Therapeutic Relationship between Primary Caregivers of School-Aged Children with Autism Spectrum Disorder and Speech-Language Pathologists

by

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Abstract

The purpose of the current investigation was to determine facilitators and barriers that contribute to the therapeutic relationship between primary caregivers of school-aged children with ASD and their child's speech-language pathologist (SLP). Because the stress levels that caregivers of children with ASD may experience could impact/be impacted by their working alliance with their child's SLP, an additional research aim was to investigate the relationship between the therapeutic alliance and parental stress levels. To do so, primary caregivers of children with ASD, between the school grades of Kindergarten and fifth grade, were recruited to take a 59-item, web-based, nationally-distributed survey. Ninety primary caregivers completed the survey. Results indicated that caregivers value every aspect of their child's speech therapy - goals, tasks, and bond with therapist—however, they place the most importance on the "tasks" their child's SLP uses in therapy. Although, no relationship was found between parental stress levels and their view of the therapeutic relationship, caregivers were noted to use various forms of social support, with sources of informal support being used by significantly more caregivers than formal sources. Additionally, the setting in which the child receives speech therapy is a potential barrier in establishing a positive bond, with caregivers of children receiving services from a school-based SLP reporting a significantly poorer working alliance. Despite barriers created by treatment setting, it is important that SLPs strive to maintain communication and keep parents informed partners in each step of the child's care. Implications for school-based SLPs will be discussed.

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Table of Contents

List of Tables

List of Figures

Chapter 1

Introduction

The rising prevalence rate of autism spectrum disorder (ASD) has led to an increased need for further exploration on how to effectively provide therapeutic services to these clients and support to their families. The most recent estimate of ASD in the United States has risen to 1 in 68 in the general population (Autism and Developmental Disabilities Monitoring Network [ADDM], 2012), with rates as high as 1 in 42 for males. This developmental disorder is characterized by deficits and impairments in social communication and interaction, as well as restricted and repetitive behaviors, interests, or activities (American Psychiatric Association, 2013).

Speech-language pathologists (SLPs) play a key role in diagnosis and treatment for children with ASD (ASHA, 2006a, 2006d, 2016a, 2016b). Specifically, the role that the SLP plays in assessment and intervention is reflected in the literature, with one study stating that an estimated 98.8% of school-based SLPs have a child or children with ASD on their caseload (Plumb & Plexico, 2013). With regard to roles and responsibilities when working with clients with ASD, ASHA (2006d) states specifically that SLPs should "[partner] with families in assessment and intervention" (p. 2). In addition, ASHA states that it is critical for SLPs to provide clients and their families with support and knowledge on how to overcome the social communication barriers associated with ASD "through counseling, education and training, coordination of services, and advocacy" for these families (ASHA, 2006d, p. 2).

Therefore, to form optimal partnerships between primary caregivers and SLPs, increased insight, into factors that are facilitators and barriers to the therapeutic relationship, is needed to help better inform current practice patterns. This therapeutic relationship, supported by the theoretical construct of *therapeutic alliance* or *working alliance*, has been heavily researched in the field of psychology, with emphasis on the client-clinician connection. This term was defined by Wampold (2001) as "the healthy, affectionate, and trusting feelings toward the therapist" (p. 149). Literature suggests that a positive parent-therapist working alliance is a crucial component for successful intervention outcomes as the relationship serves as a means to increase parent participation and commitment to treatment goals (Diamond, Diamond, & Liddle, 2000).

Although therapeutic alliance between the client and clinician serves as the foundation for relationships in therapy, children with ASD often lack the social communicative abilities to voice their personal suggestions, opinions, and/or concerns to their therapists (ASHA, 2006a). In light of this, it is not surprising that caregivers of children with ASD play a pivotal role in advocacy for their children and need to be fully informed partners in the therapy process (Auert, Trembath, Arciuli, & Thomas, 2012). Both ASHA (2006b) and Australia, Speech Pathology (2010) have published guidelines specifying that in order to fully meet the therapeutic needs of children with ASD, caregivers must be informed and valued members throughout the child's intervention journey. Central to the foundation of a strong therapeutic alliance between caregivers and healthcare providers, such as SLPs, is the creation of a positive therapeutic relationship, by establishing a harmonious connection, a good rapport, and increasing the level of comfort, between the parent(s) and the SLP (Boyd, 2002). In order to preserve this therapeutic relationship, collaboration and communication is key for parents to feel supported and achieve

the best outcomes for their children (Auert et al., 2012; Edwards, Brebner, McCormack, & MacDougall, 2016).

An additional component to consider, with regard to the therapeutic relationship, is parental stress, as parents of children with ASD experience heightened levels of stress, depression, and anxiety when compared to parents of typically developing children (Duarte, Bordin, Yazigi, & Mooney, 2005; Konstantareas & Papageorgiou, 2006) and children with other developmental disorders (Sanders & Morgan, 1997). Therefore, their ability to cope with these challenges and stressors greatly impacts the level to which they can adequately care for their child with ASD, and when parents are under significant stress, this may impact their ability to provide the care, compassion, and emotional support needed by their child. As a result, not only does the parent suffer, but the child suffers as well (Dunst, Trivette, & Cross, 1986). One factor that has shown to successfully alleviate parental stress is social support, and parents who receive adequate social support have an easier time adapting to the difficulties associated with raising a child who has ASD (Boyd, 2002; Konstantareas & Homatidis, 1989; Siklos & Kerns, 2006).

Social support occurs as one receives "information leading the person to believe that he is cared for and loved, valued and esteemed, and is important in a network of mutual obligation and communication" (Cobb, 1976, p. 300). According to Boyd (2002), social support can be provided to these parents "formally," which refers to professional agencies, organizations, and/or parent support groups, and "informally," which consists of the spouse, family members, and close friends. While Boyd's (2002) review of the literature found that "informal" support appears to be a more effective stress buffer than "formal" support, both types of support have been found to reduce parental stress. With regard to therapeutic relationships specifically, caregivers who are engaged in relationships with health care providers, with the ability and willingness to share

evidence-based information, were found to be more satisfied with the therapeutic relationship and experience less stress (Altiere & von Kluge, 2009; Meadan, Halle, & Ebata, 2010; Moh & Magiati, 2012; Rivard, Lepine, Mercier & Morin, 2015). While parents of children with ASD may or may not be experts on the disorder itself, they are experts on their child. It is crucial for health care providers to support parents of children with ASD with this in mind. Health care providers, such as SLPs, have the potential to greatly assist parents in the therapeutic journey, thereby establishing trust and providing an efficient path to services which may reduce stress-inducing burdens faced by parents as they raise their child with ASD (Altiere & von Kluge, 2009). Professionals working with children with ASD must be cognizant of familial stress factors and the impact they may have on the relationship between themselves and the families they serve. Investigation into the current state of the therapeutic relationship between parents of children with ASD and their SLPs is needed to help guide practice patterns in working with these families and establishing optimal outcomes.

Chapter 2

Review of the Literature

This chapter describes literature relevant to the research purposes of the thesis. It is organized in the following sections: a) Therapeutic Alliance, b) Parental Stress, c) Support Systems for Caregivers.

Therapeutic Alliance

According to research conducted in the field of psychotherapy, *therapeutic alliance*, which in its simplest terms refers to individualized and interpersonal treatment provided by a trained professional, is critical to positive treatment outcomes (Wampold, 2001). According to Grencavage and Norcross (1990), the most commonly repeated factor contributing to successful outcomes, across psychotherapy literature, is the strong influence of therapeutic alliance. This term, which refers to the relationship or bond formed between the client and clinician, was initially conceptualized and proposed by Sigmund Freud in 1893, through his theoretical construct of "transference" (Breuer & Freud, 1893-1895/1955). His theory postulates that both positive and negative attitudes/behaviors of the analyst/clinician are intentionally, or unintentionally, "transferred" or imparted on the person/client they are providing therapeutic services to (Freud, 1912). Freud's idea of transference has been studied, researched, and eventually transformed into this working therapeutic relationship, termed by Bibring (1937) as "therapeutic alliance." Further, Zetzel's findings (1956, 1966) highlighted the idea that this alliance is not an optional aspect when therapeutic services are rendered; in fact, it is essential to

the success and positive outcome of any treatment or therapy provided. She also believed and argued for the notion that this "stable trusting relationship" must be established early in therapy, and the earlier this bond is formed, the more effective treatment will be (Safran & Muran, 2000, p. 8; Zetzel, 1956). Previous empirical research in the psychotherapy realm, which has heavily emphasized the importance of establishing a positive relationship early in the therapy process, states that the TA is established in the first three therapy sessions with little to no change in the strength of the relationship throughout the therapeutic journey (Zetzel, 1956; Luborsky, 1976; Hartley, 1978; Horowitz et al., 1984; Marziali, 1984; Marziali, Marmar, & Krupnick, 1981; Eaton, Abeles, & Gutfreund, 1988; Safran & Muran, 2000).

Contributing factors. Wampold (2001) defines therapeutic alliance as "the healthy, affectionate, and trusting feelings toward the therapist," as differentiated from the neurotic component (i.e. "transference" by Freud) of the relationship (p. 149). Therefore, professionals must understand the basic concepts of establishing therapeutic alliance with their clients and realize that this relationship must be individualized and client-specific. According to Bordin (1979), three main elements contribute to therapeutic alliance. These elements are the goals of therapy, the tasks of therapy, and the actual relationship/bond between the client and therapist. Bordin's framework provides professionals with an outline of how alliance is achieved to ultimately ensure that their patients "trust, hope, and have faith" in the therapist's abilities, which is pivotal to their progression of change (Safran & Muran, 2000, p.13).

With regard to the goals of treatment, in order to obtain optimal therapeutic alliance, the end goal/result of the client's treatment journey must look the same to both the client and his or her clinician. The two must come to an agreement on the ultimate target they hope to achieve or surpass by receiving/providing therapeutic services (Bordin, 1979). Per Bordin, the tasks of

therapy are equally important to establishing therapeutic alliance. The client and clinician have to decide on the short-term objectives, tasks, and activities they are going to use as steps to reach their ultimate goal. If either the client or clinician does not agree or believe in the procedures implemented, the positive relationship between the two will decrease, as will their overall level of motivation. The third, final, and most critical aspect of Bordin's framework is the bond component. This is the degree to which the client feels respected and understood by the therapist, and the connection between the two is highly dependent on the ability to pleasantly negotiate with one another to come to a common understanding of the client's tasks and goals in therapy. Without this agreement, alliance cannot and will not be attained, and as a result, the level of treatment success will not be as high.

Following the framework established by Bordin (1979), Wampold compiled findings of Gaston (1990) and Horvath and Luborsky (1993), to develop an additional set of dimensions, used to further define the aspects that combine together and form this therapeutic relationship. Although this newly established framework seems to encompass ideas similar to Bordin's, Wampold included additional aspects, related to the bond between the two, which were not emphasized in Bordin's original outline. Wampold (2011) extended the concept of bond by specifying the importance of the level of affect between the client and therapist, the willingness and motivation the client has to cooperatively work with the therapist, and the therapist's level of empathy and ability to relate to the client on a personal level. Finally, Wampold echoed the concurrence between the therapist and client about the goals and tasks of the client's therapeutic journey.

Importance to treatment outcomes. The framework for a positive therapeutic relationship created by Wampold (2001) has been supported by meta-analytic evidence found in

research studies that examined the effect of therapeutic alliance on treatment outcomes. Wampold's (2001) findings suggest that when this framework is followed, positive progress and therapy outcomes will result. In 1991, Horvath and Symonds conducted a meta-analysis study to assess therapeutic alliance. This was rated by the client, therapist, or observers. The meta-analysis also reported a quantitative measure of the relationship between the alliance and the outcome of psychotherapy. They examined 20 studies to determine the relationship between therapeutic alliance and treatment outcomes. They found an aggregated correlation coefficient of .26, which is converted to a Cohen's *d* of 0.54, yielding a medium-sized effect between the measured variables. Therefore, when interpreted as a percentage, this *d* statistic tells us that 7% of a client's overall treatment outcome is attributed to therapeutic alliance. These statistics not only display a positive relationship between the two variables, but the significant percentage of 7% can be compared to previous studies looking at treatment differences, in which it was found that only 1% of overall treatment outcome is solely reliant on the type of treatment the client receives. Based on these findings and differences in the two percentages, "alliance accounted for at least seven times the variance that is due to treatment differences" (Wampold, 2001, p. 151). Nine years later, after numerous researchers conducted approximately 60 different studies to explore this intriguing relationship, Martin, Garske, and Davis (2000) looked at 79 studies that provided quantitative data on this alliance-outcome association and found a correlation of .22 and a *d* of .45, which allows one to interpret that 5% of the variance in treatment outcomes can be attributed to therapeutic alliance. Although this is slightly less than the percent variance estimated by Horvath and Symonds (1991), both meta-analyses provide evidence to show that there is a "moderately strong relationship between the alliance and outcome in psychotherapy" (Wampold, 2001, p. 154).

Assessing therapeutic alliance. Therapeutic alliance has been documented as an important aspect of one's therapy journey. Martin and colleagues (2000) meta-analytic review found it to be a significant contributor to the clients' overall treatment outcomes. Investigations on methods for strengthening the therapeutic alliance have revealed a variety of findings, partly due to the fact that tools and assessment protocols for assessing therapeutic alliance are lacking. Therefore, researchers in the psychotherapy realm continue to search for effective and efficient methods for evaluating this crucial component.

The Working Alliance Inventory (WAI) by Horvath (1989) has been the most widely used instrument for assessing this factor. The authors developed this assessment tool using a "theory-based approach," encompassing Bordin's (1979, 1980) model, which claims therapeutic alliance is developed through negotiation and collaboration, between client and therapist. Bordin suggests this is accomplished through the following three aspects: (1) an agreement on the goals of therapy; (2) the client's agreement that the tasks the therapist uses will effectively treat the client's problems; (3) and the strength of the bond between the client and therapist (Hatcher & Gillapsy, 2006). Using this model, Horvath (1989) developed a 36-item questionnaire, with 12 questions attributed to each of the three parts of Bordin's (1979) model: (1) goals, (2) tasks, and (3) bond.

Tracey and Kokotovic (1989) conducted a confirmatory factor analytic (CFA) study of 84 clients' and 123 therapists' ratings of the WAI following one therapy session. Next, the two developed a short form of the WAI (WAI-S) which consisted of 4 questions from each of the 3 dimensions from Bordin's theoretical framework. They chose the "four highest loading items" from the CFA and published their own 12-item questionnaire. Due to the small sample size, lack of study replication, and the fact that ratings collected by Tracey and Kokotovic followed only

the participants' very first therapy session, Hatcher and Gillaspy (2006) suggested that the questions chosen for the WAI-S may not be most appropriate for assessing the working alliance domain.

Therefore, Hatcher and Gillapsy (2006) developed an alternative 12-item WAI (WAI-SR), aligning with Bordin's (1979) model. To do so, they first examined the validity of factors represented in the WAI-36 by having 231 clients and their therapists (Sample 1) complete the WAI (Horvath & Greenberg, 1986), in addition to three similar models/measures: *The Penn Helping Alliance Questionnaire* (HAQ; Alexander & Luborsky, 1986); *The California Psychotherapy Alliance Scale* (CALPAS; Gaston, 1991; Marmar, Horowitz, Weiss, & Marziali, 1986), and *Estimate of Improvement* (EI; Hatcher & Barends, 1996; Hatcher 1999). Clients and therapists completed measures in this cross-sectional investigation at different times in their therapeutic journeys, ranging from session 2 to session 274. Also, a separate sample of participants (Sample 2) consisted of 235 outpatient clients who were asked to complete the WAI after their third therapy session. Using the CFA-estimated correlations derived from the participants' results, the WAI-SR was put together—consisting of 12 positively worded items. The WAI-SR was found to better differentiate the *Goal, Task*, and *Bond* alliance dimensions than the two previous versions (WAI, WAI-S), and also, results on the WAI-SR correlated well with other alliance measures (Hatcher & Gillapsy, 2006).

Further, Munder, Wilmers, Leonhart, Linster, and Barth (2010) conducted an investigation to assess the psychometric properties and generalization of the *Working Alliance Inventory-Short Revised* (WAI-SR) by comparing it to the *Helping Alliance Questionnaire* in German outpatient and inpatient participants. Their study results validated previous findings to suggest good reliability and convergent validity of the refined measure. Munder and colleagues

reported good confirmatory factor analysis of the WAI-SR, which also supports the validity of this instrument to assess Bordin's three domains of therapeutic alliance, and further, this assessment tool displayed the ability to better distinguish the *Goal* and *Task* aspects described above. And finally, since this measure had only been reliably used to assess outpatient individuals in the United States, the generalizability of results was limited prior to this 2009 investigation. However, Munder and colleagues expanded the population base on which this instrument may be used to assess by finding it to be successful in examining non-English speaking patients, receiving inpatient and/or outpatient care (2009).

The current WAI-SR consists of 12 positively worded items assessing the client's view of level of agreement and alliance between the client and his/her therapist. The client is instructed to read the 12 sentences, inputting his/her therapist's name in the blank provided, and use a five-point Likert scale to select one of the following: "*1 = seldom, 2 = sometimes, 3 = fairly often, 4 = very often, 5 = always*." The range of total scores on this instrument is from 12 to 60, with a higher score being indicative of a stronger therapeutic alliance between the client and his/her therapist.

Breakdowns in therapeutic alliance. Despite the ample amount of research that exists supporting the importance of therapeutic alliance to treatment outcomes, there are times when the alliance is ruptured. According to Bordin's three-part conceptualization (1979), this breakdown can result from either "disagreements about the tasks or goals of therapy or from problems in the bond" between therapist and clinician (Safran & Muran, 2000, p.16). Before the pair can move forward in the therapeutic process, the issue or problem must be addressed, changes must be made, and a common understanding must be re-established. When there is a disagreement about the tasks and goals, the therapist should be willing to put his or her fixed

ideas and opinions aside to focus on what is most meaningful and important to the client. This will not only build the alliance and bond between the two in the short-term, present context, but it will likely demonstrate the clinician's level of flexibility and understanding to the client. As a result, the client will build further trust in the clinician and possibly, later in therapy, be more willing to engage in tasks that the clinician feels will be most beneficial to the client. By following the client's lead and catering to his or her wants/needs, the client will feel more valuable and understood by the therapist, and therefore, he or she will likely be more open to the therapist's future suggestions and ideas (Safran & Muran, 2000). As mentioned by Safran and Muran, (2000), therapists often lose sight of the importance of the therapeutic relationship when things seem to be running smoothly, but in fact, ruptures in alliance occur more frequently than we realize. Therefore, in order to appropriately and effectively provide services to our clients, we should constantly self-monitor and work to improve the ongoing bond between ourselves and the individuals we serve.

Role of the therapist. In striving to attain therapeutic alliance with clients, it is critical for therapists to be aware of and let go of their own professional and clinical preconceptions and be more accepting of their clients' expressed desires for their own therapeutic journeys. Although a therapist may feel anxious, unprepared, or incompetent when they see a client and do not have a set plan for them to follow to reach their therapy goals, Safran and Muran (2000) say that establishing this so-called, "plan," can "limit our ability to see what is taking place" (p. 36). As therapists gain more experience in their field, they also gain massive amounts of knowledge, and this often causes them to fall into habitual practices and routines when treating clients. To overcome this barrier, Wilfred Bion (1967) is famously known for advising clinicians to "approach every session 'without memory and desire'" (Safran & Muran, 2000, p.36). Although

asking therapists and clinicians to completely abandon the theories and beliefs that they base their practice on is an unrealistic expectation, it is important for therapists to remember that treating their clients is a "process of construction" and "new information and new possibilities are constantly emerging in every moment of interaction with the patient" (Safran & Muran, 2000, pp. 36-37). Therefore, we must be aware that that the therapy we provide is often guided through our previous experiences with former clients, but according to Zen master, Shunru Suzuki (1970), "If your mind is empty, it is always ready for anything; it is open to everything. In the beginner's mind, there are many possibilities; in the expert's mind, there are few" (p. 21). In view and careful consideration of this quote, therapeutic alliance, which we have found to be a major predictor of treatment outcomes, can only be successfully achieved when the therapist is able to put his or her own preconceptions aside and make each client's therapeutic experience individualized and focused around their personal desires.

Therapeutic alliance and caregivers of children with ASD. Autism spectrum disorder (ASD) was first explained in Leo Kanner's (1943) paper, through which he described the case studies of eleven children with autism and emphasized comparable characteristics he observed. Kanner (1943) found that the children he observed preferred being alone, displayed poor imaginative abilities, resisted change, and demonstrated exceptional skills in repetition and memorization tasks. Additionally, he highlighted obvious differences in the development and use of language in these children. According to the American Psychiatric Association (2013), ASD is currently defined as a developmental disability characterized by differences in the individuals' social interaction and behavior patterns, which begin in early childhood and often persist through adolescence and into adulthood. According to the Autism and Developmental Disabilities Monitoring (ADDM) Network's Community Report on Autism, which summarizes the findings

from Christensen and colleagues (2016) , those with ASD present with specific, identifiable characteristics “such as difficulties with social interaction, difficulties with communication, and highly focused interests and/or repetitive activities,” and the severity of the disorder depends on the degree to which his/her functional and self-care abilities are limited by these social interaction issues (p. 1). ASD is now used to diagnose individuals presenting with these similar characteristics, and the “spectrum” portion of ASD refers to the fact that each person can be affected by ASD differently, and as a result, each exhibits their own, unique set of traits and symptoms, across the severity range, from low to high functioning (Christensen et al., 2016). Therefore, with the prevalence of ASD on the rise, there are key implications indicating the need for children to be diagnosed as early as possible in order to receive the services and support they need.

Evidence supports the need for effective interventions for children with ASD and the positive outcomes that can result (Eldevik et al., 2009), with general agreement that a family-centered model is key, and collaboration between parents and therapists is necessary in the planning and delivering of intervention (Hanna & Rodger, 2002). Despite recognition of the importance of a therapeutic relationship between parents and therapists, a dearth of research exists on the subject. Of interest, is a qualitative investigation by Edwards and colleagues (2016) who explored the qualities that parents seek in their child's therapist, and to effectively do so, the researchers interviewed parents of children with ASD, and two major themes were identified. First of all, the parents expressed the need for a “partnership” between themselves and the therapist providing services to their child. They want to establish a working relationship and have the informed ability to work in collaboration with the therapist to promote progress in treatment progress. Additionally, the second theme, “effective therapy,” was found to be of great

importance to the parents in this study, as they highly desire their child to receive treatment that specifically targets their child's individual needs, and as a result, advancements in therapy will be achieved. By taking these two factors into consideration and analyzing the parental perspectives of their participants, the authors concluded that while parents considered positive treatment outcomes to be paramount, the collaboration, communication, and overall relationship between themselves and their child's therapist are factors found to be essential to achieving success in therapy (Edwards et al., 2016).

Stress

Researchers propose that treatment provided to children with ASD is often compromised when parents are enduring overwhelming levels of stress, exhibiting symptoms of anxiety and/or depression, or experiencing difficulties in raising and caring for their child with ASD (Robbins, Dunlap, & Plienis, 1991). And in comparison to parents of typically developing children and children with other developmental disorders, parents of children with ASD report significantly higher levels of stress (Benson, 2014; Hayes & Watson, 2013; Sanders & Morgan, 1997) and are at increased risks for the development of psychological issues and mental disorders themselves (Duarte et al., 2005; Sanders & Morgan, 1997). These negative impacts likely result from the severity of symptoms and behavioral characteristics of ASD, such as echolalia, anxiety, breakdowns in times of transition, tantrums, mood swings, the inability to communicate, and a lack of self-help skills (Luther, Canham, & Cureton, 2005; Papageorgiou & Kalyva, 2010; Rapin, 1997). Themes across the literature claim that the child's severity of problem behaviors is the greatest source of parental stress, as compared to the effects caused by concomitant characteristics of ASD, such as language disorders, social deficits (Ekas, Lickenbrock, &

Whitman, 2010), cognitive abilities (Davis & Carter, 2008), and adaptive functioning issues (Davis & Carter, 2008; Lecavalier, Leone, & Wiltz, 2006).

Estes and colleagues (2013) lead a study in which one of their purposes focused on which category of children's ASD symptoms, behavioral problems or deficits in daily living skills, had the greatest impact on parental stress and psychological distress. The authors issued a comprehensive questionnaire to all 96 participating families, which consisted of an ASD group, a developmentally delayed (DD) group, and a typically developing (TD) group. The authors' assessment instrument included the *Questionnaire on Resources and Stress (QRS)* to measure parental stress, the *Brief Symptom Inventory (BSI)* to measure psychological distress, the *Aberrant Behavior Checklist (ABC)*, to evaluate problem behaviors, and the *Daily Living Skills (DLS)* domain of the *Vineland Adaptive Behavior Scales (VABS)* to assess daily living skills (Estes et al., 2013, p. 135). The mothers of each family answered the questions pertaining to their personal stress, distress, and characteristics observed in their child, and the results of this study found child behavior problems to be a "significant predictor of parenting-related stress and psychological distress" in this sample of participants (p. 136). Although higher levels of problem behavior were reported in the ASD group, as compared to the DD group, heightened stress and distress levels, caused by these problem behaviors, was found in both groups. Therefore, these findings suggest that problem behaviors increase the stress and distress levels of mothers of children with developmental disorders (ASD and non-ASD), but daily living skills were not found to be significantly associated with the stress levels of these parents (Estes et al., 2013). Estes and colleagues' results aligned with those documented by earlier researchers (Lecavalier et al., 2006) and supports their hypothesis that emphasizes the importance of targeting child problem behaviors in future research and intervention approaches for children with ASD and

DD, and by working to alleviate these behaviors, the children's functioning levels will increase while their parents' stress levels decrease (Estes et al., 2013).

According to Boyd (2002), who explored the relationship between stress and social support in mothers of children with ASD, proper training is crucial for parents to adequately cope and regulate their child's challenging ASD characteristics. Therefore, it is the professional responsibility of service providers, therapists, and professionals to identify the families' practical problems, provide the skills and/or solutions that will successfully alleviate these issues, and help these caregivers "better cope with an already difficult, and potentially lifelong, situation" (Boyd, 2002, p. 214). By doing so, these mothers will better adapt and more easily meet the needs of their child with ASD and also, their family as a whole.

Assessing caregiver stress. Therefore, in order to overcome this parental stress barrier, that so often inhibits the improvement of symptoms and positive treatment outcomes in children with ASD (Robbins et al., 1991), clinicians must have a method to accurately assess, monitor, and alleviate the overwhelming stress levels experienced by these parents. However, the only published instrument known to directly assess parental stress, stemming from the relationship between a parent and his/her child, is the *Parenting Stress Index (PSI)* (Abidin, 1986), and although this assessment demonstrates high reliability and validity, it is a lengthy assessment which primarily focuses on the stress caused by children belonging to special clinical populations (Berry & Jones, 1995). Therefore, Berry and Jones (1995) developed an adapted form of Abidin's (1986) 101-item questionnaire, in an attempt to provide a quick and easy way to generally assess the stress caused by parenting a child with or without clinical problems; their 18-item instrument is known as the *Parental Stress Scale (PSS)* (Berry & Jones, 1995).

Because the majority of stress surveying instruments only focus on the negative child behaviors and characteristics that contribute to parental stress, Berry and Jones (1995) sought to develop a scale that accounted for both the rewards and strains of being a parent. In order to do so, the authors surveyed literature on related topics to identify common themes empirically supported to contribute to parental stress. After gaining reasonable insight and compiling findings from related studies, Berry and Jones (1995) incorporated positive items, assessing affectional/emotional advantages and personal growth, and negative items, assessing life limitations, monetary adjustments, time demands, and energy expended, which were suggested in *The Child in the Family* by Belsky, Lerner, & Graham (1984), to be predictors of parental stress. Berry and Jones' original instrument was a 20-item questionnaire, in which half of the items were statements contributing to higher stress levels, the other half were indicative of lower stress levels, and they were all to be answered on a scale ranging from "strongly disagree" to "strongly agree" (1995). However, this scale was found to have poor reliability after its initial administration to 125 parents of typically developing children (18 years and younger), and as a result, two items were removed from the original 20-item questionnaire. The second administration of the *PSS* consisted of the current, 18-item questionnaire and was given to 233 parents of typically developing children, and the overall reliability and test-retest correlation coefficients were found to be greater than 0.80. However, although they increased with the removal of the two additional items, the mean inter-item and item-whole correlation coefficients were 0.23 and 0.43 respectively (Berry & Jones, 1995, p. 466).

The validity of the *Parental Stress Scale* was assessed by comparing participants' scores on the *PSS* to their scores on the *Perceived Stress Scale* (Cohen, Kamarck, & Mermelstein, 1983)—the most widely used instrument for assessing perceived stress levels in adults. Both

stress scales were administered to the sample mentioned above, which consisted of 233 parents of typically-developing children (group 2), and to a sample of 51 mothers of children receiving therapy for psychological and/or behavioral issues (group 3). The authors of the *PSS* found a significant correlation between parents' scores on the stress scales administered, for both the typically developing (r = 0.50) and the clinical group (r = 0.41). Next, the authors sought to compare *PSS* results between the mothers of the two groups. To do so, they analyzed the mothers' scores from group 2 (*n* = 116) to the mothers' scores from group 3 (*n* = 51), and hypothesized that increased stress levels and *PSS* scores would be found in the mothers of the clinical sample (group 3) as compared to the non-clinical sample (group 2). The average *PSS* score for group 3 was 43.2, while the mean for group 2 was 37.1. This provided that higher stress levels correlate with higher PSS scores for parents of children with psychological and/or behavioral problems, as compared to parents of typically developing children. According to Mathur (2014), scores between 18 and 41 signify a mild stress level, 42-65 yields a moderate stress level, and *PSS* scores falling between 66-90 indicate severe parental stress. Therefore, the difference between group scores provided support of the authors' hypothesis and validity of the *PSS*. To further solidify the validity of this instrument, the authors matched the non-clinical group of mothers to 78 mothers of children with developmental disabilities, and their scores on the *PSS* were compared. Again, as expected, a higher mean score (40.1) of parental stress was found for the clinical group, as compared to the mothers' of typically developing children (37.1) (Berry & Jones, 1995, p. 467).

Next, the authors compared the *PSS* to the instrument it was adapted from, the *Parenting Stress Index (PSI).* Both scales were administered to 43 parents of typically developing children, and a correlation coefficient of 0.75 was found between scores on the *Total Parenting Stress*

Index of the *PSI* and the *PSS*. This significant relationship was further confirmed as the authors individually examined each subscale of the *PSI* and found statistically significant relationships between eleven of the thirteen domains evaluated by the *PSI* and scores on the *PSS* (Berry & Jones, 1995, p. 468). The authors' final validity analysis tested the convergent validity of their stress scale by comparing scores on the PSS to measures of role satisfaction and emotional well-being in a sample of 746 parents (mothers=540, fathers=206) with a child less than 6 years old, and as expected, a significant correlation was found between scores on the PSS and the combined (mothers and fathers) scores on measures of psychological well-being (Berry & Jones, 1995, p. 469)

The extensive measures taken by the authors to ensure reliability and validity of the *Parental Stress Scale (PSS)* makes it a highly-recommended instrument to administer and assess the stress levels of mothers and fathers of all children, with and without clinical problems and/or diagnoses. Although it is suggested that further research be done to assess the scale's accuracy in assessing the stress levels of parents from a variety of ethnic, racial, cultural, and socioeconomic backgrounds, the *PSS* currently stands as an instrument that adequately assesses the stress levels of parents in a brief, but effective manner (Berry & Jones, 1995).

Since this instrument's development, Silva and Schalock (2012) formulated a measure to assess the stress levels of parents of children with ASD by identifying specific areas of need and/or support, and also, to determine the effect of intervention on parental stress. This instrument, the *Autism Parenting Stress Index (APSI)*, is ultimately intended to be used by clinicians to gain a clearer understanding of how "core and co-morbid symptoms of autism" heighten the stress experienced by these parents (Silva & Schalock, 2012, p. 566). However, although there is strong validation data supporting its use, the *APSI*'s initial psychometric

evidence was based on the parents of children between 24 and 72 months of age. As a result, the majority of the ASD symptoms presented on the questionnaire are those found in young children with ASD (e.g. potty training) and can possibly be resolved and/or alleviated as the child ages.

Support Systems for Caregivers

The challenges of caring for and/or parenting a child with ASD results in increased stress levels (Duarte et al., 2005; Konstantareas & Papageorgiou, 2006; Sharpley, Bitsika, & Efremidis, 1997), which yield the need for social support, as those parents who are adequately supported are less stressed (Boyd, 2002; Siklos & Kerns, 2006) and display decreased levels of depression, anxiety, and anger (Gray & Holden, 1992). As a result, the alleviation of stress levels enables these parents to be more successful in managing their child's behaviors, implementing interventions, and providing them with quality care (Konstantareas & Homatidis, 1992; Lecavalier et al., 2006; Osborne & Reed, 2008).

In an investigation of mothers of children with ASD, Boyd (2002) found that the mother's personality traits combined with the child's challenging characteristics, impact the mother's motivation to search for support, and those who receive minimal or no social support suffer emotionally (Boyd, 2002; Gray & Holden, 1992; Konstantareas & Homatidis, 1989; Sanders & Morgan, 1997). Next, Boyd (2002) researched the effects of informal and formal supports. According to Bristol and Schopler (1983) and cited by Boyd (2002), *informal support* includes "the immediate and extended family, friends, neighbors, and other parents of children with disabilities," while *formal support* is characterized as "assistance that is social, psychological, physical, or financial and is provided either for free or in exchange for a fee through an organized group or agency" (p. 212). Although both have been found to be beneficial across the literature (Meadan et al., 2010), Boyd's review found sources of informal support to

be better at decreasing parental stress levels, as compared to formal sources, while Siklos and Kerns (2006) discovered that parents of children with ASD rated formal support and services provided by professionals as being more important than various types of informal support. Nevertheless, due to the challenging behaviors and the cognitive deficits displayed by individuals with ASD, parents report higher levels of stress and depression, and these two factors ultimately lead mothers of children with ASD to seek out social support (Boyd, 2002). As a result, social support, or the "source of comfort found within group and individual relationships" (Turnbull, Turnbull, Erwin, & Soodak, 2006, p. 213), has been heavily researched, both formally and informally, and found to be successful in alleviating parental stress. Therefore, health care providers/professionals working with this population should be prepared to provide parents with a variety of services and suggestions, so that they may establish a support system that best suits the needs of themselves and their families (Boyd, 2002; Siklos & Kern, 2006).

Informal support. Informal sources include support from spouses, extended family members, friends, religious groups, and respite care services. Konstantareas and Homatidis (1989) found that mothers of children with ASD typically seek informal sources of support before turning to professional organizations, individuals, or agencies for help, and this type has been found to be more effective than formal support in alleviating parental stress (Boyd, 2002; Herman & Thompson, 1995). Research on informal support has also been found to promote parental well-being (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Gill & Harris, 1991; Henderson & Vandenberg, 1992; White & Hastings, 2004; Wolf, Noh, Fisman, & Speechley, 1989), and this correlation promotes a need for individualized, on-going support and counselling for mothers of children with ASD (Bromley, Hare, Davison, & Emerson, 2004).

Spouses. It has been widely documented across the literature that parents of children with disabilities initially turn to their spouse for support before seeking external help (Boyd, 2002; Gray & Holden, 1992; Konstantareas & Homatidis, 1989), and this internal source has been found to be the most helpful form of social support for both mothers and fathers of children with ASD (Boyd, 2002; Herman & Thompson, 1995). However, current research suggests that fathers are less likely to provide social support to their wives when their child with ASD displays more challenging and severe behavioral characteristics (Brobst, Clopton, & Hendrick, 2009). Therefore, mothers, who are typically the primary caregivers and spend the most time with their children with ASD (Boyd, 2002; Higgins, Bailey, & Pearce, 2005), express the need for additional support from their husbands. Specifically, these mothers desire their husbands to relieve them of their caregiving duties, be more assertive in disciplining their child, and offer to assist in daily, household chores and tasks (Konstantareas & Homatidis, 1989). However, it has been noted across the literature that marriage rates are lower (Reichman, Corman, & Noonan, 2004) and divorce is more prevalent among parents of children with a disability, when compared to those of typical children (Higgins, Bailey, & Pearce, 2005). As a result, when spouses do not provide this support, and in the cases of single parents, other sources of informal support have to be sought out and used.

In order to further explore how raising a child with ASD impacts the functioning and feelings of the family, Myers, Mackintosh, and Goin-Kochel (2009) conducted a study in which they posted an online questionnaire containing one, open-ended question, ‘‘How has your child in the autism spectrum affected your life and your family’s life?’’ (p. 673). With regard to how this diagnosis may place strain on the parents’ relationship, one participant’s statement, “‘We [my husband and I] have no social life together,’’ provided that marital problems may arise in

parents of children with ASD, because of the social isolation and stress they are forced to endure, and this is a recurring theme found across the literature (Myers et al, 2009, p. 680; Kuhlthau et al., 2014). Multiple studies on this topic have found spousal relationship issues to be highly prevalent in those who have a child with ASD, and reasoning behind these struggles has been linked to amount of time parents have to devote to their child (Altiere & von Kluge, 2009). An increase in time dedicated to the child leads to less time available for building their relationship with one another (Fleischmann, 2004). Also, the overwhelming stress they endure (Olsson & Hwang, 2001) is often linked to the following factors: financial burdens (Quintero & McIntyre, 2010), lack of social support (Boyd, 2002; Luther et al., 2005), and the inability to control the severity of their child's ASD behaviors (Degrace, 2004; Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Stuart & McGrew, 2009; Estes et al., 2013; Seymour, Wood, Giallo, & Jellett, 2013). As a result, the rate of divorce in parents of typically developing children compared to those of children with ASD was investigated by Hartley et al. (2010), and their study found divorce to occur more frequently (23.5%) among parents of children with ASD than in parents of children with no disability (13.8%).

Further, in consideration of the extraneous expenses associated with parenting a child with ASD, Papageorgiou and Kalyva's (2010) study also explored the financial burden placed on these parents and how this factor may partially be responsible for the divorce percentage gap mentioned above. According to a poll of married men and women, conducted by Dew, Britt, and Huston (2012), financial conflicts and disagreements predict divorce more strongly than other common marital issues (p. 624), and a recent survey of Certified Divorce Financial Analysts (CDFA) reported that one professional claimed "financial disagreements to be the most common cause of marital conflict and ultimately divorce" (Institute for Divorce Financial Analysts, 2016).

Therefore, because financial issues alone have the potential to destroy familial relationships, when this factor arises in families of children with ASD, its level of severity is likely to be even more elevated. In 2014, Lavelle and colleagues, of Harvard University, reported the extraneous costs required to care for a single child with ASD is greater than $17,000 annually. Children with ASD do require more medications and doctor visits than typically developing children; however, the majority of this financial burden consists of expenses outside the health care realm (p. 520). Although this substantial amount is broken down and covered by the child's family, insurance companies, societal/community organizations, and state and federal tax dollars, one can assume that the financial impact of this diagnosis places a heavy burden on the marital relationship of parents of children with ASD.

Friends, co-workers, and religious groups. Other sources of informal support come from friends, co-workers, and religious groups. In a study by Altiere and von Kluge (2009), which investigated challenges encountered by parents of children with ASD, over half of their participants reported that when their child was diagnosed with ASD, they noticed an improvement in relationships with their "true" friends (p. 149), and a portion of the couples found their child's diagnosis to lead to increased support from their family members (Altiere & von Kluge, 2009). They reported spending more time together as a family unit, and as a result, felt more supported by their loved ones. In fact, one parent stated, "it (raising a child with autism) brought our family closer together, it created a bond through adversity" (Altiere & von Kluge, 2009, p. 149). However, because parents of children with ASD have increased caregiving responsibilities and have less time available to spend with outside individuals, they lose touch with them, and as a result, sources of social support are lost as well (Altiere & von Kluge, 2009). Papgeorgiou and Kalyva (2010) asked parents of children with ASD how their family, friends,

and co-workers responded to their child's diagnosis, and the majority of parents reported that they accepted their child and emotionally supported their family. However, others reported feelings of rejection, disapproval, unacceptance, and a lack of understanding from these individuals. Also, because of the social stigma associated with a diagnosis of ASD and the fear of promotion limitations in the workplace, many parents reported that they have withheld their child's diagnosis from employers, co-workers, and colleagues (2010). Therefore, parents have to search elsewhere for informal sources of social support. Altiere and von Kluge (2009) found that many individuals rely heavily on their church and/or religious congregation as a form of social support, but only one couple in the study reported support, both financially and emotionally, from their church congregation. Due to a decreased understanding of their child's disorder, other parents reported receiving "dirty looks" from church members and never felt adequately supported or accepted by those they once felt so close and connected to (p. 146). As a result, another source of social support was lost.

Extended family members. Although the informal relationships and sources of support mentioned above have been found to alleviate the stress levels of parents of individuals with ASD, extended family members, specifically grandparents, have been found to be the most helpful form of informal support outside the immediate family (Hillman, 2007; Katz & Kessel, 2002) and most critical (Altiere & von Kluge, 2009; Hastings, 1997). Grandparents serve as a source of practical support, as they often assist parents by providing financial support, babysitting, transporting children to and from appointments/therapy sessions, helping control problematic behaviors, and advocating on their grandchild's behalf. Additionally, grandparents provide parents of children with developmental disabilities with emotional support by simply lending a listening ear, providing encouragement, and/or giving advice (Hillman, 2007; Katz &

Kessel, 2002). Because having a child with a developmental disability often leads to broken marriages, employment changes, and heightened levels of stress, more single mothers and grandmothers are found to be the primary caregivers of children with disabilities (Cohen & Petrescu-Prahova, 2006; Glass & Huneycutt, 2002; Hillman, 2007). Additionally, parenting a child with a disability highly impacts the daily lives of those living with the child; therefore, social support provided by close family members outside the nuclear family, such as grandparents, can lessen the parents' daily battles (Dunst & Trivette, 1986; Tinsley & Parke, 1987).

In fact, past researchers found extended family support to be more important and helpful than the support provided by professionals (Prudhoe & Peters, 1995; Sandler, Warren, & Raver, 1995). However, it is also important to note that involvement of grandparents in the lives of children with disabilities may negatively impact and/or place a burden on the child's parents (Altiere & von Kluge, 2009; Hastings, 1997). According to a literature review by Lee and Gardener (2010), the level to which grandparents are willing and able to be involved in their grandchild's life depends on the grandparents' knowledge on the child's disability (Gardner, 1996; George, 1988; Sandler, 1998; Shaw, 2005; Vadasy, 1987; Vadasy, Fewell & Meyer, 1986), how far away the grandparent lives from the grandchild (Baranowski & Schilmoeller, 1999; Gardner, 1996; Gardner, Scherman, Mobley, Brown, & Schutter, 1994; Nybo, Scherman, & Freeman, 1998; Scherman, Goodrich, Kelly, Russell, & Akbar, 1988; Shaw, 2005), and the relationship between the grandparent and the parent of the child (Baranowski & Schilmoeller, 1999; Hornby & Ashworth, 1994; Mirfin-Veitch, Bray, & Watson, 1997; Nybo et al., 1998; Schilmoeller & Baranowski, 1998). Also, differences between how the parents and the grandparents perceive the child's disability (Glasberg & Harris, 1997)

and the level of grief expressed by the grandparents (Hastings, 1997) may also be sources of conflict between the two generations. Oftentimes, grandparents are unable to assist in caregiving responsibilities because they lack the information, knowledge, supports, and skills to do so (Altiere & von Kluge, 2009; Vadasy et al., 1986), and therefore, they feel helpless and incompetent and may begin to reject and/or deny their grandchild's disability. As a result, this may impede the level to which they are able to socially support their child in his/her parenting (Vadasy et al., 1986). Additionally, how grandparents perceive and act toward their grandchild's disability often influences other members of the extended family, as grandparents often serve as role models in family unit (Vadasy et al., 1986), and their reactions often place an added burden on the parents of the disabled child, who are already struggling to deal with their child's diagnosis (Scherman, Gardner, Brown, & Schutter, 1995; Hastings 1997). In Altiere and von Kluge's (2009) qualitative study, 8 of the 26 couples reported extreme challenges and lack of support from extended family members, with one couple stating, "our extended family does not understand autism, so they are incapable of being supportive,'' and another couple shared that outside family members found their child with ASD to be "an embarrassment" (p. 146). However, various studies have found that as time progresses and the child ages, involved grandparents learn to accept and better adjust to the child's disability than the parents (Lee & Gardner, 2010; Schilmoeller & Baranowski, 1998).

SLP's role in informal support systems. To enhance the therapeutic relationship between service providers and parents of children with ASD and highlight the crucial role that families play in the therapeutic journey of children with disabilities, family-centered care is suggested (Bruce & Ritchie, 1997). By doing so, the professional will consider, respect, and recognize all aspects of the client's family structure, and provide support, information, and training to all those

involved in enhancing the life of the child, both within and outside the immediate family (Hillman, 2007; Katz & Kessel, 2002). By including the parents' sources of informal support, including grandparents specifically, all individuals involved will feel more knowledgeable and competent in their caregiving abilities (Scherman et al., 1995). As a result, the parents will be able to rely on them more which will increase the level of support they receive, and in turn, reduce their stress levels (Johnston et al., 2003).

Formal support. Formal support is provided to parents of children with ASD through respite care services, support groups, and healthcare professionals/service providers. Across the literature, researchers have found sources of formal support to have less influence on reducing stress levels of parents of children with developmental disabilities than informal sources (Boyd, 2002; Renty & Roeyers, 2006), and this is often due to the fact that formal support services are not suggested or made readily available to the parents (Herman & Thompson, 1995). Although Boyd's (2002) literature review found that parents of children with ASD seek informal sources of support first, specifically from their spouses, more recent literature suggests that parents initially turn to formal sources of support, upon receiving the diagnosis, in search of answers (Altiere & von Kluge, 2009).

Respite care services. Because of the stressful demands associated with parenting a child with a developmental disability, disruptions in familial functioning may result in parents choosing to institutionalize their disabled child (Blacher & Bromley, 1990). However, current studies suggest that, before choosing institutionalization, parents are now taking advantage of respite care services as a formal form of social support. Short-term use of respite care services, which relieve parents of their caregiving duties by allowing another adult to temporarily take on these responsibilities, have been found to reduce stress in parents, and as a result, they are less

likely to seek out long-term, more permanent placements for their child (Bruns & Burchard 2000; Chan & Sigafoos, 2001; Mullins, Aniol, Boyd, Page, & Chaney, 2002; Storey, 1993). Additionally, parents of children with ASD typically have very little time, apart from their child, to enjoy leisure activities (Sanders & Morgan, 1997); therefore, the use of respite care services will allow these parents to engage in enjoyable activities, which may decrease stress levels and promote personal growth (Meadan et al., 2010). Initially, parents of children with disabilities may turn to extended family members or friends for respite services, but oftentimes these individuals do not have the knowledge and/or skills to provide adequate care; therefore, formal sources of respite care are sought out (Gafford, 1987). However, in a study conducted on mothers of children with ASD, by Bromley and colleagues (2004), over half of the participants (55%) requested further help locating and utilizing respite care services. Therefore, to decrease parental stress levels and reduce the likelihood of children being permanently placed outside the home (Raif & Rimmerman, 1993), Boyd (2002) emphasizes that professionals must help parents find the social support services they need.

Support groups. Another source of formal support is provided to parents through support groups. According to Rawlins and Horner (1988), support groups provide the parents with a community-style support system that allows them to develop friendships and share information with others who are dealing with the shared disability, and Boyd (2002) found this type to be the most valuable form of formal support utilized by parents of children with disability. Parents who are most likely to be part of ASD support groups are those who have children that are older, present with self-harming behaviors, sleep difficulties, and/or complex communication deficits (Mandell & Salzer, 2007). In Papageorgiou and Kalyva's (2010) qualitative study, the majority of parents reported that they were involved with parent support groups to learn about new

developments/treatments in ASD research (64.5%), and further, others used this form of formal support to obtain advice from other parents, to receive psychological support, and to interact with those who experience similar challenges related to parenting a child with ASD. These support groups not only provide advice and support, but they also decrease feelings of isolation, initiate maternal friendships, reduce stress levels, and provide coping strategies (Altiere & von Kluge, 2009; Mandell & Salzer, 2007; Shu and Lung, 2005). However, parents report having trouble finding individuals to care for their child while they attend support group meetings (Hall & Graff, 2010), and it has been highly emphasized across the literature that parents do not feel that they are provided with adequate information on resources and supports available to them; therefore, they are often unaware of how to get involved with support groups (Huws, Jones, & Ingledew, 2001; Osborne & Reed, 2008). However, when health care providers make referrals, parents are more likely to take advantage of services for their children and sources of support for themselves (Carlon, Carter, & Stephenson, 2015; Green, 2007; Hebert, 2014; Rivard et al., 2015; Valentine, 2010). Therefore, Mandel and Salzer (2007) suggest that clinicians play a critical role in this referral process, by seeking out local support groups and helping form them in areas they are needed. Further, the investigators suggest that as service providers develop and implement interventions that will guide parents to use support group services, they will be more successful and confident in managing their child's challenging behaviors and their own stress levels (Mandel & Salzer, 2007).

Health care providers. Professionals, clinicians, and health care providers make up another domain of formal support for parents of children with ASD. Siklos and Kerns' study (2006) found this type of support to be ranked the most important by parents of children with ASD; however, it is highly reported across the literature to be a significant "unmet need" by

these struggling parents (Altiere & von Kluge, 2009; Brown et al., 2010; Nealy, O'Hare, Powers, & Swick, 2012; Silva & Schalock, 2012). From the beginning, when signs of ASD begin to present themselves in children, parents spend years transitioning from professional to professional in hope of receiving answers on why their child displays these atypical behaviors, but oftentimes, professionals do not initially suspect a developmental disability and assume the behaviors to be the result of poor parental discipline (Altiere & von Kluge, 2009; Braddock & Twyman, 2014; Dabrowska & Pisula, 2010; Moh & Magiati, 2012; Mooney, Gray & Tonge, 2006; Nealy et al., 2012; Silva & Schalock, 2012). Therefore, parents of children with ASD report significant issues in obtaining a prompt, formal diagnosis, as this process is usually delayed, and this results in worried parents who experience heightened stress levels caused by the uncertainty of their child's situation and significant trouble developing coping strategies (Goddard, Lehr, & Lapadat, 2000; Goin-Kochel, Mackintosh, & Myers, 2006; Osborne & Reed, 2008; Quine & Pahl, 1987).

According to an investigation of the communication between parents of children with ASD and professionals, the majority of formal ASD diagnoses are made by a medical practitioner (i.e., doctor, primary care provider) (Osborne & Reed, 2008); therefore, it can be assumed that these professionals play a crucial role in supporting parents upon disclosure of the child's diagnosis (Brogan & Knussen, 2003). Primary care professionals (PCPs), who lack knowledge on the management of the atypical characteristics of ASD (Carbone, Behl, Azor, & Murphey, 2010), are often challenged to provide options for treatment, locate sources of support, and teach and behavior management strategies (Chiri & Warfield, 2012). As a result, parents report dissatisfaction with PCPs as they fail to provide family-focused intervention (Montes & Halterman, 2011), which was further validated by Russesl and McCloskey's (2016) study

participants, who reported feelings of anger as PCPs made false accusations and judgmental remarks when parents voiced their concerns. Additionally, these parents reported that PCPs led them to experience guilt. They felt as if they were to blame for their child's behavior, and as a result, reported a lack of confidence in requesting advice/information from their child's PCP. Although they were praised for providing empathy, a sense of understanding, and compassionate care to the child and his/her family, PCPs are typically only consulted on topics of physical health/medical needs. However, when PCPs took the time to listen and incorporate parental concerns/suggestions into treatment plans, parents felt further respected and valued by their child's doctor. In conclusion, this study claims that "PCPs are the initial gatekeepers of diagnosis" when it comes to identifying children with ASD. However, the assistance of local resources and alternative service providers is highly valued by parents when PCPs lack the knowledge, skills, and expertise to provide these parents with the information and support they need (Russell & McCloskey, 2016, p. 29).

Overall, parents desire a quick and efficient process for obtaining an ASD diagnosis initially (Goin-Kochel, Mackintosh, & Myers, 2006; Mansell & Morris, 2004; Osborne & Reed, 2008), and when they finally receive a diagnosis, parents claim that health care providers are not providing them with the support, education, and information on ASD that they need to manage challenging behaviors, obtain services, and effectively care for their child (Bonis, 2016; Osborne & Reed, 2008; Renty & Roeyers, 2006). Additionally, parents feel that professionals often lack training and knowledge on ASD, and it is difficult for them to locate qualified clinicians who provide individualized care that is specific to their child's needs (Altiere & von Kluge, 2009; Bonis, 2016; Brown et al., 2010; Nealy et al., 2012; Osborne & Reed, 2008; Renty & Roeyers, 2006; Silva & Schalock, 2012) Bonis (2016) found that professionals play a key role in the

support and stress management of parents of children with ASD, and they must develop and implement programs that promote parental decisions to use support services available to them. According to Derguy and colleagues (2015), professional guidance is required—as a source of relational and emotional support—not only for obtaining information on ASD. Overall, Bonis (2016) concludes that the "cumulative effect of early diagnosis, access to services, and parental stress self-management" leads to positive life outcomes for both the parent and child (p. 160).

SLPs. Speech-language pathologists (SLPs), professionals who assess and treat the social and communication deficits in children with ASD (Australia, Speech Pathology, 2010), also serve as a source of formal support to parents. Behind medical practitioners and psychologists, SLPs are reported by parents to be the third most common professionals to provide an ASD diagnosis (Osborne & Reed, 2008), and speech therapy was found to be the most commonly used type of ASD treatment parents use (Green et al., 2006). Green and colleagues' (2006) internet survey yielded that 70% of the participating parents reported to be currently using speech therapy services, and another 23% noted that their children had previously received this treatment type. Therefore, because speech therapy services are widely used by this population, SLPs are in an optimal position to promote parental involvement and an "intimate reciprocal relationship," in order to promote positive treatment outcomes for the child with ASD (Carroll, 2010, p. 353; Glogowska, Campbell, Peters, Roulstone, & Enderby, 2001; Royal College of Speech and Language Therapists (RCSLT), 2006; Watts Pappas & McLeod, 2009). It has been found that SLPs believe parent involvement is essential to positive treatment outcomes, and specifically, a survey of SLPs by Pappas, McLeod, McAllister, and McKinnon (2008) reported SLPs' workplace as the most influential factor impacting parental involvement in therapy. SLPs working in a school/educational setting were much less likely to have a caregiver involved in

their children's therapy sessions, when compared to SLPs working in private practices and other medical-based therapy settings. Therefore, the setting in which the child receives therapy may be a potential barrier to the amount of communication with the child's SLP (Pappas et al., 2008)—likely impacting the opportunity for he/she to be a successful source of social support. However, by identifying and overcoming barriers, multiple research studies have found that parents who have a positive relationship with their child's health care provider (e.g. SLP) experience heightened levels of satisfaction with the services provided, and as a result, are less stressed (Altiere & von Kluge, 2009; Meadan et al., 2010; Moh & Magiati, 2012; Rivard et al., 2015).

Based on these recommendations and an in-depth review of the current literature, SLPs play a critical role in the diagnosis and treatment of ASD in school-aged children, and additionally, SLPs' specialization in communication underlies their professional obligation to provide social support to parents of children with ASD. In order to do so, SLPs must first identify the needs, expectations, and stressors these parents struggle with, and then, assist in the alleviation of their heightened stress levels by exploring beneficial ways to serve as a source of formal support. As a result, when collaboration is promoted, education is provided, and compassion is displayed by these professionals, both toward the parent and the child, family-centered services are delivered and positive treatment outcomes will most likely result.

Chapter 3

Justification

The theoretical construct of therapeutic alliance is evidence-supported and serves as the basis for clinician-client relationships in the psychotherapeutic realm, but aspects of this concept also provide a solid foundation for the importance of a positive therapeutic relationship between the clinician and the client's parents. Children with ASD receive therapy services from a number of different professionals across various settings, including speech-language pathologists, occupational therapists, developmental psychologists, behavioral therapists, etc. Because at least one SLP is usually present in every school, SLPs are standard members of the treatment team for every school-aged child with ASD, but based on the previous literature, this setting may be a barrier for the communicative efficiency between therapists and caregivers. However, SLPs provide services in the communicative realm, they should be one of the service providers responsible for breaking down these barriers, investigating available options, and providing parents with sources of social support.

Stress and depression are two critical variables that lead parents of children with ASD to seek social support (Wolf et al., 1989), and therefore, effective intervention should focus on remediating the child's characteristics of ASD and alleviating the stress level of the parents, by providing them access to multiple sources of social support. Therapeutic service providers must be able to provide a continuum of support services to families, and by giving these parents an array of options to choose from, it is likely that they will find a support system that meets the

specific needs of their family (Boyd, 2002). By helping these parents learn to cope with their child's challenging characteristics, they will likely feel more confident in their parenting abilities and experience decreased levels of stress (Papageorgiou & Kalyva, 2010).

To further examine what types of social support would be most beneficial to these parents and implement intervention strategies that benefit both the child with ASD and his/her family, service providers, specifically SLPs, information is needed on the needs, expectations, perceptions, and desires of these parents. Through this knowledge, professionals in the field of communication disorders will be more successful in meeting familial needs by helping them accept their child's condition, cope with the stressors it may cause, and adapt to parenting a child with ASD.

The aim of the current study is to determine facilitators and barriers that contribute to the therapeutic relationship between parents of school-aged children with autism spectrum disorder (ASD) and their child's speech-language pathologist (SLP). Because the levels of stress that parents of children with ASD experience may be impacted by the resources available to them, such as social support, an additional research aim is to investigate the relationships between these variables and parental stress levels. Further, because the majority of employed SLPs are providing services in the school setting, the current study will also explore whether the child's therapy setting impacts the quality of the working alliance between the primary caregiver and the therapist. As researchers have found that bonds begin very early in the therapeutic relationship, a final aim is to investigate whether similar results will extend to this population. This study will provide professionals in speech-language pathology and related fields with valuable information and recommendations to incorporate into family-centered intervention for school-aged children with ASD. Specifically, the research study hopes to answer the following questions:

1. What element of a positive therapeutic relationship is most valued by primary caregivers of children with ASD?
    - Hypothesis – Participants will value all elements queried—goals, tasks, bond—with *tasks* leading to "effective therapy" and "positive outcomes" to be ranked as most important (Edwards et al., 2016).
2. Is there a relationship between caregiver views of the therapeutic relationship and their reported stress levels?
    - Hypothesis – A negative linear relationship will exist – Primary caregivers who indicate positive relationships with their child's SLP will report decreased stress levels, and those indicate poor relationships will report higher stress levels.
3. Is there a relationship between the setting in which the child receives speech therapy services and the degree of therapeutic alliance between the child's caregiver and SLP?

    Hypothesis—Primary caregivers of children receiving services from a school-based SLP will report a weaker therapeutic alliance between themselves and the child's therapist, when compared to those whose children receive therapy in a medical setting (Pappas, McLeod, McAllister, & McKinnon, 2008).

Chapter 4

Method

Participants

A total of 90 respondents completed the survey. To meet inclusion criteria, respondents were primary caregivers of children with ASD between the school grades of Kindergarten and fifth grade. Participants' children were required to be currently receiving speech-language intervention. Individuals who did not meet inclusion criteria were taken to the end of the survey.

Materials

To answer the questions of the study, the investigators created an electronic, web-based, 59-item survey via Qualtrics software (see Appendix 2) to address questions in five main areas: (I) Background/Demographic Information, (II) Factors Influencing the Therapeutic Relationship, (III) Adapted Version of the Working Alliance Inventory-Short Revised , (IV) Parental Stress Scale, and (V) Social Support.

· Part I questions were designed to acquire background and demographic information on the primary caregiver and his/her child, by asking questions regarding the child's diagnosis, the type of school he/she attends, the length of time the child has been treated by his/her current SLP, who the child lives with, etc.

· The question in Part II addressed factors contributing to the therapeutic alliance by inquiring about the caregivers' views on topics such as goals, tasks, and the relationship/bond between

parent and SLP. Participants were asked to rate the value they place on these factors via a sliding scale.

· Part III consisted of 12 questions adapted from the *Working Alliance Inventory- Short Revised (WAI-SR)* per permission from the Society for Psychotherapy Research (2016). This measure was created by Adam Horvath as a short and simplified version of the 36-item *Working Alliance Inventory*, which was published in 1989, also to assess therapeutic alliance. The original WAI was based on Bordin's theory; however, the *WAI-SR* was designed to be a quick and easy instrument for assessing three main areas of the therapeutic alliance, "(a) agreement on the tasks of therapy, (b) agreement on the goals of therapy, (c) development of an effective bond" (Munder, Wilmers, Leonhart, Linster, & Barth, 2010, p. 231). Munder and colleagues (2010) compared this measure to the *Helping Alliance Questionnaire* to assess the validity and reliability of the revised instrument. Their study results suggested good reliability and convergent validity of the instrument, and also, they reported good confirmatory factor analysis of the *WAI-SR* in its ability to distinguish between and adequately assess Bordin's three domains. To expand on investigations that examined the efficacy of this measure for only English-speaking individuals, Munder and colleagues' investigation assessed German respondents and found it to be an adequate measure for examining non-English speaking patients as well, receiving inpatient and/or outpatient care (2009). Because much research has been conducted to confirm the psychometric properties of the *WAI-SR*, and it has been deemed appropriate for assessing a broad population, this measure was included in the current study's survey. However, for this study's intended participant population, the questions were adapted to be answered using a caregiver's perspective of the relationship, rather than the child/client's view of the relationship.

· Part IV questions came directly from *The Parental Stress Scale* developed by Berry and Jones (1995). The two authors developed this brief, 18-item scale as an alternative to the *Parenting Stress Index,* which consists of 101 items. Part IV consisted of these 18 statements, and the participants either agree or disagree with each statement, using a 5 point scale, in terms of their relationship with their child. This section of the survey was preceded with specific instructions adapted from the original instrument by Berry and Jones. It has certain advantages over other stress scale evaluation instruments, as it measures the specific construct of interest, and is appropriate for determining the stress levels of both mothers and fathers of children with and without disabilities (Berry & Jones, 1995).

· Part V questions addressed the caregivers' use of social support, and the question specifically asked the participant to identify which sources of social support they currently use to cope with caring for a child with ASD. Further, the participant is asked to identify which, if any, sources of social support have been initiated and/or recommended by their child's SLP.

Procedure

Prior to the distribution of the survey, an initial draft was piloted by two faculty members with an expertise in ASD to provide feedback about the survey's content and format. Per their suggestions, survey questions were added to address estimated frequency of communication between SLP and caregiver and the context in which the child with ASD receives speech therapy treatment. For the current investigation, participants were recruited by contacting state autism societies and autism-specific organizations in each of the 50 states. Upon an initial query of support via email, the researcher confirmed agreement of participation from two or more states in each of the four major regions of the United States, as indicated by the U.S. Census Bureau (2010). Massachusetts and New Jersey in the Northeast; Michigan, Wisconsin, Iowa, Kansas,

Minnesota, Missouri, and North Dakota in the Midwest region; Florida, Virginia, Alabama, and Tennessee confirmed in the South; and California, Hawaii, and Idaho from the West agreed to help recruit for the current study.

Upon approval from the Auburn University Human Research Protection Program, the researcher sent an introductory e-mail (Appendix 1) to the coordinators of the consenting autism societies or autism-specific outreach. The email sent to the agencies allowed each *Autism Society* or organization to individually decide how they dispersed the information letter and embedded survey link to potential participants. When potential participants clicked on the embedded link, they were directed to an alternate version of the survey in which the first question was the information letter; participants were instructed to indicate their consent by selecting either "yes" or "no" and continuing the survey.

Additionally, a message containing a brief description of the survey and its purpose was posted on the primary investigator's Facebook page. The post was made public so that it could be shared by anyone on Facebook. An invitation to participate was also shared on 79 Facebook pages and online support groups for families of children with ASD in which the primary investigator and/or faculty advisor were members. All data was collected anonymously. A total of 148 individuals initiated the survey. Results were then filtered for survey completion. While response rates could not be calculated due to the recruitment methods, a total of 90 participants met inclusion criteria and completed the survey. With regard to recruitment measures, the majority (87.8 %; n = 79) of participants indicated they were informed about the survey opportunity via Autism support groups and Autism awareness pages on Facebook. Five (5.6%) respondents stated they learned of the survey through their local *Autism Society* webpage, 1 (1.1%) saw the link on an *Autism Society*'s newsletter, and 1 (1.1%) learned of the survey

through an invitation email from the *Autism Society* developed in the state in which they reside. Four (4.4%) respondents indicated they heard of the survey from other local, Autism-related advocacy groups/organizations.

Chapter 5

Results

Data Analysis

Upon closing the survey, survey responses were exported to an excel spreadsheet and SPSS for analysis. In total, 90 respondents initiated the survey, met inclusionary criteria, and completed the survey. In cases where some participants chose not to respond to a question, the mean responses were calculated using the number of respondents who responded to that item, as opposed to the number who completed the survey.

Background Information

Demographics of caregivers. With regard to the respondents' relationship as the primary caregiver to the school-aged child with ASD, almost all participants (97.8%; *n* = 88) responded "mother;" while one participant (1.1%) responded "father," and one participant (1.1%) responded "non-biologically related custodial caregiver." It should be noted that one participant did not answer this question. The responses of this participant continued to be included for analysis as they indicated being the "mother" of a child with ASD in a later question. The age of primary caregiver respondents ranged from the "19 years or younger" category to the "50-54 years old" category, and the greatest number of participants indicated they were "35-39 years old" (24.4%; *n* = 22) or "40-44 years old" (24.4%; *n* = 22) (see Table 1). When asked to indicate if they were of "Hispanic, Latino, or Spanish origin," 84.4% (*n* = 76) primary caregivers answered "No," while 15.6 % (*n* = 14) selected "Yes."

Next, the respondents were asked to provide their race and were specifically instructed to "select all that apply." The majority of respondents 84.4% (*n* = 76) selected only the "White" option (see Table 1). The final demographic asked specifically to and about the primary caregivers themselves was with regard to their current marital status, and the majority (86.7%; *n* = 78) of participants indicated they were married (see Table1).

Table 1

Participant Demographics

Category	*n* (%)
Age	
19 years or younger	1 (1.1%)
20-24 years	0 (0%)
25-29 years	9 (10%)
30-34 years	20 (22.2%)
35-39 years	22 (24.4%)
40-44 years	22 (24.4%)
45-49 years	13 (14.4%)
50-54 years	3 (3.3%)
55-59 years	0 (0%)
60-64 years	0 (0%)
Older than 64 years	0 (0%)
Race	
White (only)	76 (84.4%)
Black or African American (only)	3 (3.3%)
Native American or Other Pacific Islander (only)	0 (0%)
Asian (only)	1 (1.1%)
American Indian or Alaska Native (only)	2 (2.2%)
Other or Mixed Race	8 (8.9%)
Marital Status	
Married	78 (86.7%)
Committed partnership (not married)	4 (4.4%)
Widowed	1 (1.1%)
Divorced	5 (5.6%)
Separated	2 (2.2%)
Never Married	0 (0%)

Note: N = 90; *n* = number of respondents; % = percentage of respondents

Residency. With regard to the location in which participants were currently residing, participants represented the four main demographic regions according to the 2010 United States Census: South, Midwest, Northeast, and West. The largest percentage of participants reported residence in the South, followed by the West, Midwest, and Northeast. (see Table 2).

Table 2

States in Which Participants were Currently Residing

Area of Residence	*n* (%)
South	**45 (51.1)**
Alabama	10 (11.4)
Arkansas	1 (1.1)
Florida	3 (3.4)
Georgia	5 (5.7)
Maryland	2 (2.3)
North Carolina	11 (12.5)
South Carolina	4 (4.6)
Tennessee	3 (3.4)
Texas	2 (2.3)
Virginia	2 (2.3)
West Virginia	2 (2.3)
Midwest	**11 (12.5)**
Illinois	3 (3.4)
Iowa	1 (1.1)
Michigan	3 (3.4)
Minnesota	1 (1.1)
North Dakota	1 (1.1)
Ohio	1 (1.1)
Wisconsin	1 (1.1)
Northeast	**7 (8.0)**
Massachusetts	1 (1.1)
New Jersey	2 (2.3)
New York	2 (2.3)
Pennsylvania	1 (1.1)
Rhode Island	1 (1.1)
West	**25 (28.4)**
Arizona	13 (14.8)
California	6 (6.8)
Oregon	5 (5.7)
Washington	1 (1.1)

Note: N = 88; *n* = number of respondents; % = percentage of respondents

Further, respondents were asked to describe the location in which they currently reside, given three options, "urban," "rural," or "suburb." The majority of participants reported "suburb," (54.44%; *n* = 49) followed by "urban," (27.8%; *n* = 25) and "rural" (17.8%; *n* =16).

Demographics of children. Participants were also asked demographic questions about their child with ASD. With regard to elementary school grade level, the most frequently chosen grade indicated was "Kindergarten," followed by "2nd grade," and the smallest number of respondents indicated they had a child with ASD in the "5th grade" (see Figure 1). Of the 89 participants who answered the question regarding their child's age, the greatest number of respondents indicated their child was "5 years old," followed by "7 years old," and the least number of respondents indicated having a child with ASD who was "12 years old" (see Figure 2).

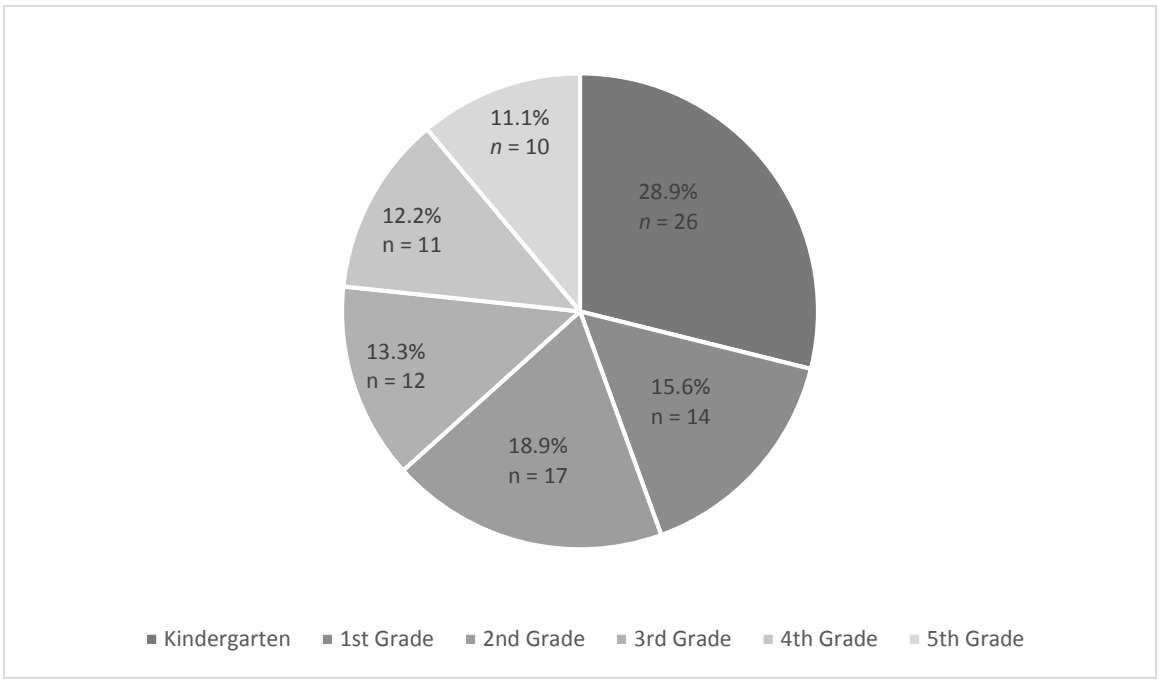

Figure 1. Current grade level of participants' children with ASD

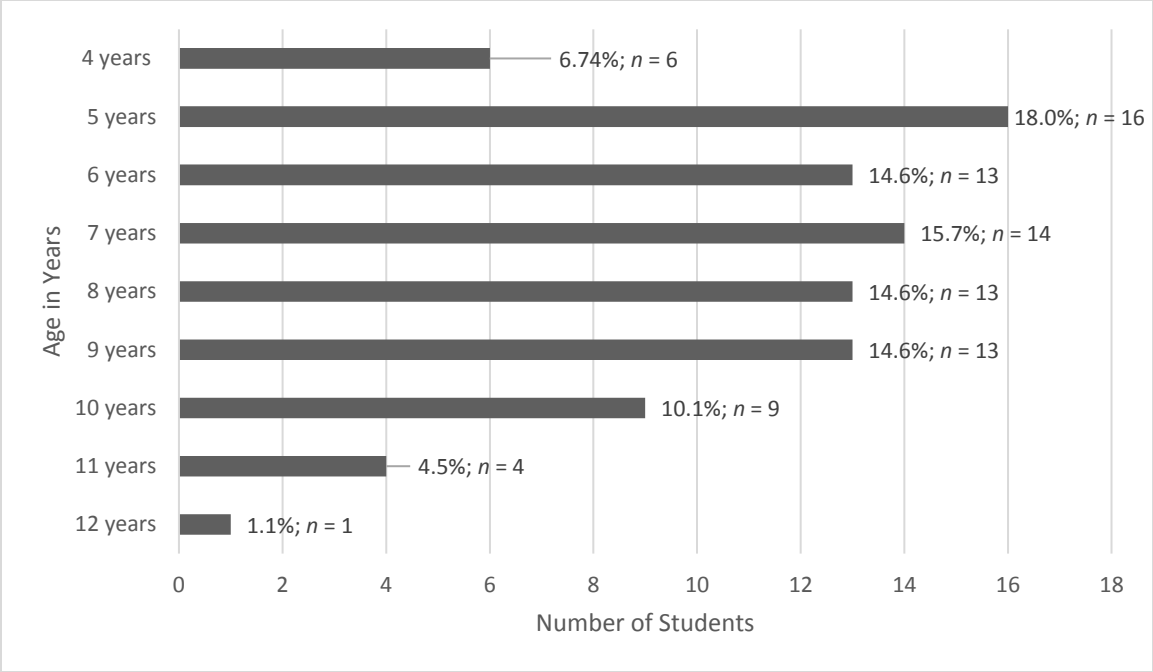

Figure 2. Current age of participants' children with ASD

Parents were also asked to indicate their child's sex, race, and if their child was of "Hispanic, Latino, or Spanish origin." Of the 90 respondents, 75.6% (*n* = 68) indicated their child with ASD was a male, and 24.4% (*n* =22) indicated having a female child with ASD. With regard to race, again, "White" was most frequently selected, with 81.2% (*n* = 82) respondents choosing this option. Also, primary caregivers were asked to "select all that apply," 84.4% (*n* = 76) selected only "White," 4.4% (*n* = 4) selected only "Black or African American;" one respondent (1.1%; *n* = 1) selected "Asian" only; and 10% (*n* = 9) selected more than one option and/or "Other." Further, 83.3% (*n* = 75) reported their child was not of "Hispanic, Latino, or Spanish origin," and 16.7% (*n* = 15) selected "Yes" in response to this question.

ASD diagnosis. When queried about their child's ASD diagnosis, one respondent did not answer the question to indicate his/her child had a diagnosis of ASD; however, this participant's answers were still included in the investigator's analyses because the same respondent later provided information on who gave their child the diagnosis and the amount of time that had

passed since a diagnosis was provided. With regard to further diagnosis details, the majority of the 90 respondents indicated their child received the ASD diagnosis from a "psychologist/developmental psychologist" (57.8%; *n* = 52). Almost a quarter of the respondents indicated that a diagnostic team provided the diagnosis of ASD for their child (24.4%; *n* = 22) while 9 respondents (10%) stated their child was diagnosed with ASD by their "primary care physician/pediatrician." Additionally, 7 (7.8%) respondents selected "other" and provided, in text, that the diagnosis was made by one of the following: a developmental or behavioral pediatrician (3.3%, *n* = 3), a neuropsychologist (1.1%; *n* = 1), or the child's school district (1.1%; *n* = 1). Two (2.2%) respondents provided "other" with no further "in-text" details. No participants (*n* = 0) indicated that an SLP made the diagnosis.

With regard to the amount of time that had passed since their child received a diagnosis of ASD, the greatest percentage of respondents (18.0%; *n* = 16) indicated "approximately 5 years" had passed since the diagnosis was made. Further, the majority (62.2%; *n* = 56) of participants responded within the "approximately 2 years" to "approximately 5 years" estimation range. No participants (*n* = 0) reported that "more than 10 years" had passed since their child was diagnosed with ASD (see Figure 3).

Speech therapy. Participants were also asked to estimate the amount of time their child had been receiving speech-language therapy. Again, the greatest number (19.1%; *n* = 17) of respondents selected "approximately 5 years," with the largest percentage (61.1%; *n* = 55) of participants responding within the "approximately 2 years" to "approximately 5 years" estimation range. No participants (*n* = 0) reported that their child had had "approximately 10 years" or "more than 10 years" of speech-language therapy (see Figure 4).

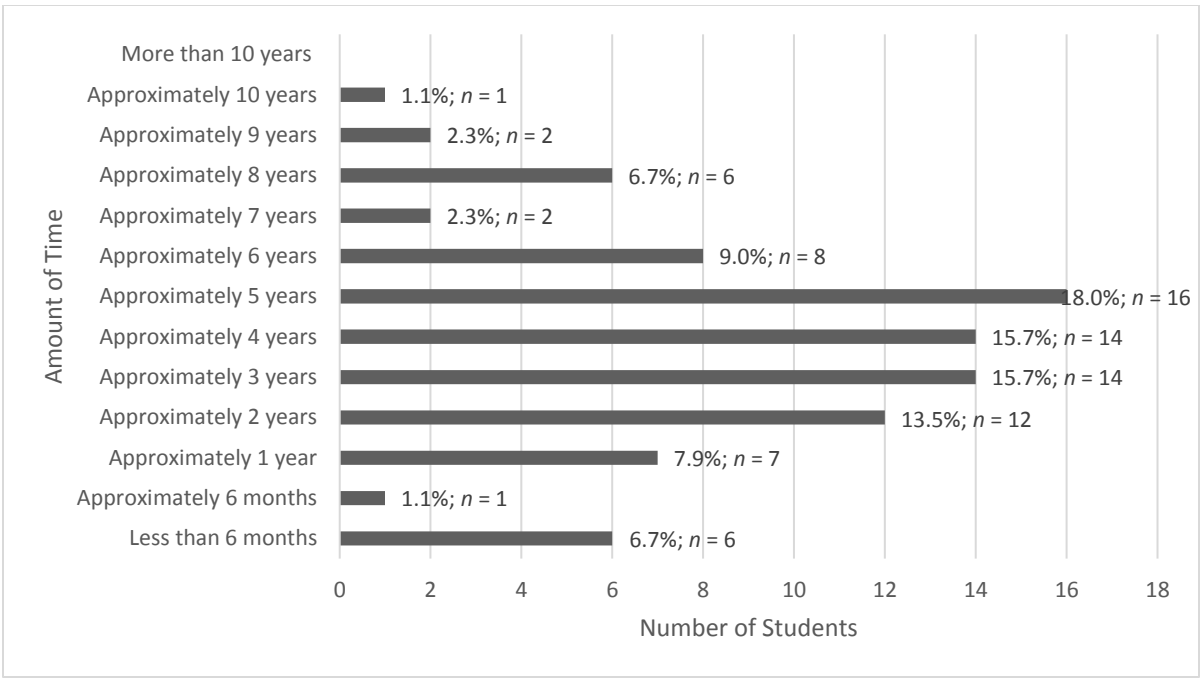

Figure 3. Time passed since participants' child received a diagnosis of ASD

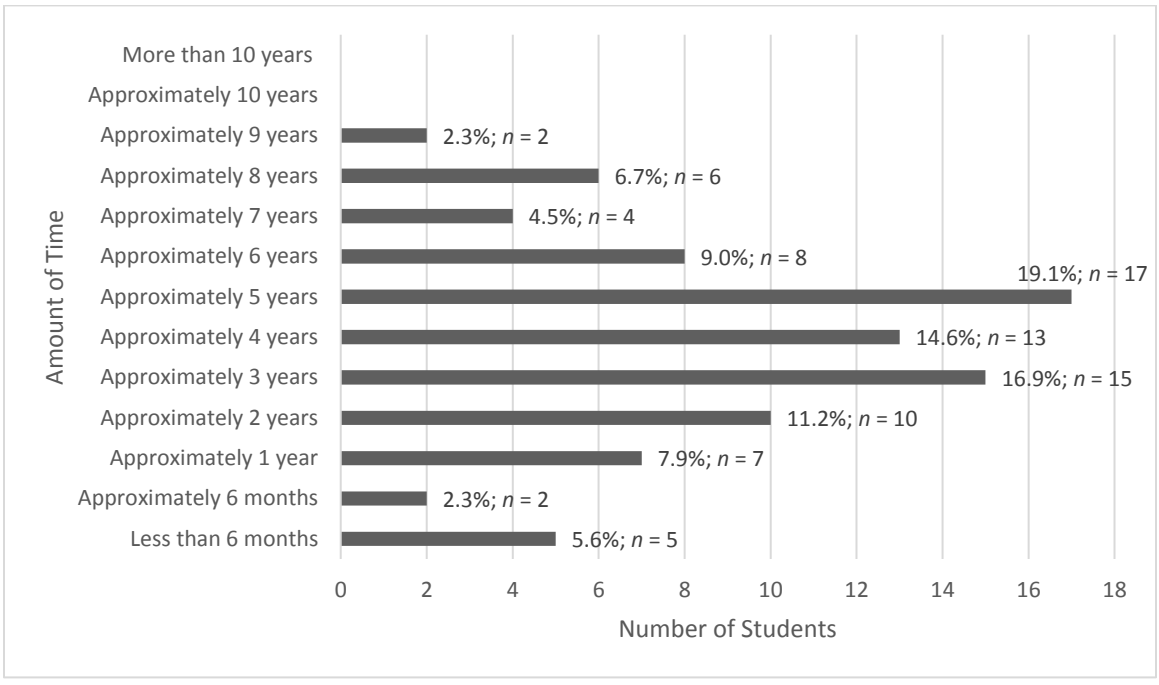

Figure 4. Time participants' children with ASD have been receiving speech therapy

Details regarding speech-language pathologist. Caregivers were queried with regard to the setting, context, time with, and communication frequency with his/her child's speech-

language pathologist. The greatest number of respondents indicated their child receives speech/language services, from the indicated SLP, within the "public school," and this setting was closely followed by "private practice," with one-third of respondents choosing this option. No participants indicated their child with ASD received therapy from the indicated SLP at a "university clinic." Respondents who indicated "other" indicated their child received speech therapy by a single speech-language pathologist in settings such as a "private practice and public school," "home," and "Autism Charter." (see Figure 5). Primary caregivers were also asked to provide the context in which their child receives speech-language therapy from the specific speech-language pathologist he/she has had in mind since beginning the survey. The majority of respondents indicated their child receives services only in a "one-on-one" context, followed by "one-on-one & in the classroom," and the least amount of participants chose the "in the classroom & in a group outside of the classroom" option (see Table 3). With regard to the time the primary caregivers indicated their child with ASD had been receiving therapy from the indicated speech-language pathologist, the greatest percentage (43.3%; $n = 39$) revealed "more than 1 year;" 10% ($n = 9$) reported "approximately 1 year," and 10% ($n = 9$) also reported "approximately 6 months." Further, 23.3% ($n = 21$) stated their child had been receiving therapy from this SLP for "approximately 3 months;" 8.9% ($n = 8$) indicated "approximately 1 month," and 4.4% ($n = 4$) indicated "less than 1 month." When asked to describe their communication frequency with their child's SLP, one-third of respondents reported to speak with the therapist "1 time per week," and the lowest percentage of respondents indicated "I have never spoken to my child's SLP" (see Table 4).

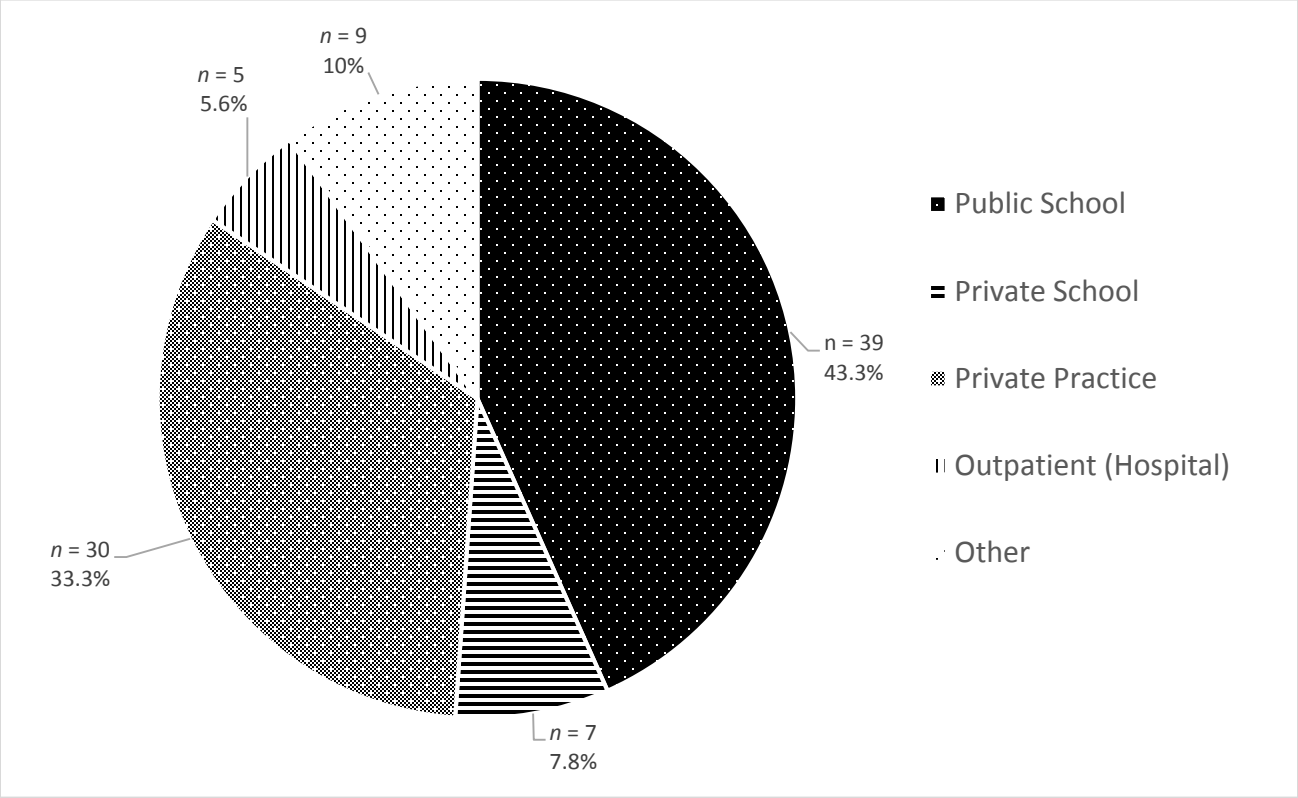

Figure 5. Setting in which participants' children receive speech-language therapy

Table 3

Context in which Child with ASD Receives Speech-Language Therapy

Context	%	*n*
One-on-one	55.6	50
One-on-one & In the classroom	17.8	16
One-on-one & In a group outside of the classroom	7.8	7
One-on-one, In the classroom, & In a group outside of the classroom	6.7	6
In a group outside of the classroom	5.6	5
In the classroom	3.3	3
I am unsure of the context in which my child receives speech-language therapy	2.2	2
In the classroom & In a group outside of the classroom	1.1	1

Note: N = 90; *n* = number of respondents; % = percentage of respondents

Table 4

Communication Frequency (in person OR on the phone) between Primary Caregivers and SLPs

	%	*n*
Multiple times per week	14.4	13
1 time per week	33.3	30
1 time per month	15.6	14
1 time per semester (one-half of a school year)	18.9	17
1 time annually	10	9
I have never spoken to my child's SLP	7.8	7

Note: N = 90; *n* = number of respondents; % = percentage of respondents

Child's intellectual and verbal abilities. Participants were also asked to describe their child's intellectual and verbal abilities, given 4 options with corresponding descriptions. With regard to intellectual ability, the greatest percentage of respondents (41.1%; *n* = 37) felt their child with ASD demonstrated "Below average" in this domain, while 24.4% (*n* = 22) indicated "Above average;" 21.1% (*n* = 19) indicated "Average;" and 13.3% (*n* = 12) indicated "Significantly below average" intellectual abilities for his/her child with ASD. When queried as to their child's level of verbal ability, primary caregivers most frequently reported their child to be "Below (45.6%; *n* = 41), while 34.4% (*n* = 31) of respondents indicated their child's verbal abilities were "Significantly below average" verbal abilities, 11.1% (*n* =10) indicated "Average," and 8.9% (n = 8) indicated their child's verbal abilities were "Above average."

Reason for not receiving speech therapy. Ten respondents began the survey, but were unable to be included in the study because they indicated their child with ASD was not currently receiving speech-language therapy. Once this was indicated, one further question was asked before these respondents were taken to the end of the survey—"Why is your child with ASD not currently receiving speech therapy by a speech-language pathologist?" The greatest number of respondents indicated one of the two following answer choices: "My child met his/her treatment

goals and was discharged from speech therapy" and "I do not believe that my child needs speech therapy at this time." No participants indicated "I do not have transportation to take my child to speech therapy" or "I removed my child from speech therapy because I did not have a good relationship with his/her speech-language pathologist" as the reason for discontinuing speech therapy for their child with ASD (see Table 5).

Table 5

Reasons for Children with ASD Not Receiving Speech-Language Therapy

Response	%	*n*
My child met his/her treatment goals and was discharged from speech therapy.	30	3
I do not believe that my child needs speech therapy at this time.	30	3
My child is taking a "break" from speech therapy services.	10	1
I cannot afford for my child to receive speech therapy.	10	1
I removed my child from speech therapy because he/she was not making progress.	10	1
Other ("Waiting on evaluations to determine how many times a week it will be needed")	10	1
I removed my child from speech therapy because I did not have a good relationship with his/her speech-language pathologist.	0	0
I do not have transportation to take my child to speech therapy.	0	0

Note: N = 10; *n* = number of respondents; % = percentage of respondents

Factors Contributing to the Therapeutic Alliance

Seventy-seven (85.6%) of the ninety primary caregivers ranked the following factors, which contribute to therapeutic alliance, with regard to their importance in the child's speech therapy: the child's goals, the tasks/activities in therapy, and the bond/relationship between themselves and their child's SLP. Participants were instructed to move the sentences to rank them in order of importance, with (1) being the most important and (3) being the least important factor in their child's speech therapy. The greatest number of respondents indicated the tasks/activities their child's SLP uses in speech therapy with their child as most important,

followed by goals, and finally, the bond/relationship with the child's SLP was indicated as the least important factor of the three (see Figure 6).

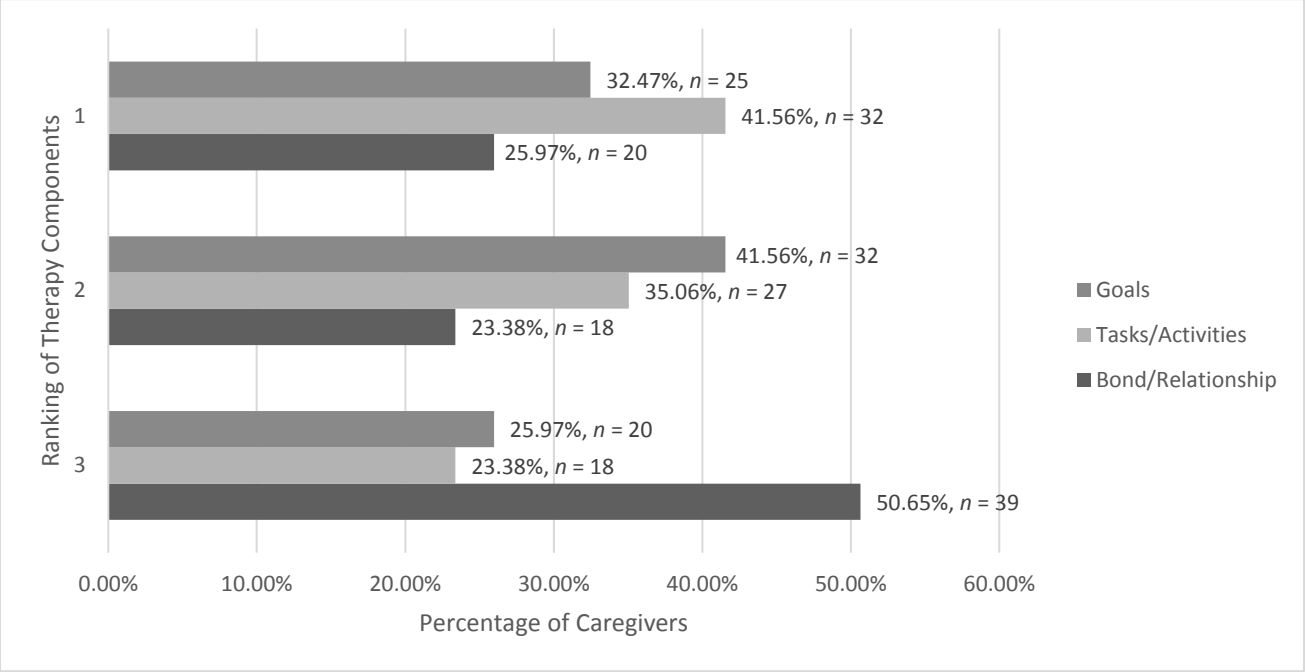

Figure 6. Components of therapy—Goals, Tasks, and Bond—ranked in order of importance by primary caregivers
Note: 1 = most important; 3 = least important

Working Alliance Inventory-Short Revised (WAI-SR)

The *Working Alliance Inventory- Short Revised* consisted of twelve questions, which per permission of the original author, were adapted to fit the participant population of the current study; however the same multiple choice options were provided: "*Seldom, Sometimes, Fairly Often, Very Often,* and *Always.*" Of the twelve questions asked, in a random order, four were focused on the caregivers' view of and agreement with the child's speech therapy goals, four were asked with regard to the caregivers' feelings toward the therapy tasks their child's SLP implements, and four were used to gain a clearer idea of the caregivers' depiction of the bond/relationship he/she has with his/her child's SLP. The scoring key provided for the shortened, adapted version of the WAI, by Hatcher-Gillaspy, was used to calculate the

respondents' scores, given the fact that a numeric value corresponds to each multiple choice option provided. Only 85 of 90 respondents answered all questions of the WAI-SR and PSS; therefore the five who did not answer all questions of both measures were excluded from further analyses. A numerical score was obtained, and the higher the score, the stronger the participant views the working alliance he/she shares with their child's SLP.

Participants' scores for this portion of the survey ranged between 12 and 60, with a mean of 41.99 and a SD of 12.55. With regard to the three question categories included in the WAI-SR (goals, tasks, bond/relationship), after totaling all participants' scores in each domain and determining averages for each, the category with the greatest mean score was the "bond" component of the WAI-SR. This result provides that participants of the current study feel the strongest agreement/alliance with their child's SLP when it comes to the "bond," followed by "goals" and lastly, the "tasks" (see Table 6).

Table 6

Descriptive Statistics of the WAI-SR

Categories of the *WAI-SR*	M	*SD*
WAI-SR (total score)	41.99	12.55
Goals	14.13	4.81
Tasks	13.13	3.85
Bond	14.73	5.01

Note: N = 85; M = mean; SD = standard deviation.

Parental Stress Scale (PSS)

This part of the survey consisted of 18 statements focused on feelings toward parenting. Primary caregivers were instructed to read the statements and indicate the degree which they agree or disagree with the statement provided, given the following multiple choice options on a 5 point scale : "*Strongly Agree, Agree, Undecided, Disagree,* or *Strongly Disagree*." Possible

scores on the PSS range from 18 to 90, with a score between 18 and 41 noting a low level of stress, a score between 42-65 indicating a moderate level of stress, and a score between 66 and 90 indicating a high stress level (Mathur, 2014). The participants' scores in the current study ranged from 18 to 67, with a mean of 42.1 (SD = 10.6), indicating on average these parents suffer from mild stress according to this assessment instrument. However, the range indicates individual parents demonstrated mild to severe stress levels.

Social Support

The final two questions inquired about the primary caregivers' use of social support, and when asked to select all types he/she currently confides in, the 90 respondents provided a total of 467 responses. This reveals that caregivers of school-aged children with ASD typically use more than one source of social support. The most frequently selected option in the current study was *spouses (husband, wife*), followed by *other parents of children with ASD, friends*, and *family members.* The least frequently chosen options was, "*I do not use any source of social support*," with only 3 respondents selecting this choice (see Table 7).

A McNemar Test of dependent proportions was conducted in SPSS to determine whether caregivers used informal sources of social support more than formal sources. These two variables were collapsed from an original 11 in the survey as follows: informal (i.e., spouses, family members, extended family members, co-workers, religious groups, friends, other parents of children with ASD) and formal (i.e., respite care, ASD parent support group, health care providers, speech-language pathologist). In addition three-text entries were considered to be formal in nature (i.e., ABA therapist, counseling services, Facebook autism group) and included in this category. Ninety-four percent (94%) of caregivers reported indicated they used informal social support, while 72% indicated they used formal sources of social support. While this

indicates the majority use both formal and informal supports, significantly more caregivers used informal sources, $p = .000$.

The final question asked the caregiver to select all types of social support recommended and/or initiated by the child's SLP, and the 90 respondents selected a total of 113 options, and almost three-quarters of the participants reported, "*My child's SLP has never initiated or recommended any type of social support to me*." Of those caregivers who reported their SLP recommended and/or initiated social support for the family, the highest percentage (15.6%) reported referral to "ASD-specific health care providers and/or therapy providers." One respondent that selected "*Other*" typed "*None, but if they did it would be highly unlikely I would use it"* in the text box provided (see Table 8).

Table 7

Sources of Social Support

Sources of Social Support	%	*n*
Spouse (husband, wife)	75.6	68
Other parents of children with ASD	68.9	62
Friends	64.4	58
Family members	62.2	56
ASD parent support groups	58.9	53
Extended family members (e.g. child's grandparents)	53.3	48
Health care providers (e.g. physician, psychologist, etc.)	33.3	30
Speech-language pathologist	30.0	27
Religious groups	23.3	21
Respite care services	22.2	20
Co-workers	18.9	17
Other	4.4	4
I do not use any source of social support	3.3	3

Note: N = 90; *n* = number of respondents; % = percentage of respondents

Table 8

Sources of Social Support Initiated/Recommended by SLP

Sources of Social Support	%	*n*
My child's SLP has never initiated or recommended any type of social support to me.	71.1	64
My child's SLP refers me to ASD-specific health care providers and/or therapy providers.	15.6	14
My child's SLP has offered to educate/train my spouse on how to support myself and my child with ASD.	14.4	13
My child's SLP has offered to educate/train other individuals in my life (e.g. family members, friends, co-workers, and religious groups) on how to support myself and my child with ASD.	11.1	10
My child's SLP has helped me locate ASD parent support groups.	8.8	8
My child's SLP has helped me locate respite care services.	2.2	2
Other	2.2	2

Note: N = 90; *n* = number of respondents; % = percentage of respondents

Correlational Data

In the current study, 85 of 90 participants answered all questions of the PSS and WAI-SR; therefore, comparative analyses of data was calculated only for those who completed both measures ($n = 85$). No standard score guidelines have been published for either assessment instrument used, therefore, scoring keys, created by the instruments' authors, were used to score assessments accordingly and obtain raw scores for each. Additionally, because the WAI-SR assesses three individual components (goals, tasks, and bond) which are summed to obtain a total score. Four questions are contributed to each domain, and raw scores were also calculated for each. Mean values and standard deviations for each were also derived.

Relationship between PSS and WAI-SR. In order to examine the relationship between the participants' reported stress levels and their view of the relationship between themselves and their child's SLP, raw scores from the PSS ($M = 42.07$; $SD = 10.63$) and WAI-SR ($M = 41.99$; $SD = 12.548$) were analyzed using a Pearson product correlation ($n = 85$). Based on the

correlation coefficients calculated, no significant relationship (r = -.01, p = .896) was found between PSS and WAI-SR total scores.

Group Differences

WAI-SR and speech therapy setting. An independent sample *t* test was conducted in SPSS to evaluate whether caregivers of children receiving services from school-based SLPs reported a weaker working alliance than caregivers receiving services in a more medical model. The two variables were: (a) setting (school-based and non-school based) that were collapsed from the initial 6 choices in the survey (*public school, private school, private practice, university clinic, outpatient-hospital, other*) and (b) total score on the WAI-SR. Results of the WAI-SR were used to examine the differences in the therapeutic alliance created by setting, and significantly lower working alliances reported by caregivers of children receiving services by a school SLP, $t(82) = 29.71$, $p = .03$. (see Table 9 for the two groups' WAI-SR score means and standard deviations).

School-based services and caregiver ranking of goals, tasks, and bond. A chi-square analysis was conducted to evaluate whether differences exist between: (1) caregivers of children receiving services from school-based SLPs and (2) caregivers whose children receive services in a medical setting with regard to the ranking of their child's goals, therapy tasks, and bond with the SLP. The two variables were (a) setting (collapsed as above) and (b) the therapeutic factor ranked as most important by caregivers (goals, task, or bond). No significant difference was found between primary caregivers of children receiving speech-language services by a school-based SLP and those whose children received services in other settings, Pearson χ^2 (2, N = 71) = .526, p = .769, Cramer's V = .086.

Table 9

WAI-SR and Speech Therapy Setting

	School-based *n* = 47		Non-school based *n* = 36			
	M	SD	M	SD	*F*	*p*
WAI-SR Total	39.47	13.806	45.44	10.272	4.733	.033**
Goals	13.04	5.209	15.64	3.965	6.109	.015**
Tasks	12.66	4.244	13.75	3.350	1.608	.208
Bond	13.77	5.386	16.06	4.336	4.345	.040**

Note: N (total) = 83; M = Mean; SD = Standard Deviation

Chapter 6

Discussion

Demographics of Participants

All respondents included in the study self-identified as being a primary caregiver of a child with ASD. Of the 90 respondents, the majority (97.8%; $n = 88$) identified as being the "mother," which was expected based on previous research and survey findings suggesting mothers, as opposed to fathers, typically take on caregiving responsibilities of children with special needs (McLinden, 1990), especially when it comes to children diagnosed with ASD (Boyd, 2002; Higgins, Bailey, & Pearce, 2005). With regard to marital status, the majority of respondents indicated being married (86.7%). This percentage is in keeping with findings from multiple studies which also cited marriage rates of over 75% for caregivers of children with disabilities (Hartley, 2010; Tomanik, Harris, and Hawkins, 2004; Pottie & Ingram, 2008; Lyons, Leon, Phelps, and Dunleavy, 2010); however, there is some amount of disagreement in the literature with regard to marital status as some research suggests a higher divorce rate among families of children with disabilities, while other research has not shown there to be a difference when compared to families of children without disabilities (Hayes, 1997; Hecimovic et al., 1999). In addition, it should be noted that marital satisfaction was beyond the scope of this investigation and therefore not addressed as a question. Further, the survey question regarding marital status in the current study did not specify being "legally" married.

With regard to the recruitment measures indicated and the respondents' area of residence, it is likely these two factors not only impact one another but also impact the diversity of participants in the current study. With the majority of respondents indicating that they heard of this research study via online support groups (e.g. Facebook autism groups), the primary investigator found that some of the state *Autism Society* organizations were active on Facebook as well; therefore, as this is a trusted, nationally-renowned organization known for supporting the ASD community, the investigator sought to join these groups and share the survey link with the *Autism Society* social media pages. One state, North Carolina, stood out above the rest in the number of regional *Autism Society* pages they had on Facebook and the large number of caregivers subscribed to each page. Because the second most frequent chosen state of residence was North Carolina, one may assume that the level of caregiver involvement may be linked to the amount of publicity, advocacy, support, and social media presence of these state-based *Autism Society* organizations. Further, in discussion of the residency regions noted by respondents, the least number of caregivers indicated living in the Northeast (8%), and the greatest number of respondents noted being from the South (51%). *Autism Speaks*, an advocacy group dedicated to awareness, education, and research for the ASD community, surveyed 848 members to determine caregiver satisfaction in raising a child with ASD in their area of the United States (Jaslow, 2012). The respondents living in the cities on the East Coast (e.g. New York City, Boston, and Philadelphia) reported highest satisfaction, as a result of the largest amount of therapies and quality treatment options for their children with ASD. Therefore, this could indicate that because therapy services and treatment opportunities are more prevalent and available for children in this region of the United States, their caregivers are less likely to be involved in online support groups or in search of opportunities to improve/advance their child's

care. Therefore, this could be a rationale for why the smallest amount of caregivers were recruited from this region to participate in the current study (Jaslow, 2012).

ASD Diagnosis

With regard to who provided the ASD diagnosis, the majority (57.8%; *n* = 52) of caregivers indicated their child received the ASD diagnosis from a "psychologist/developmental psychologist," which does not coincide with previously reported data by Osborne and Reed (2008), in which the majority of their participants received the diagnosis from their "medical practitioner." In the current study, only 13.3% (*n* = 12) respondents stated their child was diagnosed with ASD by their "primary care physician/pediatrician." However, both the current study and the 2008 investigation by Osborne and Reed provide results that coincide with Siklos and Kerns (2006) diagnostician results. Their 2006 survey of families of children with ASD reported an equal amount of respondents (30.9%) received a diagnosis from either a clinical psychologist or pediatrician/family doctor. Overall, the majority of participants in the Siklos and Kerns study received a diagnosis from one of the two options mentioned above. With regard to SLPs specifically, behind medical practitioners and psychologists, Osborne & Reed (2008) reported SLPs to be the third most common professionals to provide an ASD diagnosis; however, no respondents in either the Siklos & Kerns (2006) investigation or the current study reported receiving an ASD diagnosis for their child by an SLP. Additionally, because primary care professionals (PCPs) are often challenged to provide options for treatment, locate sources of support, and teach and behavior management strategies for families of children with ASD (Chiri & Warfield, 2012), parents report dissatisfaction with PCPs. This, in turn, could contribute to the lack of overall support and guidance provided following a diagnosis of ASD, as only one-third (*n*

= 30) of the current study's respondents chose "health care providers (e.g. physician, psychologist, etc.)" as a source of social support they currently use.

Speech Therapy

Although speech-language therapy has been deemed the most widely used intervention by children with ASD (Green et al., 2006), with reported rates as high as 88% (McLennan, Huculak, & Sheehan, 2008), research reporting the setting and context in which children receive speech therapy is lacking. It stands to reason that the private/public school setting (51%; *n* = 46) would be the most highly reported by the respondents of the current study, due to the population targeted—primary caregivers of children with ASD between K-5th grades. The majority of caregivers in the current study indicated their child only receives speech therapy "one-on-one," and although this is the case for many clients in private clinics, the large caseloads of SLPs practicing in the elementary school setting often does not allow for many children to strictly receive individual therapy sessions. This assumption does not align with the finding of Plumb and Plexico (2013), who surveyed school-based SLPs to determine their competency and confidence in treating children with ASD. Of the SLPs who reported currently treating children with an ASD diagnosis, 79% reported to typically provide therapy to these students individually and in groups, and only 6.6% indicated they provide only individual therapy to their students with ASD (Plumb & Plexico, 2013). The possibility exists, however, that parents may not know the context in which their child is receiving services at school. Pappas and colleagues (2008), for example, reported that SLPs who work in a school/educational setting were significantly less likely to have a caregiver present for or participating in their children's therapy sessions, when compared to SLPs working in private practices and other health settings. Therefore, if not present, it is expected that the parent would be less knowledgeable with regard to the context in

which their child is receiving intervention. However, due to the fact that the majority individuals indicated they were a member of an online support group, it is likely that through frequent communication with other parents of children with ASD online, they are more aware of how to advocate for their child to receive one-on-one/individual therapy services through the school system. Therefore, based on the sample population queried, the study's results may indicate a fairly higher "one-on-one" therapy percentage, as compared to the general population of children with ASD receiving speech therapy services.

Verbal and Intellectual Ability

When asked to describe their child's verbal ability, 80% of caregivers described their child's status in this domain as "Below Average" or "Significantly Below Average," which were the two options associated the child having a diagnosed language disorder and/or delay. According to a literature review by May and colleagues (2018), the most current research indicates that approximately 60% of children with ASD also have a language disorder and/or delay. Although 60% is slightly lower than cited in the current study, this result was expected due to the fact that respondents had to indicate their child was currently receiving speech-language therapy to continue with the survey. Therefore, in order to recruit the target population for this investigation, the children of the participants were expected to show slightly more severe language/communication issues, as compared to the general ASD population.

With regard to the caregivers' description of their child's intellectual ability, 54.4% indicated their child displayed "Below Average" or "Significantly Below Average" in this domain, which closely aligns with the most current prevalence data on the comorbidity of ASD and ID by Christensen and colleagues' (2016), which cited that approximately 56% of children with ASD also have a co-occurring intellectual disability or are considered in the "borderline

range," with an IQ between 71 and 85. Also, in the current study, 45.6% caregivers provided their child exhibits "Average" or "Above Average" intellectual abilities, and this result also closely correspond with the most recent national investigation, which 44% of children with ASD scored average or above average in this domain (Christensen et al., 2016).

As expected, verbal abilities were described to be slightly more severe by respondents in the current study (80%), as compared to most recent published estimates of children with ASD (60%); however in order to recruit participants needed to fulfill the mission of the current study, the investigators expected this result. However, the results of the study closely aligned with published findings of the comorbidity of ASD and ID. Therefore, this further supports the diversity of respondents recruited for the study and promotes the generalization of these results.

Factors Contributing to Therapeutic Alliance

In order for intervention gains to result, Edwards and colleagues' (2016) described two core themes—"partnership" and "effective therapy"—which parents found to be crucial aspects in providing optimal, "family-centered" care to their children (p. 501). However, parents are willing to forego previously prioritized evidence-based services (Auert et al, 2012) and push aside the relationship, collaboration, and overall therapeutic alliance with their child's therapist(s), in order to ensure positive therapy outcomes will result. No matter the sacrifice(s) that has to be made, parents of children with ASD want their children to make gains toward their intervention goals (Edwards et al., 2016). Therefore, it was of interest in the current study to explore which of Bordin's (1979) three elements of therapeutic alliance—goals, tasks, or bond—parents feel is most important in therapy, ultimately providing progress toward the specific skill(s) and/or behavior(s) their child is working to develop. In the current study, the greatest number of respondents indicated the tasks/activities their child's SLP uses in speech therapy with

their child as most important, followed by goals, and finally, the bond/relationship with the child's SLP was indicated as the least important factor of the three. In addition, no significant difference was found between parents of children receiving services in a school-based therapy and those receiving therapy in a more medical-based setting, indicating that caregivers prioritize the contributing factors of TA, similarly. This finding indicates that parents, regardless of setting, want to be certain that the therapy activities their child's SLP is implementing will actually provide progress toward his/her treatment goals. In order to assure parents that the "tasks" are appropriate however, the bond/relationship between the therapist and caregiver must also be a positive one, so that the therapist is comfortable further explaining his/her clinical rationale for employing specific treatment tasks to an accepting caregiver. Although the bond/relationship was ranked as "least important" by the largest percentage of parents in the current investigation, it was still strongly correlated with the WAI-SR. Therefore, it seems that parents may fail to see the importance of this aspect of the therapeutic alliance. Because the "bond" was not specifically defined in the survey, the meaning of this term may have been interpreted differently than the investigator intended. Because a "bond" between two people can suggest a heightened level of intimacy, closeness, and/or affection, the parents may not particularly desire to have this type of relationship with their child's SLP; therefore, this could be a reason caregivers ranked this factor to be least important in their child's therapy. As mentioned above, it is likely that the caregivers want their child's therapy to produce positive outcomes for the child, and they are not concerned whether or not they have a friendship, relationship, or "bond" with the therapist. However, it is expected that as therapists are able to establish trust with the caregiver, through this "bond," and provide them with a better understanding of their child's symptoms and related behaviors, it is more likely that he/she will be a more educated and involved member of the child's treatment

journey, and as a result, will be more willing to follow through with home plans, carry out clinician recommendations, and promote generalization of therapy tasks/activities outside the therapy room.

Social Support

Of the caregivers in the current study who indicated which source(s) of support they use, informal sources were chosen significantly more frequently (94%) than formal sources of support (72%). Of the 90 respondents, 68 caregivers (76%), indicated receiving support from his/her spouse, making this source of social support the most frequently chose option. This finding is in keeping with the literature that parents of children with disabilities turn to their spouse as an initial source of support (Boyd, 2002; Gray & Holden, 1992; Konstantareas & Homatidis, 1989), and that spouses can be the most helpful form of social support for both mothers and fathers of children with ASD (Boyd, 2002; Herman & Thompson, 1995). Further, the second most popular source of social support chosen by caregivers in this study was "other parents of children with ASD," While of interest, it should be noted that the majority of respondents were recruited to participate via Facebook groups, whose membership is dependent on being a parent/caregiver of a child with ASD. Therefore, by being a part of this online community, it is expected that these respondents are using this source of social support. As a result this finding may not be as representative of the general population.

A smaller number of individuals indicated using formal support sources, and as stated by previous researchers (Meadan et al., 2010), this could be related to access to and/or quality of services available, likely driven by the caregivers' residential community, SES, education level, and/or employment status (Bromley et al., 2004; Mandell & Salzer 2007). However, because these demographics were not queried in the current investigation and 64 respondents indicated

their child's SLP had never recommended and/or initiated any type of social support, it is assumed that the limited use of formal sources is likely due to the fact that caregivers of children with ASD are not provided with information and/or opportunities for obtaining/utilizing sources of formal support. Only 2 respondents were assisted in locating respite care resources, and 8 stated their SLP helped them seek out ASD support groups; therefore, these results suggest that parents are not being informed via their child's SLP of these formal support options. However, when asked to indicate which sources of support their child's SLP had initiated/recommended, one respondent provided, "None, but if they did it would be highly unlikely I would use it." This statement is likely indicative of a poor working alliance between the caregiver and SLP. Further, the lack of information provided to caregivers, regarding formal support options, may be related to the frequency of communication between the SLP and caregiver. When queried, the results of this question were scattered—somewhat evenly—across the range of options provided, with the most popular option being "one time per week" (n = 30). It is likely that this question would also be impacted by the setting in which the child is receiving services. For example, less communication between therapist and caregiver is expected when a child is receiving services in the school system, as opposed to children receiving therapy in a more medical model, where the caregiver is responsible for making sure the child arrives to therapy appointment(s). It is assumed, therefore, that when communication is not frequent between the two, the caregiver may not view the SLP as a source of support.

Relationship between PSS and WAI-SR

Based on the results of the assessment tools used in the survey, no correlation was found between scores on the PSS and the WAI-SR, indicating there is no direct relationship between caregiver stress and the working alliance they perceive between themselves and their child's

SLP. Although the investigators originally hypothesized that higher stress levels would indicate a lower working alliance and lower stress levels would lead to a more positive working alliance, the results of the current investigation did not display these results. With regard to the PSS, the mean for the caregivers in the current study was 42.1, yielding a mild stress level, which corresponds with previous investigations, which found mothers of children with psychological, behavioral, and/or developmental diagnoses/disabilities to provide scores averaging around 40.1 and 43.2, as compared to their controls (mothers of typically developing children) with mean scores of 37.1 (Berry & Jones, 1995). Although heightened stress levels are present in caregivers of children with ASD, the stress is most likely related to the severity of the child's ASD and associated symptoms/behaviors, rather than the level of support they receive. (Konstantareas & Papageorgiou, 2006; Lyons et al., 2010; Kissel & Nelson, 2016). Therefore, because the working alliance scores showed no significant relationship with the caregivers' reported stress levels, this may indicate that caregivers with heightened stress are more inclined to be open to and benefit from a positive relationship with his/her child's SLP, resulting in a stronger working alliance between the two. Equally, a strong bond with their child's SLP does not mean that the parent's overall stress level will decrease as stress is a multi-faceted construct influenced by a variety of factors. Kissel and Nelson (2016) found no direct relationship between self-reported stress and perceived social support in parents of children with ASD. Therefore, if the SLP is viewed as a sources of social support, the current study's results may coincide with Kissel and Nelson's (2016) findings and indicate that a positive working alliance between the two may be indicative of family involvement and treatment outcomes for the child, but may not be a direct mediator of caregiver stress.

WAI-SR and Speech Therapy Setting

As mentioned previously, the SLPs' workplace has been deemed the most influential factor impacting parental involvement in therapy, with SLPs working in a school/educational setting indicating significantly less caregiver participation/input in therapy sessions, when compared to SLPs working more medical settings (Pappas et al., 2008). Aligning with previous research in this domain, the results of the current investigation found that caregivers of children receiving services in school-based settings (public or private) compared to those receiving therapy in a more medical model, display a significantly lower total WAI-SR score, indicating a poorer working alliance.

Although ASHA's position statement on the roles and responsibilities of SLPs emphasizes the importance of familial collaboration and cooperation to optimize students' progress and success (ASHA, 2010), even for those practicing in the schools (ASHA, 2014), the school setting leads to the least amount of communication between caregivers and the child's SLP (Pappas et al., 2008), with the primary communication avenue being via homework folders sent home with the child (Tambyraja, Schmitt, & Justice, 2017). Therefore, communicative efforts on behalf of the SLP are usually filtered through the child's classroom teacher, and then, delivered to the parent (Pappas et al., 2008). However, research is still needed to examine the degree to which parents are actually completing speech homework with children, and in doing so, if the assignments sent home are actually educating parents on the treatment tasks/goals being targeted in therapy (Tambyraja, Schmitt, & Justice, 2017). Because the school setting has been deemed a barrier to communication avenue between the two, it is likely that the child's actual therapy goals are only being communicated during annual IEP meetings or through quarterly progress reports. If caregivers are either unwilling or unable to attend the meetings, they may not

be knowledgeable of their child's goals or view them as important. With regard to the tasks and bond components of this working alliance, caregivers of children receiving school-based services typically aren't responsible for getting their child to therapy appointments, and therefore, may never actually meet the child's school SLP and/or observe the tasks the child's clinician is implementing to work toward treatment goals. While homework may allow the caregiver to have a better understanding of the "tasks" which may take place in therapy (Tambyraja et al., 2017), it is likely that communication between the SLP and caregiver will not flourish and the bond between them will never be established and/or sustained in the absence of face to face meetings.

Strengths

A primary strength of the current investigation is that this is the first study of its' kind investigating facilitators and barriers of the therapeutic relationship between primary caregivers of children with ASD and their child's SLP. Because children with ASD often are unable to communicate their wants/needs to their therapists, the bond between the caregiver and therapist is of utmost importance in providing "family-centered" services and client-specific care. Additionally, the representation of participants across the four main geographic regions of the United States further promotes the generalization of this study's findings.

Limitations and Future Directions

With regard to limitations of the current study, the small sample size is important to note, with only 85 participants completing the entire survey instrument. Additionally, because the primary recruitment measure was via support groups on social media sites, such as Facebook, the participant population may not represent lower SES caregivers, as they may not have access to such internet sites and online support groups. Because Tambyraja and colleagues (2017) found that caregivers of children from higher SES backgrounds communicate more frequently with

their child's SLP, children from low SES areas may have caregivers who are unable to be heavily involved in their child's care, due to other time-demanding responsibilities and/or the lack of knowledge about the services the child is receiving at school. Therefore, because the participants' SES was not queried in the current investigation and children with ASD have been cited as a financial burden (Lavelle et al., 2014), future research should investigate how SES impacts the alliance between caregivers of children with ASD and SLPs. Additionally, significantly lower working alliance scores were found among caregivers whose children were receiving services in a school setting; more than 50% of SLPs work in education (ASHA, 2018); and the "bond" between caregiver and therapist was found to be the most influential factor in the overall working alliance between the two; further research is needed on how to establish and sustain the bond—between school-based SLPs and caregivers of children with ASD—in the initial stages of the therapeutic journey.

Conclusions and Clinical Implications

With regard to stress and social support, the results of this study found that the participants' stress levels highly correlate with previously documented stress levels of parents of children with disabilities and behavioral and/or emotional disorders (Berry & Jones, 1995); however, higher stress levels were not significantly related to lower working alliance scores and lower stress levels were not significantly related to higher working alliance scores. Therefore, it is possible that when caregivers feel the most parenting stress, they are open to and benefit from a stronger bond with those providing services to their child—strengthening their view of the working alliance. For SLPs, this means that they should always be offering and suggesting sources of support for caregivers, specifically formal sources, as those were noted as underutilized by participants. SLPs should not isolate their social support suggestions to only

parents who seem highly stressed, as all parents may benefit from additional support, even if they feel their parenting duties are not currently a major cause of stress.

Because caregivers of the current study ranked "tasks" as most important to them in their child's therapy, it is critical that therapists involve caregivers in the creation of goals and functional activities to support these goals, and then, explain the clinical rationale behind tasks being used in therapy. This will further support the "partnership" and "effective therapy" (Edwards et al., 2016) parents desire from their child's therapist, and in turn, will indirectly promote the "bond" between the two, which was found to be the strongest component of a positive working alliance.

In order to optimally serve school-aged children with ASD, the communication gap between SLPs and caregivers must be addressed. Because positive therapeutic relationships do not change with the length of time with the therapist, and the TA is established with utmost positivity early in the therapeutic journey (Zetzel, 1956; Luborsky, 1976; Hartley, 1978; Horowitz et al., 1984; Marziali, 1984; Marziali, Marmar, & Krupnick, 1981; Eaton, Abeles, & Gutfreund, 1988; Safran & Muran, 2000), it is recommended that parents of children with ASD are involved in each step of their child's care, especially when it comes to school-based services. Caregivers should be fully informed partners in the child's therapy—beginning with evaluation and goal-setting, leading into treatment tasks and target changes, through times of transition and ultimately, with discharge. In order to do so, homework—sent home via classroom teacher—cannot be the sole source of communication between home and school. While caregivers who do not maintain a presence at school may be viewed as "uninvolved" or "uneducated" members of their child's support team, it is important to remember that there are many reasons that a caregiver may not be able to regularly attend events such as IEP meetings and parent-teacher

conferences. Caregivers may have a myriad of other responsibilities, such as employment requirements and family obligations. In addition, in the absence of a strong working alliance with their child's SLP the caregiver may lack insight into the importance of these meetings with regard to staying informed on their child's needs and progress. As a formal source of support, at the beginning of each school year, SLPs should educate caregivers on the services their child receives and how, by working together, they can ensure the child is utmost successful, both inside the classroom and at home. By making caregivers aware of the three factors contributing to the working alliance, helping them understand their role as the caregiver in the child's therapeutic journey, and working with them to ensure they can be involved as possible, the communication, level of comfort, and overall bond will likely be strengthened. If there seems to be a disconnect or breakdown in this communication pathway, phone calls, emails, meetings, home visits, and other avenues should be explored to determine optimal methods for getting information to caregivers and receiving feedback from them. By doing so, caregivers will likely become more involved in their child's therapy, develop a better understanding of their goals, and ultimately, generate carryover, familial support, and progress in their child's functional communication skills.

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Appendix 1. Recruitment Email

To Whom It May Concern,

My name is Rachel Nokes, and I am a graduate student in speech-language pathology at Auburn University working on my master's thesis. My thesis will be an electronic survey to determine factors that contribute to the therapeutic alliance between primary caregivers of school-aged children with autism spectrum disorder (ASD) and their child's speech-language pathologist (SLP). Through this study I hope to discover how this therapeutic relationship is viewed and valued by parents, factors that guide a positive relationship, factors that negatively impact this relationship, and what needs/expectations these caregivers have. An additional research aim is to investigate the relationships between these variables and parental stress. This study will provide professionals in speech-language pathology and related fields with valuable information and recommendations to incorporate into their clinical treatment of children with ASD. Gaining a clearer understanding of therapeutic alliance and the role it plays in client success will help equip speech-language pathologists with the qualities they need to establish a positive rapport with caregivers of children with ASD, provide them with the support they need, and deliver more effective treatment to their children.

Because your organization focuses on educating, advocating, providing support, and improving services for those with ASD, I was hoping that you could assist me in this research process. Any assistance you could provide to help me reach parents of individuals with ASD would be highly appreciated. I am currently developing the methodology for the investigation

and would be happy to share the survey instrument with you when it is completed. Please email me with any further questions you have regarding my study or possibilities with which your organization may be able to help disseminate the information letter and link to the survey to potential participants (following approval by the Auburn University Human Research Protection Program). Thank you for your time and consideration. I hope to hear back from you soon!

Rachel Nokes, B.S.

Graduate Research Assistant

Department of Communication Disorders-Graduate Student

Auburn University

Appendix 2. Survey

Therapeutic Relationship between Primary Caregivers of School-Age Children with ASD and SLPs

Start of Block: Demographics/Background Information

Thank you for participating in this survey. The aim of the current investigation is to examine factors influencing the therapeutic relationship between caregivers of children with ASD and their speech-language pathologist. Therefore, this survey was designed to be taken by the primary caregiver of the elementary school (K-5th grade) child with ASD. As families may have more than one child with ASD or more than one speech-language pathologist providing services to their child/children, please answer the following questions with one particular child and one particular speech-language pathologist in mind.

1. How did you hear about this survey?
   - Autism Society webpage
   - Autism Society newsletter
   - Invitation email from Autism Society
   - Facebook Page
   - Other _____

2. Does your child currently have a diagnosis of autism spectrum disorder (ASD)?
   - Yes
   - No

3. Are you a primary caregiver for your child with ASD?
   - Yes
   - No

4. Which of the following best describes your relationship as primary caregiver?
    - Mother
    - Father
    - Sibling
    - Grandmother
    - Grandfather
    - Biological Aunt
    - Biological Uncle
    - Cousin
    - Non-biologically related custodial caregiver
    - Other

5. Does your child currently receive speech-language therapy by a speech-language pathologist?
    - Yes
    - No

6. Why is your child with ASD not currently receiving speech therapy by a speech-language pathologist?
    - My child met his/her treatment goals and was discharged from speech therapy.
    - My child is taking a "break" from speech therapy services.
    - I cannot afford for my child to receive speech therapy.
    - I do not have transportation to take my child to speech therapy.
    - I removed my child from speech therapy because he/she was not making progress.
    - I removed my child from speech therapy because I did not have a good relationship with his/her speech-language pathologist.
    - I do not believe that my child needs speech therapy at this time.
    - Other _____

7. Who provided a diagnosis of ASD for your child?
    - Previous speech-language pathologist
    - Speech-language pathologist he/she is currently receiving services from
    - Primary care physician/pediatrician
    - Psychologist/developmental psychologist
    - ASD diagnostic team
    - Other _____

8. Please estimate the amount of time that has passed since your child was diagnosed with ASD.
    - Less than 6 months
    - Approximately 6 months
    - Approximately 1 year
    - Approximately 2 years
    - Approximately 3 years
    - Approximately 4 years
    - Approximately 5 years
    - Approximately 6 years
    - Approximately 7 years
    - Approximately 8 years
    - Approximately 9 years
    - Approximately 10 years
    - More than 10 years

9. Please estimate the amount of time that your child has been receiving speech-language therapy.
    - Less than 6 months
    - Approximately 6 months
    - Approximately 1 year
    - Approximately 2 years
    - Approximately 3 years
    - Approximately 4 years
    - Approximately 5 years
    - Approximately 6 years
    - Approximately 7 years
    - Approximately 8 years
    - Approximately 9 years
    - Approximately 10 years
    - More than 10 years

10. How would you describe your child's intellectual ability?
    - Average- My child's intellectual abilities are at the level expected for his/her age.
    - Above average – My child's intellectual abilities are advanced when compared to his/her peers.
    - Below average – My child's intellectual abilities are lower than expected when compared to his/her peers.
    - Significantly below average- My child has been diagnosed with an intellectual disability.

11. How would you describe your child's verbal abilities?
    - Average – My child is verbally communicating at the level expected for his/her age.
    - Above average – My child's verbal communication abilities are advanced when compared to his/her peers.
    - Below average – My child is verbal, but has been diagnosed with a mild to moderate expressive language delay or disorder.
    - Significantly below average – My child is nonverbal or minimally verbal and/or has been diagnosed with a severe expressive language delay or disorder.

12. What is the setting in which your child currently receives services by this specific speech-language pathologist?
    - Public School
    - Private School
    - Private Practice
    - University Clinic
    - Outpatient (Hospital)
    - Other _____

13. In what context does your child receive speech-language therapy from this specific speech-language pathologist?
    - One-on-one
    - In the classroom
    - In a group outside of the classroom
    - One-on-one & In the classroom
    - One-on-one & In a group outside of the classroom
    - In the classroom & In a group outside of the classroom
    - One-on-one, In the classroom, & In a group outside of the classroom
    - I am unsure of the context in which my child receives speech-language therapy.

14. How long has your child been receiving speech-language therapy from this specific speech-language pathologist?
    - Less than 1 month
    - Approximately 1 month
    - Approximately 3 months
    - Approximately 6 months
    - Approximately 1 year
    - More than 1 year

15. How often do you speak (in person OR on the phone) with your child's SLP?
    - Multiple times per week
    - 1 time per week
    - 1 time per month
    - 1 time per semester (one-half of a school year)
    - 1 time annually
    - I have never spoken to my child's SLP

16. What grade is your child currently in?
    - Kindergarten
    - 1st
    - 2nd
    - 3rd
    - 4th
    - 5th
    - My child is not in any of these grades.

17. What is the age of your child with ASD?
    - 4 years old
    - 5 years old
    - 6 years old
    - 7 years old
    - 8 years old
    - 9 years old
    - 10 years old
    - 11 years old
    - 12 years old
    - Older than 12 years old

18. What is the sex of your child with ASD?
    - Male
    - Female

19. Is your child with ASD of Hispanic, Latino, or Spanish origin?
    - Yes
    - No

20. What is the race of your child with ASD? Select all that apply.
    - ❑ White
    - ❑ Black or African American
    - ❑ Native American or Other Pacific Islander
    - ❑ Asian
    - ❑ American Indian or Alaska Native
    - ❑ Other _____

21. What is your age?
    - 19 years or younger
    - 20-24 years old
    - 25-29 years old
    - 30-34 years old
    - 35-39 years old
    - 40-44 years old
    - 45-49 years old
    - 50-54 years old
    - 55-59 years old
    - 60-64 years old
    - Older than 64 years

22. Are you of Hispanic, Latino, or Spanish origin?
    - Yes
    - No

23. What is your race? Select all that apply.
    - ❑ White
    - ❑ Black or African American
    - ❑ Native American or Other Pacific Islander
    - ❑ Asian
    - ❑ American Indian or Alaska Native
    - ❑ Other _____

24. What is your current marital status?
    - Married
    - Committed partnership (not married)
    - Widowed
    - Divorced
    - Separated
    - Never married

25. Which state do you currently live in?

26. Which of the following terms best describes the location in which you live?
    - Urban
    - Rural
    - Suburb

Factors Influencing the Therapeutic Relationship

27. Please rank the following factors in regard to their importance to you in your child's speech-language therapy. Move the cursor to arrange the sentences in their order of importance.
    _____ The goals that my child's SLP has put in place for my child.
    _____ The tasks/activities that my child's SLP uses in therapy with my child.
    _____ The bond/relationship between myself and my child's SLP.

Adapted Version of the Working Alliance Inventory-Short Revised

The following 12 questions were adapted from the Working Alliance Inventory- Short Form. Reprinted by permission of the Society for Psychotherapy Research © 2016.

28. As a result of my child's speech therapy sessions I am clearer as to how my child might be able to change.
    - Seldom
    - Sometimes
    - Fairly Often
    - Very Often
    - Always

29. What my child is doing in therapy gives me new ways of looking at his/her problem.
    - Seldom
    - Sometimes
    - Fairly Often
    - Very Often
    - Always

30. I believe my child's SLP likes me.
    - Seldom
    - Sometimes
    - Fairly Often
    - Very Often
    - Always

31. My child's SLP and I collaborate on setting goals for my child's therapy.
    - Seldom
    - Sometimes
    - Fairly Often
    - Very Often
    - Always

32. My child's SLP and I respect each other.
    - Seldom
    - Sometimes
    - Fairly Often
    - Very Often
    - Always

33. My child's SLP and my child are working towards mutually agreed upon goals.
    - Seldom
    - Sometimes
    - Fairly Often
    - Very Often
    - Always

34. I feel that my child's SLP appreciates me.
    - Seldom
    - Sometimes
    - Fairly Often
    - Very Often
    - Always

35. My child's SLP and I agree on what is important for my child to work on.
    - Seldom
    - Sometimes
    - Fairly Often
    - Very Often
    - Always

36. I feel that my child's SLP cares about me even when I do things that he/she does not approve of.
    - Seldom
    - Sometimes
    - Fairly Often
    - Very Often
    - Always

37. I feel that the things my child's SLP does with my child in therapy will help my child accomplish the changes I want.
    - Seldom
    - Sometimes
    - Fairly Often
    - Very Often
    - Always

38. My child's SLP and I have established a good understanding of the kind of changes that would be good for my child.
    - Seldom
    - Sometimes
    - Fairly Often
    - Very Often
    - Always

39. I believe the way my child's SLP is working with my child's problem is correct.
    - Seldom
    - Sometimes
    - Fairly Often
    - Very Often
    - Always

Parental Stress Scale

The statements listed below describe feelings and perceptions associated with parenting. Please consider each of the items in terms of how your relationship with your child typically is. Then, select the degree to which you agree with the following statements.

40. I am happy in my role as a parent.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

41. There is little or nothing I wouldn't do for my child if it was necessary.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

42. Caring for my child sometimes takes more time and energy than I have to give.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

43. I sometimes worry whether I am doing enough for my child.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

44. I feel close to my child.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

45. I enjoy spending time with my child.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

46. My child is an important source of affection for me.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

47. Having child gives me a more certain and optimistic view for the future.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

48. The major source of stress in my life is my child.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

49. Having child leaves little time and flexibility in my life.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

50. Having child has been a financial burden.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

51. It is difficult to balance different responsibilities because of my child.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

52. The behaviour of my child is often embarrassing or stressful to me.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

53. If I had it to do over again, I might decide not to have child.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

54. I feel overwhelmed by the responsibility of being a parent.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

55. Having child has meant having too few choices and too little control over my life.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

56. I am satisfied as a parent.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

57. I find my child enjoyable.
    - Strongly agree
    - Agree
    - Undecided
    - Disagree
    - Strongly disagree

Social Support

58. In which of the following, if any, do you currently confide in for social support? Please select all that apply.
    - ❑ Respite care services
    - ❑ ASD parent support groups
    - ❑ Health care providers (e.g. physician, psychologist, etc.)
    - ❑ Speech-language pathologist
    - ❑ Spouse (husband, wife)
    - ❑ Family members
    - ❑ Extended family members (e.g. child's grandparents)
    - ❑ Co-workers
    - ❑ Religious groups
    - ❑ Friends
    - ❑ Other parents of children with ASD
    - ❑ Other _____
    - ❑ I do not use any source of social support.

59. Which of the following, if any, types of social support has your child's SLP initiated and/or recommended for you? Please select all that apply.
    - ❑ My child's SLP has helped me locate respite care services.
    - ❑ My child's SLP has helped me locate ASD parent support groups.
    - ❑ My child's SLP refers me to ASD-specific health care providers and/or therapy providers.
    - ❑ My child's SLP has offered to educate/train my spouse on how to support myself and my child with ASD.
    - ❑ My child's SLP has offered to educate/train other individuals in my life (e.g., family members, friends, co-workers, and religious groups) on how to support myself and my child with ASD
    - ❑ .
    - ❑ Other _____
    - ❑ My child's SLP has never initiated or recommended any type of social support to me.

Appendix 3. Information Letter

(NOTE: DO NOT AGREE TO PARTICIPATE UNLESS IRB APPROVAL STAMP WITH CURRENT DATES HAS BEEN ADDED TO THIS DOCUMENT.)

INFORMATION LETTER

for a Research Study entitled

"Therapeutic Relationship between Primary Caregivers of School-Aged Children with Autism Spectrum Disorder and Speech-Language Pathologists: An Electronic Survey"

You are invited to participate in a research study to determine factors that contribute to the therapeutic relationship between primary caregivers of school-aged children with autism spectrum disorder (ASD), in Kindergarten through 5th grade, and their child's speech-language pathologist (SLP). This study is being conducted by Rachel L. Nokes, Master's student in Communication Disorders at Auburn University, and Dr. Allison M. Plumb, Associate professor in the Auburn University Department of Communication Disorders. You were selected as a possible participant because of your membership in the *Autism Society* for the state in which you reside.

What will be involved if you participate? If you decide to participate in this research study, you will be asked to complete an online survey form that includes 59 questions. Your total time commitment will be approximately 20 minutes.

Are there any risks or discomforts associated with participation? There is always a risk of breach of confidentiality with surveys, but this possibility is being addressed by keeping all responses completely anonymous with no identifying information whatsoever being collected and using all reasonable and customary security measures. The data will be stored behind a secure firewall, and all security updates are applied in a timely fashion.

***Are there any benefits to yourself or others*?** There is no direct benefit to you for participating in this study, but it is hoped that the results of this study will help to provide needed information on how the parent-clinician relationship is viewed and valued by parents, factors that guide a positive relationship, factors that negatively impact this relationship, and what needs/expectations these parents have. This study's purpose seeks to provide professionals in speech-language pathology and related fields with valuable information and recommendations to incorporate into family-centered intervention for children with ASD.

Will you receive compensation for participating? You will receive no compensation for completing this survey; however, your participation would be greatly appreciated.

Are there any costs associated with participation? There are no costs associated with this survey, except for the few minutes of your time that it takes to complete the survey.

If you change your mind about participating, you can withdraw at any time by closing your browser window. Once you have submitted anonymous data, it cannot be withdrawn due to it being unidentifiable. Your decision about whether or not to participate or to stop participating will not jeopardize your future relations with Auburn University or the Department of Communication Disorders.

Any data obtained in connection with this study will remain anonymous. We will protect your privacy and the data you provide by NOT asking for any identifiable information. Information

collected through your participation may be presented at state or national conferences and may be published in a professional journal.

If you have questions about this study, please contact Dr. Allison Plumb at amp0016@auburn.edu

If you have any questions about your rights as a research participant, you may contact the Auburn University Office of Research Compliance or the Institutional Review Board by phone (334) 844-5966 or email at IRBadmin@auburn.edu or IRBChair@auburn.edu.

HAVING READ THE INFORMATION ABOVE, PLEASE DECIDE IF YOU WISH TO PARTICIPATE IN THIS RESEARCH STUDY. IF YOU DECIDE TO PARTICIPATE, INDICATE THAT YOU AGREE TO DO SO BY CLICKING ON THE FOLLOWING LINK TO ACCESS THE SURVEY.

I AGREE TO PARTICIPATE:
https://az1.qualtrics.com/jfe3/preview/SV_beVZ6H2OMT7YxhP

The Auburn University Institutional Review Board has approved this document for use from August 26, 2017 to August 25, 2020. Protocol #17-330 EX 1708.

YOU MAY PRINT A COPY OF THIS LETTER TO KEEP.

Thank you for your time,
Rachel L. Nokes, B.S.
Allison M. Plumb, Ph.D., CCC-SLP

Appendix 4. Information Letter for Facebook Link (Embedded in the Survey)

(NOTE: DO NOT AGREE TO PARTICIPATE UNLESS IRB APPROVAL STAMP WITH CURRENT DATES HAS BEEN ADDED TO THIS DOCUMENT.)

INFORMATION LETTER

for a Research Study entitled

"Therapeutic Relationship between Primary Caregivers of School-Aged Children with Autism Spectrum Disorder and Speech-Language Pathologists: An Electronic Survey"

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What will be involved if you participate? If you decide to participate in this research study, you will be asked to complete an online survey form that includes 59 questions. Your total time commitment will be approximately 20 minutes.

Are there any risks or discomforts associated with participation? There is always a risk of breach of confidentiality with surveys, but this possibility is being addressed by keeping all responses completely anonymous with no identifying information whatsoever being collected and using all reasonable and customary security measures. The data will be stored behind a secure firewall, and all security updates are applied in a timely fashion.

***Are there any benefits to yourself or others*?** There is no direct benefit to you for participating in this study, but it is hoped that the results of this study will help to provide needed information on how the parent-clinician relationship is viewed and valued by parents, factors that guide a positive relationship, factors that negatively impact this relationship, and what needs/expectations these parents have. This study's purpose seeks to provide professionals in speech-language pathology and related fields with valuable information and recommendations to incorporate into family-centered intervention for children with ASD.

Will you receive compensation for participating? You will receive no compensation for completing this survey; however, your participation would be greatly appreciated.

Are there any costs associated with participation? There are no costs associated with this survey, except for the few minutes of your time that it takes to complete the survey.

If you change your mind about participating, you can withdraw at any time by closing your browser window. Once you have submitted anonymous data, it cannot be withdrawn due to it being unidentifiable. Your decision about whether or not to participate or to stop participating will not jeopardize your future relations with Auburn University or the Department of Communication Disorders.

Any data obtained in connection with this study will remain anonymous. We will protect your privacy and the data you provide by NOT asking for any identifiable information. Information

collected through your participation may be presented at state or national conferences and may be published in a professional journal.

If you have questions about this study, please contact Dr. Allison Plumb at amp0016@auburn.edu

If you have any questions about your rights as a research participant, you may contact the Auburn University Office of Research Compliance or the Institutional Review Board by phone (334) 844-5966 or email at IRBadmin@auburn.edu or IRBChair@auburn.edu.

HAVING READ THE INFORMATION ABOVE, PLEASE DECIDE IF YOU WISH TO PARTICIPATE IN THIS RESEARCH STUDY. IF YOU DECIDE TO PARTICIPATE, INDICATE THAT YOU AGREE TO DO SO BY SELECTING YES AND CONTINUING THE SURVEY

The Auburn University Institutional Review Board has approved this document for use from August 26, 2017 to August 25, 2020. Protocol #17-330 EX 1708.

YOU MAY PRINT A COPY OF THIS LETTER TO KEEP.

Thank you for your time,
Rachel L. Nokes, B.S.
Allison M. Plumb, Ph.D., CCC-SLP