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Parent Satisfaction with Family Professional Partnerships and Services for Children with Autism Spectrum Disorder

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PARENT SATISFACTION WITH FAMILY PROFESSIONAL PARTNERSHIPS AND

SERVICES FOR CHILDREN WITH AUTISM SPECTRUM DISORDER

By

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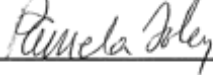
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Abstract

As an increasing number of children are diagnosed with Autism Spectrum Disorders (ASD), research on the efficacy of interventions and treatments—the way these services affect the family, the child's outcomes, and the family's experience with their child's services—are gaining importance. Children with ASD tend to be involved in multiple services to a higher degree than children with other disabilities, and parents of children with ASD have reported higher dissatisfaction with services than have parents of children with other developmental disabilities. To date, limited research has addressed the family's perception of these services and how they feel service providers improve child and family outcomes.

The present study employed a mixed-methods design to provide a thorough understanding of parents' experiences of using services for their child with ASD. It was hypothesized that parents who reported lower child problem behaviors and higher levels of child prosocial behaviors would report greater satisfaction with child- and family-focused services, and that parents who reported higher levels of stress would report lower satisfaction with services and less positive appraisals of their child's functioning. Qualitative questions were analyzed through thematic analysis and provided information on positive and negative experiences that parents had in their interactions with service providers, and how providers helped parents see their child's strengths.

Results of multiple regression analysis indicated that parent appraisals of child functional behaviors were negatively related to parent satisfaction with child- and family-focused aspects of services, such that parents who reported higher satisfaction with professional partnerships reported lower child problem behaviors and higher levels of child prosocial behaviors. In addition, hierarchical regressions indicated that parents who experienced more stressful events

over their lifetime reported lower satisfaction with services and perceived higher rates of child problem behaviors, after controlling for multicollinearity between the two measures of stress. There was a negative relationship between the age of the child and parent satisfaction with professional partnerships. Qualitative analyses revealed a number of ways in which providers helped parents feel supported, including presenting an image of competence, attempting to build relationships with parents, and helping parents understand their child's diagnosis and positive progress. Parents reported that they had negative experiences when they felt disregarded by providers, perceived that their provider lacked competency, or experienced difficulty obtaining appointments.

This study contributes to the literature by considering both parent perceptions of the severity of their child's functioning and child functional behaviors from a strengths-based approach. The importance of this mixed-methods study was to provide a forum for parents to report their experiences in a way that could meaningfully inform clinical interventions and foster best practices. Limitations and future directions for this research are also addressed.

Keywords: autism spectrum disorder, child-focused services, family-focused services, parents of children with ASD, service providers

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Chapter I

INTRODUCTION

Autism Spectrum Disorder (ASD) is a lifelong, complex neurological spectrum of disorders that involves deficits in social, relational, behavioral, and communicative development (American Psychiatric Association, 2013; Ennis-Cole, Durodoye, & Harris, 2013; Morrier, Hess, & Heflin, 2008). According to the U.S. Centers for Disease Control and Prevention (CDC), approximately 1 in 59 children are diagnosed with an ASD (2018). This represents an approximately 150% increase in the estimated prevalence of ASD from 2000 to 2014 (Baio, Wiggins, Christensen, Maenner, Daniels, Warren, et al., 2018). In addition, parents who have one child with ASD have a 2 to 18% chance of having a second child also diagnosed with ASD (Baio et al., 2018). As an increasing number of children are diagnosed with an ASD, research on the efficacy of interventions and treatments, as well as the way that these services affect the family, the child's outcomes, and the family's experience with their child and with their child's services, are gaining importance.

Statement of the Problem

Children with ASD are reportedly enrolled in a significant number and array of services for their health and educational needs, more so than children with other disabilities (Bitterman, Daley, Misra, Carlson, & Markowitz, 2008; Mackintosh, Goin-Kochel, & Myers, 2012; Mandell & Novak, 2005). Parents of children with ASD are the primary link between their child and the service provider, as the means by which children obtain services. Coordination with professionals and management of their children's treatments, in addition to the time commitment and cost of these services, can cause significant stress and dissatisfaction for parents of children with ASD (Mackintosh, Goin-Kochel, & Myers, 2012). Several studies have shown that parents

of children with ASD experience more stress within the parent-child relationship, general parenting stress, and psychological distress than parents of children with other developmental disabilities, as well as more overall stress than parents of neurotypical children (Davis & Carter, 2007; Estes et al., 2013; Huang et al., 2014; McStay et al., 2014; Wong et al., 2012). Furthermore, research also suggests that parents of children with ASD experience higher levels of stress when compared with other parents of children with disabilities (Cridland, Jones, Magee, & Caputi, 2014; DePape & Lindsay, 2015; Estes et al., 2013; Minnes, Perry, & Weiss, 2015; Robert, Leblanc, & Boyer, 2014; Russa, Matthews, & Owen-DeSchryver, 2014). There are many facets of having a child with an ASD that have been associated with higher rates of family stress and lower family well-being in the literature, including low rates of child communication abilities, high rates of child behavioral problems (Estes et al., 2013; Kissel & Nelson, 2016). In addition, parent frustration is compounded by the barriers they face in obtaining adequate services to meet the needs of their child and the needs of the family (Ngui & Flores, 2006). Compared to families with children without ASD, parents of children with ASD are at a higher risk of experiencing financial strain, as the costs of covering services sometimes require parents to pay out of pocket, travel significant distances to access treatment facilities, relocate, or make career changes (DePape & Lindsay, 2015). Children with ASD tend to be involved in multiple services to a higher degree than children with many other disabilities, and parents of children with ASD have reported higher dissatisfaction with services over and above parents of children with other developmental disabilities (Mackintosh, Goin-Kochel, & Myers, 2012). As parents spend a great deal of time interacting with service providers throughout their child's treatment, additional research that addresses how these issues might impact parents of children with ASD can help to better inform practice and policy development. Researchers have previously

investigated the impact of services on families and aspects of parent-professional partnerships

that can potentially reduce stress for parents of children with ASD or enhance family supports

and outcomes (Carlon, Stephenson, & Carter, 2014; DePape & Lindsay, 2015; Wang et al.,

2004). To fully explore and increase satisfaction within family-professional partnerships,

researchers should further investigate the family's perception of these services and how they feel

these service providers help to improve child and family outcomes. On the basis of the

aforementioned findings, an investigation that examines the influence of parent satisfaction with

services and its relationship with child behavioral challenges and strengths would provide a

balanced framework that can meaningfully inform clinical interventions and foster best practices.

Research investigating disability severity has tended to examine participants with broad

categories of disability. This analytic approach may present an over-generalization of the impact

of having a child with a disability on the family, and not truly capture the unique experience of

having a child with ASD. For example, in a study of early interventions for children with a

range of disabilities, Summers et al. (2005a) found that there was a significant correlation

between parent satisfaction and child age, such that the older the child, the less satisfied parents

were with professional services. The study however, failed to distinguish different disabilities

generally, and neglected to examine the unique needs of parents with children with ASD,

specifically. Blue-Banning, Summers, Frankland, Lord Nelson, & Beegle (2004) examined

specific indicators of professional behavior that parents of children with and without disabilities

identified as important for effective, collaborative professional partnerships. Their methods

involved interviewing families of children with a wide range of disabilities, an approach that has

been taken by several scholars (e.g., Wang et al., 2004). Given that these studies did not focus

on parents of children with ASD, the implications for these families are limited, particularly

when understood within the context of findings that suggest these parents face unique barriers in access to care.

A number of studies have highlighted the importance of investigating parent satisfaction with professional services and partnerships used by families of children with developmental disabilities. In a preliminary study, Bailey et al. (1998) noted that family-professional partnerships and family-centered approaches to care are essential for effective early intervention, as they enhance the family's capacity to meet their child's needs, empower families, and promote optimal developmental outcomes for the child. Research since this 1998 study has shown that development of these collaborative partnerships leads to effective treatment outcomes (Morrier, Hess, & Hefflin, 2008), fosters greater self-efficacy in parents (Popp & You, 2016), and leads to greater parent satisfaction with services (Blue-Banning et al., 2004; Robert, Leblanc, & Boyer, 2014). In addition, there are several federal regulations in place to protect the rights of children with disabilities that emphasize the need to ensure effective partnerships between families and professions that provide services to children with disabilities. For example, the Individuals with Disabilities Education Improvement Act of 2004 (IDEIA) created entitlements for children with disabilities to have access to transition services from the age of 16 through an individualized education program, ensured that services provided be based on evidence-based research, and emphasized a prevention and early intervention model for provision of special education services (Yell, Shriner, & Katsiyannis, 2006). The ultimate goal of IDEIA was to improve outcomes for students with disabilities by ensuring that highly qualified special education personnel, inclusive of teachers and paraprofessionals, provide evidence-based practices based on the student's individual needs (Yell, Shriner, & Katsiyannis, 2006). Furthermore, IDEIA ensures that parents receive annual updates on their child's progress from the IEP, and that parents have the

opportunity to consult with the team and discuss any necessary modifications. The New Jersey Administrative Code, Title 6A, Chapter 14 ensures that the rights of students with disabilities ages 3 to 21, inclusive of children with ASD and their parents, are protected. These rights include the requirement that general and special education personnel are provided training in evidence-based practices and collaborative skills needed to meet the individual needs of children with disabilities. Additionally, parents are mandated to be involved in team meetings where the individualized education plan for their child is created and annually reviewed, and it is required that parents be presented with information about the services, accommodations, and treatments their child is meant to receive in a language they can understand. A new education law submitted as a reauthorization of the Elementary and Secondary Education and the No Child Left Behind Acts, The Every Student Succeeds Act (ESSA, 2015) ensures that parents are involved in the decision-making process for their child's direct services, have adequate information to make meaningful choices, and be afforded multiple opportunities for the parent to be active participants in their child's education. Most importantly, Section 1116 [20 U.S.C. 6318] of the ESSA (2015) states that local educational agencies must actively involve parents and engage family members in the activities intended to improve the education for their children with disabilities. Parent and family engagement includes coordination, consultation, and integration among families and school personnel, teachers, and members of the local educational agency. This includes the rights of parents to comment on and be involved with the provision of services for their children, have ongoing communication between parents and teachers, such that parents may be appropriately engaged in their child's special education. Assessments for child functioning and progress must also solicit feedback from school leaders and parents about their satisfaction with the assessment system.

However, research suggests that there is a gap between what professionals are called to do by law and their actual practice in forming collaborative interactions with parents, resulting in parent dissatisfaction and stress (Blue-Banning et al., 2004; Hartley & Schultz, 2014; Robert, Leblanc, & Boyer, 2014; Zuna, Gràcia, Haring, & Agular, 2016). For example, even though IDEIA, ESSA, and the New Jersey Special Education Code emphasize that activities and services provided to children be clearly explained to parents, studies have elucidated that parents may misunderstand the interventions offered to them (Carlon, Stephenson, & Carter, 2014). Further, parents may generally lack understanding of the service system, including eligibility for services and which services to use at different points in their child's development (Brookman-Frazee, Baker-Ericzén, Stadnick, & Taylor, 2011). Additionally, previous studies suggest that parent dissatisfaction with services results from a lack of collaboration between the parent and the professional (Robert, Leblanc, & Boyer, 2014), even though parent engagement in service provision was written into the Special Education Code as an aspect of best practice. Research has also shown that parents' negative experiences with service provision involves ineffective communication when interacting with providers, leaving parents to wonder if their providers had the required expertise and training to care for their child properly. This is despite the fact that these federal regulations require providers be highly qualified individuals trained in the provision of evidence-based treatments (Brookman-Frazee, Baker-Ericzén, Stadnick, & Taylor, 2011; Carlon, Stephenson, & Carter, 2014). As parents are often the intermediary between the child and the child's professional service providers, additional research into parents' experiences with family-professional partnerships and family-centered services can highlight ways in which these relationships and interventions could be improved to benefit parents' satisfaction with these services, and ultimately, the treatment of their child. As family involvement in service planning

has been significantly and positively associated with satisfaction (Popp & You, 2016), and family satisfaction with services has been shown to significantly predict family wellbeing and quality of life (Summers et al., 2007a), an investigation into aspects of these services that parents perceive as leading to high, and by comparison, low satisfaction can support professionals in improving provision of services to families with children with disabilities. Research focused on ways that professional service providers assist parents in seeing the strengths in their children's functioning can provide a strengths-based approach to research with parents of children with ASD, rather than reinforce deficits as has been the tradition in the clinical science literature.

An examination of the experience of and satisfaction with professional services for the families of children with ASD is beneficial, as service providers directly intervene with the family system in order to treat the children. Parent satisfaction has been found to correlate with treatment outcomes, such that dissatisfaction has been associated with problematic outcomes including treatment non-compliance and difficulty with ease of using health care services (Ngui & Flores, 2006), and satisfaction has been associated with active participation in services, perceived benefits of services, and more favorable outcomes (Bailey et al., 1998; Russa, Matthews, & Owen-DeSchryver, 2014). Therefore, satisfaction is an important indicator of compliance and positive treatment outcomes. In addition, it is also important to investigate a range of potentially confounding variables that may impact the rating of parent satisfaction with services, as these have been consistently mentioned as goals for future investigation in previous literature. For example, studies have shown that age of the child with a disability can influence parent satisfaction with services, where parents of older children with ASD have reported lower satisfaction with the services provided to their children (Bailey et al., 1998; Summers et al., 2005a). In conceptualizing these findings, researchers have noted that children with ASD

experience an "aging out" of services, in that services are less available or reliable with increased age of the child with ASD. Still, the relationship between age of child and parent satisfaction with services is variable, and dependent upon other factors under consideration in the research, including income level, communication with service providers, and race and ethnicity of the family. A study by Rattaz and colleagues (2014) aimed to examine parents' satisfaction with professional services and investigate whether this satisfaction varied as a function of the child's age. Results showed that parents of adolescents reported a higher rate of dissatisfaction with services; however, this was best explained by dissatisfaction with specific aspects of services (e.g. parents reported being less informed about the goals of the interventions implemented and having less frequency of contact with providers) than the age of the child alone. Similarly, a previous study by Summers et al. (2005b) found that parents of children with disabilities ages three to five expressed lower levels of satisfaction with professional partnerships when they also identified as being middle income, whereas respondents of higher-income backgrounds expressed lower satisfaction with services when their children were older. In an earlier example of this research, Bailey et al. (1998) suggested that parent ratings of satisfaction with professional services may vary with the child's age due to negative experiences with transitioning between services or school systems, the challenges brought on by school-age children, children aging out of services, and the contrast between a positive experience with early intervention services and current services. In addition, early negative experiences with intervention services play an integral role in shaping negative views of the service system and associated professionals, while positive experiences with professionals can engender positive feelings for an individual service provider while families maintain negative views about the service system (Bailey et al., 1998). Bailey et al. (1998) emphasized that families may have

more negative perceptions of professionals and services as the child gets older, potentially due to challenges experienced by parents of school-aged children and in perceptions of transitions (Hablin-Wilson & Thurman, 1990, as cited in Bailey et al., 1998). As a continuation of this research, Summers and colleagues (2005a) also note the importance of focusing on family characteristics, income, and perceptions of the quality of services in future research. Thus, this study will contribute to the literature by providing additional data on the impact of contextual variables, such as child age, parent age, socioeconomic status and access to insurance, on parent satisfaction with professional services for their child with ASD, as the challenges faced by these children and families are systemic, multidimensional and complex.

In addition to family demographic variables, parents' perceptions of their child's functional behaviors are important to examine when assessing their satisfaction with professional services for their children with ASD. Children with ASD can have difficulties ranging from issues with self-regulation, social relatedness, communication, externalizing behaviors, repetitive behaviors and restricted interests. Although a number of studies have investigated how severity of a child's disability interacts with a variety of family factors (Bitterman et al., 2008; Blue-Banning et al., 2004; DePape & Lindsay, 2015; Kissel & Nelson, 2016; Wang et al., 2004), few have examined the presence of a disability or ASD from a positive lens, whereby a child's strengths and abilities are also captured. Kissel and Nelson (2016) also noted that few studies have examined how severity of ASD in children influences parents' and family functioning, and that even fewer studies to date have examined parents' perceptions of the severity of autistic behaviors. The current study will incorporate a measure that assesses parents' perceptions of the severity of their child's ASD, as well as perceived strengths associated with adaptive prosocial behaviors. In addition, asking parents directly through open-ended questions how services have

informed them of their child's strengths will provide parents with an opportunity to share these strengths as opposed to solely focusing on their child's deficits. It also reinforces positive parental beliefs about their child, which may offset frustrations experienced by child behavioral problems and systemic stressors.

Although many previous studies aimed to analyze qualities of professional partnerships that improve treatment for children with ASD, few studies have taken into account parent perceptions of the severity of the child's functioning, and even fewer have considered child functional behaviors from a strengths-based approach. Parent perceptions of the severity of their child's functioning has been shown to directly impact their feelings about, and engagement in, treatment. Parent perceptions of interventions, often measured as parent satisfaction with services, is an important outcome measure because satisfaction with services has been correlated with more active participation with services as well as higher perceived benefits of those services (Bailey et al., 1998; Russa, Matthews, & Owen-DeSchryver, 2014). Parents' feelings about the efficacy of treatments for their children with ASD, as measured by parent satisfaction with services, have been shown to have a direct influence on treatment compliance, length of treatment, and choice of therapy (Green, 2007 as cited in Mackintosh, Goin-Kochel, & Myers, 2012). Severity of disability has been associated with higher maternal stress and burden, lower marital satisfaction, higher parental depression, and lower family well-being (Wang et al., 2004). However, in past studies, severity of disability has been measured by increased behavior problems or low rates of communication in the child with ASD, and rarely incorporated a positive assessment of the child's functional behaviors. In so doing, these studies seem to attribute some of the responsibility of parental satisfaction with services to the parent, without addressing the stress imposed by systems, which often present parents with significant barriers.

This study will incorporate a measure of prosocial behaviors to assess if parent's perceptions of positive aspects of their child's functioning is related to their satisfaction with services. In addition, the study will examine the relationship between parent satisfaction with services, a variable with a meaningful influence on treatment outcomes, and stress experienced from social services to determine the influence on the family system. Thus, higher levels of stress and lower levels of satisfaction would suggest more systemically oriented contributions to the well-being of the family, as measured by parent functional appraisals of their child.

Previous literature on the severity of ASD in children and parent satisfaction with professional partnerships and services has typically incorporated additional variables (i.e. family quality of life, age of the child, social support, parent stress) to explain this relationship. In addition, research that has investigated parent perceptions of the severity of their child's behaviors has tended to focus on the presence or absence of the child's deficits, and has rarely incorporated a strengths-based approach which considers the parent's perception of their child's functional strengths and abilities. As a result, there has been an under-recognition of child and family strengths, and therefore, strengths-based approaches to treatment which consider parent's perception of their child's functional strengths and abilities. An emphasis on strengths has several benefits, including reducing stigma associated with ASD, promoting parent-child relationships, enhancing utilization of resources, and promotion of well-being in the family system.

A study that examines parents' perceptions of ASD, specifically, with an added focus on parent perceptions of their child's strengths and abilities, is merited. However, research on severity of ASD as it relates to child and family outcomes does not always measure severity empirically, and in studies that have examined this relationship, they have minimized the value

of positive aspects of functioning. Of the studies that have focused on parents of children with

ASD, researchers typically have focused on the severity of ASD, highlighting the child's deficits

and maladaptive functioning in relation to parent stress or family functioning. For example,

Kissel and Nelson (2016) measured parent perceptions of the severity of their child's autistic

behaviors using a parent questionnaire (Gilliam Autism Rating Scale-2; Gilliam, 1995), which

measures the probability of a child having an ASD by asking parents to rate the frequency of

stereotyped behaviors and problems with communication and social interactions. Blue-Banning

et al. (2004) and Wang et al. (2004) measured severity of disability through a demographic

questionnaire, asking parents to classify their child's ASD severity as mild, moderate, or severe.

Other studies have used parent rating scales or checklists that provide an opportunity for parents

to rate the frequency of problem behaviors or maladaptive functioning (i.e. Autism Behavior

Checklist, Social Responsiveness Scale, Social Communication Questionnaire, Child Autism

Syndrome Test; Fernandopulle, 2011). There is no opportunity on the GARS-2 or similar ASD

rating measures to note any positive or functional behaviors of the child, focusing instead on

counting the frequency or absence of problem behaviors. A study utilizing a measure that

incorporates the functional behaviors of a child with ASD could present more positive findings

related to the child's behaviors and family functioning, and might provide the opportunity for

research to highlight strengths in children with ASD.

Although the majority of studies have pointed to the negative impact of having a child

with ASD on the family, research on the influence of disability severity on parents of children

with ASD and the family has been mixed (Wang et al., 2004). Perhaps this is because some

studies have focused on a range of disabilities and used a control group of neurotypically

developing children, groupings that may present too different an experience for direct

comparison. In addition, resilience, early identification, and positive meaning-making of adversity have also been identified as potential protective factors for parents of a child with ASD (Bayat, 2007), which may also lead to mixed results regarding the impact on parents of having a child with ASD. Exploration of positive psychological factors such as these, which identify health as opposed to psychopathology, can provide parents with an opportunity to report on the positive impact of having a child with ASD (Bayat, 2007). Summers et al. (2005b) and Bayat (2007) have called for strengths-based approaches to studying families of children with disabilities, with a request to focus on ways in which parents use meaning-making or positively adapt to having a child with a disability. Research that considers parents' perceptions of their child's functional abilities and provides parents with an opportunity to identify their child's strengths could provide much-needed evidence of the utility of strengths-based approaches to undergoing investigative research with parents of children with ASD. Furthermore, providing parents with insights about strengths can also help to reduce stigma associated with parenting a child with ASD, and may attenuate depression and learned helplessness in parents.

Purpose of the Study

The purpose of this mixed-methods study was to investigate parent satisfaction with professional services provided to their child with ASD, and to examine whether parent satisfaction with services and professional partnerships varied as a function of the parents' perception of their child functioning. This study also examined the influence that stress associated with satisfaction had on parent perceptions of child behavioral strengths and challenges. This study aimed to fill a gap in the literature by considering parent perceptions of the severity of their child's functioning while also considering child functional behaviors from a strengths-based approach.

Secondary analyses investigated whether parent satisfaction with professional services was influenced by a number of family demographic variables, including family income (Bayat, 2007; Bitterman et al., 2008; Wang et al., 2004), access to insurance (Mackintosh, Goin-Kochel, & Myers, 2012; Ngui & Glores, 2006), size of the family unit (Bayat, 2007), socioeconomic status (Bailey et al., 2004; Bitterman et al., 2008; McNaughton, 1994; Popp & You, 2016; Wang et al., 2004), age of the child with ASD (Bayat, 2007; Mackintosh, Goin-Kochel, & Myers, 2012; McNaughton, 1994; Ngui & Glores, 2006; Summers et al., 2005a), and age of the parent respondent (McNaughton, 1994). To fully explore satisfaction and the interaction between perceived needs and outcomes, broader demographics can provide information on family situation factors (i.e. socioeconomic status, age of the parents, age of the child, severity of the child's disability) that may influence levels of family need as well as factors affecting levels of satisfaction (DePape & Lindsay, 2015; Hartley & Schultz, 2014; McNaughton, 1994; Wong et al., 2012).

Research Questions and Hypotheses

Below are the research questions and hypotheses posed by the present study, based on the rationale presented in this chapter.

1. What is the relationship between parent appraisals of the functional behaviors of their child with ASD and satisfaction with child services from professional service providers?

    a. Hypothesis: Parents who report lower child problem behaviors and higher levels of child prosocial behaviors would report greater satisfaction with child-focused services.

2. What is the relationship between parent appraisals of the functional behaviors of their child with ASD and parent satisfaction with family-focused services from professional

partnerships?

    a. Hypothesis: Parents who report lower child problem behaviors and more favorable appraisals of their child's social functioning would report greater satisfaction with parent-professional partnerships.

3. How do parents' perceived stress levels influence the relationship between satisfaction with services and appraisals of child strengths and challenges?

    a. Hypothesis: Parents who reported higher perceived levels of stress would report lower satisfaction with services and less positive appraisals of their child's functioning.

4. What is the relationship between parent satisfaction levels with professional services and age of the child with ASD?

    a. Hypothesis: There will be a negative correlation between age of the child and parent satisfaction levels, based on previous research that has found that parents of older children with ASD report higher dissatisfaction with services (Rattaz et al., 2014; Summers et al., 2005a; Wang et al., 2004)

5. How do parents qualitatively describe positive and negative experiences with service providers? How do parents feel that service providers are able to influence their ability to see strengths in their child's functional behaviors?

Definition of Terms

Autism Spectrum Disorder (ASD) is a group of neurodevelopmental disorders marked by persistent deficits in social communication and social interaction, in addition to restrictive, repetitive patterns of behavior (American Psychiatric Association, 2013). These symptoms are typically present from early childhood, persist throughout the lifespan, and can impair

functioning across multiple domains. ASD can range in severity depending upon the level of support needed and the presence or absence of co-occurring disorders, such as intellectual impairment, language impairment, or sensory processing disorder. The CDC (2018) estimates that the prevalence of ASD across the country is 1 in 59 children, per the 2014 surveillance year (Baio et al., 2018).

Family-Professional Partnerships are defined as mutually supportive and respectful interactions between families and professionals in which the primary focus is on meeting the needs of children and their families (Summers et al., 2005b). These partnerships should be collaborative, involve service integration and family involvement, and are characterized by the presence of factors such as competence, commitment, equality, purposeful communication, respect, and trust (Blue-Banning et al., 2004; Summers et al., 2005b). Family-professional partnerships include family-centered practices and child-focused services. Family-focused relationships are practices that emphasize family strengths, encourage family decision-making, and involve collaborative partnerships between parents and professional service providers (Blue-Banning et al., 2004). Child-focused relationships are those that the family or parent thinks are necessary for the child and those that had a positive impact on their child's development and behavior (Bailey et al., 1998).

Service Providers are professionals who provide treatment and interventions to children with disabilities. Service providers can include therapists, counselors, social workers, case managers, service coordinators, doctors, and nurses (Summers et al., 2005b). Domains of service provision can include behavioral, speech-language and communication, occupational, physical, social, and academic interventions.

Child Functional Behaviors are those behaviors exhibited by children with ASD that contribute

to their optimal development. For children with ASD, this study will explore functional

behaviors by focusing on prosocial behaviors as measured by the Strengths and Difficulties

Questionnaire (SDQ; Goodman, 1997). Prosocial behaviors on the SDQ include those behaviors

that are associated with positive social interactions with others, such as being considerate,

sharing, caring for others, being kind to other children, and offering help to others (Stone et al.,

2010).

Significance of the Study

This research can aid in the ongoing assessment and interventions that inform best

practices and advocacy for children with ASD and their families. These families experience

significant adversity, and given the increasing prevalence of ASD in the United States, treatment

providers and social service agencies must maintain and monitor supportive practices that will

instill positive parent efficacy and promote optimal family functioning. Unique to this study is

the inclusion of a positive psychological framework, as a departure from the longstanding

deficit-oriented models of research with these families. In doing so, the study may help to

provide readers with a balanced view of families with ASD children, by both articulating these

challenges from an individual and systemic framework and by measuring adaptive behaviors that

can be used to reduce stigma and promote strengths-based interventions.

Items of importance and satisfaction from the quantitative measure utilized in this study

can be used to facilitate discussions among family members and professional service providers,

which can lead to greater understanding of barriers to care and the importance of the presence of

particular attitudes and skills from service providers (Summers et al., 2005b). The qualitative

component of this study may provide parents with a forum to explore the aspects of their

professional-partnerships that they feel contribute to their knowledge about their child's

strengths. The opportunity for parents to be asked about their experiences with service providers, while having the chance to focus on their child's strengths, can be positive and empowering for parents of children with ASD, who have been shown to encounter significant stress surrounding access to and experiences with their child's services, particularly when asked about their child's deficits. By allowing parents to focus on their child's strengths and ways in which they are informed of these strengths, this study can help inform service providers about meaningful ways to integrate a strengths-based approach to help parents see more strengths in their children with ASD.

Furthermore, this study will also identify the contributions of social systems in parent stress levels and perceptions of their child's behavioral strengths and challenges. From this perspective, social systems disempower members of marginalized groups (e.g., people of color, individuals with disabilities) in that they favor those in power that conform to standards of perceived "normality." Children and families with developmental disabilities face stigma resulting from embedded biases and beliefs in service providers. For example, the fact that parents of children with ASD face more obstacles than other parents in receiving adequate services suggests that there are unique systemic barriers that must be understood and addressed by scholars, policy makers, and social service agencies. Parent perceptions, therefore, are partially accounted for by systemic stressors that burden family systems with feelings of isolation, rejection, and marginalization from interactions with institutions.

Chapter II

LITERATURE REVIEW

Having a child with ASD can influence various dimensions of the family and has implications for their quality of life, interpersonal functioning, and psychological well-being. From diagnosis of ASD through to the process of care and treatment for their child, parents are faced with numerous challenges and demands associated with parenting a child with ASD (Bailey et al., 1998; Estes et al., 2013; McStay et al., 2014). Yet, families of children with ASD also display resiliency in handling these challenges (Bayat, 2007). The present study will apply a strengths-based framework to understanding families of children with ASD as well as their experience with service providers. This includes a focus on positive psychological models of family adaptation and family- and child-centered approaches to service delivery. The current chapter provides a review of the literature on the family impact of having a child with ASD, including resilience models, and the literature on family and service provider relationships, including those that focus on collaborative relationships. Literature regarding parent satisfaction with services utilized for their child with ASD, parent perceptions of child functional behaviors, and parent stress will be reviewed to determine their reported associations, limitations of previous research, and future directions. The influence of having a child with ASD on the family will be reviewed, as well as positive psychological models of family adjustment. In addition, the impact of services and professional partnerships on the family and the importance of strengths-based approaches to care will be examined.

Autism Spectrum Disorder: Parent Perceptions and Family Impact

Children with ASD tend to have significant delays in their communication and language development, behavioral deficits, and problems with social interactions. These symptoms persist

across the lifespan, requiring multiple levels of support (APA, 2013). Studies have suggested

that the higher the rate of problem behaviors displayed by the child with ASD and the more

severe the problem behaviors, the higher the experience of stress in the parent-child relationship

(Davis & Carter, 2008; Huang et al., 2014; Kissel & Nelson, 2016). Child behavior problems,

particularly poor social relatedness, limited prosocial behaviors, and conduct problems, have

been shown to be significant predictors of parenting-related and psychological distress (Estes et

al., 2013; Huang et al., 2014). In addition, caregivers of children with ASD have reported higher

parenting stress than parents of children with other behavioral or neurodevelopmental disorders

in a number of studies (Davis & Carter, 2008; Huang et al., 2014; Kissel & Nelson, 2016; Lovell

& Wetherell, 2016; McStay et al., 2014; Wong et al., 2012;). Parenting stress has been partly

accounted for by the family adjustment following an ASD diagnosis. For example, a

longitudinal study by Davis and Carter (2008) provided parent-report questionnaires to 54

families of children recently diagnosed with ASD to measure family adjustment and well-being.

Results from this study showed that parents who reported clinically elevated scores on the

Parenting Stress Index demonstrated highest scores in the area of parent-child relationships,

indicating higher levels of experienced stress (Davis & Carter, 2008). Researchers also found

that the most consistent predictor of parenting stress was evidence of delays in child social skills,

as indicated by scores on the ADOS reciprocal social interaction scale and the ITSEA social

relatedness item cluster (Davis & Carter, 2008). Regression analyses revealed significantly high

levels of stress among parents when children were young, indicating high stress surrounding

diagnosis and initiation of intervention services (Davis & Carter, 2008). In another study by

Huang and colleagues (2014), caregivers of children with ASD were interviewed using the

Childhood Autism Rating Scale, the Strengths and Difficulties Questionnaire (SDQ), and the

Parenting Stress Index. Results revealed that caregivers of children with mild behavior problems reported lower parenting stress than parents of children with more severe behavior problems (Huang et al., 2014). In addition, prosocial behaviors and conduct problems as measured by the SDQ significantly predicted stress in the parent-child relationship (Huang et al., 2014). In a review of previous literature, Cridland and colleagues (2014) reported that some families of children with ASD reported negative outcomes on family functioning, evidenced by higher levels of psychological problems and higher family conflict. Based on results of these studies, family adjustment and parent-child relationships appear to be impacted by child problem behaviors or child lack of prosocial behaviors, but it is not clear how these behaviors or familial relations can be improved. Research should examine aspects of interventions that either reduce problem behaviors or improve child prosocial behaviors among children with ASD from the parents' perspective in order to potentially decrease parent stress and improve parent-child relationships.

In addition, parent stress related to having a child with ASD has been associated with stress relating to obtaining services and treatments. A number of studies have highlighted the stress of caregiving, accessing treatments, managing multiple treatments, and the financial strain associated with caring for a child with ASD (Cridland, Jones, Magee, & Caputi, 2014; DePape & Lindsay, 2015; Minnes, Perry, & Weiss, 2015; Robert, Leblanc, & Boyer, 2015). Parents may have to pay out-of-pocket for services, drive long distances to access treatment facilities, or even relocate and make career changes to ensure better insurance coverage (DePape & Lindsay, 2015). Approximately one third of individuals with ASD require assistance with self-care, communication, and activities of daily living, the majority of which is provided by family members (Cridland, Jones, Magee, & Caputi, 2014). Navigating changes in supports from

home-based to school-based and community services has also been shown to produce frustration for families, as they have to develop new relationships with different providers and adapt to different models of services delivery (Minnes, Perry, & Weiss, 2015). Results from a survey of parents of children with ASD revealed that lower family income and lower functional ability of the child was associated with barriers in accessing adequate services and less help in coordinating such services, leading to lower rates of parent satisfaction (Sobotka, Francis, & Vander Ploeg Booth, 2015). Similarly, a study by Rivard and colleagues (2014) revealed that parents of children with ASD expend considerable efforts to find and gain access to appropriate services and noted difficulty in finding availability and information regarding assessments needed to qualify for specialized services. As families are faced with multiple challenges in accessing and coordinating care for children with ASD, additional research into family perspectives on service systems and the impact of such services on the family can inform best practices and address the issues faced by families of children with ASD.

However, the findings regarding the influence on the family of having a child with a disability have been mixed. Huang et al. (2014) noted that parenting stress was not consistently associated with child social relatedness and other autistic behaviors, and that additional studies are warranted to elucidate the relationship between parenting stress and autistic behaviors. Wang and colleagues (2004) noted that research on the association between severity of disability and family outcomes are mixed, with some studies showing increased maternal stress related to disability severity and others reporting higher marital satisfaction. This may, in part, be due to the fact that families of children with more severe needs are often eligible to receive more intensive services with greater frequency of support (Wang et al., 2004). In addition, not all studies examining parents raising children with ASD have reported high levels of parenting

stress. Research has indicated that ASD severity may not significantly contribute to parenting stress over and above other child variables (Davis & Carter, 2008; McStay et al., 2014; Wang et al., 2004). Stress levels in families raising a child with disabilities have also been shown to be similar to levels of stress exhibited by parents of children with externalizing problems or conduct disorders (Hastings & Taunt, 2002). Parents of children with disabilities reported lower levels of parent stress when the family emphasized personal growth and healthier family relationships (Kissel & Nelson, 2016). Additionally, parents have described some benefits of caring for a child with ASD, inclusive of improved relationships among family members, increased patience, and improved ability to cope (DePape & Lindsay, 2015). As parents display vast differences in their adjustment and coping abilities, an examination of potentially positive outcomes of having a child with ASD would meaningfully contribute to the literature.

Positive Psychological Models of Family Adjustment

Studies conceptualizing family adjustment and coping or resilience models have suggested that families adapt to and find meaning in having a child with a disability (Bayat, 2007). Hastings and Taunt (2002) examined families' positive experiences of having a child with a disability through a qualitative analysis, and found that parents reported increased sensitivity, support among family members, and improved family dynamics as a result of having a child with developmental disabilities. Lightsey and Sweeney (2008) reported that mothers of children with disabilities perceive benefits of having a child with a disability, including experiencing a greater purpose in life and sense of meaning, personal and spiritual growth, and increased strength and closeness in the family. Bayat (2007) noted increasing evidence that families of children with ASD demonstrate strength and resilience, which suggests that having a child with a disability can foster positive contributions to the family's life and well-being. Bayat

(2007) conducted a qualitative analysis of 175 parents of children with ASD, asking parents to describe positive and negative effects of ASD on their family life and personal life. Parents who made a positive adaptation to having a child with ASD reported positive family outcomes, such as having successful marriages, emotionally well-adjusted children, and increased patience, compassion, selflessness, and respect for others (Bayat, 2007; Cridland, Jones, Magee, & Caputi, 2014). In a review of the literature, Scorgie, Wilgosh, and Sobsey (2004) found that families of children with disabilities reported developing improved perspective on what is important in life. Although parents of children with disabilities can experience hopelessness and shock, especially when they first learn of their child's condition, there are a number of family factors that that have been found to moderate family stress and well-being, including family cohesion, parental coping mechanisms, and the child's behavior problems (Lightsey & Sweeney, 2008). In a study on the predictors of relationship satisfaction for parents of children with ASD, results suggested that programs that teach parents ways to positively interpret the circumstances surrounding their child's ASD diagnosis promote better coping styles, optimism, and relationship satisfaction among parents (Ekas, Timmons, Pruitt, Ghilain, & Alessandri, 2015). Similarly, additional research has shown that parents who have lower stress levels have reported better coping strategies and more positive perceptions of their situation and the resources available to them (Minnes, Perry, & Weiss, 2015; Robert, Leblanc, & Boyer, 2014). Despite the extraordinary challenges faced by families of children with ASD and the increased demands placed on the family, families show resilience by working together, being flexible, utilizing their resources, and communicating well with one another (Bayat, 2007). Thus, research investigating the positive aspects and contributions to the family of having a child with a disability can inform service providers about the benefits of teaching and aiding families in utilizing such coping skills

to foster healthy adjustment and promote a greater sense of wellbeing for parents and their children.

Due to inconsistencies in the literature on the relationship between ASD severity and parent stress, additional research is needed to investigate parent perceptions of the severity of their child's functioning in relation to their stress and well-being. Parent perceptions of the severity of their child's disability have been significantly related to family satisfaction and parental sense of well-being (Bayat, 2007). In a study done by Bayat (2007), parents of children with ASD were asked to describe the impact of having a child with ASD on their family life. Qualitative analysis revealed that 11 of 18 subcategories coded from transcribed interviews had positive valence, indicating that families noted strengths from having a child with ASD, including being connected, pulling resources together, making meaning of adversity, affirmation of strength, and becoming more compassionate (Bayat, 2007).

In addition, research on parent perception of a positive impact from having a child with disability has shown that positive impact moderates the relationship between parent stress and child behavior problems (Lightsey & Sweeney, 2008). In a study done by Lightsey and Sweeney (2008), 64 parents of children with developmental disabilities were given the Coping Inventory for Stressful Situations, the Generalized Self-Efficacy Scale, the Family Environment Scales, the Perceived Stress Scale, the Meaning in Life Questionnaire, the Family Satisfaction Scale. Hierarchical regression analyses showed that stress, emotion-oriented coping style, and family cohesion accounted for significant variance in family satisfaction (Lightsey & Sweeney, 2008). More specifically, when entered as a predictor after stress, meaning in life significantly predicted family satisfaction. In addition, mothers who reported lower stress, used less emotion-oriented coping, and who had higher meaning in life and family cohesion reported experiencing higher

family satisfaction (Lightsey & Sweeney, 2008). In fact, meaning in life was able to

significantly predict family cohesion and family satisfaction. As a change in meaning in life was

shown to predict positive changes in family functioning and greater psychological well-being,

results from this study have practical implications for counselors to help clients tolerate stress,

achieve greater self-efficacy, and utilize more coping skills (Lightsey & Sweeney, 2008).

A review of previous research on the utility of family systems and family-focused

approaches with families of children with ASD presented a mix of negative and positive

outcomes for families and indicated that strengths-based and positive psychology approaches

have helped families respond to grief and confusion, improve the family's capacity to build

skills, and encourages acceptance and appreciation for the family's functioning and resilience

(Cridland, Jones, Magee, & Caputi, 2014). Research providing a more balanced perspective on

parent perceptions of both positive and negative aspects of their child's behavioral functioning,

including prosocial behaviors and behavioral difficulties, is needed.

Family-Professional Partnerships and Family-Centered Services

Family-professional partnerships are defined as equal, mutually respectful, and

collaborative relationships that benefit the interactions between children, families, and

professional service providers throughout treatment (Blue-Banning et al., 2004; Stroup-Rentier,

Summers, Palmer, & Turnbull, 2015). Family-based interventions are those focused on

improving the overall functioning of the family system in the ultimate support of the child's

treatment (Cridland, Jones, Magee, & Caputi, 2014). Aspects of these partnerships that promote

a successful relationship between families and professionals include trust, mutual respect, open

and clear communication, collaboration, dedication, and good interpersonal skills (Bailey et al.,

1998; Summers et al., 2005b). These partnerships require professionals to build trusting

relationships with families and among family members to support family well-being and promote family engagement in the service planning and intervention process (Popp & You, 2016; Stroup-Rentier, Summers, Palmer, & Turnbull, 2015). Increasing family knowledge about ASD, improving the family's ability to accept and appreciate the child with ASD, and developing the family's ability to implement skills and increase self-efficacy improves child outcomes and family functioning and resilience (Cridland, Jones, Magee, & Caputi, 2014). To generate purposeful family-professional partnerships, professionals must deliver family-focused and child-focused services. Family-focused services emphasize family strengths, collaborative partnerships between parents and professionals, and the importance of family choice and control regarding decision-making about interventions (Blue-Banning et al., 2004). Child-focused services are interventions delivered to children which meet their unique needs and goals (Summers et al., 2005b). As professionals must form close, functional relationships with parents in order to properly serve the child (Blue-Banning et al., 2004), it is worthwhile investigating whether parents perceive these professional partnerships to be effective and how parents feel these services are able to benefit their children. To assess whether these services are truly meeting the family's needs, parent perceptions of the quality of their services and their professional partnerships should be considered and further analyzed.

Families of children with ASD vary in terms of their resources, priorities, concerns, and values. Professional service providers must take an individualized approach to care in order to accommodate unique family characteristics, values, and preferences (Bailey et al., 1998), to incorporate the child's individual needs and presentation (Popp & You, 2016), and to develop meaningful treatment goals and strategies to achieve them (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Children with ASD typically use a wide range of services to accommodate

their health and educational needs, and families of children with ASD use more services at a significantly higher frequency than children with disparate disabilities (Bitterman et al., 2008; Carlon, Stephenson, & Carter, 2014). According to a study by Bitterman and colleagues (2008), children with ASD were five times more likely to be involved in different types of services than children with other disabilities, who were three times as likely to be involved in different types of services. For children with ASD, this was significantly greater than the number of services received by children with other disabilities, even after controlling for disability severity (Bitterman et al., 2008). In a review of the literature done by Carlon, Stephenson, and Carter (2014), research on treatments used with children with ASD revealed that more than half of the sample used at least two interventions, inclusive of empirically supported treatments and complementary or alternative interventions. It has been consistently found throughout the research that children with ASD are often enrolled in numerous treatments concurrently, such as speech therapy, occupational therapy, behavior therapy, and social skills training (Carlon, Stephenson, & Carter, 2014), which can be difficult for parents to coordinate and manage alongside their existing responsibilities (Mackintosh, Goin-Kochel, & Myers, 2012).

Given the scale of their needs and the wide range of treatments and services available, families of children with ASD need the support of professional service providers to inform them of available treatment options, involve them in the process of service delivery and decision-making, and enhance their ability to meet their child's needs. Informing parents of children with ASD about treatment options and involving them in the decision-making process has been shown to be integral to successful treatment outcomes (Auert, Trembath, Arciuli, & Thomas, 2012; Popp & You, 2016). In a qualitative study done by Popp and You (2016), parents were interviewed on their satisfaction with services and service providers, involvement in service

planning, and parental self-efficacy. Findings suggested that involving families in service planning from the outset of treatment had indirect, positive effects on parental self-efficacy, and that a collaborative relationship between the parent and provider in which the parent felt supported in meeting their child's needs led to higher parental self-efficacy and reported feelings of empowerment (Popp & You, 2016). Based on previous research, best practice indicates that parents should be fully informed about the process of treatment from the outset and their preferences should be valued in this process in order to ensure satisfaction with services and, ultimately, that their children's needs are met (Auert, Trembath, Arciuli, & Thomas, 2012). To accomplish these goals, research has suggested that professionals take a family-centered approach to care.

A family-centered approach to service delivery is based on the collaborative relationship between parents and the professional service providers. Collaborative partnerships between families and professionals is a recommended practice that increases effective service delivery by allowing parents and professionals to work toward mutually agreed upon goals (Blue-Banning et al., 2004). Collaborating on goals can foster parent engagement in treatment and strengthen the parent-professional partnership (Stroup-Rentier, Summers, Palmer, & Turnbull, 2015). Family-centered approaches call for professionals to collaborate with and involve families as full partners in the decision-making process in order to incorporate family needs, preferences, and priorities into the intervention (Auert, Trembath, Arciuli, & Thomas, 2012). Turnbull and Turnbull (2002) emphasized that parents want control in the decision-making process to preserve family values and goals, and to feel ownership in the process of implementing interventions. Parent involvement and collaboration in decision-making directly influences parents' ability to have more positive partnerships with professionals (Scorgie, Wilgosh, & Sobsey, 2004). This is

especially important because parent engagement and involvement in professional partnerships

has been shown to lead to positive treatment outcomes for children with ASD (Auert, Trembath,

Arciuli, & Thomas, 2012). This may be because families of children with ASD play an integral

role in the advocacy of their child's needs to the service provider (Auert, Trembath, Arciuli, &

Thomas, 2012), as they know best their child's strengths and weaknesses, and can speak to

family system preferences and values (Dunlap & Fox, 2007). In addition, parent involvement

and collaboration with professionals is necessary to individualize treatment and to make services

more accessible to families (Bailey et al., 1998), and it allows families to utilize their expertise in

determining goals for treatment (Popp & You, 2016). Communication between parents and

service providers regarding a child's treatment and goal attainment have been identified as

elements of parent-professional partnerships that empower parents in the treatment process by

helping them make informed decisions about which they can feel confident (Auert, Trembath,

Arciuli, & Thomas, 2012; Goin-Kochel, Mackintosh, & Myers, 2007). Studies indicate that

collaborative partnerships that promote individualization of intervention and attend to family

access and resources improve family engagement with services and adherence to treatment.

Therefore, investigating aspects of these partnerships that parents identify as satisfactory and

purposeful can inform professional practice and improve treatment outcomes. In addition,

measuring particular aspects of family-professional partnerships that parents perceive as

satisfactory can enhance evaluation of such programs, provide a basis for comparison across

treatments, and identify specific skills that can be improved through training and professional

development (Summers et al., 2005b).

   Although federal laws such as IDEIA (Yell, Shriner, & Katsiyannis, 2006) and ESSA

(2015) mandate that professional service providers ensure collaborative partnerships among

families of children with disabilities, research has indicated that there is a gap between professional ethics regarding best practice and their actual practice (Blue-Banning et al., 2004; DePape & Lindsay, 2015). Parents of children with disabilities have reported feeling alienated or marginalized by the system and the professionals providing services for their children, noting that these professionals make decisions without them and force them to take more passive roles in their child's care (Scorgie, Wilgosh, & Sobsey, 2004). In addition, parents reported dissatisfaction with simply being the recipients of information as opposed to being directly involved with service providers in the provision of care (Scorgie, Wilgosh, & Sobsey, 2004). DePape and Lindsay (2015) reported that parents had difficulty navigating the service system, reporting that teachers appeared to have a lack of understanding of ASD and how to resolve behavioral issues, while others complained of ineffective communication in accessing treatment, leaving parents wondering if certain health care professionals had the required expertise to care for their child. In a study by Blue-Banning and colleagues (2004) utilizing qualitative inquiry and focus groups with parents of children with disabilities, parents explained the importance of having professionals acknowledge their expertise and perceptions as the parents of the child in treatment, and the need for professionals to empower parents by validating their points of view and helping them participate in decision-making. Results of this early study utilizing focus groups consisting of ethnic minority parents of adolescents with disabilities showed that the disparity of power and authority in relationships with professionals was a major barrier to forming a successful partnership with their service provider (Blue-Banning et al., 2004). Parents emphasized that when professionals maintained control of the service planning process, they did not feel like they were seen as equal partners in the professional relationship (Blue-Banning et al., 2004).

Parents can be disadvantaged in professional partnerships because of obstacles created by the system, highlighting the importance of establishing equality and reciprocity on the part of professionals to empower and value families (Blue-Banning et al., 2004). There are a number of systemic factors that can complicate shared decision-making between professionals and parents of children with ASD, including parent education level (Robert, Leblanc, & Boyer, 2014), parent resources and support systems (Minnes, Perry, & Weiss, 2015), financial resources (Zuna, Gràcia, Haring, & Aguilar, 2016), and family understanding of the service system (Brookman-Frazee, Baker- Ericzén, Stadnick, & Taylor, 2011). Parents have indicated considerable stress and frustration with understanding the service system. In a study done by Brookman-Frazee, et al. (2011), parents reported organizational factors that impacted the effectiveness of their care, such as high turnover of staff in the clinic, and also noted that they experienced challenges in determining their eligibility for services. In particular, parents noted that changes in staff, lack of coordination across service providers, and perceived lack of provider knowledge about treating children with ASD required additional efforts on the part of the family find ways to communicate changes between these service delivery systems (Brookman-Frazee, Baker-Ericzén, Stadnick, & Taylor, 2011). These systemic factors impact treatment efficacy, parent engagement in treatment, and ultimately reduce optimal child outcomes.

Previous research has shown the importance of professionals sharing authority with families and having a more family-centered, collaborative orientation in order to better engage with parents and form true partnerships (Dunlap & Fox, 2007). Supportive professional partnerships can facilitate positive transformations for parents of children with disabilities by enhancing parents' self-awareness and acceptance, empowering parents, and helping parents focus on positive attributes of the family (Minnes, Perry, & Weiss, 2015; Scorgie, Wilgosh, &

Sobsey, 2004). The ultimate goal of a family-centered approach is to emphasize family choices and strengths, make services more accessible, and empower families to enhance their capacity to meet their child's needs (Bailey et al., 1998; Minnes, Perry, & Weiss, 2015). Effective family-centered approaches that are individualized to each family's needs and goals have the potential to increase successful implementation of services, family adherence to services, and feelings of competency and self-efficacy among parents of children with disabilities. As parents are often disenfranchised members in the health care system, who often feel disempowered in the process of service provision, a greater understanding of their experiences from their own perspectives can be acquired by elevating parents' voices and opinions through research. Assessing parent perceptions of family-centered approaches and family-professional partnerships can lead to a better understanding of aspects of care that lead to greater parent satisfaction and, thus, better treatment outcomes.

Parent satisfaction with professional partnerships and services. Parents of children with ASD have reported mixed satisfaction with the services that their child receives. This is dependent upon a host of different factors, including number of services and amount of services received (Bitterman et al., 2008), the quality and quantity of communication with professionals (Rattaz et al., 2014), their relationships with professionals and the perceived efficacy of treatment (Mackintosh, Goin-Kochel, & Myers, 2012). When surveyed about their satisfaction with health care services, families of children with ASD reported being less satisfied with the help they received than families of children with Down Syndrome, physical disabilities, or intellectual disabilities (Bitterman et al., 2008). Research by Bitterman et al. (2008) revealed that parents of children with ASD reported less satisfaction regarding the quantity of services provided, in terms of both the hours of services delivered and the number of different services

received, when compared with parents of children with other disabilities. Although parent interviews indicated that parents of children with ASD were satisfied with the quality of services, parents expressed concern about quantity, despite the fact that children in this study were shown to receive more services on average than children with other developmental disabilities (Bitterman et al., 2008). Additionally, in a study by Rattaz et al. (2014), parents of children with ASD expressed more dissatisfaction with services than other parents, citing a lack of available services and skilled service providers.

Parents of children with ASD have also reported negative relationships with service providers based on perceived lack of respect, and lack of trust with professionals who were perceived to have neglected attending to the child's individual needs (Mackintosh, Goin-Kochel, & Myers, 2012). In a study done by Mackintosh, Goin-Kochel, and Myers (2012), 486 parents were asked to respond to the question, "what do you like/dislike about the treatment(s) you're currently using?" Qualitative coding of responses generated themes including effectiveness of treatments, relationships with professionals, access to desired treatments, costs, and stress (Mackintosh, Goin-Kochel, & Myers, 2012). Regarding relationships with professionals, three quarters of parent responses indicated perceptions of negative relationships, as parents reported a lack of respect from providers and feeling as though providers did not listen to them or respect them (Mackintosh, Goin-Kochel, & Myers, 2012). In another study done by Rattaz and colleagues (2014), parents of children diagnosed with ASD were asked open-ended questions regarding their experiences with service provision and quality. Parents reported that a lack of information about their child's involvement in the intervention, difficulty communicating with professionals, a lack of contact with professionals, and feeling as though they were not considered partners by the professional were the factors that contributed to their dissatisfaction

with services (Rattaz et al., 2014).

Parents of children with ASD have expressed frustration with the high turnover of service providers, a lack of available specialists, long waiting lists, and the cost and effort required of parents to utilize available services for their children (Mackintosh, Goin-Kochel, & Myers, 2012). For example, Ngui and Glores (2006) surveyed Black and Hispanic parents of children with disabilities and found that parents reported dissatisfaction with care and difficulties regarding ease of using health care services. Results utilizing multivariate logistic regression modeling revealed that parents of racial and ethnic minority children with disabilities had significantly greater odds of being dissatisfied with healthcare services when compared to parents of White children with special healthcare needs (Ngui & Glores, 2006). Specifically, results showed that lack of insurance coverage, severity of the child's behaviors, and difficulty with ease of using health care services were all significantly associated with greater dissatisfaction with care (Ngui & Glores, 2006). Taken together, research in this area has suggested that there are significant sources of dissatisfaction for parents of children with ASD, and that this dissatisfaction may be higher for parents of children with ASD than for other parents. Thus, clarifying characteristics of professional partnerships that increase parent satisfaction with services through additional research can improve partnerships, enhance service delivery, and promote family engagement in service provision (Stroup-Rentier, Summers, Palmer, & Turnbull, 2015).

Services that are more family-focused, and that foster meaningful partnerships between families and professionals, result in greater parent satisfaction with services (Blue-Banning et al., 2004). Clear communication, which has been identified as an essential component of family-professional partnerships, significantly contributes to parent satisfaction with services (Robert,

Leblanc, & Boyer, 2014). Communication with service providers that includes psychoeducation regarding treatment and the nature of the child's disability has been shown to promote family engagement and satisfaction with services (Stroup-Rentier, Summers, Palmer, & Turnbull, 2015). Rattaz and colleagues (2004) interviewed parents of children with ASD about their satisfaction with special education and care services for their children. Results indicated that parents reported the importance of coordinated, family-centered services in which providers communicate frequently about their child's behavior, development, and care (Rattaz et al., 2004). Therefore, it is important to measure the extent to which services are perceived to positively influence child development and help children work toward established goals so that parents can determine whether services received are appropriate and purposeful in their delivery (Bailey et al., 1998; Robert, Leblanc, & Boyer, 2014).

A better understanding of family perspectives on the factors that have been identified as essential to successful family-professional partnerships could enhance professional practice and refine the meaning of partnerships from the perspectives of the parent partners (Blue-Banning et al., 2004; McNaughton, 1994; Zuna, Gràcia, Haring, & Aguilar, 2016). Measuring parent satisfaction with care is an important indicator of quality of care and access to care, which are key measures for monitoring and evaluating the performance of service provision systems (Ngui & Glores, 2006). Parent satisfaction with services has been used as an outcome measure to assess the appropriateness, efficacy, responsiveness, and individualization of services for the child and their family in a number of studies (Bailey et al., 1998; Summers et al., 2005b). In this way, parent satisfaction can be used as an indicator of the effectiveness of interventions and service programs, and thus can be assessed as an outcome measure (Rattaz et al., 2014). Using satisfaction as an outcome measure fits conceptually with a family-centered approach to care, as

it provides an assessment of the perceived benefits of services from the parents' perspective (Bailey et al., 1998). In addition, measuring and ensuring parent satisfaction is required by the IDEIA (Yell, Shriner, & Katsiyannis, 2006), which states that the goal of interventions should be to enhance the ability of families to meet their child's needs and to include families in the decision-making process regarding their child's care (Bailey et al., 1998; Summers et al., 2005b), both of which have been indicated as predictors of parent satisfaction. Parent satisfaction with services has also been associated with parent involvement and positive treatment outcomes (Bitterman et al., 2008; Russa, Matthews, & Owen-DeSchryver, 2014; Summers et al., 2005a), and thus can be used as a measure by which service delivery and outcomes can be improved (Rattaz et al., 2014). Parent satisfaction can be used as a proxy variable for positive outcomes and treatment compliance, making this an essential variable for intervention planning and research. And as children with ASD have been shown to utilize a greater number of health care services with more frequency than children with other disabilities, an analysis of parent satisfaction with services for children with ASD, specifically, is warranted.

Parents' feelings about the treatments they utilize directly influence the level of the family's compliance in treatment (Mackintosh, Goin-Kochel, & Myers, 2012). In a study done by Ngui and Glores (2006), parents of children with special health care needs were asked to identify satisfaction with care and factors that contribute to ease or difficulty regarding their use of health care services. Lack of insurance and cost barriers were found to be associated with dissatisfaction with care and problems with ease of using health care services, indicating the need for insurance outreach efforts to increase retention of eligible patients (Ngui & Glores, 2006). Parent satisfaction with care has also been shown to influence health behaviors, including adherence to treatment, changing service providers or health care plans, and involvement in

litigation (Ngui & Glores, 2006). Negative experiences with professionals and the special

service system can result in low adherence to services, low parenting self-efficacy, and a

negative view of professional service providers as seemingly insensitive or unresponsive (Bailey

et al., 1998). Negative experiences and difficulties in relationships with professionals have also

been shown to be significant sources of stress for families (Mackintosh, Goin-Kochel, & Myers,

2012). Based on parent survey data, factors of adequate family-centered care, including provider

listening skills, flexibility of providers, time spent with providers, the amount of information

given by providers to families, and perceived partnership with families, were all determined to

contribute to greater satisfaction with services (Ngui & Glores, 2006). The strong association

between these family-centered care factors and satisfaction with services has been shown in

general health care settings, but has yet to be investigated among services for children with

special health care needs (Ngui & Glores, 2006). In addition, parent opinions and satisfaction

were determined to have yet to be sufficiently considered in care services proposed for their

children (Rattaz et al., 2014). As parent perceptions of and experience with service providers has

been shown to influence treatment compliance (Mackintosh, Goin-Kochel, & Myers, 2012),

research on aspects of parent experiences with professional services that are associated with

greater treatment compliance would help inform professionals and interventions. Thus, parent

satisfaction and dissatisfaction with programs and service providers can be used to create better

services, increase adherence to treatment, and enhance program effectiveness.

Measures of parent satisfaction with services should incorporate the quantity and quality

of services from the parent's perspective, as well as provide opportunities for discussion

regarding the perception of child benefits through involvement with these services (Bailey et al.,

1998). The Beach Center Family-Professional Partnership Scale has been identified through

extensive qualitative research as an appropriate tool to evaluate parent perspectives of professional-partnerships and parent satisfaction with services (Summers et al., 2005b). Qualitative approaches, including open-ended questions and rank-ordering services, can provide researchers with a richer understanding of the subjective perspectives of parents regarding satisfactory service provision (Bailey et al., 1998; Cridland, Jones, Magee, & Caputi, 2014; DePape & Lindsay, 2015; Robert, Leblanc, & Boyer, 2014). Multi-method measurement approaches that combine quantitative measures and qualitative data should be used in conjunction to provide in depth information on deficiencies and strengths in the services provided, and should assess a wide variety of factors that may influence perceptions of family need and satisfaction with services, including socioeconomic status, severity of the child's disability, age of the parents, and age of the child (McNaughton, 1994; Minnes, Perry, & Weiss, 2015). Quantitative approaches complemented with qualitative sections can help capture the multifaceted issues often present in the lives of families with ASD and can also avoid restricted responses as a result of either method utilized alone (Cridland, Jones, Magee, & Caputi, 2014; Minnes, Perry, & Weiss, 2015).

Strengths-Based Research on Family Perceptions of Children with ASD

Parent satisfaction has been identified as an important aspect of research on parents of children with ASD and their service utility, with the goal of improving family-professional partnerships and child-centered care. Identifying areas in which families exhibit strengths and report positive effects from raising a child with ASD can help service providers capitalize on these strengths and utilize coping mechanisms in treatment to improve child and family functioning. Families face many challenges in adjusting to and coping with having a child with a disability, such as increased demands and stress on the family (DePape & Lindsay, 2015),

learning about and accessing the service system (Hartley & Schultz, 2014), and managing the

child's behavioral challenges (Minnes, Perry, & Weiss, 2015). However, solely focusing on

these negative aspects and experiences of having a child with a disability prevents the research

from highlighting the meaning-making and enrichment that families have reportedly experienced

by having a child with a disability. There is evidence to show that a significant number of

families experience resilience and report becoming a stronger, closer family as the result of

having a child with a disability in the family (Bayat, 2007; Hastings & Taunt, 2002). Factors

that contribute to family resilience and their ability to adapt to a challenging situation include

meaning making of adversity, keeping a positive outlook, utilizing resources, flexibility, and

communication (Bayat, 2007; Scorgie, Wilgosh, & Sobsey, 2004). Although some research has

highlighted positive experiences of raising a child with a disability (Bayat, 2007; Hastings &

Taunt, 2002; Summers et al., 2005a), family resilience and adaptive functioning in families of

children with disabilities is less often explored in the research than the negative impact on

families of having a child with ASD. Researchers have advocated for an emphasis on family

strengths and resilience in researching families of children with disabilities to better understand

family strengths, coping strategies, support mechanisms, and a range of possible parent and

family outcomes (Bayat, 2007; Cridland, Jones, Magee, & Caputi, 2014; Scorgie, Wilgosh, &

Sobsey, 2004; Summers et al., 2005a; Taunt & Hastings, 2002). The role of positive perceptions

may even serve as a coping function for families, helping them adapt to the experience of raising

a child with a disability (Hastings & Taunt, 2002). More research is needed to investigate the

way in which positive perceptions of having a child with a disability can positively influence the

family.

　　　　Although the majority of research on families of children with disabilities has focused on

negative aspects of caring for a child with a disability, some, albeit fewer, studies have shown that families report positive perceptions of having and raising a child with disabilities (Hastings & Taunt, 2002; Minnes, Perry, & Weiss, 2015). Research on the relationship between child behaviors and parent stress has more often emphasized problems and challenges in child functioning, with little to no exploration of the child's areas of strength or competency (Davis & Carter, 2008). Researching strengths-based approaches to service provision can help providers focus on family strengths and build on the positive when providing interventions (Bayat, 2007). Considering positive aspects of children's behaviors is important when working with parents who are already experiencing stress from the demands of caring for their child and other parenting-related challenges. Within family-professional partnerships, communication can be used as a vehicle to convey sensitive information to families, avoiding the implication of blame, and including positive comments about the child as well as their challenges (Blue-Banning et al., 2004). By promoting factors associated with resilience, service providers can help families recognize their own capacity for strength and promote further well-being in the family (Bayat, 2007). In a study done by Minnes, Perry, and Weiss (2015), parents of children with developmental delays and disabilities completed surveys assessing their child's adaptive behaviors, parent coping strategies, family resources, and positive and negative treatment outcomes from the parents' perspectives. Results indicated that parents perceived greater positive gain when they were able to use coping skills such as reframing, and when service providers helped parents feel empowered in their parenting self-efficacy (Minnes, Perry, & Weiss, 2015). There are clear implications for additional research to be conducted which evaluates the role of positive perceptions in moderating the impact of a child's disability on the family (Hastings & Taunt, 2002). Minnes, Perry, and Weiss (2015) recommend that research

into parents' perceptions of involvement with professionals and their child's outcomes as a result of interventions should use multi-method measurement approaches inclusive of interview data to strengthen their findings.

Questionnaires utilized in a number of research studies are often parent-report measures that tend to focus on deficits of the child's functioning in order to confirm diagnosis or highlight the severity and pathology of the child's autistic behaviors (Bayat, 2007). Hastings and Taunt (2002) noted that a parent from their pilot study complained that the questionnaires provided did not offer the opportunity to describe any positive experiences of having a child with disability on the family. Investigators in other studies have also reported that families tend to identify negative, stressful experiences alongside positive experiences of raising a child with a disability (Hastings & Taunt, 2002), highlighting the need to present a balanced view, if not also to provide opportunities to report positive experiences and perceptions. To obtain a more holistic view of the family's experience, both positive and negative perceptions of experiences need to be collected and analyzed. Qualitative research can be used as an effective tool to explore and refine the meaning of professional partnerships from the perspectives of parents (Blue-Banning et al., 2004). Cridland, Jones, Magee, and Caputi (2014) suggest that those conducting research with families living with ASD should consider using qualitative approaches to capture the multifaceted issues often present in families, which benefit from being complemented with quantitative research through a mixed-methods approach to more fully capture the subjective experiences of parents. Providing a voice for the stakeholders of this process in the context of their experience can generate a better understanding of the parent experience and indicate aspects of professional partnerships that can be emphasized for more effective and satisfactory treatment. A mix of open-ended questions, Likert-scale satisfaction statements, and quantitative

questionnaires can elicit subjective experiences alongside measured expressions of satisfaction and dissatisfaction from parents in areas of importance for each family (Cridland, Jones, Magee, & Caputi, 2014; McNaughton, 1994; Minnes, Perry, & Weiss, 2015).

Although previous studies have highlighted some of the negative impacts of having a child with ASD on the family, such as increased stress and negative parent-child relationships, there is a considerable amount of research which suggests that there are positive and transformative effects on the family of having, raising, and treating a child with ASD. Changes of perspective on life, opportunities to learn, and improved family dynamics have been posited as some of the positive impacts of having a child with ASD on the family (Hastings & Taunt, 2002). In addition, research on positive psychological models of family adjustment indicate that families exhibit resilience and report having become stronger as the result of having a child with a disability (Bayat, 2007). As opposed to researching aspects of family functioning that may limit child progress and development, research that investigates factors of service provision and broader systemic issues that may prevent families from receiving and accessing effective accommodations for their children, and thus being able to form productive professional partnerships, can explore potentially positive child outcomes. A significant characteristic of interventions for children with ASD involves family-professional partnerships, and in particular, parent satisfaction with services and service providers. Family-centered care should emphasize family strengths and family involvement in decision making to make services accessible, individualized, and flexible with family values and needs in mind (Bailey et al., 1998; DePape & Lindsay, 2015; Popp & You, 2016). Therefore, it is important to research aspects of service provision and family-professional partnerships with which parents experience satisfaction and dissatisfaction to improve family-centered approaches to care and thus enhance the family's

capacity to meet their child's needs.

Chapter III

METHODS

Purpose of the Study

This chapter will review the study methods in detail, including research design, psychometric instruments, study procedures, participants, methods of data collection, and plans for analysis. The purpose of this study was to investigate the relationship among three main variables (parent satisfaction with professional partnerships; parent stress; child functional behaviors), in addition to demographic variables (parent age, child age, family SES, access to insurance), through a mixed-methods design that provided both quantitative and qualitative analyses.

Participants

Participants were parents, primary caregivers, or legal guardians of children and adolescents between the ages of 4 and 17 who were diagnosed with an ASD. Ages of children with ASD included in the study met inclusion criteria for all questionnaires and measures under consideration, particularly the SDQ which is normed on a population of children ages 4 to 17. The focus on this age range will allow the researcher to focus on the developmental period following early intervention and prior to the transition to adulthood. Parent participants must have been involved with service provision for their child at some point during their child's development. Parents may have been actively and currently involved with social service systems at the time of this study, or not currently involved but have been previously involved with service systems. No exclusion was made based on gender, sexual orientation, race, ethnicity, or religion.

Method of Data Collection

Parents or legal guardians completed questionnaires regarding their levels of stress, their experience of stressful life events, their perceptions of their child's functional behaviors and difficulties, and their satisfaction with the services utilized for their children with ASD. Participants were recruited through Amazon's Mechanical Turk (MTurk), a web resource that allowed the researcher to pay a nominal advertising fee to recruit subjects for surveys. Participants were offered two dollars per unique assignment; this amount was decided upon due to the length of the study and the considerable effort required to complete the combination of questionnaires and open-ended questions. I made efforts to ensure that participants were indeed parents by selecting that the qualification of workers in MTurk include only those participants who have previously indicated that they were parents. In addition, I selected keywords in the design of the study in MTurk, including the words "survey, autism, autism spectrum disorder, parent, stress, satisfaction, psychology, child, teenager, services, provider" to help individuals search for the survey. Participants were first directed to a letter of solicitation, and then were able to complete questionnaires via a link to the Qualtrics survey.

This study was conducted through anonymous online surveys. Participants were informed that their names were not going to be used in connection with the study, and that their responses would not be linked to their identity. Participants were provided access to the web survey on Qualtrics through a unique link which was included on MTurk. Participants were first directed to review the letter of solicitation, which explained that continuing through to complete the surveys through the link constituted consent to participate in the study. After reading the letter of solicitation, participants could click a button which read, "I Agree to Participate - Take me to the Survey" in order to provide their consent. Participants were then directed to complete

the online questionnaires, beginning with two screening questions that assessed their relationship to the child and ensured that they had a child ages 4 to 17 with an ASD who has received services. Participants that did not meet the inclusion criteria (parent, legal guardian, or primary caregiver of a child ages 4 to 17 with ASD who has received services) were immediately skipped to the end of the survey, where they received the following message: "Thank you for your time. Your response has been recorded." Participants who met eligibility criteria were directed to complete the surveys on Qualtrics. Participants were instructed that they were able to withdraw from the study at any time by closing their browser window and exiting the survey.

Participants were administered the Family-Professional Partnership Scale, Cohen's Perceived Stress Scale, the Holmes-Rahe Social Readjustment Rating Scale, and the Strengths and Difficulties Questionnaire. Measures were administered via Qualtrics in a randomized order to control for any order effects. The Beach Center Family Professional Partnership Scale (FPPS; Summers et al., 2005b) was designed to measure satisfaction with services and programs for family members of children with disabilities. Cohen's Perceived Stress Scale (PSS; Cohen et al., 1983) assessed how much control participants feel they have over their own life events and how much stress they have experienced over the past month. The Holmes-Rahe Social Readjustment Rating Scale (SRRS; Holmes & Rahe, 1967) provided a list of contextual life events that may be a source of stress or significant personal adjustment. The Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) measured positive and negative psychosocial and behavioral characteristics of children from their parents' perception.

Lastly, participants were directed to answer a short series of open-ended questions to evaluate how parents felt service providers influenced their ability to see strengths in their child's functional behaviors. The following questions were asked:

1. With which service provider(s) have you and your child with ASD worked? Check all

   that apply:

   a. Speech/Language Therapist

   b. Occupational Therapist

   c. Physical Therapist

   d. Social Worker or Case Manager

   e. Counselor or Therapist

   f. Behavior Therapist

   g. Special Education Teacher

   h. Paraprofessional

   i. Other (Please Specify)

2. Briefly describe a positive experience you had with a service provider where you and
   your child felt supported.

3. Briefly describe a negative experience you had with a service provider where you and
   your child did not feel supported.

4. From the list of service providers below, select ONE service provider that you feel has
   helped you and your family the most. Provide an example of a time when they helped
   you understand something positive about your child.

   a. Speech/Language Therapist

   b. Occupational Therapist

   c. Physical Therapist

   d. Social Worker or Case Manager

   e. Counselor or Therapist

      f.   Behavior Therapist

      g.   Special Education Teacher

      h.   Paraprofessional

      i.   Other (Please Specify)

Instruments

      Beach Center Family Professional Partnership Scale (FPPS; Summers et al., 2005b)

The Family-Professional Partnership Scale (FPPS) was developed by the Beach Center on

Disability for use with family members of children with disabilities to measure their satisfaction

with service providers and programs. The FPPS was developed through extensive literature

review, focus groups, and factor analyses across two national studies to develop components of

interpersonal partnerships and to refine the scale (Blue-Banning et al., 2004). There are two

factors of the FPPS: Child-focused Relationships and Family-focused Relationships. Child-

focused relationships refer to families' perceptions regarding the care provided by professionals

to the child with a disability. Family-focused relationships measure families' perceptions

regarding their own partnerships with the professionals providing care for their child. The FPPS

rates satisfaction items on a 5-point Likert scale, from 1 (very dissatisfied) to 5 (very satisfied).

The FPPS was piloted on 291 parents (87% women, 13% men; 89% biological or foster parents

of a child with a disability, 7% guardians, 4% grandparents) using a nationwide sample. An

exploratory factor analysis led to the elimination of items that did not load above .40 Cronbach's

alpha on a factor and produced a two-factor solution: child-focused relationships and family-

focused relationships. Following a second national study that included 205 families,

confirmatory factor analysis led to the revision of the scale to a total of 18 items, with 9 items

each in the Child-Focused and Family-Focused domains. For satisfaction ratings, the fit

statistics for the Child-Focused factor was $X^2(27) = 47$, $p < .001$, $CFI = .97$, $RMSEA = .07$ (Summers et al., 2005b). For the Family-Focused factor, the fit was $X^2(27) = 61$, $p < .001$, $CFI = .94$, $RMSEA = .09$ (Summers et al., 2005b). The two-factor satisfaction model fit statistics were $X^2(134) = 270$, $p < .001$, $CFI = .90$, $RMSEA = .08$ (Summers et al., 2005b). Cronbach's alpha for the 9 Child-Focused items was .94 and .92 for the 9 Family-Focused items (Summers et al., 2005b), demonstrating high internal consistency for the two subscales. Cronbach's alpha for satisfaction ratings on the 18-item scale was .97 (Summers et al., 2005b).

The Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) The Strengths and Difficulties Questionnaire (SDQ) has been widely used in research and practice to screen for positive and negative child psychosocial and behavioral characteristics. The SDQ was based on the Rutter Questionnaires, and updated to reflect issues of child psychopathology by adding items regarding concentration, peer relations, and social competence (Goodman, 1997). There are two versions of the SDQ included in this stud – one for 4 to 10-year olds, and another for 11 to 17-year olds. Both versions of the SDQ are to be completed by parent informants and take approximately 5-10 minutes to complete. Each version of the SDQ consists of 25 questions measuring 5 domains: emotional symptoms; conduct problems; hyperactivity and inattention; peer relationship problems; and prosocial behaviors (Goodman, 1997). The first four domains listed can be totaled to generate an overall difficulties score, based on 20 items. The prosocial scale was added to make the assessment more strengths-based and positive for respondents, and items were based on the Prosocial Behavior Questionnaire (Goodman, 1997). All items were specifically written to reflect DSM-IV and ICD-10 diagnoses, which provides the scale with high content validity. For example, the inattention-hyperactivity domain includes two items for inattention, two items for hyperactivity, and one item for impulsivity to cover key

symptomatology for a diagnosis of ADHD (Goodman & Scott, 1999). The SDQ has been

translated into more than 60 languages and has been widely used as a screening and research tool

in clinical assessment across over 10 different countries (Stone et al., 2010). Items on the SDQ

were written to allow parental endorsement of positive items, such that there is a greater

emphasis on positive attributes (Goodman & Scott, 1999). Internal consistency results for the

SDQ completed by parent informants produced adequate reliability, with a Cronbach's alpha for

the total difficulties scale of .80. Concurrent validity of the SDQ was reported to be high when

compared with the Child Behavior Checklist (CBCL; Achenbach, 1991), another widely-used,

informant-rated questionnaire of child psychological functioning. Correlations between the SDQ

and CBCL were all high for total scores and domain specific scores (Goodman & Scott, 1999;

Stone et al., 2010). Specifically, weighted correlations of .76 for parent ratings were found

between the total difficulties score of the SDQ and the CBCL total score. In addition, the SDQ

was found to be significantly better at detecting inattention and hyperactivity than the CBCL,

and equally as able to detect internalizing and externalizing problem behaviors (Goodman &

Scott, 1999). The SDQ is significantly briefer than the CBCL, and reliability among

commensurate scales shows strong criterion validity for the SDQ (Goodman & Scott, 1999).

Support for the five-factor model for the parent versions of the SDQ were found in four studies

reviewed by Stone et al. (2010), showing strong construct validity. Parents in a study comparing

the use of the SDQ and the CBCL in a low-risk sample reported a strong preference for the SDQ

due to the brevity and strength-based emphasis of the items (Goodman & Scott, 1999). The SDQ

has shown evidence of strong predictive validity through the stability of parent ratings over a

one-year period ($r = .77$ for total difficulties; $r = .77$ for hyperactivity-inattention subscale; $r =$

.64 for prosocial; $r = .65$ for conduct; $r = .71$ for emotional; $r = .61$ for peer problems; Stone et

al., 2010). A Flesch-Kincaid reading level analysis determined that the SDQ is at a fourth-grade

reading level.

       The Perceived Stress Scale (PSS; Cohen et al., 1983) The Perceived Stress Scale (PSS)

is the most widely used psychological instrument for measuring the perception of stress. The

PSS is a self-report questionnaire that was designed to measure "the degree to which individuals

appraise situations in their lives as stressful" (Cohen et al., 1983, p.385). On the PSS,

participants rate 10 items concerning their feelings and thoughts during the last month on a 5-

point Likert scale ranging from 0 (never) to 4 (very often). Items on the PSS evaluate the degree

to which individuals believe their life has been unpredictable and uncontrollable, and how much

control individuals feel they have over life events that have occurred in the previous month. The

PSS was designed for use in community samples and was normed on a population of 2,387

adults across the United States (mean age = 43, SD = 17; Cohen et al., 1983). As parents

represent a high base rate of the general population, parents are likely well represented in this

norming group. In addition, the PSS has been used in studies with parents to assess their levels

of stress in relationship to having a child with ASD (Conner & White, 2014; Lightsey &

Sweeney, 2008; Lovell & Wetherell, 2016). A recent meta-analysis by Lee (2012) strongly

supports the valid and reliable psychometric properties of the PSS. The PSS has a single-factor

structure and yields a single total score. Higher scores reflect higher levels of perceived stress.

Lee (2012) reviewed the psychometric properties of the PSS and found that the Cronbach's

alphas of the PSS were evaluated at > .70 in all 12 studies in which it was used. The internal

consistency of the PSS has an alpha of .89, indicating that the items on the questionnaire measure

the same construct. Additionally, the test-retest reliability of the PSS was assessed in four

studies and met criterion of > .70 in all cases. The review done by Lee (2012) also found strong

evidence for validity, as the PSS was either moderately or strongly correlated with the

hypothesized emotional variables, including depression and anxiety, as measured using the

Center for Epidemiologic Studies Depression Scale (Radloff, 1977). A Flesch-Kincaid reading

level analysis was conducted for readability. This analysis confirmed that the PSS is at a 6.4

grade reading level.

Holmes-Rahe Social Readjustment Rating Scale (SRRS; Holmes & Rahe, 1967) The

Holmes-Rahe Social Readjustment Rating Scale (SRRS), also referred to as the Holmes-Rahe

Stress Scale, is a self-administered questionnaire consisting of a list of 43 significant life events

that have been identified through clinical psychological experiences and are commonly reported

as stressful or requiring personal adjustment (Holmes & Rahe, 1967). The items listed in the

SRRS, "are change events...that precipitate movement from one equilibrium or the steady state to

another. Events address family constellation, marriage, occupation, economics, residence, group

and peer relationships, education, religion, recreation, and health" (Holmes & Rahe, 1967, p.

216). Life events include positive and negative incidents to account for the predictability,

centrality, desirability, and controllability of events (Dohrenwend, 2006). On this measure,

participants are instructed to respond 'yes' or 'no' to each of the listed life events dependent

upon whether the event has or has not occurred within the past 12 months. Respondents are also

instructed to rate the perceived stressfulness of each experienced life event on a 5-point Likert

scale, with the higher score indicating higher perceived Stress (Ngai & Ngu, 2013). Each life

event is assigned a number of Life Change Units, which refer to the amount of readjustment

required and the level of stress of the event (Ngai & Ngu, 2013), with undesirable and

uncontrollable events accounting for a higher magnitude of stress (Dohrenwend, 2006). The

more events that the participant has experienced, the higher the score, and the higher the risk that

the patient will experience psychological and/or psychosomatic responses to stress (Scully, Tosi, & Banning, 2000). A total score of 150 or less indicates a low level of stress and low probability of developing a stress related disorder; a total score of 150 to 299 suggests a moderate level of stress, and a higher probability of developing a stress-related disorder. A score of 300 or more indicates a high level of stress and an 80% chance of developing a stress related disorder. This measure will be used to provide context for parent participants' experiences of stress to account for additional life stressors that may contribute to parents' experiences of stress.

The SRRS is a frequently used measure among researchers and practitioners to study a wide range of common life stressors and has been cited in over 140 research publications (Scully, Tosi, & Banning, 2000). The SRRS was developed through survey of over 5,000 medical patients who were asked to report whether they had experienced any events in a series of 43 life events in the past two years. Holmes and Rahe (1967) found a positive correlation of 0.12 between the SRRS life change scores and illness scores, showing strong validity of the relationship between life events and illnesses. In addition, Gerst et al. (1978) tested the reliability of the SRRS and reported that rank ordering of the amount of readjustment required by life events was highly consistent for both healthy adult controls ($r = .89 - .96$) and patients ($r = .70 - .91$). Controls also demonstrated consistency in the weights assigned to life events over time ($r = .83$; Gerst et al., 1978). Test-retest reliability was reportedly high ($r = .94$) for total number of events over a two-week period (Dohrenwend, 2006).

Research Design

The proposed study employed a mixed-methods design, combining quantitative and qualitative methods to provide a more thorough understanding of parents' experiences of using services for their child with ASD. The benefits of mixed-methods include triangulation,

whereby both qualitative and quantitative approaches can be contrasted and compared to see if they support the same conclusions or provide divergent perspectives (Maxwell, 2013). For example, the strengths that parents identify about their children through open-ended questions can be compared with their scores on the SDQ. In addition, parent responses regarding their experience with service providers can be compared with their satisfaction scores on the FPPS. In this way, the qualitative and quantitative components of the research can complement each other and broaden the range of understanding of parents' experience with services utilized for their children with ASD. Secondary analyses were conducted to investigate whether parent satisfaction was influenced by additional demographic variables, as indicated in the previous literature (Bayat, 2007; Bitterman et al., 2008; Mackintosh, Goin-Kochel, & Myers, 2012; McNaughton, 1994; Ngui & Glores, 2006; Summers et al., 2005a; Wang et al., 2004;).

The mixed-methods design included cross-sectional and correlational analyses of self-report psychometric instruments and thematic analysis of qualitative open-ended questions. The benefits of employing mixed-methods included triangulation of data to corroborate and strengthen results, evidence of the prevalence of participant responses per demographic category, and it allowed participants the opportunity to participate through empirical questionnaires as well as open-ended responses. Participants' responses to the open-ended questions were analyzed through thematic analysis. Thematic analysis allowed the researcher to identify themes and patterns within data, and also provided additional interpretations of the research topic (Braun & Clarke, 2006). In thematic analysis, the researcher should take on an active role in identifying patterns found within participant responses (Braun & Clarke, 2006). Themes were generated from the data in an inductive manner to elicit the reality of participants' lived experiences and to retain the value of their responses (Mackintosh, Goin-Kochel, & Myers, 2012). Validity checks

were employed through an evaluation of contradictory evidence that challenged conclusions of

the study (Maxwell, 2013). Potential validity threats that may have arisen from data and data

collection methods were addressed by searching for discrepant evidence and negative cases

within the data, and an examination of such cases alongside data that support research

hypotheses. Triangulation was also employed by using both qualitative and quantitative methods

to reduce systematic bias when reporting study findings. Quantitative support for qualitative

data was used to show prevalence of themes and to assess the amount of evidence within the data

that supported or was discrepant from proposed hypotheses. Thematic analysis highlighted

particularity to promote integrity of individual cases through coding individuals first and then

returning to the data to ensure the breadth of participant responses had been captured (Morrow,

2005). Comparisons were made within the data between different types of primary caregivers,

socioeconomic backgrounds, and for different ages of children to ensure that data was re-

contextualized with consideration of demographic variables that might have influenced data and

participant responses (Morrow, 2005).

Recruitment

The participants in this study were parents or legal guardians of children with an autism

spectrum disorder (ASD) who have received and utilized services for their children with ASD.

All participants were recruited through MTurk, an recruitment service through online retailer

Amazon.com, which allowed participants to complete the questionnaires and open-ended

questions online via Qualtrics, a web-based survey software. When participants clicked the link

to the questionnaire, the first screen presented the letter of solicitation, which explained the

purpose of the study, the details of participant involvement, and the voluntary nature of

participation. Once participants volunteered to participate in the study, they were first given two

screening questions to ensure that they were the parent or legal guardian of a child with ASD and that the child with ASD was between the ages of 4 and 17 to meet inclusion criteria for the study. Parent participants then completed the demographic questionnaire and were presented with the 4 questionnaires (FPPS, PSS, Holmes-Rahe SRRS, and SDQ) in random order to account for order effects. Lastly, parents were given the opportunity to answer 5 open-ended questions about their satisfaction with the services and services providers with which they and their children with ASD have been involved.

Procedure

Questionnaires were uploaded and formatted to Qualtrics to ensure that participants could complete the surveys online and at their own convenience. Parent participants were recruited through Mechanical Turk (MTurk). A link to Qualtrics was provided to participants via the MTurk messaging system, which automatically notifies participants of studies listed on the site. Once on MTurk, participants who clicked on this study's information were presented first with the letter of solicitation, which included a definition of the consent to participate and an explanation of the financial incentives via MTurk. A copy of the letter of solicitation is included in Appendix I. At the end of the letter of solicitation, participants had the option to press a button which read: "I agree to participate. Take me to the survey." The letter of solicitation informed participants that should they wish to withdraw participation or not participate, they could simply close their browser window. The first part of the survey contained a demographic questionnaire, asking parents to clarify their relationship to the child (biological parent, legal guardian, step-parent, etc.), age, gender, marital status, highest level of education completed, their average annual income, the age and gender of the child with ASD about which they would be answering questions, and the number of children in the immediate family. Once the

demographic questionnaire was completed, participants pressed a button at the bottom of the screen that said "Next," which brought them to the quantitative questionnaires. The four questionnaires (FPPS; PSS; Holmes-Rahe; SDQ) were presented in random order to each participant to account for any order effects. Questionnaires were presented one at a time, and at the end of each questionnaire, participants needed to press a button that said "Next" to continue. When the last of the four questionnaires was completed, the participant was directed to the open-ended questions. Participants were not allowed to move on to the next open-ended question unless they provide text in the box provided. When participants completed the open-ended questions, their participation was considered completed, and a window appeared which stated: "Thank you very much for your time and participation. Your responses have been recorded. You should now close all browser windows to protect your privacy."

MTurk is a web resource through Amazon that allows researchers to pay nominal advertising fees to recruit subjects for the completion of questionnaires. These fees help to cover small monetary payments that Amazon provides to the individuals for their participation in the study via the MTurk website. Fees paid to participants in the present study amounted to two dollars per survey. As MTurk charges the researcher one bulk advertising fee, and then manages the distribution of small monetary payments in the form of credit for purchases on Amazon's website, participants were able to receive small payments while retaining their anonymity to the researchers.

Analysis of participant responses through open-ended questions was inductive and used thematic analysis. Thematic analysis involved initial coding of the data followed by the generation of themes and sub-themes, extraction of data into themes, and an interpretation of data in a final analysis (Braun & Clarke, 2006).

Statistical Power Analyses

Below is a description of each study research question and hypothesis, along with the associated planned statistical analysis and estimated power. With respect to the quantitative analyses, the current study examined the hypotheses through correlation and regression methods. Prior to hypothesis testing, the data was screened to ensure that it was appropriate for parametric analysis. The data was examined for outliers, normality, and multicollinearity and singularity; all of which can significantly distort correlational and regression findings.

Hypothesis 1: It was hypothesized that parents who reported lower child problem behaviors and higher levels of child prosocial behaviors would report greater satisfaction with child-focused services.

Analysis: The hypothesis was tested using the Child-Focused Relationships subscale of the Family Professional Partnership Scale (FPPS), the total difficulties score on the Strengths and Difficulties Questionnaire (SDQ), and the prosocial scale of the Strengths and Difficulties Questionnaire. This research question was tested with a multiple regression analysis, with total difficulties score of the SDQ as the predictor of the Child-Focused Relationships subscale of the FPPS. It was hypothesized that the total difficulties score of the SDQ (comprised of subscales: Emotional Problems, Conduct Problems, Hyperactivity, and Peer Problems) would be negatively correlated with the Child-Focused Relationships subscale of the FPPS, and that the prosocial behavior subscale of the SDQ would positively correlate with the Child-Focused Relationships subscale of the FPPS.

Power analysis was based on use of an F test, specifically linear multiple regression with a fixed model and R^2 deviation from zero. Based on an a priori power analysis with moderate power and effect and two predictors (SDQ total and prosocial behavior subscale) and a single

criterion variable, Child-Focused Relationships, the estimated sample size for adequate power was estimated at 68 participants.

Hypothesis 2: It was hypothesized that parents who reported lower child problem behaviors and more favorable appraisals of their child's social functioning would report greater satisfaction with family-professional partnerships.

Analysis: This hypothesis was analyzed with the Family-Focused Relationships subscale of the FPPS, the total difficulties score of the SDQ, and the prosocial subscale of the SDQ. This research question was tested with multiple regression analysis, using the SDQ subscales as predictors of the Family-Focused Relationships subscale of the FPPS. The four problem subscales of the SDQ were hypothesized to negatively correlate with the Family-Focused Relationships subscale of the FPPS, and the prosocial behavior subscale of the SDQ was hypothesized to positively correlate with the Child-Focused Relationships subscale of the FPPS.

(SAA) Power analysis was based on use of an F test, specifically linear multiple regression with a fixed model and R^2 deviation from zero. Based on a priori power analysis with moderate power and effect and two predictors (SDQ total and prosocial behavior subscale) and the criterion variable, Family-Focused Relationships, the estimated sample size was 68.

Hypothesis 3: It was hypothesized that parents who reported higher levels of stress would report lower satisfaction with services and less positive appraisals of their child's functioning.

Analysis: This hypothesis was tested with two hierarchical multiple regression analyses. In the first analysis, the subscales of the SDQ were entered as independent predictor variables, stress as measured by Cohen's Perceived Stress Scale and the Holmes-Rahe Social Readjustment Rating Scale as the second block of independent variables, and satisfaction as measured by the

Child-Focused Relationships subscale of the FPPS was entered as the outcome variable. In the second analysis, the subscales of the SDQ was entered as predictor variables, stress as measured by Cohen's Perceived Stress Scale and the Holmes-Rahe Social Readjustment Rating Scale were entered as the second block of independent variables, and satisfaction as measured by the Family-Focused Relationships subscale of the FPPS was entered as the dependent variable. In each of the models, stress (as measured by the Holmes-Rahe Inventory and Cohen's Perceived Stress Scale) was entered into the hierarchical regression at the same time as one block of predictors. To ensure that the measures were not redundant, Pearson correlation were evaluated to ensure that the correlation between the two stress variables did not exceed .80. Furthermore, the multicollinearity statistics served as a second test for overlapping variance between the two stress measures.

Power analysis was conducted using G*Power. Power analysis was based on use of linear multiple regression with a fixed model using change from zero, and R^2 increase. Based on a priori analysis with moderate effect size and power set at .80, an error set at 0.05, and 7 predictors, the estimated sample size was 116 participants.

Hypothesis 4: It was hypothesized that there would be a negative correlation between age of the child and parent satisfaction levels, as evidenced by previous research, which has found that parents of older children with ASD reported higher dissatisfaction with services.

Analysis: This hypothesis was tested through Pearson correlations.

Qualitative Analysis: What do parents experience as both positive and negative in their interactions with service providers? How do providers help parents see strengths in their child's functional behaviors?

Analysis: These qualitative questions were analyzed through inductive thematic analysis,

generating themes and a concise analysis through the direct use of participant responses. A semantic approach to the data was used to first identify themes from explicit description of the data, followed by an interpretation of the data to theorize the significance and implications of participants' responses (Braun & Clarke, 2006). As the researcher, I familiarized myself with the data by reading through participant responses and making initial codes. Once initial codes were generated, codes were organized into potential themes, specific phrases and statements were placed into those themes in order to present participants voices directly. This data-driven process involved reading and re-reading the data to ensure the researcher covered the breadth of the content of participants' responses. Thematic analysis allowed me to track coding schemes, themes, and sub-themes, and link themes back to the research question during the final analysis.

Qualitative Paradigm

Ponterotto (2005) and Morrow (2005) suggested that qualitative researchers address the conceptual framework of their research and the reasons behind their chosen framework in order to describe the goals of their analytic method and orient the researcher and the reader to the guiding theory held by the researcher throughout the analysis. In this section, I will address the postpositivist qualitative paradigm that I chose for this research study, how the facets of this research paradigm were addressed and carried out within a phenomenological framework, and how the use of inductive thematic analysis served the goals of a postpositivist paradigm.

Postpositivism and phenomenology. The guiding qualitative paradigm for this research study was that of postpositivism within a framework of phenomenological inquiry. Phenomenology aims to focus on the lived experience of those individuals involved in the research from their own perspectives (Wertz, 2005). Phenomenology directs the researcher to focus on the concrete experience of the reality of those under investigation, and promotes researcher neutrality in order

to better represent others' experiences in their own terms (Gergen, 2014). In line with the

premise of phenomenological inquiry, the goal of working from a postpositivist paradigm was to

explain phenomena objectively in an attempt to minimize bias (Morrow, 2005) while searching

for falsifications within and consensus among the data to enhance internal validity (Ponterotto,

2005). Qualitative research from a postpositivist approach is idiographic and emic, meaning that

the focus was on understanding the experiences of individual participants and the constructs that

are unique to those individuals within a social and historical context (Ponterotto, 2005).

Postpositivist research claims that researchers cannot find "absolute truth" through research, and

that research will always be imperfect (Creswell, 2003). To explain the postpositivist paradigm

further with regards to this research study, the following facets of qualitative research will be

defined: ontology, epistemology, axiology, rhetorical structure, and methodology.

　　　Ontology. Ontology allows researchers to make claims about what is knowledge

(Creswell, 2003) and what is the view of reality as held by the researcher (Ponterotto, 2005).

The ontology of postpositivism is one of "critical realism," in which researchers accept that

while there may be a true reality for participants' experiences, it can only be gathered and

measured imperfectly (Ponterotto, 2005). Postpositivism posits that the apprehension of an

objective reality is inherently flawed and that it is not possible to fully capture the true reality of

participants through an evaluation of data (Ponterotto, 2005). In this study, I constructed a set of

open-ended questions in order to get a collective of participant experiences with the hope of

identifying and describing an "approximal reality" (Ponterotto, 2005) for a group of parents of

children with ASD. With an understanding that this reality would be inherently impacted by my

own biases as well as by my chosen research methods, I chose to have another researcher audit

the data in order to gather another perspective of the data, resolve divergent opinions regarding

themes, and promote stronger support for themes in the final data analysis. In addition, I have

provided a reflexivity statement to acknowledge the discrepancies between my own experiences

and context versus that of my participants, and to explain some of the factors, such as my

expectations and clinical experiences, that could have impacted my data analysis.

Epistemology. Epistemology, or how we know what we claim to know (Creswell,

2003), is concerned with the relationship between the researcher and participants (Ponterotto,

2005). In this study, I tried to maintain a postpositivist position by emphasizing objectivism and

dualism (Ponterotto, 2005). I tried to maintain objectivity during data collection and analysis by

preserving dualism, defined as maintaining independence between myself and the participants

throughout the research process (Ponterotto, 2005). For example, dualism was maintained

through the research methods, as I conducted the study online and had no direct contact with

participants. I also tried to maintain objectivity by following standard procedures in my analysis

through use of quantitative methods for survey data as well as following the steps of thematic

analysis to analyze the qualitative data. In addition, I tried to collect a wide array of responses so

that I could compare and contrast numerous participant experiences and find support for themes

through the presence of ideas across multiple participant responses. Although I attempted to

study the research participants without directly influencing them, I recognize that it is inevitable

that I had an influence on the phenomena being researched through the methods that I chose, the

way that I asked my research questions, and the methods I chose to analyze the data. The

epistemology of this research is limited to the responses provided by participants that were

willing to volunteer and complete the open-ended questions. Participants needed to have access

to the internet and have prior knowledge of MTurk in order to be registered and receive notice to

participate in the research study. Additionally, participants had to be willing to spend time to

complete the questionnaires as well as the open-ended questions. Questions were only asked in English, and while I ensured that the questions posed throughout the study were at a fourth grade reading level, the accessibility of survey was further limited to those individuals with an English proficiency of at least fourth grade reading level. This limits the generalizability of results to those individuals who had internet access and were registered to the internet survey platform MTurk, who had the time and motivation to complete surveys online for small monetary compensation, and who were able to understand the questions and provide responses in English. I also acknowledge that my interpretation of the data is biased by my reading and understanding of the available responses. I attempted objectivism through my data analysis by remaining independent from the participants and by utilizing thematic analysis to guide the process of data analysis.

   Axiology. Axiology is defined as the researcher values that go into the researcher's assumptions of knowledge, or what the researcher claims they will learn and how they will learn it through their inquiry (Creswell, 2003). The assumption of axiology within postpositivism emphasizes the role of researcher values in the scientific process (Ponterotto, 2005). The use of thematic analysis for the qualitative portion of the study as well the use of mixed-methods consisting of quantitative measures supported the assumption of axiology by providing standardized, systemic investigative methods for data analysis (Ponterotto, 2005). The postpositivist design was also consistent with phenomenology, which calls for a bracketing of researcher preconceptions in order to maintain openness to the experiences told by participants (Gergen, 2014). From a postpositivist orientation, I tried to evaluate how my values influenced the research process through the use of a researcher reflexivity statement and consultation with my advisors. Despite this, it was inevitable that my values were reflected throughout the study,

from the selection of the research topic to the research design. I value a strengths-based approach to intervention and this motivated me to create a mixed-methods research design that would provide a space for parents in the qualitative portion of this study to discuss positive aspects of their children.

Rhetorical structure. The rhetorical structure, or the language used to present procedures and results of the research, reflected the epistemology and axiology of the postpositivist position, and was presented objectively to enhance researcher neutrality.

Methodology. Postpositivism offers methods to help objective researchers explain phenomena in a way that leads to predictions and generalization of the data (Ponterotto, 2005). The methodology of the research study was that of a mixed-methods approach. Within a postpositivist framework, the goal of utilizing a mixed-methods approach was to explain relationships among variables such that a broader conceptualization of the phenomena being studied could be presented. In addition, the study used mixed-methods to concurrently collect both quantitative and qualitative data to provide a more thorough understanding of parents' experiences of using services for their children with ASD. The mixed-methods strategy employed for this study was the concurrent triangulation strategy (Creswell, 2003), wherein quantitative and qualitative methods were collected at the same time, and then compared and contrasted to see if methods and results supported the same conclusions or provided divergent perspectives (Maxwell, 2013). This strategy integrated results of the mixed-methods in the interpretation phase of qualitative analysis to strengthen substantiated claims and explain divergent findings (Creswell, 2003).

Inductive thematic analysis. Thematic analysis (Braun & Clarke, 2006) is a qualitative analytic method for identifying, analyzing, and reporting patterns within data that can be applied

across different epistemologies and theoretical frameworks, and provides a rich and detailed analysis of data. I chose thematic analysis because it allowed me to report on the reality of participants while maintaining a focus on the limits of that reality (Braun & Clarke, 2006). This theoretical underpinning made thematic analysis a good fit for the qualitative analysis of this study as it is consistent with the ontology of a postpositivist paradigm, which posits that the reality of participants can only be apprehended and measured imperfectly (Ponterotto, 2005). I chose to analyze the data with an inductive, or bottom-up, approach, which involved a process of coding the data without a pre-existing frame and instead tried to allow the themes to emerge from the data itself (Braun & Clarke, 2006). Inductive thematic analysis ensured that the themes were strongly linked to the data as opposed to my research topic or preconceptions, which also helped to promote trustworthiness. Thematic analysis acknowledges that the researcher should take an active role in identifying patterns and themes across the data set and selecting important aspects of the themes of interest to report in the results (Braun & Clarke, 2006).

The data was analyzed throughout the six recursive phases of thematic analysis: becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (Braun & Clarke, 2006). Becoming familiar with the data involved reading and re-reading the data while taking notes of initial ideas and codes. I made an excel spreadsheet for each qualitative question which listed the participant responses in the first column, and I wrote initial codes in the adjacent column. These notes and codes included key words or ideas that I derived from the data, which were eventually formed into themes through repeated readings of the data and revisions of these codes based on patterns of meaning and issues of interest that I found across the data set. Once I generated initial themes, I read through the data set again to ensure that the majority of the data

was accounted for within the themes, and created additional themes and subthemes to clarify

meaning within the data and account for all participant responses. As suggested by Braun and

Clarke (2006), I re-read through the data during each phase of the analysis to ensure that I

represented the participant responses as accurately as possible within the broader themes that I

generated.

       Trustworthiness and validity. There are parallel criteria in postpositivist qualitative

research that correspond to validity and reliability criteria in quantitative methods, including

triangulation. In order to improve reliability, I asked another qualitative researcher who has 5

years of qualitative research experience to audit the qualitative data in order to increase interrater

reliability by discussing identified themes to reach a consensual agreement (Ponterotto, 2005).

Validity tests for qualitative research, such as the use of an external auditor, do not guarantee

validity, but rather they increase the credibility of results by testing the validity of results and

acknowledging the existence of threats to the validity of research results (Maxwell, 2013). An

external audit of qualitative data can enhance a research study's dependability by promoting the

repeatability and replicability of patterns and themes that emerge from the data (LaBanca, 2011).

Additionally, an external audit helps to support researcher objectivity and confirm findings by

providing the researcher with another perspective on the data and the methods used to analyze

the data (LaBanca, 2011). During the audit process, Maxwell (2013) notes that it is important to

look for contradictory evidence that challenges the conclusions of the study as opposed to

attempting to verify the results. To deal with validity threats in this study, I searched for

discrepant evidence and negative cases within the data provided and examined these cases

alongside data that supported the aforementioned research hypotheses to determine whether

conclusions required modifications. I consulted with my external auditor following her audit of

the data so that we could discuss discrepancies in the data and reach a consensus on themes derived from the data for each qualitative question, as well as discuss specific examples that we felt best highlighted the themes and should thus be included in the results. In addition, I used triangulation through the collection of information from a large group of individuals from disparate contexts using both qualitative and quantitative methods. This helped reduce systematic bias due to the use of one method alone, and helped conclusions be more extensively assessed by comparing survey data with participant response data and including this triangulated analysis in the results.

Trustworthiness in postpositivist qualitative research calls for credibility, transferability, dependability, and confirmability (Morrow, 2005). Credibility in qualitative research corresponds to internal validity in quantitative research (Morrow, 2005), and addresses how the researchers describe their chosen methods to ensure that the research process did indeed measure what the researcher intended to measure. Credibility can be achieved through a number of methods, and in this research study, was achieved through the use of an external audit with a peer researcher and researcher reflexivity (Morrow, 2005). To allow for fair interpretation of the data, within my reflexivity statement I addressed involvement with this research topic, subjectivity regarding the research, and previous experiences interacting with the population under investigation. Transferability, parallel to external validity, refers to the extent to which research findings can be generalized to make claims about a broader implication of the results beyond the research sample (Morrow, 2005). Transferability was achieved by providing sufficient information about the researcher through reflexivity, and was addressed in the descriptions of the research context, process, and participants (Morrow, 2005). However, given that this study had a large sample size that was collected through survey sampling, transferability

can only be marginally considered through generalizability. MTurk gave me the option of specifying my sample by choosing a category of participants. The option I selected was to have the survey sent to individuals who had identified as parents. I then asked two questions to ensure that the participants met inclusion criteria for the study before continuing on to the surveys. Therefore, the study results do not extend beyond parents of children with ASD aged 4 to 17, and cannot be assumed for those individuals who do not have internet access, or for whom English is not their primary language. In addition, results need to be considered as impacted by self-selection bias, as participants selected themselves into a group of "parents" through MTurk, and thus the sample is biased by nonprobability sampling.

Dependability, parallel with reliability, addresses the way that the study is conducted to ensure that it is consistent across researchers and data analysis techniques (Morrow, 2005). Dependability was accomplished through tracking of the research design and the data analytic method chosen, inductive thematic analysis. Dependability was also bolstered by use of an audit trail, which contained memos on my thoughts about themes and categories that emerged from the data following multiple readings of the data provided by study participants (Morrow, 2005), and through an external audit of the data. Emerging themes and categories derived through thematic analysis were evaluated by a peer researcher and research advisors to further promote dependability (Morrow, 2005). Confirmability, or objectivity, is based on the premise that the integrity of findings exists within the data itself, and that the researcher has the responsibility to assess and analyze data in such a way that adequately explains such findings (Morrow, 2005). Confirmability also acknowledges that research can never be wholly objective. I attempted to promote confirmability through researcher reflexivity and the procedures I used to tie the data together, including thematic analysis and triangulation.

Researcher reflexivity. Researcher threats to validity and credibility within qualitative analysis include researcher bias and reactivity, requiring the researcher to engage in reflexivity (Maxwell, 2013). Reflexivity provides the researcher with an opportunity to understand how their own experiences and understanding of the research influence the research process (Morrow, 2005). By addressing researcher bias and subjectivity, inclusive of the researcher's values and expectations of the study throughout the process of data analysis, the researcher can consider the potential influences over the treatment of data. Inclusion of reactions to the data can also help the researcher understand how existing perspectives influence codes and themes inferred from participant responses (Ponterotto, 2005). Researcher reflexivity is expanded upon below, and an audit trail of memos collected during data analysis will be addressed in the results.

The mixed-methods design of this study and the number of individuals required for power in the quantitative analysis prompted me to address this research from a postpositivist paradigm, which allowed me to view both the quantitative and qualitative components of the research study more objectively. I am aware that my research design allowed for a broader breadth of data at the expense of more in depth information which could have been obtained via individual interviews or focus groups. After committing to a design that promoted power and data integrity for mixed-methods analysis, I maintained the goal of providing a platform for parents of children with ASD to share their experiences and perspectives on the services and providers they have utilized through use of open-ended questions. In order to do this with objectivity and while maintaining the goal of emphasizing the lived experiences of the participants who were willing to share their perspectives, I wrote my own experiences and reflections as I read the data for coding, noting my reactions as they emerged during thematic analysis so that I could examine these reactions and incorporate them into the final analysis

(Morrow, 2005). I acknowledged that my physical and psychological distance from the participants impacted the analysis of the data that I was able to collect. I also knew that the anonymity of respondents required for the mixed-methods design would prevent me from contacting participants following data analysis and thus prevent me from member checking and promoting further participant engagement in the research. In approaching the data, I decided to use the anonymity of participants to promote objectivity, in alignment with my postpositivist paradigm.

I must address the privilege and conferred power that I hold as a researcher and as a person moving through the world, as this interacted with the multiple identities held by my study participants. As a White, heterosexual, graduate-school educated, married woman from an upper-middle class background without children, I am privy to a number of comforts and advantages that my participants may not, including access to high-quality healthcare and no financial or psychological stress from child-rearing. Therefore, I considered how my socioeconomic status and cultural background influenced my interpretation and analysis of the data. My privileges have also brought me into a field where, as a researcher and a clinician, I often hold a position of conferred power. I conducted research that relied on willing participants and their permission to use their experiences to inform service delivery and family-professional partnerships, and I endeavored to use my position of power to highlight the experiences of the often underserved. I recognized and reflected upon how my identities and privileges influenced the data, from acquisition through to interpretation, and have added these to the results of the qualitative analysis.

My experience working with children with autism and their families is extensive, and my role as a service provider has influenced the way in which I designed my research questions and

generated the empirical framework of this research study. I have worked with families with children with autism for approximately 12 years. I have been a teacher's aide and teacher to children with autism in special needs schools, a therapist providing Applied Behavior Analysis to children with ASD, a counselor in the school system providing individual and group-based play therapy to students with ASD, a researcher recruiting families with at least one child with an ASD to longitudinal studies, and I have also provided neuropsychological assessments to children with ASD. In each capacity, I have provided feedback to families about their child's cognitive, emotional, and behavioral well-being and development, and have integrated the work of other multidisciplinary team members in my analysis of their child's progress. My experience working with children with ASD and their families has highlighted the difficulty that parents experience around the receipt of an ASD diagnosis, finding resources, implementing new treatments, and experiencing stigma from families, schools, and professionals. In particular, long wait lists for services and limited access to care due to insurance or geographic location have been specific challenges noted by families of children with ASD with whom I have worked. From these experiences, I have valued the important role that parents have in the treatment, care, and advocacy of their children. I went to graduate school with the intention of receiving more training in counseling so that I could treat the family as a whole and learn how best to work with families of children with disabilities. Therefore, the goals of my research are directly in line with my educational and career goals and motivate me to make effective use of the data afforded to me in the service of the families with whom I have and will continue to work.

I must also address the fact that I am not a parent of a child, nor a parent of a child with ASD, and I do not have any family members with ASD. This may have posed as a barrier to my

understanding of parent participants' experiences. This also contributed to my bias toward the research, as I have preconceived notions of what it may be like to parent a child with ASD based on my literature review and clinical experience, and this has certainly influenced the questions I have generated for the study. Throughout involvement and analysis of the research, I anticipated that my values and assumptions would change based on what was revealed through participants' responses and survey results. I was able to bracket my experiences and potential biases by frequently rereading the open-ended responses and actively writing memos of any ideas for categories or assumptions that arose. I also utilized an external auditor to review my thematic analysis in order to make use of an objective reviewer. Memos and results of the external audit will be discussed in the following chapter.

Chapter IV

RESULTS

The purpose of this mixed-methods study was to investigate parent satisfaction with professional services provided to their child with ASD, and to examine whether parent satisfaction with services and professional partnerships varied as a function of parents' perceptions of their child functional behaviors and parent stress. The goal of this study was to consider parent perceptions of the severity of their child's functioning in relation to their satisfaction with service providers, and also to provide parents with a forum to share both positive and negative experiences with service provision from their perspectives.

A total of 171 parents completed the questionnaires. The data collected from the questionnaires were exported into SPSS for analysis. Approximately 120 parents completed the qualitative portion of the study, comprised of the open-ended questions. The qualitative responses were analyzed using inductive thematic analysis. There are six phases of thematic analysis: becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (Braun & Clarke, 2006).

Descriptive Statistics

The mean age of children with ASD about whom the parent participants reported was 7.86 years old ($SD = 3.59$). Of the 171 children with ASD, 119 (69.6%) were male, and 52 (30.4%) were female. This is commensurate with the most recent report from the Centers for Disease Control and Prevention on the overall prevalence of ASD by sex, which reported that ASD was significantly higher among males than among females at a prevalence ratio ranging from 3.2 to 4.9 (Baio et al., 2018). The majority of families in the sample reported having one

child (43.9%), 33.9% of the sample had families with two children, and 22.2% of the sample

reported having three or more children in the immediate family.

The mean age of the parent participant was 32.23 years ($SD = 5.24$). The majority of the

sample was comprised of fathers ($N = 94$, 55%) while 40.4% ($N = 69$) of the sample consisted of

mothers, six individuals identified as the legal guardian of the child, and two identified as foster

parents. It is of note that this study is evaluating a participant pool in which fathers are the

majority, in contrast with previous research, in which respondents are typically mothers or are

comprised of a majority of mothers. The majority of participants ($N = 148$, 86.5%) reported that

they were married, 7.6% ($N = 13$) of participants were reportedly single, 2.9% ($N = 5$) were

separated, 2.3% ($N = 4$) were divorced, and one participant was widowed.

Demographic information on the average annual household income for families who

participated in the study is listed in Table 1. The majority of families who participated in the

study reported an annual household income of less than $50,000 per year.

Table 1

Average Annual Household Income of Participants

Average Income	Frequency	Percentage
Less than $25,000	38	22.2
$25,000 to $49,999	58	33.9
$50,000 to $74,999	34	19.9
$75,000 to $99,999	26	15.2
$100,000 to $149,999	9	5.3
$150,000 or more	6	3.5

Participants' access to insurance or health coverage plans was predominantly through current or

former employers or unions (39.2%), followed by Medicare (24.6%), insurance purchased

directly through an insurance company (19.9%), and Medicaid, medical assistance, or other

government-provided plans (15.8%). One parent participant indicated a status of uninsured.

Data Analysis

This study answered four quantitative research questions in addition to incorporating a qualitative analysis. The first four research questions analyzed participant responses to the FPPS, SDQ, SRRS, and PSS questionnaires. The qualitative analysis used inductive thematic analysis to explain parents' positive and negative experiences with service providers, and how their service providers impacted parents' views of their children with ASD.

Research Question 1: What is the relationship between parent appraisals of the functional behaviors of their child with ASD and parent satisfaction with child services from professional service providers?

A linear multiple regression analysis was conducted with data from 171 participants who completed the *Beach Center Family-Professional Partnership Scale* (FPPS) and the *Strengths and Difficulties Questionnaire* (SDQ). Predictors were both problem and prosocial behaviors, measured by the total difficulties score of the SDQ, (comprised of the Emotional Problems, Conduct Problems, Hyperactivity, and Peer Problems subscales), and the Prosocial scale of the SDQ. Parent satisfaction was measured by the Child-Focused Relationships subscale of the FPPS. It was predicted that parents who reported lower child problem behaviors and higher levels of child prosocial behaviors would report higher levels of parent satisfaction with child-focused services. More specifically, it was hypothesized that the total difficulties score of the SDQ would be negatively correlated with the Child-Focused Relationships subscale of the FPPS, and the Prosocial Behavior Subscale of the SDQ would be positively correlated with the Child-Focused Relationships subscale of the FPPS. Alpha level was set at .05. Table 2 shows a multiple regression model of predictors of the total difficulties score and prosocial behavior subscale of the SDQ.

Table 2

Linear Multiple Regression Analysis for Variables Predicting Parent Satisfaction with Child-Focused Relationships

	Model 1			Model 2		
Variable	*B*	*SE B*	*β*	*B*	*SE B*	*β*
SDQ Total Difficulties Score	-.18	.07	-.20***	-.25	.07	-.28***
SDQ Prosocial Scale				.71	.18	.30***
R^2		.041			.123	
F for change in R^2		7.21**			11.74***	

$**p < .01 \ ***p < .001$

The overall regression equation with two behavior predictors was significantly related to the parent satisfaction index, $R^2 = .12$, *adjusted* $R^2 = .11$, $F(2, 168) = 11.74$, $p < .001$. The SDQ Total Difficulties Score and the SDQ Prosocial Scale were both determined to be significant predictors of the Child-Focused Scale of the FPPS. As expected, the Total Difficulties Score of the SDQ was negatively correlated with the Child-Focused Scale of the FPPS, and the Prosocial Scale of the SDQ was positively correlated with the Child-Focused Scale of the FPPS.

To obtain further clarification of the specific components of behavior that were associated with parent satisfaction on the Child-Focused Scale of the FPPS, a multiple regression analysis was conducted listing all of the subscales of the SDQ as predictor variables. When each of the subscales of the Total Problem Score of the SDQ were entered as individual predictors of the criterion variable, results indicated that the Conduct Problems Scale, $β = -1.06$, $t(169) = -.20$, $p < .01$, and Peer Problems scale, $β = -.56$, $t(169) = -2.36$, $p < .001$, were significantly correlated with parent satisfaction on the Child-Focused Scale of the FPPS.

Research Question 2: What is the relationship between appraisals of the functional behaviors of

their children with ASD and parent satisfaction with parent services from professional

partnerships?

It was predicted that parents who reported lower child problem behaviors and more

favorable appraisals of their child's prosocial functioning, as measured by the SDQ, would report

greater satisfaction with family-professional partnerships, as measured by Family-Focused

relationships subscale of the FPPS, It was hypothesized that the four problem subscales of the

SDQ (Emotional Problems, Conduct Problems, Hyperactivity, and Peer Problems) would be

negatively correlated with the Family-Focused Relationships subscale of the FPPS, and that the

Prosocial Scale of the SDQ would be positively correlated with the Family-Focused

Relationships subscale of the FPPS. A linear multiple regression analysis was conducted with

the Total Difficulties scale and Prosocial scale of the SDQ entered as the predictors, and the

Family-Focused Relationships scale of the FPPS entered as the criterion variable. Alpha level

was set at .05. Table 3 shows a multiple regression model of predictors of the total difficulties

score and prosocial behavior subscale of the SDQ.

Table 3

Linear Multiple Regression Analysis for Variables Predicting Parent Satisfaction with Family-

Focused Relationships

	Model 1			Model 2		
Variable	B	$SE\ B$	β	B	$SE\ B$	β
SDQ Total Difficulties Score	-.22	.07	-.24***	-.28	.07	-.31***
SDQ Prosocial Scale				.66	.18	.27***
R^2		.126			.203	
F for change in R^2		12.15***			8.38***	

***$p < .001$.

The overall regression equation with two behavior predictors was significantly related to the parent satisfaction index, $R^2 = .13$, *adjusted R^2* = .12, $F(2, 168) = 12.15$, $p < .001$. The SDQ Total Difficulties Score and the Prosocial Scale were both determined to be significant predictors of the Family-Focused Relationships Scale of the FPPS. The Total Difficulties Score of the SDQ was negatively correlated with the Family-Focused Scale of the FPPS, and the Prosocial Scale of the SDQ was positively correlated with the Family-Focused Scale of the FPPS.

To obtain further clarification of the specific subscales of the SDQ that were associated with parent satisfaction on the Family-Focused Scale of the FPPS, a multiple regression analysis was conducted listing all of the subscales of the SDQ as predictor variables. When each of the subscales of the Total Problem Score of the SDQ were entered as individual predictors of the criterion variable, results indicated that the Emotional Problems Scale, $\beta = -.10$, $t(169) = -.45$, $p < .05$, Conduct Problems Scale, $\beta = -.70$, $t(169) = -3.08$, $p < .01$, and Peer Problems scale $\beta = -.44$, $t(169) = -1.80$, $p < .01$, were significantly correlated with parent satisfaction on the Family-Focused Scale of the FPPS.

Research Question 3: How do parent perceived stress levels influence the relationship between appraisals of child strengths and challenges and satisfaction with services?

It was predicted that parents' who reported higher levels of stress would report lower satisfaction with services and less positive appraisals of their child's functioning. To test this question, two hierarchical multiple regression analyses were conducted. In the first analysis, the subscales of the SDQ were entered as independent predictor variables, stress as measured by the Perceived Stress Scale (PSS) and the Holmes-Rahe Social Readjustment Rating Scale (SRRS) were entered at the same time as the second block of predictor variables, and satisfaction as measured by the Child-Focused Relationships subscale of the FPPS was entered as the outcome

variable. When the SRRS and PSS were added to the model, this accounted for a further 7.2%

variance, which increased the model's capacity in predicting parent satisfaction with child-

focused aspects of professional relationships in a statistically significant way ($p < .001$). Adding

these stress measures to the model increased the percentage of variance accounted for to 28%.

When the PSS and SRRS were added to the model, the Peer Problem Scale, $\beta = -.49$, $t(169) = -$

2.02, $p < .05$, and Prosocial Scale, $\beta = .84$, $t(169) = 4.12$, $p < .001$, of the SDQ were significant

predictors of parent satisfaction with Child-Focused Relationships. Further analysis revealed

that the PSS was not a statistically significant unique contributor to the model, but the SRRS was

a statistically significant predictor of satisfaction with child-focused relationships.

Table 4

Hierarchical Multiple Regression Analysis for SDQ Rated Child Behaviors, Stress, and

Parent Satisfaction with Child-Focused Relationships

	B	$SE\ B$	β
Step 1			
Constant	32.23	2.79	
SDQ Emotional Problems Scale	.01	.22	.01
SDQ Conduct Problems Scale	-.62	.22	-.26**
SDQ Hyperactivity Scale	.49	.22	.16
SDQ Peer Problems Scale	-.56	.24	-.20
SDQ Prosocial Scale	.79	.20	.33***
Step 2			
Constant	31.80	2.84	
SDQ Emotional Problems Scale	.13	.21	.06
SDQ Conduct Problems Scale	-.35	.22	-.15
SDQ Hyperactivity Scale	.40	.21	.13
SDQ Peer Problems Scale	-.49	.24	-.17*
SDQ Prosocial Scale	.84	.20	.35***
SRRS	-.004	.001	-.28**
PSS	-.08	.08	-.09

*$p<.05$ **$p<.01$ ***$p < .001$.

In the second analysis, the subscales of the SDQ were entered as predictor variables,

stress as measured by the PSS and SRRS were entered simultaneously in one block as

independent variables, and satisfaction as measured by the Family-Focused Relationships

subscale of the FPPS was entered as the dependent variable. When the SRRS and PSS were

added to the model, this accounted for a further 6.6% variance, increasing the model's predictive

capacity to predict parent satisfaction with family-focused aspects of professional relationships

in a statistically significant way ($p < .01$). Adding these stress measures to the model increased

the percentage of variance accounted for to 26.8%. When the PSS and SRRS were added to the

model, the Prosocial Scale of the SDQ, $\beta = .86$, $t(169) = 4.08$, $p < .001$, was a unique predictor of

parent satisfaction with Family-Focused Relationships. The hierarchical regression model

revealed that the PSS was not a statistically significant predictor to the model, but the SRRS, $\beta = $

$-.004$, $t(169) = -3.35$, $p < .001$, was a statistically significant predictor of satisfaction with family-

focused aspects of professional relationships.

Table 5

Hierarchical Multiple Regression Analysis for SDQ Rated Child Behaviors, Stress, and

Parent Satisfaction with Family-Focused Relationships

	B	SE B	β
Step 1			
Constant	33.66	2.87	
SDQ Emotional Problems Scale	-.10	.22	-.05
SDQ Conduct Problems Scale	-.70	.22	-.30**
SDQ Hyperactivity Scale	.46	.23	.14*
SDQ Peer Problems Scale	-.44	.25	-.15
SDQ Prosocial Scale	.80	.21	.33***
Step 2			
Constant	33.06	2.93	
SDQ Emotional Problems Scale	.01	.22	.004
SDQ Conduct Problems Scale	-.43	.23	-.18
SDQ Hyperactivity Scale	.37	.22	.12
SDQ Peer Problems Scale	-.38	.25	-.13
SDQ Prosocial Scale	.86	.21	.35***
SRRS	-.004	.001	-.27**
PSS	-.06	.08	-.07

*$p<.05$ **$p<.01$ ***$p < .001$.

To ensure that the stress measures were not redundant, Pearson correlations were conducted to ensure that the correlation between the PSS and the SRRS did not exceed .80. Results revealed that there was no singularity between the PSS and SRRS, as the correlations did not exceed the .80 limit and thus were not redundant measures of stress. Multicollinearity statistics were also conducted as a second test to check for overlapping variance between the two stress measures. In each of the hierarchical regressions that were run, Tolerance for each scale was above .2 and the VIF was very close to 1, indicating good protection against multicollinearity in the model.

Research Question 4: What is the correlation between parent satisfaction levels with professional services and age of the child with ASD?

It was predicted that there would be a negative correlation between age of the child and parent satisfaction levels, commensurate with previous research which has found that parents of older children with ASD report higher dissatisfaction with services and service providers (Rattaz et al., 2014; Summers et al., 2005a; Wang et al., 2004). This hypothesis was tested through Pearson correlations. The correlation between age of the child and parent satisfaction levels was significant at the .05 level, $r(169) = -.190$ for child-focused relationships and $r(169) = -.192$ for family-focused relationships. These results support the hypothesis and are consistent with previous research, indicating that as the age of the child with ASD increases, levels of parent satisfaction with child-focused and family-focused aspects of professional partnerships decreases.

Qualitative Analysis: Parents were asked to describe positive and negative experiences with service providers, and to provide examples of experiences in which providers influenced parents' abilities to see strengths in their child's functional behaviors. The following open-ended

questions were asked at the end of the Qualtrics surveys in MTurk:

1. With which service provider(s) have you and your child with ASD worked?

2. Briefly describe a positive experience you had with a service provider where you and your child felt supported.

3. Briefly describe a negative experience you had with a service provider where you and your child did not feel supported.

4. From the list of service providers listed, select one service provider that you feel has helped you and your family the most.

5. Based on the provider you selected in question 4, provide an example of a time when this provider helped you understand something positive about your child.

Qualitative questions 1 and 4 were analyzed using descriptive statistics. The first question was proposed to get a holistic picture of all of the providers with whom participants had been involved. Results indicate that the majority of the sample have worked with a Behavior Therapist (50.9%, $N = 87$), followed by a School Psychologist (43.9%, $N = 75$). Table 4 indicates the frequency and percentage of providers with whom the families with children with ASD have worked.

Table 6

Qualitative Response 1: Providers who have worked with participants

Provider	Frequency	Percent
Behavior Therapist	87	50.9
School Psychologist	75	43.9
Special Education Teacher	59	34.5
Speech-Language Specialist	53	31.0
Physical Therapist	50	29.2
Occupational Therapist	33	19.3
Counselor or Therapist	36	21.1
Physician	33	19.3
Child Study Team Member	30	17.5
Social Worker or Case Manager	23	13.5
Paraprofessional	12	7.0

Of the service providers listed, the majority of participants indicated that they felt the Behavior

Therapist helped them and their family the most (27.5%, $N = 47$). Further, while only 51% of

the sample had worked with a behavior therapist, it was the highest frequency of contact with a

service provider reported. Of the 87 individuals that selected having worked with a behavior

therapist, 47 individuals (54%) indicated that their behavioral therapist helped them the most out

of the other providers with whom they worked. Three participants (1.8%) indicated that none of

the professional providers listed helped them and their family the most. Table 5 lists the

frequency and percentage of providers that parent participants indicated were the most helpful to

them and their families.

Table 7

Qualitative Response 5: Most Helpful Providers

Provider	Frequency	Percent
Behavior Therapist	47	27.5
School Psychologist	26	15.2
Special Education Teacher	31	18.1
Speech-Language Specialist	20	11.7
Physical Therapist	12	7.0
Occupational Therapist	4	2.3
Counselor or Therapist	13	7.6
Physician	4	2.3
Child Study Team Member	5	2.9
Social Worker or Case Manager	5	2.9
Paraprofessional	1	0.6
None	3	1.8

Qualitative Thematic Analysis

Qualitative questions 2, 3, and 5 were analyzed using inductive thematic analysis (Braun & Clarke, 2006). Thematic analysis allows the researcher to generate themes and a more concise analysis of the direct responses provided by participants in their own words. The inductive approach is a data-driven form of analysis that allows the researcher to identify themes that strongly link to the data, allowing for a richer description of the data (Braun & Clarke, 2006). Themes were identified at the semantic level, which means that codes were identified from the explicit meaning of the data, and then the codes were described and summarized into themes in order to show patterns of semantic content; these themes were then interpreted for broader meanings and implications (Braun & Clarke, 2006). Thematic analysis highlighted particularity in order to promote the integrity of individual cases by coding each individual first and then returning to the data multiple times to ensure that the breadth of participant responses was captured (Morrow, 2005). An external auditor was involved in the data analysis to promote data integrity, trustworthiness, and dependability of the qualitative analysis, as well as to minimize

researcher bias and promote objectivity (Morrow, 2005). Quantitative support for qualitative

data was used to show prevalence of themes, which helped the researcher assess the amount of

evidence within the data that supported or was discrepant with proposed conclusions.

Positive Experiences

Major themes that emerged from participants' descriptions of positive experiences with

providers included the following: provider competency, relationship building between provider

and family, and parent involvement in multidisciplinary team.

Table 8

Themes Derived from Thematic Analysis on Positive Experiences with Service Providers

Theme	Subthemes
Provider Competency	a. Provider improved parent understanding of ASD and their child b. Treatment provided evidence of child improvement
Relationship Building between Provider and Family	a. Provider demonstrated good communication skills b. Provider developed positive rapport with the family c. Provider went the extra mile
Parent Involvement in Multidisciplinary Team	N/A
Providers Helping Parents Understand Their Child's Positive Traits	a. My child has a skill I did not know about b. Provider gave hope that child would improve

Provider competency. Many parents indicated that they felt supported in working with

service providers when the providers seemed competent. Competency on the part of the provider

was defined by participants as the ability to do the job well, to provide an understanding of ASD

diagnosis and treatment, to provide psychoeducation on ASD treatment to families, and the

ability to highlight treatment outcomes. One parent specifically stated that a positive experience

with a service provider had to do with the fact that this individual was "totally satisfied with [the provider's] training and support and way of caring." Parent participants in this study shared a number of examples in which providers demonstrated knowledge about ASD, provided them with good advice, and delivered appropriate treatment to their child, all of which made them feel supported. Provider competency became a larger theme containing the following subthemes: provider improved parent understanding of ASD and their child, and treatment provided evidence of child improvement.

   Provider improved parent understanding of ASD. Participants shared that part of the positive experience they had with their service provider included the fact that the provider helped them understand their child's diagnosis better. For example, one parent shared how the provider's ability to share knowledge of ASD made the parent feel supported: "I spoke to the school social worker and she was able to relate and provide advice about autism based on her training and experience, it was good support." Parents also indicated feeling supported when providers offered psychoeducation on ASD and how this diagnosis might impact their child and their family. One parent stated, "the psychologist has helped me understand autism better and what it entails for my son." Similarly, another parent shared, "My child's school psychologist is absolutely amazing, as she helps my child through understanding herself, as well as helping us, her parents, understand her better." In some examples, parent participants felt that because service providers showed an understanding of ASD and were willing to provide psychoeducation to parents, parents were then able to understand their children better. In one such response, a parent shared:

   The school counselor who helped him through his problems also helped us to understand

   exactly the signs and symptoms he was expressing. It really helped us to see what she

was seeing, and it took ten years to find someone who gave us that.

Psychoeducation helped one parent view ASD in a more positive way:

> I just had this stipulation in my head about my daughter's condition and thought
>
> something was wrong with her and I was embarrassed. Her therapist helped me
>
> understand that she special and unique and showed me ways to celebrate that.

Similarly, another parent wrote: "[The provider] explained to us once what our child was going through and feeling when she was having problems with other kids, and how to deal with it and react to our child that would benefit her most. It was great." Another parent responded:

> My child didn't start talking until she was four. My in-laws were not very kind about the
>
> whole situation. I was very down for a long time. Luckily, we have met a wonderful
>
> social worker through the service center. She taught me a lot about autism and always
>
> was there for me when I was depressed. I feel thankful for her.

Some participants shared examples that highlighted ways in which parents gained perspective about the impact of ASD on their child as a result of working with their provider. In these examples, parents emphasized how providers helped them understand their child better and, as a result, be more understanding of their child's behaviors. For example, one parent shared how the provider "really helped me understand my child's plight and allow me to have empathy." Another parent noted that the provider helped him and his wife realize that their child experiences things differently: "The school psychologist helped my wife and I understand how my child thinks about things, which is different than how we may think about things." When a provider was able to provide reasons for the child's behaviors, this parent felt enabled to work with the child better: "This specialist helped me realize why my son did what he did and helped with ways to coach him and discipline him in a way that would work well." Parents also

mentioned that when the provider improved their understanding of their child with ASD, they

were able to be more patient and empathic regarding their child's abilities and behaviors: "They

helped me understand that not every experience is the same for my child as it is me, patience is

definitely key." Similarly, another parent shared that the service provider, "helped me to

understand my child's emotions and how to be patient cause my child is frustrated about their

speech as well." In one example, psychoeducation helped a parent gain empathy and reduce

blame:

> This therapist has helped me understand my child more than I ever had been able to
>
> before. I used to believe that the behavior was intentional. After working with the
>
> therapist, I can see now that it is not something that is easily controllable.

Treatment provided evidence of child improvement. This was the most predominant

subtheme within the broader theme of provider competence. A number of parent participants

indicated that they felt the most supported by service providers when it was clear that working

with their provider led to improvements in their child's functioning. Some parents mentioned

specific behaviors that were resolved, while others noted that working with the provider led to

general overall improvement for their child. Notably, parents indicated that treatment led to

child improvement when the provider individualized treatment to their child's unique needs or

problem areas. One participant described how the provider made a child feel confident: "When

we first started taking him to a behavior therapist, he was slightly withdrawn, and she was able to

bring him out of his shell and make him feel confident about his abilities." In another example, a

parent shared how the provider's demeanor and patience led to child improvement:

> Our speech therapist is always happy to see my daughter and is always very kind and
>
> patient with her as she is a strong-willed child. Through numerous sessions she has

helped our daughter be better able to verbalize what she is trying to get out and we have

seen marked improvement in her social skills and development.

Another parent explained how the child's improvement generalized to settings outside of

therapy: "Recently, my child had been having trouble coping with large groups. We have been

working with our provider for some time now and now we have been able to take our child to

church without any breakdowns or issues." In one example, a parent described how the provider

made the parent's goal a priority in treatment, leading to parent satisfaction as the child

demonstrated improvement in this specific skill area: "My child struggled in saying common

words like daddy, mummy…My service provider made her speak this as her first step. When she

did this my family felt really happy." It was reportedly helpful when parents were shown their

child's progress directly: "A time in which my provider helped me understand something

positive was when they took the time to put together a little portfolio type project to show me the

progression of my son." A parent similarly shared the positive experience of seeing the child's

progress:

> Just last week the teacher made a phone call to me to update me on her progress. She had
>
> such glowing praises for my daughter. She compared my daughter's scores to a typically
>
> developing child so that I could know how much she has improved.

 In other examples, parents indicated that they were pleased to know that their child had

improved. For example, one parent shared how the provider, "helped us to see that [the child]

has come a long way, much longer than we ever expected at the time of diagnosis." Similarly,

another parent described how the provider explained, "that [my child] is getting better and she

feels that the speech issue will not cause a problem with him learning to read." Below is another

example of a time when a speech pathologist helped a parent understand something positive

about the child with ASD:

> I thought my child was going to have a lot of problems learning to speak because at first
> all his words were slurred and slow. But, thankfully … my child sounds almost the same
> as other children his age now. He showed me that my child has the ability to learn just
> like any other child does.

Relationship building between provider and family. Parent participants indicated that they felt supported when the provider showed compassion, was accessible, communicated well with the family, and was able to put the family at ease. All of these aspects of the provider's skillset and demeanor appeared crucial in maintaining a positive relationship between parents and providers, and in some instances, improving existing parent-professional relationships. The theme of relationship building between provider and family contained the following subthemes: provider demonstrated good communication skills, provider developed positive rapport with family, and provider "went the extra mile."

Provider demonstrated good communication skills. Participants responded that they felt supported by service providers who were able to talk with them about their ideas, concerns, and expectations. One parent participant shared a notable experience with a provider who was able to understand the hardship this parent experienced in understanding the child's diagnosis:

> When talking about my fears about my son's future and feeling hopeless, she was great at
> listening and encouraging. And let me grieve "losing" the child I thought I had and the
> hopes I had for him. And encouraged me to welcome the idea of a child who is still great
> but whose life is probably going to be much different than I thought. It was an important
> process for me as a parent to be able to "grieve" and give up that idea I had for my son's
> life. But, it helped to feel like it is OK and normal and be able to get those emotions out

with a professional that understood rather than with family members that just don't seem

to get it.

In another example, the provider's ability to elucidate how the child's skills had progressed led

the parent to feel supported:

Several months ago, we had a meeting because my son was unhappy with things. He felt

as if the whole sessions were a waste. We sat down, and both talked to [the provider] and

this helped him see how much and how far he has come. He felt great afterwards as did I.

Other parents shared experiences of their providers making sure to keep them informed.

For example, one parent noted that the special education teacher "would give me updates

practically daily, and if something bad happened, she'd give tips on how to help." A few parents

indicated that they felt support when providers gave them tips that helped them and their child,

as in the following example: "The counselor gave me a few tips that help me to deal with my

child properly whenever he is having problems." Another said "I remember the first time his

special education teacher called to congratulate my boy on his kindness to others. It was such a

good moment to realize someone else cared." Participants noted that it felt good to hear how

well their children were doing in treatment, as in this example: "I met the paraprofessional who

my child adores and they told me about all the improvements he is making and where we can

work to improve in other areas."

Provider developed positive rapport with family. When describing positive experiences

with service providers where participants and children felt supported, participants often referred

to such providers as "nice," "kind," "friendly," "honest," and "caring." One parent described

that the provider made the family "feel very wanted and welcome" at appointments. One parent

shared how the provider's positive attributes and willingness to help relayed a sense of caring

and commitment to the parent: "They were willing to help with my child. They were safe,

reliable, caring, honest, and were actually interested in helping my child with his condition."

Some parents noted that they had positive experiences when the provider had a positive

disposition and was playful: "We had an appointment and the therapist was calm and made our

child very comfortable. He acted as if he was a kid and tried to communicate with our child." In

some instances, parents noted that the provider was encouraging to the child and that time spent

with the provider led their child to appear happy. In these examples, it seemed that the

provider's disposition not only put parents at ease and made them feel comfortable and confident

with the provider, but parents noted that it put their children at ease, as well. One parent

emphasized how the provider's relatability was key to a positive experience:

> When my child was first diagnosed they were able to really get into his mind. They made
>
> him feel at ease, like he was speaking to a friend. The relatable way they went about
>
> helping my child cope and change was great.

Provider went the extra mile. There were a number of responses provided by

participants indicating that families felt supported when they felt that their provider was acting

on their behalf in way that proved to be a step beyond what was required. One parent stated that

the behavioral therapist was often available outside of regularly scheduled sessions: "whenever I

called him up with a question, he was there with an answer." In another response, a participant

felt supported when the provider checked-in outside of scheduled appointments: "Her therapist

will often call between appointments to find out how she is doing behaviorally. He likes to get

updates on how our day to day routine is going." Another example provided by a parent

participant indicated feeling supported when the provider was understanding of and

accommodated the family's schedule:

The behavior therapist stayed late one evening when my son and I were going to be late. He was very nice and did what he could to make sure we didn't miss our appointment. It made us feel very wanted and welcome.

In a few other responses, parents expressed that they felt the most support when providers helped the family during a critical time or when they were particularly stressed. For example, "our service provider helps in a critical situation when we suffer;" and "our service provider helps in serious situations in many times that makes us feel very supported." Within the same category of going the extra mile, a few parents noted that providers gave additional support to families in the form of financial aid. One parent noted that the school psychologist made sure that the child was fed during school, noting that it was not necessary on the part of the school psychologist and thus was an added demonstration of care:

The positive experience that comes to my mind is, sometimes my school psychologist will feed my child in her lunch time. Though it is not necessary for her, but sometimes my child will be adamant of not taking lunch. So the school psychologist will take good care of my child whenever he needed.

In another response, a parent shared how a special education teacher understood the family's financial struggles and provided the family with extra clothing for the child:

The schools here have been great, well relative to before…I really have nothing but good things to say about the schools he has been to since we moved, they all treat him with dignity, actually care that he's learning things. Not to mention that we don't have the most money in the world by any stretch of the imagination, his teacher has a big kid too and since he's been in her class they've given him a coat, 3 pairs of nice shoes that I can remember and every Friday he comes home with a bag of goodies they give him from

somewhere.

Another participant wrote that the doctor understood the family's financial predicament and provided services regardless of the parent's ability to pay: "One day I had faced a financial problem and I don't have enough money to spend it for my son. At that time my doctor have helped and provided the treatment."

Parent Involvement in Multidisciplinary team. Parent participants indicated that they felt supported by their service providers when they were able to coordinate multiple service providers to help their child or when they were included in team meetings. One parent was able to meet with the team and agree on how best to meet her/his child's needs: "We had a team meeting with his special education teacher and behavior therapist and agreed on rewards for good behavior and they went and supported mine and my child's suggestions." Similarly, another participant shared, "My son's team of providers are amazing. They make us feel listened to and cared for." In another example, a participant noted that she was able to work with multiple individuals in the school to help her child with a specific concern:

> My daughter doesn't have her biological father in her life and she had watched a lot of kids shows where fathers were involved. She became very sad. I spoke to the teacher and psychologist at her school and they helped me to get her to understand and redirect her attention. We created a social story.

One parent participant noted how effective team meetings were in meeting the child's individual needs:

> Our school has provided ample staff at meetings for both ISP and 504 development, and this staff has readily been available to support my son's progress through his challenges. In particular, one of his counselors stepped up to assist him with specific tasks and was

able to encourage him to great progress. We were sad when he left that school because

we lost some of her support.

In the following example, a parent described how the child's provider supported the family's

wishes by speaking with the broader institution on the family's behalf:

We have been very lucky to have found our current teacher. She just works really hard

for [our son] and always goes to bat for him when needed. She and I both felt that a

younger classroom would have been better for [him] and my word carried very little

weight. She had numerous meetings with the school to get him in that class, and he is

doing really well.

Providers Helping Parents Understand Their Child's Positive Traits

In response to a request for parents to provide an example of a time when a provider

helped them understand something positive about their child with ASD, parents shared

experiences in which providers were able to point to evidence that their children had developed

certain skills or reminded parents that children had skills or abilities that were innate. Parents

indicated feeling support and even relief when providers were able to elucidate the presence of

their child's specific abilities. When skills were still in development, parents indicated feeling

supported when providers gave them hope that their child would improve with additional time

and services. The following were the two major themes that emerged from participants who

described experiences with providers that helped them see something positive about their

children: my child has a skill I did not know about, and the provider gave hope that child would

improve.

My child has a skill I did not know about. A number of parent participants indicated

that they appreciated when their provider helped them recognize that their child had certain

abilities or characteristics that they had not yet seen or understood. One parent noted that the service provider "really showed me that there was quite the personality in [my child] and the ability to show affection and happiness." Another parent shared the realization that the child was more prosocial than the parent had known: "my child was more social than I thought and had quite a few friends." One parent wrote "This provider helped me to understand my child has a unique side of creativeness I really was unaware of." Parents shared ways in which providers elucidated specific skills that their child had that they may not have noticed before. Some parents indicated that their provider helped them see specific areas in which their child excelled. For example, one parent said, "The current special education teacher has saved the tests my child takes at school and showed me that my son excels at reading comprehension which I never realized about him." One parent indicated appreciation that the provider pointed out the child's positive behaviors, stating, "The social worker would remark on the things my daughter was excelling in and learning and improving on, it wasn't just negative aspects." Some examples provided by participants indicated that providers helped parents see their child's unique interests and abilities in a positive way, as in the following example:

> There are times when I don't realize the good my son is doing because all I'm looking for is for him to speak and convey emotion properly. My speech therapist helps me understand that this is just his way and that he is actually doing just fine. I can't look at him with the same scale like I would another kid, and she helps me understand that better. With this knowledge, I can view my son's learning in a better light and I have only his speech therapist to thank.

In some instances, parents noted that they benefited from having the provider point out the areas in which their child excelled as a point of comparison:

> She helped me to see that my child may not have all the skills of other children but that the skills she does have are important because she can do them so well. Like science for example. She excels in that.

In one example, a parent noted that the provider highlighted an activity that the child enjoyed, which helped parents connect to their child better:

> Our new behavior specialist who we started working with last year helped explain to us how our daughter wants to use art as a way to express herself and communicate her thoughts. She thinks that our daughter has a gift of art and will be able to find comfort and joy in her drawings. This is something that has helped my wife and I better connect with our daughter recently.

Provider gave hope that child would improve. Parents expressed relief, hope, and satisfaction in instances where the provider indicated that their child would likely progress with more time, treatment, and services. Some providers helped parents feel positive by providing psychoeducation on how their child's difficulties were likely to improve with time:

> She helped us to understand that our daughter will be able to speak one day when she wants to. There are many cases that children do not speak and suddenly begin when they want to. It just takes some time to get the speech to come out of them.

Another parent shared that the provider was supportive by sharing an important reminder: "she said "don't worry, we have all the time in the world. He will get there. Patience." It was a year ago and I still remember that. She knew what she was doing." One parent indicated that with appropriate communication and listening skills, the provider was able to give the parent hope for the child's future:

> When my son was diagnosed I was having a hard time accepting it. His teacher talked to

me and helped me see the positive in the situation. She helped me see how smart and
special my son was. She helped me see that even though he was different, he was not less
than anyone. She helped me see how he could still do a lot, and be successful with the
right guidance.

Negative Experiences

In response to questions about any negative experiences with service providers in which
participants and children did not feel supported, approximately 44% of the respondents indicated
no negative experience (49 of the 112 responses). Major themes that emerged from participants'
descriptions of negative experiences with providers included the following: scheduling and
administrative issues, perceived provider disregard, perceived lack of provider competency, and
financial concerns.

Table 9

Themes Derived from Thematic Analysis on Negative Experiences with Service Providers

Theme	Subthemes
Scheduling and Administrative Issues	a. Difficulty getting an appointment b. Lack of continuity of care
Perceived Provider Disregard	a. Disregard perceived at time of ASD diagnosis b. Parents concerns were ignored
Perceived Lack of Provider Professionalism	N/A
Financial Concerns	N/A

Scheduling and Administrative Issues. Participants shared a number of negative experiences
regarding scheduling issues with service providers. The theme of scheduling and administration
issues included the following subthemes: difficulty getting an appointment and lack of continuity
of care.

Difficulty getting an appointment. Participants shared negative experiences in which they felt a lack of support from providers due to difficulties in scheduling appointments for their child to receive services. Difficulties included dissatisfaction when service providers were chronically late to scheduled sessions, inconsistent or unreliable with regard to scheduling and attending sessions, or canceled sessions at the last minute. One parent highlighted dissatisfaction due to a mismatch between expectations and the constraints of the provider's schedule: "the counselor is not available on holidays or weekends when I need his assistance, he is only available on weekdays." In another example, a parent shared: "A provider was unreliable and inconsistently came to my house like they were supposed to." Some of these scheduling issues were accompanied by a caveat of understanding, whereby parents blamed traffic for the provider's lateness, or mentioned that they knew the provider had a busy schedule: "She has showed up late maybe once, but this was just due to traffic;" "Sometimes she was late for appointment and sometimes she had to cancel, but I understand she has a very busy schedule with her personal life." In some instances, participants shared that they felt unsupported when the process of obtaining services for their child with ASD was slower than desired: "I sometimes had to wait a long time for an appointment. The therapist at the office was often overbooked and sometimes this caused long wait times." Similarly, another participant mentioned that "it would take forever to be able to get an appointment" with their provider.

Lack of Continuity of Care. There were a few examples in which parents indicated that provider turnover led to an unsupportive, negative experience with their service provider. In one instance, a parent noted that a combination of scheduling issues and provider turnover led to a regression in the child's skills:

The original teacher quit, so there was a period where [my child] did not have his

services. They hired another teacher, but the school system is not letting her do two days

a week, which is the normal time, and I can tell that his speech development is slowing

down a little.

In another example, a participant shared that it was difficult for the child to transition to another

provider, stating, "When [my child] had to move on from one teacher to the next, that was a very

scary time for him." Similarly, another parent responded: "There were some instances where the

therapist had a replacement because of a family emergency, and my son did not take well to that

situation."

      Perceived Provider Disregard. A number of participants mentioned that negative

experiences with service providers had to do with experiences in which they felt disregarded,

unheard, or ignored. A number of parents noted that their negative experiences with service

providers were based on the perception that the provider did not seem to care about them or their

child. Parent participants mentioned how service providers did not consider their concerns

during consultations or when planning interventions, and that this often left them feeling stressed

and in need of finding alternate care. Three subthemes emerged from the larger theme of

participants feeling disregarded by providers, including the fact that participants had the least

satisfaction surrounding the time of their child's diagnosis, participants felt disregarded when

providers ignored their concerns, and participants had negative experiences when they felt that

their visits were rushed.

      Disregard perceived at time of ASD diagnosis. In many instances, participants noted

that they felt a lack of support upon receiving their child's diagnosis. In one example, a

participant shared,

        Our first trip to be diagnosed wasn't very pleasant, as we were just blown off and told

that it was normal for her at her age to be acting the way she was. Our concerns were not

taken into consideration, and we left feeling absolutely devastated and looking for more

answers than we had come in with.

Similarly, another parent shared an experience of disregard at the time of the child's diagnosis:

"In his original diagnosis, the doctor who provided it was incredibly arrogant when answering

our questions related to the diagnosis and was extremely unhelpful." There were other

participants who had negative experiences with the provider who diagnosed their child, leading

the family to feel stressed, as in the following example:

> The physician that diagnosed my son with autism basically told us to give up on him ever
>
> being normal. He said he will always be the oddball in class and grow up to be a weird
>
> adult because of his autism and won't be able to function as a normal person in society. I
>
> felt dejected and stressed at that time.

> ***Parents concerns were ignored.*** In some responses, parents expressed feeling that their

values or concerns were ignored by the provider. One parent explained an experience as follows:

> When talking about discipline, [the provider] seemed to just always want to
>
> accommodate to my son and completely disregarded our values and our way of life. I
>
> wish she had tried to work with us and understand that we want our child to be able to be
>
> a successful adult and we want to prepare him for life rather than accommodate in every
>
> single aspect that he struggles in.

In another example, a mother felt that the provider dismissed her concerns outright:

> I took my son to his doctor because we were having a lot of issues with him self-harming.
>
> I told his physician how he was biting himself and banging his head, but he dismissed me
>
> saying I just had to be more firm with him. I felt that he was just very dismissive and not

supportive in that situation. I wanted him to refer me to someone that could help and he did not.

Perceived Lack of Provider Professionalism. A number of parent participants pointed out negative experiences with services providers that involved the provider's lack of professionalism in working with their children, or a general lack of understanding of the behaviors and needs associated with ASD. Some parents experienced the provider as being negative about the job, toward the parent, or toward the child, while other parents reported poor communication and interpersonal skills, as well as a lack of perceived competency. Participants wrote similar terms about negative experiences with their provider, including that the provider was "accusatory," "harsh," "angry," and "unhelpful," which led to a negative and unsupportive experience. Other responses indicated that parents felt as though the provider did not like their child due to their child's behaviors. One parent shared, "my daughter is so playful and throws things everywhere. One of the service providers hated her since he needs to clean every time and he was disappointed in my daughter in the class. It was a totally negative experience." In a similar example, another parent noted,

> Many years ago we had a special instructor that would come to the house. I felt that she was a bit too rough and strict in what she wanted my daughter to do. It didn't seem like she liked my daughter or her job.

In some instances, the experience of working with a provider who reacted negatively or too harshly with the child led the family to discontinue service. One parent stated,

> During a visit with a counselor, one we don't see anymore, she got overly aggravated with my child and actually started yelling at him. This caused my child to yell back and it was all bad from there. We never went back there again, and I let her know how I felt.

Another parent indicated that the reason for leaving the provider was because of his negative demeanor:

> We have been to many therapists and unfortunately had some bad ones. There was one in particular that was an older man who I would describe as gruff and seemed to genuinely dislike his job. We had been going to him for a couple months and one day he just seemed to be very frustrated and short-fused. He got upset with me as I was frustrated with his behavior and we just left in the middle of one of our sessions. We were very happy to find someone else.

Similarly, another parent was prompted to leave the service provider after the provider did not seem willing to help any longer: "About a year ago the provider just seemed to get tired of us. She would not listen, she would give vague answers and suggestions and just stopped engaging. We then left and found a new provider." In one shocking report, a participant claimed that one day the provider arrived and was drunk.

Financial concerns. A number of participants pointed out that the cost of service provision was expensive, sometimes so expensive that it prevented parents from getting the services they wanted, needed, or were referred to receive. One parent shared, "Sometimes I felt like I was facing a lot of troubles with money and I can't spend it for her treatment." Another parent stated feeling unsupported "when my money does not work out to cover the needs of my child." Three additional participants shared that the fees for obtaining consultations were simply too expensive.

Analytic Memo

An exploration of the data from a postpositivist lens within a phenomenological line of inquiry required me to read and re-read participant responses in order to become fully immersed

in the data. This involved repeated readings of participant responses during initial coding, when

finalizing themes, and again to integrate important quotes within each theme, as well as during a

final review of the data analysis. Throughout this analysis, I maintained a focus on allowing

themes to emerge inductively from the data so that the voices of the participants could be

presented as accurately as possible. In this way, credibility of data was upheld through having

adequate engagement in the data so patterns in the data could be properly identified (LaBanca,

2011). In addition, I aimed to achieve triangulation across data sources by coding responses first

at the individual level and then across multiple participant responses in order to derive themes

(Barusch, Gringeri, & George, 2011). With the understanding that researcher bias is always

present and that a true reality of participant experiences can never be fully apprehended, I took

notes during the analytic process as a way to conduct a self-reflective audit in order to uncover

any interpretations, questions, and ideas that arose.

My first thought was regarding the chosen method of data collection and how this may

have impacted the quality of the data, and thus the analysis of data collected. The qualitative

portion of the study was conducted online, and responses were requested but not required. This

resulted in participants giving variable time to their responses; some participants skipped

responses, some wrote very brief one or two-word responses, and others wrote more in-depth

responses with broader explanations of their experiences. During data analysis, I considered

how the multiple backgrounds of participants may have influenced their responses, with

consideration of English fluency, comfort with technology, and willingness to invest time. I

considered my status in each of these identity categories, as well, and committed to interpreting

all responses, particularly those that were not written concisely or clearly, with the same care as

longer and more fluent responses. It also became apparent during the analysis that the open-

questions I posed may not have been written as clearly as I intended, which may have resulted in some responses that were difficult to interpret or categorize appropriately. Encountering responses that did not seem to fit the question exhibited one of the downsides of anonymous qualitative research conducted via online survey – the opportunity to clarify questions posed and answer participant queries was not available. Shorter responses may have indicated a lack of understanding, a lack of interest in responding, or discomfort in sharing personal experiences.

While initially reading through participant responses across all three qualitative questions, my first reaction was one of grateful surprise that so many participants were willing to share their experiences in the open-ended responses following the online surveys. Perhaps one of the benefits of conducting this study online was that it gave individuals the space and anonymity to think about and provide such rich responses. Additionally, offering small monetary compensation for the completion of surveys may have prompted some individuals to be more willing to share their experiences and spend a few more minutes writing in the open-ended responses. Some of the responses were very short or skipped entirely, perhaps due to participant disinterest, discomfort, or fatigue. However, there were a number of respondents that provided answers that were so informative and personal, and I was impressed by the honesty of these respondents and their trust in the research and in me as the reader analyzing these responses. Due to the fact that so many parent participants were willing to share their stories, I endeavored to return to the data multiple times throughout the analysis to ensure that I was representing participant responses by remaining as close to their own words and experiences as possible. This took a few months in total to ensure that all of the responses were attended to with equal consideration.

As I reviewed responses for the second qualitative question regarding negative

experiences with service providers, I found it interesting that so many individuals reported not having had any negative experiences with their providers. In designing the study, I wanted to ensure that parents had an outlet for both positive and negative experiences to promote unbiased responses, but I did not consider that one of the benefits of highlighting positive experiences would be that positive experiences proved to be more multidimensional and prolific than the negative experiences that participants had with service providers. Contrary to my expectations, the opportunity to provide negative experiences actually highlighted the overarching positive experiences that families had with their service providers. In my researcher reflexivity statement, I addressed my experience working with families with children with ASD and noted that there were a number of negative experiences that families shared with me regarding their experiences with service provision, particularly regarding access to care, inclusive of long wait lists and difficulty obtaining services that were covered by insurance. While these issues were addressed by participants through expression of the financial constraints and wait times when accessing services, these responses were not as prolific as I would have predicted. In fact, the negative experiences that were the most common among participants were those that exhibited feelings of disregard by service providers, and these responses had a personal impact on me as a service provider. In particular, participants shared some of the things that their provider said regarding their child's ASD status and ability to improve, and these statements were so negative and vivid in my mind, that I felt disappointed in these service providers, perhaps much like the participants themselves. It made me think about how difficult it must be to continue to remain motivated to find further treatments when previous experiences with service providers were so negative. Some statements were so powerful and concrete that they readily generated themes that were easily confirmed by an external reviewer, who also shared similar sentiment.

Throughout data analysis, I continuously considered the additional unknown participant identities that could have interacted with the data. I was limited in my pursuit of further data analysis due to the limited demographic data I collected from participants. A further analysis of participant experiences with service providers based on racial and ethnic background, language of origin, geographic location, and SES inclusive of parent occupation would have provided more information about the interaction of these variables with satisfaction with service delivery. During the design of the research study, it was necessary to make a choice of variables to pursue in the analysis in order to keep the research focused. I decided to focus on satisfaction with services and parent perspectives of child behaviors instead of focusing the study on racial background, which could have also included research into beliefs about disability and ASD from racial and cultural perspectives and the interaction between the family's racial identity and satisfaction with and outcomes of treatment, although these are variables that I was very interested in pursuing. The curiosity that has resulted from this data analysis has prompted me to focus future research on the interaction between the family's racial background and family satisfaction with ASD services in order to uncover barriers to care that may be due to racial disparities between provider and recipient.

To enhance data integrity and trustworthiness, a credibility check was conducted through an external audit of the data. An external verification of findings was employed with a peer reviewer to confirm findings as well as uncover divergent opinions on data patterns and categories (LaBlanca, 2011). An external auditor reviewed the empirical framework and design of the research study before reviewing the data directly in order to become familiar with the phenomenon being explored (Creswell & Miller, 2000). After the auditor reviewed the data, she then reviewed the codes, themes, and categories derived from the data and written by the

researcher to resolve any discrepancies in the analysis and to highlight points of convergence. The auditor reflected the same process as the researcher in noting that the second qualitative question regarding positive experiences was much more difficult to categorize than the other two qualitative questions. The auditor noted that perhaps there was a reason that the negative experiences shared by participants were so seemingly concrete while the positive experiences were more abstract and multidimensional. The peer reviewer helped me reconfigure themes and subthemes for the second qualitative question regarding positive experiences with service providers to better represent the concepts of provider compassion and relationship building between providers and families that emerged from the data. Initially, one of the major themes for the second qualitative question was that of provider competency, containing subthemes that the provider demonstrated good communication skills, the provider developed positive rapport with the family, the provider improved parent understanding of ASD, treatment provided evidence of child improvement, and provider gave positive feedback. The auditor agreed with the theme of parent involvement in the multidisciplinary theme and examples contained within this theme, but suggested that the theme 'provider goes the extra mile' be included in a larger category of relationship building between the provider and family, as this seemed to be a perspective held by participants that providers were going above and beyond when, in fact, the provider was working to improve their relationship with the family to try to work with them more functionally. I then reorganized the themes for the second qualitative question regarding positive experiences with service providers based on auditor feedback. The auditor agreed with the themes derived from participant responses for the third and fifth qualitative questions and confirmed the need to move a number of participant responses from the fifth question to the second question for clearer categorization of responses.

Working with an external auditor proved to be a very worthwhile and helpful endeavor. In rereading the data multiple times, I found that certain responses began to apply to different themes, particularly those expressing positive experiences with service providers, and the more that these themes overlapped, the more convoluted the presentation of participant responses. In working with an individual who could review the background of the research, participant data, and the themes derived from participant responses, I felt more confident following her feedback that I had organized themes in such a way that provided an accurate representation of participant experiences. Additionally, it was validating to share reactions to the data with an outside reader who agreed that the positive experiences were more multifaceted and complex while the negative experiences were so concrete that they were almost easier to represent. This made me consider the nature of previous research in this area of study, as much of the research on parents of children with ASD has focused on negative aspects of child behaviors or negative outcomes for parents and parent relationships. Perhaps this is due to the concrete, easily interpretable nature of negative experiences, as I experienced in an analysis of the second and third qualitative questions. This consideration made me even more excited to have provided the opportunity for parents to rate positive aspects of their child's behaviors and share positive experiences with their service providers in this research so that I could share the more complex and diverse nature of positive outcomes of having a child with ASD and working with service providers.

Chapter V

DISCUSSION

The goal of this study was to examine the relationship between parent satisfaction with service providers, parent stress, and parent perceptions of the adaptive behaviors of their child with ASD. In addition, this study utilized a mixed-methods approach to expand quantitative methods by incorporating qualitative questions that would provide parents the opportunity to share positive and negative examples of their experiences working with service providers, and to describe how working with service providers helped them see positive attributes of their child with ASD.

The first research question examined the relationship between parent satisfaction with child-focused services from professional service providers and parent appraisals of the functional behaviors of their child with ASD. Child-focused professional partnerships are intended to meet the individual needs of children to help them succeed, build on child strengths, provide parents with information and support in the best interests of the child, provide positive feedback on child progress, treat the child with dignity, and value parent opinions on their child's needs (Summers et al., 2005a; Summers et al., 2005b). The hypothesis for the first research question proposed that parents who reported lower child problem behaviors and higher levels of child prosocial behaviors would report higher levels of parent satisfaction with child-focused services and partnerships. Results indicated that parent appraisals of child functional behaviors were negatively correlated with parent satisfaction with child-focused aspects of services. It was revealed that parent appraisals of their child's prosocial skills were positively correlated with their satisfaction with child-focused services, such that parents who reported higher satisfaction with child-focused aspects of professional partnerships reported lower child problem behaviors

and higher levels of child prosocial behaviors. Parents that indicated that their children had high levels of problem behaviors, most specifically in the domains of conduct problems and peer problems, reported low satisfaction with child-focused aspects of professional partnerships. Results help elucidate how child-focused aspects of services, which are meant to provide parents with positive feedback about child progress as well as meet the individual needs of the child, led parents to feel satisfied with their services and helped them to recognize and evaluate their child's functional abilities. Results supported the first hypothesis, as parents who reported that their children presented with lower problem behaviors and more prosocial behaviors were more satisfied with the services being provided to their children. Previous research has highlighted that parents have felt stressed, exhausted, drained, and overwhelmed from providing care to their child with ASD, particularly when parents reported high rates of child behavior problems (DePape & Lindsay, 2015). Additionally, family involvement with services and service planning has been shown to increase family satisfaction with service providers and improve child and family outcomes (Popp & You, 2016). Taken together, results of this study are consistent with previous research, in that parents who reported higher satisfaction with child-focused aspects of services were shown to be more likely to report lower child problem behaviors. This finding implies that professional service providers can make purposeful efforts to inform parents about their child's development and improvements in order to help parents perceive the benefits of their treatment and, thus, to be more actively involved and motivated in their child's treatment.

For the second research question, it was hypothesized that parents that reported lower child problem behaviors and more favorable appraisals of their child's social functioning would report higher satisfaction with family-professional partnerships would report. Family-focused relationships are those that focus on aspects of the service provider, including that the provider is

honest, dependable, respectful, friendly, demonstrates appropriate communication skills, and understands the importance of privacy (Summers et al., 2005a; Summers et al., 2005b). A multiple regression analysis revealed that parent satisfaction with family-focused relationships was negatively correlated with parent perceptions of child problem behaviors and positively correlated with parent perceptions of child prosocial behaviors. Parents that rated their children as high on the emotional problems scale, conduct problems scale, and peer problems scale of the SDQ reported having low satisfaction with family-focused aspects of professional partnerships, whereas parents who rated their children as high in positive prosocial behaviors reported high satisfaction with family-focused aspects of professional partnerships. Similar to the first research question, this hypothesis helped to clarify how aspects of the provider's competency led parents to feel satisfied with services as well as assisted in their ability to positively perceive and rate their child's skills and abilities. Results were as expected and consistent with results from previous empirical research. This research question helped further clarify that parent satisfaction with both aspects of family-professional partnerships, inclusive of child-focused and family-focused aspects of care, was related to parent perceptions of higher rates of child prosocial and functional behaviors. Similar to the results of the first research question, these results emphasize the importance of helping parents see their child's improvement and linking this improvement to child-focused and family-focused aspects of care. By doing so, parents will be more satisfied with their treatment providers and their child's improvements and will be more likely to be involved in their child's treatment. This may also lead to improved family outcomes, as the benefits of parents being more involved in the treatment process allows parents the opportunity to learn coping strategies, gain access to and knowledge of available resources, and increase their ability and self-efficacy to implement helpful interventions for their child in between sessions

(Robert, Leblanc, & Boyer, 2014). While it is clear that satisfaction with services leads to improved child and family outcomes, another element that remains to be determined is the specific modality of service provision that led to the greatest satisfaction and reasons behind their efficacy. Future research could specify types of interventions (i.e., behavioral, relational) utilized by service providers in their treatment of children with ASD and determine which empirically validated treatments of ASD lead to increased parent satisfaction and improved child functioning.

The third research question proposed that parents who reported higher levels of stress would report lower satisfaction with services and less positive appraisals of their child's functional behaviors. Two hierarchical multiple regression analyses were conducted to determine if stress accounted for additional variance within the relationship between parent perceptions of child functional behaviors and parent satisfaction with child-focused and family-focused professional relationships. Results indicated that experiences of life stress impacted the relationship between appraisals of child behaviors and parent satisfaction with child-focused services, such that parents who experienced more stressful events over their lifetime reported lower satisfaction with child-focused services and perceived that their child had higher rates of peer problems and conduct problems. Experience of stressful events over the lifetime was also a significant predictor of parent satisfaction with family-focused aspects of professional relationships and parent perceptions of child behavior problems. Parents who reported more experiences of lifetime events that were stressful reported lower satisfaction with family-focused aspects of professional relationships and higher child behavior deficits in the domains of emotional problems, conduct problems, and peer problems. Moderation analysis revealed that total experiences of lifetime stress was a significant predictor of the relationship between

satisfaction with family-focused relationships and parent perceptions of their child's problem behaviors. However, the interaction revealed that there was a significant negative relationship between parent perceptions of child problem behaviors and parent satisfaction with family-focused relationships at low levels of lifetime experiences of stress, and this interaction lost significance as reported lifetime experiences of stress increased. These results were not as expected, as previous research indicated a strong relationship between parent stress and higher rates of reported child problem behaviors (Minnes, Perry, & Weiss, 2015). In addition, previous research indicated a strong link between parent stress levels and their perceptions of support services, such that parents who had lower stress levels had more positive perceptions of their situation and the resources available to them (Robert, Leblanc, & Boyer, 2014). Of note, experiences of stress over the past three months, as measured by the Perceived Stress Scale, significantly moderated the relationship between parent satisfaction with both child-focused and family-focused relationships and child problem behaviors. However, the confidence interval for the interaction in both of these moderation analyses included zero, indicating that there was a moderation effect in the population which may not be consistent. Even though experiences of stress did contribute to the interaction between parent satisfaction with service providers as well as parent perceptions of child functional behaviors, the relationship could also have been accounted for by the measures utilized in this study, as well as various other factors that were not under investigation. These findings suggest that it may be beneficial for service providers to not only assess for current stressors in the family unit, but to also place considerable focus on the family's lifetime experience of stress. For those parents who have experienced greater stress over their lifetime, service providers can increase parental support within their treatment plan, as well as focus on helping parents develop additional coping strategies to not only manage their

child's behaviors, but also to manage their own reactions to their child's behaviors.

The fourth quantitative question hypothesized that there would be a negative correlation between the age of the child with ASD and parent satisfaction levels with professional partnerships. Pearson correlations confirmed this hypothesis and revealed that there was a negative correlation between the age of the child and parent satisfaction with both child-focused and family-focused aspects of professional partnerships. Thus, as the age of the child increased, parent satisfaction with professional partnerships decreased. These findings were as expected and are commensurate with previous research, which has found that parents of older children with ASD reported less satisfaction with multiple aspects of services, including coordination of care, financial barriers, and limited availability of services (Mackintosh, Goin-Kochel, & Myers, 2012; Robert, Leblanc, & Boyer, 2014; Sobotka, Francis, & Vander Ploeg Booth, 2015). The implications of this finding suggest that parents are more satisfied with their child's services when parents are able to obtain these services when their children are at a younger age. This may provide parents and children with more time and opportunities to utilize services and thus improve child functioning while children are still in an early stage of their development. Parents may experience more hope and motivation for treatment when services are obtained earlier and children are able to demonstrate improvements before they reach school age and receive additional negative feedback about their functioning from peers, other parents, or teachers. This also indicates additional advantages for children to be diagnosed at an earlier age, so they can obtain the necessary services as early as possible for the most optimal outcomes.

The fifth research question introduced a qualitative component to the research, and asked parents to describe both positive and negative experiences with service providers and to provide an example of an experience in which their service provider influenced their ability to see their

child's strengths. The qualitative portion of the study was analyzed through responses from a series of open-ended questions, and each question was analyzed using an inductive thematic analysis approach. Parents were asked to provide examples of positive experiences of working with their service provider that made them feel supported. Parents described a number of ways that their provider made them feel supported which resulted in a positive experience with the service provider. Themes of positive experiences with service providers include perceptions of provider competency, relationship building between the provider and the family, the provider involving the parent in the multidisciplinary team, and providers helping parents understand their child's positive traits. With regards to parent perceptions of provider competency, parent participants reported feeling supported when the professional they worked with was able to improve the family's understanding of ASD and the specific ways in which their child was impacted. This reportedly helped parents understand their children and the ASD diagnosis more clearly. Parents shared that they had positive experiences with the provider when their provider helped them understand their child better. This subtheme included ways that the provider was able to help the parent see the symptoms of an ASD diagnosis from their child's perspective. Some parents indicated that they felt relief after understanding why their child acted the way they did, and that their child may also be frustrated by experiencing certain limitations. Notably, parents reported that their experiences with service providers were positive when treatment showed evidence of their child's improvement. As children's behavior problems reduced and prosocial behaviors emerged, parents reported feeling confident and happy both in their child's and in their provider's abilities. This appeared consistent with the quantitative results from the first two hypotheses, which indicated that parents reported more satisfaction with child-focused and family-focused relationships with service providers when they perceived their children to

have more prosocial abilities. These results are also consistent with items on the FPPS that were rated by parents as important for parent satisfaction with professional partnerships, including that the provider has the skills to help the child succeed and that the provider is able to meet the individual needs of the child.

Parents also described positive experiences in which the provider was able to build a strong relationship with the family. In particular, parents identified aspects of professional partnerships including good communication skills and developing positive rapport that made them feel supported in their interactions with service providers. Open and clear communication has been identified in previous research as a critical component of parent satisfaction with services. Past studies have highlighted how communication between providers and parents has helped families better understand the provider's skills and expertise in caring for their child (DePape & Lindsay, 2015), allows families to have choices and control over treatment decisions, which helps parents establish stronger relationships with their service providers (Hartley & Schultz, 2014), provides a space for families to voice their concerns and feel respected by the professionals with whom they work (Hidalgo, McIntyre, & McWhirter, 2015), and assists in the collaboration between parents and providers for treatment that is personalized and adapted to meet their child's individual needs (Robert, Leblanc, & Boyer, 2014).

Supportive experiences for parent participants also included the professional's ability to include parent concerns and interests while meeting with the multidisciplinary team. Some parents noted that they were able to collaborate with multiple providers within a single system, such as the school, in order to work towards the same goal for their child, or that their provider was able to work with the team on the parent's behalf to best meet the needs of their child. This is consistent with one of the child-focused relationship items on the FPPS, which asks parents,

"how satisfied are you that your child's provider speaks up for your child's best interests when working with other staff." 138 out of 171 respondents (81%) reported being either satisfied or very satisfied on this item of the FPPS, indicating that this is an important aspect of child-focused relationships and resultant parent satisfaction with services. Parent participants also shared experiences in which they felt that their provider went above and beyond what was required to support them. Sometimes this involved flexibility with scheduling, and in other examples this involved providing services regardless of the family's ability to pay. These issues are important to note, as they appear again in the inverse when parents note that scheduling issues and financial concerns led to negative experiences which led them to feel a lack of support from their service providers.

Parents were also asked to provide an example of a time when their provider helped them understand something positive about their child. Parents reported that their providers helped them see something in their child of which they were previously unaware, such as a positive personality trait, a specific skill, or a general interest. Parents noted that this helped them connect with their children better, and also allowed them to view some of their child's behaviors in a more positive manner, particularly when their child was reportedly excelling in a specific area. Parents also shared that providers helped them see that their child had improved, or was likely to improve with time and additional provision of services. In both of these subthemes, parents expressed relief and hope that there was evidence that working with the provider was going to help their child's functional behaviors improve. Positive feedback was indicated as very important to parents, as it was a direct indication that the child was doing well, and perhaps a sign that parents were doing well for their children, too. Regarding hope for the future, parents

indicated that patience and good communication with their provider helped them have hope for their child's future.

Parents reported a number of important examples about times when they did not feel supported by their provider. However, it is important to note that 44% of the sample reported that they had no negative experience with their service provider, further promoting the importance of asking parents about their positive experiences of service providers and of their children. Of the negative experiences shared, themes emerged regarding scheduling and administrative issues, feelings of disregard coming from the provider, perceived lack of provider competency, and concerns about the high cost of service provision, which in some cases prevented individuals from getting the care they needed. Scheduling and administrative issues included difficulty in obtaining an appointment and issues regarding provider turnover and continuity of care. This is consistent with an item on the FPPS that rates provider dependability, indicating that without this aspect of professional partnerships, parents tend to be dissatisfied with service providers.

Parents wrote multiple responses indicating that their negative experience with service providers involved instances when they felt disregarded by their provider. Some parents wrote particularly distressing experiences where their provider was unsupportive of them at the time that their child was diagnosed. Parent participants also reported that they had negative experiences with their providers when their concerns were dismissed or ignored, and they did not feel understood or attended to appropriately during interactions with their service provider. These responses seem consistent with a number of items on the FPPS that are designed to measure important aspects of child- and family-focused relationships, including that the provider shows respect for family values and beliefs, values parent opinions about their child's needs, and

pays attention to what parents have to say. This finding does present the possibility that the

FPPS primed parents to recall these experiences, since the quantitative questionnaires were

presented prior to the qualitative questions on Qualtrics. An exploratory factor analysis

produced these items on the FPPS, indicating that a number of parents felt these items were

important for good partnerships to be developed between families and professionals (Summers et

al., 2005a). Parents in this study further corroborate those results by indicating that when these

factors did not exist within the professional partnership, parents felt unsupported and unsatisfied

with their provider. In addition, these results are consistent with results obtained in another

thematic analysis, which queried caregiver satisfaction with medical professionals; results from

this study indicated that parents faced a number of challenges with service delivery from medical

professionals, most commonly reporting that pediatricians did not listen to parents or validate

their concerns (Hidalgo, McIntyre, & McWhirter, 2015).

        Some of the more egregious examples of negative experiences with service providers

indicated that participants perceived their provider to lack competency and professionalism.

Some parents shared experiences where providers were inappropriately harsh towards their

children or with the parents themselves. In some responses, parents shared that the provider did

not seem to like their job, which in turn did not make it appear that the provider was doing their

job well. This not only emphasizes how providers fail parents on an individual level, but these

experiences could also lead parents to feel dissatisfaction in other areas of service provision. For

example, if parents want to terminate services with a provider due to their perceived negative

demeanor or ineffective practice, they will have to expend more energy and resources to obtain

alternate services, which can add additional stress to the family system. Previous research

indicates that challenges for parents of children with autism include the need for parents to try

different types of services and treatments before finding the best fit for their child, requiring

parents to dedicate a great deal of time, money, and energy (AL Jabery et al., 2012). Since

parents of children with ASD face greater challenges in obtaining services for their children than

do parents of children with other disabilities (Rivard, Lépine, Mercier, & Morin, 2014), ensuring

that the providers that are available are able to provide services with professional competency is

vital to child outcomes and parent satisfaction with their service experience.

Conclusions

The results of this research imply that parent satisfaction with both child- and family-

focused aspects of professional partnerships with service providers was directly related to their

perception of their child's functional abilities, such that the more parents reported satisfaction

with services, the higher they rated positive aspects of their child's behaviors and the lower they

rated negative aspects of their child's behaviors. Quantitative analysis also aligned with

qualitative responses in this regard, as parents who felt supported by service providers

overwhelmingly reported ways in which their child's behaviors had improved as a result of

receiving treatment with their service provider. In addition, mixed-methods results indicate that

when providers were able to provide positive feedback on child improvements and functional

prosocial abilities, parents had more positive experiences and were more satisfied with their

professional relationships with their service providers. Results indicate that in order to provide

satisfactory services that promote parent engagement, service providers need to spend a

significant portion of treatment planning focused on providing feedback regarding the child's

progress in treatment. When child-focused aspects of care focus on improving the child's

functioning and family-focused aspects of care provide feedback to parents about ways in which

their child's skills or functioning has improved, parents are likely to be more involved and more

satisfied with their treatment.

Thematic analysis of qualitative responses revealed a number of ways in which service provision could be enhanced to lead to better quality services and an overall better experience with service providers. Results from this research study indicate that communication, competency, and respect were very important aspects of professional partnerships for parents that providers could focus on within their practice. As parent satisfaction with services has been found to contribute to positive child outcomes (Popp & You, 2016; Hartley & Schultz, 2014; Russa, Matthews, & Owen-DeSchryver, 2014), analyzing both positive and negative experiences from parents' perspectives helps directly inform changes that could be made in service provision to increase parent satisfaction with services, and thus could improve child outcomes in treatment. Results gathered from this study suggest that professionals should focus their communication efforts on providing families with adequate psychoeducation on ASD as a diagnosis, inclusive of reasons behind their child's behaviors, an understanding of the child's experience of their diagnosis, and an understanding of expected outcomes and future functioning of their child as a result of engagement in treatment. In addition, providers can help parents not only by listening to their concerns and validating their experiences, but also by individualizing treatment in alignment with the values of the family system to best meet their child's needs. This relates to the facet of respect within professional partnerships, as parents who felt that their provider took the time to listen to them and address their concerns indicated that they felt more supported.

Qualitative analysis strongly supported the use of the quantitative measures used in the study. A large proportion of the qualitative responses from parent participants paralleled items on the FPPS that were determined to be key aspects of satisfactory partnerships between families and providers. This provided further evidence of the importance of certain aspects of service

provision and provider competencies being present in order for parents to be satisfied with their provider and service experience, namely competency, listening and communication skills, and respect. In addition, parents often wrote about their child's behavioral problems alongside negative experiences with service providers, and expressed improvement in their child's behaviors or positive aspects of their children when reporting positive, supportive experience with service providers. This supports the use of the SDQ as a quantitative measure of child behavior problems and child prosocial behaviors. It is important to consider, however, that the order in which quantitative and qualitative questions were presented in Qualtrics may have primed parents to think about experiences with service providers related to items listed on the quantitative measures, themselves. Future research studies may want to account for an order effect across methods as opposed to focusing on the order effects of quantitative measures, only, as was employed in this research design.

Results of this study suggested that stress does not strongly predict parent satisfaction or parent perceptions of child functional behaviors. The hypothesis that high levels of stress would predict low satisfaction with services and higher reports of child problem behaviors was based on results reported in many previous studies. Research has shown that families with a child with ASD experience more stress than families with typically developing children and children with other disabilities (Cridland, Jones, Magee, & Caputi, 2014; Russa, Matthews, & Owen-DeSchryver, 2014) due to a number of factors, including expenditure of effort in learning about and accessing the service system (Hidalgo, McIntyre, & McWhirter, 2015; Minnes, Perry, & Weiss, 2015), managing child behavioral challenges (Brookman-Frazee, Baker-Ericzén, Stadnick, & Taylor, 2011; Myers, Mackintosh, & Goin-Kochel, 2009) as well as comorbid disorders that co-occur with ASD (Hartley & Schultz, 2014), and financial struggles associated

with the cost of utilizing often multiple services (Minnes, Perry, & Weiss, 2015). The lack of a significant association between parent stress and parent satisfaction with services as well as parent perceptions of child functional abilities in the current study may be due to the fact that parents had the ability to rate a number of specific factors that led to satisfaction and dissatisfaction with services that may have been more impactful on their experience with service provision than the presence or absence of stress. However, this could also be due to the quantitative measures chosen to measure stress. The PSS measures stress within the past three months, and while this is a frequently used and empirically validated measure for stress, it may not accurately reflect the broader picture of parents' experiences. The Holmes-Rahe SRRS was able to better predict the relationship between satisfaction with child- and family-focused relationships with service providers and total problem behaviors of the children, but only at low levels of reported lifetime experiences of stress. This may reflect that for some parents, stress levels resolved as their child behaviors and functioning improved. However, this also indicates that measuring stress of parents in this study through use of the PSS and SRRS did not significantly predict parent satisfaction with services or parent perceptions of child behaviors. This suggests that the questionnaires chosen to measure stress did not sufficiently capture the precipitants or causes of stress for this population of parents. A measurement of parenting stress particular to the participant and to having a child with ASD (such as the Parenting Stress Index or Autism Parenting Stress Index) would have provided a more accurate assessment of the stress variable under consideration. A further exploration of different aspects of stress, as well as different measures of stress, should be considered for future research in the area of parent satisfaction with ASD services.

The results of this study can help a broad range of service providers consider the

subjective experiences of the parents who coordinate their services and use these perspectives to incorporate aspects of service provision that have been shown to lead to more satisfactory and beneficial treatment. Based on the results of this mixed-methods study, parents' responses highlighted the importance of individualized, accurate, strengths-based feedback about their child with ASD from service providers as an integral part of satisfactory service provision. The ability to provide psychoeducation about an ASD diagnosis helps parents feel confident about their provider's knowledge, and the ability to individualize treatment for the child also leads parents to feel confident in their provider's abilities. Such child-focused aspects of care are important for providers to consider when meeting with a family for the first time and determining the initial goals for treatment. Service providers can also make efforts to strengthen their family-focused interventions, particularly those that help parents understand their child's treatment and see their child's improvements. Service providers may want to make efforts to incorporate feedback to parents often throughout treatment, with a focus on the prosocial and functional behaviors of the child with ASD, in order to bolster their family-professional partnership.

Results from previous research indicated that incorporating parents in the treatment process with shared decision-making helps improve parent self-efficacy (Minnes, Perry, & Weiss, 2015; Popp & You, 2016). In looking at parent satisfaction with services, results from this study should reinforce the number of benefits to involving parents in their child's treatment beyond coordination of care and gathering collateral information. The more involved parents are in their child's treatment planning, the more opportunities there are for providers to relay positive feedback to parents about their own parenting skills and abilities in helping their child. In addition, results indicated potential benefits for service providers to assess for parent and

family stressors in order to determine how treatment can support parents in the delivery of interventions and in caring for their child with ASD. The results of this study remind service providers from myriad service provider systems the importance of attending to the family system when working with children with ASD. Since the child functions within the family system, it behooves providers to consider the needs of the family holistically when planning for treatment and implementing services. Service providers can think about how to best assess for and incorporate family and child goals in their overall treatment plan in order to enhance parent satisfaction and optimal outcomes for the child and the family. As families of children with ASD have been shown to work with many providers over their child's lifetime, the goal of this study was to help service providers think about parent experiences with their service delivery and be motivated to improve their practice to best meet the needs of these often underserved families.

Limitations

This study had some notable limitations, particularly due to the fact that the extent of the analysis that could be done was limited by the choice to minimize the number of potentially intrusive demographic questions, particularly those that were not planned to be under investigation. Although demographic variables were collected regarding family make-up and financial access to care, a thorough analysis of the broader context of participants' cultural experience was beyond the scope of this study. This is a limitation when making final conclusions about connections between family experiences and results reported in quantitative and qualitative analyses. When scoring the stress associated with life events on the SRRS, for example, it is important to consider that some cultural groups may react differently to certain life stressors and events based on their previous experiences or beliefs (Ennis-Cole, Durodoye, & Harris, 2013; Morrier, Hess, & Heflin, 2008). Demographic information was collected regarding

the age of the child and the age of the parent participant, the gender of the child with ASD and gender of the parent participant, the parent participant's marital status, the size of the immediate family, access to insurance, and average annual household income. These details were collected to gain a broader picture of potential stressors that may impact the family, including financial access to care and services, as well as to remain consistent with previous research that reported on similar demographic information. However, demographic information was not gathered on the race or ethnicity of participants, their geographic location, occupations of parents, or the timing of the diagnosis of their child with ASD, which could have provided additional valuable information to the study. Information regarding the race and ethnicity of participants could have provided information on barriers to care access with regards to the family's cultural background. In addition, it was beyond the scope of this study to consider disparate views of child behavior problems in light of families' cultural backgrounds. Research has shown that certain cultures have different views of ASD and thus different preferences for treatment, and previous research has also revealed that different cultures hold stigmatizing views of an ASD diagnosis (Ennis-Cole, Durodoye, & Harris, 2013; Patel, Preedy, & Martin, 2014), which may also pose as a barrier to treatment.

Other demographic information that was not collected included the geographic location of participants. Details about the geographic location of participants could have provided additional information about access to state health insurance and the presence of state legislation regarding access to services for children with ASD. Additionally, previous research shows that families in rural areas may obtain diagnoses of ASD for their children later than families in urban areas, they may need to travel greater distances to reach trained professionals, and they also may face longer waiting times to obtain appropriate services (Rivard, Lépine, Mercier, & Morin,

2014). Therefore, asking about geographic location, distance to services, and urbanicity may have provided the research with more explanation behind parent satisfaction with services in their area.

This study explored the impact of a broad category of service providers on parent satisfaction with services. As previous research has indicated that parents of children with ASD often interact with a number of service providers over the course of their child's treatment, the goal of focusing on service providers in general was to evaluate parent satisfaction with the many providers with whom they were likely to interact. The list of providers under investigation in this study were those providers often included in IEPs, those covered under the IDEIA regulations, and those reviewed in previous research as the providers with whom children with ASD most often interact. The decision to focus on such a wide range of professionals with presumably different training and approaches to treatment also introduced limitations to the results of this study, particularly the possible effects that the type of service provider could have had on other variables. Even though information was gathered on the areas of specialty of the service providers with whom families worked, information was not collected on the specific interventions or modalities provided by these service providers. Parent perceptions of the services they obtained and their satisfaction with the service providers with whom they worked may have been impacted by the modality of the intervention utilized in service provision as opposed to the individual providing the services. Clarification of the difference between the services provided and the service provider themselves may have provided clearer information on aspects of services that parents found satisfactory and unsatisfactory.

Other study limitations were due to the manner in which the study was conducted. This study was conducted online through MTurk, an Amazon service that distributes surveys for

researchers for a small fee that is paid to participants. The researcher obtained convenience

benefits of this service, and data was collected very efficiently. However, limitations of

conducting the study online need to be considered in terms of generalizability of results and

quality of the data collected. Beyond the qualifications assigned in MTurk to increase the

likelihood that participants were parents, the keywords included in the survey design, and the

two screening questions provided, there were no additional mechanisms in MTurk used to verify

participants met inclusion criteria (i.e., parents of children with ASD). Individuals may have

completed the survey to obtain compensation, which is a clear limitation of the study. To

address this, while reviewing the data, I removed questionnaire sets that were completed in less

than 3 minutes, questionnaires whose scores contained only one response across the questions,

and those where the open-ended questions contained non-pertinent responses, such as Amazon

advertisement information or wingdings. With respect to access, the online survey system may

only be available to individuals who have access to the internet, and who have time to commit to

completing the surveys outside of their existing responsibilities, and who have previous

knowledge of this service being available as a means of earning money. Internal generalizability

may be limited by the participant sample, even though random sampling via online methods aims

to promote diversity of participants.

As the study was conducted online to obtain enough participants for power to satisfy

quantitative methods, the qualitative methods of the study was also conducted online per IRB

guidelines and to help preserve confidentiality and anonymity of participants. The

methodological use of open-ended questions, however, was a limitation with regards to the

information provided in the qualitative portion of the study. In-person and semi-structured

interviews may have allowed for clarification of questions, follow-up questions, and a more

personalized experience for participants. Interviews, focus groups, observation, or community involvement could also have aided the researcher in the formulation of the research and interview questions, as well.

Recommendations for Future Research

Future directions for this research should investigate satisfaction with service providers by also reviewing satisfaction with the treatment modalities provided. This would help to further determine specific aspects of service provision and treatments that lead to satisfaction and dissatisfaction for parents. Additionally, it would be beneficial to gain the perspective of the service provider in such research by assessing and interviewing both the family and their service provider on similar aspects of care. In particular, providers could rate their levels of competency on aspects of service provision while families reported on their experiences of service provision to determine whether or not discrepancies exist between provider and service recipient along certain aspects of service provision. Further research in the area of parent satisfaction with professional services provided to families with children with ASD should also focus on how to implement changes within the service system by addressing areas of professional partnerships in which parents reported low satisfaction levels. Such research could be conducted by interviewing at community centers, training programs, and clinics to determine how best to effect positive changes at the institutional level, as well as by utilizing focus groups to brainstorm methods by which such changes could be functionally implemented. Discursive psychology research could help provide a space for families, service providers, and organizations to collaborate on ideas to institute change.

Future research should pursue a more thorough evaluation of the impact of culture on the variables being researched. The role of the service provider's race and training in multicultural

competent service provision should be considered alongside parent satisfaction to determine training goals for individuals seeking to work with families with children with ASD. In addition, future directions should consider the influence of culture and socio-historical context on the family's ideas of disability, and how this impacts their perspectives on their child's functional abilities as well as their work with a service provider. Strength-based approaches that assess the positive impacts of having a child with ASD on families of different backgrounds should be instilled in such research. In this way, research in this area can promote the strengths of the family with a child with ASD and inform service providers as to the family's resources and skills.

As the results of this study indicated a number of facets of service provision that families deem important for satisfaction, a future study in this domain should assess treatment outcomes for families who report the presence and absence of these factors. A longitudinal study that assesses satisfaction along a continuum of treatment can track whether treatment goals were achieved and factors that parents and clinicians feel led to goal attainment. In addition, this study indicated what parents felt were important aspects of service provision, and the same should be assessed from the perspective of their providers. Research that includes both clinicians and the families with whom they work could highlight areas of discrepancy between service provider and recipient on facets of satisfaction with professional partnerships, and further inform training programs on important issues to help clinicians develop better partnerships with families.

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Appendix I: Letter of Solicitation

Dear Participant,

The researcher is a PhD student at Seton Hall. This research study is looking at the link between parent satisfaction with services, parent stress, and child behaviors. The study is looking for parents of children with autism. Taking part in this study means filling in five surveys:

- Demographic Questionnaire

- The Strengths and Difficulties Questionnaire

- The Perceived Stress Scale

- The Holmes-Rahe Social Readjustment Rating Scale

- The Family Professional Partnership Scale

It will take about 30 minutes to fill out these surveys. After the surveys, volunteers will be asked 4 questions about experiences with service providers.

Volunteers must be parents. Their child must be between 4 and 17 years old. The child must have a diagnosis of an autism spectrum disorder. Taking part in this study is voluntary. If the volunteer does not want to take part, they can close their browser window at any time. Consent to volunteer is given by finishing the surveys.

Parents will fill out surveys online. The "demographic questionnaire" will ask about family details. Questions include the child's age and gender. The "Perceived Stress Scale" asks about feelings of stress over the past month. An example question is, "In the last month, how often have you felt nervous and stressed?" The "Strengths and Difficulties Questionnaire" measures parents' views of their child's behaviors. It will ask parents to mark how true statements are about their child. An example is, "has at least one good friend." The "Family Professional Partnership Scale" asks about parent satisfaction with services. An example

question is, "how satisfied are you that your child's service provider is friendly?" The "Homes-Rahe Social Readjustment Rating Scale" asks volunteers to check events that have happened in the past year. Examples are vacation and marriage.

Information from surveys will be reported together. Survey information will not be linked to personal details in the study. Please know that personal details could be linked on Amazon. There is no confidentiality or anonymity for participation in the study because payment for participation is linked to the user's Amazon account. Participants can see Mechanical Turk's Privacy Policy at https://www.MTurk.com/MTurk/privacynotice. Volunteers can stop at any time by closing their browser window. Volunteering will earn participants $0.50 via Amazon's MTurk. Surveys will be done on Qualtrics. Qualtrics is a secure online service. Please note that there is still a chance of hacking with online studies. Data gathered from the study will be kept in a locked office.

There is little discomfort involved in the study. Some of the questions may bring up feelings of stress. To reduce distress, surveys are short. Surveys also ask positive questions. Volunteers can leave the study at any time with no problem. Volunteers can contact the researcher with any questions or concerns. For any distress, volunteers can use the APA locator to find a mental health provider in their area at http://locator.apa.org.

This study will show the link between parent satisfaction with services, parent stress, and views of child behaviors. Results can help researchers understand what parents feel is important in relationships with service providers. There are no direct benefits to the volunteer.

If volunteers have questions about the study, they may contact the researcher. For questions about rights as a volunteer, contact the Director of the Institutional Review Board, Dr. Mary F. Ruzicka, Ph.D., at (973) 313-6314, or by email at irb@shu.edu.

Thank you,

Amanda R. Templeman, Ed.M., MA, MA

Counseling Psychology PhD Doctoral Student

Department of Professional Psychology and Family Therapy

Seton Hall University

400 South Orange Avenue

South Orange, NJ 07079

amanda.rosenberg@student.shu.edu

Appendix II: Demographic Questionnaire

1. Relationship of participant to child with ASD:

☐ Mother

☐ Father

☐ Legal Guardian

☐ Foster Parent

☐ Other (please specify): _____

2. Participant's age: _____

3. Participant's Marital Status:

☐ Single

☐ Married

☐ Separated

☐ Divorced

☐ Widowed

4. Average household annual income:

☐ Less than $25,000

☐ $25,000 to $49,999

☐ $50,000 to $74,999

☐ $75,000 to $99,999

☐ $100,000 to $149,000

☐ $150,000 to $199,000

☐ $200,000 or more

5. Age of Child with ASD: _____

6. Gender of Child with ASD: _____

7. Number of children in immediate family unit: _____

8. Access to insurance or health coverage plan:

☐ Insurance through current or former employer or union

☐ Insurance purchased directly from insurance company

☐ Medicare

☐ Medicaid, Medical Assistance, or other government-assistance plan

☐ Military health care or VA

☐ Other

Appendix III: Permission to use the SDQ

From: **Youthinmind** youthinmind@gmail.com
Subject: Re: Use of SDQ in Research
Date: August 21, 2017 at 11:24 AM
To: Amanda R Templeman

Dear Amanda,

We have now received your payment and are pleased to authorize you to use the SDQ under the terms of the license (please see below – terms (c) and (e) having been part of your pre-authorization).

I hope all works out well and we will be glad to respond if you have further queries at any point.

Best wishes,

James Goodman

Youthinmind Limited

Licensees pay a small license fee to Youthinmind (currently 0.20 USD per SDQ administered, **increasing to 0.40 USD from 1st September 2017**). Please note that this is only for online systems – we do not currently license Apps. Our standard terms for allowing the online use of the SDQ include:

a) Licensees need to keep track of the exact number of SDQs administered, and be able to justify, if requested, the total that they declare.

b) Licensees pay Youthinmind the license fee at regular intervals: quarterly, 6-monthly or yearly at the Licensee's convenience. The fee is strictly per item, with no reduction for large users. (Since we expect users to save money by using the license, larger users are already advantaged by saving larger amounts of money).

c) The web presentation of the SDQ cannot involve any change in wording and needs to be as close as possible to the standard paper version in appearance - no bright colours, flashing icons etc. This is because changes in presentation can undermine the comparability of SDQ data collected in different ways, making it harder to combine or contrast SDQ data from different studies or clinics. The copyright notice on the paper version also needs to be present on the electronic version. **To ensure that these terms are respected, we do need to see and approve of the licensee's proposed online version before you are authorized to use it.**

d) The license will be revoked if the SDQ were being used in a way likely to bring it into disrepute.

e) There is a one-off authorization charge of 100 USD at the time of authorization

Please let us know if you need further clarification.

Appendix IV: License to use the Holmes-Rahe SRRS

**ELSEVIER LICENSE
TERMS AND CONDITIONS**

Aug 16, 2017

This Agreement between Seton Hall University -- Amanda Templeman ("You") and Elsevier ("Elsevier") consists of your license details and the terms and conditions provided by Elsevier and Copyright Clearance Center.

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Appendix V: IRB Approval Letter

SETON HALL ⛪ UNIVERSITY.
1 8 5 6

November 6, 2017

Amanda Templeman
██████████

Dear Ms. Templeman,

The Seton Hall University Institutional Review Board has reviewed the information you have submitted addressing the concerns for your proposal entitled "Parent Satisfaction with Family Professional Partnerships and Services for Children with Autism Spectrum Disorder." Your research protocol is hereby accepted as revised and is categorized as exempt.

Please note that, where applicable, subjects must sign and must be given a copy of the Seton Hall University current stamped Letter of Solicitation or Consent Form before the subjects' participation. All data, as well as the investigator's copies of the signed Consent Forms, must be retained by the principal investigator for a period of at least three years following the termination of the project.

Should you wish to make changes to the IRB approved procedures, the following materials must be submitted for IRB review and be approved by the IRB prior to being instituted:

- Description of proposed revisions;
- *If applicable*, any new or revised materials, such as recruitment fliers, letters to subjects, or consent documents; and
- *If applicable*, updated letters of approval from cooperating institutions and IRBs.

At the present time, there is no need for further action on your part with the IRB.

In harmony with federal regulations, none of the investigators or research staff involved in the study took part in the final decision.

Sincerely,

Mary F. Ruzicka, Ph.D.

Mary F. Ruzicka, Ph.D.
Professor
Director, Institutional Review Board

cc: Dr. Daniel Cruz

Office of Institutional Review Board
Presidents Hall · 400 South Orange Avenue · South Orange, New Jersey 07079 · Tel: 973.313.6314 · Fax: 973.275.2361 · www.shu.edu

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