to work and take care of their child (Goodwin, 2011). Lack of knowledge on how to care for children with ASD within a family’s social network and community can also affect the overall wellness of the family. The parents of children with ASD often report difficulties finding appropriate respite and childcare services (Goodwin, 2011).

Although pediatricians, psychologists, and other interventionists may identify the objections of parents and families as barriers to the implementation of interventions and intervention programs for their children, parents’ views of barriers or their reasons for refusing services have not be extensively researched (Grewal, 2010; Sanchez, 2005; Johnson & Hastings, 2002). Parents cite many reasons for not following through with recommendations or referrals for services such as scheduling conflicts and an inability to afford treatment. Although scheduling and finances are common barriers to services that can be overcome with service planning and financial assistance, closer examination is needed to understand the decision making processes associated with parents’ difficulties, inability, or refusal to access services necessary for their children’s treatment.

Unfortunately, the reasons parents may choose to start or reject a recommended treatment are still not fully understood. There is still much to discover about effective practices for families at the time of diagnosis that may increase parents’ service utilization which, for the purposes of this study, is defined as “the extent to which a given group uses a particular service in a specified period” (Mosby’s Medical Dictionary, 2009). Many factors can influence which services parents choose to utilize for their children following a diagnosis of ASD. Metz, Mulick, & Butter (2005)
postulated many factors that may influence parents’ decision making process regarding choice of
treatment and service utilization, including:

The severity of the disorder; poor prognosis and emphasis on the need for early
intervention encourages parents to find a treatment that will have a quick and
significant impact; lack of knowledge related to the diagnosis and evaluating
evidence-based intervention leads to ill informed decisions; and conflicting
information from professionals with whom they interact and receive services
leaves parents overwhelmed and vulnerable (Metz et al., 2005; Bowker et al.,
2011).

Another under-researched factor in the treatment of ASDs that may inhibit or facilitate
service utilization involves parents’ perception of service characteristics. While lack of available
services is a “clear systems level barrier” to service utilization, perceptions of services that occur
at the familial level can impact a family’s willingness to initiate or continue with recommended
services (Srebnik, Cauce, & Baydar, 1996). Attitudes of professionals, amount of cultural
sensitivity, or simply, hours of operation can have a significant impact on service utilization.
However, in the field of autism research, little research has been conducted to measure the effect
of parents’ perceptions of service characteristics on service utilization.

The purpose of this study is to gain information regarding parents’ perceptions of the
multiple factors that may affect their decision making process when deciding which
recommended services to utilize for their children following a diagnosis of ASD. This study
primarily aims to examine reasons why parents may voluntarily choose to decline recommended
services for their child. There are two research questions that guide the study:
1. According to parents, what factors are the most influential in their decision-making process when deciding which services to utilize for their children following a diagnosis of ASD?

2. What factors may influence parents to voluntarily reject recommended services for their child following a diagnosis of ASD?
CHAPTER 2
REVIEW OF THE LITERATURE

The purpose of this chapter is to review the literature relevant to understanding the perspectives of parents of children with ASD about characteristics of services and their potential impact on their abilities to utilize services. This review presents theoretical and empirical information that serves as the framework for the present study. This review describes commonly recommended treatments for ASDs as well as previous research regarding level of access to services and parents’ perception of their abilities to access these recommended services. A description of a theoretical framework for help-seeking behaviors and service utilization is also provided. Lastly, a summary of the literature review and implications for the present is provided.

2.1 Treatment and Interventions

As research in neurobiology, cognition, affective developmental neuroscience, and genetics have advanced, methods for early detection and treatment have improved (Dawson, 2008). Many different methods rooted in various concepts have been applied to treat autism spectrum disorders. Oftentimes, their effectiveness in a given specific case depends upon many factors, such as characteristics of the child, their environment, and level of education (Pisula, 2003). Many forms of treatments and interventions have become available over the years, such as stimulants, hormone therapy, vitamins, antipsychotic medications, intensive behavioral therapies, educational therapies, ancillary services, and strict diets. However, many parents still experience difficulties when finding treatments that have been scientifically supported to help their children and attempting to access them (Exkorn, 2006; Goodman, 2011). Despite these newly available
treatments, it is still unclear which treatments will be most effective and who will receive benefits from utilizing these treatments (Rogers & Vismara, 2008). Many interventions address core deficits, such as social connectedness, self-control, and awareness, and associated conditions, such as anxiety and ADHD. Early screening and diagnosis is important for the treatment of ASD as core symptoms may be best overcome when treatment is begins in early childhood (Wagner et al., 2006).

As Vismara & Rogers (2008) and others have found, the recent trend toward diagnosing ASD at younger and younger ages has made the development and evaluation of interventions for young children absolutely crucial. As ASD has been regularly identified at earlier developmental stages and more infants and toddlers have been referred to early intervention programs, empirical research has come to demonstrate that children receiving such treatment at younger ages “make greater gains than those who enter programs at older ages” (Corsello, 2005; Harris & Handleman, 2000; Sheinkopf and Siegel, 1998; Vismara & Rogers, 2008). Indeed, the positive outcomes of early intervention (EI) for children with ASD have been thoroughly documented (Hume, Bellini, & Pratt, 2005; Hurth, Shaw, Izeman, Whaley, & Rogers, 1999; National Research Council, 2001; Rogers, 1999, 1996; Simpson, 1999; Woods & Wetherby, 2003). These and other studies suggest that the best outcomes result where treatment begin prior to age 5 (Hume, Bellini, & Pratt, 2005; Fenske, Zalenski, Krantz, and McClannahan, 1985).

Despite these outcomes, there are still questions about what intervention strategies, settings, and materials are most suitable for supporting and stimulating growth in the social, communication, motor, and cognitive functioning domains in preschool aged children (Corsello, 2005). Most professionals agree about the vital facets of treatment, such as “intensity” and
“family involvement,” and there is empirical evidence supporting the efficacy of some interventions. There remains a lack of research, however, that compares the vast array of intervention programs (Corsello, 2005). Although various philosophies have formed the basis of many different treatment programs for children and their families affected by ASD, families, five treatment areas have established empirical support and are commonly recommended by psychologists following an ASD diagnosis: Behavioral, educational, allied health and ancillary services, medical, and complementary and alternative medicine (Warren et al., 2011).

2.1.1 Behavioral Treatments

When autism was first described and treated in the 1940s, the distinguishing behaviors related to it “were found to be unresponsive to the prevailing psychoanalytic treatments” (Matson, Benavidez, Compton, Pacalawskyj, & Baglio, 1996). With increased popularity in behaviorism in the 1960s, Ferster (1961) first attempted to understand the behavior of “autistic children” within a behaviorist framework. He, and other researchers of that time, postulated that the distinguishing features and behaviors of autistic children were “controlled contingently by the reinforcers and punishers in the environment” (Prizant & Rubin, 1999). Ferster and DeMyer (1962) concluded that “autistic children’s” behaviors could be linked to environmental changes through modifications to behavioral consequences. These results steered the creation of behavioral interventions that ultimately improved the individual’s behaviors and outcomes and thus validated the long-term, intensive, and individualized behavioral interventions provided by behavioral analytic theory (Dawson & Osterling, 1997; Lovaas, Koegel, Simmons, & Long, 1973; Matson et al., 1996; Prizant & Rubin, 1999).
Treatments very often focus on the behavioral or developmental expressions of core symptoms because these are among the most noticeable symptom (Levy et al., 2009). As children are developing communication and social skills, early intervention utilizing a behavioral approach appears to be the most effective form of treatment, particularly when dealing with “aggressive, self-injurious, hyperactive, hyperarousal, and anxiety symptoms” (Twedell, 2008). As noted above, mounting evidence suggests “intensive early intervention services” for children who were diagnosed with autism before the age of 5 years may lead to better overall outcomes. One of the most popular and widely cited studies of “early intensive interventions” with young children, conducted by Ivar Lovaas (1987), reported the effects of using “one-to-one” behavioral training for 40 hours a week over a course of two years. Children participating in the study had a mean age of 2.8 years. The methods Lovaas utilized focused on the acquirement of “compliance behavior, imitation activities, language acquisition, and integration with peers using repeated discrete behavioral trials to accomplish goals” (Pediatrics, 2001). After completing the two year course of treatment, almost 50% of participants were functioning at age and developmentally appropriate levels in intellectual and academic areas. After five years, most had maintained their gains (McEachin, Smith, & Lovaas, 1993). The methods used in this study would later shape the framework for the widely used ASD treatment intervention known as ABA or applied behavioral analysis therapy.

Applied behavioral analysis is “the process of systematically applying interventions based upon the principles of learning theory to improve socially significant behaviors to a meaningful degree, and to demonstrate that the interventions employed are responsible for the improvement” in behaviors (Baer, Wolf, & Risley, 1968; Sulzer-Azaroff & Mayer, 1991). Applied behavioral analysis uses different procedures, such as Discrete Trial Training, to teach play, social,
communication, and relationship building skills through the use of rewards system, peer modeling, activity schedules, inclusion support, and the breaking down of tasks into small teachable steps that children can learn more easily (Exkorn, 2006). Myers and Plauché (2007) listed six ways ABA methods are used to support children with ASD:

1. “To increase behaviors (e.g. reinforcement procedure increase on-task behavior or social interactions);”
2. “To teach new skills (e.g. systematic instruction and reinforcement procedures teach functional life skills, communication skills, or social skills);”
3. “To maintain behaviors (e.g. teaching self-control and self-monitoring procedures to maintain and generalize job-related social skills);”
4. “To generalize or to transfer behavior from one situation or response to another (e.g. from completing assignments in the resource room to performing as well in the mainstream classroom);”
5. “To restrict or narrow conditions under which interfering behaviors occur (e.g. modifying the learning environment);” and
6. “To reduce interfering behaviors (e.g. self injury or stereotypy).”

Many studies have demonstrated how ABA interventions utilized by children with ASD at a young age can improve intellectual and communicative functioning (Vismara & Rogers, 2008; Anderson, Avery, DiPietro, Edwards, & Christian, 1987; Birnbrauer & Leach, 1993; Fenske, Zalenski, Krantz, & McClannahan, 1985; Harris, HANDLEMAN, Gordon, Kristoff, & Fuentes, 1991; Lovaas, 1987; Sheinkopf & Siegel, 1998; Weiss, 1999). ABA can be taught in a number of settings, including formal one-on-one treatment sessions at home or at school. Parents are
encouraged to participate in their child’s treatment so they can help generalize their child’s skills to the outside world (Exkorn, 2006).

Research shows that the most beneficial type of treatment involves the combination of developmentally oriented treatments, parental support, and special education is likely to be most beneficial (Rutter, 2006). Providing parents and other family members of children with ASD support and training “empowers families to advocate for their child, allows them to continue to teach their child, improves the child’s compliance, and decreases stress within the family” (Shattuck & Grosse, 2007). The Early Start Denver Model (ESDM) integrates a “relationship-focused developmental model” and the teaching of Applied Behavioral Analysis (ABA). Developed by Rogers and Dawson, ESDM is an “early-age extension” of the Denver Model, defined as a “developmental play approach geared towards children ages 2 to 5 years, that features naturalistic applied behavioral analytic strategies; sensitive to normal developmental sequence; deep parental involvement; focus on interpersonal exchange and positive affect; shared engagement with joint activities; and language and communication taught inside a positive, affect-based relationship” (Eikeseth, 2008; Rogers & Dawson, 2009; Vismara & Rogers, 2008).

Designed to be effective for children with ASD at ages 12 to 48 months across a wide range of abilities and learning styles, (Autism Speaks, 2005), ESDM has been proven effective for children with ASD as young as 18 months and older children with significant learning challenges (Vismara & Rogers, 2008). One study showed that children who received 20 hours of “ESDM therapy a week over a 2-year span showed greater improvement in cognitive abilities, language
abilities, and adaptive behavior than children who were referred for interventions commonly available in their communities” (Rogers & Dawson, 2009).

Pivotal Response Training (PRT) is also grounded in the principles of ABA. PRT, previously called the Natural Language Paradigm (NLP), was developed by Koegel and Koegel and is used to increase primary “pivotal” behaviors, like “motivation, responding to multiple cues, self-management, self-initiation,” and initiation of communication with others (Koegel & Koegel, 1988; Koegel, Schreibman, Good, Cerniglia, Murphy, & Koegel, 1989). According to Vismara and Bogin (2009), these skills are described as “pivotal” because they are the “foundational skills upon which learners with ASD can make widespread and generalized improvements in many other areas.” PRT aims to improve “communication skills, play skills, social behaviors and the child's ability to monitor his or her own behavior” through targeting individual behaviors based on an established curriculum (Vismara & Bogin, 2009). In addition to helping children increase motivation, Koegel, Koegel, and Surrat (1992) found that the implementation of PRT also leads to decreases in disruptive behaviors and parental stress (Koegel, Bimbela, & Schreibman, 1996). Incorporating pivotal behaviors into parent education programs allows parents to become “active intervention agents” in their child’s rehabilitation process, which aids in the creation of an ideal learning environment for the child and decreases parental stress (Koegel, Koegel, & Carter, 1998).

PRT’s objective is to provide children with ASD “the social and educational skills to participate independently in enriched and meaningful lives in inclusive settings” (Vismara & Bogin, 2009). PRT has been utilized in a variety of “naturalistic settings” in large part to PRT’s emphasis on training parents, family members, staff and typically developing peers as
“intervention agents.” PRT’s use of diverse and naturalistic teaching environments has also been found to encourage the generalization of skills (Vismara & Bogin, 2009). Studies have indicated that children with ASD from 2 to 16 years of age can benefit from PRT interventions. However, the most significant gains have been shown in children who receive PRT interventions before the age of 5. Research has shown that PRT techniques, specifically motivational techniques, can lead to the development of verbal communication as a main mode of communication in 85-90% of children (Koegel, Camarata, Koegel, Ben-Tall, & Smith, 1998; Vismara & Rogers, 2009).

Floortime is a developmental therapeutic technique grounded in the ideals of Developmental Individual Difference Relationship Model (DIR) developed Stanley Greenspan. Floortime is based on the premise that an adult can help a child “expand their circles of communication” and move more increasingly towards complex interactions by meeting the child at their developmental level, entering their activities so as to build on the child’s strengths, and by sometimes following the child’s lead. (Greenspan & Wieder, 1997). Instead of addressing cognitive, speech, and motor development separately, Floortime addresses cognitive, speech, and motor skills “through a synthesized emphasis on emotional development” (Greenspan & Wieder, 2005). Emotional development and intellectual growth is achieved through the attainment of six developmental milestones: “Self-regulation and interest in the world; intimacy or a special love for the world of human relations; two-way communication; complex communication; emotional ideas; and, emotional thinking” (Greenspan & Wieder, 1997). Greenspan and Wieder (2005) reported that 16 teenage boys who participated in DIR/Floortime therapy during early childhood had “healthy peer relationship[s] and solid academic skills” ten to fifteen years later.
Cognitive behavioral interventions commonly used to treat typically developing children can also be used to ameliorate anger and anxiety symptoms often comorbid with symptoms of ASD. (Chalfant, Rapee, & Carroll, 2007; Reaven, Blakeley-Smith, et al., 2009). Other challenging behaviors, like defiance, tantrums, self-injury, and aggression can be targeted using parent training protocols to teach behavior prevention, intervention, and management strategies and enable parents to act as “co-therapists” who can help shape their children’s behaviors to reduce negative behaviors in daily life. Parent training interventions have also been shown to improve parents’ “feelings of self-efficacy and decreasing parental stress” (Reaven & Hepburn, 2003). Neurofeedback and sleep interventions have also been used to target specific behaviors associated with ASDs by remediating abnormal brainwave activity and improving difficulties associated with sleep respectively (Muris, Steerneman, Merckelback et al., 1998).

2.1.2 Educational Treatments

One area where parents often advocate for their children is in the area of education. Most children with ASD receive at least some treatment in an educational setting, beginning with preschool (Warren et al., 2011). Special interventions that target children with ASDs in the classroom are not only necessary in helping them learn academic subjects and acquire reading skills. According to Myers & Johnson (2007), educational interventions help children with ASDs “improve functional communication, enhance social skills such as joint attention, gain cognitive skills such as symbolic play, reduce disruptive behavior, and generalize learned skills by applying them to new situations.” Several educational intervention models have been developed, such as “early intervention services, low student/teacher ratio, family involvement and parent training, interaction with neurotypical peers, structure that includes predictable routines and clear
The combination of “intensive, sustained special education programs and behavior therapy early in life” has increased children’s abilities to acquire self-care, social abilities, and job skills in previous studies. It has also been shown to improve overall functioning and reduce “symptom severity and maladaptive behaviors” (Howlin, Magiati, & Charman, 2009; Myers & Johnson, 2007; Rogers & Vismara, 2008). In one study, children with ASDs whose parent received a home-based training program for the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) experienced significantly greater educational achievement than those children with ASDs whose parents received no such training (Ozonoff & Cathcart, 1998). Previous studies have indicated that behavioral management in the classroom must be combined with “structured teaching of skills” to prevent the development of undesirable behaviors and improve adaptation. It has also been found that integrating children with ASDs into child care centers, classrooms and other learning centers where typically developing children participate effectively reduced the incidence of undesirable behaviors because, it is believed, the typically developing children serve as role-models for the children with ASDs (Shattuck & Grosse, 2007).

Recently, early intervention services have attempted to provide more “naturalistic educational experiences.” Federal law and the Office of Special Education Programs have followed suit with regulations stating “To the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate” (Part C of the
Individuals with Disabilities Education Act, 34 CFR Part 303, Early Intervention Program for Infants and Toddlers with Disabilities, section 300.12b). This approach often includes educating children with disabilities and integrating specialized services in the classroom alongside same-aged typically developing children. Classroom- and center-based approaches include a blend of teaching strategies that rely on principles and techniques of ABA including reinforcement-based procedures such incidental teaching, discrete trial training, and Pivotal Response Training. Computer-based programs can be used in the classroom to deliver behaviorally-based teaching in areas like language acquisition and reading skills (Warren et al., 2011).

TEACCH is an internationally renowned special education program for children with ASD (Eikeseth, 2008). Developed in 1966 by Eric Schopler (Schopler & Reichler, 1971), TEACCH seeks to “address multiple problems, such as communication, cognition, perception, imitation, and motor skills and emphasizes teacher in multiple settings with the involvement of several teachers” (Eikeseth, 2008). TEACCH interventions contain five components: “Structured Teaching, strategies to enhance visual processing, communication systems based on gestures, pictures, signs, or printed words, pre-academic skills, and parent involvement” (Eikeseth, 2008; Mesibov, Shea, & Schopler, 2005; Schopler & Mesibov, 1985). TEACCH interventions are designed to be “meaningful” to the child with ASD and capitalize on common strengths shared by many individuals with ASD, such as visual and motor skills and enjoyment of routine (Boswell & Gray, 2011; Corsello, 2005.) The result is a highly structured environment that supports learning, increases independence and self-esteem, and reduces behavior problems, confusion, anxiety, and stimulation (Boswell & Gray, 2011).

Another comprehensive curriculum that uses practices from popular developmental behavioral interventions is SCERTS. Developed by Barry Prizant, Amy Wetherby, Emily Rubin,
and Amy Laurant (2003), SCERTS an evidence-based curriculum most concerned with helping children with ASD enhance their communication and socio-emotional functioning and improve family interactions and support in a variety of settings (Walworth, 2007). The acronym SCERTS refers to the three specific areas the intervention focuses on: Social Communication, Emotional Regulation, and Transactional Support. Social Communication is divided into the developmental domains of joint attention and symbol use. It focuses on helping the child develop functional communication, emotional expression, shared attention, reciprocal interactions, and the ability to repair communication breakdowns (Walworth, 2007). Emotional Regulation, divided into self-regulation and mutual regulation, refers to the ability to maintain a “well-regulated emotional state,” respond to social and sensory experiences with differentiated emotions, and ability to respond appropriately to feedback (Prizant, Wetherby, Rubin, & Laurant, 2003; Walworth, 2007). Lastly, Transactional Support contains the areas of interpersonal support and learning support and refers to “the development and implementation of supports to help partners respond to the child's needs and interests, modify and adapt the environment, and provide tools to enhance learning” (Autism Speaks, 2005; Prizant, Wetherby, Rubin, & Laurant, 2003; Walworth, 2007).

LEAP, which stands for “Learning Experiences - An Alternative Program for Preschoolers and Parents,” is a “developmentally-integrated preschool” program for typically developing children and children with ASD (Strain & Bovey, 2011). Typically developing peers as young as 36 months are taught to facilitate the social and language skills of children with ASD (Goldstein & Wickstrom, 1986; Strain & Danko, 1995; Strain & Bovey, 2008; Strain & Bovey, 2011). Peer facilitated strategies result in higher rates of communicative interaction and increased social
participation for preschoolers with ASD (Goldstein & Wickstrom, 1986; Strain, 1987; Kohler & Strain, 1999; Strain & Bovey, 2011).

LEAP also utilizes multiple other evidence-based practices, such as “Conscious Discipline” and ABA techniques, which are embedded into typical preschool routines each day and allow for teachers to address problem behaviors by teaching compatible, more adaptive and pro-social skills (Bovey & Strain, 2011). Transdisciplinary service delivery is used to encourage the generalization of skills throughout settings and systemic, daily data collection on children’s progress on IEP objectives is used to determine future instructional plans (Strain & Bovey, 2011).

2.1.3 Allied Health and Ancillary Services

Children with ASDs often receive specialized ancillary services in both school and private settings. These can include speech therapy, physical therapy, occupational therapy, sensory integration therapy, and auditory integrative therapy (Baker-Ericzen et al, 2005). Speech and language therapy is essential in helping a child to communicate more effectively both verbally and nonverbally. With the help of speech and language pathologists, children learn how to form words, develop a system of communication, process information, and express themselves. Speech and language pathologists also teach children the pragmatics of language how to read body language and facial expressions, and organize their thinking (Exkorn, 2006).

Case-Smith and Arbesman (2008) note that “children with ASD often have a range of motor and performance problems that interfere with their full participation in school, home, and community activities.” Physical therapy is often prescribed for children with ASDs to enhance their physical abilities by treating low muscle tone, poor posture, balance, and coordination.
Physical therapists can assist children with ASDs to increase endurance, develop motor control and motor planning, and facilitate body awareness (Exkorn, 2006).

Occupational therapy provides support for young children with ASDs who have difficulty with “sensory, motor, neuromuscular, and/or visual functioning” by focusing on the enhancement of sensory processing, sensorimotor performance, social-behavioral performance, self-care, participation in play, balance, and appropriate response to touch. In older children and adolescents, Case-Smith and Arbesman note that occupational therapy goals “may focus on social and behavioral performance, transition to work, and independence in the community.”

Sensory integration is specialized occupational therapy based on the premise that the brain’s response to basic sensory input must be normalized before higher order processes can be addressed (Baron-Cohen, Ashwin, Ashwin, Tavassoli, & Chakrabarti, 2009). Sensory integration therapy focuses on tactile, auditory, vestibular, and proprioceptive senses and involves “taking information through the senses,” organizing, and integrating this information in the brain (Exkorn, 2006). The approach anticipates that a child who is better able to process, modulate, and integrate sensory information will then be better able to acquire higher order skills (Warren et al., 2011).

2.1.4 Medical and Related Interventions

A 2009 Minnesota study found that parents are significantly more likely to follow medical recommendations than they are to follow behavioral treatment recommendations (Moore & Symons, 2009). Medical treatments for ASDs comprise a variety of interventions including medication, supplements, and other treatment modalities. Although there is no pharmacologic
cure for autism, psychotropic medications have been use to combat aggressive behaviors, self-injurious behaviors, affective instability, hyperactivity, hyperarousal, and anxious behaviors (Twedell, 2008). Medical treatment for symptoms of ASDs comprise a variety of pharmacologic agents including antipsychotics, psychostimulants, and serotonin reuptake inhibitors (SRIs) that are generally intended to treat common comorbidities of ASDs, such as hyperactivity, aggression, and obsessive preoccupations (Exkorn, 2006; Warren et al., 2011). McDougle et al. (2006) reported the use of methylphenidate, atomoxoetine, and the alpha-adrenergic agonists clonidine and guanfacine to address motor hyperactivity and inattention. Fluoxetine and risperidone have been helpful in treating interfering repetitive behavior and reducing and treating aggression, self-injurious behaviors, tantrums, and irritability (Twedell, 2008). Exkorn (2006) notes that medication can “help increase the benefits of other interventions” that specifically target ASD symptoms that hinder a child’s overall ability to function in “educational, social, and family settings” (Exkorn, 2006).

Modalities such as therapeutic diets, supplements, hormonal supplements, and immunoglobin also have been employed to treat ASD symptoms (Warren et al., 2011). The most popular diet for children with ASDs is the gluten-free/casein-free diet. There is evidence that children with ASDs may be deficient in some vitamins and minerals; and have difficulties digesting gluten, casein, and certain proteins. They are also more likely to suffer from food allergies, increased levels of yeast, and other gastrointestinal problems that may exacerbate symptoms of ASD, such as lack of focus and irritability (Exkorn, 2006). Multiple studies have reviewed the efficacy of vitamin B6 and magnesium in the treatment of ASD. Pfeiffer, Norton, Nelson, and Shott (1995) reviewed 12 studies on the effectiveness of megavitamins, specifically vitamin B6 and magnesium, and found that combined B6 and magnesium treatment “may be a
promising adjunct to the treatment of autism.” Pfeiffer et al. (1995) also noted an amelioration of autistic behaviors during treatment with vitamin B6 and magnesium.

Other medical treatments, such as hyperbaric therapy and chelation therapy have also been used to treat ASD. However, little is known about how efficacious these therapies are in treating ASD. Hyperbaric therapies have shown possible effects in chronic neurological conditions, but they have only undergone preliminary exploration in treatment for ASDs (McDonagh, Morgan, Carson, et al., 2007; Warren et al., 2011). Chelation is a treatment that is administered either orally or intravenously to remove unwanted metals, specifically mercury, from the bloodstream (Exkorn, 2006). Although no clear evidence suggests that mercury or ability to remove mercury from the body is involved in ASDs, researchers are still evaluating the ability of chelation therapy to affect ASD symptoms (Boscolo, Antonucci, Volpe, et al., 2009).

### 2.1.5 Complementary and Alternative Medicines Interventions

Complementary and alternative medical (CAM) treatments are utilized by more than thirty percent of children and families living with ASD. CAM is defined as a “range of treatments and their theories outside of traditional medicine” (Levy & Hyman, 2002). Acupuncture and acupressure, a component of traditional Chinese medicine, is based on the balance of energy flows in which imbalance is through to result in disease (Warren et al., 2011). Acupuncture has been used to treat symptoms of hyperactivity, sleep disturbances and touch aversion (Exkorn, 2006). Massage has also been used to ameliorate imbalance in the energy fields of the body and improve sensory difficulties (Warren et al., 2011).
The variety in the development of treatments, and differences in the symptomatology and comorbidity among children with ASDs has limited the availability of novel intervention methods (Shattuck & Grosse, 2007). Most researchers agree that intensive intervention can reduce or alleviate ASD’s symptoms but little research has focused on which specific interventions work best for different groups of children (National Research Council, 2001; Rogers and Ozonoff, 2006). Most research, however, has specifically focused on autism (as opposed to the broader spectrum of ASDs) and, even then, has examined the efficacy of treatments within tightly controlled, small sample sizes with wide variations in individual treatment outcomes (Rogers and Ozonoff, 2006). As a result, there is a lack of certainty as to whether intensive intervention would benefit every child diagnosed with ASD. This makes it difficult for policy makers to respond to growing demand for specific interventions (Atkins et al., 2005; Lomas et al., 2005). Before they can properly allocate limited resources, policy makers need to know what interventions work best, which are most readily adopted by caregivers, and how they are best delivered (i.e., at home or in more inclusive environments) (Shattuck & Grosse, 2007). Unfortunately, data answering these questions is scarce especially on a larger scale.

In conclusion, research has shown that early intervention for children with ASDs can improve their overall development, especially in the areas of speech development and social skills. Research supports that gains in cognitive performance, academic achievement, adaptive skills, and language can be mostly attributed to early, intensive developmental and behavioral interventions (Warren et al., 2011). Other educational and ancillary services are often used in conjunction with developmental and behavioral interventions to create a “complete treatment program” for children diagnosed with ASD (CDC, 2012). Some dietary treatments and
medication have been used to treat related symptoms of ASD, such as high energy, difficulties focusing, and repetitive behaviors. While some parents have observed positive changes to their children’s behaviors when dietary changes and medication management are implemented, many of the treatments do not have the empirical support to warrant widespread recommendation (CDC, 2012). Complementary and alternative treatments, although utilized by a report 1/3 of parents of children diagnosed with ASD, are often prescribed and/or utilized without the advice or supervision of pediatrician and other health care professionals. These may include special diets, the use of hyperbaric chambers, or chelation therapies (CDC, 2012, Warren et al., 2011). These treatments also lack empirical support and may potentially be dangerous (Warren et al., 2011).

2.2 Use of Services for Autism Spectrum Disorders

The prevalence and complexity of ASDs have put huge demands on evaluators and therapeutic service providers (Ruble & McGrew, 2007). Children with ASDs and their families require and utilize the services of multiple service agencies, professionals, and funding sources. Typically, the youngest patients and their families receive the widest array of such services (Liptak et al., 2006; Thomas et al., 2007; Young, Corea, Kimani, & Mandell, 2010). The National Health Interview Survey conducted by Newacheck and Halfon (1998) found that children with disabilities reported three times the rate of physician contacts when compared to children without disabilities. These findings were corroborated by Croen et al. (2006) who demonstrated that, “in comparison to the general population and to other children with special health care needs, children with autism spectrum disorders use services at a significantly higher rate” (Young, Corea, Kimani, & Mandell, 2010). Specifically, Croen et al. (2006) and Young,
Corea, Kimani, & Mandell (2010) found that children diagnosed with ASDs “have a higher annual mean of total clinic, pediatric, and outpatient visits” and a higher percentage inpatient and outpatient hospitalizations.

Thomas et al. (2006) surveyed 383 families with a child diagnosed with ASD 11 years or younger. Results indicated that many of the services that children with ASDs and their families utilize are provided from outside the child’s school system (e.g., “medical intervention, biomedical treatments, speech and language therapy, occupational therapy, behavior intervention, respite care, social skills therapy, family counseling, and case management”). While behavioral interventions have been found to be the most effective treatment for ASD, many families commonly use other treatments and seek alternatives to commonly recommended treatments (Bowker, Angelo, Hicks, & Wells, 2011; Goin-Kochel et al., 2007; Green et al., 2006). Croen et al. (2006) found that children with ASDs “were nearly 9 times more likely to use psychotherapeutic medications and twice as likely to use gastrointestinal agents.” Goin-Kochel et al. (2007) found that children diagnosed with ASDs received four to six different treatments simultaneously. In a 1999 study, Kohler found that many of the families participating in the study interacted with multiple agencies to receive recommended services. On average, families “received approximately 37 hours of intervention a week comprising of six different services from four or more agencies involving seven or more professionals” (Kohler, 1999). Treatment use also differs by age. Goin-Kochel et al. (2007) found that younger children often utilize more behavioral, educational and alternative treatments while older children were found to utilize more medication management.

Despite the large number of intervention hours used, evidence suggests that children with ASD do not receive the full amount of services recommended. In a national survey of children
with special health care needs, Krauss, Gulley et al. (2003) found that over a third of children with ASD had difficulties utilizing “needed care” in the previous year. Parents reported difficulties receiving referrals and finding appropriately trained providers. In comparison to children with other disabilities or health care needs, children with ASD were more likely to experience overall access problems (Krauss, Gulley et al., 2003). Kohler (1999) identified several problems with service utilization for ASD treatments and interventions including difficulties accessing services, limited involvement of parents and other family members in intervention, and reports that providers were unwilling to engage in interagency collaboration. A survey of 383 families with a child with ASD found that “access to care” was limited for individuals with ASD living in racial and ethnic minority families. “Access to care” was also limited for individuals with ASD whose parents had low levels of education, were living in nonmetropolitan areas, and for individuals who were not utilizing a major treatment approach (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). These barriers to service utilization create complications in addressing questions about treatment effectiveness (Makrygianni & Reed, 2010).

With recent estimates from the CDC indicating that the number of children diagnosed with ASD is increasing from 1 in 150 children in 2007 to 1 in 88 in 2011 (CDC, 2007; CDC 2012), the states’ capacity to provide children with ASDs and their family related services and supports has been limited due to budgetary constraints, lack of qualified practitioners to deliver evidence-based services, inconsistent health insurance coverage, lack of standardized training for screening, and lack of accurate and localized information for parents (Finneman, 2010; Young, Corea, Kimani, & Mandell, 2010). Ruble, Heflinger, Renfrew, and Saunders (2005) found that, over time, more and more children are receiving services but that the rate of utilization was only
one-tenth of the projected amount based on the prevalence of ASD diagnoses. Among children with a mean age of 8.9 years (SD = 4.4 years,) the number of service days each child received declined by approximately 40%. The most prevalent forms of treatment have also changed. Day treatment programs have declined drastically while the use of medication and case management has grown disproportionately to the number of children served (Ruble et al., 2005). Stahlmer and Mandell (2007) suggested that that state policies were major contributors to these changes. They found “an absence of uniformity among states in policies and practices regarding the identification and care of infants and toddlers with autism” (Young, Corea, Kimani, & Mandell, 2010). Drastic differences in criteria for the diagnosis, assessment, and care of infants and toddlers with ASD were found in a national study of states’ policies and procedures for EI services. Only a few states have guidelines and policies in place to provide services to children with ASD, with 20% of states having “diagnostic guidelines” and one fourth having “treatment guidelines.” Only 7% of states require that professionals use a specific discipline for diagnosis (Stahlmer & Mandell, 2007; Young, Corea, Kimani, & Mandell, 2010).

Once a child receives a diagnosis of ASD, there are still many difficulties accessing recommended EI services. Only 15.9% of families report access to social skills development curricula or inclusion support in preschool programs (Hurth et al., 1999). Meanwhile, only 25.6% of families strongly agreed “that integration opportunities were provided for their children” (Hume, Bellini, & Pratt, 2005; Hurth et al., 1999). Though family involvement is strongly encouraged in EI services, only 21% of parents of young children diagnosed with ASD reported receiving parent training (Hume, Bellini, & Pratt, 2005; Hurth et al., 1999). Surprisingly, 66% of respondents in the Hurth et al. (1999) study reported that they received less than the recommended number (25) of service hours per week.
In a 2011 study conducted by Bowker, D’Angelo, Hicks, and Wells, 23% of the 281 children and families participating in the study reported that they had never received treatment for ASD. The factors surrounding their lack of service utilization was unclear. However, specific diagnosis of the child and where the individual lived affected the likelihood of the child receiving treatment (Bowker et al, 2011). Information regarding discontinuation of services was also provided, with nearly a third of families participating in the study discontinuing at least one type of treatment for their child with ASD. Medications, alternative diets, and physiological treatments were found to be the most commonly discontinued, with parents citing that their child was not benefiting from the services (Bowker et al., 2011). In situations where parents believed that their child was benefiting from services, they still reported instances where they had to discontinue services because the services were no longer available to them (Bowker et al., 2011). These findings support the findings of Goin-Kochel et al. (2007) who concluded that, often, the parents of children with ASDs simultaneously utilize both empirically-supported treatments, and those treatments for which little scientific evidence has been amassed (Bowker et al., 2011).

Overall, while parents of children diagnosed with ASDs accessed and utilized more services, on average, than the parents of typically developing children or children with other special health care needs, parents of children with ASDs reported more difficulties accessing and utilizing services for their children. Although some researchers have postulated a number of reasons why parents of children with ASDs might have difficulties accessing and utilizing services, the factors surrounding parents’ lack of service utilization is unclear.
2.3 A Theoretical Framework for Help-Seeking Pathways and Service Utilization

“Individuals’ beliefs affect their decision making and their behavior” (O’Brien & Daggett, 2006). This same sentiment rings true for parents of children diagnosed with ASDs. Parents’ beliefs about ASDs and its causes are reflected in how they approach the diagnostic process; which recommendations they choose to follow; which interventions they consider effective; their satisfaction with these services and their providers; and how best to respond to their children’s behavior (O’Brien & Daggett, 2006). Many theoretical frameworks have been created and adapted to identify and explain factors affecting help-seeking behaviors and service utilization. However, none of them conceptualized help-seeking behaviors and service utilization within a familial context. The first help-seeking model was created by Anderson and Newman (1973) and later reformulated by Goldsmith et al. (1988) and Aday et al. (1993). In 1996, Srebnik, Cauce, and Baydar adapted Anderson and Newman’s (1973), Goldsmith et al.’s (1988), and Aday et al.’s (1993) theoretical frameworks to create a model for help-seeking pathways and service utilization for children and adolescents that included the family context. Given the importance of family centered care in the early intervention system, it may make more sense to view service utilization “from the perspective of the family” (Arcia, Keyes, Gallagher, & Herrick, 1993). The theoretical framework illustrated below describes factors and stages along a “help-seeking pathway” that include “problem recognition,” “decision to seek help,” support and service utilization. According to Srebnik, Cauce, & Baydar (1996), “movement” along these stages is associated with “illness profile variables, predisposing factors, and barriers and facilitators to care” (Srebnik, Cauce, & Baydar, 1996).
Figure 2.1: Youth help-seeking and service utilization model (Srebnik, Cauce, & Baydar, 1996; Aday et al., 1993; Anderson & Newman, 1973; Goldsmith et al., 1998).
The Illness Profile includes “clinically assessed need” and “subjectively assessed need.” Clinical Assessment of Need refers to “symptoms, diagnosis, and functional impairment likely to be related to problem recognition” (Srebnik, Cauce, & Baydar, 1996). Clinical diagnosis and symptom severity have been shown to be powerful predictors of help-seeking behaviors that distinguish between children who attain “formal mental health services” from those who attain assistance from “informal support networks” (Srebnik, Cauce, & Baydar, 1996; Freeman et al., 1992; Rickwood & Braithwaite, 1994).

Subjective assessment of need is related to “problem recognition,” which leads to help-seeking behaviors (Costello & Janiszewski, 1990). A critical component to the help-seeking, service selection, and service utilization behaviors of parents is their interpretation of their child’s behaviors and functioning and its impact on their overall well-being (Burns, Angold, & Costello, 1992; Combs-Orne, Kager, & Chernoff, 1991; Pottick et al., 1992). Goldsmith et al. (1988) postulated that the relationship between clinical assessment of need and perceived or subjective need would improve “understanding of the reasons underlying the extent of unmet need as well as of the early stages of help-seeking pathways.”

In order to create a theoretical model more appropriate to the needs of children, Srebnik, Cauce, and Baydar (1996) adapted extant theoretical models by including “family characteristics” related to “family structure and relations in the illness profile.” Over the years, researchers and their theoretical models had paid little attention to examining the social impacts—and impacts on the family unit, in particular—of children with illness or disabilities. An available and expanding body of research suggests, however, that chronic illness and disability adversely impact family functioning (Sanders & Morgan, 1997). Conversely, family characteristics, such
as “marital or family conflict, family disorganization, or large family size,” can impact both clinical interpretations of a child’s symptoms and caregivers’ ability to recognize and report symptoms and functioning (Srebnik, Cauce, & Baydar, 1996).

While parenting, in general, can be a stressful experience, research indicates that parenting a child with a disability leads to increased risk of experiencing elevated levels of stress. In particular, parents of children with autism spectrum disorders report “higher stress levels, lower parenting competency,” and significant impacts on parental and family functioning than parents of children without disabilities (Fisman & Wolf, 1991; Rao & Beidel, 2009; Rodrigue, Morgan, & Geffken, 1990).

Children diagnosed with autism spectrum disorders often represent constant sources of stress on their families. Parents and other traditional caregivers are not the only family members affected; siblings and the relationships within the family unit are also affected (Sanders & Morgan, 1997). Various specific sources have been identified as causes of such family stress. Among those identified, the “extremely antisocial, disruptive behaviors” associated with autism spectrum disorders, such as “self-injurious, tantrum, and obsessive-compulsive behaviors” appear to be the primary cause (Gray & Holden, 1992). Struggling with the many burdens of caring for a child expressing such behaviors poses a significant threat to--and often deteriorates--the psychosocial well-being of parents and caregivers, particularly in their “self-confidence and self-” (Higgins et al., 2005). As a result, parents and other caregivers of children with autism spectrum disorders often experience “helplessness, feelings of inadequacy and failure, anger, shock, guilt, frustration, and resentment” (Jones, 1997; Powers, 1989; Tommasone and Tommasone, 1989).
Additional, related sources of family stress related to having a child with an autism spectrum disorder include the possibility of “ongoing dependency,” and difficulties participating in respite activities as a family (Koegel et al., 1992). Other sources psychological problems such as are depression and anxiety that too often results among the parents of children with autism as a result of the emotional upheaval they experience (Bristol & Schopler, 1984; Hoppes & Harris, 1990).

Predisposing factors and characteristics are “stable conditions of an individual that influence one’s readiness to seek help” (Srebnik, Cauce, & Baydar, 1996). Effects of “demographic characteristics,” such as gender, age, and ethnicity are consistently measured in the help-seeking and service utilization literature (Srebnik, Cauce, & Baydar, 1996). In general, “minority ethnicity,” “young parental age,” “low level of parent education,” “family composition,” and “large family size” have all been factors associated with the underutilization of services (Allen, Affleck, McGrade, & McQueeney, 1984; Butler, Winter, Singer, & Wenger, 1985; Fergusson, Dimond, Horwood, & Shannon, 1984; McDonald & Coburn, 1988; Neighbors, 1984; Rudolph & Porter, 1986; Singer, Butler, & Palfrey, 1986; Stein, 1983, Wolinsky, 1982). Similarly, “sociocultural values and beliefs” of children and their families affect their experience with “illness, perception and definition of the problems, beliefs about the desirability of symptoms, the manifestation of symptoms, and methods of coping – including whether or not to obtain help and from whom” (Rogler & Cortes, 1993).

Barriers and facilitators to help-seeking behaviors and service utilization can be defined as “social and environmental pressures that can occur at the individual, community, or broader political level.” Srebnik, Cauce, and Baydar’s theoretical model (1996) includes “community and
social networks characteristics,” “economic factors”, “service characteristics,” and “policy” issues as potential “external influences” that can either enhance or impede help-seeking behaviors and service utilization. Because community and social network characteristics and service characteristics are a variable in the current study, they will be discussed in their own sections later in the paper.

The importance of the impact of community and social networks on parents’ ability to utilize services for their children with ASD is highlighted by Bailey’s (2001) observation that research is needed to study the relationship between parental involvement and family support programs and how the practices that service providers promote produce the outcomes sought by the families of children with ASDs. Understanding how the community and social networks impact parents’ abilities to access services for their children with ASD will be critical to designing effective intervention strategies. However, there is paucity in autism spectrum disorders literature regarding the impact of the community and social networks on service utilization. Most of the literature focuses on the lack of social support and service utilization amongst individuals diagnosed with severe mental illness, such as schizophrenia, bipolar disorder, and major depression. For the most part, the literature indicates that those with smaller social networks or who receive less social support more frequently require hospitalization than those with larger networks or who receive great social support. The literature, however, does not appear to have established the existence of a relationship between the size of social networks or degrees of social support, and the utilization of other types of services (Albert, Becker, McCrone, and Thornicroft, 1998). The literature does give some insight into how the community and social support networks are oftentimes the first stop on the path to help-seeking and service utilization when children and families experience health concerns (Cohen et al., 1991; Pottick et al., 1992).
For example, Ruble, Heflinger, Renfrew, and Saunders (2005) found that community-based early intervention services are a very common source of individualized family service plans for children with ASDs. Twoy, Connolly, and Novak (2006) found that 68% of their sample of 55 parents of children with autism sought “general support” from their social networks (Banach, Iudice, Conway, & Couse, 2010). However, 93% sought “information and advice from families with a similar diagnosis,” and 80% sought information from professionals (Banach, Iudice, Conway, & Couse, 2010; Twoy, Connolly, and Novak, 2006). These findings indicate that support from professionals and families with specific knowledge and experience with ASDs is especially desired by the families of children with autism.

The autism literature offers limited research concerning the influence of community and social networks on the parents and family members of children with ASDs. A recent literature review found that only one prior study had examined whether support groups were effective for parents whose children were recently diagnosed with autism (Banach, Iudice, Conway, & Couse, 2010). Parents have reported that a diagnosis of an autism spectrum disorder can limit the amount of community and social support they, their children, and their families receive. Sharpley et al., (1997) reported that, along with the permanency of the condition, the “lack of acceptance of autistic behavior by society and family members and the low levels of support provided by health care serves and other social services” were two of the greatest causes of stress for parents raising children with an ASD. Higgins, Bailey, and Pearce (2005) described “a lack of understanding from the wider community of behaviors associated with ASD.” They reported that the families of children with ASDs tend to have limited contact their natural social networks because the parents felt that their communities (e.g., family, friends, teachers, etc.) did not understand how children with ASDs behave and why the act the way they do. (Higgins, Bailey,
Similar findings were reported in a study of 14 parents of children with ASD by Woodgate, Ateah, and Secco (2008). Parents participating in this study described feelings of “extreme social isolation” and a “lack of understanding from others” (Woodgate et al., 2008). Interviews by Midence and O’Neill (1999) found that participant families felt they did not receive the support they needed after their child was diagnosed with ASD. Subsequent interviews by Boullier et al. (2008) with 10 families corroborated Midence and O’Neill’s (1999) conclusions regarding the “need for improved follow-up services after diagnosis.” Drake, Couse, DiNapoli, and Banach (2008) concluded, based on case studies, that families were left to fend for themselves in multiple service arenas including their children’s schools. Building on these findings, a 2010 study by Banach, Iudice, Conway, and Couse found that parents participating in support groups following their children’s diagnosis with ASD felt empowered to support their children thanks to improved advocacy skills, better understanding of their children’s individualized educational plans (IEP), and information about the best way to secure services for their children. These findings suggest that “one of the greatest needs for families coping with a diagnosis is finding acceptance and support from others” (Banach, Iudice, Conway, & Couse, 2010).

Economic factors have long been described in the literature as having the potential to facilitate or inhibit service utilization. Many researchers have concluded that the socioeconomic status (SES) of families with children with autism and their utilization of formal services reflect a curvilinear relationship (Cohen & Hesselbart, 1993; Koot & Verhulst, 1992). Greater access to Medicaid or private insurance has meant that families with “very low or very high SES backgrounds” are more likely than those with median incomes to utilize formal health services. Despite the efforts of Federal and State legislations and the high rates with which children with
autism spectrum disorders demand and receive services, several studies have demonstrated that
children with autism spectrum disorders have difficulties accessing recommended services.
Patrick, Padgett, Burns, Schlesing, & Cohen (1993) found that service utilization decreases when
insurance coverage is reduced or insurance copayments are increased. When compared to
children with other disabilities, data suggest that children with autism are underinsured. The
parents of children with autism are more likely than the parents of children with other disabilities
to report that their health plans have refused to pay for service or that they cannot afford the out-
of-pocket expenses either are not covered in their insurance plans or go toward their deductibles
(Krauss et al., 2003; Ruble et al., 2005). In fact, when compared to families of children with
other special health care needs, families of children with ASD have been found to be twice as
likely to report difficulties receiving “service referrals” and an “adequate number of service
visits” (Young, Ruble & McGrew, 2009; Krauss et al., 2003). Data from a state-wide Medicaid
managed care program indicated children with ASDs accounted for less than 10% of service
utilization by the program’s members. The data also revealed that, over a six-year period,
utilization rates had significantly declined among children ASDs (Young, Ruble & McGrew,
2009; Ruble et al, 2005). According to a survey conducted in several states, 37% of children
with ASD had difficulties obtaining “needed care” from doctors in the previous year (Liptak et
al., 2008; Krauss et al., 2003).

Policies and programs mandated by the Individuals with Disability Education Act
(IDEA) face many barriers to the delivery of intensive intervention. These include, most
notably, the significant costs associated with intensive intervention and the law’s failure to
clearly state program’s legal obligations to provide such intervention. The legal uncertainty
regarding programs’ obligations has been dominated by three issues: The “type of intervention to
be provided,” “the intensity and duration of intervention,” and the “setting” (Mandlawitz, 2002). IDEA mandates that schools must offer a “free appropriate public education.” In Board of Education of the Hendrick Hudson Central School District v. Rowley, 458 U.S. 76 (1982), the United States Supreme Court held that services offered pursuant to IDEA must offer some “educational benefit” but are not obligated to provide “optimal benefit.” Despite not having to provide “optimal or maximal benefit,” the average full-time intensive intervention program for students with ASDs costs approximately $40,000 per year per child (Ganz, 2006). Outside of full-time programs, intensive intervention programs incorporated into a more typical educational environment also add significant costs to the average education costs. By way of illustration, during the 1999-2000 school year, the national average expenditure on autism special education was $18,790 per student. This amount was almost three times as high as the $6,556 average expenditure per student not receiving special education (Chambers et al., 2003). Although such cost estimates are specific to public-school provided programs, privately intervention programs are similarly expensive.

In response to these barriers, former President George W. Bush signed into law the Combating Autism Act of 2006, which authorizes “nearly one billion dollars in expenditures over five years to ‘combat’ autism spectrum disorders through screening, education, early intervention, prompt referrals for treatment and services, and research.” The legislation increased federal spending on autism spectrum disorders by 50% and stated that the law’s purpose regarding autism education, early detection of ASD, and intervention was:

“(1) to increase awareness, reduce barriers to screening and diagnosis, promote evidence-based interventions for individuals with autism spectrum disorder or other developmental disabilities, and train professionals to utilize valid and reliable screening tools to diagnose
or rule out and provide evidence based interventions for children with autism spectrum disorder and other developmental disabilities; and

(2) to conduct activities under this section with a focus on an interdisciplinary approach (as defined in programs developed under section 501(a)(2) of the Social Security Act) that will also focus on specific issues for children who are not receiving an early diagnosis and subsequent interventions” (PL 109-416).

In general, the law seeks to:

“(1) provide information and education on autism spectrum disorder and other developmental disabilities to increase public awareness of developmental milestones;”

“(2) promote research into the development and validation of reliable screening tools for autism spectrum disorder and other developmental disabilities and disseminate information regarding those screening tools;”

“(3) promote early screening of individuals at higher risk for autism spectrum disorder and other developmental disabilities as early as practicable, given evidence-based screening techniques and interventions;”

“(4) increase the number of individuals who are able to confirm or rule out a diagnosis of autism spectrum disorder and other developmental disabilities;”

“(5) increase the number of individuals able to provide evidence-based interventions for individuals diagnosed with autism spectrum disorder or other developmental disabilities;”

and

“(6) promote the use of evidence-based interventions for individuals at higher risk for autism spectrum disorder and other developmental disabilities as early as practicable” (PL 109-416).
The law also expanded and intensified “biomedical research on autism, including an essential focus on possible environmental causes” (Autism Speaks, 2006).

On May 20, 2008, State of Florida Governor Charlie Crist also signed into law the “Window of Opportunity Act” whose efforts sought to expand services and coverage for autism spectrum disorders by:

“authorizing the Agency for Health Care Administration to seek federal approval through a state plan amendment to provide home and community-based services for Autism spectrum disorder and other developmental disabilities; specifying eligibility criteria; specifying limitations on provision of benefits; requiring reports to the Legislature; requiring legislative approval for implementation of certain provisions; creating s. 624.916, F.S.; creating the "Steven A. Geller Autism Coverage Act"; directing the Office of Insurance Regulation to establish a workgroup to develop and execute a compact relating to coverage for insured persons with developmental disabilities; providing for membership of the workgroup; requiring the workgroup to convene within a specified period of time; directing the office to establish a consumer advisory workgroup and providing purpose thereof; requiring the compact to contain specified components; requiring reports to the Governor and the Legislature; creating s. 627.6686, F.S.; providing health insurance coverage for individuals with autism spectrum disorder; providing definitions; providing coverage for certain screening to diagnose and treat autism spectrum disorder; providing limitations on coverage; providing for eligibility standards for benefits and coverage; prohibiting insurers from denying
coverage under certain circumstances; specifying required elements of a treatment plan; providing, beginning January 1, 2011, that the maximum benefit shall be adjusted annually; clarifying that the section may not be construed as limiting benefits and coverage otherwise available to an insured under a health insurance plan; prohibiting the Office of Insurance Regulation from enforcing certain provisions against insurers that are signatories to the developmental disabilities compact by a specified date; creating s. 641.31098, F.S.; providing coverage under a health maintenance contract for individuals with autism spectrum disorder; providing definitions; providing coverage for certain screening to diagnose and treat autism spectrum disorder; providing limitations on coverage; providing for eligibility standards for benefits and coverage; prohibiting health maintenance organizations from denying coverage under certain circumstances; specifying required elements of a treatment plan; providing, beginning January 1, 2011, that the maximum benefit shall be adjusted annually; prohibiting the Office of Insurance Regulation from enforcing certain provisions against health maintenance organizations that are signatories to the developmental disabilities compact by a specified date; providing an effective date” (Florida Senate Bill 2654, 2008).

As illustrated above, issues resulting from various local, state, and federal health-care policies often affect children with ASDs’ access to services (Combs-Orme et al., 1991). Health-care policies and manage care initiatives affect not only individuals’ eligibility to receive services but also the nature of the services they receive after they have been deemed eligible for services and the degree to they are financially responsible to pay for those services. As such,
policies may lead to increased access to services for some and a decrease of services for other
groups (Ehreth, 1996).

“Poor availability of services” is a clear “systems-level barrier” to formal treatment and
intervention services, “just as an inadequate social network is a barrier to informal support”
(Srebnik, Cauce, & Baydar, 1996). “Lack of sufficiently trained staff members,” “high staff
turnover,” “negative staff attitudes,” and “use of negative practices” is also a widespread barrier
to supporting families at the systems level. (Ruef, Turnbull, Turnbull, & Postdon, 1999). Other
barriers to formal services can include “lack of transportation,” “long waiting lists,” “inflexible
hours,” “lack of childcare,” “distance to services,” and “poor match between services and a
family’s language and/or culture” (Combs-Orme et al., 1991; Goldsmith et al., 1988; Meinhardt
& Vega, 1987; Srebnik, Cauce, & Baydar, 1996; Sue, 1988). Service providers’ attitudes
sometimes also stand in the way of service utilization. This is especially true where those
attitude conflict with the beliefs of children with ASDs’ families. For example, providers have
been known to sometimes consider a families failure to attend services or their underutilization
of services as the families’ being “resistant” to the services. The families, meanwhile, may
refrain from attending services because they perceive system barriers of which service provider
are oblivious (Trupin et al., 1993). In their investigation of the 2005-2006 National Survey of
Children with Special Health Care Needs (NS-CSHCN), Chiri and Warfield (2011) found that
families of children with ASD were significantly more as risk for having “unmet specialty and
therapy care needs.” Parents reported “provider lack of skills” to treat their child as a barrier to
obtaining necessary and recommended services (Chiri & Warfield, 2011). The result of these
differing points of view can greatly reduce both professionals’ and families’ motivation to reduce
barriers to service utilization (Srebnik, Cauce, & Baydar, 1996).
In the autism literature, service characteristics are often defined in terms of how closely they match aspects of “family-centered care.” According to Dunst (2002), a family-centered approach is characterized by “practices that treat families with dignity and respect; information sharing so families can make informed decisions; family choice regarding their involvement in and provision of services; and parent/professional collaborations and partnerships as the context for family-program relations.” In this model, service characteristics must include “practices that are individualized, flexible, and responsive to family concerns and priorities, and which involve informed choices and family involvement in achieving desired goals and outcomes” (Dunst, Trivette, & Hamby, 2007). In their meta-analysis, Dunst, et al. (2007) found that family-centered practices influenced “parents’ judgments of their child’s behaviors.” Although family-centered practices did not relate to “child development outcomes” directly, it did so indirectly by increasing parents’ self-efficacy beliefs. As a result, parents felt more confident and capable and tended to offer their children more and better learning and development opportunities (Teti & Gelfand, 1991; Coleman et al., 2002). Unfortunately, there is no research that that is able to illustrate a direct relationship between family-centered practices, service characteristics, and child development outcomes.

2.4 Summary of the Literature Review: Implications for the Present Study

In 2006, Croen et al. conducted a comparison of health care utilization and costs between children diagnosed with ASD and not diagnosed with ASD. Results of the study indicated that the utilization and cost of health care are significantly higher for children with ASD. However, as previously stated, evidence suggests that ASD children do not receive the full amount of services recommended. Several problems with service utilization for ASD treatments and interventions have been identified including difficulties accessing services, limited involvement
invention efforts by the children’s families, and reports that providers were unwilling to engage in interagency collaboration.

Evidence strongly suggests that parents and caregivers of children with ASD are critical to their children’s treatment. This is particularly so where specialty mental health resources are limited. Unfortunately, the intensive care that children with ASDs require can are major causes of stress and strain on their family’s resources. Such financial and psychological strain too often leads to the underutilization of services. Identifying what encourages or discourages parents from seeking more help with these stressors and utilizing ASD treatments is therefore critical to helping the parents of children with ASDs and, through the parents, the children themselves. (Pottie, 2008).

Despite the mounting quantitative research analyzing specific barriers to service utilization, paucity in the literature still remains. Little research has been conducted that examines the decision making process families go through when deciding which services they will utilize for their children following a diagnosis of ASD. In particular, no research exists that qualitatively examines why parents may voluntarily choose to reject recommended services for their children following a diagnosis of ASD. As a result, it is vital that research be conducted in order to gain greater insight into why children diagnosed with ASD are not receiving all the necessary and recommended services.
CHAPTER 3
RESEARCH AND METHODOLOGY

While there are multiple theories that address service utilization, there are no theories that describe parents’ experiences accessing and utilizing services for their children following a diagnosis of ASD. Specifically, there is no research examining why parents may voluntarily choose to reject recommended services for their children following a diagnosis of ASD. This study will examine reasons why parents may choose to reject recommended services.

The most appropriate methodology to utilize for this study is a mixed methods approach, in particular Concurrent Nested Strategy, because there is paucity in the literature regarding parents’ experiences accessing and utilizing services for their children. The concurrent nested strategy allows the researcher to “gain broader perspectives” by using both qualitative and quantitative methods. In this particular study, quantitative methods will be embedded into a primarily qualitative design in order to “enrich the description of sample participants” (Morse, 1991). A qualitative design will be primarily used in this study as there are aspects of parents’ experiences that cannot be quantified (Morse, 1991). Bogdan and Biklen (2003) described qualitative methods as being more concerned “with process rather than an outcome or product” while Patton (2002) described it as a “facilitator” to examining issues “in depth and detail.”

This methodology allowed for the researcher to extend conceptually the theoretical framework first described by Srebnik, Cauce, and Baydar (1996) by asking parents to provide first-hand accounts of their experiences through the use semi-structured interview questions based on the youth help-seeking and service utilization model (Srebnik, Cauce, & Baydar, 1996).
This methodology allowed for the researcher to begin understanding parents’ experiences when choosing which services to utilize for their children following a diagnosis of ASD. In addition, parents were asked to identify which treatments and/or interventions have been recommended to them and by whom. The interviews were transcribed, analyzed, and coded using the directed content analysis approach, which allowed for the researcher to use the key concepts or variables found in existing theory or prior research as initial coding categories (Hsieh & Shannon, 2005; Potter & Levine-Donnerstein, 1999). Interviews with parents of children diagnosed with ASD were analyzed to expand upon existing theory in order to help explain parents’ experiences choosing which recommended services to utilize for their child following a diagnosis of ASD. This expansion aimed to address the specific barriers and facilitators to service utilization faced by parents of children with ASD as well as other factors that impacted their decision making process when choosing which services to utilize for their child.

### 3.1 Setting

Participants in the study were allowed to choose the location of the interview in order to ensure their convenience, comfort, and privacy when sharing their experiences with the researcher. Five of the nine parents participating in the study chose to be interviewed in their homes. Two parents chose to be interviewed in their place of work. Two parents chose to be interviewed in public restaurants.

### 3.2 Procedures for Protecting Participants’ Confidentiality

The researcher provided each participant with a code number that was used to identify the
participant throughout the study. Any documents collected for the study were stored securely in a locked file cabinet.

### 3.3 Participants

Participants were recruited for this study using a purposeful sampling technique in order to ensure that the issues being examined were well covered by a range of families. Patton (2002) described stratified purposeful sampling as a “sample within a sample” that can be utilized to, not only identify a “common core,” but to capture major variations between groups. Bogdan and Biklen (1985) described purposeful sampling as choosing “particular subjects to include they are believe to facilitate the expansion of the developing theory.”

Participants were nine parents or caregivers of children aged 3-5 diagnosed with an autism spectrum disorder within the last year who completed a semi-structured interview for this study. At least three Caucasian, three Hispanic, and three African American families were recruited for the study in order to compose strata that are heterogeneous. Informants were recruited through their participation in the community-based program Parent to Parent of Miami. Inclusion criteria for this study was as follows: participants must be 18 years of age or more and be the biological mother or father or legal guardian of a child with an autism spectrum disorder, specifically Autistic Disorder, Asperger’s syndrome, and Pervasive Development Disorders NOS. Participants must be currently raising the child with autism spectrum disorder in their home. Participants must also reside in the South Florida area and be willing to complete an interview in person and provide the researcher with a copy of the evaluation that diagnosed the child with ASD including recommendations. Participants must also be able to speak and understand English proficiently. Exclusion criteria for this study were as follows: Participants
who have a child diagnosed with other autism spectrum disorders such as Rett’s Disorder or Childhood Disintegrative Disorder will be excluded from participating. Persons who have a biologically-born child with a diagnosis of an autism spectrum disorder but are not raising the child in their home will also be excluded from the study.

3.4 Procedure for Soliciting Participants

A community based parent resource center, Parent to Parent of Miami, agreed to email a copy of the recruitment flyer in a weekly email message to over 5,000 families who receive their support and services. Parents interested in participating were asked to contact the primary investigator. During the telephone conversation, parents were asked if they met basic participation requirements to participate in the study. If participation requirements were met, a date and time for the interview was established. Before the interview was conducted, parents received a packet that included informed consent to be signed and a demographic questionnaire to be filled out and returned to the researcher prior to the interview in order to confirm that participation requirements were met. Additionally, the consent informed parents that they would receive a twenty five dollar gift certificate for participating in the study following completion of the interview. Parents also needed to provide the researcher a copy of the evaluation diagnosis the child with ASD and subsequent recommendations at the time of the interview.

A total of twenty-two families responded to the emailed flyer. Six families were excluded from the study because they contacted the primary researcher after the maximum number of families participating in each stratum had been secured. Three families were excluded from the study because they were not proficient English speakers and translation of the interview questions and measures would have been required for their participation. Two families were
excluded from the study because their children were over the age of 5. Two families were excluded from the study because they were unable to provide the primary researcher with a copy of the psychological/psychoeducational evaluation that diagnosed their child with ASD.

3.5 Data Collection

Multiple data sources were used in this study. Semi-structured interviews with open-ended questions were conducted with parents of children with ASD to discover the rationale behind which services they choose to utilize for their children. Special attention was paid to examining reasons why parents may choose not to utilize a recommended service. Additionally, a demographic questionnaire and document analyses of psychological and psychoeducational evaluations and recommendations were utilized as additional sources of data.

3.5.1 Parent Interview

Charmaz (2006) described qualitative interviewing as a method that “provides an open-ended, in-depth exploration of an aspect of life about which the interviewee has substantial experience, often combined with considerable insight.” Because of its in-depth nature, interviewing allows for each participant to provide an interpretation of their experience. This interpretation will “shed light” on the topic that the interviewer seeks to understand. (Fontana & Frey, 1994; Seidman, 1997).

Participant interviews were the primary data collection method used in this study. Participants completed one interview that was audio-taped and transcribed. The interview questions that guided initial data collection are found in Appendix A. A semi-structured
interview process ensured that both participants and researchers were able to expand on the
questions asked as part of the interview process.

The questions focused on the help-seeking and service utilization attitudes, perceptions,
experiences, and behaviors described by Srebnik, Cauce, and Baydar’s (1996) model of help-
seeking and service utilization. A few broad, semi-structured, open-ended questions were
devised in order to encourage unanticipated statements and stories to emerge (Charmaz, 2006).
Questions were primarily devised with the gaps in the research and the research questions in
mind. The factors listed in Srebnik, Cauce, and Baydar’s (1996) model of help-seeking behaviors
were also utilized in order to ensure that parents were able to share the full scope of their
experiences with the researcher. Questions were also devised using the literature describing
parents’ experiences accessing and utilizing services for their children as well as a number of
help-seeking surveys designed to assess parents experiences with services and service providers
(e.g. Trivette & Dunst, 1994; Dunst, Trivette, & Hamby, 1996). The researcher’s experiences
working with parents of children recently diagnosed with ASDs, keeping in mind the unique
characteristics of the study’s participants, were also utilized to develop interview questions. A
few follow-up interview questions were also created to invite for a more detailed discussion of a
specific topic. In the appendix, questions have been categorized into the three categories
described by Srebnik, Cauce, and Baydar (1996) that are most associated with help-seeking and
service utilization: “Illness profile variables,” “predisposing factors,” and “barriers and
facilitators to care.” Although questions were categorized in the appendix for convenience the
order of questions and wording differed depending on the responses of the participant during the
course of the interview in order to explore and help the participant elaborate on their experience
(Charmaz, 1991). Additional questions were also added during the course of some interviews in
order to clarify details, obtain accurate information, or learn more about the participants’ experiences and reflections (Charmaz, 2006).

A pilot study was utilized in the current study in order to ensure that the interview questions devised by the primary researcher met the goals of the study. Analysis of the responses of the parents participating in the pilot study confirmed that their responses to interview questions were sufficient in meeting the goals of the proposed study.

3.5.2 Demographic Questionnaire

A demographic questionnaire was utilized as a secondary source of data in this study. The demographic questionnaire was used to ensure that participants have met participation requirements. Information gathered from the demographic questionnaire was also used to individualize interview questions or clarify information gathered during the interview. Items asked participants questions about their ethnicity, age, level of education, income, child’s diagnosis, and family structure. Demographic data is often utilized in qualitative research to support thick descriptions and the triangulation process, techniques used to increase the validity of qualitative inquiries. Further information regarding thick descriptions and triangulation will be discussed later in the chapter.

3.5.3 Document Analysis

A third source of data in this study was document analysis. Extant texts, such as psychological and psychoeducational evaluations, can complement qualitative interviewing methods and are often used as supplementary sources of data (Charmaz, 2006). Such texts provided useful statements about the participant’s experience and redirected analysis in pivotal ways (Charmaz,
Like the demographic questionnaire, document analysis was primarily used to support the triangulation process.

Participants provided the researcher with a copy of the psychological or psychoeducational evaluation that provided the diagnosis of ASD and subsequent recommendations. The researcher analyzed the evaluation and recommendations for information related to Srbenik, Cauce, and Baydar’s (1996) model of help-seeking practices and service utilization. Specifically, the researcher will look for information that describes (1) “clinical assessment of need,” (2) “perceived need,” “family characteristics,” (3) “demographic characteristics,” (4) “sociocultural values/beliefs,” (5) “community and social networks,” (6) “service characteristics,” and (7) “policy.” Additionally, the researcher examined the specific recommendations listed in the evaluation. All the information analyzed in the document was compared with the information gathered during the interview.

3.5.4 Treatment and Interventions Checklist

Each participant was asked to identify services that were recommended to their children and families following a diagnosis of ASD as well as the first name of the person who provided the recommendation and their relationship to the family. Treatments and interventions listed were categorized within the five treatment modalities listed in the literature review. Participants’ responses on the checklist were utilized during the interview to generate a series of questions regarding community and social support, barriers or facilitators to treatment, and their experiences choosing, accessing, or utilizing services. Participants’ responses were used to examine how many services were recommended to families, how many they are chose to utilize, and who recommended specific kinds of services.
3.6 Data Analysis

3.6.1 Open Coding

Open coding is conceptualizing on the first level of abstraction (Strauss and Corbin, 1998). When an open coding procedure is used, all data are broken down into concepts that represent ideas, acts, incidents, or events. In this study, all interview responses were transcribed into NVIVO10© within a week of the interview. After transcription, interviews were examined and dissected into sentences and phrases representative of the main ideas and concepts expressed by the participants. These sentences and phrases were then coded according to their unit of meaning. Participants received lists of the main ideas and were asked to confirm that they accurately capture the ideas that the participants thought to be most important. Participants’ agreement or disagreement with their individual transcripts and lists of main ideas will be indicated in the results.

Once a list of concepts was assembled and agreed upon, the concepts were assembled into categories representing the perceptions and practices of the participants. This second step in the coding process is often referred to as “conceptual coding” and allows the researcher to organize open codes into groups based upon their similarities. Interviews were coded using the category list generated. Coding involved two steps. First, each interview was independently coded by the researcher and a colleague. Then, the researcher and her colleague discussed their category assignments and reached a consensus as to the code categories that each passage represented. For each category created, an examination of the category’s properties and dimension was noted.
3.6.2 Axial Coding

Charmaz (2006) described axial coding as “a type of coding that treats a category as an axis around which the analyst delineates relationship and specifies the dimensions of the category.” Axial coding is principally used to reassemble data that has been fractured as a result of the open coding process (Strauss and Corbin, 1998). The result is that large amounts of data are sorted, synthesized, organized, and reassembled in new ways following open coding, allowing for relationships between categories to be linked on a conceptual rather than descriptive level (Creswell, 1998; Strauss and Corbin, 1998). During this phase of analysis, the dimension and properties of categories created during the open and conceptual coding process were examined and grouped into “main” and “subcategories” that represented the majority of experiences described by the participants.

3.6.3 Selective Coding

Selective coding is a “process of integrating and refining categories” (Strauss and Corbin, 1998). There are two primary goals during this step of analysis. First, the researcher seeks to develop an overarching theoretical scheme regarding the relationship between the different categories. The second goal is determine which “core category” best explains the experiences of the participants (Glaser, 1998). During this step, the main categories created during axial coding were examined for similarities and differences. These main categories were then sorted in order to create a set of overarching theoretical categories or constructs. Relational statements were analyzed in order to begin linking constructs. A “diagram” and “narrative” of the emerging theory was developed to help determine if one core category existed that represented the participants’ experiences. Lastly, each participant’s story was reviewed in order to assess the fit with the theory proposed.
3.7 Trustworthiness and Validity of Data

Trustworthiness, or validity, of data is an important component of any research study (Creswell, 1998). In qualitative studies, the method of data collection, analysis, and interpretation are the primary considerations weight when determining the study’s trustworthiness. In this study, the trustworthiness and validity of data were established through triangulation, member checks, disconfirming evidence, thick descriptions, theoretical sampling, and auditing.

3.7.1 Triangulation

Triangulation is used to increase the credibility and validity of data through “cross verification from more than two sources” (Bogdan & Biklen, 2006). In this study, two types of triangulation were utilized in order to increase the trustworthiness of the research: Data triangulation and investigator triangulation. In this study, data triangulation was achieved through the use of various data sources to collect data: Participant interviews, demographic questionnaires, and psychological/psychoeducational evaluations. Information obtained through interviews, questionnaires, and evaluations was analyzed in order to evaluate the trustworthiness of information sources and data collected was compared to the expanded theory to confirm the main concepts proposed in the theory. Investigator triangulation was achieved in this study through inter-rater reliability checks. The researcher collaborated with a colleague to achieve inter-rater reliability on coded data. Each interview was independently coded by the researcher and a colleague. Then, the researcher and her colleague discussed their category assignments and reached a consensus as to the code categories that each passage represented.
The colleague was a fifth year doctoral student in school psychology from an APA accredited institution. At the time the research was conducted, the colleague was employed as a pre-doctoral intern in South Florida. The colleague primarily performed developmental disability and learning disability assessments for preschool aged children, including children with ASDs.

3.7.2 Member Checks

Feedback from participants is the “single most important way of ruling out the possibility of misinterpretation of the meaning of what they say and the perspective they have on what is going on” (Maxwell, 1996). In this study, participants received a transcript of their interview as well as a list of main ideas as interpreted by the researcher. Participants had the opportunity to review the transcripts and lists of main ideas and confirm the accuracy of data and researcher interpretations. Participants received lists of the main ideas via mail or email. Participants were asked to demonstrate their agreement by contacting the primary investigator via phone or email and stating their approval. Participants were asked to demonstrate their disagreement by providing the primary investigator with a corrected list of main ideas. In the current study, all participants approved of the list of main ideas generated by the researcher. None of the parents participating in the study offered any edits or asked for any information regarding their transcripts or the lists of main ideas to be corrected or changed. Participants were asked to consent to the use of the data and information included in the results. All parents participating in the study returned the transcripts and lists of main ideas and consented to the researcher’s use of their data and information in the results.
3.7.3 Disconfirming Evidence

After preliminary concepts and main ideas were established, the researcher looked for evidence that is inconsistent with these themes. Inconsistent information will be coded as outlying information and will be included in the results (Miles & Huberman, 1994).

3.7.4 Rich Data and Thick Descriptions

Charmaz (2006) described thick descriptions and rich data as “detailed, focused, and full material that reveals the participants’ views, feeling, intentions, and actions as well as the contexts and structures of their lives.” In this study, rich data and thick descriptions were obtained through the writing of extensive field notes of interview observations and the compiling of detailed narratives through transcriptions of interviews.

3.7.5 The Pilot Study

A pilot study has been defined as “a small-scale methodological test conducted to prepare for a main study and intended to confirm that methods or ideas would work in practice” (Jariath et al., 2000; Prescott and Soeken, 1989; van Teijlingen and Hundley, 2002). Conducting a pilot study gives researchers an opportunity to make adjustments and revisions to their design prior to conducting their main study, specifically in regards to data collection methods, sample recruitment strategy, and overall “proposed research process” (Muoio et al., 1995; Perry, 2001; Prescott and Soeken, 1989; van Teijlingen and Hundley, 2002).

In the proposed study, the pilot study was used to (1) assess the acceptability of the interview, observations, document analysis, and the recommended services/interventions
checklist; (2) help the researcher assess and prepare interview and observation techniques as well as self-evaluate readiness, capability, and commitment as a qualitative researcher; (3) help the researcher uncover and resolve any ethical and key practical issues that may hinder the proposed study; and (4) help the researcher identify specific methodological issues so that the researcher can “affirm, sharpen, or revise how to pursue and achieve the goals of the proposed study” (Kim, 2010). Overall, piloting the proposed allowed for the researcher to “focus on, expand, or narrow the proposed research topics and gain a clear conceptualization of the focus of the topic” (Kim, 2010).

The goal of the pilot study was to test the researcher’s ideas and methods. The pilot study was designed to provide an opportunity to create an understanding of the concepts, beliefs, and experiences held by the parents participating in the study. According to Maxwell (2008), conducting a pilot study in qualitative research can provide the researcher with “an understanding of the meaning that these phenomena and events have for the actors who are involved in them, and the perspectives that inform their actions.” Therefore, a pilot study was necessary to ensure that interview questions provided the information necessary to answer research questions.

In the pilot study, three families, one family from each stratum (one Caucasian, one Hispanic, one African American), who met the participation requirements of the study were asked to participate. The methods used to collect and analyze data in the pilot study are described in the “Data Collection” and “Data Analysis” sections. Once data was collected and analyzed, the results of the pilot study were reviewed by the professor directing the dissertation, Dr. Steven Pfeiffer, in order to ensure that the methods for data collection and analysis utilized
allowed the researcher the meet the goals of the proposed study. After consultation with Dr. Pfeiffer, it was agreed that the sampling frame and the methodologies were sufficient in meeting the goals of the proposed study and would remain the same for the main study. Therefore, results of the pilot study and the main study will be reported together in order to increase the efficiency and power of the study overall.

3.7.6 Treatment and Interventions Checklist

Each participant was asked to identify services that were recommended to their children and families following a diagnosis of ASD as well as the first name of the person who provided the recommendation and their relationship to the family. Treatments and interventions listed were categorized within the five treatment modalities listed in the literature review. Participants’ responses on the checklist were utilized during the interview in order to generate a series of questions regarding community and social support, barriers or facilitators to treatment, and their experiences choosing, accessing, or utilizing services.

3.7.7 Auditing

All documentation created by the researcher, including interview transcriptions and field notes of observations, were reviewed and stored securely in order to ensure that any theory generated is grounded in the data and that qualitative methodology was adequately followed.

3.8 Risk / Benefit Analysis

No risks were reported for participants involved in this study. Anticipated benefits include the possibility of participants’ perspectives influencing policy decisions. Multiple participants reportedly enjoyed sharing their experiences in a safe, confidential, and non-
judgmental environment. Many parents also reported that they hope their experiences could help other parents of children diagnosed with ASDs.
CHAPTER 4
RESULTS

In this chapter, findings from the study will be shared. The purpose of the current study is to examine the decision making process families go through when deciding which services they will utilize for their children following a diagnosis of ASD. The current study also examines the reasons why parents may voluntarily choose to reject recommended services for their children following a diagnosis of ASD. A concurrent nested strategy was used in an effort to extend conceptually the theoretical framework first described by Srebnik, Cauce, and Baydar (1996) by gaining broader perspectives of parents’ experiences accessing and utilizing services for their children following a diagnosis of ASD using both qualitative and quantitative methods.

Table 4.1: Demographic information for pilot study participants

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<th>FAMILY 1</th>
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<td>31</td>
<td>39</td>
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<tr>
<td>AGE OF FATHER</td>
<td>41</td>
<td>45</td>
<td>42</td>
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<tr>
<td>AGE OF IDENTIFIED PATIENT</td>
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<td>5</td>
<td>4</td>
</tr>
<tr>
<td>AGE OF SIBLING</td>
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<td>N/A</td>
<td>2</td>
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<tr>
<td>OCCUPATION OF MOTHER</td>
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<td>Paralegal</td>
<td>Unemployed</td>
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<tr>
<td>OCCUPATION OF FATHER</td>
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<td>County Employee</td>
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<tr>
<td>MOTHER’S HIGHEST DEGREE EARNED</td>
<td>Bachelor’s</td>
<td>Bachelor’s</td>
<td>Associate’s</td>
</tr>
<tr>
<td>FATHER’S HIGHEST DEGREE EARNED</td>
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<td>Associate’s</td>
<td>Juris Doctorate</td>
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<tr>
<td>ETHNICITY</td>
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</tr>
<tr>
<td>LENGTH OF TIME SINCE DIAGNOSIS</td>
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<td>12 months</td>
<td>11 months</td>
</tr>
<tr>
<td>MEDICAID RECIPIENT</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>PARENT INTERVIEWED</td>
<td>Father</td>
<td>Mother</td>
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Three parent interviews were conducted during July 2012. Interviews took place in a setting chosen by the parents. Two participants chose for the interview to be conducted in their homes and one participant chose for the interview to be conducted at his place of business. Interviews lasted approximately 60 – 90 minutes.

The pilot study aided the investigator in testing the parent interview protocol and evaluating potential methodological issues that might need to be modified or adjusted prior to initiating the study. Analysis of the pilot interviews indicated that the parent interview provided the information necessary to examine which factors are the most influential in their decision making process when deciding which services to utilize for their children following a diagnosis of ASD and what factors may influence parents to voluntarily reject recommended services for their child following a diagnosis of ASD. Questions appeared easy to understand and parents were able to respond to questions appropriately and candidly with considerable and detailed sharing of information. The pilot study also allowed the researcher to gauge the appropriateness of interview questions as well as her own ability to conduct interviews. After analysis of the pilot study indicated that the same methodology utilized in the pilot study would also be utilized in the main study, the results of both the pilot and the main study were combined and analyzed.

Interviews with the six remaining families participating in the study were conducted in August and September 2012. Three parents asked for interviews to be conducted in their homes. Two parents asked for interviews to be conducted in a public location of their choosing. One parent asked for the interview to be conducted at her place of business. Interviews lasted approximately 60 – 180 minutes. Demographic information for the six families participating in the main study is as follows:
Table 4.2: Demographic information for main study participants

<table>
<thead>
<tr>
<th></th>
<th>FAMILY 4</th>
<th>FAMILY 5</th>
<th>FAMILY 6</th>
<th>FAMILY 7</th>
<th>FAMILY 8</th>
<th>FAMILY 9</th>
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<td>Teacher’s Assistant</td>
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<td><strong>OCCUPATION OF FATHER</strong></td>
<td>N/A</td>
<td>Teacher</td>
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<td>Computer Programmer</td>
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<td><strong>MOTHER’S HIGHEST DEGREE EARNED</strong></td>
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<td>Caucasian</td>
<td>African-American</td>
<td>African-American</td>
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<td>Hispanic</td>
</tr>
<tr>
<td><strong>LENGTH OF TIME SINCE DIAGNOSIS</strong></td>
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<td>11 months</td>
<td>11 months</td>
<td>12 months</td>
<td>10 months</td>
<td>10 months</td>
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<tr>
<td><strong>MEDICAID RECIPIENT</strong></td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td><strong>PARENT INTERVIEWED</strong></td>
<td>Mother</td>
<td>Mother</td>
<td>Both</td>
<td>Both</td>
<td>Mother</td>
<td>Mother</td>
</tr>
</tbody>
</table>

Of the nine families participating in the study, six interviews were conducted solely with the mother of the identified patient; two interviews were conducted with both parents of the identified patient; and one interview was conducted with the father of the identified patient. All of the parents participating in the study were high school graduates. One parent reported that she had completed her Associate’s degree, while nine parents had reportedly completed their Bachelor’s degree. Three parents reported that they had completed graduate programs. Two
parents participating in the study also reported that they were Medicaid recipient, while the other seven parents reported they received coverage from private insurance agencies. The length of time since their children had been diagnosed with an ASD ranged from 4 months to 12 months.

After conducting interviews with all nine families participating in the study, Strauss and Corbin’s (1998) grounded theory method was used to analyze the interview transcriptions. Following the analysis, a list of 19 open codes was developed. The 19 open codes were incorporated into one or more of six conceptual categories which formed the foundation for three themes and one core category.

Table 4.3: Factors influencing parents’ decision-making process when choosing or rejecting recommended services

<table>
<thead>
<tr>
<th>THEMES</th>
<th>FACTORS INFLUENCING PARENTS’ DECISION-MAKING PROCESS WHEN CHOOSING OR REJECTING RECOMMENDED SERVICES</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Parents’ Perception of Diagnosis / Illness</td>
</tr>
<tr>
<td></td>
<td>Diagnostic Experience</td>
</tr>
<tr>
<td>CONCEPTUAL CATEGORIES</td>
<td></td>
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<tr>
<td>OPEN CODES</td>
<td></td>
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<tr>
<td>Symptom recognition</td>
<td>Need for assistance before diagnosis</td>
</tr>
<tr>
<td>Perceived Knowledge of the disorder</td>
<td>Need for assistance following diagnosis</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
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</tbody>
</table>
The core category, Factors Influencing Parents’ Decision Making Process When Choosing or Rejecting Recommended Services, summarizes parents’ experiences deciding which services to utilize for their child following a diagnosis of ASD. Regardless of the race, ethnicity, socioeconomic status, occupation, or child’s diagnosis, there was an overwhelming sense of parents’ self-reliance and parents’, ultimately, making decisions regarding their child’s treatment that reflected their perception of their child’s need and their values as a family. Overall, while all the parents participating in the study acknowledged the influence of family, community, and service providers in their decision making processes, parents often relied upon their own knowledge of their children and of their symptoms when picking and choosing appropriate services and providers. Additionally, all nine families acknowledged a lack of assistance regarding coordination of services and specific behavioral interventions. All nine families expressed that, while they received general information regarding services or service providers from family, friends, service providers, and community support groups, it was necessary for them to individually find more specific information regarding their child’s symptoms, recommended treatments, services, and service providers using the internet. The result was that parents’ decision making processes were mostly influenced by how they perceived their child’s symptoms and how closely they believed the services aligned with their beliefs about what was best for their child.

4.1 Themes, Categories, and Open Codes

The research questions regarding which factors are most influential in parents’ decision making processes when deciding which services to utilize or reject for their children following a diagnosis of ASD are addressed at the level of thematic codes, and within the underlying categories and codes, findings will be exemplified. The following sections will describe the
following three themes: Parents’ Perception of Diagnosis/Illness, Predisposing Characteristics, and Barriers/Facilitators to Treatment. Within the description of each theme, the individual conceptual categories contained within these themes as well as the open codes that form each conceptual category will be broken down. In order to make clear which areas were most influential in parents’ decision making processes, thick and rich descriptions of findings will also be provided.

4.2 Results of the Study

4.2.1 Theme 1: Parents’ perception of symptoms/diagnosis

Parents’ perceptions regarding their child’s illness was one of the most influential factors in parents’ decision making processes regarding which services to utilize for their children following a diagnosis of ASD. The current findings are slightly different from the Srebnik, Cauce, & Baydar’s (1996) findings, which stated that the child’s diagnosis and symptom severity were the most “powerful predictors” of help-seeking behaviors.

Diagnostic experience. This category refers to the parents’ experiences regarding their child’s ASD diagnosis. This category contains the open codes symptom recognition, perceived knowledge of the disorder, and diagnosis.

Many of the parents participating in the study reported that they identified symptoms related to ASD before their children were two years old. All nine parents also reported delayed developmental milestones. Surprisingly, while all nine parents reported concerns regarding their children’s developmental milestones, many also reported that they were discouraged from seeking a diagnosis or treatment from family, friends, and even pediatricians. The
discouragement they felt led them to wait longer than they wanted to address their children’s
needs. Family 2 said:

When I started to feel something wasn’t right was at about 6 months. The lady taking
care of him said to me, “You know, when I lay him down, his legs go up.” And it looked
weird, but he was kind of chubby so I thought maybe it was just that. But, now I know he
has some problems with trunk support. And then, with the speech delays. Like I said,
everything was late, but it happened. But the speech really got me. And I even waited an
extra 4 months longer than I wanted to before I took him to get evaluated.

Family 1 described a similar experience:

Since he was about 2 we’ve been observing that he was meeting his milestones just in the
nick of time, and lack of eye contact was very noticeable and distracting, and ultimately,
over time, we started to realize that is was something that needed to be looked at. So
we’ve been monitoring since he was about 2 until he was about 4 or 4½ that we went to a
neurologist to get a diagnosis. I think my wife was influenced at the beginning because
everyone was telling her to just wait and see and she was just watching, watching,
watching, watching to see what would happen and if he would grow out of it, and now
she is frustrated she didn’t act 2 years ago.

Family 9 reported how she noticed speech delays and lack of eye contact in her son. However, at
the advice of her pediatrician, she waited until her son was 3 ½ to receive a formal diagnosis:

I noticed he lacked eye contact so I took him to the pediatrician. So, I asked the
pediatrician and the pediatrician said, “I want to refer him to a neurologist.” So, I went to
the neurologist and the neurologist said he had high functioning autism. The pediatrician
noticed something but didn’t want say he was autistic because he can’t say that. He can’t
diagnose autism so quickly. But, he noticed a speech delay too. I told him, and he told me
“Oh, it’s just a speech delay.” He just told me to hold on and wait and see if it got better.
And then, when he was 3 ½, and we both realized it wasn’t getting better, so he referred
me to a neurologist and that’s when he was diagnosed.

Family 7 reported that, shortly after her son’s first birthday, she noticed his speech, attention, and
behavior regressing. However, she had no idea that her son had autism. In fact, she was angry
when an audiologist suggested that her son may have autism:

The next day, after his first birthday, was his vaccination. After his vaccination, it took
like 4 or 5 months, and I saw a decrease in his focus, hearing, and attention. We started
going crazy because of his lack of attention. We started trying to take him places to see if people could help us. We took him to an ENT (ear, nose, and throat specialist). I even took him to the ER at Miami Children’s Hospital because getting an appointment to see an ENT or a neurologist would take at least 6 months. As we were trying to find him services, I honestly thought he was becoming deaf. He wouldn’t answer us. We would snap our fingers and he would look away. We really thought it was hearing problems or maybe a cold or something that was messing with his ears. So, one day, we decided to go to the ER at Miami Children’s Hospital…So, they moved me to a room where they would test his hearing. We had to pay another $100. I went to the room and this lady came in and said, “Don’t get mad. I know you might think I’m crazy. But, I’ve been working with children for over 20 years and your son has all the characteristics of a child with autism.” And I said, “What is autism?” And all the hair all over my body just stood up. Looking back on it, I know what she did was a favor, but at that time, I just wanted to strangle her. She was the audiologist. She told me he had no problems with his hearing, but she saw how he was playing with my husband’s ears and my husband’s hands and she said that she saw some things that looked like autism. So, when she told us this, I wanted to strangle her.

Family 6 reported that, while she had some concerns about her son’s behavior, she and her husband were unaware that their son’s behaviors were associated with ASD. Family 6 and her decided did not get treatment for their son until her sister pointed out that her son was demonstrating characteristics of ASD:

We were suspicious of things that may have been going on with him because he had difficulties. He wouldn’t answer questions. He arranged his toys in a certain way. But, we couldn’t make sense of it. I mean, we’re not professionals. We’re just parents. And our parents said, “Oh, he’s two years old. This is just natural for him.” We didn’t know any better. Well, the issue of autism was first brought to my attention by my eldest sister when she visited us. She said, “Seek professional help. If it’s nothing, then you’ve ruled it out.” So, first I spoke to my pediatrician, and he referred me to Early Steps at the Mailman Center and, from there, they took me through the process. He was in the midst of transitioning to being a 3 year old, so he was transitioning into the public school system since the Early Steps program ends at 3 years old. And then, from there, they referred me to a neurologist who diagnosed him officially. Then, they referred me to a speech and occupational therapist, which he continues to get to this day.

Like Family 6, Family 8 reported that she noticed concerning behaviors in her son at eighteen months, but did not associate them with ASD until she started to learn more about the disorder when her son was approximately two years old:
I didn’t really know what autism was until he was 2. But, at a year and half, he started lining up stuff. He liked looking at the fan. He liked using switches. Very repetitive stuff. That was at a year and a half. And he would scream for everything. He would never ask for things.

Family 4 also started noticing concerning symptoms in her son at eighteen months old and immediately took him to see his pediatrician:

At 18 months, he started to show weird behaviors. I spoke with a physician about him and she would just say, “Oh he’s fine. He’s very smart and has a lot of energy. Take him to Gymboree or swimming class and he’ll get better.” But nothing happened. Then, she said, ‘Oh, he’s just going through the “Terrible Twos,” but it just started early in him. At that time, what concerned me the most was that he would bang his head against the wall and beat his hands on the floor. He was running around a lot. His behavior was terrible. I couldn’t take him anywhere because he wouldn’t behave. And the tantrums were out of control and I kept taking him to the pediatrician and nothing. So, I changed to a different pediatrician because I was so concerned because time would go on and his behavior would not change. So, the new pediatrician referred me to early intervention and she said that he needed to be evaluated.

However, all nine parents reported that they, eventually, sought a diagnosis, services, and support from different providers. Family 5 reported how she described her concerns to the school psychologist at her son’s school and how her referral led to her son’s diagnosis:

I was worried about his communication skills. The school psychologist suggested I take him to the neurologist. When she suggested that, it clicked. I just knew he was on the spectrum. I knew that would be it. As soon as I walked into the neurologist, she told me she saw some autism traits. She did the tests and he was diagnosed with PDD-NOS. He’s very talkative, but he has trouble communicating. He has difficulty finding the words and he needs to hear things a lot before he’ll understand. That was why I was having so much trouble in his schools.

Family 2 described her experience as follows:

He just always hit his milestones very late. Like, right when I would start to get very stressed out about something, he would hit the milestone. And the doctor told me, “No, let’s wait. Let’s wait and see b/c I didn’t start talking until I was three.” But, I don’t know, that’s just my personality; I wouldn’t let it go. And everyone thought I was hysterical. Like, this is just something I had in my head and I wouldn’t let it go. But, I
didn’t care. That was just the point that I honestly did not care. So, we kept on fighting and they finally gave us an OT eval.

Family 2 went on to report that it was through her son’s occupational therapist, not his pediatrician, that she received a referral to see the neurologist that eventually diagnosed her son with PDD-NOS.

While all parents participating reported that they recognized symptoms consistent with ASD, parents’ perceived knowledge of the disorder may have also impacted how quickly they initiated the diagnostic process and subsequent services. Family 6, for example, noticed concerning behaviors in her son, but did not associate them with ASD until her sister made her aware of ASD. Family 3 reported that, even after receiving a referral from her son’s pediatrician to see a neurologist, her lack of knowledge regarding the symptoms and treatment of ASDs led to her postponing a visit with a neurologist.

First, I wish I could have done it before. I believe I waited too long to take him to the Neurologist. I never thought he had Autism, you know? This was my first child. I had no experience and no contact with anybody who had a kid with autism. So, I took him to the doctor because he wasn’t really looking at me and I wanted to know what was going on and the pediatrician was the first to notice. He said, “You know, why don’t you take him to the neurologist,” because he still wasn’t talking, you know, and that’s what I did, but it took so long.

Family 2’s knowledge of ASD symptoms led her to continue to seeking evaluations and services for her son until she believed he had received an accurate diagnosis.

First, we went through the whole early intervention thing. They told us he had some delays but not too bad; that he just needed speech therapy. But, I always thought that there was more to it. As a matter of fact, when we left there, me and my mom both said, “Thank God. I thought they were going to tell us that he was autistic.” We were relieved that they said he just had a speech delay. But, as time went on, he was evaluated at 20 months, as time went on, I kept saying, “There’s more to this than just speech.”
Family 5 reported how her older son’s diagnosis of autism led to her recognition of her younger son’s PDD-NOS symptoms:

It was easier since we already had one previous experience. I already knew what to do. I took him to the pediatrician because I saw some concerns in his communication. She recommended Early Steps, but he was too old for Early Steps. So I took him to the school system for a psychologist evaluation. The psychologist mentioned I should take him to the neurologist after I mentioned that my oldest son had autism. So, I took him to the neurologist and that’s how he got diagnosed with PDD-NOS.

Family 9 reported that her former job working at a school put her in contact with a young boy diagnosed with Asperger’s. Her experience with this child helped her to notice symptoms of ASD in her own son. The experience also helped her better work with her son following his diagnosis:

Well, I used to work at a school and there was a boy diagnosed with autism or Asperger’s. And, there is a little bit more challenge but I never had a problem with him and I knew my way around. I had a picture of what autism was because I had worked well with this little boy. A lot of people had trouble with him, but he always behaved well with me.

Family 7 reported that, shortly after an audiologist suggested her son had autism, she began researching autism and starting the process of getting him formally diagnosed and treated:

And then, I took him to his yearly checkup with the pediatrician and I told them that I felt he was losing his verbal skills. She referred me to a speech therapist and he started speech therapy, right before he turned two. I mean, he used to say things. He used to say things in Spanish and ask for him and now he was just babbling and making noises. So, we started putting him in speech and I would sit in the waiting room and I would see all the kids with autism in the waiting room and I would try to ask the parents questions but, I was told by the staff, that it was wrong of me to ask the parents questions, like it was unprofessional or something. So, I called Miami Children’s again for another evaluation and I got an evaluation for 7 months later, but I didn’t want to wait that long. So, I called every day and I would cry to this lady to see if I could get an appointment, and they got the appointment moved up. So, by the time he went to the evaluation, he was about 2½ and they diagnosed him, But, before that, I took him to another audiologist up north b/c I didn’t believe what the first audiologist had told me. They told me he had nothing wrong. Just a little wax and they cleaned it up. So, I took all the paperwork they gave me and I
took him to Miami Children’s because I wanted her to see that I was really trying to get him services and that I was really serious about getting help for him and that I had already started him in speech therapy. So, she said, “I can tell you are trying to do a lot for him and I can tell you are strong.” And she called the psychologist on the third floor and she sent us up there because she could see that he really needed help. She said that the earliest intervention gave the best result. So, that day, I went upstairs and I got an evaluation and I left with a diagnosis.

Despite Family 8’s lack of knowledge of ASD and lack of support from her son’s pediatrician, Family 8 initiated both formal and informal services for at least a year before her son was formally diagnosed with PDD-NOS:

I had raised some concerns to my pediatrician. But, because he was so young, the doctor kept on insisting to wait until he gets older. But, I didn’t want to wait. I figured that if I thought something was wrong now, I should just do something about it. I did everything on my own in the beginning, without the recommendations or approval of my pediatrician. I found out about Early Steps doing internet searches. I started him in Speech and OT. I also started him in play therapy about twice a week, where someone would just come to the house and play with him. I also started him on speech therapy b/c he wasn’t talking. He was screaming and stuff like that. To this day, it’s hard, trying to get to the right place. So, before he even had a diagnosis, he was getting services for about a year. And I brought it up to the pediatrician and she said that, if I was really concerned about it, I should go to the neurologist. So, she referred me to a neurologist and he did a general evaluation and diagnosed him with high functioning autism because of the repetitive stuff he was doing and his language difficulties. He asked me to do further testing, like scans and blood work and things like that, and that threw me back again. That was very scary for me because I didn’t want to put him to sleep and stuff like that. So, I delayed the process for about another 6 months, but I kept on with the speech and OT. Then, the neurologist referred me to FDLRS because he was getting ready to finish his time at Early Steps. Early Steps took care of all the paperwork for me to transition him into FDLRS and he started in the public school system, a LEAP program, from there. After all that, just recently, I went to a psychologist to do a formal evaluation because the neurologist never gave him a formal evaluation and diagnosis, and he was diagnosed with PDD-NOS.

Like Family 8, Family 4 did not receive support from her son’s pediatrician. Her concern for her son’s behaviors led her to learn more about ASD on the internet. After gaining some knowledge of the disorder, Family 4 decided to change pediatricians and found a pediatrician that offered
her the support she was seeking for her son. However, despite finding a psychologist to finally diagnose her son, Family 4 expressed concerns regarding the authenticity of the diagnosis:

I started trying to do things for my son after I spoke with the first pediatrician and she told me that there was nothing wrong. I didn’t believe her. I knew there was something wrong. I would see my son and he would be on the couch and he would be rocking. He wouldn’t do anything else. He didn’t want to play with me. Nothing. So, I went on the internet and started looking around and they said it was Autism. So, I knew before he got a diagnosis that he was on the spectrum. There were a few websites that had checklists and lists of red flags for possible autism. So, I just kept pushing for his diagnosis. I changed to a different pediatrician because I was so concerned because time would go on and his behavior would not change. So, the new pediatrician referred me to early intervention and she said that he needed to be evaluated. So, we started that process and we looked at all the results of the testing I received through Early Steps. They recommended us to a speech pathologist and another therapy to address his behavior. They diagnosed him with Pervasive Developmental Disorder, but there was no psychologist there that provided the diagnosis. But, I knew I needed to find a psychologist in order to get the formal diagnosis in order to get the medical and insurance coverage I needed. The psychologist only took about an hour to diagnose him. And, I don’t blame her for it because I told her about his behavioral difficulties in advance. And, she said to me, “Well, it’s almost impossible to keep him in a room for an hour to complete the evaluation.” And I told her it was difficult for me too. So, I was OK with that. She sent me a lot of forms to fill out and I filled them all out and sent them back to her and then she met with him for the evaluation and, like I said, it only took an hour for her to make that distinction and diagnosis. I, sometimes, don’t think the diagnosis is accurate. I’ve heard about other institutions that take at least a few sessions in order to make the diagnosis, but they don’t take my insurance and I don’t have the money to afford that. And this lady only charged me $250 and that was all I could pay at the time. But, on his report, it says that she performed an ADOS, but I know she didn’t give him an ADOS. Her report is inaccurate. She said she did a lot of things on the report that she didn’t actually do. But, I don’t know what I can do. That was really all I could afford. I’ve tried calling other psychologists, but I haven’t been able to find anyone else that I could afford or that would take my insurance.

All nine parents reported that the diagnosis, although “overwhelming” and “emotional,” acted as a catalyst for action where their priority became finding the most suitable and appropriate treatments for their children. Despite having another child previously diagnosed with an ASD, Family 5 also reported initial overwhelming feelings regarding her younger son’s diagnosis with PDD-NOS:
You know, I said, “Not again.” But then, I felt relief because it was something I already knew about and I knew how to deal with it. Thank God it wasn’t something else that I knew nothing about because I wouldn’t have had the time to learn about it and deal with it.

Family 9 reported similar overwhelming feelings that impacted her entire family:

It broke my heart. I didn’t know what to do. But, the minute we found out, we started researching everything, we tried to find everything to try to move forward so he has a normal life. And it really impacted the family a lot. We all cried. We didn’t know if to be sad or what to do, or what can be done to help him. It’s…it’s just hard. But, now we are doing better and he is doing better.

Family 7 reported that, while she was initially angry and in denial, she was able to learn more about autism so that she could better help her son:

I thought it was the end of the world. The whole world was falling apart on me. I just wanted to strangle that first woman that told me that he had autism. And I remember that I turned to my husband and I said, “Is this woman crazy?” And I remember that I even made fun of her and I would go around my house making fun of her to my husband. And then, after he was diagnosed, I just kept asking God to forgive me because she was right. But, I wanted to be in denial. I’ve seen these moms that have kids that are like 9 years old and they’ve never gotten their children help because they say that their children don’t have a problem. I saw myself going down that path, but I had to snap out of it. I saw that God gave me a gift in diagnosing my son as early as he did. I thought, “I have to be strong enough to help myself because maybe my son will be the person who changes the world.” You always see people who have overcome some sort of adversity to achieve something great. Maybe that will be my son. But, it was a very harsh experience. I didn’t know what I was doing. I didn’t know anything about autism. I never had anyone close to me that had autism. It was very harsh for me to find out that my baby, my last baby, was diagnosed with autism. That was hard. I had to catch myself. I had to do a lot of research and I started to learn that children with autism are just like us, but smarter. They live in their own special world and we just have to bring them to us.

Like Family 7, Family 6 reported that she was also in denial when her sister first mentioned to her that her son may have autism. In fact, Family 6 reported that she did not even want to attend her son’s first Early Steps appointment out of fear that he would receive a diagnosis of ASD:

I just remember that I didn’t want to go to the Early Steps appointment. I don’t know why. I don’t know if I knew what was going to happen, but I didn’t want to go. The strange part was that, once he was diagnosed, I didn’t have a problem with it. I didn’t
have a problem accepting it. I knew he would get the help he needed. But, that first appointment, it was just really hard for me to go. It was hard for me to admit that he may have a problem. And I was scared he would be labeled. I didn’t want that for him. I think that’s why I didn’t want to go.

However, after her son was diagnosed, Family 6 immediately began researching interventions and services for her son:

I tried to inform myself as much as possible. I like to education myself as much as possible. I like to go and see and try. I brought back all the information Early Steps gave me in regards to his development and activities I could try with him at home. And, in the meantime, I would Google certain websites and they would say, “These are certain things you can do at home while you wait for a formal diagnosis because it could take a long time.” So, I was googling and just, in general, trying to get more information and get a handle on it. I would google activities on different websites and he would give ideas like, “Practicing communication skills by using a toy telephone and try to label things as you go along a daily routine so they can practice their speech.”

Family 4 reported that, although the diagnosis was an “emotional” process, it was also a relief as she could now start getting help for her son:

I felt relieved. I felt like a release. I knew from my research through the internet that he had autism. I mean, I felt bad. I cried a lot at that time. And I was alone during the process, so that was hard. But, I already knew that he had autism and I was psychologically prepared for it. And now, I had something to go on so that I could get him help and get him the services he needed. I have been involved in some parent groups for parents of children with autism and all of the parents have told me that they felt the same way when their children were diagnosed. When the doctor’s gave the diagnosis, they felt like me. They knew before also.

Family 2 reported:

So, right there, he told us that he had autism. And it was a shock. But, at the same time, it was a relief because I felt like, now I know what it is. Now I can do something. Yes, it was devastating. Yes, I cried. And you cry and cry…But then I had to start working.

Family 3 described a similar experience:

You can’t understand this experience until you have a child with autism. You can have an idea. But, until you hear that diagnosis, you will never know… But it’s completely different to have a child who is diagnosed with autism. You just have to keep working
hard and doing the best you can... You just have to go on. To not stop anywhere. Go on and do what you have to do. If he needs therapy, go and fight for it because you’re covered by the law. Fight your insurance or find the best insurance that will give your child what he needs. Go on the internet and research everything and get into contact with people who already have experience with their children.

Family 1, whose son was very recently diagnosed and only began services within the last month, is still dealing with the effects of the diagnosis:

It was an overwhelming experience. We didn’t know what to do. Trying to find out what the options are, those were really the big ones. Just trying to make sure that you get the best education possible. In the beginning, everything is so anxiety provoking that it is something you think you will not be able to overcome. But, the more you are going into it, the more you realize it’s going to be ok, But you just don’t know. We’re just hoping for the most positive outcome.

Family 8 used his diagnosis as a catalyst for action, saying that the time of diagnosis was, “Time to start working! I had to start working with him. Try to get the best education for him. Try to make him the best person he can be.”

Parents’ perceived needs. This category contains the open codes need for assistance before diagnosis and need for assistance following diagnosis. These codes refer to parents’ expressed needs before, during, and following the diagnostic process. Parents’ views of their child’s symptoms and diagnosis largely impacted their experiences throughout the diagnostic process and when deciding which services to utilize.

While all parents interviewed reported concerns regarding their children’s development, as is illustrated in the description of the symptom recognition open code, many of the parents expressed different needs for their children before they received a formal diagnosis. Family 1, for example, attempted to implement informal services and parenting techniques at home to address his son’s behavioral concerns before his diagnosis, while Family 2 and Family 3 chose to initiate
formal speech services to address their children’s speech delays prior to receiving an ASD diagnosis. Although all three parents were told by pediatricians to “wait and see” how their children’s symptoms developed before receiving a formal diagnosis or initiating services, Family 2 and Family 3, who both perceived their son’s symptoms as “severe,” reported being frustrated at the lack of assistance and guidance they received having their children evaluated or initiating services before receiving a formal diagnosis:

So, I think that if they had, even at the pediatrician’s office, someone who could counsel families who suspect their children have autism because, once you get to the neurologist, you already know that something is wrong. And, pediatricians should be educated better. They shouldn’t be telling families to just “wait and see.” No. They should send families for evals. If we would have started all the therapies earlier, we would have gotten more progress.

Another mother reported that, despite her attempts to initiate an evaluation and services for her son to address his speech delays and behavioral concerns through her pediatrician, it was necessary for her to contact a community early intervention system in order to receive an evaluation and services for her son prior to his diagnosis of Autism. Family 3 reported:

I wish I could have had more information on what to do and where I could go for more services. I mean, if it wasn’t for my sister-in-law, I wouldn’t have known about Early Steps. I was lucky because I knew someone. Things would have been different if I didn’t know her.

Family 5 reported that she initiated formal services for her son while waiting for his diagnosis:

I went to this pediatrician and they sent me to Early Steps, but he was too old for that. So, I went through the school system. That took a while. So, around the same time that we were waiting for the results from the neurologist, I started him in speech and OT because I knew what they were going to say. I did everything very quickly.
Like Family 5, Family 8 also took her son to Early Steps for an evaluation in order to start receiving services prior to a formal diagnosis:

Well, the pediatrician told me to wait and see. Early Steps said he had a language delay. I took him back to the pediatrician and they referred me to the neurologist. The neurologist referred me for a bunch of different tests, but that took about 6 months because I was reluctant to conduct all those tests on him. Then, the neurologist referred me to a psychologist. Then, the diagnosis of PDD-NOS was actually through the Medicaid waiver. I saw a few psychologists and a social worker and, through their evaluations, he was diagnosed with PDD-NOS.

Family 4 also expressed difficulties getting support from her son’s pediatrician. Lack of support from her son’s pediatrician led her to seek a number of formal, informal, and educational services prior to his recent diagnosis of autism:

I started trying to do things for my son after I spoke with the first pediatrician and she told me that there was nothing wrong. I didn’t believe her. I knew there was something wrong. I would see my son and he would be on the couch and he would be rocking. He wouldn’t do anything else. He didn’t want to play with me. Nothing. So, I went on the internet and started looking around and they said it was Autism. So, I knew before he got a diagnosis that he was on the spectrum. There were a few websites that had checklists and lists of red flags for possible autism. So, I just kept pushing for his diagnosis. And there was nothing that I could really do for him. I didn’t know how to treat it or anything. I just knew he needed the diagnosis so he could get help. I tried to take him to a private school because I thought that, maybe, his behavior would improve in a stricter environment with smaller class sizes where he could interact with other children and receive some services. But, he really proved to me that he had a problem when the teachers started to also complain about his behavior. They told me that he didn’t want to participate in classroom activities. He didn’t want to participate in circle time with his classmates. He would go to the couch in the classroom and just rock back and forth all the time. He also has difficulties sleeping as well as speech delay. He also has echolalia. That is why I wanted the diagnosis. And he was in Early Steps until he was 3 and then they moved him to FDLERS. We did the IEP meeting and everything and, right now, we’re in the public school system since January. He’s in a full-time, self-contained classroom. And I’ve noticed a lot of improvements in his behavior.

Family 7 reported initiating speech therapy services while waiting for her son to be evaluating and formally diagnosed with autism. Even though she had no accepted that her son might have autism, she was concerned about his speech regression:
And then, I took him to his yearly checkup with the pediatrician and I told them that I felt he was losing his verbal skills. She referred me to a speech therapist and he started speech therapy, right before he turned two. I mean, he used to say things. He used to say things in Spanish and ask for him and now he was just babbling and making noises.

Family 6 expressed a desire for education regarding developmental delays that begins long before symptoms of ASD are even present:

You know, but I do wish that people would give you more information from the beginning. Like, maybe it’s because of the stigma attached to developmental disabilities but, I wish when I was at the hospital having him that someone would have taught me about autism. Maybe not then, but early on. I wish I would have known about it earlier. I mean, when you have a baby, you’re mostly worried about feeding and diapers, all the obvious stuff. But, not the other things that we should have been worried about.

After receiving a formal diagnosis of ASD, the expressed needs of the parents changed dramatically. Although the needs of all nine parents participating in the study were different, parents participating in the study reported a similar need for immediate formal services based on their children’s specific needs. Family 1, whose son was recently diagnosed with Asperger’s, expressed concerns that, while he and his wife were happy with the services their son was receiving, they felt that the services were too generalized and did not address specific concerns he and his wife had about their son’s behavior and how they could manage those behaviors as parents. Family 1 was primarily concerned with his son’s social skills development, but did not perceive his son’s other symptoms as severe. Therefore, this father expressed a need for services that would address specific parenting and social skills interventions:

We need guidance as parents to understand that what we are doing is right or if we need to do something different. Specific questions like when he is pacing, should we explain to him that is not appropriate to pace or should we dismiss and re-direct him without saying anything, should we bring to the attention so that he is aware of it, maybe he’ll set the corrections himself. Should we tell him that he going to have social issues at school? Should we start communicating with him in that matter?
Family 2 whose child was also diagnosed with Asperger’s, perceived her son’s symptoms as more severe than the previous parent. Because she perceived her son’s symptoms as more severe than the previous parent, Family 2 reported utilizing many services from multiple service providers. As a result of the many services she was utilizing, Family 2 did not express a need for specific services or intervention. Rather, she expressed a need for service coordination.

I think if there was someone who could make finding services easier that would help… if there was someone in the pediatrician’s office that was a counselor that just dealt with helping families with delays or insurance. Just someone who knew about the policies…I would like to see a counselor that can help families understand developmental milestones but also how to work with insurance companies to get all the services their child needs. Like a coordinator.

Like Family 2, Family 6 also described a need for “centralized” services that would offer assistance to families following a diagnosis of ASD:

I feel like there’s something missing in terms of something being centralized, like an umbrella organization that can moderate all these other organizations that are being recommended to me. I mean, there’s just so many handouts and so many websites and so many things being recommended to me and so many magazines and so many organizations and there’s nothing where I can go or click just to see everything that’s out there for him. Just a centralized, umbrella, location, where I can access all the information I need. I think it would be helpful for families to have an individual case manager that can help you sort through your insurance and sort through the services you need to help refer you to services that would help your child. I had one through Early Steps, but it stopped at 3 years old and I felt like I was left on my own.

Family 5 reported concerns regarding her son’s behaviors, specifically lack of eye contact and tantrums. Therefore, Family 5’s concerns regarding accessing services were primarily focused on accessing ABA therapy for her son:

Getting ABA – that was really hard. Everywhere you called, someone could help you with other services, but not ABA. Even now, not a lot of people can tell you where to go. I called UMBH and they do offer help. We called them and they helped with locating providers and they told us which insurance to use for whatever you need. I also called CARD. I went there for help for ABA, but they didn’t help.
Like Family 5, Family 4 has also had difficulties accessing ABA therapy for her son following her son’s diagnosis:

The neurologist told me, “First, speech. Second, behavior. Third, occupational therapy. He doesn’t really need it, but if you can get it, it might help.” So, we started speech, behavioral, and occupational therapy. But, the problem is that the behavioral is not covered by my insurance. So, I’m currently paying for that out of pocket. The problem is that he really needs behavioral therapy three times a week, but I can only pay for one time a week. I know that it’s not really working, but he needs something. The cheapest I have been able to find it is $50 a session, but I don’t have enough money to pay $150 a week for him to go the three times a week that he needs. I know there are some people who can afford that, but I can’t. I don’t have a job right now. And it’s just me taking care of him b/c I’m a single mom. Insurance will cover him through a mental health program to receive behavioral services, but they are not ABA certified. I mean, they’re professional and mental health providers, but I don’t feel they have the experience he needs. Luckily, the speech and OT are covered three times a week for 1 hour.

Family 8 also reported difficulties accessing ABA therapy for her son as well as finding a speech therapist that will address the evolving needs of her son as he develops:

His speech has improved tremendously. He has a great vocabulary. But, his pragmatic skills still aren’t there, though. So, he was discharged from therapy because they said there was nothing more they could do for him. I’m in the process now of finding someone else because that’s not good enough for us. So, we’ll continue with the speech therapy and we also continue with the LEAP program, which is helping him focus on his social skills. Therapy wise, I haven’t done anything except for really focusing on social skills. I’d like to get him in ABA because I heard it would help with the repetitive stuff, as well as the tantrums and things like that, but with my insurance, it’s not covered. I haven’t gone further with that yet.

Unlike the other parents participating in the study, Family 7 reported that she believed the MMR vaccination had caused her son’s autism. Therefore, shortly following her son’s diagnosis, Family 7 took her son to a “natural doctor” in order to address his body before continuing formal therapeutic interventions. Specifically, Family 7 focused on treating her son through using natural supplements and therapeutic diets:
I went on the internet and started researching and that’s when I started reading about the MMR vaccinations and how bad they are and I started reading all the things they do. I just sat there and just started thinking about when all this started and I remembered that at his birthday, he was fine. And then, after his birthday, he was vaccinated. I realized these people were right. I saw what these vaccines did to his body. So, I found a natural doctor for him and that’s where he gets the supplements from. So, the natural doctor told us that we may have had a vitamin deficiency that caused a vitamin deficiency in him in utero. And, I thought that could be right since I had him older and while I was pregnant with him, I was going through a lot of stress. I was a mortgage broker, I was losing my properties, I was losing my job and I thought that might explain why he had a diagnosis of autism. All of this contributed to his problems and then, when we gave him the MMR, it just pushed him out of balance. All of our bodies are not the same. My grandson took the injection and he’s fine. All bodies are not the same…I also got a special scan of his body on everything that causes allergies in the body b/c the allergies cause inflammation that that inflammation makes it difficult for you to focus and retain information. So, I decided to start treating his body first because I didn’t want to feed him things that would continue to damage his body and make it difficult for the therapies to work. I figured I had to work with his body from the inside out so that his brain could start functioning better. So, then, I met a doctor who was giving a lecture on natural supplements and, I remember just holding hands with my husband and saying that God had brought us here. So, then we started giving the supplements to our son. We had noticed that, over time, he had really lost the ability to focus. I mean, he was really getting worse with each day. He would walk around the house on his tippy toes just screaming all day. He never rested, just to eat or drink. And he would just walk around, screaming and staring at walls. And my grandson would go looking for him to play and he would just push him away. He never paid attention to anything. So, we started giving him the supplements and, after two weeks, I saw that he would start following the ball when my grandson would play with it. I saw that detail and I saw a spark. I told my husband, “God just showed me that I’m on the right path.” So, I picked up the ball and I showed it to him and I said, “blue ball,” and he just ran away. But, two or three days later, I was eating and he walked up to me with the blue ball and he said, “blue ball.” I just freaked out. I called my husband, I called my family, everyone to tell them. I called my natural doctor and she said, “We have to keep on this treatment to kill call the candida that’s in his stomach.” You know, the yeast. The yeast absorbs all the nutrients from the food that are supposed to be going into the bloodstream and that keeps them from developing the neurons they’re supposed to. We have to kill this yeast to conserve these vitamins. So, I cook a lot with garlic, lemon, and ginger to kill the yeast. So, I think the special diet, along with the supplements, is helping. After using the supplement and the diet for a few months, I saw that the reports of the therapists were showing that my son was improving so, I really think that he is responding well to the natural treatments. And the natural doctor says that he looks and acts totally different. I noticed that he’s playing in closer proximity to other children. He doesn’t play directly with them but, little by little, I see him getting closer and closer to them and paying more attention to what they are doing.
4.2.2 Theme 2: Predisposing characteristics

According to Srebnik, Cauce, and Baydar (1996), predisposing characteristics are described as “stable conditions of an individual that influence one’s readiness to seek help.” Oftentimes, predisposing characteristics refer to demographic characteristics of the population being studied. However, the parents participating in this study did not cite demographic characteristics such as gender, age, or ethnicity, as factors affecting their decision making processes. Instead, parents often cited their abilities rely on themselves, or self-reliance, as having the greatest impact on their ability to access and utilize services for their children before and after receiving an ASD diagnosis. These predisposing characteristics also had an impact on parents’ perceptions of their children’s needs and illness as well as their barriers and facilitators to treatment.

Self-Reliance. This conceptual category contains two open codes: resourcefulness and values and beliefs. The ability to cope and deal with their child’s diagnosis “in a quick or clever way”, or resourcefulness, was cited by parents as having a major impact on their ability to access and utilize services for their child (Resourceful, 2013). All nine parents participating in the study cited how aspects of their character and life experiences increased their ability to access and utilize for their children, even when they were not receiving support or information from other sources. When asked what had the most “influence” on her ability to access and utilize services for her son, Family 3 responded:

I do things by myself. I just hear about something and I go. I go to the computer and I research everything. I say that I can’t be laid back. Any opportunity that comes for him, I take it. You know, I hear, “Oh, there’s a camp for him.” I check it out right away. It’s hard because I don’t always have the money, but I sacrifice.

When asked if anyone had an influence on her decision making processes, Family 2 responded:
People have tried. My pediatrician. Family members. But I don’t really care. I sometimes second guess myself, but I do what I have to do. I’m the only one who knows exactly what is going on with him. I’m the only one who really knows what he needs.

Following his son’s diagnosis, Family 1 reported how he and his wife responded:

A lot of reading, went to the bookstore and we got a couple of books to find out exactly what Asperger’s is; how it affects the child and what it can affect in later life, how it affects him in school. Then we also, at the same time we were dealing with the diagnosis, we were also trying to find psychologists at different places so they can help us to further understand the extent of his disability, and find out if there is anything that could be done to remedy it.

Family 5 reported that, following her first son’s diagnosis with Autism, she spent over 2 years educating herself about ASDs. This knowledge helped her to recognize ASD symptoms in her younger son early on. Family 5 said, “Once I knew my oldest child was autistic, I did about two years of research, just reading about it, learning about it, and looking for services. With this one, things were a lot easier.” Family 7 reported that meeting other mothers who had children with autism really helped her learn more about ASD and find services for her son following his diagnosis:

I mean, when he was first diagnosed, I really didn’t know anything about autism. I was just meeting so many moms and learning about things and now that I’m in that situation, I’m seeing autism everywhere and I’m meeting more and more moms who have children with autism and I’m getting a little bit of knowledge from everyone one I meet. See, I love to talk, and I start conversations with parents. And I see parents in denial and that’s not me. I know my son has autism and I know he was diagnosed with it. But, I don’t look at my son and say, “That’s all there is about him.” This is just a little stone in my path that I have to kick aside. So, every time I meet parents, I share with them my experience and I learn from their experiences. I see that maybe their child has a strength that my son hasn’t achieved yet so I’ll ask them how they helped their child learn that skill. It’s that communication. It’s that word of mouth with other moms and also hearing about things on the Internet.

Family 6 reported that she immediately began research ASD following her son’s diagnosis:

I had zero knowledge. I immediately went to Googling these disorders as soon as he was diagnosed. The first thing I remember learning was that this is really a spectrum disorder.
It can go from very mild to really severe. And I learned about the subcategory of Aspergers. And, even though I’m a nurse and I went to nursing school, I didn’t know about developmental disorders. They never taught us about that. I learned all about the physical disorders, but nothing about that.

Both Family 8 and Family 4 reported that, despite being told by their pediatricians to “wait and see,” they decided to pursue and formal diagnosis and services for their sons. Specifically, Family 8 said:

With my son, I noticed things a few things and the pediatrician just kept telling me to “wait it out” and I didn’t like that answer, so I went someplace else to help him get the services he needed without her. You just have to continue trying different things and researching other options until you get what you think your child needs. Trust your instincts and get the help your child needs. The earlier the better.

Family 4 reported that, in many instances, she felt more knowledgeable than the providers working with her son:

I’m always trying to do something. I need to get better treatment for my son. I’m just trying to do the best I can. I have to know everything. I feel like I have to study medical stuff. Like, I feel that the pediatricians and the doctors don’t know anything. I mean, the developmental pediatricians are really the only ones that know how to work with children with autism. But, here in Miami, we really don’t have any developmental pediatricians. And the other pediatricians don’t really know anything. I mean, other pediatricians I’ve worked with just said that he had “challenges.” And, at that time, I didn’t know what that meant. And I would look on the Internet and I would see that what he had was autism.

Family 5 reported how her children’s diagnosis with ASDs impacted her values and beliefs. Specifically, her children’s diagnosis made her rethink her ability to work full time while parenting two children with ASDs, saying “Well, it has changed in the way that I can’t work. I only have time to be with them for school and therapy. We go to 14 hours a week of therapy. I spend all my time with them. Other than that, everything is ok.”

Family 7 reported how her values have changed dramatically since her son’s diagnosis. Specially, Family 7 reported how her sense of self has changed:
I’ve changed my values for him. I mean, I have to better myself so that I can do better for him. I have to put myself in better places for him to help him more. I have to push myself more. I donate my time to help him. If I don’t sleep so that I can give more myself to get him the help he needs, I don’t care. I have to do it.

Family 6 reported that, while their values may not have drastically changed, they have changed the way they “parent” their son. They have also increased their religious faith:

It’s helped me to be more open and understand these issues. I understand that children with autism have the potential to learn, but they just learn in a different way. Things need to be very visual for them and, as a parent, I need to have a lot more patience to teach him. But, they have the potential to reach any goal they set. Not having understood it before and not having been affecting, I really didn’t understand it. I wasn’t even concerned about children with ASD. But now, we’re just working much harder to help him get where he needs to be. We have increased our faith. We know that he’ll come through this and we pray together more than we did before.

Both Family 2 and Family 3 reported how their values and beliefs impacted their ability to access and utilize services. Family 3 said:

When you have a child, that changes everything. Whether or not he has something, I was working hard for him anyway. I will do whatever I have to do. I’m telling you, when you have that baby in your hands, you see how the whole world changes. You do everything you can. You do what you think is right. Don’t listen to anyone else. Just don’t give up. You have to find a way. Whatever it is. You have to keep trying. If you can’t do something right away, keep trying.

In regards to how her values have changed since her son was diagnosed with ASD, Family 2 responded:

Just life. Things that I thought were important. You know, I was in line at the grocery store and there were these people huffing and puffing because they had to wait 5 minutes in line b/c there was only one register and this lady in front of me said, “you see people like that? They act like that because they don’t have real problems.” I could relate to that. Certain things just don’t bother me. My house isn’t perfect. And my mother will ask me, “What happened to you?” And I tell her that something has got to give. So if my clothes aren’t perfect and my house looks like a preschool, oh well. I can’t care what other people think or say.
4.2.3 Theme 3: Barriers/Facilitators to treatment

Srebnik, Cauce, and Baydar (1996) described barriers and facilitators to treatment as “social and environmental pressures that can occur at the individual, community, or broader political level.”

In this study, barriers and facilitators to treatment are described in three categories: Outside Influences, Economic Factors, and Services. All nine parents participating in the study described experiences that both impeded or enhanced their ability to utilize services for their children.

**Outside Influences.** This category contains the open codes Community-Social Support, Family Support, Work, and Internet. Outside Influences refers to any influence that the families participating in the study received from outside the immediately family not directly related services providers, service utilization, economic factors, or policy. All nine parents participating in the study reported mixed feelings regarding the effect of outside influences on their ability to access and utilize diagnostic and formal services. Prior to receiving a diagnosis, community and social support appeared to have an almost negative impact on parents’ ability to access services. One parent reported that, while she recognized symptoms of ASD, she waited to have him formally diagnosed since she had no contact with anyone who had ASD. Family 3 said:

I believe I waited too long to take him to the Neurologist. I never thought he had Autism, you know? This was my first child. I had no experience and no contact with anybody who had a kid with autism.

As previously mentioned, Family 1 reported that, while he and his wife had some concerns regarding his son’s development of social skills, his wife was “influenced” to “wait and see” if his social skills would improve before receiving a formal diagnosis and services:

I think my wife was influenced at the beginning because everyone was telling her to just wait and see and she was just watching, watching, watching, watching to see what would
happen and if he would grow out of it, and now she is frustrated she didn’t act 2 years ago.

Family 2 reported that people believed she was “hysterical” when she would share her concerns with others regarding her son’s behaviors and delays in reaching his developmental milestones.

But, I don’t know; that’s just my personality. I wouldn’t let it go. And everyone thought I was hysterical. Like, this is just something I had in my head and I wouldn’t let it go. But, I didn’t care. That was just the point that I honestly did not care.

Family 7 reported that her son’s diagnosis with autism had the biggest influence on her actions:

The only thing that really influenced me was his diagnosis. That influenced all my actions. Knowing that he has autism and reading that, they can be the smartest kids ever but they just need a lot of love and attention and therapy, that was really all I needed to see. I just tried to find what would work for him and figure out how I would get it for him.

Family 6 reported that her family, as well as her pediatrician, greatly influenced her course of action for having her son evaluated with autism:

We had a few concerns even before my sister told us she was concerned he had autism. And my pediatrician asked us if we wanted to investigate further and, I don’t know what came over me, but I just said, “No. It’s ok.” I think both our parents influenced us because I guess they felt that it wasn’t something that their own grandchild would have. But, the pediatrician didn’t push me either. She didn’t seem to think it was serious enough and she didn’t pick up on anything. And it wasn’t until after we provided her with all the reports of his diagnosis that she started saying, “Oh, I do see a little bit of a delay, but I wish you had told me sooner.” It started making me think that maybe our pediatrician isn’t informed enough. I mean, shouldn’t our pediatrician have that kind of information? I felt that was another issue. Maybe pediatricians are not informed enough?

Indirectly, community and social relationships did have some positive influence on parents’ decision making before receiving a formal diagnosis. Family 8 reported that a friend whose daughter was diagnosed with autism was a huge source of support and information for her and her family. Before receiving a formal diagnosis of autism, Family 7 also reported that seeing children with autism in the waiting room of her son’s speech therapist helped her to learn more
about the disorder and accepting of it when her son was finally diagnosed months later. Family 3 reported that a teacher recommended she attend some behavioral management classes to address her son’s behavior before he was diagnosed with an ASD. While attending the classes, Family 3 noticed multiple children who shared similar behavioral characteristics with her son. Family 3 also heard about the experiences of other mothers:

The classes were for behavior, you know, what to do when your child is behaving a certain way, and I realized that some of the characteristics of the other kids that were there, my son had them too, but I didn’t know about it. So, I mentioned it to my husband and my husband said, “Oh, he’s fine.” And I said, “No, but it’s very similar.” And I remember, I don’t know how it happened, but I remember, I think it was God or something … the parent was saying, “My son…” her son had autism. “My son goes like this when he’s watching TV.” And that night, my son did the same thing. I started seeing the similarities.

For Family 3, hearing about the experiences of other mothers and seeing, first hand, some of the behaviors of children with ASDs helped Family 3 pursue a formal diagnosis for her son.

Following their children’s diagnosis of ASD, family support, as well as community and social support appeared to have a primarily positive influence on the parents’ abilities to access services. Many of the families participating in the study reported receiving support from family and friends as well as referrals and recommendations for community support and services, formal services, and informal services. Family 2 reported how her mother retired from her job to help her take care of her son following his diagnosis, while Family 3 reported how she and her husband have become a “wonderful team” following their son’s diagnosis. Family 7 reported how all members of her family have received training on how to work with children with autism so that they can better interact with her son:

My oldest son has received special training and he now volunteers at a ranch working with autistic children. I’ve made all members of my family attend special classes and
trainings so that everyone who spends time with him knows how to work with him and deal with his behaviors. I make sure that everyone understands his behaviors and why he acts the way he does. Everyone has to learn.

However, Family 4 and Family 8 reported that they have received little or no support from family following their sons’ diagnoses. Family 4 reported:

It was difficult because no one really knows what autism is. My family had no idea. And I talk to my family and friends and we talk about his autism and they tell me, “Oh, don’t worry about it. There’s nothing wrong with him. It’s just because he’s so intelligent. He’s so smart.” They know nothing. They’re wrong. Autism is so much more than that. It’s every day I deal with his behaviors.

Family 8 also reported similar experiences with her mother-in-law saying, “My mother-in-law lives with us. She doesn’t think anything is wrong. She’s not helpful at all. She’s in denial.” Despite her difficulties garnering support from her mother-in-law, Family 8 reported that her relationship with her husband has grown stronger since her son’s diagnosis with ASD saying, “He’s been very supportive. We do everything together. He assists me in taking him to therapy sessions and evaluations.”

All nine reported how other parents of children diagnosed with ASD offered some sort of advice, assistance or referrals. Family 1 reported how his wife’s work became a main source of support and assistance:

My wife runs a developmental and educational facility for infants and toddlers, so she is constantly interacting with mothers and other mothers have the same concerns for their children. So, in communications with them, we were also able to get information about where to go for now.

Both Family 1 and Family 2 reported that supervisors at work have been “very understanding” following their children’s diagnoses and have allowed “flexibility” in their schedules so that they
can attend therapies and evaluations for their children. Family 8 described her experience balancing her work schedule with her son’s therapy schedule, saying:

Taking time off of work to get him to services. I have to take a lot of vacation time and sick days to get him all the services and evaluation he needs. Thank goodness they’re flexible. It’s tough because of all the time I have to take off. And most doctors aren’t open on evenings or weekends so it’s difficult when you work full time like I do. But, I’ve changed my schedule around to make it happen.

Family 3, however, reported that it was necessary for her to leave her job following her son’s diagnosis.

Both Family 2 and Family 3 reported how they received referrals to community organizations from members of the community that were outside of their family and social circles. For example, Family 2 reported how she first heard about the community organization Parent to Parent:

I was at a store and I overheard this lady talking about how her son had autism. So, I stopped her and I told her that I overheard what she was saying and she said, “Oh, you must be so upset.” And she took me outside and we started talking and she told me about Parent to Parent.

Family 3 shared a similar experience regarding how she learned about Parent to Parent:

There was a parent in the school and she said to me, “Oh, have you heard of this place called Parent to Parent.” And as soon as I heard it, boom, I didn’t wait. I went right away.

Family 8 reported that a combination of networking with other parents of children with autism and Parent to Parent has been very helpful to her and her family following her son’s diagnosis saying, “Networking. Talk to other parents. I know every child is different, but you can learn a lot from them. Parent to Parent is also a very good place to start with learning about the diagnosis and what you can do.” Family 7 reported that, in addition to Parent to Parent and
Autism Speaks, a community religious organization has been very helpful for her and her families’ peace of mind:

Parent to Parent and Autism Speaks. Also, Windows to the Sky. It’s a religious organization. I go every Saturday for a support group as well as prayer group. They also offer prayer groups for the children and they work very well with my son. They just offer inspiration, support, relaxation, and peace of mind. I feel like I have time away from everything to participate in meditation and be calm for a little bit.

Family 4 reported that she has received some assistance through both Parent to Parent and CARD:

I go to parent groups through his school and I go to Parent to Parent, but they don’t help me with referrals for services. I have to go to CARD for that. Parent to Parent was very helpful to me because they told me about IDEA and what my rights were. And they’ve been able to help advocate for me so that his IEP addressed all the concerns I had for him. CARD has been helpful, but not completely. They have sent me information and referrals, but they don’t exactly know how to work with your insurance. So, that’s difficult because most of the referrals they have given me don’t take my insurance.

Family 6 reported how the community organization Community Committee for Developmental Handicaps (CCHD) offered her assistance following her son’s diagnosis:

Just calling up different organizations, like CCDH. They asked a lot of questions and, based on my answers, they were able to give me advice regarding different things. Like, she asked me, “What is your income?” and, point blank, she told me, “Don’t bother applying for Medicaid.” That was extremely helpful b/c I don’t have time to waste with raising two babies. She also told me about two grants that I would be eligible for and she also told me about the Medicaid waiver, but there’s a huge waiting list. She’s tried to help me speed up the process.

As mentioned previously, another source of assistance outside of the family and social circles of the nine families participating in the study has been use of the Internet. All nine parents reported using the Internet to find information regarding their children’s diagnoses, behaviors, formal services, informal services, service providers, parenting skills and techniques, and educational information, just to name a few. According to Family 7, “Whatever you don’t know,
the Internet will find and they’ll give you videos and everything. Specifically, the Autism Speaks website.” Family 4 reported how the Internet helped her first realize that her son may be exhibited behaviors related to ASD. Her research led her to pursue a formal diagnosis for her son even though her pediatrician did not believe her son had a problem. The Internet has also continued to provide Family 4 that she uses to advocate for her son. Before her son was diagnosed, Family 8 also used the Internet to learn about Early Steps, which provided her with access to formal services for her son before his diagnosis. Following his diagnosis, Family 8 reported that the Internet has continued to be very helpful, saying:

The computer. The Internet. I’m always reading stuff on different websites, like autism speaks or other autism website. Parent to Parent has also been helpful. I’m always trying to find parent meetings and seminars and I’m finding a lot of web-based seminars and classes that are an hour long that I can take during my lunch break. I’m learning a lot from those webinars and I’m able to take the information I learn and apply it at home.

Family 6 also reported that the Internet has been very helpful following her son’s diagnosis:

The Internet. Seriously, the Internet has given me access to the websites that are full of so much information and forms and community events and happenings. I even get on email lists and message boards that provide information.

Family 2 reported participating in an online community designed for parents of children diagnosed with ASD in order to gain information and support.

I came across this website Momsreach.org. It’s a really nice website by a mom who has a child on the spectrum and she puts on there things that she has done or therapists she has worked with or therapists that have been recommended to her by other people that actually work with them. Like, I even recommended to them my ABA therapist. And, she called me and asked me questions about them and then put my recommendation on the website. So, it’s nice.
While many of the families participating in the study reported that they have eventually received support from family, friends, and members of the community at large, Family 2 still expressed an overall sense of frustration:

The support is there, but it’s always superficial. I mean, there’s not much people can do. My mother takes care of him and she helps him and I tell her everything but they don’t really get it. And I feel bad for her because I feel like she can’t really enjoy her grandchild. Like, she always has to be careful about what she says or that he might take something the wrong way or that it might impede on his functioning.

**Economic factors.** Economic factors are described in three open codes: *Finances, Policy,* and *Insurance.* All three factors were reported to have an impact on the types of services families received as well as the duration and intensity of the services. Almost all of the families participating in the study reported financial difficulties that often negatively impacted their ability to receive services for their children. All nine families reported that they required insurance in order to help cover the cost of services. However, all nine families also reported that lack of insurance coverage would not deter them from utilizing services they believed were necessary for their children. Family 1 said:

We were in agreement that we weren’t going to allow the coverage or non-coverage of insurance to determine which services we chose. If we found somebody that was highly recommended and was going to help us a lot, then we were going to pay for them.

Family 5 reported that, although insurance would not cover some services, she still tried to find ways to have her son’s treatments covered:

The most difficult is when the insurance doesn’t cover services and then there’s no way you can pay for it. As long as insurance pays for it, it’s OK. But, if insurance doesn’t pay for it, I have to call every day and find a way to get it covered.

Family 5 also reported, however, that despite her best efforts, she was unable to receive ABA services for her son until ABA services were approved by Medicaid in March 2012:
ABA – it wasn’t approved for autism. My kids have Medicaid, but they didn’t approve it for autism until March. So, they could get it, but I had to pay for it and the cheapest I could find was $50 an hour. But, they need like 10 – 12 hours a week and there was no way I could pay for that.

Family 2 reported that, in situations where insurance does not provide adequate coverage for services, she was willing to “whatever it [takes]” to get services for her son:

Do everything you can. Do what you think is right. Don’t listen to anyone else. Just don’t give up. You have to find a way. Whatever it is. You have to keep trying. If you can’t do something right away, keep trying. I mean, sell purses on eBay if you have to. I’ve sold everything I can think of, but you have to do it.

Family 2 also explained some of the difficulties working with insurance companies to make sure her son continues to receive services:

I know that therapists have to word reports in certain ways in order to get services covered by insurance. There are just so many things that affect him, but we can’t really ask for services. So, things have to be worded in certain ways to make sure he continues to get services.

Family 3 reported how both insurance and policy impacted the amount of services she received for her son:

The insurance, actually. They were giving us 15 hours of ABA therapy a week and then they gave us 10 hours…Actually 5. And I called them to fight, but I felt like I was walking on glass because I don’t know anything about that. But, my husband called them and said, “You can’t do that by law.” So, they gave us 10 hours instead of 5. We decided to leave it at 10 hours because we’re going to change insurance companies soon. Also, he started therapy at 15 hours a week and it’s been good, but now he’s starting kindergarten and I think that 2 hours a day Monday through Friday will be good and then I can work with him the rest of the day. I was thinking about dropping the hours from 15 to 10 anyway, but I was surprised that the insurance dropped it to 5. But, my husband took care of that. Plus, we’re going to change insurances soon. I just feel bad for the other kids who maybe need 20 hours of therapy. I don’t know much about it but, by law, every insurance has to cover autism services. They have to cover everything. It helped us because when they cut his coverage from 15 hours to 5 hours, we were able to fight it. My husband was excellent at writing letters. So, they put it back up to 10. So, it was because of those laws that we were able to fight to get his services.
When asked what factors had an impact on her ability to access services, Family 2 responded:

Not having money, I guess. I mean, money doesn’t bring you happiness, but it gives you options. If I’m not happy with services, I can go out and find a therapist that makes me happy. But, I have to find the money to do that, and it’s hard.

Family 9 reported multiple difficulties accessing ABA therapy as well as continuous speech therapy for her son:

Well, the speech therapist, like every 6 months, they got to reevaluate him and you got to wait like a whole month to see if the insurance will continue to cover you. In the meantime, the child is getting worse, you know, they don’t have therapy for about a month or two, they start, you know, to regress. And the tantrums and screaming start again because he doesn’t know how to express himself.

In regards to the ABA therapy, Family 9 added, “I finally got his ABA covered through Medicaid. At first, it was like a $120 an hour, and I had trouble affording that, but now we have Medicaid and we have that covered.” Family 7 reported also using the Medicaid waiver to get her son’s ABA therapy covered. However, Family 7 also reported that Medicaid does not cover all the therapies she believes her son needs. Therefore, she has to “barter” her skills for services:

And the neurofeedback he’s receiving I’m getting covered because I went to the office and I said to the woman in charge of the office, “I know that Medicaid won’t cover this service. I’m willing to work in your office so that he can get the neurofeedback.” So, I donate my time and services to the organization to make sure that he gets the services he needs.

Family 6 reported that insurance has been a hindrance in her ability to access and utilize recommended services for her son in a timely manner. Her insurance’s lack of coverage as also negatively impacted the amount of services her son receives each year:

You miss out on so many opportunities to provide interventions for your child just in the waiting. I mean, I must have waited a month or two just for insurance to classify our disorder. I mean, I would talk to the billing specialist and they would say, “No, we can’t cover that service. He has a developmental delay.” And that was not the case. They needed to see a neurologist’s official diagnosis and the code he put down in his report before they would cover anything. And, in the meantime, we’re wasting time. The longer
we wait, the more impact it’s going to have on his life. It just should have been a lot quicker b/c this is such a crucial time; a pivotal point in his development. And we were just waiting to see if insurance would cover it. And, finally, the insurance did cover it, but they’ll over cover it up to a point. Like, they’ll only cover 60 visits in a year. So, if I go to one visit and I see both the speech therapist and occupational therapist, they count that as two visits. If he got the physical therapy I think he needs, they would evaporate even faster.

Therefore, as a result of the minimal amount of services that their insurance will cover, Family 6 must pick and choose which services she believes are the most crucial for her son’s development.

Family 8 also reported concerns regarding her insurance. While she is able to get many recommended services for her son, there are specific services, such as ABA and specific speech services, that she believes her son needs that she cannot get covered through her insurance:

I think he needs speech. I mean, his speech is good. He pronounces everything wonderfully. But, he needs more speech where he’s in a group setting to learn pragmatics, but our insurance doesn’t cover that. Also, there aren’t a lot of speech therapy offices that offer groups. All the therapy is one on one. And, one on one, his speech and conversational skills are OK. But, when it comes to communicating in a group, that’s a lot harder for him. And the speech therapists, at least the ones I’ve seen, do not do those types of therapies. I’d like to get him in ABA because I heard it would help with the repetitive stuff, as well as the tantrums and things like that, but with my insurance, it’s not covered. I’m trying to get our insurance cover to cover ABA since they have a big exclusion on ABA. I wrote them a letter so let’s see what happens.

Despite not getting group speech therapy for her son privately, Family 8 did report that her son is currently receiving group speech therapy through his school.

Family 4 reported a number of difficulties getting services, specifically ABA, covered for her son through Medicaid:

But, the problem is that the behavioral is not covered by my insurance. So, I’m currently paying for that out of pocket. The problem is that he really needs behavioral therapy three times a week, but I can only pay for one time a week. I know that it’s not really working, but he needs something. The cheapest I have been able to find it is $50 a session, but I don’t have enough money to pay $150 a week for him to go the three times a week that
he needs. I know there are some people who can afford that, but I can’t. I don’t have a job right now. And it’s just me taking care of him b/c I’m a single mom. Insurance will cover him through a mental health program to receive behavioral services, but they are not ABA certified. I mean, they’re professional and mental health providers, but I don’t feel they have the experience he needs.

Family 4 also reported that many of the providers recommended to her do not take Medicaid or, if she does find a Medicaid provider, she often has to wait on a long waiting list before her son receives services.

When asked what factors had an impact on her ability to access services, Family 7 reported that, while not having a job impacted her ability to access ABA therapy services sooner for her son, she was eventually able to access ABA services through the use of the Medicaid waiver:

Well, if I had a job, I would be able to pay for services instead of donating my time. I mean, if I still had my job, I would have been able to pay for ABA out of pocket as soon as he was diagnosed instead of having to wait for the federal aid.

Family 7 also reported that, while her lack of finances makes it difficult for her to sometimes access the “exact” services she wants for her son, she is able to make due with finding alternative and affordable services for her son:

Well, right now, if I had money, I would have been able to put him in the autism summer camp, but I can’t afford that. It’s almost $500 a week. I mean, they offer ABA, speech, and OT and they are able to interact with other kids. And they take them on field trips to the Seaquarium and things like that. I wish I could do that for him, but I can’t afford it. Instead, he goes to a different camp that is funded by the government. They basically just offer swimming classes. But, it’s $30 a session and I can afford that. At least the swimming will help with his coordination and will help him to interact with others.

Family 6 reported that, once she runs out of the sixty sessions covered a year by insurance, she will have to “access grants” to continue ensuring that her son receives the services he needs.
Family 4 reported that she attempts to pay for as many services as she can out of pocket, even if what she can afford does not add up to the amount of services recommended for her son.

_Services_. This category contains the open codes Formal Services, Informal Services, Service Providers/Characteristics, Voluntary Refusal of Services, and Education. Although difficulties were reported before receiving a formal diagnosis of ASD, all nine families participating in the study reported little to no difficulties receiving referrals for formal services following their children’s diagnosis with ASD. In fact, all nine families reported receiving referrals for services and even specific service providers from their children’s neurologist when their children were diagnosed with ASD. Family 9 reported how her son has been able to receive consistent formal services through a private school that specializes in working with children with ASDs:

_When he first was diagnosed with autism, it was really hard to find therapist, everybody was closed or we can’t take your insurance or you have to go on this waiting list. We finally found a place called Promise Land, that provides a school for children with autism, and we’ve been able to get all his services through the school._

Family 7 reported that her son has been able to get consistent referrals for formal and informal services from his pediatrician:

_We have him in all sorts of therapies: art, music, horseback riding, and we’re starting him in swimming now. I still don’t know how I’m going to schedule it, but I will make the time. We just try to keep adding more therapies because the more therapies he gets, the more interactions he gets. So, I pretty much do the research, I see which therapies I want him to get and then I go to my doctor and have her give me referrals. I have a great primary doctor. Whatever I ask for, she gives me the referral. She sees that my son needs it and she doesn’t give me a hard time._

Family 6 reported that service providers have had the biggest impact on the kinds of services she chooses to utilize for her son. Family 4 had a similar experience, reporting that her son’s
neurologist has been the biggest influence on the services she has utilized by providing her with a “roadmap” of services her son needed following his diagnosis. Family 8 also reported a similar experience, saying:

When it comes to health services, the neurologist helped a lot. I mean, he gave me a paper with a list of things I needed to get done and then he said, “When you’re finished, come back to me and we’ll keep getting services.”

Family 3 reported:

I took him to the neurologist and he told me, “I think you should take him to this place, ABA, because he needs therapy, and now that you have the diagnosis, you can go, get the therapy, and it will be covered by your insurance. Before, he was getting speech therapy through Early Steps and some therapy through his school, but it wasn’t very much. So, that’s what we did, very quickly. Right there. We called the same day. We didn’t wait. We got an appointment that same day and the ABA was covered by our insurance. And, about three weeks after, he started with the ABA therapy.

All nine parents participating in the study also reported receiving referrals for specific services and service providers from other service providers. In fact, Family 2 reported that other service providers were a primary source of receiving referrals for other formal services and providers. Service providers also provided assistance in preparing Family 2 for the personality differences and service characteristics of service providers:

I said, “Do you think he needs to be evaluated for autism.” And she [occupational therapist] said, “Well, I would do if for your own peace of mind. He’s not a clear case, but if it’s going to make you feel better, go ahead and do it.” And I said, “I already have an appointment.” And she said, “Who are you going to see?” And I told her his name and she said, “I like him, but if you can’t handle being told straight out, then don’t go to him because he’s going to tell you straight out what it is and he’s not going to sugar coat it. So, if you’re one of those people who can’t handle it then don’t go to him.” And I said, “No no no. I can handle it.”
Informal services and interventions were most often recommended to parents through family, friends, community organization, and/or the Internet. Family 1 also reported that many of the informal services and interventions he implemented were “common sense.” Family 1 reported:

We tried group play dates. We tried forced direct eye contact when talking to him and that got him much better as a result. On play dates, there’s still an isolation factor, but we’re seeing some progress there.

Family 2 also reported on the benefits of a summer camp a community organization recommended to her:

He goes to the JCC camp for children with special needs. It was a wakeup call for him. He really changed. My husband always says, “My son learned more in those 8 weeks of camp than in the whole pre-k. The routine that they used and the counselor. There was one counselor for two kids. And he learned how to swim and they also do academic activities and I noticed that it helped him a lot.

All three parents also reported attending classes, lectures, and workshops through the community and implementing the interventions and parents skills they learned in their homes and families.

Family 3 reported:

I’ve had a lot of help from Parent to Parent. The workshops have been the most helpful. They taught me a lot about the transitions; how the system works; how to work with my son, especially at the beginning with all his behaviors. I mean, it’s not easy, you know. You get very frustrated sometimes. But then, once you start practicing and doing it, you get it. So, those workshops about behavior were helpful.

Family 3 also shared a story about how Parent to Parent, along with her son’s ABA’s therapist, helped her son receive accommodations while in school:

My son is very allergic. And now that he’s going to kindergarten, he’s going to eat in the school’s cafeteria by himself. You know, the teacher leaves the kids in the cafeteria. But, the school didn’t want me to go every day to monitor what he eats, you know, to make a smooth transition for him. Instead, they wanted to put him in the office to eat lunch. And I said, “No. He’s not going to learn anything. If you put him in the office, how is he going to learn that he can’t accept food from other kids.” So, I was talking with the
supervisor of ABA and an advocate for Parent to Parent and, with their help, I was able to get someone who will monitor him at lunch so he can stay with his classmates. They helped me to figure out how I could talk with the school and what ideas I could give to the school so that we could better accommodate my son. I was able to coordinate a meeting with the school and get someone to monitor him during lunchtime.

Family 9 reported how Parent to Parent has helped her find informal services for her son saying, “Basically, they get you resources, summer camps, stuff like that, and they help you how to pull through your child, and stuff like that.” Family 5 also reported utilizing informal services in her home in order to better help communicate with her son:

I tried to speak to him in Spanish, but he would respond in English. So I tried to make the switch to see if that would improve his skills. He seems to understand everything, but when he goes to communicate, he has a lot of trouble finding the words. He really does understand but when I saw that he still had trouble in both languages, I knew he needed more help.

Family 7 reported how she tries to expose her son to different sensory stimuli that he has difficulties processing:

Right now, for example, he’s having a problem with creams. Anytime I try to put a cream or lotion on his skin, he starts screaming. I’m trying to work at home with him on that by, little by little, putting creams in his hand and telling him to rub his hands together and telling him, “Nice. Smells good.” It works a little bit, but it takes time. I’m also using a mirror to try to show him different textures. Like, I put shaving cream on the mirror so he can touch it and move it and see it.

Family 7 also works on helping her son respond to basic commands while at home:

Now, we’re working on commands and we’re practicing his responses. Simple commands like, “put this in the garbage” or “pick this up.” You know, you have to be strong. You have to do a lot of one on one with them. You have to bring them to your world; you can’t go to theirs. In all the studies I’ve done and all the therapies I’ve done, I’ve learned a lot and I really act as his therapist at home.

Family 6 reported how many of the informal services and interventions she utilized in her home were idea she found on different autism websites like, “Practicing communication skills by using
a toy telephone and trying to label things as you go along a daily routine so they can practice their speech.”

While previous research has indicated that “provider lack of skills” is a detriment to parents’ ability to access and utilize services (ie: Chiri & Warfield, 2011), providers’ service characteristics were not found to be a detriment to service utilization in the current study. Family 5 reported how location played a key role in her decision to terminate speech services with one provider and receive speech therapy from another provider. Family 7 reported that “price” kept her for accessing some informal services for her son, specifically a service that would help potty train her son. Family 7 also reported that she has a wonderful relationship with her son’s therapists, specifically his occupational therapist, who incorporates the family into her sessions:

We love to bike ride as a family, but my son had trouble with his tricycle. So, we would attach a little trolley to the bike so he could ride with us. When I mentioned it to the OT, she started incorporating tricycle riding into the therapy so that he could ride with us. And she incorporates me into the therapy as well so that I can learn how to continue showing him how to ride his tricycle at home.

Unlike the other parents participating in the study, Family 6 reported how service characteristics, along with insurance, are negatively impacting the amount of services she receives for her son. Family 6 reported:

I think what has impacted me the most and what is causing me to look for other speech and OT providers is the fact that they only offer me 30 minutes of speech a week and 30 minutes of OT a week. I know they are very busy, but they claim it’s because of his attention span. However, they bill my insurance for a full hour of speech and a full hour of OT each week. I feel like my son is getting cheated out of the therapy he needs. I mean, that doesn’t jive with what was recommended to him by his neurologist. They recommended that he needed 3 hours of each a week, but he’s only getting 30 minutes.
Family 8 and Family 4 also reported similar experiences. Family 8 reported how her son’s speech therapist discharged him “abruptly” in March after feeling as if he could no longer provide treatment for her son:

Like, the last speech therapist he was seeing just discharged him abruptly, so now we’re looking for another therapist. I don’t think the speech therapist should have done that. He should have known more about autism and he should have known what my son really needed from the speech therapy. We haven’t been able to resolve those issues yet, especially with the speech therapy. He hasn’t received speech therapy since March. His speech has improved tremendously. He has a great vocabulary. But, his pragmatic skills still aren’t there, though. So, he was discharged from therapy because they said there was nothing more they could do for him. I’m in the process now of finding someone else b/c that’s not good enough for us.

Family 4 reported how service provider characteristics have greatly impacted the services her son receives, saying:

That was an issue. It took me a long time to find good therapists. You’ll find a lot of places that offer services, but they won’t treat you well and they won’t treat your child well. And I found that they weren’t even practicing what they claimed to practice, so I’ve had to change therapists a lot. If something isn’t working for me or something isn’t work for my son, I change his therapist and we go someplace else. I’m happy now with the therapists we’re working with now. They’re excellent therapists and I feel like they have a connection with my son.

Family 2 said:

Well, I always trust my gut. I look at the way they interact with my child and I pay close attention to his reaction to them. And I never think any of the therapists would do anything bad to him but I just saw with that first OT that there was no connection. She was calm and very businesslike. It just didn’t work with him. Just personality differences, I guess.

Family 2 also shared with the therapist her decision making process in choosing her son’s ABA’s therapist:

I was having trouble finding a therapist because there were a couple therapists I liked but I couldn’t see them because they were booked or they didn’t take my insurance. So, I
finally found Lisa through my insurance. I told them I needed a therapist that would come
to my house or something close by because it’s easier. I mean, I couldn’t go to a therapist
that was far away. I needed a therapist that would was close by and would be more
available. So, I wanted someone closer and they gave me a couple names. I spoke to her
and from the first time I spoke to her, I just got this feeling. And I said, “You know what?
I’m not going to look any further.” And she’s been amazing. I liked the fact that she’s a
little bit older and I felt like she had a lot of experience. Like, it wasn’t just experience
about autism. It was experience about life.

Family 3 reported how a combination of service characteristics and lack of insurance coverage,
initially, made it difficult for her to attain services. However, she was able to eventually receive
speech and language services for her son:

The location [of the service provider] was fine. But there were services that I wanted to
get for him because of his speech delay that I could not get because it wasn’t covered by
my insurance because we didn’t have a diagnosis of ASD yet. But, I found one place and
I didn’t like it because I didn’t like the speech therapist that was working with my son. I
felt like he was too rough with my son. I didn’t like his attitude. So, I spoke with the
company and they sent me a therapist that agreed to work with him in the home, so it
actually made my life a lot easier.

Family 2 also reported how services providers, specifically her son’s ABA therapists, have
included her in her son’s therapy:

The ABA therapists also include me in the therapy. They don’t just come here and do the
therapy. The supervisor looks at his progress each week and they look at what he needs to
change. They’ll add more goals each week. They do one hour of individual of therapy
and then one hour working with me and what I can to help him. They also ask me if I
have any goals I’d like to add and we work together.

Overall, parents in the study were happy with the services and accommodations their children
were receiving through the public school system. Eight of the nine parents believed that school
administrators and teachers were working closely with them to meet their children’s needs and
help their children attain specific goals. Family 3 also reported that she was able to attend
behavioral management and parenting courses offered by the school before her son received a
formal diagnosis of ASD. After not being able to receive diagnostic services through Early Steps,
Family 5 was able to receive initial diagnostic services and referrals through her son’s school psychologist. Family 5 also reported that teachers at her son’s school also provide her with behavioral interventions she can utilize in the home. Through her son’s school, Family 6 reported that her son is able to receive services through the LEAP program and she and her husband have had access to parent training courses. Family 8 also reported that the LEAP program had been a great source of services for her son and support for her and her family:

The LEAP program is a great program and is a great model for other programs. I think all children on the spectrum should be able to interact with regular kids and learn from them. In his class, he has a group of girls that are very social, so he learns from them. They’re always socializing. Very friendly. So that has helped him a lot.

Family 8 also reported how the LEAP program has consistently provided speech services for her son even after his private speech services were discontinued.

Unlike the other parents participating in the study, Family 4 reported negative feelings towards her son’s teachers and assistants:

Now, I feel like the school system is helpful because they are following the IEP. However, I don’t like my son’s teacher and I don’t like the assistant that works with him. I don’t like the way they treat the children. So, I’m going to move him to another school. You go in the classrooms and they’re crowded and I wonder if he’s getting enough services there. He’s in a public school right now in a self-contained classroom, but I’m trying to get him moved to a reverse mainstream classroom so that he can be around typically developing peers and, hopefully, learn from there.

In the current study, parents reported that they utilized all formal services recommended to them. The only services parents reported refusing were specific recommendations or treatments recommended by service providers of formal services. Family 7 reported being recommended a number of services through other mothers in the autism community. However, these services did
not have empirical support and Family 7 decided not to pursue them further. Family 7 discussed how stem cell therapy has been recommended to her to treat her son’s autism symptoms:

Well, I’ve heard parents recently talking about taking their children to South and Central America for stem cell studies to treat autism. I can’t tell you much about it because I don’t know much about it, but I don’t think I’ll be trying that out.

Family 6 reported that her speech therapist recommended that her son visit an orthopedist. However, after following up with her pediatrician, Family 6 decided not to utilize this recommended service. Family 4 reported that she discontinued horseback riding therapy after becoming fearful that her son may be injured during the process:

I also tried the horseback riding therapy, but the neurologist said it was dangerous and it probably wouldn’t be helpful for him, so we quit that. I started to get scared, too, that he would fall off a horse. There was no proof that it actually worked for children with autism, either. Then, I was also concerned about the safety aspect of it and him falling and getting a head injury. Also, it was very far away from me and I don’t have time to take him down to Homestead for the appointments, especially with all the other therapies he’s receiving each week. It was also a lot of money to pay for the horseback riding.

For example, Family 2 reported discontinuing use of vitamin supplements:

The supplements. The sound therapist recommended them and I tried them but I discontinued them. It was really expensive and they tasted bad. It’s already hard to feed him, so that made it worse.

Family 1 reported that he refused some neurological testing after feeling it was not necessary for his son’s diagnosis and treatment:

An EEG was suggested but we decided not to get it because it was not related to this issue. We were also told that is pretty standard because there are neurological disorders that will try mimic an autistic diagnosis symptoms so they just wanted to rule it out. I didn’t think it was necessary. They were just going to charge our insurance for a test that would basically come out normal.

Of the nine parents participating in the study, five parents reported refusing or discontinuing recommended services. However, the services they reported refusing or discontinuing are not
services that are empirically supported for the treatment of ASD. Only one family reported refusing a service recommended by the diagnosing neurologist. However, the service they refused was a service that was not necessary to treat ASD symptoms and was a test to rule out possible neurological disorders. One other family reported refusing a service recommended by a service provider. However, the service they refused was a service that was not necessary to treat ASD symptoms and their refusal was based on the advice of their pediatrician.

4.3 Quantitative Study Results

According to Warren et al. (2011), five treatment areas have established empirical support and are commonly recommended by psychologists following an ASD diagnosis: Behavioral, educational, allied health and ancillary services, medical, and complementary and alternative medicine. Based on research, thirty-nine different treatments are commonly recommended to parents of children diagnosed with ASDs under these five categories.
In the present study, parents reported that they were recommended twenty-one out of the thirty-nine commonly recommended treatments. Only one treatment, occupational therapy, was recommended to all nine parents participating in the study. Speech and language therapy was recommended to eight parents while ABA therapy was recommended to seven parents. The remaining eighteen treatments were recommended to less than half of parents participating in the study.

Treatments were recommended to parents by the following: Neurologists, pediatricians, service providers, family members, friends, school system/teachers, and community-based early intervention programs. Surprisingly, some parents reported that they, themselves, asked pediatricians and neurologists for referrals for their children to receive ABA therapy, speech and language therapy, and neurofeedback. Two mothers also reported that they have placed their children on therapeutic diets without the advice or recommendation of professionals. Parent report on the Treatment and Interventions Checklist was supported by findings of the document analyses and demographic questionnaires.

In regards to the treatments that were not commonly used by or recommended to parents participating in the study, many parents reported that, while they had heard about some of the treatments through their own research, they chose not to pursue those interventions due to lack of information. For example, Family 6 reported that, shortly after her son’s diagnosis, she considered pursuing hyperbaric chamber treatments. However, after having difficulties finding information regarding its efficacy, she chose not to utilize hyperbaric chamber treatments. Similar experiences were shared by all the parents participating in the study. While they may have heard or read about certain treatments, the parents participating in the study would not
pursue those treatments without a recommendation from someone they trusted or multiple reports regarding the treatments efficacy.

It is important to note that some of the treatments listed in the Warren et al. (2011) study are not readily available in South Florida and, therefore, would likely have not been recommended to parents participating in the current study.
CHAPTER 5

DISCUSSION

The goal of this study was to use direct content analysis to examine the experiences of parents regarding their ability to access and utilize services for their children following a diagnosis or ASD by expanding upon an established model of help-seeking behaviors (Cauce, Srebnik, Baydar, 1996). The model was expanded to specifically describe the experiences of parents of children recently diagnosed with ASDs by gaining information regarding parents’ perceptions of the multiple factors that may affect their decision making process when deciding which recommended services to utilize for their children. Cauce, Srebnik, and Baydar’s model of help-seeking behavior was also utilized to examine reasons why parents may voluntarily choose to decline recommended services for their child. In this chapter, components of the expanded theory will be discussed in regard to the specific research questions that guided the study. The discussion will be organized by the research questions that guided the current study and the codes the generated by the research and interview questions. Limitations of the study and the implications of study findings will also be discussed in this chapter.

There are two research questions that guided this study:

1. According to parents, what factors are the most influential in their decision making process when deciding which services to utilize for their children following a diagnosis of ASD?

2. What factors may influence parents to voluntarily reject recommended services for their child following a diagnosis of ASD?
Research Question #1: According to parents, what factors are the most influential in their decision making process when deciding which services to utilize for their children following a diagnosis of ASD?

The main research questions that guided this study explored the factors that are most influential to parents when decided which services to utilize for their children following a diagnosis of ASD. The information provided by parents participating in the study gave insight into the decision making processes of parents, especially during the very emotional time following their child’s diagnosis. It also shed light onto the specific needs of parents before, during, and after the diagnostic process.

Parents participating in the study reported a variety of different experiences when describing the process by which they first identified possible symptoms of ASD in their children and initiated the diagnostic process. Despite the varying ages and symptoms of their children, all parents were able to identify that their children were not developing typically and required additional assistance or follow-up. While some parents reached this conclusion on their own or required the assistance of family, friends, or service providers, all nine parents were able to start initiating services to treat their children’s ASD symptoms before or immediately following their children’s diagnosis. The services parents chose to first access and utilize depended greatly on how the parents perceived their children’s symptoms.

As reviewed earlier, O’Brien and Daggett (2006) postulated that the recommendations chosen by parents; the interventions they consider effective; their satisfaction with services and service providers; and their responses to their children’s behaviors are all reflected in parents’ beliefs about ASD and its causes. These beliefs impact the way parents approach the diagnostic
process (O’Brien and Daggett, 2006). This view is supported by the responses of the current study’s participants. While most parents participating in the study chose to first access speech and language services to treat their children’s speech delays, one mother, who believed her son’s autism was caused by vaccinations, chose to work with a “natural doctor” that prescribed vitamin supplements and therapeutic diets for her son before enrolling him in formal therapeutic services. Therefore, how parents perceived their children’s symptoms and the severity of the symptoms greatly impacted how quickly parents chose to access therapeutic and diagnostic services as well as the types of services their utilized. These experiences are represented in the conceptual code “Diagnostic Experience.” The conceptual code “Diagnostic Experience” is comprised of three open codes: “Symptom Recognition,” “Perceived Knowledge of Disorder,” and “Diagnosis.”

**Symptom Recognition**

Srebnik, Cauce, and Baydar (1996), Freeman *et al.* (1992), and Rickwood and Braithwaite (1994) reported that parents’ abilities to recognize the severity of their children’s symptoms was a “powerful predictor” of help-seeking behaviors and formal mental health services. These findings are supported in the current study. While all nine parents reported that having a “formal diagnosis” of an ASD was helpful in receiving more access to services and coverage from insurance, their perception of their children’s symptom severity appears to be the most influential factor in their decision to seek a diagnosis and services. In fact, four of the nine parents interviewed reported initiating formal services prior to receiving a diagnosis of ASD.

Parents’ perception of their children’s symptoms also influenced their opinions of service providers and service characteristics. More than half of parents participating in the study reported that they did not agree with pediatricians who recommended that they “wait and see” if their
children’s ASD symptoms improved. All nine parents reported that they were not happy with or
did not agree with the services their children were receiving from at least one service provider.
Parents’ discontent with service providers was largely based on how parents perceived their
children’s symptoms and whether or not they believed their children’s symptoms were
improving. Despite their disappointment with some services or service providers, all nine parents
reported that they are currently receiving recommended services from a different service
provider or are in the process of changing service providers.

Knowledge of Disorder

Parents’ perceived knowledge of the disorder impacted parents’ ability to access and
utilize services for their children in multiple ways. Knowledge of the disorder may have
impacted how quickly they shared concerns about their children’s behaviors with pediatricians or
it may have impacted whether or not they pursued a formal diagnosis with or without the support
or referrals from pediatricians. In the current study, four parents reported that they pursued
formal services for their children through community early intervention programs against the
advice of pediatricians and prior to receiving a formal diagnosis of ASD. Knowledge of the
disorder also impacted how parents responded to the amount of support they received from
family and social circles. Goodwin (2011) reported that lack of knowledge on how to care for
children with ASD within a family’s social network and community can also affect the overall
wellness of the family. This was evident in the reports of multiple parents who stated that they
did not pursue diagnostic services for their children based on the advice of family or friends.

Knowledge of the disorder also impacted how quickly parents pursued formal treatments
for their children as well as the kinds of treatments they chose to access and utilize. As
mentioned previously, while most parents chose to access speech, behavioral, or occupational therapy services before or immediately following their children’s diagnosis, one mother chose to pursue a number of alternative treatments in order to counteract the effects of the vaccinations she believed caused her son’s autistic symptoms. Multiple parents also reported that they noticed “odd” behaviors in their children, but did not associate the symptoms with ASD. As a result, they did not mention their concerns to service providers as quickly as they would have liked in retrospect. In fact, more than half of participating families reported that they did not pursue assistance in diagnosis and treating their children’s ASD symptoms as quickly as they should have because they lacked knowledge of the disorder.

Diagnosis

Along with parents’ perception of symptom severity, clinical diagnosis has also been shown to be a powerful predictor of help-seeking behaviors in parents seeking services for their children (Srebnik, Cauce, & Baydar, 1996). Despite the knowledge some of the families participating in the study may have had about ASD and their children’s symptoms, it is clear that none of the families were really prepared to receive the diagnosis of ASD. The parents participating in the study experienced a wide range of emotions regarding their children’s diagnosis. However, for all nine parents participating, diagnosis acted almost as a “call to action,” where all nine parents immediately started or continued pursuing formal and informal services for their children.

Although all parents reported concerns regarding their children’s behaviors, as reported in the symptom recognition open code, all parents still expressed similar “overwhelming” experiences when their concerns were confirmed with an ASD diagnosis. Despite receiving a
diagnosis and some input and referrals from providers, all parents still felt it necessary to research ASDs and treatments individually. Unlike other disorders affecting children, a diagnosis of ASD does not necessarily produce a “roadmap” to service utilization. All parents reported very different experiences regarding the diagnostic process and eventual service selection and utilization.

In Srebnik, Cauce, and Baydar’s help-seeking and services utilization model (1996), “need” is related to diagnosis, symptom severity, and problem recognition. In the current study, the conceptual category “Parents’ Perceived Need” was shown to continue to be related to diagnosis, symptom severity and problem recognition. However, parents’ reported need was observed to change drastically from before the diagnosis to after the diagnosis.

The “Parents’ Perceived Need” category contains the open codes need for assistance before diagnosis and need for assistance following diagnosis. These codes refer to parents’ expressed needs before, during, and following the diagnostic process. Parents’ views of their child’s symptoms and diagnosis largely impacted their experiences throughout the diagnostic process and when deciding which services to utilize. Subjective assessment of need is related to “problem recognition,” which leads to help-seeking behaviors (Costello & Janiszewski, 1990). A critical component to the help-seeking, service selection, and service utilization behaviors of parents is their interpretation of their child’s behaviors and functioning and its impact on their overall well-being (Burns, Angold, & Costello, 1992; Combs-Orne, Kager, & Chernoff, 1991; Pottick et al., 1992). Goldsmith et al. (1988) postulated that the relationship between clinical assessment of need and perceived or subjective need would improve “understanding of the
reasons underlying the extent of unmet need as well as of the early stages of help-seeking pathways.”

Need for assistance before diagnosis

While all parents interviewed reported concerns regarding their children’s development, as is illustrated in the description of the symptom recognition open code, many of the parents expressed different needs for their children before they received a formal diagnosis. All nine parents reported a desire to “understand” and “treat” their children’s symptoms, whether through formal or informal services or through a formal evaluation and diagnosis. Family 1, for example, attempted to implement informal services and parenting techniques at home to address his son’s behavioral concerns before his diagnosis, while Family 2 and Family 3 chose to initiate formal speech services to address their children’s speech delays prior to receiving an ASD diagnosis. Although more than half of parents participating in the study were told by pediatricians to “wait and see” how their children’s symptoms developed before receiving a formal diagnosis or initiating services, most parents perceived their children’s symptoms as “severe” enough to warrant the initiation of formal services or an evaluation from a different service provider against the advice of pediatricians. Many parents reported being frustrated at the lack of assistance and guidance they received having their children evaluated or initiating services before receiving a formal diagnosis. Three parents participating in the study specifically reported that they wished pediatricians and other service providers received more training in identifying ASD symptoms in young children because they believed their children’s symptoms should have been identified, diagnosed, and treated when their children were younger. One parent specifically stated that they wished symptoms of developmental delay were discussed shortly after their son’s birth so they
could have begun monitoring for ASD symptoms at a much younger age. Therefore, before receiving a formal diagnosis, most parents’ needs centered on symptom recognition and a broad treatment of symptoms.

Need for assistance following diagnosis

Following a formal diagnosis of ASD, parents’ needs still continued to center around treatment of their children’s symptoms. However, following the diagnosis, parents’ needs regarding their children’s treatment becomes more specific. Often utilizing the advice and recommendations of the psychologists or neurologists that diagnosed their children, most parents express a need to access and utilize formal therapeutic services, such as speech therapy, occupational therapy or ABA therapy. As a result, parents’ reported that they required specific “case management” type services related to accessing specific services and providers, insurance coverage, and scheduling and managing the numerous recommended treatments. Almost all parents participating in the study also reported that they required assistance “making sense” of the multiple treatments, whether formal or informal, available for treating their children’s autism symptoms. Specifically, many parents required assistance recognizing empirically supported treatments for ASD as well as assistance deciphering which treatments would be the most appropriate for treating their children’s specific symptoms. Some parents also reported a need for assistance recognizing the effectiveness of informal parenting strategies they were utilizing in the home to treat their children’s ASD symptoms and behaviors.

Predisposing characteristics are defined by Srebnik, Cauce, and Baydar (1996) as “stable conditions of an individual that influence one’s readiness to seek help.” In their model of help-seeking behaviors, Srebnik, Cauce, and Baydar listed factors like gender, age, ethnicity, family
size, and level of parent education as predisposing characteristics. However, in the current study, these factors were found to have no impact on parents’ ability to access or utilize services. Because of this, it was necessary to expand upon Srebnik, Cauce, and Baydar’s model (1996) and include predisposing characteristics related to parents’ abilities to rely on their own judgment, capabilities, or resources, which appeared to have more of an impact on their ability to access and utilize services than biological factors related to gender, age, or ethnicity. Parents’ ability to rely on their own judgment, capabilities, and resources is described by the conceptual category “Self-Reliance,” which is split into two open codes: “Resourcefulness” and “Values and Beliefs.”

Overall, parents’ abilities to cope with their children’s diagnoses appeared to have the greatest impact on their ability to access and utilize services for their children. While all nine parents reported that their child’s diagnosis was “sad,” “overwhelming,” or “emotional,” all nine parents shared that they were able to quickly act on their child’s diagnosis and start accessing and utilizing services, with or without the assistance of others. Despite the popular representation of parents of children diagnosed with ASD as being “warriors,” this concept has been under-researched. Little to no research has been conducted that analyzes the personality traits, predisposing characteristics, or constructs that impact parents’ ability to advocate for their children before or following a diagnosis of ASD.

Resourcefulness

The Oxford English Dictionary (2013) defines resourceful as “having the ability to find quick and clever ways to overcome difficulties.” Resourcefulness is a common characteristic reported by all nine families. Almost all nine parents participating in the study reported that they,
themselves, were the most “influential” aspect of their ability to access and utilize services for their children. Many of the parents reported that their resourcefulness also helped them pursue diagnoses and services for their children without the support of pediatricians, professionals, family, friends, or community.

Surprisingly, the “resourcefulness,” of parents of children with ASD is an under-researched construct in the field. Little to no research has been conducted that explores how parents utilize aspects of their personality, pre-disposing characteristics, or other potential barriers or facilitators to treatment to advocate for their children and access and utilize services for their children following a diagnosis of ASD. In the present study, all nine parents reported how life experiences, such as skills they’ve learned through their occupations or education, helped them cope with their children’s diagnoses and make decisions regarding which services to utilize. Parents’ abilities to “make it work” when it came to accessing and utilizing services for their children was found to be most highly impacted by parents’ perception of their children’s symptoms or illness; the more severe parents perceived their children’s symptoms, the more parents were willing to advocate and fight for treatments they believed their children needed. To a much lesser extent, parents’ ability to access and utilize services for their children was also impacted by barriers and facilitators to treatment. While parents reported that lack of support from family, friends or service providers or difficulties navigating insurance benefits may have delayed the initiation of diagnostic or therapeutic services, all parents participating in the study reported that they have been able to access or are in the process of initiating services they believe are necessary to treat their children’s ASD symptoms through other means.
Values and Beliefs

According to the Oxford English Dictionary, values are defined as “the principles or standards of a person or society, the personal or societal judgment of what is valuable and important in life” (“Values,” 2013). The Oxford English Dictionary also defines beliefs as “something one accepts as true or real; a firmly held opinion or conviction” (“Beliefs,” 2013). These definitions are used in the current study to qualify the values and beliefs described by parents participating in the study. Parents’ values and beliefs also impacted parents’ abilities to advocate for their children as well as their ability to access and utilize services. Almost all parents participating in the study reported that they believed it was their job to “fight” for their children. Many parents reported that they believed it was their responsibility to access the “best” services for their children in order to make sure that their children could reach their fullest potential. Many parents also reported a need to better themselves in order to better advocate for their children.

Some parents did report that their values changed drastically following their children’s diagnosis. Four parents reported that they made decisions to leave their jobs or not to return to work following their children’s diagnosis in order to care for their children full time. Almost all parents participating in the study reported that their child’s diagnosis made them “reevaluate” what was important in their lives. Surprisingly, less than half of parents participating in the study reported that religion or faith has played a role in their ability to access or utilize services. Two parents reported that their faith has increased following their children’s diagnoses, which has led to increased family cohesion and community support. One parent reported that a faith based parent support group has impacted her abilities to care for her son by providing her with respite
and support services, as well as social activities for her son and assistance funding therapeutic services.

Srebnik, Cauce, and Baydar (1996) defined “Barriers and Facilitators to Treatment” as “social and environmental pressures that can occur at the individual, community, or broader political level.” Srebnik, Cauce, and Baydar’s theoretical model (1996) includes “community and social networks characteristics,” “economic factors,” “service characteristics,” and “policy” issues as potential “external influences” that can either enhance or impede help-seeking behaviors and service utilization. In the current study, it was necessary to expand upon this theoretical model to in order to describe the specific experiences of parents of children diagnosed with ASD. The theme “Barriers/Facilitators to Treatment” is split into three conceptual codes: “Outside Influences,” “Economic Factors,” and “Services.”

Srebnik, Cauce, and Baydar (1996) describe all “social and environmental pressures” as “external influences.” However, in the present study, “outside influences” refers only to social pressures that may influence the decision-making processes of parents when deciding which services to utilize for their children following a diagnosis of ASD. The conceptual category “outside influences” contains four open codes: “Community-Social Support,” “Family Support,” “Work,” and “Internet.”

Community-Social Support

As previously stated, Ruble, Heflinger, Renfrew, and Saunders (2005) found that community-based early intervention services are a very common source of individualized family service plans for children with ASDs. This finding was supported by the experiences of families
participating in the current study. When parents could not access diagnostic or formal therapeutic services through pediatrician referrals, more than half of parents utilized community-based early intervention services as a means to initiate the diagnostic and therapeutic process. While families did not receive a formal ASD diagnosis through these services, they were able to begin the process of treating ASD symptoms by utilizing speech, occupational, and play therapies prior to receiving a formal diagnosis. In some cases, parents were utilizing speech, occupational, or play therapy services for their children for over a year before receiving a formal ASD diagnosis.

Following a diagnosis of ASD, community-based services continued to play an important role for families. All nine families reported utilizing a variety of community-based programs in order to receive parent-training, case management services, funding for therapeutic services, referrals for services, and information regarding educational planning for their children, just to name a few. Multiple families also reported that community-based groups had provided them with grants to pay for their children’s services as well as low-cost or free options for services.

Twy, Connolly, and Novak (2006) found that 68% of parents of children with autism sought “general support” from their social networks, while 93% sought “information and advice from families with a similar diagnosis,” and 80% sought information from professionals (Banach, Iudice, Conway, & Couse, 2010). Surprisingly, while almost all families participating in the study reported receiving some advice from other parents of children with ASD, parents most commonly referred to their service providers, specifically their child’s neurologist, or their own research as the most influential factor in their decision-making process when deciding which services to utilize for their children. Less than half of parents participating in the study reported that they had received referrals for formal services from social networks or from other
parents of children with autism. Overwhelmingly, informal services, such as parenting techniques or behavioral interventions, were most often referred to parents through community groups, social relationships, parents of other children with ASD, or the Internet.

In the current study, social support was found to have both positive and negative influences. Six out of the nine parents participating in the study reported having some experience socializing with the parent of a child diagnosed with ASD. In these cases, parents reported receiving advice regarding formal services, informal services, and community-based programs from the parents of other children with ASD. However, prior to a diagnosis of ASD, multiple families reported a general lack of social support regarding their children’s symptom recognition and diagnostic process. Three families specifically reported that family friends had discouraged them from pursuing diagnostic services for their children when they shared their concerns regarding their children’s behaviors. However, following their children’s diagnosis, eight out of the nine parents participating in the study reported that they felt supported by their friends and social networks. Despite the majority of parent reports that they felt supported by social networks following their children’s diagnosis, most of those parents reported feeling as if others could not really understand or support them unless they also had a child who was diagnosed with ASD. One parent specifically reported feeling as if social support was “superficial” while another parent reported that she did not feel as if she was receiving any support from family or friends. These findings support Higgins, Bailey, and Pearce’s (2005) findings that the families of children with ASDs tend to have limited contact with their natural social networks because the parents felt that their friends and family did not understand how children with ASDs behave and why they act the way they do. Similar findings were reported in a study of 14 parents of children with ASD by Woodgate, Ateah, and Secco (2008) who described feelings of “extreme social
isolation” and a “lack of understanding from others” (Woodgate et al., 2008). With the exception of contacts with other parents of children diagnosed with ASD, almost all nine parents in the study reported feeling as if they lacked social support.

Family Support

Parents’ experiences regarding their familial support were similar to their experiences regarding social support. Prior to receiving a diagnosis of ASD, the majority of participants reported that they were discouraged from pursuing diagnostic services by extended family members, such as grandparents, aunts, uncles, and cousins. Only two parents reported that family members played a vital role in encouraging them to seek diagnostic services for their children and only one parent reported that family members participated in specialized trainings to better manage her son’s behaviors following his diagnosis with ASD. While the majority of parents did report that family members assisted them financially or through babysitting services, four out of the nine participating parents reported that family members did not agree with their children’s diagnosis of ASD and, therefore, did not follow recommended behavioral interventions when socializing with their children. These four parents reported that family members were in denial and did not believe that there was “anything wrong” with their children. These four parents reported feeling frustrated and feeling as if they could trust family members in caring for their children. These findings support Goodwin’s (2011) findings that parents of children with ASD have difficulties finding appropriate childcare or respite services.

In the current study, seven out of nine participating parents were married. Six out of the seven married parents reported that their spouse was their primary source of support. Parents often reported that their marriages were “collaborative” and that they often made decisions together regarding their children’s services. This may be due in large part to their participation in
parent-training programs and support groups, which were shown to improve overall functioning for families with children diagnosed with ASD (Koegel, Bimbela, & Schreibman, 1996; Symon, 2001). Only one mother participating in the study reported feeling as if she did not receive support from her husband when making decisions about her son’s treatment. She also reported that, following her son’s diagnosis, her husband appeared to have difficulties relating to their son and she felt as if he had “distanced himself” from their son.

Work

According to Goodwin (2011), only 55% of parents reported that their employers had flexible work schedule policies that enabled them to work and take care of their child. Finding of the current study revealed that, for most families, it is very difficult for both parents to work full time. Four of the nine families participating in the study reported at least one parent who was currently out of work. Two parents reported that they quit work after their children were diagnosed with ASD so they could care for them. The other two parents reported that, after losing their jobs, they decided not to actively seek employment because of their children’s diagnosis. Two of the nine parents were currently self-employed and, therefore, had flexible schedules that allowed them to take their children to all appointments. One parent reported that she received permission to work part-time from home in order to make therapeutic appointments. One parent reported that she was returning to work after quitting her job to care for her son. She reported that she was able to return to work after her son received a McKay scholarship to attend a private school where he would be receiving his therapies during the school day. Only one family participating in the study had both parents working outside of the home full time. In this family’s case, the mother reported that her supervisors provided her with the flexibility to attend
her son’s therapy sessions. She also reported that she and her husband equally split time taking
their son to therapy so either one wouldn’t miss too much work.

Internet

Because Srebnik, Cauce, and Baydar’s model was created in 1996, the potential impact of
the Internet on help-seeking behaviors was still not fully understood. Therefore, it was necessary
to include this experience in the help-seeking model as all nine parents shared similar
experiences regarding the impact of the Internet on their abilities to access and utilize services
following their children’s diagnoses.

The impact of the Internet on families seeking assistance related to ASDs is undeniable.
For all nine families participating in the study, the Internet was often the first place parents went
to seek information regarding their children’s behaviors, potential treatments, advice, and
support before and after the diagnostic process. Surprisingly, the extent of the Internet’s impact
on parents’ abilities to access and utilize services for their children is not fully understood and is
overwhelmingly under-researched. According to a study conducted by Fain (2009), “parents of
children with ASD have difficulty obtaining adequate information and support to guide them in
the care of their children (Huws et al., 2001), hence, many use the Internet to get their
information needs met.” According to Fain (2009):

Data analysis revealed that the parents of children with ASDs used the Internet to search
with intensity and urgency about ASD-related information, especially right after
receiving the diagnosis of ASD. They were motivated to search the Internet due to
inadequate information and support received from healthcare and educational systems.
Parents in the study searched to confirm their child’s diagnosis, research possible causes
of ASD, improve their understanding of symptoms, and to evaluate and locate
practitioners, therapies and treatments. They used search engines and evaluated websites
for credibility by assessing their professional appearance and sponsorship; some parents
relied on their education and training to assess quality of online information.
Similar findings were reported in the current study. All nine parents reported using the internet to gain information regarding ASDs. The majority of parents reported that, other than themselves and their resourcefulness, the Internet was oftentimes the most helpful thing to them before and after their children received a diagnosis. Four out of the nine parents participating in the study reported that they used the Internet before their child’s diagnosis to research their children’s behaviors. All four parents reported that they had some idea that their child would be diagnosed with an ASD based on their research and, therefore, were more likely to push for diagnostic services even against the advice of pediatricians. The remaining five parents reported that they “immediately” began researching ASDs and possible treatments after their children received a diagnosis of ASD. All nine parents reported using the internet to research potential treatments, whether formal or informal, and service providers. Eight out of nine parents reported using the Internet to find community-based programs, parent support groups, or parent education programs. Two parents specifically reported that their participation in Internet-based support groups for parents of children with ASDs had a positive impact on their ability to access and utilize services for their children. One mother reported that she regularly contributes information, resources, support, and reviews of services and service providers to an Internet-based group for parents of children with ASDs.

Despite the strong positive impact the Internet had on parents’ ability to access and utilize services, some negative impacts were also reported. Two families specifically reported feeling “overwhelmed” and “confused” by the amount of information they received on the internet. They reported having difficulties “making sense” of the information they received as well as determining which information was correct or appropriate for their children.
The results of the current study indicate a need for the inclusion of the Internet in an expanded model of help-seeking behaviors and decision-making processes for parents of children diagnosed with ASD. The findings of the present study also reveal the need for increased research on the impact of the Internet on parents’ abilities to access and utilize services for their children before and following a diagnosis of ASDs.

As previously mentioned, “Economic factors have long been described in the literature as having the potential to facilitate or inhibit service utilization.” Despite the efforts of Federal and State legislations and the high rates with which children with ASDs demand and receive services, several studies have demonstrated that children with autism spectrum disorders have difficulties accessing recommended services. Surprisingly, this was not found to be the case in the current study. Despite the multiple families who complained about lack of finances, insurance coverage, or difficulties receiving Medicaid benefits, the majority of families reported that they felt as if their children were receiving all recommended and “necessary” services. In order to explain the economic factors associated with parents’ abilities to access and utilize services for their children, the conceptual category “economic factors” is split into three open codes: “Finances,” “Policy,” and “Insurance.”

**Finances**

Lack of finances was a common problem affecting all nine families participating in the study. All nine families reported some level of financial difficulty when it came to affording services for their children. Even families who received insurance or Medicaid benefits to cover the majority of recommended services reported some difficulties getting all the services they believed were necessary for their children covered financially. Although all nine families
reported that economic factors had a large impact on their ability to access services, each parent ultimately reported that lack of finances, insurance, or policy would not deter them from utilizing services they believed were necessary for their children. The potential negative impact of a lack of finances on parents’ ability to access and utilize service appeared to be largely counterbalanced by parents’ resourcefulness. Parents were able to find alternative funding sources and treatments for their children when their own finances or insurance would not cover costs. Multiple parents reported utilizing community-based groups or grants in order to afford services they believed were necessary to treat their children’s ASD symptoms when they lacked finances or insurance coverage. One mother reported that she sold personal items to get extra money to pay for services while another mother reported that she bartered her services in order for her son to receive neurofeedback therapy that was not covered by Medicaid. The same mother reported that, although she was unable to afford all the services she wanted for her son, she was able to access more affordable alternatives within the community that also addressed her son’s needs. Despite financial difficulties, seven of the nine parents participating in the study reported that they believed their children were getting all the services they needed.

Policy

On March 26, 2012, a federal judge ordered that Medicaid must cover ABA treatment in Florida. *K.G. ex rel. Garrido v. Dudek*, --- F.Supp.2d ----, 2012 WL 1438974 (S.D. Fla. 2012). The judge found the treatment “medically necessary” and not “experimental,” as it had been previously claimed by the state. *Id.* at *5. This recent ruling was fresh in the minds of many of the current study’s participants who had just either begun receiving ABA services or were in the process of waiting to be approved for the Medicaid waiver to cover ABA therapy. At the time interviews were conducted, two families had recently begun receiving ABA therapy for their
children through use of the Medicaid waiver. Three additional families had applied for the waiver but had been denied because their children’s symptoms were not considered “severe enough” to receive the waiver. Of those three additional families, two families were in the process of contesting the decision and were re-applying to receive coverage Medicaid coverage for ABA therapy. Two mothers reported that the recent policy changes in the state of Florida inspired them to write letters to their insurance companies demanding coverage of ABA therapies for their children. One mother reported that, despite being a Medicaid recipient, her son was still unable to access behavioral therapies with certified ABA therapists. Additionally, she also reported that she had a lot of difficulties finding a psychologist who could perform another evaluation as she did not believe the original psychologist provided an accurate diagnosis. Only one mother participating in the study reported being unhappy with the level of services provided by the state of Florida. Overall, recent changes in policy had very little impact on the amounts of services accessed and utilized by families, with the exception of ABA therapy. With the exception of the two families receiving ABA therapies through the Medicaid waiver, all but one family recommended ABA services was receiving ABA services, whether by paying “out of pocket,” receiving ABA therapy through school, or accessing grants to cover services.

Insurance

When compared to children with other disabilities, data suggest that children with autism are underinsured. The parents of children with ASD are more likely than the parents of children with other disabilities to report that their health plans have refused to pay for service or that they cannot afford the out-of-pocket expenses (Krauss et al., 2003; Ruble et al., 2005). Surprisingly, similar findings were not reported in the current study. Of the nine families participating in the study, two families were receiving Medicaid benefits. Of these two families, only one parent
reported that she was believed her son was not receiving all the recommended services, specifically ABA therapy and visits with a psychologist. Of the seven remaining families receiving insurance coverage through private companies, only one parent reported that she believed her son was receiving an inadequate number of speech and occupational therapy services. While many parents did report that their insurance did not cover all the recommended or “necessary” services, only two parents reported that they believed their children were not receiving enough services or an “inadequate number of service visits” because they lacked insurance coverage. Therefore, despite the numerous complaints parents had about their insurance, the majority of parents participating in the study felt that their children were receiving an adequate number of services, with the exception of ABA therapy.

Difficulties navigating insurance benefits were found to have some negative impact on parents’ ability to initiate services for their children following an ASD diagnosis. Multiple families reported that it took months before they received coverage for all recommended treatments. One parent reported that, every six months, her son’s speech therapy services discontinue so that the child can be reevaluated in order to determine whether his speech services will continue to get covered. These parents reported that they believed their children lost “critical time” when they should have been receiving services because they were waiting for insurance companies to approve coverage.

In the present study, aspects of different services were shown to impact parents’ ability to access and utilize for their children. Some parents reported receiving referrals from service providers or having to access alternative services, whether formal or informal, when they could not receive coverage for other services. Additionally, some parents also reported that their
children were able to receive recommended services through their schools when they were unable to access services privately. As a result of these varied experiences, the conceptual category “services” is split into four open codes: “Formal Services,” “Informal Services and Intervention,” “Service Providers/Characteristics,” and “Education.”

**Formal Services**

Parents’ abilities to access formal services for their children were greatly impacted by their ability to receive a formal ASD diagnosis. While four parents were able to initiate formal services through community-based early intervention programs prior to receiving an ASD diagnosis, all nine parents reported having a significantly easier time receiving referrals for formal services and receiving insurance coverage once their children received a formal diagnosis. All nine parents reported that referrals for formal services were most often made the provider who diagnosed their child with ASD, typically a neurologist.

**Informal Services and Interventions**

In the current study, informal services and interventions were most often recommended by members of the parents’ social networks, such as family, friends, community-based groups, and the Internet. All nine parents participating in the study reported utilizing informal services and interventions, such as increased eye contact in the home, play groups and play dates, and after school activities such as athletics or camps in order to increase social interactions and skills. Before receiving a diagnosis of ASD and receiving formal services, five out of the nine participating families reported that they only utilized informal services to help treat their children’s ASD symptoms. Following a formal diagnosis and/or receipt of formal services, all
nine families reported utilizing informal services and interventions with their children in conjunction with formal services.

Service Providers/Characteristics

Chiri and Warfield (2011) found that families of children with ASD were significantly more at risk for having “unmet specialty and therapy care needs.” Parents reported “provider lack of skills” to treat their child as a barrier to obtaining necessary and recommended services (Chiri & Warfield, 2011). This was not found to be the case in the current study. While some parents participating in the study did cite providers’ services characteristics as a reason why services were terminated, all parents continued to receive services for their children with a different provider. Overall, 2/3 of parents participating in the study had a positive attitude towards their children’s service providers. Service providers were frequently described as “supportive” and parents were able to see improvements in their children’s behaviors. Even when the parents did not feel that the service provider was a “good match” for their child, parents were able to find another provider to provide the same service. Therefore, negative perceptions of service providers or characteristics did not act as a barrier to parent’s service utilization.

Education

Children’s education played a vital role in the current study, specifically relating to parents’ ability to access and utilizes services. Seven out of the nine parents participating in the study reported positive experiences with their children’s schools. Overall, parents felt that teachers were following IEPs and were providing recommended interventions in the classroom. Two parents reported that their children participated in LEAP programs, which they believed provided their children with many social benefits. One parent reported that, while her son was
not receiving “necessary” services privately, he was able to receive the therapy she believed he needed through his school. Another parent reported that, while she has had difficulties affording private services for her son, she was able to enroll her son in a private school that provided him with all recommended services during the school day by using the McKay Scholarship. Only one parent participating in the study reported that she was unhappy with her son’s teachers. However, she reported that the teacher did follow all recommendations listed on her son’s IEP.

Before receiving a diagnosis of ASD, one parent reported that her son’s teachers were the ones who helped her identify ASD symptoms in her son and initiate the diagnostic process. Multiple parents reported that, following their children’s diagnosis, they received support from teachers who encouraged them to join parent education programs or support groups offered by the school. Overall, parents reported positive experiences regarding their children’s education and they reported that their children’s schools positively impacted their ability to access and utilize services for their children.

Research Question #2: What factors may influence parents to voluntarily reject recommended services for their child following a diagnosis of ASD?

Voluntary Refusal of Services

No research has been previously conducted that examines parents’ voluntary refusal of recommended services for their children following a diagnosis of ASD. The majority of research regarding “refusal of services” describes insurance companies and their refusal to cover recommended services for the treatment of ASD. While there is no formal research that examines parents’ voluntary refusal of services, many websites and message boards geared
towards parents of children diagnosed with ASD contained multiple first hand accounts of parents’ refusing recommended services. In particular, parents participating in these websites often discussed their refusal of recommended special education programs in their children’s schools. Specifically, parents reported that, although their children were diagnosed with ASDs, they did not believe that their children “suffered” from any learning disabilities that required them to participate in special education programs. Rather, these parents preferred that their children be allowed to remain in classrooms with “typically developing” children as they believed that their children were missing out on acquiring critical educational and social skills by participating in special education programs. On one message board, a teenager diagnosed with Asperger’s chimed in, stating that he opted out of special education programs as he believed he was being “cheated out of a proper education” since he was not diagnosed with a learning disability.

In the present study, none of the parents participating in the study reported a voluntary refusal of special education services for their children. While some parents did report that they wished to change the type of classroom setting their children were in (ie: self-contained classroom to a reverse mainstream classroom), the majority of parents were either content with the special education services they were receiving or were seeking more intensive special education services for their children. These findings are not consistent with the self-reports of parents on autism message boards or websites. However, this may be due, in large part, to the age of the children participating in the study. Since the children participating in the study are preschool and kindergarten aged, parents may not have had sufficient experience with the special education system and, therefore, may not have established opinions on special education services.
Of the nine parents participating in the study, five parents reported refusing or discontinuing recommended services. However, the services they reported refusing or discontinuing are not services that are empirically supported for the treatment of ASD. Only one family reported refusing a service recommended by the diagnosing neurologist. However, the service they refused was a service that was not necessary to treat ASD symptoms but, rather, a test to rule out other possible neurological disorders. Three parents reported refusing or discontinuing services that were not empirically supported treatments for ASD and one parent reported refusing orthopedic treatment for her son’s difficulties walking at the advice of her son’s pediatrician. Therefore, findings of the present study suggest that parents will not refuse or discontinue empirically supported ASD treatments that have been recommended to them by service providers, specifically diagnosing neurologists or psychologists. Parents were found to discontinue or refuse services if the service was not found to be an empirically supported treatment for ASD or if a neurologist or pediatrician advised that the services were not necessary in order to treat their child’s symptoms.

While some families had been receiving some services, such as speech and occupational therapy, for a few years prior to receiving a diagnosis of ASD, it was evident that the parents participating in the study were still, in my many ways, adjusting to their children’s diagnosis and learning how to navigate the system. Because many of the parents in the study lacked knowledge of ASDs, many of the parents may still not be knowledgeable of all the available treatments for ASDs. Therefore, they may have been reluctant to refuse services recommended to them by diagnosing neurologists or psychologists. Instead, it appears that parents of recently diagnosed children are willing to explore and even initiate whatever services are recommended to them in an attempt to find services that will improve their children’s skills. Similarly, because parents
participating in the present study had only been accessing and utilizing services for their children within the last year, parents may not have had the opportunity to fully evaluate or develop their opinions about recommended services they were currently utilizing for their children. Similarly, since their children had only been receiving services for a short amount of time, they also may not have been able to accurately evaluate the impact of services on their children’s development and, therefore, may not have made a decision to discontinue services.

Parents’ decision making processes following their children’s diagnosis with an ASD also appeared to be influenced by the person recommending treatment. Parents appeared reluctant to refuse services that were recommended by the diagnosing neurologist or psychologist. Even if services were not recommended by the diagnosing neurologist or psychologist, parents often discussed recommendations from other service providers with the diagnosing neurologist and psychologist before making a decision whether to access or refuse services. Despite some parents’ original disagreement with their pediatricians’ attitudes towards their children, some parents also reported that they refused recommended services after receiving advice from their pediatricians.

While parents also reported that other parents of children diagnosed with ASDs were influential in their decision making processes regarding which services to utilize for their children, parents participating in this study reported that they were willing to not pursue recommended services if their service providers advised against it or if research indicated that the treatments were not empirically supported. Participating parents also reported that they were willing to discontinue services if their children did not immediately respond well to services or if they perceived services as potentially dangerous.
5.1 Limitations of the Study

Although the research has reached its aims, there were several foreseeable threats to internal and external validity that may impact the validity of this study. One limitation of the study is that the data collected was “self-reported” by participants. Despite attempts to verify data using various data checks and triangulation techniques, it is impossible to verify all of the information provided by participants. Along these lines, the fact that the study is retrospective can also be considered a limitation. Many factors, such as length of time from diagnosis to participation in the study, may have impacted parents’ ability to accurately recollect clinicians’ recommendations or report their perceptions of events. Hindsight bias, where parents may have intentionally or unintentionally attributed or exaggerated outcomes when reporting their opinions regarding their access to services and service utilization, may have also occurred. The researcher’s presence during interviews and the participants’ lack of anonymity may have also affected participants’ responses.

Despite attempts to recruit participants from multiple agencies and organizations, all participants were recruited through their affiliation with the Parent to Parent Organization of Miami. Parents affiliated with this organization may differ demographically from other parents asked to participate in the study and may also affect the generalizability of results. These limitations may be addressed in future studies by recruiting parents from multiple agencies shortly following their children’s diagnosis with an ASD. The researcher would then follow-up with parents regularly throughout the course of the year, collecting parents’ feedback and opinions as they go through the process of accessing and utilizing services.

Another limitation of the study is that the data gathered and the interpretation of the data is heavily reliant on the researcher. For example, the actions of the researcher during may have
affected participants’ responses. In order to address these concerns in the present study, a pilot study was implemented in order to ensure that the researcher assessed and prepared interview and observation techniques as well as self-evaluated readiness, capability, and commitment as a qualitative researcher. Member checks were also utilized, giving participants the ability to review and confirm the accuracy of interview transcripts as well as the researcher’s interpretation of the main ideas generated by the interviews.

5.2 Conclusion and Project Implications

Many parents of children recently diagnosed with an ASD report a number of mixed feelings. Many parents, including the parents participating in this study, reported feeling overwhelmed, sad, and even relieved that their concerns regarding their children’s behaviors were validated. During this often confusing time, parents’ decision making processes can be influenced by a number of factors, including their own beliefs, family, community, and finances, just to name a few. The purpose of this study was to examine parents’ decision making processes when deciding which services to utilize for their children following a diagnosis of ASD as well as examine the factors that may influence a parent’s decision to voluntarily reject or discontinue recommended services to treat their child’s ASD symptoms. This was achieved through utilizing Cauce, Srebnik, and Baydar’s model of help-seeking behaviors to guide the current study. The results of the current study also represents the first attempt to expand upon a previous model of help-seeking behaviors in order to create a model of help-seeking behaviors that explains the specific and unique experiences of parents of children diagnosed with ASD. The expanded theory proposes that, overall, parents’ perceptions of the severity of their children’s symptoms proved to have the greatest impact on their ability to access and utilize services for their children following a diagnosis of ASD. Parents’ resourcefulness and ability to seek treatments and
interventions for their children independently also greatly impacted their ability to access and utilize services. To a lesser extent, “outside influences,” such as family, social, and community support also affected parents’ ability to access and utilize services. Family, social, and community influence as well as pediatricians’ feedback appeared to have the biggest impact on parents’ decision making processes when initiating the diagnostic process. Service providers also had an impact at this stage in the diagnostic and treatment process. The findings of the study did not support previous research which stated that finances and lack of insurance coverage had the greatest impact on a parents’ ability to access and utilize recommended services following their children’s diagnosis with ASD. In fact, all nine parents participating in the study reported that lack of finances or insurance coverage has not stopped them from utilizing services they believe are necessary in treating their children’s ASD symptoms. Even when parents are not able to have treatments covered for their children by insurance, parents will seek other alternatives to fund the treatments they believe their children needs, whether through the use of grants, federal funding, Medicaid waivers, community organizations, bartering of services, or accessing services through public and/or private schools.

Parents’ refusal or discontinuation of services appeared to be largely impacted by the person recommending services. Parents were often reluctant to refuse or discontinue services that were recommended to them by diagnosing neurologists, psychologists, or pediatricians. Similarly, parents were often reluctant to pursue services that were not empirically supported for the treatment of ASD. Parents were also found to discontinue services if they felt that their children responded poorly to the treatment or that they treatments were potentially dangerous.

Despite parents’ reports that they currently felt their children were receiving an adequate number of services, many of the parents reported that they wished they had they had pursued and
diagnosis services for their children sooner. The expressed needs of parents participating in the study should be taken into serious consideration. Throughout the interviews, almost all participating parents reported feeling as if no one could really “understand [their] experience” unless they had a child that was diagnosed with an ASD. Despite the reports that the family’s felt they were receiving support from their family, social networks, and community, it is likely that families are not receiving the amount of support they need, which might explain why families require assistance and support from a variety of resources. The symptoms and behaviors of children diagnosed with ASD are so variable as well that each family has an individual set of needs that requires individualized and specialized assistance. Therefore, parents may have also needed to seek assistance from multiple resources because there are no resources that allowed for parents and families of children with ASDs to have most or all of their needs met in one location.

Many of the parents reported a desire for coordinated services before, during, following their children’s diagnosis as they had difficulties “navigating the system.” Many parents reported difficulties understanding developmental milestones or accurately identifying symptoms of ASD early on. Following their children’s diagnosis, many parents had difficulties deciding which services to access first and which service providers accepted their insurance. It is important to acknowledge that, while many of the families participating in the study reported similar needs, the needs expressed by each family are highly differentiated based on multiple pre-existing factors, such as the symptoms of the children and the parents’ finances. Therefore, a coordinator that follows up regularly with families during and following the diagnostic process and addresses the individual needs of each family may help families more efficiently access and utilize services. This need was further supported by the analysis of the diagnostic reports, all of which
listed recommendations for services, but did not indicate specific service providers or interventions that address the specific symptoms or behaviors of each child.

5.2.1 Implications for Future Research

Findings from the current study suggest the need for researchers to explore and expand upon the present study’s findings regarding the importance of parents’ self-reliance, resourcefulness, and values and beliefs on their ability to access and utilize services for their children. While the strength of parents of children diagnosed with ASD has been overwhelmingly documented in popular culture and media, little empirical research has been conducted that explicitly examines its impact on parents’ abilities to access services or the overall improvement of ASD symptoms in their children.

Findings from the current study also suggest a need for researchers to follow up with parents on a regular basis to determine which services parents may have discontinued or refused, especially as their children reach different developmental milestones. As the children of the parents participating in the current study age, parents are likely to seek out different services for their children and, possibly, discontinue currently utilized services. It may be interesting to follow up with parents annually to determine how their decision making process regarding which services to utilize for their children changes as their children age and their developmental, educational, emotional, and social needs change.
APPENDIX A

PARTICIPANT INTERVIEW QUESTIONS

- Tell me about your experience going through the process of having your child evaluated and diagnosed with Autism?
- What did you do before you received a diagnosis?
- What happened following the diagnosis?
- How did you deal with the diagnosis before you had services?
- Tell me about your experiences deciding which services to utilize?

Ilness Profile

- When did you first start to notice symptoms of ASD in your child?
- Could you describe the events that led up to the diagnosis?
- Do you believe you need help planning and coordinating medical care services or health care support for your child?
- Describe any difficulties accessing services for your child? Do you believe that your child isn’t receiving enough services?
- Describe any help you’ve received finding service providers for your child?
- Are there any services in particular that you’re having difficulties accessing? Please explain.
- Did anyone influence your actions? Tell me about how they influenced you.
- Was there anything going on in your life or in your family that may have impacted your ability to access services? Please explain.

Predisposing Characteristics

- What, if anything, did you know about ASD before your child was diagnosed?
• Tell me about your thoughts and feelings when you learned that your child was diagnosed.

• Tell me how your views may have changed since your child was diagnosed with ASD?

• How have your values changed since your child was diagnosed with ASD?

• After having these experiences, what advice would you give to someone whose child has just been diagnosed with an ASD?

• Is there anything you think I should know to understand your experience better?

**Barriers/Facilitators**

• Of the treatments you identified having been recommended, did you experience any difficulties accessing those services? What was the nature of those difficulties?

• Were you able to resolve these difficulties and access these services for your child? How?

• Did you receive assistance in resolving these difficulties from any outlet(s) outside of your immediate family?

• Were there any services recommended for your child that you chose NOT to access or utilize? Who recommended those services? Why did you decide not to utilize them?

• Overall, what have you found to be most helpful in your ability to access services for your child?

• What have you found to be the most difficult in your ability to access services for your child?

• Do you have any difficulties receiving support from family and friends regarding your child’s diagnosis? Community support?

• Has your employment impacted your ability to access or utilize services for your child?

• Who was involved in the diagnosis and initial treatment? When was that? How were they involved?
• Who/What has been the most helpful to you during this time? How has he/she/it been helpful?

• Has any organization been helpful? What did they help you with? How has it been helpful?

• Has your economic situation or insurance impacted your ability to access or utilize services for your child? How?

• Do you feel that service providers have worked closely with your family to help you reach goals for your child with ASD and your family as a whole? How?

• In what way did service characteristics impact which services you chose to utilize for your child?

• How do federal, state, or local health-care policies impact the services your child receives?
Please circle any treatments/interventions for an Autism Spectrum Disorder that have been recommended to you, your child, or your family in the first column. In the second column, please list the first name of the person who recommended the treatment/intervention and their relationship to you.

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<tr>
<th>Behavioral Interventions</th>
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<td>Cognitive Behavioral Interventions/Therapy</td>
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<td>Early Start Denver Model (ESDM)</td>
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<td>Pivotal Response Training (PRT)</td>
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<td>DIR / Floortime</td>
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<td>Parent training</td>
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<td>Neurofeedback</td>
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<td>Sleep interventions</td>
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<td>Family involvement and parent training</td>
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<td>Interaction with neurotypical peers</td>
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<td>Structure that includes predictable routines and clear physical boundaries to lessen distraction</td>
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<td>Ongoing measurement of systematically planned intervention</td>
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<td>Extended school year/Summer School</td>
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### Allied Health & Ancillary Services

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<td>Sensory integration therapy</td>
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<td>Auditory integration therapy</td>
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<tr>
<td>Music therapy</td>
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<tr>
<td>Horseback riding therapy</td>
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<tr>
<td>Art therapy</td>
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<tr>
<td>Assistive technology</td>
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<tr>
<td>Individual/Family counseling</td>
<td></td>
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<tr>
<td>Other (please specify):</td>
<td></td>
</tr>
</tbody>
</table>

### Medical & Related Interventions

<table>
<thead>
<tr>
<th>Interventions</th>
<th>First Name of Recommender / Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pharmacologic agents (i.e. antipsychotics, psychostimulants, and serotonin reuptake inhibitors (SRIs))</td>
<td></td>
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<tr>
<td>Therapeutic diets</td>
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<tr>
<td>Vitamins/Supplements</td>
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<tr>
<td>Hormonal supplements</td>
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<tr>
<td>Immunoglobin</td>
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<tr>
<td>Hyperbaric chamber</td>
<td>________________________________</td>
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<tr>
<td>Chelation therapy</td>
<td>________________________________</td>
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<tr>
<td>Other (please specify):</td>
<td>________________________________</td>
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</tbody>
</table>

### Complementary & Alternative Treatments

<table>
<thead>
<tr>
<th>Complementary &amp; Alternative Treatments</th>
<th>First Name of Recommender / Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acupuncture</td>
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<tr>
<td>Acupressure</td>
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<tr>
<td>Massage</td>
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<tr>
<td>Other (please specify):</td>
<td></td>
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</tbody>
</table>
APPENDIX C

DEMOGRAPHIC QUESTIONNAIRE

1. Please list all members of your household (relationship only) and their birthdates.

2. What is your race?

3. What is your highest degree earned? __________

4. What is the gender of your child with ASD?

5. What is the age of your child with ASD?

6. What is your child’s primary diagnosis?

7. Has your child ever been classified by a professional organization, such as the school system, as having:
   a. Developmental Disability
   b. Intellectual Delay
   c. Other (please specify) __________

8. Has your child ever been diagnosed with any additional disabilities or disorders? Select any that apply:
   a. Complex medical needs
   b. Intellectual limitations
   c. Physical limitations
   d. Cerebral Palsy
   e. Fragile X Syndrome
   f. Visual impairment
   g. Hearing impairment
   h. Neurological disorders (including seizures or epilepsy)
   i. Emotional or behavioral disability
   j. Spina Bifida
   k. Tuberous Scierosis
   l. Fetal Alcohol Syndrome
   m. Attention Deficit Disorder (ADD)
   n. Attention Deficit Hyperactivity Disorder (ADHD)
o.  Head Injury
p.  Other (please specify) __________

9.  When did you first start receiving services for your child? ____________ (Month/Year)

10. Are there any other children in your household diagnosed with a disability or disorder? Please explain.
Dear Parent/Guardian:

My name is Tarah Rogowski Martos, and I am a doctoral candidate in the Counseling Psychology and School Psychology Program at Florida State University. I am conducting a study parents’ perceptions of factors that affect their help-seeking behaviors and utilization of services for their child following a diagnosis of Autism Spectrum Disorder (ASD). We are interviewing parents/guardians of children with ASD to assess their perceptions and experiences utilizing recommended services.

We would appreciate your participation in this study as the results of this study will help us add to the growing autism literature regarding service utilization and, hopefully, support future research regarding ways in which service providers can assist parents in accessing services for their children more easily following a diagnosis of ASD. Your participation will entail completing an approximately 60 minute interview with the researcher, a demographic questionnaire, and providing the researcher with a copy of the psychological/psychoeducational evaluation that diagnosed your child with ASD.

If you agree to participate in this study, please carefully read and sign the attached form and then complete the attached demographic questionnaire. You will receive a $25 gift card for your participation in the study.

Please feel free to ask any questions you may have before agreeing to participate in the study. You can contact me directly at [redacted], or [redacted]. Alternatively, you can reach my direct supervisor, Dr. Steven Pfeiffer, Professor at Florida State University. Dr. Pfeiffer can be reached at [redacted] or [redacted]. If you have any questions or concerns about your rights as a research participant, you may contact the FSU Institutional Review Board (“IRB”) at (850) 644-8633 or you may access their website at http://www.fsu.research.edu.

Thank you for your time and attention.

Sincerely,

Tarah Rogowski Martos, M.S.Ed
Doctoral Candidate
Florida State University

Steven I. Pfeiffer, PhD
Professor
Florida State University
**About this Study**

**Risks and benefits:** This study presents no risks. There may be direct benefits to you if you participate in the study. The information you provide through this survey may help expand research for autism spectrum disorders and may support future research regarding ways in which service providers can assist parents in accessing services for their children more easily following a diagnosis of ASD. Once the interview is completed, you will also receive a $25 gift certificate.

**Confidentiality:** The information recorded in the interview and questionnaire will be kept confidential, to the extent permitted by law. The evaluation data generated from parents/guardians may be published in a report and may be used in future publications regarding autism spectrum disorders. Any published or distributed materials will not contain information that could in any way identify any individual parents, guardians, or children. Any information that appears in a publication will be aggregated data. Any individual comments will be fully disguised to protect the anonymity and privacy of the parent, guardian, or child. Interview transcripts and questionnaires will be kept in a locked cabinet in a locked office at Florida State University for three years after this study ends.

**Voluntary Participation:** Your participation in this study is completely voluntary. Participation in this study will take approximately 1 to 2 hours. You may skip any questions you don’t feel comfortable answering. Your decision to participate will in no way affect your current or future relationship with service providers or Florida State University. If you decide to participate, you are free to not complete the questionnaire, skip any questions, and/or stop at any time. You are free to withdraw your participation at any time.

**Questions Regarding the Study:** You are encouraged to ask all questions to Tarah Rogowski Martos, the primary research associate for this program development study. You may reach Mrs. Martos at [Contact Information], or [Contact Information]. Mrs. Martos is under the direction and supervision of Dr. Steven Pfeiffer, Professor at Florida State University. You may reach Dr. Pfeiffer at [Contact Information] or [Contact Information]. You may also direct questions or concerns about your rights as a research participant to the FSU Institutional Review Board (“IRB”) at (850) 644-8633 or you may access their website at http://www.fsu.research.edu.

YOU ARE MAKING A DECISION WHETHER OR NOT TO PARTICIPATE. YOUR SIGNATURE INDICATES THAT YOU HAVE DECIDED TO PARTICIPATE, HAVING READ THE INFORMATION PROVIDED ABOVE.

Date: ____________________

Signature of Participant: ____________________________________________

Signature of Investigator: ____________________________________________
APPENDIX E

HUMAN SUBJECTS COMMITTEE APPROVAL

Florida State University

Office of the Vice President for Research
Human Subjects Committee
Tallahassee, Florida 32306-2742
(850) 644-8573 - FAX (850) 644-4302

APPROVAL MEMORANDUM

Date: 06/26/2011
To: Tarah Martinez <tarahvanessa@gmail.com>
Address: 2167 Allananda Street Miami, FL 33133
Dept.: EDUCATIONAL PSYCHOLOGY AND LEARNING SYSTEMS
From: Thomas L. Jacobson, Chair
Re: Use of Human Subjects in Research

A QUALITATIVE EXAMINATION OF FACTORS INFLUENCING PARENTS’ DECISION MAKING PROCESS WHEN CHOOSING OR REJECTING RECOMMENDED EARLY INTERVENTION SERVICES FOR

The application that you submitted to this office in regard to the use of human subjects in the proposal referenced above have been reviewed by the Secretary, the Chair, and two members of the Human Subjects Committee. Your project is determined to be expedited per 45 CFR § 46.110(b) and has been approved by an expedited review process.

The Human Subjects Committee has not evaluated your proposal for scientific merit, except to weigh the risk to the human participants and the aspects of the proposal related to potential risk and benefit. This approval does not replace any departmental or other approvals, which may be required.

If you submitted a proposed consent form with your application, the approved stamped consent form is attached to this approval notice. Only the stamped version of the consent form may be used in recruiting research subjects.

If the project has not been completed by 06/24/2013 you must request a renewal of approval for continuation of the project. As a courtesy, a renewal notice will be sent to you prior to your expiration date, however, it is your responsibility as the Principal Investigator to timely request renewal of your approval from the Committee.

You are advised that any change in protocol for this project must be reviewed and approved by the Committee prior to implementation of the proposed change in the protocol. A protocol change/amendment form is required to be submitted for approval by the Committee. In addition, federal regulations require that the Principal Investigator promptly report, in writing any unanticipated problems or adverse events involving risks to research subjects or others.

By copy of this memorandum, the chairman of your department and/or your major professor is reminded that he/she is responsible for being informed concerning research projects involving human subjects in the department, and should review protocols as often as needed to insure that the project is being conducted in compliance with our institution and with DHHS regulations.

This institution has an Assurance on file with the Office for Human Research Protection. The Assurance Number is IRB000003446.

Cc: Steven Pfeiffer <spfeiffer@fsu.edu>, Advisor
HSC No. 2012.8100
REFERENCES


BIOGRAFICAL SKETCH

Tarah Rogowski Martos

EDUCATION

Florida State University, Department of Educational and Psychological Learning Systems, Tallahassee, Florida  
Ph.D. in Counseling Psychology and School Psychology, Anticipated: May 2013  
Concentration in Counseling Psychology – Assessment Track  
American Psychological Association approved program

University of Miami, Department of Educational and Psychological Services, Coral Gables, Florida  
M.S.Ed. in Counseling Psychology: May 2007  
Concentration in Marriage and Family Therapy

University of Miami, College of Arts and Sciences, Coral Gables, Florida  
B.A. in Psychology, Minor in English: December 2004

Barry University, Miami Shores, Florida  
Dual Enrollment Student: August 1998 – May 2000

CLINICAL EXPERIENCE

Miami-Dade County Community Action and Human Services Department, Miami, Florida  
Doctoral Intern: August 2011 – August 2012

- Administer a wide range of psychoeducational and functional assessments in order to assist in the diagnostic and treatment process of pre-school aged children.
- Write, dictate and edit psychological reports, which include relevant background information, medical history, assessment results, and recommendations.
- Contact parents and guardians of testing referrals in order to determine questions and concerns, obtain previous developmental, medical, and educational evaluations and records, and obtain progress summaries from therapists and teachers.
- Provide feedback regarding testing results to parents and guardians and assist parents and guardians in effectively advocating for their child in order to access and utilize necessary interventions and services.
- Provide trainings and seminars to teachers and staff at local Head Start centers.
- Conduct classroom observations of teachers and students to ensure that best practices and appropriate interventions are being implemented in the classroom.
- Provide weekly individual therapy services to approximately 5 – 10 adult clients residing in a drug treatment facility with various concerns including addiction, relapse prevention, co-occurring psychological and medical disorders, trauma, sexual abuse, domestic violence, and anger management.
- Develop a curriculum and conduct weekly group therapy sessions for adult female clients residing in a drug treatment facility.
- Assist the training director in providing supervision for a Doctoral level Psychology student participating in a counseling practicum.
- Participate in weekly individual and group supervision meetings with supervisors and colleagues.

University of Miami, Miller School of Medicine Department of Pediatrics – Mailman Center for Child Development, Miami, Florida  
Practicum Intern: June 2009 – August 2010

- Work in an interdisciplinary center with psychologists, pediatricians, endocrinologists, audiologists, speech and language therapists, physical therapists, educational specialists, and medical students in order to provide optimal physical and mental health services and assessments for toddlers, children, and adolescents with developmental disabilities, chronic illness, and other special health care needs.
- Administer a wide range of psychoeducational and functional assessments in order to assist in the diagnostic and treatment process of child and adolescent outpatient clients.
- Write, dictate and edit psychological reports, which include relevant background information, medical history, assessment results, recommendations, and DSM-IV diagnosis.
- Maintain a caseload of approximately two individuals and two families per week.
- Counsel children, adolescents, and families with various concerns including obesity, weight management, diabetes, asthma, chronic illness, treatment adherence, pain management, behavioral management, and educational concerns.
- Consult weekly with Endocrinologists and provide psychological services to toddler, child, and adolescent Endocrinology patients and their families with various concerns including obesity, weight management, diabetes, asthma, cancer, and chronic illness.
- Review intakes to determine which cases are appropriate to receive Interdisciplinary Developmental Evaluation Services.
- Contact parents and guardians of patients in order to determine questions and concerns, obtain previous developmental, medical, and educational evaluations and records, obtain progress summaries from therapists and teachers, and provide parents and teachers with assessment materials.
- Conduct intake interviews with parents and guardians of toddlers, children, and adolescents with developmental disabilities, chronic illness, Fragile X Syndrome, and other special health care needs.
- Present background information and summaries at interdisciplinary team meetings, and gather and summarize results and recommendations from evaluations from other disciplines in order to create an Executive Summary of all the findings for each client.
- Participate in weekly case management and supervision meetings with supervising professors and colleagues.
- Participate in the Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program, a program that provides advanced interdisciplinary leadership training to health professionals interested in working with children and families living with developmental disabilities, chronic illness, and other special health care needs.

**Florida State University, Department of Educational and Psychological Learning Systems – Adult Learning and Evaluation Center**, Tallahassee, Florida

*ADHD and Academic Coach: January 2009 – May 2009*

- Maintain a caseload of three individuals per week.
- Provide structure, support, skills, and strategies to clients diagnosed with ADD/ADHD, Bipolar Disorder, Anxiety and Depression in order to help them function optimally in daily life and achieve their desired goals.
- Participate in weekly case management and supervision meetings with supervising professors and colleagues.
- Refer clients to additional university and community mental health resources when appropriate.

**Tallahassee Memorial Hospital – Tallahassee Memorial Behavioral Health Center**, Tallahassee, Florida

*Practicum Intern: August 2008 – May 2009*

- Administer a wide range of neurological, psychological, personality and functional assessments in order to assist in the diagnostic and treatment process of child, adolescent, adult and elderly hospital inpatients and outpatient clients.
- Supply accurate and appropriate DSM-IV diagnoses based on clients’ assessment results, clinical interviews, medical history and relevant background information.
- Write, dictate and edit psychological reports, which include relevant background information, medical history, assessment results and DSM-IV diagnosis.
- Work in a multidisciplinary hospital setting with psychiatrists, psychologists, therapists, social workers and nurses in order to gather information and provide diagnostic impressions.
- Participate in weekly case management and supervision meetings with supervising professors and colleagues.
- Participate in weekly Dialectical Behavioral Therapy (DBT) training seminars in order to better assist outpatient clients and inpatients diagnosed with Borderline Personality Disorder.
Florida State University Career Center, Tallahassee, Florida
Career Advisor: August 2008 – May 2009
- Maintain a caseload of three individuals per week.
- Counsel college-aged and adult clients with various concerns including depression, anxiety, traumatic brain injury, memory loss and learning disabilities, with particular focus on how these concerns affect their career and educational choices including unemployment, job seeking, interviewing skills, choice of major, and financial concerns.
- Administer a wide range of career, personality, psychological and functional assessments in order to better assist clients with vocational and educational exploration.
- Assist “walk-in” clients with numerous concerns including unemployment, job seeking, choice of major, course selection and resume/curriculum vitae critiques.
- Create individualized action plans based on each client’s needs, assessment information and counseling impressions.
- Participate in weekly case management and supervision meetings with supervising professors and colleagues.

Florida State University College of Medicine, Department of Medical Humanities and Social Sciences - Panhandle Area Educational Consortium and Migrant Education Program, Quincy, Florida
Behavioral Medicine Intern / Staff Therapist: August 2007 – August 2008
- Worked in a multidisciplinary clinic with doctors, nurses, pharmacists and medical students in order to provide optimal physical and mental health services for the underprivileged migrant population.
- Maintained a client caseload of fifteen adults and five children per week.
- Counseled clients in Spanish with a number of concerns including depression, sexual abuse, physical abuse, personality disorders, psychosis, familial crisis, physical illness, mental illness, anxiety, financial concerns, marital crisis, immigration, deportation, enuresis, learning disabilities, mental retardation, developmental delays and substance abuse.
- Developed a curriculum and taught weekly parenting classes in Spanish.
- Participated in weekly case management and supervision meetings with supervisors and colleagues.

Leon County Public Schools, Sabal Palm Elementary, Tallahassee, Florida
- Administered the Kaufman Brief Intelligence Test, Second Edition (KBIT-2) to students referred to the school psychologist for gifted testing.
- Taught kindergarten through second grade classes and observed students’ social and psychological development.
- Counseled students with a number of concerns including anxiety, study skills, behavioral management and grief counseling.
- Participated in weekly case management and supervision meetings with supervisor and colleagues.

Florida State University, Department of Educational and Psychological Learning Systems - Human Resources Center, Tallahassee, Florida
Practicum Intern / Staff Therapist: August 2007 – December 2007
- Maintained a client caseload of four individuals per week.
- Counseled clients with a number of concerns including substance abuse, depression, personality disorders, vocational exploration, physical abuse, familial crisis and physical illness.
- Recommended interventions based on client information and impressions.
- Participated in weekly case management and supervision meetings.
University of Miami, Department of Educational and Psychological Services - Institute for Individual and Family Counseling, Coral Gables, Florida  
Practicum Intern / Staff Therapist: August 2006 – August 2007  
- Maintained a client caseload of approximately two adults, two couples and one family per week.  
- Counseled clients with a number of concerns including alcoholism, drug abuse, depression, anxiety, ADHD, personality disorders, eating disorders, vocational exploration, sexual abuse, sexuality, transgender issues and marital crisis.  
- Recommended interventions based on client information and impressions.  
- Participated in weekly case management team meetings and supervision with supervisors and colleagues.

Miami-Dade County Public Schools, Miami Palmetto Senior High School, Miami, Florida  
- Maintained a client caseload of seven adolescents per week.  
- Counseled clients with a number of concerns including anger management, depression, substance abuse, personality disorders and eating disorders.  
- Co-led weekly anger management group meetings.  
- Organized weekly group meetings focusing on eating disorders and healthy peer/romantic relationship maintenance.

Miami-Dade County, Department of Human Services, St. Albans Child Enrichment Center, Miami, Florida  
Intern: June 2004 – September 2004  
- Performed psychological and classroom observations of students.  
- Appointed to aid in the development of a psychological department.  
- Teachers aid to students with psychological and emotional disorders.  
- Recommended interventions based on client information and impressions.

Research Experience

University of Miami, Miller School of Medicine Department of Pediatrics – Mailman Center for Child Development, Miami, Florida  
Topic: Dr. Alan Delamater’s Cognitive Maturity in Children and Adolescents with Type I Diabetes  
Assistant Examiner: June 2009 – August 2010  
- Responsible for collecting data, administering and proctoring assessments for adolescents with Type 1 Diabetes participating in the study.  
- Collaborated with fellow graduate students on an ethnically diverse and highly talented research team.

Florida State University, Department of Educational and Psychological Learning Systems, Tallahassee, Florida  
Topic: The relationship between social support and career thoughts in the college student population.  
Co-Researcher: August 2008 – July 2009  
- Responsible for collecting data, administering and proctoring assessment for college students participating in the study.  
- Code assessments, enter data into SPSS and analyze data.  
- Chosen to present findings at the National Career Development Association’s 2009 Conference.  
- Collaborated with fellow graduate students on an ethnically diverse and highly talented research team.
Florida State University, Department of Educational and Psychological Learning Systems, Tallahassee, Florida

**Topic: Florida Governor’s School for Science, Mathematics and Space Technology Professional Development Questionnaire**

**Principal Investigator: January 2008 – October 2010**

- Develop the Florida Governor’s School for Science, Mathematics and Space Technology Professional Development Questionnaire in order to assess the present professional development opportunities available in the state of Florida and the preferred professional development activities of teacher of Gifted, Advanced Placement, International Baccalaureate and/or Honors high school math, science and engineering teachers.
- Administer questionnaire to eligible teachers participating in the study in Florida school districts and process collected data.
- Garnered Institutional Review Board (IRB) approval from Florida State University and various districts throughout Florida.

Florida State University, Department of Educational and Psychological Learning Systems, Tallahassee, Florida

**Topic: Dr. Steven I. Pfeiffer’s Governor’s School for the Gifted Project**

**Graduate Research Assistant: January 2008 – July 2008**

- Assist the development of a Science, Technology, Engineering and Math Magnet School for the gifted.
- Administered assessments to student and teacher participants in summer pilot program and collected resulting data.
- Mentored and chaperoned a group of twenty gifted high school students participating in the summer pilot program and study.

University of Miami, Department of Psychology, Child Division, Coral Gables, Florida

**Topic: Dr. Annette La Greca’s Healthy Adolescent Project**

**Undergraduate Research Assistant: May 2003 – December 2004**

- Assisted the implementation of a study designed to “investigate issues pertinent to child and adolescent mental health; particularly, the role of peer relations in child and adolescent adjustment and psychopathology.”
- Administered assessments to over 200 high school students.
- Coded assessments and entered data into SPSS.
- Collaborated with graduate students on an ethnically diverse and highly talented research team.

**SUPERVISION EXPERIENCE**

Miami-Dade County Community Action and Human Services Department

Miami, Florida

**Doctoral Intern: August 2011 – August 2012**

- Supervised three Doctoral level Clinical Psychology students participating in a counseling and assessment practicum.
- Reviewed live sessions, client notes, and psychoeducational assessments of supervisees’ weekly caseloads.
- Assisted in developing and reaching the practicum, counseling, and assessment goals of the supervisees.
- Participated in weekly supervision meetings with supervisees and with other doctoral level supervisors.

Florida State University, Department of Educational and Psychological Learning Systems - Human Resources Center, Tallahassee, Florida

**Supervisor / Practicum Intern: January 2008 – May 2008**

- Supervised two Master’s level Mental Health Counseling students participating in a counseling practicum.
- Reviewed live sessions, videotapes, and the client notes of supervisees for case load of up to four clients weekly.
- Assisted in developing and reaching the practicum and counseling goals of the supervisees.
- Participated in weekly group supervision meetings with other doctoral level supervisors and the Director of Clinical Training.
**Professional Work Experience**

**University of Miami, Miller School of Medicine Department of Pediatrics – Mailman Center for Child Development, Miami, Florida**

*Interdisciplinary Developmental Evaluations Services Care Coordinator/Autism Fellow: August 2010 – June 2011*

- Work in an interdisciplinary team with psychologists, pediatricians, endocrinologists, audiologists, speech and language therapists, physical therapists, educational specialists, and medical students in order to provide optimal physical and mental health services and assessments for toddlers, children, and adolescents with developmental disabilities, chronic illness, and other special health care needs.
- Review intakes to determine which cases are appropriate to receive Interdisciplinary Developmental Evaluation Services.
- Contact parents and guardians of patients in order to determine questions and concerns, obtain previous developmental, medical, and educational evaluations and records, obtain progress summaries from therapists and teachers, and provide parents and teachers with assessment materials.
- Conduct intake and developmental interviews with parents and guardians of toddlers, children, and adolescents with developmental disabilities, chronic illness, Fragile X Syndrome, and other special health care needs.
- Present background information and summaries at interdisciplinary team meetings, and gather and summarize results and recommendations from evaluations from other disciplines in order to create an Executive Summary of all the findings for each client.
- Conduct regular follow-up interviews with families and guardians of those who have previously received interdisciplinary services in order to assess their adherence to recommendations and assist them during the year following their evaluation.
- Participate in weekly case management and supervision meetings with supervising professors and colleagues.
- Conduct research in the field of Autism Spectrum Disorders.

**Our Lady of Lourdes Academy, English and Theology Departments, Miami, Florida**

*Teacher: August 2003 – May 2007*

- Served as a substitute teacher in all areas of study from August 2003 - July 2005.
- Organized and led classroom discussion, activities, projects and exams focusing on development of Christian identity.
- Assisted Student Council moderator in organizing, leading and chaperoning numerous school events, pep rallies, fundraisers, dances and educational field trips including study abroad opportunities in Europe.
- Participated in the Admission Standards and Practices group of the SACS Committee, a committee focused obtaining renewal of the high school’s accreditation.

**Kids Hope United, Miami, Florida**

*Family Case Manager / Social Worker: February – May 2005*

- Completed the Florida Department of Children and Families social work training courses.
- Placed children in suitable foster homes and assisted foster families in garnering services to better provide for the children.
- Participated in court proceedings to speak on behalf of the best interest of the children.
- Performed bi-weekly phone calls and visitations with foster families and children to ensure the well-being of the children.
- Transported children to and supervised visitations.
Summer Scholars Program, University of Miami, Department of Continuing Education, Coral Gables, Florida
Resident Advisor: June - July 2002, June – July 2004
- Mentored and chaperoned groups of over fifty high school students participating in the Health and Medicine program.
- Assisted professors in teaching and tutoring students.
- Organized and chaperoned educational field trips to conduct and assist in research and shadow physicians at Jackson Memorial Hospital.
- Performed routine checks on program participants to ensure their safety and well-being.

Presentations


Specialized Training and Professional Development
Department of Children and Families – Attachment Difficulties, Childhood Trauma, and Reactive Attachment Disorder: Clinical Guidelines for Assessment, Diagnosis, and Treatment. Presented by Donna Potter, MSW and Kelly Sullivan, Ph.D.
October 12 – 13, 2011

Baker Act Training
Presented by University of South Florida
September 16, 2011

Association of University Centers on Disabilities – Leadership Education in Neurodevelopmental and Related Disabilities
Presented by University of Miami, Miller School of Medicine Department of Pediatrics, Mailman Center for Child Development
June 2009 – June 2011

Florida Psychological Association – Dialectical Behavioral Therapy: Clinical Applications
Presented by Dr. Marylin Jennings, Licensed Psychologist
January 2009 – May 2009

Florida Psychological Association – Effective Clinical Interventions with Suicidal Clients
Presented by Dr. Marylin Jennings, Licensed Psychologist
March 20, 2009

Florida Psychological Association – Introduction to Neuropsychological Assessment
Presented by Dr. Larry Kubiak, Licensed Psychologist
January 16, 2009
Florida Psychological Association – Administering the Rorschach
Presented by Dr. Larry Kubiak, Licensed Psychologist
April 11, 2008

ASSessment experience
Ages and Stages Questionnaire, Third Edition (ASQ-3)
Barkley Clinical Interview
Battelle Developmental Inventory – Second Edition
Beery-Buktenica Developmental Test of Visual-Motor Integration, Fifth Edition (Beery VMI)
Career Thoughts Inventory (CTI)
Child Behavior Checklist (CBCL)
Children’s Category Test (CCT)
Finger Tapping Test
Gordon Diagnostic System (GDS)
Kaufman Assessment Battery for Children- Second Edition (KABC-II)
Kaufman Brief Intelligence Test, Second Edition (KBIT-2)
Kaufman Test of Educational Achievement-Second Edition (KTEA-II)
Leiter International Performance Scale, Revised (Leiter)
Millon Adolescent Clinical Inventory (MACI)
Millon Clinical Multiaxial Inventory, Third Edition (MCMI-III)
Minnesota Multiphasic Personality Inventory, Adolescent (MMPI-A)
Minnesota Multiphasic Personality Inventory, Second Edition (MMPI-II)
Modified Checklist for Autism in Toddlers (M-CHAT)
Myers-Briggs Type Inventory (MBTI)
Neuropsychological Assessment, Second Edition (NEPSY-II)
Purdue Pegboard
Repeatable Battery for the Assessment of Neuropsychological Status (RBANS)
Rorschach
Self-Directed Search, Fourth Edition (SDS)
Social Responsiveness Scale – Parent and Teacher Report (SRS)
Stanford-Binet Intelligence Scale, Fifth Edition (SB-V)
Strong Interest Inventory (SII)
Trail Making Test
Vineland-II
Wechsler Adult Intelligence Scale, Third Edition (WAIS-III)
Wechsler Individual Achievement Test, Second Edition (WIAT-II)
Wechsler Intelligence Scale for Children, Third Edition (WISC-III)
Wechsler Intelligence Scale for Children, Fourth Edition (WISC-IV)
Wechsler Preschool and Primary Scale of Intelligence, Third Edition (WPPSI-III)
Weschler Abbreviated Scale of Intelligence (WASI)
Woodcock-Johnson Battery, Third Edition (WJ-III)
Wide Range Assessment of Memory and Learning (WRAML)

ProFESSIONAL AFFILIATIONS
American Psychological Association
Student Affiliate: May 2006 – Present

Florida Psychological Association
Student Affiliate: January 2008 – Present

National Career Development Association
Student Affiliate: January 2009 – Present
National Latina/o Psychological Association  
*Student Affiliate: October 2009 – Present*

**HONORS & AWARDS**

**Golden Key International Honour Society**  
*Inducted: October 2008 – Present*  
- Nominated and recognized by professors for exemplary academic achievement in graduate school.

**FSU Fellows Society, Florida State University**  
*Inducted: July 2008 – Present*  
- Recognized by the university for academic excellence and leadership.

**Florida Education Fund - McKnight Doctoral Fellowship**  
*Award Recipient: August 2007 – Present*  
- Awarded full tuition plus an annual stipend at any Florida public university for outstanding academic performance amongst Hispanic and African American doctoral students.

**Florida Department of Education - Bright Futures Florida Academic Scholarship**  
*Award Recipient: August 2001 – December 2004*  
- Awarded three-quarters tuition at any Florida public university for outstanding academic performance during high school.

**University of Miami - Jay F. W. Pearson Academic Scholarship**  
*Award Recipient: August 2001 – December 2004*  
- Awarded approximately 1/3 tuition at the University of Miami for outstanding academic performance during high school.

**University of Miami, Department of Continuing Education, Summer Scholars Program**  
*Certificate of Recognition: July 2002 and July 2004*  
- Recognized by supervisors for outstanding employment performance and contribution to the Summer Scholars Program as a Resident Advisor.

**Kappa Kappa Gamma, Delta Kappa Chapter, University of Miami**  
*Certificate of Recognition: December 2004*  
- Recognized by members of the sorority for exemplary standards of sisterhood and outstanding service and contribution to Kappa Kappa Gamma and the community.

**SERVICE**

**University of South Florida, Project Conectar, Miami, Florida**  
*Student Volunteer: September 2010*  
- Conducted screening tests for autism spectrum disorders in Spanish to underprivileged and uninsured Hispanic families.

**University of Miami, Kappa Kappa Gamma, Queen for a Day, Coral Gables, Florida**  
*Fundraising Chair and Assistant Program Director: August 2002 – December 2004*  
- Organized & conducted parties for hospitalized young girls.  
- Arranged fundraisers in conjunction with local high schools to raise money and supplies.  
- Educated high school students and peers about the importance of volunteering and working with children with illness.

**Epiphany Parish, Continuing Christian Development, Miami, Florida**  
*Instructor: August 1997 – June 2002*  
- Instructed sacramental preparation and religious education to middle school and high school students from the community.  
- Organized weekly lessons and activities, and collaborated with other instructors on school-wide projects.
**Epiphany Parish, Music Ministry**, Miami, Florida

*Soloist / Choir Leader: August 1996 – June 2005*

- Led congregation through music during weekly services.
- Organized and performed in seasonal pageants and fundraisers.
- Educated children about religion, spirituality and Christian development through music.