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Problem Behavior of a Child With Autism and Problem Behavior of a Typically-Developing Sibling Moderated by Maternal Parenting Stress

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Abstract

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by

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MA, Adelphi University, 2006

BA, St. Joseph's College, 2004

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
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Abstract

Drawing on Bowen's family systems theory, this study was designed to fill a gap in research regarding how raising a child with autism impacts the systemic functioning of a family unit, and provide evidence of the need for more comprehensive resources and support for families of children with autism. In this study, families of children with autism were invited to complete the Parenting Stress Index and the Strengths and Difficulties Questionnaire. These measures were used to determine the relationship between the level of problem behavior of a child with autism and the level of problem behavior of a typically-developing sibling when these variables are moderated by maternal parenting stress. For each family, a secondary caregiver perspective on the problem behavior of the typically developing sibling was also considered. A purposeful sampling procedure yielded only 21 usable pairs of data on primary caregiver parenting stress and problem behavior of a child with autism; thus, the planned analyses were revised and a bivariate correlation was run on these variables. Although this revised study did not yield significant results in the particular sample obtained, it highlights the challenges encountered when intending to run research such as this and indicated ways future researcher could attempt to proactively address these challenges. This study also shows the potential for positive social change from more comprehensive supports for families of children with autism that may decrease parenting stress, reduce problem behaviors of typically-developing siblings, and improve treatment outcomes for children with autism.

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Dedication

This dissertation is dedicated to all of the children with autism that I have been blessed to know, teach, and support over the past ten years. You are my purpose, my passion, and my pride and joy. You are a spectrum of beauty and potential. My heart beats every single one of your names. To the families of all the children I've worked with, thank you for the privilege of being in your lives, for trusting me with your greatest treasures, and for allowing me to find my strength in yours.

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To all those I haven't named specifically, know that your role in this journey, no matter how brief, has impacted me in some way. Thank you for being a part of my story.

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Chapter 1: Introduction to the Study

Introduction

In this study, I sought to explore the relationship between the level of problem behavior exhibited by a child with autism and the level of and problem behavior of a typically-developing sibling when these variables are moderated by maternal parenting stress. Schall (2000) asserted that raising a child with autism impacts not only individual members of a family (parents, siblings, etc.), but also the family as a whole unit. Schall's assertion compelled me to explore how individuals within a family of a child with autism relate to each other and how one member's role or behavior influences another. Efforts have been made to understand the dynamics of the parent-child relationship for parents of children with autism (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Osborne & Reed, 2010; Phetrasuwan & Miles, 2009) as well as the effect on typical children of having a sibling with autism (Hastings, 2003; Tarafder, Mukhopadhyay, & Basu, 2004; Verte, Roeyers, & Buysse, 2003). However, few researchers have explored the triangular relationship between the level of problem behavior of children with autism, the level of problem behavior of typically-developing siblings, particularly when a secondary/alternate caregiver (father, grandparent, nanny, etc.) provides information about the children. With a clear understanding of this relationship, clinicians and other professionals working with individuals with autism may better understand the need for more comprehensive support for families of children with autism. The need for family-based resources that treat and support the family as unit and not simply a cluster of individuals with different needs is evident throughout this study.

In this chapter, I provide a brief background of the problem and identify scope of the study and the gap in scholarly knowledge. I then state the research problem and purpose of the study, and present the research question. Next, I discuss the theoretical foundation for this research and the nature of the study, offer key definitions, and outline my assumptions. The chapter concludes with a discussion of the study's scope, delimitations, limitations, and significance.

Background of the Problem

The relationship between the level of problem behavior of children with autism and parenting stress has been thoroughly identified and explored in the scholarly literature. Phetrasuwan and Miles (2009) concluded that the presence of particular problem behaviors and symptoms related to the child's autism and not the overall severity of disability was more associated with higher levels of parenting stress. Osborne and Reed (2010) showed the directionality of this relationship by identifying maternal parenting stress as a strong predictor of problem behavior of children with autism. Similarly, Verte, Roeyers, and Buysse (2003) found an association between increased problem behaviors of a child with autism and increased problem behaviors of a typical sibling. Petalas, Hastings, Nash, Lloyd, and Dower (2010) indicated that siblings of children with autism exhibited increased levels of emotional problems. What has not been established, however, is the extent to which maternal parenting stress in families of children with autism acts as a moderating variable for the level of problem behavior of typically-developing siblings. Herein lays the gap that I sought to address in this study.

Previous researchers have relied predominantly on the mother's perspective in reporting on the behavior of her children, both with a disability and with typically-developing children (Hastings, 2003; Macks & Reeve, 2006; Petalas et al. 2010). This has been identified as a limitation in studies similar to this one, and both Petalas et al. (2006) and Quintero and McIntyre (2010) acknowledged the need to have an alternate perspective on the children's functioning by recruiting the participation of other informants. The increased objectivity of a secondary/alternate caregiver such as a father, grandparent, or nanny when reporting on the behavior of the children may allow for a more accurate exploration of the relationship between the level of problem behavior a child with autism and the level of problem behavior of a typically-developing sibling when moderated by maternal parenting stress. In this study, I sought to gain that alternate perspective.

Problem Statement

The amount of scholarly literature available on autism spectrum disorders, from diagnostic information and theories to treatment and statistics, indicates that there is a substantial effort to understand more about this disorder and the individuals affected by it (Badcock & Crespi, 2006; Deer, 2011; Rao, Koch, Ghoshi, & Kumar, 2010; Soden, Lowry, Garrison, & Wasserman, 2007). Similarly, researchers have shown considerable interest in the parents of these individuals, particularly regarding how autism impacts their health, quality of life, and efforts to raise their child (Lee et. al, 2009; Menjack, Mavrinac, & Simetim, 2009; Mickeviciene, Sinkariova, & Perminas, 2009). However, individuals do not live in a vacuum and the impact of raising a child with autism extends beyond the parent-child dynamic to create an overall familial impact as well, including an impact on typically-developing siblings (Schall, 2000). Although efforts have been made to understand the impact of having a sibling with autism on typically-developing children (Petalas, Hastings, Nash, Lloyd, & Dower , 2010; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004; Verte, Roeyers, and Buysse, 2003), minimal research has been devoted to exploring the systemic relationships that exist within these families, such as those between the level of problem behavior exhibited by a child with autism and the level of problem behavior of a typically-developing sibling when these variables are moderated by maternal parenting stress. This gap creates a problem in how children with autism and their families are treated because, while resources and support options are available for mothers of children with autism who are known to experience increased levels of parenting stress, greater amounts of resources and support need to be available for siblings and for the family unit as a whole who may be adversely impacted by this family dynamic.

Purpose of the Study

Previous researchers have indicated there is a predictive relationship between parenting stress and the level of problem behavior of children with autism (Osborne & Reed, 2010). Researchers have also shown that the level of problem behavior of children with autism impacts the behavior of typically-developing siblings (Petalas, Hastings, Nash, Lloyd, & Dower, 2010; Verte, Roeyer, & Buysse, 2003). This leads to the hypothesis that perhaps parenting stress, which has been found to impact problem behavior of children with autism, also impacts the behavior of typically-developing siblings. The purpose of this study was to explore the relationship between the level of problem behavior exhibited by a child with autism and the level of problem behavior exhibited by a typically-developing sibling when these variables are moderated by maternal parenting stress.

In this study, I sought to provide evidence which professionals can use to call for more comprehensive resources and support for families of children with autism. Two different phenomena were of interest to me. First, I was interested in how maternal parenting stress moderates the relationship between the level of problem behavior of a child with autism and the level of problem behavior of typically-developing siblings. Second, I was interested in gaining alternate/secondary caregivers' perspectives on the level of problem behavior of a typically-developing sibling.

Research Question

In this study, I addressed the following research question: What is the relationship between the level of problem behavior exhibited by a child with autism and the level of problem behavior of a typically-developing sibling as reported by an alternate caregiver when these variables are moderated by maternal parenting stress?

Null hypothesis (H_o): There is no relationship between the level of problem behavior exhibited by a child with autism and the level of problem behavior of a typically-developing sibling, as reported from an alternate caregiver, when these variables are moderated by maternal parenting stress.

Alternate Hypothesis (H_a): There is a relationship between the level of problem behavior exhibited by a child with autism and the problem behavior of a typically-developing sibling, as reported from an alternate caregiver, when these variables are moderated by maternal parenting stress.

Theoretical Framework: Family Systems Theory

Kerr and Bowen (1988) discussed how clinicians in the field of psychology tend to address problems by focusing on specific components such as causes or symptoms. However, they claimed that problems may be more successfully treated when one employs a broader evaluation of the problem to include the contextual and systemic factors surrounding the issue (Kerr & Bowen, 1988). Bowen's family systems theory departs from traditional approaches to treatment by taking individuals and placing them within a larger context that helps to account for their functioning (Kerr & Bowen, 1988). This is important to consider when seeking to effectively understand and assist families of children with autism because each member is a part of a greater familial unit that can impact how each member relates to and functions with another.

In family systems theory, the family is conceptualized as one emotional unit whose member relationships are interlocked and impacted by one another. Bowen (Kerry & Bowen, 1988) identified several different examples of this concept in his observations. First, he concluded that no one individual's functioning could be understood exclusive from that of the other members of the family, as two or more members of a family often engaged in what he referred to as "relationship reciprocities" (Kerr & Bowen, 1988, p. 8). In this phenomenon, cycles of problem behavior and anxiety escalate between two members of a family, which lead to further problems and anxiety for other family members. There is usually one person whom the rest of the members consider to be the "problem," and this may lead to feelings of fault or inadequacy (Kerr & Bowen, 1988). In families of children with autism, while the child may not necessarily experience guilt or inadequacy regarding his or her diagnosis and related challenges, mothers have reported feeling such. Mothers interviewed by Fitzpatrick (2009) reported feeling "guilt" and "blame" pertaining to their child's autism, particularly in regard to not recognizing their child's delay, experiencing denial, or not being able to find the right treatment. The emphasis on the importance of early intervention and the large number of treatments options, both scientifically-supported and alternative therapies, puts many moms in the position of feeling that they are never doing enough to help their child and fosters feelings of frustration and stress when challenges arise (Fitzpatrick, 2009). One of the purposes of this study was to determine how this maternal stress impacts the familial unit, particularly typically-developing siblings.

Emotional System

Bowen (Kerr & Bowen, 1988) identified three systems in families that influence human functioning and behavior. The first of these, and the most important, is the emotional system. The emotional system is the way by which an individual receives, integrates, and responds to information from its environment. These may include responses for the sake of oneself or responses for the sake of the group. According to Bowen (Kerr & Bowen, 1988), the emotional system serves three important purposes. First, it founds the assumption that behavior of all life forms is influenced by "fundamental life forces" (Kerr & Bowen, 1988, p. 28) that predate the reasons rooted within logic and biological processes to which humans more typically attribute their behavior. Second, it bridges gaps that exist in the way humans compartmentalize what they know and understand about such biological processes and behavior. Third, the emotional system considers the very important relationship between an individual and those around him or her. In this system, Bowen transcends the physical components of an individual and emphasizes that one's functioning cannot be comprehended outside the context of one's relationships with others (Kerr & Bowen, 1988). Bowen highlights one of the main components of family systems theory and the conceptualization of the family as an interconnected emotional unit in which this study is rooted.

Feeling System

The feeling system is the second system in Bowen's family systems theory. While the emotional system is centered on how individuals respond to their environment, the feeling system speaks to how people feel. According to Kerr and Bowen (1988), feelings indicate a cognitive awareness that layers on top of one's emotional reaction. While other animals have the capacity to react emotionally to a particular stressor, evolution has led to the capacity for humans to express the cognitive feelings that accompany their emotional reactions such as anger, anxiety, and guilt (Kerr & Bowen, 1988). Although emotional reactions may occur more instinctively without an individual being fully aware of what is driving his or her response, Kerr and Bowen (1988) asserted that humans are more aware of how they feel during such instances. Further insight into how maternal parenting stress related to having a child with autism impacts the behavior of typically-developing siblings may be beneficial in considering the best ways to support these families. One of the social change implications of this study was to expand the understanding, treatments, and supports for families of children with autism to promote a cycle of decreased parenting stress, reduced problem behaviors of typically-developing siblings, and improved treatment outcomes for children with autism.

Intellectual System

While the emotional and feeling systems focus on how individuals respond and feel, the intellectual system represents the important process of understanding these complexities (Kerr & Bowen, 1988). Kerr and Bowen asserted that making sense of and communicating such ideas is a unique trait of human beings. Each of these three systems influences the others, and not one is greater than another (Kerr & Bowen, 1988). They often manifest themselves simultaneously as individuals experience their lives, and something that, for instance, first registers on an intellectual level can help one interpret the experiences on the feelings level and subsequently change the overt responses that occur within the emotional system. For families of children with autism, a greater understanding from a family systems perspective about the internal processes that drive their daily experiences and characterize their interconnectedness may help clinicians to better define what areas of both the child's and family's life need support. Clinicians can then use this understanding to formulate and implement comprehensive treatments in such a manner that benefits not only the child diagnosed with autism but his or her parents and typically-developing siblings too.

Nature of the Study/Methodology

This study planned to employ a non-experimental, correlational design. Researchers using this design observe a representative sample at one point in time to provide information about a larger population of individuals or to describe it in some way. The researcher can determine the relationship between the identified variables found within the overall target population by observing a representative subset at a single point in time. In this study, I sought to explore the relationship between the level of problem behavior of a child with autism and the level of problem behavior of a typically-developing sibling (measured by an alternate caregiver) moderated by maternal parenting stress. I intended to collect data on mothers and children from families with two parental figures or caregivers who have one child with autism and at least one typically-developing sibling using several instruments. While mothers complete a measure of parenting stress and a measure of problem behavior for the child with autism, an alternate or secondary parental figure or caregiver (father, grandparent, nanny, etc.) would report on the problem behaviors of a typically-developing sibling. I planned to analyze the data in a step-wise regression using SPSS software.

Definition of Terms

In order to understand the research, it is important that key terms that will be used throughout the study are defined.

Autism or autism spectrum disorder: refers to a child who has been formally diagnosed with “persistent deficits in social communication and social interaction across multiple contexts” and “restricted, repetitive patterns of behavior, interests, or activities” where such symptoms are present “in the early developmental period,” “cause clinically significant impairments in social, occupational, or other important areas of current functioning,” and “are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay” (American Psychiatric Association, 2013, p. 50-51).

Typically-developing sibling: A child who has no known diagnosis of a developmental disability, learning disability, or other disorder, who resides in the same household as the child with autism, and who is raised by the same parents or caregivers (Kaminsky & Dewey, 2001).

Alternate/secondary caregiver: An individual other than the children’s mother (i.e. father, grandparent, nanny) who participates in the hands-on daily roles and responsibilities of caring for the child and can serve as an informant about the child’s daily behavior and functioning (Petalas et al., 2006 & Quintero & McIntyre, 2010).

Behavior: Any act exhibited by an individual that is observable and measurable (Alberto & Troutman, 2009).

Assumptions

This study was premised on several assumptions. First, I assumed that the individuals who choose to participate in this research were able to adequately read and understand the directions and questions for the instruments in use so that they could answer appropriately. Second, I assumed that mothers responded with honest reports of their level of stress and levels of problem behavior of a child with autism while alternate caregivers provide accurate measures of the typical children’s behavior so that valid and reliable results were yielded. I also assumed that extraneous factors that were not included within the scope of this study would not significantly impact the results so that the true nature of the systemic relationships between the variables could be investigated. Finally, I assumed that I maintained awareness of my own personal conceptions throughout the research so as not to taint the study with bias while interpreting the results.

Scope and Delimitations

In this quantitative study, I explored the relationship between the problem behavior of children with autism and the problem behavior of typically-developing siblings. Included in the scope of this study were reports of the child with autism's problem behavior as reported by the mother, the problem behavior of a typically-developing sibling from the perspective of an alternate/secondary caregiver, and the moderating effects of maternal parenting stress between the variables. I chose these specific factors to address the gap in current literature regarding the more systemic family effects of having a child with autism. I neither intended to explore the relationship between maternal parenting stress and the level of problem behavior of children with autism, nor was the relationship exclusively between problem behavior of a child with autism and problem behavior of a typically-developing sibling meant to be within the scope of this study. These areas of focus have been researched in previous literature and were meant to serve as a part of the foundation upon which the scope of this study was built.

Families with two parental figures with at least one child diagnosed with autism and at least one typically-developing child under the age of 16 were invited to participate in this study. I recruited families from institutions and organizations that educate and serve children with autism. For each family, one parental figure recruited was the mother of both children while the other parental figure recruited was a father, grandparent, extended family member, or nanny who resides with the family and participates in the daily care of the children. Single-parent families were excluded given the purpose of obtaining the perspective of an alternate caregiver and because of the variance that this dynamic would introduce into the sample population. Similarly, families whose children are older than 16 were excluded due to the naturally changing role and involvement of parental figures as their children mature, and because of the variance in concerns and experiences as both children with autism and typically-developing children enter adulthood.

Limitations of the Study

Generalization of the results of this study was limited due to the use of a convenience sample representing families within a particular geographical area. Moreover, recruiting families from institutions and organizations who serve the target population indicated that these particular families have access to at least some level of external support and guidance, which may impact their experience of having a child with autism and render it different from those who do not have access to such resources. Additionally, the criteria of participation itself, particularly in being a member of a two-parent household, limited the number of representative families. For these reasons, I contacted several different institutions and organizations that serve families from various neighborhoods with different demographic make-ups, and extended the definition of "parental figure" to include adult caretaking members of the household other than a father for families who may not have both parents involved in the children's lives.

Significance of the Study

In this study, I intended not only to expand the scholarly knowledge of the impact of raising a child with autism, but also to help fill the gap that exists in the literature by providing a more familial understanding of the experience from a family systems theory perspective. I worked to synthesize the experiences of parents and children to understand how they interrelate and influence each other. This study has several implications for social change. First, it sheds light on how autism affects 1 in 68 *families* rather than 1 in 68 children (Center for Disease Control and Prevention, 2012). With a greater understanding of the family experience, clinicians can seek to treat a child with autism as an interrelated member of a single emotional and dependent unit, rather than as a client or student exclusive of his or her larger family context. Second, I sought to highlight the need for treatments that are tailored in such a way that more appropriately suits the needs and is conducive to the functionality of all members within the family unit so that all can participate to not only be an active part of but also a beneficiary of treatment. Third, the study highlights the need for greater resources and support for siblings and parents of children with autism. If their challenges and limitations are addressed, then that they can more effectively address the challenges and limitations of their child with autism. The effects of this expansion in understanding, treatments, and supports for families of children with autism can potentially change the entire experience of autism for a family unit to promote a cycle of decreased parenting stress, reduced problem behaviors of typically-developing siblings, and improved treatment outcomes for children with autism.

Summary

In this chapter, I introduced the study and provided a brief background of (a) the relationship between parenting stress and the problem behavior of children with autism, and (b) the relationship between problem behavior of children with autism and that of typically-developing siblings. I then identified the gap in current research and offered the problem statement to highlight the need for more comprehensive resources and support for families of children with autism. The purpose of the study was to explore the relationship between the level of problem behavior exhibited by a child with autism and the problem behavior of a typically-developing sibling when these variables are moderated by maternal parenting stress in order to support the need for such resources. Additionally, a secondary/alternate caregiver's perspective (rather than solely the mother's as has been most often relied upon in previous research) of the children's behavior was of interest to me in this study. After outlining these foci, I posed the following research question: What is the relationship between the level of problem behavior exhibited by a child with autism and the level of problem behavior of a typically-developing sibling as reported by a secondary caregiver when these variables are moderated by maternal parenting stress?

After introducing the research question, I provided an overview of the theoretical foundation for this study, Bowen's family systems theory, and introduced the methodology I used to collect data. Key terms were defined and assumptions about the study and its participants were communicated. I then outlined the scope, delimitations, and limitations of the study, and closed by explaining the significance of this research, including its implications for positive social change.

Chapter 2: Literature Review

Introduction

The term *autism spectrum disorder* (ASD), as defined by the *DSM-5*, refers to a neurodevelopmental disorder that is diagnosed during the “early developmental period” of an individual who exhibits “persistent deficits in social communication and social interaction across multiple contexts” and “restricted, repetitive patterns of behavior, interests, or activities” (American Psychiatric Association [APA], 2013, p. 50). For families of children with ASD, the deficits that are associated with this diagnosis and manifested uniquely within each individual are often accompanied by daily challenges and struggles for both the parents and children alike. Indeed, having a child with ASD impacts both the individuals within a family and the family as a unit (Schall, 2000).

While previous researchers have explored the impact of children with ASD on parents and siblings exclusive of each other, more extensive research is needed to determine the more systemic interactional effects that occur within families of children with ASD, particularly as they relate to levels of parenting stress and behavior development of typically-developing siblings. In this chapter, I review the challenges associated with raising a child with ASD and identify sources of parenting stress related to these challenges. Further, I discuss the nature and levels of parenting stress in parents of children with ASD as compared to the stress of parents of children with other disabilities and of typically-developing children along with other psychological well-being considerations for parents of children with ASD. Next, I explain the relationship between parenting stress, the problem behaviors of children with autism, and the functioning of the family unit, and then explore the emotional development and behavioral concerns of typical siblings of children with ASD. Finally, I identify the need for a better understanding of the relationship between parenting stress associated with having a child with autism and the behavioral development of typically-developing siblings.

This literature review is composed of research articles obtained from online databases that I accessed via the Walden University Library, namely, Academic Search Complete, ProQuest, PsycARTICLES, PsycINFO, and SAGE. The research presented in this review is published in a wide variety of scholarly journals, including but not limited to *Focus on Autism and Other Developmental Disabilities*, *Journal of Autism and Developmental Disorders, Journal of Intellectual and Developmental Disability*, and *Research in Autism Spectrum Disorders*. Key search terms and combinations of terms included *autism, parenting stress, typical siblings, adjustment, development,* and *behavior*.

Children with Autism Spectrum Disorder

Parents of children with ASD are often faced with daily struggles related to their children's behaviors that characterize their autism. In this section, I identify and describe several traits of ASD that can be particularly stressful for parents to manage. Although not all children with ASD exhibit all of these characteristics, the following qualities are common in many children with ASD and are often sources of stress for their parents.

Isolation

ASD is characterized by a range of deficits in various domains of development that manifest themselves to varying degrees in each individual. One of the qualities of ASD is a “persistent deficit in social communication and social interaction,” often manifested in isolated recreation, little or no interest in interacting with family and friends, and resistance or non-responsiveness in engaging with those who solicit their attention (APA, 2013, p. 50). While a child’s tendency to be isolated does not necessarily affect parents’ abilities to bond with a child, it can impede the child’s bond with extended family and friends who might not have a good understanding of the disorder. Hoffman, Sweeney, Hodge, Lopez-Wagner, and Looney (2009) compared scores from the Attachment subscales of the Parenting Stress Index (PSI) of 104 mothers of children with ASD to those of 342 mothers of typically-developing children and found that no significant differences in closeness and bonding with their children were reported between the groups. This is interesting considering that notable differences were observed on all the other 13 subscales of the PSI between mothers of children with ASD and mothers of typically-developing children, with mothers of children with ASD reporting significantly higher levels of stress (Hoffman et al., 2009). While it may be that the unique needs of a child with ASD have driven these mothers to be aptly in tune with their children’s needs, thus developing a great sense of closeness, it is possible that social desirability influenced their responses to items relating to closeness and bonding with their child. Sensitive feelings towards the historical, albeit refuted, “refrigerator mother” theory about the cause of ASD as well as guilt regarding their child’s disorder may linger with these mothers and prompt then to respond with caution when issues of closeness and bonding arise (Hoffman, 2009).

Despite mothers' best efforts to bond with and be close to their children with ASD, a sample of 52 parents (26 sets of mothers and fathers) who were interviewed by Altiere and von Kluge (2009) admitted that many ties between themselves and their family and friends were quickly severed upon their child being diagnosed with ASD. They reported that this loss of support was distressing for them, particularly when family members as close as grandparents stopped engaging with the child and family (Altiere & von Kluge, 2009). However, the distance perceived by immediate families of children with ASD may not always be due to reasons suspected. Some parents interviewed by Altiere and von Kluge described "dirty looks" received from members of their community when their child misbehaved or embarrassment experienced by extended family members. However, these reactions can be interpreted as a genuine lack of understanding about ASD rather than blatant rejection, and indeed one couple realized that their family simply did not understand autism but grew tired of trying to explain it to them. Another couple admitted to initiating the separation between themselves and their family out of the similar frustration. Moreover, the search for assistance and treatment upon receiving a diagnosis of ASD can drive parents to focus tirelessly on their child, perhaps leaving little to no time or energy for maintaining familial and social connections (Altiere & von Kluge, 2009).

Social Deficits

Children with ASD exhibit social deficits to varying degrees that appear unusual or odd to others. For example, a child with ASD may choose recreational activities that are repetitive and often involve an inanimate object (APA, 2013). Other manifestations of social deficits observed in individuals with ASD include the inability to engage in some forms of representational play, lack of joint attention, and non-responsiveness to the interests and emotions of play partners (Ruskin & Sigman, 1999). White and Roberson-Nay (2009) determined that children who were reported as being more withdrawn and having higher levels of anxiety by their mothers were also thought to be less likely to initiate with peers. These characteristics, coupled with deficits in verbal communication exhibited by many children with ASD, can greatly impede the child's ability to form friendships with other children, increasing social isolation and rejection among peers and raising concerns about the child's social prognosis as he or she gets older.

It is important to note that social deficits were among the most common factors contributing to parenting stress for both mothers and fathers of children with ASD. In studying child characteristics associated with parenting stress, Davis and Carter (2008) found that although mothers of 54 newly-diagnosed toddlers uniformly reported higher levels of parenting stress than their fathers did (though not significantly), concerns about their child's social prognosis was identified as one of the most stressful conditions of raising their child with ASD. Perhaps this is because children with ASD, as a group, tend to exhibit some level of deficit in social skills with continuity over time (Ruskin & Sigman, 1999). Ruskin and Sigman observed a sample of 70 children with ASD for a baseline and follow-up assessment of their communicative abilities and social competence noting that, as a group, the children continued to have difficulty with social interaction, peer relations, emotional responsiveness, and language as they aged. In their study a decade later, White and Roberson-Nay (2009) also indicated that children with autism who experience social isolation at younger ages are likely to continue to do so as they get older, particularly if their social skills are hindered by anxiety.

Rigidity and Routine

Individuals with autism are often rigid in established routines and environments, and react with extreme distress when these are disrupted (APA, 2013). For this reason, many parents of children with ASD often find themselves refraining from social activities, community events, or family trips that may prompt an anxious response from their children due to the unpredictable nature of these events. One might argue, then, that a child with ASD would respond and adhere well to an established daily family routine. Larson (2006) explained that many families develop routines in order to organize their lives and promote stability and continuity in their systemic functioning. However, having to develop a routine which includes an individual who requires highly structured activities, restricted social events and outings, high predictability, and modifications to family and holiday traditions is a stressful and difficult task. Larson (2006) interviewed nine mothers of children with ASD to determine how their families used daily routines and how the presence of a child with ASD impacted their maintenance. These mothers reported that establishing regularity in the family's daily life is exceptionally challenging, especially when having to consider their children's social and behavioral issues, some of which are unpredictable. Although the use of routines was meant to promote participation of the child with autism in the daily family life, often activities or tasks embedded in the routine such as homework, chores, and personal care proved to be difficult for the children to comply with (Larson, 2006). Moreover, Larson suggested that although many children with ASD prefer a routine of activities, they might adopt a routine that conflicts with the functioning of the family unit.

Stereotypical behavior

Individuals with ASD may engage in stereotypical motor or verbal self-stimulatory behavior such as rocking, hand flapping, repetitive and peculiar verbalizations, and echolalia (APA, 2013). Although these behaviors may be understood as a child’s means of coping with an overly stimulating environment or as his or her mechanisms for self-soothing during bouts of anxiety, they can be difficult to redirect (Schall, 2000). In addition to being difficult to manage, behaviors such as these often draw negative attention from spectators. Schall reported the experiences of several parents who admitted that they could not go to stores or go out to eat because they could not handle their children’s behavior. Altiere and von Kluge (2009) explained that some parents who were interviewed reported feeling rejected by people and groups in their community, including their church congregations, due to their children’s maladaptive behavior. Such animosity towards and misunderstanding about their disabled children not only limited the opportunities of the children to be an active member of their own community, but also limited social engagement opportunities of the parents, leaving them feeling stressfully isolated and unsupported (Altiere & von Kluge, 2009).

Sensory Difficulties

Children with autism often experience “hyper- or hyporeactivity to sensory input” (APA, 2013, p. 50). Their behavioral responses to sights and sounds in their environment, including those that typical individuals may not even notice or attend to, can be extreme. Schaaf et al. (2011) explored the impact that “sensory-related behaviors” (p. 374) can have on the functioning of the family unit. Interviewing parents of children with autism in four families, Schaaf et al. identified the following five themes related to these challenges: (a) having to remain flexible in tasks or outings that may be overwhelming for the child with autism, (b) limiting outings to unfamiliar spaces such as a relative’s house or new store, (c) difficulty in completing family activities such as morning and evening routines and family vacations, (d) the impact of less attention being given to siblings during activities, and (e) the need for constant monitoring of the child with autism when engaging in environments or activities that may become overwhelming. While Schaaf et al. determined that families often created and implemented their own strategies for managing such challenges, the need to anticipate how an environment may impact a child with autism as well as the need to utilize such strategies can be both a parent and family stressor when attempting to engage in a family activity.

Eating and Feeding Behavior

Many parents of children with ASD struggle to expand their child with ASD's food repertoire and feeding behavior. Schreck, Williams, and Smith (2004) recruited over 400 parents to compare the eating problems and food intake inventory of children with ASD to typically-developing children, as reported via a standardized questionnaire. These parents of the 138 children with ASD and 298 control children between the ages of seven and nine and a half years of age indicated that children with ASD exhibited more feeding problems including food refusal and food selectivity based on texture or color. Moreover, parents reported that children with ASD required a more ritualistic food presentation, such as on a specific plate or using a specific utensil. Schreck et al. (2004) indicated that children with ASD eat a narrow variety of foods and fewer foods from each food group than to typically-developing children. However, it is important to consider the limited age group targeted by researchers when considering the generalizability of these reports. Additionally, parents can be inaccurate in their self-reports and potentially reflect factors pertaining to familial food/mealtime habits and the extent to which they attempt to expose their children to new foods or teach different eating behaviors. Still, Schreck et al. asserted that investigation into these problematic feeding and eating behaviors is important to study because early issues could lead nutritional deficits and nutrition-related medical problems.

Johnson, Handen, Mayer-Costa, and Sacco (2008) conducted a later study and sought to fill in some of the of previous research on the eating and feeding behaviors of children with ASD by collecting information from the parents of 19 children with ASD and 15 typically developing children about their eating behaviors and nutritional intake. Consistent with Schreck et al. (2004), Johnson et al. also found that children with ASD exhibited significantly higher problematic feeding behaviors including food refusal, restrictive preferences, and ritualistic practices. However, the researchers suggested that despite these behavioral challenges associated with eating and feeding, children with ASD do not suffer from nutritional deficits. No significant differences were found in the intake of calories, carbohydrates, proteins, and fats of children with ASD and typically developing children (Johnson et al., 2008).

Martins, Young, and Robson (2008) offered a different perspective about the problematic eating and feeding behaviors of children with ASD. Gathering information from the parents of 41 children with ASD versus 14 of their typically developing siblings and 41 matched typically developing children, they found that while children with ASD did adhere to ritualistic eating behavior, need more assistance in feeding themselves, and engage in rejection of foods due to food traits, the rate at which this sample exhibited these eating and feeding challenges was only marginally different from that of their siblings and other typically developing children (Martins et al., 2008). Martins et al. suggested that intra-familial factors and parents' emotional and behavioral response to their child's eating and feeding issues may influence the extent to which these challenges persist. Still, it is important to note that regardless of whether or not feeding and eating issues are directly related to the child's ASD diagnosis, parents continue to consider these challenges as one of the most frustrating stressors of raising their child. Perhaps this is so because while typical children may experience a "phase" of picky eating or problematic mealtime behaviors, the eating and behavior challenges of children with ASD are often less transient (Martins et al., 2008).

Treatment Options

There is no known cause or cure for ASD; thus, a plethora of treatments have been developed for helping these individuals, all of which have received both great opposition and great support. Parents of children with ASD have the arduous task of researching a multitude of treatment options to select the one they feel would be most effective for their child. Various models and methods of interventions are available. Many parents find themselves trying multiple approaches in hopes of finding the one that will most help their child, although they don't necessarily find "the one" (Altiere & von Kluge, 2009). Moreover, most treatments are not covered by health insurance, leaving parents to finance their child's care. Altiere and von Kluge identified some of the measures parents took to pay for their child's therapy, including taking out loans, selling property, and using retirement funds. Many families are forced into having one parent, usually the mother, stop working due to the high demands of caring for a child with ASD (Altiere & von Kluge, 2009). In a later study, Zuckerman et al. (2014) further supported the health care and financial burdens of treatment for families of children with autism. Reviewing data from over 3000 families of children with special health care needs and autism, over 6000 families of children with special health care needs and functional limitations, as well as 28,000 families of children with other special health care needs, Zuckerman et al. found that families of children with special health care needs and autism received poor quality of health care and experienced greater adverse impacts. These adverse impacts included out-of-pocket expenses related to health care, financial struggles resulting from the child's condition, inability of an adult to continue to working, inability to change jobs due to fear of losing health care, and time spent managing child's care and treatment (Zuckerman et al., 2014). Thus, the overwhelming number of approaches from which to choose, the parental commitment expected in engaging in therapy, and the cost of these treatments can contribute to the high levels of parenting stress experienced by parents of children with ASD. A brief overview of some of these treatments will be discussed.

TEACCH

The Treatment and Education of Autistic and Communication Handicapped Children, or TEACCH, is a training and research program for individuals with autism who exhibit various levels of abilities and functioning (University of North Carolina [UNC], 2011). This evidence-based cognitive approach targets areas of development that show the most potential for skill acquisition as opposed to identifying and building up areas that show the greatest deficits (Tsang, Shek, Lam, Tang, & Cheung, 2007). Inappropriate behaviors are addressed from an internal perspective; that is, professionals who utilize the TEACCH approach seek to determine the underlying cognitive basis behind the problem behavior and facilitate appropriate expression of the associated antecedents (anxiety, pain, boredom, etc.) (Tsang et al., 2007). TEACCH professionals assert that in improving the individual's cognitive understanding of his or her environment, it will become more predictable and less anxiety-provoking. Fostering modes of appropriate communication and expression serve to create a more autonomous individual (Tsang et al., 2007). Ultimate goals of TEACCH include that the individual will develop skills necessary to lead an independent, active, dignified, and meaningful life within his or her community (UNC, 2011).

Applied Behavior Analysis

Intensive behavioral approaches are popular in treating individuals with autism. Applied Behavior Analysis, or ABA, draws on the assumptions of behaviorism to achieve socially acceptable developmental goals and age-appropriate learning objectives through the interactions of antecedents and consequences (Simpson, 2001). Inappropriate behaviors such as self-stimulating behavior and stereotypical play are redirected and shaped to become behaviors that are more socially appropriate (Orey, 2002). Important developmental skills such as daily living skills or social skills may be taught in a repetitive fashion through successive approximations to an ultimate goal, such as learning to wash one's hands or complete an age-appropriate activity. While the approach can be tailored to suit the child's needs, the ABA model as a whole is comprised of many components including discrete trial teaching, errorless procedures, a commitment to non-aversive methods, and consistent reinforcement of desired responses (Simpson, 2001). Additionally, ABA requires a great level of commitment on the part of the parents and other individuals involved in the direct caretaking of the child, as consistency across people and environments in the contingencies outlined in the behavior plan is essential for the success of this empirically based and scientifically validated treatment option (Simpson, 2001).

DIR/Floortime

Developmental, Individual-Difference, Relationship-Based (DIR/Floortime) is a model that addresses the developmental process from the very beginning and takes the child back to the first developmental milestones to begin the process anew rather than targeting currently exhibited symptoms (Hilton & Seal, 2007). Clinicians utilizing this approach take into consideration where the child is in the developmental sequence of skills, his or her individual way of taking in, understanding, and responding to the environmental stimuli around him or her, and the relationships that surround the child such as parents, siblings, peers, caregivers, and others who influence the way in which a child develops and acquires skills (The Interdisciplinary Council on Development and Language Disorders, n.d.) Children are walked through the developmental process to master the steps they are missing with a multidisciplinary team of professionals (Hilton & Seal, 2007). The Floortime component especially emphasizes the importance of interpersonal relationships in a child's life. Parents and professionals take part in this aspect and engage playfully with their children for a specified duration of time in order to facilitate not just the ability to interact but the desire to do so (Hilton & Seal, 2007). Floortime provides a model in which adults can follow the child's lead while encouraging them to work towards greater social capabilities (The Interdisciplinary Council on Development and Language Disorders, n.d.)

Detoxification and Diet

Detoxification via methods such as chelation or allergy cleansing is a treatment approach that continues to spark heated debate among parents and professionals of the autism community. An individual undergoing chelation therapy is injected with a solution that binds minerals in the body to eliminate heavy metals such as mercury (Cohen, 2006). Although the use of chelation as an effective treatment for autism is adamantly disputed by the medical community, parents who feel concerned about their child's exposure to environmental toxins do consider this option (Cohen, 2006).

Limiting the diet of an individual with ASD to foods that do not contain gluten (wheat) or casein (dairy) is a treatment that emerged from models that seek to explain the physiological basis for autism for those who subscribe to the theory that diet is a factor in the manifestation of characteristics associated with ASD (Elder et al., 2006). Parents sometimes report that gastrointestinal irregularities in their children, such as the inability to process wheat and dairy products, contribute to problematic behaviors (Irvin, 2006). Supporters of this approach assert that elimination of these ingredients from one's diet stabilizes levels of peptides, which some claim alters an individual's social and communicative functioning in a positive way (Elder et al., 2006). However, there is insufficient empirical data to support these assertions and research continues to be gathered with inconsistent results. Elder et al. investigated the differences in functioning for a sample of 15 children with ASD who were assessed at baseline while on a regular diet compared to their functioning after being on a gluten-free, casein-free (GFCF) diet for six weeks. Using the Child Autism Rating Scale and urinary peptide levels as both a baseline and follow-up measure of autistic features, Elder et al. reported that no significant differences were found in the participants' CARS or their peptide levels. However, anecdotal data gathered from parents suggests that they claim to see improvements in their children's behavior, focus, and language (Elder et al., 2006). Irvin (2006) conducted a case study to determine the effects of a GFCF diet on the self-injurious, aggressive, and destructive behaviors of an adolescent male with ASD. The researchers' results indicated that the individual's rates of target behaviors did not decrease with the implementation of a GFCF diet, nor did the rates increase when his diet was reverted back to foods containing gluten and casein (Irvin, 2006). Two limitations to this study can be highlighted; the first being that it only bears the results of one subject, and the second addressing the duration of treatment phases. The two periods of the participant's GFCF diet lasted 10 days and 12 days, respectively. While positive effects can sometimes be observed within days, it can take up to several weeks or even months before full benefits are in effect (Irvin, 2006).

In contrast to these findings, other researchers have found significant differences in children before being placed on a GFCF diet versus after. Whiteley et al. (2010) compared the Autism Diagnostic Observation Schedule (ADOS), Gillian Autism Rating Scale (GARS), Vineland II Adaptive Behavior Scales (VABS-II), and Attention Deficit Hyperactivity Disorder- IV (ADHD-IV) scores of 54 children with ASD who were assigned to either one of two groups, those who would be adhering to a GFCF diet and those who wouldn't be. At 12 months, the ADOS, GARS, and ADHD scores of the children who were placed on the GFCF diet had improved significantly (Whiteley et al., 2010). In a second part of the research, participants in the non-diet group were also placed on the GFCF restrictions. Following another 12 months, significant effects were observed in both groups' behaviors associated with the ASD diagnosis, although the changes observed later in the study were not as dramatic as those observed earlier, possibly due to a developmental plateau being reached (Whiteley et al., 2010). Thus, the implementation of a GFCF diet may not deliver a continuing effect on individuals with ASD.

It should be noted that attempting to adhere to a limited gluten-free casein-free diet can compound the eating and feeding behaviors indicated previously by Martins, Young, and Robson (2008). In fact, Whiteley et al. (2010) suggested that more research is needed to investigate the nutritional risks of maintaining a long-term GFCF diet. However, in an earlier study, Cornish (2002) acknowledged that most research focused on the behavioral changes of diet rather than the potential nutritional deficiency. Cornish examined this topic and compared detailed dietary information of eight children with ASD on a GFCF diet compared to 29 children with ASD who had no dietary restrictions. Although there were differences in the types of foods that each group of children ate, no significant differences were found in the energy, protein, and micronutrient intake of children limited to a GFCF as compared to the children who were on no diet. However, it should be noted that the diet did not improve their nutritional intake either. Interestingly, parents of children who were on the GFCF diet reported that their children had become more willing to try new foods since being placed on the diet (Cornish, 2002). However, the small sample size limits the extent to which these results can be generalized to a larger population.

Medication

Individuals with autism may be prescribed various psychotropic medications to treat severe levels of symptomatic behavior. Rosenberg et al. (2009) investigated patterns of medication use via on online database and found that out of 5,181 children with ASD whose parents submitted information, 35% of them were taking at least one psychotropic medication, most commonly from the classes of stimulants, neuroleptics, and antidepressants. Posey, Stigler, Erickson, and McDougle (2008) noted the use of antipsychotic medications to decrease aggression and hyperactivity in individuals with autism such as haloperidol, fluphenazine, and respidol. Frazier et al. (2010) investigated the efficacy of combining psychopharmacological treatment of antipsychotic medications with intense behavioral intervention (IBI) on decreasing the rate of aggressive behaviors for 32 children with ASD. Twenty-five children received combined treatments of medication and IBI while seven received IBI only. Those receiving a combined treatment approach reached their criteria for success (an average of less than one aggressive behavior per session for five sessions) in an average of 83.2 IBI sessions while those who received IBI only reached the criteria for success within an average of 228.1 sessions (Frazier et al., 2010). Antipsychotics emerged as being significantly effective in reducing aggressive behavior over stimulants and neuroleptics, and more specifically risperidone (Frazier et al., 2010). It is important to highlight that the use of medication alone prior to the implementation of IBI did not produce a significant decrease in aggressive behavior. Frazier et al. (2010) suggested that behavioral interventions continue to be an essential component of treatment for children with ASD, although they require time and patience.

Parents of Children with ASD

The variety of ways that ASD can manifest itself in a child coupled with the choices of treatments parents must comb though as well as the related social and familial influences comprise a considerable amount of parenting stress. One might wonder if each of these sources of stress plays an equal role in reported stress levels or are some more difficult to deal with than others. Another factor to consider, in addition to common sources of parenting stress, is the variation with which ASD manifests itself in each diagnosed child. In other words, how does the severity of a child's disability compound these sources of stress that parents of children with ASD commonly experience? To answer this question, Tomanik, Harris, and Hawkins (2004) examined the relationship between the behaviors of 60 children with autism and their mothers' levels of parenting stress. Specific characteristics such as irritability, lethargy, social withdrawal, hyperactivity, non-compliance, inability to take care of themselves, and inability to communicate with others were linked with reports of greater parenting stress. In a later study, Phetrasuwan and Miles (2009) examined 108 mothers of children diagnosed with ASD and performed correlations between child symptom severity, parenting stress, and overall parent psychological status to explore the same relationship between variables as well as to explore the relationship between parenting stress and overall parental psychological status. Similar to Tomanik et al.'s study (2004), Phetrasuwan and Miles found that specific characteristics emerged as being most strongly associated with parenting stress, namely adaptation to change, emotional responses, fear or nervousness, verbal communication, and relating to people. However, they also determined that the child's overall severity of autism did not correlate with levels of parenting stress, suggesting that particular problem behaviors and symptoms manifested in a child's autism, but not the severity of the autism itself, yield higher levels of parenting stress (Phetrasuwan & Miles, 2009). Thus, one can assert that a parent of a lower functioning child with autism may report a lower level of parenting stress than a parent of a high functioning child with autism, depending on the extent to which each child exhibited specific characteristics.

Parenting Stress and Problem Behaviors of Children With ASD

The notion that parents of children with ASD experience higher levels of parenting stress is well established in the literature; however, researchers have started to focus more on how parenting stress impacts the functioning of members within the family unit. Osborne and Reed (2010) examined the relationship between parenting stress and child problem behaviors. Previously, it was noted that problem behaviors were most associated with reports of parenting stress rather than the child's severity of ASD, indicating that higher levels of problem behaviors yield higher levels of parenting stress (Phetrasuwan & Miles, 2009). Osborne and Reed (2010) concurred that parenting stress was associated with problem behaviors not ASD severity, however they determined a different directionality of this relationship in studying behavior ratings and stress reports from 65 parents of children with autism. Collecting self-reports of stress levels and behavior ratings of the children from parent participants at two different points in time, Osborne and Reed found that a high level of parenting stress was a strong predictor of future child problem behaviors, rather than child problem behaviors predicting high levels of parenting stress. Speculations surrounding this finding suggest that parents of children with ASD may be more reactive in their parenting style and response to stress which could form a cycle of occurrence between child behavior problems and stress, however Osborne and Reed asserted that little empirical data supports this notion.

In an effort to identify a mechanism that explains the directionality of relationship between parenting stress and child problem behaviors, Osborne and Reed (2010) also explored how stress impacts parenting behaviors of parents of children with autism. One hundred thirty-eight parents completed self-report questionnaires on their stress and relationship with their child. This sample of parents yielded lower scores for involvement, communication, and limit-setting than what is found in the general population. Additionally, the researchers observed significant negative correlations between parenting stress and involvement, communication, and limit-setting (Osborne & Reed, 2010). Osborne and Reed suggested parenting stress negatively impacts parenting behaviors which, in turn, negatively impact the child's behavior.

Sikora et al. (2012) looked at a more familial impact of problem behaviors of children with autism, seeking correlations between internalizing and externalizing problem behaviors (indicated by the Child Behavior Checklist) and various domains of family functioning in 136 families of children with autism. Greater externalizing behavior was linked to increased impact on family functioning in regards to siblings, marriage, feelings about parenting, and relationships. Internalizing behaviors were not significantly correlated with family impact (Sikora et al., 2012). Additionally, parents who reported greater externalizing problem behaviors were more likely to indicate increased negative feelings about parenting as well as increased impact on siblings (Sikora et al., 2012). This suggests that children with autism affect both parents and siblings and reinforces the need for more comprehensive resources and support for families of children with autism, a main social change implication of my study.

Well-Being of Parents of Children With ASD

The variety of stressors that parents of children with ASD face on a daily basis and the relationship between problem behavior and parenting stress that is evident in the research suggest that parents of children with ASD may be experiencing a lower level of psychological well-being when compared to other parents. The next section discusses various dimensions of well-being that are affected by having a child with ASD.

Quality of life. Lee et al. (2009) compared the self-reported health-related quality of life of parents of children with high-functioning ASD (HFASD) with parents of typically developing children. One may assume that children with HFASD, including Asperger syndrome and pervasive developmental disorder- not otherwise specified, do not elicit the same levels of parenting stress as do children with ASD because they do not generally demonstrate high levels of cognitive or communication deficits, however Lee et al. concluded that parents of children with HFASD experience a significantly lower quality of life than parents of typically developing children. In assessing factors that contribute to health-related quality of life, Lee et al. noted that parents of children with HFASD reported lower levels of coping, higher levels of parenting stress, and fewer sources for obtaining support. The researchers imply that despite the relative strengths in cognition and communication that typically characterize HFASD, parents are still faced with challenges stemming their child's social deficits, rigidity, and repetitive problem behavior (Lee et al., 2009).

Allik, Larsson, and Smedje (2006) also explored health-related quality of life for parents of children with HFASD as compared to parents of typically-developing children; however, they also examined the difference between maternal and paternal reports within the sample of children with HFASD. As a group and consistent with the findings of Lee et al. (2009), parents of children with HFASD reported lower levels of health-related quality of life than parents of typically developing children (Allik et al., 2006). Within the sample of HFASD parents, Allik et al. determined that mothers reported significant impairments in their quality of life, particularly as it related to their children's problematic behaviors, but not fathers. In a later study, Johnson et al. (2011) compared differences in perceptions of mothers and fathers as well, examining discrepancies in family functioning expectations versus reality and the impact on parental stress and quality of life. Mothers indicated a greater discrepancy than fathers between what they felt their family functioning should be and what it actually is, and this discrepancy was correlated with decreased mental health. The researchers supported that it is important for clinicians to consider the differing expectations of parents and open a discussion between them about these discrepancies in an effort to promote a more effective parenting dynamic in families of children with autism spectrum disorders (Johnson et al. (2011).

Lee, Harrington, Louie, and Newschaffer (2008) explored quality of life on a more familial level, comparing families of children with ASD to families of children with ADD/ADHD as well as families of children with typically developing children. Using national survey data, the researchers solicited information about participating families' quality of life as manifested in several domains. They found that parents of children with ASD alluded to increased burdens of child care including difficulty in maintaining employment, fewer opportunities to engage in social activities, and decreased involvement in their communities (Lee et al., 2008). Kuhlthau et al. (2014) discovered similar trends in factors related to quality of life, although they compared their sample of 224 parents of children with autism to the normative population and used a mixed methods procedure. Special needs parents yielded lower health scores than parents in the general population with 40% of the sample indicating symptoms of clinical depression. This and other themes such as obtaining support for caring for their child, maintaining relationships, and managing financial factors were among the those yielded from common experiences of these parents (Kuhlthau et al., 2014).

A study by Baghdadli et al. (2014) took a broader look at quality of life for parents of children with autism; however, their study focused on adolescents rather than children. Biological mothers of 152 teenagers (mean age = 15) with autism were asked to rate their quality of life using a standardized measure including the following domains: emotional, daily disturbance, and global. Weekly interventions, comorbid medical diagnoses, symptom severity, adaptive behaviors, behavior problems, and psychological development were considered "predictors" of quality of life. When compared to a sample of parents of individuals with severe chronic diseases, parents of adolescents with autism reported lower quality of life related to daily disturbance while their emotional and global quality of life scores were similar (Baghdadli et al., 2014). The difference these researchers noted, although in different domains, is consistent with comparisons made between the current population of interest and parents of children high functioning autism (Allik, Larsson, & Smedje, 2006) as well as parents of children with ADD/ADHD (Lee et al., 2008), supporting that parents of children with autism experience challenges related to caring for their children that are unique to their population.

When exploring predictors of quality of life for parents of teenagers with autism, Baghdadli et al. (2014) found that daily living skills, communication, socialization, psychological development, severity of symptoms, and problem behavior were all linked to lower quality of life. Interestingly, parents whose teenagers received increased intervention time during the week and psychoactive treatment also reported lower quality of life, although the researchers hypothesized that this may be related to the observation that these teenagers were also reported as having increased problem behavior (Baghdadli, 2014). Overall, the researchers supported that there is a need for increased support for families of children with autism, particularly as it impacts the parental/familial quality of life (see Baghdadli, 2014).

Depression. Mickeviciene, Sinkariova, and Perminas (2009) compared depression between mothers and fathers of children with ASD to parents of children with no disability, noting that parents of children with ASD reported greater levels of depression. However, unlike the gender differences found by Allik et al. (2006), Mickeviciene et al. (2009) determined that levels of depression did not differ between mothers and fathers of children with ASD, although it peaked at different times. Fathers reported higher levels of depression in children ages 8-11 while mothers' depression heightened during later adolescent ages. No differences in levels of depression were reported between mothers and fathers for younger children between the ages of 3 and 7 (Mickeviciene et al., 2009). One can hypothesize that during this younger age bracket, parents are consumed with obtaining treatment and maintain high hopes for their child's prognosis, while parents of older children may be facing the reality of their child's potentially lifelong limitations and challenges.

Phetrasuwan and Miles (2009) turned their focus specifically to mothers in exploring levels of depression. In examining the symptom-related stress of 108 mothers of children with ASD, Phetrasuwan and Miles (2009) asked participants to rate their level of stress associated with raising a child with ASD as well as a self-report measure of depressive symptoms that they experienced. The researchers concluded that higher levels of parenting stress were significantly correlated with greater reports of depressive symptoms. Moreover, higher greater levels of stress and depression were consistent with reports of a lower sense of psychological well-being (Phetrasuwan & Miles, 2009). Although this was a large sample that was representative of varying ethnicities, education levels, and income, the study did not account for the range of disorders that comprise the autism spectrum nor did it take into consideration the different treatment approaches that influence the lives of these families (Phetrasuwan & Miles, 2009).

Zablotsky, Bradshaw, and Stuart (2013) reported on stress levels and mental health in a much larger sample of over 56,000 mothers of children with autism with data drawn from the 2007 National Survey of Children's Health. Their findings were consistent with earlier research, supporting that mothers of children with autism were more likely to experience higher stress levels and decreased mental health (Zablotsky, Bradshaw, & Stuart, 2013). Demographic factors besides having a child with autism such as low income and minority backgrounds also contributed to mothers' stress and mental health. Additional complications with the child with autism, such as comorbid diagnoses, were correlated with mothers' increased mental health problems and stress. However, the use of social supports mediated these impacts on mothers of children with autism and reduced their risk of negative psychological outcomes levels (Zablotsky, Bradshaw, & Stuart, 2013). It is also interesting to include that the researchers noted that this rather large sample was limited solely to mothers due to the "lack of availability of measures of father's mental health" (p. 1382), indicating that even in drawing from data in a national pool of participants of families of children with autism, fathers' perspectives are not adequately represented. Although perhaps not on as large of a scale, I sought to address the limited representation of fathers' perspectives in my study.

Physical health. Conflicting conclusions have been drawn regarding the impact on the physical health of parents who are raising a child with ASD. Allik, Larsson, and Smedje (2006) compared self-reports of physical health between 61 parents of children with Asperger's syndrome and high-functioning autism (AS/HFA) and 59 parents of children with no disabilities. Additionally, they investigated each sample by gender, comparing mothers and fathers to each other. An analysis of health surveys indicated that mothers of children with AS/HFA reported lower levels of physical health than did mothers of children with no disabilities. Additionally, these mothers also reported lower levels of physical health than fathers of children with AS/HFA. No difference in self-perceived physical health was reported by fathers in this study (Allik et al., 2006). Limitations to this study include a small sample size and the reliance on self-reports without corroboration from the participant's physicians regarding the participants' physical health status (Allik et al., 2006).

In a later study, Menjack, Mavrinac, and Simetim (2009) contradicted the results found by Allik et al. (2006). Comparing the health status reports of 178 parents of children with ASD to 172 matched parents of children with no disability, Menjack et al. found that parents of children with ASD reported significantly poorer levels of many factors of well-being including their energy, emotions, mental health, and social functioning. Out of the eight dimensions of health measured in their study, the only one that participating parents did not differ significantly from was physical health (Menjack et al., 2009). The researchers offered several explanations. Characteristics of the participant pool itself could have impacted the results. First, parents of children with ASD were not randomly selected but recruited from a center for children with ASD and their families. Thus, these parents, who had volunteered their answers, were receiving support services for their children and families. Second, a majority of the parents surveyed were under the age of 50 and perhaps not experiencing some of the health concerns of older parents (Menjack et al., 2009). It can also be hypothesized that parents of children with ASD strive to maintain their physical health in order to provide optimal care for their disabled child.

While the previous researchers relied on self-reports and surveys to ascertain health status and impact of caregivers for children with ASD, Ruiz-Robledillo, Gonzalez-Bono, and Moya-Albiol (2013) sought to analyze a biological marker to compare the health differences not only between caregivers of children with autism and non-caregivers, but also with caregivers who received supports (parent training, Cognitive Behavioral treatment, counseling, support groups, etc.) for their care of a child with autism versus caregivers who do not. The researchers assessed symptoms of health status, depression, and caregiver burden via standardized instruments as well as collected 2-day samples of saliva from 36 participants (n=12 per group) in order to measure their cortisol awakening response, a biological marker for health and stress response. Ruiz-Robledillo, Gonzalez-Bono, and Mova-Albiol found that caregivers of children with HFA reported greater health-related and depressive symptoms than non-caregivers. Moreover, caregivers without support yielded lower CAR responses than did supported caregivers and non-caregivers. This is consistent with Allik, Larsson, and Smedje's earlier study (2006), but also indicates that proper supports for caregivers of individuals with ASD may serve to mediate the health differences observed between caregivers and non-caregivers. Moreover, Cappe et al. (2011) suggested that a range of supports including strategies for problem-solving and social supports are more effective in promoting better mental health and parenting positivity than emotion-focused strategies.

Parenting Children With ASD Versus Other Disabilities

Due to the predominant homogeneity of participants' gender, ethnicity, and income level in much of the research addressing parenting stress in parents of children with ASD (Caucasian, middle class mothers), the issue of generalization is salient in interpreting many of these studies. Moreover, the children compared in studies are either diagnosed with an ASD or have no reported disability. This warrants exploration as to whether or not these differences in parenting stress are present exclusively within the autism spectrum or if they withstand significance when compared to parents of children with other disabilities. The next section reviews research that has compared the parenting stress reported by parents of children with autism with parenting stress reported by parents of children with other disorders.

ASD versus developmental disabilities. Although ASD is a prominent branch in the domain of developmental disabilities, there are individuals diagnosed with a developmental disability that are not considered part of the autism spectrum. While these individuals may exhibit some developmental delays that are similar to those of ASD, they generally do not demonstrate the level of social impairment or odd and ritualistic behavior that individuals with ASD do (Estes et al., 2009). Davis and Carter (2008) concluded that social deficit was one of the highest contributors to parenting stress for parents of children with ASD. One might wonder, then, how the absence of this characteristic in children with developmental disabilities (but not specifically ASD) would influence experiences of parenting stress. Estes et al. recognized that much of the existing research comparing parents of different diagnostic populations focused on comparing ASD with completely different disorders and sought to determine how the experience of parents of children with ASD differed from parents of children with other developmental disabilities. Mothers of children with ASD reported significantly higher levels of parenting stress when compared to mothers of children with developmental disabilities. Additionally, mothers of children with ASD also rated themselves as experiencing more psychological distress as measured by mean scores of anxiety and depression (Estes et al., 2009).

In comparing the children and their diagnoses, it was discovered that children with ASD were measured as exhibiting significantly higher levels of problem behavior and significantly lower levels of daily living skills. Previously, it was discussed that problem behaviors were more associated with parenting stress as opposed to the severity of the child's disability itself (Phetrasuwan & Miles, 2009). This is important in regards to the findings of Estes et al. (2009) because while neither the child's diagnosis nor level of daily living skills was found to contribute significantly to reported levels of parenting stress, levels of problem behavior were positively associated to both parenting stress and psychological distress.

ASD versus Down's syndrome. Dabrowski and Pisula (2010) compared levels of parenting stress and coping styles in parents of children with autism to parents of children with Down syndrome. Unlike Lee (2009) and (Phetrasuwan & Miles, 2009), Dabrowski and Pisula (2010) recruited a fairly equal number of mothers and fathers for participation in each of their groups. They confirmed what Lee et al. (2009) had asserted earlier; parents of children with autism reported the highest levels of parenting stress, not only over parents of typically developing children but also over parents of children with Down syndrome (Dabrowski & Pisula, 2010).

Several differences between the groups also emerged in exploring factors associated with the children's diagnoses that contributed to levels of stress. For example, parents of children with autism differed from parents of children with Down syndrome on scales addressing dependency and management, limits on family opportunities, and life span care (Dabrowski & Pisula, 2010). Additionally, mothers of children with ASD yielded significantly higher levels of stress than fathers did which was not found between mothers and fathers of children with Down syndrome (Dabrowski & Pisula, 2010). The researcher's findings of this study are important because they indicate that all parenting stress is not created equal, and parenting stress among parents of children with disabilities in particular is not experienced to the same extent across diagnostic populations. Moreover, the researchers also suggest that mothers and fathers of children with autism also differ in their experiences of parenting stress, which was something observed exclusively within the ASD sample population and alludes to the need for more systemic exploration of families of children with autism (see Dabrowski & Pisula, 2010).

ASD versus cerebral palsy. Eisenhower, Baker, and Blacher (2005) conducted a longitudinal assessment with the participation of parents of a number of diagnostic populations regarding negative impact (stress) and behavior problems, however among the groups compared (ASD, cerebral palsy, undifferentiated delays, Down's syndrome, and typically-developing children), reports from parents of children with ASD versus parents of children with cerebral palsy were especially interesting. First, it was noted that when children were 3 and 4 years old, parents of children with ASD reported the highest levels of stress, depression, and child problem behaviors. Parents of children with cerebral palsy reported the second highest levels of these measures (Eisenhower, Baker, & Blacher, 2005). However, by the time these children reached the age of 5, reports of stress and child problem behavior from parents of children with cerebral palsy surpassed those reported by parents of parents of children with ASD. The researchers indicated a particular interaction effect between age and syndrome and suggested that, unlike what has been observed in studies of other diagnostic populations, the physical challenges associated with children with cerebral palsy serves as a unique stressor for these parents (Eisenhower, Baker, & Blacher, 2005).

The level of parenting stress and psychological, physical, and social consequences related to having a child with ASD, while differing from those associated with parents of children with other diagnoses, are not experienced solely by parental figures within the family. A more familial stress and consequence related to having a child with ASD in the home exists that affect other children within the household as much as it does their parents. It would be important to acknowledge and understand the sibling experience as held by those growing up with a brother or sister with ASD.

Typically Developing Siblings of Children with Autism

Tsao, Davenport, and Schmiege (2012) asserted the importance of including siblings of children with autism when considering effective interventions for this clinical population, particularly as modern focus has been more family-centered. This next section will discuss the typically developing siblings of children with ASD. Growing up with a brother or sister with a disability provides a sibling experience unlike the one that most other children have. Considering their experience and involving them in treatment can result in positive outcomes for all of the partied involved; the child with autism, his or her typically-developing sibling, and the overall family unit (Tsao, Davenport, & Schmiege, 2012). In this section, specific dimensions of the sibling experience including sibling relationships, perceptions and understanding of ASD, personality traits, and the effects of having a sibling with ASD are addressed.

Sibling Relationships

Harris and Glasberg (2003) noted that unlike friends, siblings are “imposed” on us and that there is no one specific relationship style that constitutes a “normal” sibling relationship. Rather, relationships between typically-developing siblings start the moment a new brother or sister is born and continue to evolve through periods of jealousy, rivalry, closeness, distance, and loyalty as both individuals grow (Cicirelli, 1995). The extent to which typically developing children can form relationships with their siblings with ASD, however, is often challenged by the social deficits and problem behaviors that characterize the disorder. There are several different components that play an important role in the development of positive sibling relationship between two typically-developing children. The challenge of achieving these components when one sibling is a child with ASD can make the formation of a good sibling relationship more difficult.

Access. Siblings need to have access to each other in order to form a relationship. Access refers to the extent to which siblings have the opportunity to engage in shared activities and common experiences (Bank & Kahn, 1982). Access tends to be higher in siblings who are the same gender and close in age, leading to a stronger bond, however it is possible for siblings of opposite genders and farther ages to experience access if the family dynamics provide for the opportunity (Harris & Glasberg, 2003). Neither sameness of gender nor closeness in age, however, may lend itself to access when one sibling is a child with ASD. While a typically-developing child may attempt to engage in collaborative activities with their sibling with ASD, the sibling may not always reciprocate these intentions or share the typical child's goals (Knott, Lewis, & Williams, 2007). A study of a sample of adolescent siblings of male individuals with autism interviewed by Petalas, Hasting, Nash, Reilly, and Dowey (2012) found common difficulties with interaction relayed to their brothers' behavioral outbursts. Often turning aggressive and destructive, these unpredictable outbursts lead siblings to feel disappointed and/or frustrated when wanting or trying to engage with their brothers with autism. This is consistent with a Hastings and Petalas' later research which determined that increased problem behaviors of children with autism challenged the development of a warm and close sibling relationship and predicted increased conflict between siblings (2014). Thus, access between typical children and their siblings with ASD, despite gender or age, may be limited, straining the relationship between them (Harris & Glasberg, 2003).

Play skills. As stated previously, children with ASD may not always reciprocate their typically-developing siblings' interest in interaction and collaboration in activities. Thus, children with ASD do not always make the best play mates for their siblings; at least, not in their siblings' eyes (Harris & Glasberg, 2003). Bass and Mulick (2007) discussed three phases of social play: orientation (awareness of another child), parallel play (engaging next to another child), and common focus (playing cooperatively with another child). They asserted that both socio-emotional and cognitive development is important in social play, two areas that children with ASD can significantly lack (Bass & Mulick, 2003). Traditionally, young siblings can offer each other a companionship and built-in loyal friendship that exists before external friendships come into the picture. However, in addition to their socio-emotional and cognitive deficits, children with ASD may engage in aggressive behavior, temper tantrums, and rigid play behavior that render him or her a challenging playmate and companion to rely upon for the typically-developing sibling (Harris & Glasberg, 2003). Repeated unsuccessful attempts at engaging the child with ASD in mutually enjoyable play activities may result in the typically-developing sibling giving up or feeling resentful, impeding the potential for a sibling bond (Harris & Glasberg, 2003).

In some cases, typically-developing siblings may be called upon to assist their siblings with autism in learning appropriate skills. Chu and Pan (2012) examined the effects of sibling and peer-assisted instruction versus a control group without these types of assistance for teaching social interaction and aquatic skills to 21 children with autism. They not only found that children being instructed with the assistance of peers and siblings showed greater improvement in both interaction and aquatic behaviors but that the skills of the typically developing siblings and peers improved as well (Chu & Pan, 2012). Walton and Ingersoll (2012) also explored the use of typically-developing siblings as trainers for children with autism for social play skills. Although some siblings found this role of engaging, speaking, modeling, and prompting difficult to learn, the research supported that siblings can be effective trainers of social skills. Following ten weeks of structured Reciprocal Imitation Training play sessions guided and observed by the researchers, positive changes in play behavior of four children with autism were noted, including increased imitation and joint attention (Walton & Ingersoll, 2012). Consistent with the impact on typically developing siblings noted by Chu and Pan, changes were observed in the six siblings' play behavior as well. Siblings enjoyed the value of learning how to better interact with their sibling with autism and parents reported an increase in the quality of play and interaction between siblings (Walton & Ingersoll, 2012). Although generalization of these play skills outside of the sibling dynamic was not observed during the follow-up, the incorporation of typically-developing siblings into play skills for children with autism is an approach that, at the very least, may positively influence the social relationship between siblings.

Responsibility. The task of raising a child with ASD is an overwhelming one for parents, especially those who also maintain jobs outside of the house. They might rely on others to assist with various tasks for the disabled child both before school and after school. Typically-developing siblings assume greater amounts of responsibility, particularly in the care of their sibling with ASD, than children with typically-developing siblings (Seligman & Darling, 1997). They may assist in dressing the child in the morning, help him or her with personal care tasks, and provide supervision while the parent takes care of chores around the house (Harris & Glasberg, 2003). Additionally, as children mature, they may be given household responsibilities such as taking out the garbage, cleaning up after meals, or taking care of a pet. If a sibling with ASD cannot assume such household responsibilities as well, this may breed distress in the sibling relationship and prompt difficulty in the typically-developing sibling in asserting independence from the family as he or she grows into adolescence (Harris & Glasberg, 2003). Typically-developing siblings who are given an unequal share of familial and household responsibility can become frustrated and resentful, harming the sibling relationship (Harris & Glasberg, 2003). Moreover, the responsibility of the future can weigh heavily on a typically-developing sibling. Siblings interviewed by Petalas et al. (2012) spoke of concerns about their siblings' lack of independence as they matured into adulthood and need for ongoing care. Although none of the siblings expressed resentment or reluctance towards the possibility of having to be a caregiver for their sibling, each of them conveyed general worry about what would ultimately happen to their sibling into adulthood (Petalas et al., 2012).

Equality. Harris and Glasberg (2003) asserted that children with ASD require a great amount of their parents' attention and that this factor can prompt a typically-developing sibling to feel less loved or less regarded by his or her parents. Rivers and Stoneman (2008) noted the same dynamic, with differential parenting often favoring children with disabilities, and explored how differential parenting impacted the relationship between children with ASD and their typically-developing siblings. Fifty typically-developing siblings of children with ASD were asked to assess the amounts of attention devoted to their sibling with ASD and themselves as well as rate their levels of satisfaction with the perceived differential parenting via a standardized scale. Parents were also asked to rate how they believed their typically-developing children felt about their parenting. Not surprisingly, children who claimed to be satisfied with differential parenting described a more positive relationship with their disabled sibling (Rivers & Stoneman, 2008). Rivers and Stoneman suggested that perhaps these children possessed a greater understanding of or appreciation for why their sibling with ASD required so much of their parents' attention, or perhaps they were happy enough to pursue their own interests and activities and did not desire so much attention. These findings are consistent with Kowal, Kramer, Krull, and Crick (2002) who argued that it is not the differential parenting itself that creates conflict, but rather the extent to which children understand it and perceive it as being fair.

An interesting disconnect was observed between parents of children with ASD and their typically developing children when reporting on levels of satisfaction. Parents significantly overestimated their typically developing children's level of dissatisfaction with both distribution of parental attention and differential parenting, as children reported higher levels of satisfaction than parents had anticipated (Rivers & Stoneman, 2008). This suggests that perhaps parents do not always have an accurate perception about the experience of their typically developing children in regards to having a sibling with ASD, and supports the need for further research into the relationship between parents of children with ASD and their typically developing children.

Perceptions and understanding. Past research has produced conflicted accounts about the way typically developing siblings of children with ASD perceive and understand the disorder which, as alluded to earlier, can impact the way typically-developing children relate to and bond with their siblings with ASD. Some have observed positive sibling perceptions about the child with ASD while others reported more negative attitudes (Mascha & Boucher, 2006). Petalas, Hastings, Nash, Dowey, and Reilly (2009) noted the scarcity of research addressing the perceptions about ASD that solicited accounts directly from typically developing siblings rather parents' observations and employed a qualitative approach to identify common themes as expressed by the participants themselves (three brothers, four sisters, and one twin of eight male children with ASD). The siblings described how their daily lives were affected, noting disruptions in family life due to challenging behaviors, aggressive actions, caretaking responsibilities, and making concessions to compensate for their disabled brothers (Petalas et al., 2009). Siblings also described dealing with negative social reactivity, being angered and anxious by observing others people's ignorance, prejudice, and misunderstanding about their brothers. Often these feelings were accompanied by levels of frustration and embarrassment. At times they were able to explain their brothers to other people while some people simply withdrew themselves (Petalas et al., 2009). The participating siblings described experiencing conflict between accepting their brothers for who they are while at the same time wishing that somehow things were different. They spoke of their brothers' ASD as a natural part of who they are and exhibited a positive regard for the reality of the condition. Still, comments indicating at least some level of desire that things could change was apparent. Despite the challenges of having a brother with ASD, all of the siblings interviewed were able to share positive experiences about their brothers. Some recalled rare but enjoyable moments of interaction while others took pride in their brothers' accomplishments and abilities. Some of the siblings shared that growing up with a brother with ASD had a positive effect on them, possessing a valuable understanding of the disorder and teaching them to be more empathetic towards others (Petalas et al., 2009). All of the siblings interviewed asserted the importance of support systems including family, friends, and organized support groups for siblings of children with ASD, and asserted that having outlets in which to discuss their experiences and express their range of emotions was essential (Petalas et al. 2009).

Sage and Jegatheesan (2010) conducted a more in-depth case study to understand typical siblings' perceptions of children with ASD, interviewing one European-American family and Asian-American family. Using a "draw and tell" technique to allow the children's responses to be more natural and expressive, the researchers interviewed the children about their siblings, their disability, and their relationship. In addition to gathering information about siblings' perceptions and understanding of ASD, cultural factors were important to note. Two extremely contrasting sibling experiences emerged between the European-American family and the Asian-American family. First, background information provided the researchers with a foundation of familial understanding about and approach to their child with ASD. The European-American parents' attitude towards ASD was characterized by acceptance, openness, determination, and equal expectations of both their typically-developing child and their child with ASD. In contrast, the Asian-American parents responded to their child's diagnosis with shame, fear, a belief that they were given a child with a disability as punishment for their ancestors' sins, and an expectation that their typically-developing son must always be a role model for his disabled brother and remain passive and patronizing in their interactions (Sage and Jegatheesan, 2010). This familial attitude is consistent with what has been observed in studying other Asian families who have children with ASD, as their response to such devastation is rooted in the taboos of their religious and cultural beliefs (Jegatheesan, Miller, & Fowler, 2010). Not surprisingly, these parental attitudes and responses to ASD were reflected in the way their typically-developing children perceived their siblings' disabilities. The typically-developing son in the European-American family, age 7, reported a happy and satisfying relationship with his disabled sibling, one characterized by mutual respect, interaction, and enjoyment of each other's companionship. His pictures depicted him and his brother smiling and playing together. He also reported that he knew and understood his brother better than anyone, even his parents. Although he did communicate that his brother most often preferred to play with trains, he also stated that he was trying to teach his brother to play baseball which was very important to him (Sage and Jegatheesan, 2010). The typically-developing son in the Asian-American family, also age 7, drew pictures that depicted him as being very angry on the inside but smiling on the outside, expressing that this is what he is expected to do. His understanding of his brother's disability appeared to be limited to "tantrums." He did not draw ears on his brother because he felt that his brother did not listen. This sibling, throughout his drawing and subsequent interview, characterized a relationship of resentment, distance, and obligation. He did not like that his disabled sibling always got what he wanted in his parents' efforts to avoid tantrums. One thing that this sibling did wish for was for his brother to be able to sit and listen to him read him a story.

These case studies, while perhaps not generalizable to larger populations due to their limited number of participants, offer a personal and in-depth look at the experience of siblings as impacted by their perceptions and understanding of ASD. It is evident that many factors extraneous of the siblings themselves impact how the disorder is understood and the quality of relationship they develop, including parental attitudes and cultural influences. In noting these factors, researchers highlight the need for a more familial understanding of ASD and how the interactional dynamics of a family impact its functioning both as individuals and as a whole (see Sage and Jegatheesan, 2010).

Adjustment to Having a Sibling With ASD

Just as previous researchers have offered conflicting conclusions about siblings' understanding and perceptions of ASD, so, too, have the effects of having a child with ASD on typically developing siblings been debated. Several researchers have explored the adjustment qualities and personality traits of siblings of children with ASD as manifested in behavioral and socio-emotional characteristics. These studies and their implications about the impact of having a sibling with ASD on typically developing siblings will be discussed in this section.

Personality traits. Tarafder, Mukhopadhyay, and Basu (2004) reviewed the potential effects on typically developing siblings of living with a child with ASD, highlighting that the time and attention a disabled child requires to tend to his or her challenges could result in feelings of jealousy, anger, resentment, and deprivation which could contribute to higher levels of familial conflict and stress. In an effort to develop a personality profile of typically developing siblings of children with ASD, Tarafder, Mukhopadhyay, and Basu administered the Rorschach to 20 individuals between the ages of 12 and 18, half of whom had siblings with ASD and half of whom had a sibling with no disability. The participants in the control group were matched to those in the experimental group according to a number of demographic characteristics. After the Rorschach assessments were completed, the protocols were sent to be scored by three experts who did not have knowledge of the details of the study. The projections made by the participants on the assessment indicated that typically developing siblings of children with ASD tend to exhibit stimulus overload and defensiveness. However, they also demonstrate greater tolerance to stress and a greater awareness of impulses. Siblings of typically developing children exhibit better coping mechanisms and less reactivity.

Tarafder, Mukhopadhyay, and Basu (2004) discussed how typically developing siblings of children with ASD work harder to meet expected demands in order to compensate for their siblings' lack of ability to do so, and that this likely increases their defensiveness and impedes their ability to cope easily. They suggested that siblings of children with ASD could benefit from special attention and therapeutic help in order to decrease their defensiveness and increasing coping efforts (Tarafder, Mukhopadhyay, & Basu, 2004).

Acknowledging that siblings of children with autism may become aware of stressful family situations and internalize such stress, Shivers, Deisenroth, and Taylor (2013) were interested to determine if there are specific patterns of and predictors for anxiety problems in these typically-developing siblings. Recruiting over 1,700 siblings between the ages of 3 and 18, the researchers hypothesized that these siblings would yield higher anxiety levels dependent upon presenting characteristics of the child with autism (problem behaviors and autism severity) and of their parents (history of anxiety disorders and broader autism phenotype [BAP]) (Shivers, Deisenroth, & Taylor, 2013). Interestingly, when looking solely at anxiety levels comparisons, there was no significant differences noted between anxiety levels of siblings of children with autism and those of the general population. However, a number of within-group differences were noted (Shivers, Deisenroth, & Taylor, 2013). First, gender comparisons revealed that male siblings were much more likely to have scores within the borderline range of anxiety. Age comparisons determined the same range for siblings between the ages of 6 and 11 years with greater differences observed within males of this age range compared to their normative sample. Follow-up analyses confirmed that these differences were not merely due to increased problems related to this age group in general (Shivers, Deisenroth, & Taylor, 2013).

When looking at predictors, the child with autism's higher levels of problem behavior were linked to increased sibling anxiety. Severity of autism did not appear to be related (Shivers, Deisenroth, & Taylor, 2013). These findings are consistent with Phetrasuwan's and Miles' study (2009) who indicated the same predicting factors for parenting stress. Parental history of anxiety disorders was linked to increased sibling anxiety, as was maternal BAP scores. Interestingly, paternal BAP scores exhibited no influence on sibling anxiety. The researchers hypothesize that perhaps this is so because, similar to the general population, mothers take the dominant role in child-rearing activities and thus, their behavior and means of interaction with children are more influential (Shivers, Deisenroth, & Taylor, 2013). This supports the need for a closer consideration of the familial dynamic of children with autism, particularly considering the perspective of an alternate caregiver other than the mother and how the presence of a child with disability influences other members of the family, especially siblings.

Behavioral adjustment. It was previously asserted that parents of children with high-functioning ASD do experience higher levels of parenting stress when compared to parents of typically developing children despite their children's high cognitive capabilities (Lee et al., 2009). In an earlier study, Verte, Roeyers, and Buysse (2003) also studied families of children with HFASD but focused specifically on their siblings. Comparing 29 siblings of children with HFASD with 29 siblings of children with no disorder, the researchers found that, according to their parents' reports, siblings of children with HFASD exhibited significantly more behavior problems within both internalizing and externalizing scales (Verte, Roeyers, & Buysse, 2003). This difference was particularly reported in siblings between the ages of 6 and 11 years old. However, further analyses revealed that although children of siblings with HFASD were reported as having more behavior problems, their scores in and of themselves were not in the clinical range (Verte, Roeyers, & Buysse, 2003). In other words, the behavior problems exhibited by siblings of children with HFASD are higher than other children, but they are not to the clinical extent of the behavior problems exhibited by children with ASD.

Like Verte, Roeyers, and Buysse (2003), Hastings (2003) also focused on the behavioral issues of typically developing siblings of children with ASD, although he expanded his sample of children to include a wider range of ASD rather than specifically studying HFASD and used a different measure. Twenty-two mothers completed questionnaires to assess the behaviors of their children with ASD as well as the behaviors of their typically-developing children. When compared to normative data, Hastings' (2003) results were consistent with Verte, Roeyers, and Buysse (2003), also determining that siblings of children with ASD were reported as having more behavior problems. Moreover, a larger proportion of these children fell into the abnormal range than what was expected in the normative population. Interestingly, however, as it was earlier discussed that child problem behaviors were not necessarily a predictor of high parenting stress (Osborne & Reed, 2010), Hastings (2003) concluded that behavior issues of the child with ASD did not emerge as a predictor of sibling problem behaviors. Over a decade later, Hastings (2014) maintained this same finding in another research study that looked at child with ASD problem behavior and maternal depression as predictors of sibling problem behavior, neither of which indicated a correlation. This suggests the complexity of the issues facing parents and siblings of children with ASD and implicates the role of other factors within the family system in the manifestation of these issues. Petalas et al (2012) factored in features of a Broad Autism Phenotype (BAP) in siblings with behavior problems of a child with ASD and mental health problems of parents to determine that siblings with a greater BAP being raised in an environment with greater autism problem behaviors and increased mental distress among parents exhibited decreased adjustment, increased behavior problems, and reported more difficult relationships with their siblings. This interactive dynamic of variables supports the need for a more systemic understanding of families of children with ASD.

Socio-emotional adjustment. A review of studies from researchers examining the social-emotional adjustment of typically developing siblings of children with ASD paints somewhat of a different picture about them as compared to studies about their behavior. For example, Macks and Reeve (2006) recruited a sample of mothers and siblings of children with ASD to assess the siblings' socio-emotional qualities from both the parents' perspectives and the children's perspectives. Similar to Rivers and Stoneman (2008), they, too, found a significant disconnect between the way parents rated their typical children's socio-emotional adjustment and the way the children rated themselves. While the children presented a positive interpretation of their personal characteristics, behavior, and anxiety, parents reported a more negative view of their socio-emotional adjustment, particularly in how they are affected by their siblings with ASD (Macks & Reeve, 2006). Several theories were proposed for this difference in perceptions. First, Macks and Reeve proposed that parents project their own frustrations and stress levels regarding their children with ASD onto their typical children, assuming that they share the same experience. Second, they suggested that parents fail to perceive an accurate view of their typical children's functioning due to the amount of the time they spend attending to the needs of their children with ASD (Macks & Reeve, 2006). This is consistent with the theory asserted earlier by Rivers and Stoneman regarding the experience of their typical children.

Pilowsky et al. (2004) found similar results in their study of the socio-emotional adjustment of typical siblings of children with ASD, however they compared their sample of children to typical siblings of children with other clinical diagnoses. In comparing children with ASD to children with no disability, the question of whether or not observed differences are unique to ASD is always salient. Previously, it was asserted that higher stress levels were found consistently among parents of children with ASD when compared to parents of children with other diagnoses (Estes et al., 2009; Dabrowski & Pisula, 2010; & Eisenhower, Baker, & Blacher, 2005). Recruiting two different comparison groups, siblings of children with a developmental language delay and siblings of children with mental retardation of unknown etiology, Pilowsky et al. (2004) hypothesized that siblings of children with ASD would be rated as having a lower level of socio-emotional adjustment. Rather, they did not find significant differences in the adjustment of siblings of children with ASD when compared to their comparison groups and normative data, concluding that siblings of children with ASD are actually well-adjusted (Pilowsky et al., 2004).

Petalas et al. (2010), turning their focus to siblings of children with ASD versus siblings of children diagnosed with an intellectual disability, found results that conflicted with the earlier studies. Based on maternal reports, siblings of children with ASD were rated as having more emotional problems than siblings of children with an intellectual disability and when compared to normative data (Petalas et al., 2010). There was also a higher proportion of siblings of children with ASD whose scores were considered "abnormal" than what was found in the intellectual disability sample and the normative data (Petalas et al., 2010). However, the researchers admitted that one of the limitations of their study was relying on maternal reports of the typical children (Petalas et al., 2006). In later study, Griffith, Hastings, and Petalas (2013) recognized the lack of paternal input in research regarding siblings and families of children with autism and sought to consider their perspective, particularly as it compared to maternal reports. A sample of 130 fathers and 168 mothers of children with autism were asked to complete the Strengths and Difficulties Questionnaire about their typical child's behavioral and socio-emotional adjustment. Interestingly, mothers' and fathers' reports were generally moderately correlated with both parents indicating increased emotional and behavioral difficulties for their typically-developing child when compared to the normative population. Any significant differences in scores on the questionnaire that were ascertained presented with a small effect size (Griffith, Hastings, & Petalas, 2013). These consistencies challenge the notion that reports from both parents would be more clinically beneficial, and Griffith, Hastings, and Petalas asserted that the benefit of considering multiple perspectives within an autism-sibling family dynamic may need to be further explored. This was one of the intended goals of my study.

The Impact of Parenting Stress on Typically Developing Siblings of Children with ASD

This section addresses what past research has already established regarding the impact of parenting stress and typically developing siblings in families of children with ASD. Research addressing this specific concern is limited and should be further pursued in order to gain a more comprehensive understanding about the systemic functioning and effects of having a child with ASD as it relates to the interaction between all members of a family unit.

Hastings et al. (2014) completed a longitudinal study that proposed surprising results regarding the triadic relationship between mothers, children with autism, and typically developing siblings. Analyzing data about maternal depression with pro-social and problem behavior of both children with autism as well as a typically developing sibling, Hastings et al. found that in a study of 60 families of children with autism spanning three years, neither maternal depression nor pro-social behavior of the typically developing sibling did not predict any behavior, neither pro-social nor problem, of the child with autism. However, it was indicated that early indications of problem behavior of typically developing siblings predicted later problem behavior of children with autism. Although several limitations and biases related to the sample were noted in this research, the researchers raise a new consideration that children with autism are impacted by their siblings' behavioral/socio-emotional adjustment (see Hastings et al., 2014). Hastings et al. asserted that these findings were not consistent with earlier research.

Rao and Beidel (2009) studied a number of interacting dimensions for families of children with ASD and compared them to families with typical children. Consistent with the other studies that have been discussed, parents of children with ASD reported significantly higher levels of parenting stress associated with child problem behaviors (Rao & Beidel, 2009). These same families reported lower levels of personal growth, particularly in regards to member independence, and participation in social and recreational activities (Rao & Beidel, 2009). Interestingly, and consistent with the variance of results observed in other research, no significant differences in sibling adjustment were reported between siblings of children with ASD and siblings of typically developing children (Rao & Beidel, 2009). However, as was determined by Verte, Roeyers, and Buysse (2003) and Hastings (2003), siblings of children with ASD were reported as exhibiting significantly greater problem behaviors than siblings of typically developing children (Rao & Beidel, 2009). As seen the limitations of other studies, fathers as respondents were minimally represented, with 24 mothers and only 5 fathers participating in this study.

Quintero and McIntyre (2010) produced results that were consistent with Rao and Beidel (2009). Their investigation of maternal well-being and sibling adjustment in families of children with ASD versus families of children without ASD reported increased stress and depression among mothers of children with ASD (Quintero & McIntyre, 2010). Additionally, no significant differences between groups of siblings were reported in the domains of socio-emotional adjustment and academic functioning. Behavioral adjustment of siblings of children with ASD was associated with maternal well-being. More specifically, a significant correlation was established between daily hassles of parenting, levels of stress, and problem behaviors of siblings (Quintero & McIntyre, 2010). When mothers of children reported higher stress and depression, teachers of their typically developing children reported increased problem behaviors. Quintero and McIntyre concurred with previous research that suggested that although siblings of children with ASD are seemingly well-adjusted in terms of socio-emotional functioning, maternal stress does appear to have an impact on sibling problem behavior as reported by both parents and teachers. Quintero and McIntyre explicitly asserted that gaining paternal insight on siblings' well-being could offer an alternative perspective on family dynamics of families of children with ASD.

Conclusion

In this chapter, the challenges of raising a child with ASD were described and some of the prominent parenting stressors for parents of children with ASD were identified. Characteristics of ASD that set the child apart from typically developing peers, including rigidity and social deficits, as well as other compounding factors such as selecting appropriate treatments and related expenses, serve as unique challenges faced by parents of children with ASD. In examining symptom-related parenting stress, Phetrasuwan and Miles (2009) concluded that particular problem behaviors and symptoms manifested in a child's autism, but not the severity of the autism itself, yield higher levels of parenting stress. Previous researchers have established that social deficits were among the most common factors contributing to parenting stress for both mothers and fathers of children with ASD, and that social prognosis was identified as one of the most stressful conditions of raising a child with ASD (Davis & Carter, 2008).

Parents of children with ASD reported higher levels of parenting stress over parents of typically developing children (Lee et al., 2009) as well as over parents of children with developmental disabilities not on the autism spectrum (Estes et al., 2009). These higher levels remained evident across other diagnostic populations, as parents of children with ASD reported higher levels of stress than did parents of children with Down's syndrome (Dabrowski & Pisula, 2010). Several significant effects of higher levels of parenting stress in parents of children with ASD were noted. First, Osborne and Reed (2009) observed that higher levels of parenting stress were a reliable indicator of child problem behaviors, however the inverse relationship of these factors was not empirically supported. Second, parents of children with ASD reported a lower quality of life and greater depressive symptom (Lee et al., 2009; Phetrasuwan & Miles, 2009).

The effects of having a child with ASD does not cease with his or her parents. Typically developing siblings of children with ASD also exhibited differences when compared to siblings of typically developing children. Parents of children with ASD rated their typically developing children as demonstrating a higher level of responsibility and greater empathy as compared to siblings of children without ASD (Barak-Levy, Goldstein, & Weinstock, 2010). Additionally, siblings of children with ASD exhibited a more positive self-concept and maintained a more positive view of their behavior, their intelligence, and their scholastic performance (Macks & Reeve, 2007). However, Orsmond and Seltzer (2009) reported that they also demonstrated greater levels of stress, depression, and anxiety. Moreover, a higher level of maternal depression was associated with higher depression and anxiety for siblings (Orsmond and Seltzer, 2009). Verte, Roeyers, and Buysse (2003) found that brothers and sisters of children with ASD, especially between the ages of 6 and 11, exhibited more behavior problems than siblings of typically developing children. Mothers of children with ASD reported more feelings of guilt towards their typically developing children than their children with ASD. Feelings of incompetence, self-efficacy, role restriction, and depression related to their children with ASD were positively correlated with experiencing these same feelings towards their typically developing children (Meirrschaut, Roeyers, & Warreyn, 2010).

The literature reviewed in this chapter establishes that parents and siblings of children with ASD experience unique challenges and distress. Research addressing the experience of parents, the experience of siblings, the relationship between parents and children with ASD and the relationship between typically developing siblings and children with ASD was discussed. Upon exploring the interactional effects between parents and children with ASD as well as siblings and children with ASD, it is evident that more research is needed to better understand the triangular relationship between the problem behavior of children with ASD, maternal parenting stress, and the problem behavior of typically developing siblings. Perspectives from parental figures other than mothers on sibling well-being are severely lacking in the research produced thus far. The intended aim of my study was to address these gaps.

Chapter 3: Research Method

Introduction

The purpose of this quantitative study was to determine the relationship between the problem behavior of a child with autism and the problem behavior of a typically-developing sibling as reported by an alternate caregiver when moderated by maternal parenting stress. In this chapter, I define the variables of the study and discuss the research design. Next, I explain the target population, sampling strategy, and recruitment procedures, and then discuss the operationalization of constructs and instrumentation. I conclude by discussing data analysis procedures, potential threats to validity, and ethical considerations.

Variables

The independent variable in this study as originally planned was the problem behavior of a child with autism as reported by his or her mother. The dependent variable was intended to be the problem behavior of a typically-developing sibling as reported by a parental figure other than the mother, such as a father, grandparent, or other daily caregiver (e.g., nanny). Maternal parenting stress as reported by the mother of the children was meant to serve as a moderating variable between the independent and dependent variables. Challenges in obtaining the required data to analyze these variables as intended are discussed later in my study.

Research Design and Rationale

I intended to use a cross-sectional correlational design in this research. Researchers use cross-sectional research designs to observe a representative sample at one point in time to provide information about a larger population of individuals or to describe it in some way. Correlational research designs are used to observe the relationships between multiple variables. Had I been able to acquire the appropriate data, this would have been the appropriate design for my research question rather than a longitudinal study or case study because researchers use longitudinal designs to study a population over various points in time and a case study is limited to only a tiny portion of a population with specific characteristics. In contrast, researchers use cross-sectional correlational designs to describe the relationship between the identified variables (problem behavior of a child with autism, problem behavior of a typically-developing sibling, and maternal parenting stress) found within the overall population (families of children with autism) by observing a representative subset (sample population of participants) as it exists and is measured at the present time. With the appropriate data, using a cross-sectional correlational design rather than a longitudinal or case study design would have provided current and generalizable information about families of children with autism that could be used to support improved sources of familial support. Necessary revisions to the research design are discussed later in my study.

As with any research design, there are time and resource constraints associated with using a cross-sectional correlational design. Particularly in families of children with autism, behaviors of children can fluctuate from one week to another, even from one day to another, depending on various factors. These include sleeping patterns, eating habits, health status, medication changes, setting events such as environmental changes, and antecedents such as misplacing a favorite item or denied access to a preferred place or activity. It is important to consider the potential limitation that reported measures of problem behavior may be reflective of behavior exhibited during the particular time of data collection rather than an overall picture of the child, especially if the child is experiencing a particularly challenging phase of behavior. That being said, it is also important to recognize potential bias in the mother's reported level of parenting stress given that this, too, can also fluctuate from week to week, or day to day, depending on their child's behavior. Maternal parenting stress can also be influenced by contextual factors including issues related to work, residual effects from severe weather or natural disasters, or life-changing family events such as the death of a loved one. In using a cross-sectional correlational design that provides an observation of participants for one moment in time, these types of constraints are important to consider.

Target Population

The general target population for this study was families of children with autism, specifically, families with at least two parental figures residing in the household (the mother plus one other) that have one child diagnosed with autism and at least one typically-developing child. In an effort to minimize a significant age variance, I limited the target population to families whose children were under the age of 16. It was essential that recruiting within the sampling frame yielded only families who have two parental figures residing in the household (a mother and one other caregiver such as a father, grandparent, nanny, au pair, etc.) in an attempt to gain the perspective of the typical children's problem behavior from a respondent other than the mother, which is lacking in the current literature (Quintero & McIntyre, 2010).

With approval from Walden University's Institutional Review Board, I recruited participants from multiple online resource groups and service organizations that support children with ASD and their families. Thus, the sample was limited to families who have internet access and use such resources.

Sampling Procedures

I recruited families for voluntary participation in this research via an online posting to several autism resources/support groups. Since participants were recruited based upon the characteristics required for this study, I used a purposive sampling method. Interested families who met the participation criteria (one child with autism and at least one typically-developing child, both under the age of 16; two parental figures residing in the household) were provided in writing with a brief introduction in which I identified my educational and professional background, explained my interest in the research area, specified participation requirements, noted their freedom to opt out at any point, provided assurance of the security of the data and information I collected, and gave instructions about how they could follow-up with research results. Interested families who met criteria were provided with a link to access the participation materials on SurveyMonkey®, which included the following: (a) a demographic questionnaire requesting basic information about the household (gender and ages of children, gender and ages of both parental figures, and ethnicity of family), (b) Autism Parenting Stress Index (Silva & Schalock, 2012), and (c) Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997). To address the research questions, I proposed using both multiple linear regression and a moderation analysis. The moderation analysis requires a higher sample size. For a moderation analysis with a confidence interval of 95% ($\alpha = .05$), Aguinis (2004) suggested that the power of the analysis can be low. Thus, a large sample size should be acquired (typically 100-200) in order to accurately detect a moderating effect and ensure empirical validity so that a large power is obtained.

Using the power calculator G*Power (Faull, Erdfelder, Buchner, & Lang, 2013) I determined an appropriate sample size for this study. The regression analysis with a moderating variable is the most involved analysis for this study, so the specifications for the power analysis were based on this analysis. With an effect size of (f^2) = .15, an alpha level (α) of .05, a power of .80, and 2 predictors (one IV and one moderator), I determined that a total of 67 participants were required in order to find statistical reliability.

Instrumentation

Autism Parenting Stress Index

I selected the Autism Parenting Stress Index (APSI; Silva & Schalock, 2012) to assess maternal parenting stress related to raising a child with autism. The APSI is a 13-item self-rating scale that measures the rater’s perceived stress in response to items of three categories pertaining to their disabled child: core social disability, difficulty in managing behavior, and physical issues. The APSI was developed by Silva and Schalock in 2012 with the purpose of identifying the areas in which parents would benefit from the most support and intervention. This is consistent with the social change intent of my study to expand the understanding of, treatments for, and supports for families of children with autism by facilitating a cycle of decreased parenting stress and improved treatment outcomes for children with autism. The APSI was thus an appropriate instrument for this study. The APSI can be administered in paper format, there is no fee to obtain the APSI, and it is permitted for use in research without written permission from the publisher.

Psychometric properties were established for the APSI by Silva and Schalock (2012) using data collected from 274 children. Internal reliability (Cronbach's alpha) for the overall parenting stress score was reported as .83 for parents of children with autism, .83 for parents with typically-developing children, and .73 for parents of children with developmental delays. Test-retest reliability for the overall stress score was examined using a subgroup of participants several months later with a coefficient of .88 (Silva & Schalock, 2012). These scores indicate an acceptable level of both test-retest and internal reliability for assessing the overall parenting stress of parents of children with autism, supporting its use in my study. Cronbach's alpha reliability will also be conducted on the new data collected.

Silva and Schalock (2012) also examined whether or not the APSI effectively differentiated between levels of parenting stress between parents of children with autism, parents of children with other developmental disabilities, and parents of children with no disability. Consistent with the findings of Estes et al. (2009), parents of children with autism reported double the level of parenting stress as compared to parents of children with developmental delays and four times the level of parenting stress reported by parents of typical children (Silva & Schalock, 2012). Fifty percent of parents of children with autism reported significant levels of stress by indicating that the factors in question, at the very least, "often" made them stressed, while only 7% of parents of typical children and

23% of parents of children with other developmental disabilities reported such prevalence of stress. In their research, Silva and Schalock (2012) asserted that the APSI is unique in its construct in that rather than measuring parenting stress in general, which often takes into consideration factors extraneous to parenting such as marital satisfaction, the APSI takes into consideration stress specifically related to raising a child on the autism spectrum, which entails factors and complexities unique to the diagnosis. For this reason, and for the acceptable psychometric properties exhibited in Silva and Schalock's (2012) research, I selected the APSI as the instrument with which to assess participants' levels of parenting stress.

Strengths and Difficulties Questionnaire

I selected the SDQ (Goodman, 1997) to assess problem behaviors of both the child with autism and their typically-developing sibling. The SDQ is a 25-item questionnaire with five sub-scales: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behavior. It can be administered to either a parent or teacher to gather information about a child between the ages of 4 and 16. Developed by Robert Goodman in 1997, its purpose is to identify behavior problems and strengths in children and adolescents. This is consistent with the variables I sought to examine pertaining to the relationship between problem behaviors of children with autism and problem behaviors of typically-developing siblings. The instrument was also appropriate given my goal of expanding the understanding of, treatments for, and supports for families of children with autism. The SDQ can be administered in paper or electronic format, there is no fee to obtain the SDQ, and it is permitted for use in research without written permission from the publisher.

Acceptable psychometric properties have been published for the SDQ. Collecting data from over 10,000 British children and adolescents, Goodman (2001) yielded an internal reliability (Cronbach's alpha) of .73. Test-retest reliability, conducted 4-6 months later, had a mean of .62. High scores (above the 90th percentile) effectively predicted an increased probability of the individual being diagnosed with a behavioral disorder using an independent clinical assessment (Goodman, 2001). Concurrent validity was established when comparing SDQ scores against those of the Rutter questionnaires in a sample of 403 children being served in either a psychiatric clinic or hospital. A high correlation between the two questionnaires was yielded for both parent reports (.88) and teacher reports (.92; Goodman, 1997). He, Burstein, Schmitz, and Merikangas (2012) confirmed concurrent validity by yielding similar results when comparing scores on the SDQ to *DSM-5* comprehensive diagnostic information in a sample of over 6,000 adolescents. Consistent with Goodman (1997), He et al. (2012) also found that the likelihood of being diagnosed with a behavioral disorder increased with higher SDQ scores.

Operationalization of Variables

I identified problem behavior of a child with autism as the continuous independent variable of the study, measured by the SDQ instrument examining the child with autism. Questions range in responses from 1 = "not true" to 3 = "certainly true."

The average of all 25 questions on the survey was used to measure this independent variable.

I identified problem behavior of a typically-developing sibling as the continuous dependent variable of the study, measured by the SDQ instrument examining the typically-developing sibling. Questions range in responses from 1 = "not true" to 3 = "certainly true." The average of all 25 questions on the survey was intended to measure this dependent variable.

Maternal parenting stress would have been the continuous moderating variable of the study, measured by the APSI instrument. There are 13 questions which are measured on a scale from 1 = "not stressful" to 5 = "so stressful sometimes we feel we can't cope." The average of all 13 questions was intended to measure this moderating variable.

I address necessary revisions to the identification of the dependent variable and use of a moderating variable later in my study.

Data Analysis

I entered data into SPSS version 22.0 for Windows and conducted descriptive statistics to describe the sample demographics and the research variables used in the analysis. I calculated frequencies and percentages for nominal data, and means and standard deviations for continuous data (Howell, 2010).

I screened the data for accuracy, missing data, and outliers. The presence of outliers was tested by the examination of standardized values. Standardized values represent the number of standard deviations the value is from the mean. Standardized values greater than 3.29 are considered to be outliers and were removed from the data set

(Tabachnick & Fidell, 2012). Cases with missing data were examined for non-random patterns. Participants who did not complete major sections of the survey were excluded.

Research Question and Hypotheses

What is the relationship between the level of problem behavior exhibited by a child with autism and the problem behavior of a typically-developing sibling as reported by an alternate caregiver when these variables are moderated by maternal parenting stress?

H_o: There is no relationship between the level of problem behavior exhibited by a child with autism and the problem behavior of a typically-developing sibling, as reported from an alternate caregiver, when these variables are moderated by maternal parenting stress.

H_a: There is a relationship between the level of problem behavior exhibited by a child with autism and the problem behavior of a typically-developing sibling, as reported from an alternate caregiver, when these variables are moderated by maternal parenting stress.

To examine the research question and hypothesis, a multiple linear regression and moderation analysis was planned to assess if maternal parenting stress moderates the relationship between problem behavior of a child with autism and problem behavior of a typically-developing sibling. The multiple linear regression is an appropriate analysis to conduct when the goal is to assess the relationship between a set of continuous independent variables and a single continuous dependent variable (Pallant, 2010). The multiple linear regression would have been conducted to assess if problem behavior of a child with autism and maternal parenting stress predicts problem behavior of a typically-developing sibling. Prior to analysis, the assumptions of normality and homoscedasticity were assessed via scatterplots of the residuals. Additionally, absence of multicollinearity was assessed by viewing variance inflation factors.

The planned multiple linear regression would have first established if the independent and moderating variables predict the dependent variable. Moderation would have been examined by adding the interaction of the independent and moderating variables into the model. The interaction would have been calculated by the product of the independent and moderating variables after they have been centered to have a mean of 0. If the interaction term was significant, then moderation could have been supported.

In both planned analyses, the *F* test would have first been examined to assess significance of the overall regression models. If significance was found, then the individual predictors would have been examined through *t* test and examination of *B* values. Additionally, the R^2 would have been interpreted, which represents the percentage of variance in the dependent variable that was accounted for by the predictor variables.

I address necessary revisions to the planned analyses later in my study.

Threats to Validity

External

External validity measures how well the results of the analyses are able to be generalized to the target population. A limitation of the study is that only parents who have access to the internet will be capable of participating in the study. Therefore, although an adequate sample size was determined, the results would have assumed that those with access to the internet and were capable of taking the survey make up an adequate representation of the target population.

Internal

Internal validity measures the extent to which the results of the analysis are warranted. To obtain internal validity, casual inferences must be accounted for. The temporal relationship between cause and effect should be accounted for and caution should be taken to ensure that the relationship is not confused. Since the intended dependent variable of the study was problem behavior of a typically-developing child, it was assumed that the problem behavior of a child with autism and maternal parenting stress is what impacted the problem behavior of a typically-developing sibling. Lastly, the validity of the results relies on the assumptions of the multiple linear regression being met. The appropriate sample size in order to conduct a moderation analysis also needed to be met. However, I took this into consideration and made the necessary adjustments to the analysis.

Ethical Procedures

In planning the results of the research, I conducted my study as ethically as possible and protected the privacy and rights of all participants. I offered no financial incentives to any of the families taking part in the study. I did not falsify or fabricate the data collected in any way. I wrote the appropriate citations. My study was not conducted or endorsed by any institution and I did not receive any federal funding. Thus, I did not have to meet any additional guidelines. I provided each participant with the consent form prior to taking the survey. Every participant was free not take the survey or to abandon the survey at any time. The data will be stored for a period of five years, and will then be destroyed.

Summary

In this chapter, I outlined a detailed explanation of the procedures used in my research. I assessed the research design, data collection procedures, and data analysis procedures and addressed the limitations and internal and external validity. Lastly, I discussed the ethical considerations. I adhered to the procedures outlined in gathering and analyzing the data to examine the relationships between the level of problem behavior exhibited by a child with autism and the problem behavior of a typically-developing sibling when these variables are moderated by maternal parenting stress.

Chapter 4: Results

Introduction

The original purpose of this study was to explore the relationship between problem behaviors of a child with autism and problem behaviors of a typically developing sibling in two-parent households when these variables were moderated by maternal parenting stress. I sought to answer the following research question: What is the relationship between the level of problem behavior exhibited by a child with autism and the problem behavior of a typically-developing sibling as reported by an alternate/secondary caregiver when these variables are moderated by maternal parenting stress? One of the following hypotheses would be retained:

H_o: There is no relationship between the level of problem behavior exhibited by a child with autism and the problem behavior of a typically-developing sibling, as reported from an alternate caregiver, when these variables are moderated by maternal parenting stress.

H_a: There is a relationship between the level of problem behavior exhibited by a child with autism and the problem behavior of a typically-developing sibling, as reported from an alternate caregiver, when these variables are moderated by maternal parenting stress.

In this chapter, I discuss several challenges during the recruitment phase of research as well as their impact on the final analyses conducted. Specifically, I discuss the challenges in data collection that warranted a change to the original study, describe the participants of the final study sample, and offer a detailed analysis of the results of the remaining variables.

Data Collection

To address the original research question of the study, participation of both mothers/primary caregivers (reporting on maternal/primary caregiver parenting stress and problem behavior of child with autism) and a secondary caregiver (father, nanny, or other relative) helping to raise the children was required. However, due to challenges during the recruitment phase of research, a vast majority of participants were primary respondents (59 out of 68, or 86.8%), with no secondary caregiver information provided. Only nine pairs of data were yielded from this initial sample. Because I determined that nine pairs of data would not be adequate to run the multiple linear regression as originally intended, I decided to perform a correlation and simple linear regression on the data received from the 59 maternal respondents to learn more about the relationship between maternal parenting stress and problem behavior of a child with autism in two-parent households. After performing initial data cleaning of the 59 primary respondents, I found that only 21 of these 59 respondents completed both instruments provided in the survey (PSI and SDQ on the child with autism) that were to be used in the correlation and simple linear regression. The other 38 participants had failed to complete either the PSI or the SDQ.

I determined that a sample of 21 was not a sufficient number to run the revised analyses without statistical justification for a larger effect size, based upon previous research similar to this study. A large effect size of at least $F^2 = .42$, would necessitate a sample size of 21 (Faull, Erdfelder, Buncher, & Lang, 2008). I conducted a review of such research, which yielded several similar studies that indicated a large effect size.

Consistent with the current study, Tomanik, Harris, and Hawkins (2004) explored the relationship between behaviors of children with autism and maternal stress levels. Their regression analysis indicated a relationship between child aberrant and adaptive behavior and parenting stress, accounting for 32% of the variance in maternal stress. G*Power was used to convert the r^2 value to an F^2 value, which is the effect size used to calculate sample size requirements for a linear regression in G*Power. With an r^2 of .32, the researchers calculated an F^2 of .47, which is a large effect size (Faul et al., 2008).

Interestingly, more recent studies similar to my study but using a variety of measures for problem behavior yielded not only large effect sizes, but also similar values of r^2 when exploring the relationship between parenting stress and problem behavior of children with autism. Consistent with my study, Huang et al. (2014) utilized the SDQ and looked at the impact of emotional and behavioral problems of children with autism on parenting stress. They determined that problem behavior accounted for 32.9% of the variance in parenting stress. Burke and Hodapp (2014) found a positive relationship between problem behaviors (assessed by the Scale of Independent Behavior-Revised) and maternal parenting stress with an r^2 of .32. Brei, Schwarz, and Klein-Tasman (2015) utilized the Child Behavior Checklist and found that when considering the total raw score as an index of problem behavior, 33.2% of the variance in parenting stress was predicted. Utilizing G*Power, all three of these recent studies yielded large effect sizes greater than .42 (. 49, .47. and .49, respectively). These researchers indicate that a large effect size can be found when exploring the relationship between problem behavior of a child with autism and maternal parenting stress, which supports my use of a smaller number of participants in this study.

Additionally, initial data screening indicated that five of the 21 primary caregiver respondents were male. Originally, the focus of the research was on maternal parenting stress. However, due to the small amount of usable data, these male participants were retained. Given the presence of male primary caregivers and lack of usable data, my revised research aim was to explore the relationship between problem behaviors of a child with autism and primary caregiver parenting stress. In this chapter, I detail the results of the analyses performed on the final collected sample. First, I report the demographic information of the participants, followed by an analysis of the results.

Description of the Sample

The final sample consisted of 21 primary caregivers who had a child with autism. For the primary caregiver, most were between the ages of 35-44 (52.4%), and were mostly female (76.2%). For the secondary caregiver, most were between the ages of 45-54 (57.1%), and were mostly male (61.9%). Most parents indicated that their family was white (95.2%), while 4.8% indicated that they were of two or more ethnicities. Each family had at least two children, while 14 had three children. There were no families with more than three children.

The most frequent age range for the first child was 10-14 (57.1%), while the second child was most frequently in the 5-9 age range (50.0%). For the third child, most were also in the 5-9 age range (42.9%). The first and second children were mostly male

(71.4%; 63.2%), while the third child was most frequently female (57.1%). The first child was most frequently diagnosed with autism (78.6%), while the second child's development was most frequently typical (69.2%). Every third child had typical development. Table 1 shows all frequencies and percentages for parental characteristics. Tables 2 to 4 show all frequencies and percentages for child characteristics.

Table 1

Frequencies and Percentages of Parental Characteristics

Variable	n	%
Parent 1		
Age		
35-44	11	52.4
45-54	7	33.3
55-64	3	14.3
Gender		
Male	5	23.8
Female	16	76.2
Parent 2		
Age		
35-44	9	42.9
45-54	12	57.1
55-64	0	0.0
Gender		
Male	13	61.9
Female	8	38.1
Ethnicity		
White	20	95.2
Two or more races/ethnicities	1	4.8

Table 2

Frequencies and Percentages of First Child Characteristics

Variable	n	%
Age		
1-4	0	0.0
5-9	5	23.8
10-14	12	57.1
15-19	2	9.5
Over 19	2	9.5
Gender		
Male	15	71.4
Female	6	28.6
Development		
Typical	3	21.4
Diagnosed with autism	11	78.6

Table 3

Frequencies and Percentages of Second Child Characteristics

Variable	n	%
Age		
1-4	1	5.0
5-9	10	50.0
10-14	7	35.0
15-19	1	5.0
Over 19	1	5.0
Gender		
Male	12	63.2
Female	7	36.8
Development		
Typical	9	69.2
Diagnosed with Autism	4	30.8

Table 4

Frequencies and Percentages of Third Child Characteristics

Child 3		
Age		
1-4	2	28.6
5-9	3	42.9
10-14	2	28.6
15-19	0	0.0
Over 19	0	0.0
Gender		
Male	3	42.9
Female	4	57.1
Development		
Typical	4	100.0
Diagnosed with Autism	0	0.0

Detailed Analysis

I tested the following hypotheses:

Null hypothesis (H_o): There is no relationship between the level of problem behavior exhibited by a child with autism and the level of primary caregiver parenting stress.

Alternate Hypothesis (H_a): There is a relationship between the level of problem behavior exhibited by a child with autism and the level of primary caregiver parenting stress.

In order to examine the relationship between problem behavior and primary caregiver parenting stress, I performed a Pearson correlation and a simple linear regression. The correlation between problem behavior and maternal parenting stress was not significant ($r = 0.09$, $p = .689$), suggesting that for this sample, problem behavior and primary caregiver parenting stress were not related. Thus, the null hypothesis could not be rejected, and it did not make sense to perform the linear regression.

Summary

In this chapter, I described the challenges I faced in recruiting participants that warranted a change to the original study and reported the results of the final data analysis. The results indicated that for this sample, there was no statistically significant relationship between problem behaviors and parenting stress. In the following chapter, I discuss these results in terms of the existing literature, address the limitations of the study will be addressed, and identify future directions for research.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of my study was to explore the relationship between the level of problem behavior of a child with autism and problem behavior a typically-developing sibling when these variables were moderated by maternal parenting stress. Specifically, these variables were to be investigated in two-parent households. Previous researchers have consistently suggested that parents—particularly mothers—of children with autism experience significantly greater levels of parenting stress than mothers of children with other disabilities and mothers of typically developing children. Researchers have also yielded a significant relationship between increased levels of problem behavior in a child with autism and increased levels of parenting stress (Dabrowski & Pisula, 2010; Estes et al., 2009; Lee et al., 2009; Osborne & Reed, 2009; Phetrasuwan & Miles, 2009). The familial implications of maternal parenting stress in relation to problem behaviors of both a child with autism and a typically-developing sibling when taking into consideration the perspective of a secondary caregiver is less understood.

In this chapter, I review the challenges I faced while recruiting participants, explain how these challenges impacted the course of the study including revisions to the proposed hypotheses and analyses, and discuss the subsequent results. I also address the limitations of my study, implications for social change, and future recommendations.

Summary and Interpretation of Findings

In the initial attempt to recruit participants for the original study, I requested and was granted permission to post an invitation to participate from NSASA, an online

Yahoo! group and local chapter of the Autism Society of America that serves over 1900 families of children with autism on Long Island, New York. During the two months of recruitment, approximately two dozen participants responded to the invitation. Because of this slow rate of response, Walden University's IRB granted a change in procedures to expand the sampling pool to request permission to recruit from five additional sources (schools, support groups, etc.) that provide services to families of children with autism. Of these five sources, two granted permission. The first was a private school that agreed to publish the invitation in its monthly newsletter, and the second was another online resource/support group that agreed to post the invitation to its private Facebook page. Only a handful of additional participants were recruited from these additional sources; thus, I requested and was granted a second change in procedures to expand the recruitment to public post-sharing of the invitation to social media (Facebook). Following this final change in recruitment, responses to the invitation to participate in this study increased and the remainder of the 68 participants in the initial sample population was obtained.

Initial data clean-up eliminated a majority (59 participants) of the sample obtained because of the lack of secondary caregiver participation. Data obtained from the remaining nine pairs of participants would not have been sufficient to address the research questions as originally proposed; thus, I revised the research questions so that I could use data obtained from 21 of the originally omitted 59 participants who provided information about the level of primary caregiver parenting stress (dependent variable) and level of problem behavior for the child with autism (independent variable). As both of these variables were addressed solely from the primary caregiver perspective rather than incorporating the perspective of a secondary caregiver as originally intended, I modified the analyses to run a correlation and simple linear regression, which only requires two variables instead of the three that were required for the originally proposed multiple linear regression. I selected these particular analyses in order to first determine if a relationship existed between the variables, and then to better describe the relationship in terms of the independent variable's predictive quality. The hypotheses about these remaining variables were revised as follows:

Null hypothesis (H_o): There is no relationship between the level of problem behavior exhibited by a child with autism and the level of primary caregiver parenting stress.

Alternate Hypothesis (H_a): There is a relationship between the level of problem behavior exhibited by a child with autism and the level of primary caregiver parenting stress.

Based upon the previous studies discussed in the literature review (Tomanik et al. 2004; Phetrasuwan & Miles, 2009), I expected that I would find a relationship between problem behavior of a child with autism and primary caregiver parenting stress. However, in contrast to the findings in earlier research, this study did not yield a significant relationship between these variables, indicating that, in this particular sample, primary caregivers whose children with autism exhibited increased levels of problem behavior did not necessarily also report increased levels of parenting stress. The correlation coefficient indicates that a very weak relationship existed between these variables.

There are several hypotheses as to why no significant relationship was found between the variables. First, I specifically recruited families with two parental figures. It may be that the active participation of a secondary caregiver reduces some of the stress experienced by primary caregivers. Malik and Irshad (2012) compared the depression, anxiety, and stress levels of single parents to that of two-parent families and found that single parents yielded higher scores in each of these domains. The researchers noted that single parents often carry the burden of "dual responsibility" (Malik & Irshad, 2012, p.10) with fewer resources and less support, while parents in a two-parent household are more likely to have access to additional financial and social support as well as someone with whom to share the parental responsibilities. It is possible that the primary caregivers who participated in my study experience less parenting stress because of their partnership with a secondary caregiver and the advantages this affords them.

Second, participant access to services, supports, and resources for their children with autism may also be a factor in the stress levels that were reported. Because I recruited participants from local special education programs and organizations that provide support for families of children with autism, caregivers who participated may already be benefitting from the education and services that they and their children receive from these schools and/or organizations, thus lowering their reported levels of parenting stress. As I reported in Chapter 2, Zuckerman et al. (2014) noted the impact of health care and financial burdens on parents of children with autism, as these factors relate to accessing services. Vohra, Madhava, Sambamoorthi, and St. Peter (2014) also found similar stressors, and determined that parents of children with autism were more likely to have a negative experience and report dissatisfaction in use of services, collaboration with care/support providers, and overall family impact of services when compared to parents of children with other developmental disabilities and mental health conditions. However, parents in the current study were informed of the opportunity to participate via their special education program or support group from which they were receiving services for their child, which may have contributed to lower rates of parenting stress.

Third, and perhaps most likely, experimental mortality may have contributed to the lack of relationship found between the variables. Herger (2010) noted that despite the advantages that web-based research offers, the challenge of attrition (participant drop-out) is prevalent and raises concerns about the representative value of the sample and generalizability of results. As I discussed in Chapter 4, only 21 out of the 68 respondents completed the required surveys in full, thus eliminating almost 70% of the original recruited participants. Zhou and Fishbach (2016) warned that high rates of attrition could result in researchers drawing false conclusions, especially if the attrition was “condition-dependent” (p. 498). For example, caregivers who were experiencing high levels of parenting stress may have been less likely to complete the requirements of the study due to feeling overwhelmed by the very stressors that I was seeking to investigate. Although the reasons for incomplete participation are unknown, the rate of attrition in this study may have yielded a final sample size that was simply not representative enough or too small to detect a relationship between the variables, resulting in inaccurate information about the population of interest.

Implications for Social Change and Recommendations for Action

I conducted this study to produce findings that would be usable for those looking to provide more comprehensive supports for families of children with autism. I sought to contribute a greater scholarly understanding of the familial experience, which could be used to inform treatments that more appropriately suit the needs of the family. Such treatments would be conducive to the functionality of all members within the family unit so that all can participate and be a beneficiary of the treatment, thereby promoting a cycle of decreased parenting stress, reduced problem behaviors of typically-developing siblings, and improved treatment outcomes for children with autism. However, as discussed in the previous chapter, I revised the analyses based on available data, and subsequently explored the relationship between primary caregiver parenting stress and problem behavior of a child with autism exclusively. Although I found no significant relationship between these two variables in the sample of this study, the implications for social change of this type of research should not be ignored.

One of the social change implications of this type of research is that it sheds light on how autism affects 1 in 88 families, rather than simply 1 in 88 children. That is, studies like this show the familial impact of having a child with autism, and how the disorder affects the parents, siblings, and other household members of an individual who is diagnosed with autism. Having this more comprehensive understanding may help inform therapists, clinicians, and other professionals how to best treat a child with autism as a member of a larger unit, and thus provide support to the family as well. Individuals don’t live in a vacuum, and the needs of a child with autism transcend that individual into the inter-dependent familial context.

Another social change implication of this type of research is that clinicians and professionals working with families of children with autism can use its findings to tailor treatments and supports in ways that are conducive to the abilities and limits of the household so that all family members can take an active part in helping the child with autism, benefitting not only the child but also the other family members. Sharing the responsibility and challenges of among family members may help to alleviate some of the maternal/primary caregiver parenting stress associated with raising a child with autism that have been documented in previous studies, thus enhancing not only the parenting experience but also the familial experience as a whole.

A third social change implication of this research stems from consideration of the challenges and stressors of parents and siblings of children with autism. In addressing these factors, parents and siblings may be more apt to effectively address the needs of the diagnosed child. Overall, better supports for parents and siblings can lead to better supports for children with autism, benefitting the entire familial unit and yielding improved treatment outcomes.

Future researchers seeking to activate these social change implications via research addressing caregiver stress and problem behaviors of children, both those with autism and their typically-developing siblings, should take into consideration the limitations of this study. These limitations and future recommendations will be discussed in the next section.

Limitations and Future Recommendations

There are several limitations of the current study that must be noted. These limitations may have contributed to the non-significant results found in exploring the relationship between the variables of interest and can serve to inform how future researchers seeking to investigate similar variables should address the research questions in a more effective manner.

Parental Figures

My study depended on the participation of two parental figures (caregivers), a primary and a secondary. This characteristic specifically can be difficult to find in families of children with autism. Hartley et al. (2010) compared the divorce rate in almost 400 parents of children with autism to that of a matched sample of parents raising typically-developing children and found that parents of children with autism had a higher occurrence of divorce. Although I took this into consideration when determining participant parameters by specifying that a secondary caregiver could be any other adult (relative, nanny, etc.) who lived in the household and participated in the daily caretaking of the child, the demographics of the current sample suggest that most of the paired data came from sets of one female primary caregiver (presumably a mother) and one male secondary caregiver (presumably a father). As my proposal was presented to potential participants as seeking the participation of "two-parent households," this characteristic may have limited the potential size of the sample. Future researchers should seek to recruit “caregivers” rather than “parents” and be more explanatory about who is eligible to participate so as to communicate to potential participants that participation is not limited to the traditional mother/father family dynamic.

Internet Access and Participant Independence.

My study depended upon the participants having access to the internet. In a time where the internet has dominated much of our communication, networking, and gathering of information (Busby & Yoshida, 2015), it was anticipated that the use of online recruitment and administration of surveys would be of benefit to my study, taking advantage of the assistance that the internet can offer in terms of recruiting a large and diverse sample population and improving the efficiency with which data is collected (Gosling & Mason, 2015), however it is possible that access to the internet served as a limitation. Busby and Yoshida (2015) noted that one of the biggest critiques of internet research is the omission of potential participants who could offer valuable information, exemplifying a limitation of my study whose recruitment method excluded participants who didn’t have access to a computer or internet access in general.

My study also depended upon participants completing their surveys independently. Primary and secondary careers had to access their individual surveys separately via the link provided to them. A majority of the participants that comprised the sample failed to complete all the required parts, contributing to the experimental mortality of the sample and requiring a revision of the variables and analyses utilized. There are a number of factors that may have hindered participants from completing their surveys. Ramsey, Thompson, McKenzie, and Rosenbaum (2015) stated that unlike traditional studies in which participants may be supervised or observed to ensure that they remain focused during data collection, the attention of online participants to the survey they are completing may be competing with any number of distractions. In my study, primary respondents were expected to respond to two different surveys, one about themselves and one about their child with autism, while secondary respondents were expected to log on separately and answer a survey about a typically-developing child. If distractions in the household were high, it is possible that participants were forced to multi-task while trying to complete their surveys or that participants never returned to the surveys upon interruption. Future researchers should seek to streamline the participation process by perhaps allowing for both caregivers to complete their surveys consecutively or simultaneously, making participation more efficient.

Monetary Incentives

Future researchers may also want to consider offering a motivating incentive to encourage participants to complete the requirements, which may be delivered after participation of both caregivers is achieved. There are a variety of ways that incentives can be utilized in online research, including monetary compensation. Busby and Yoshida (2015) explored the use of different monetary incentives in online research for couples and families, seeking to determine if “different types of monetary incentives improve response rates to internet research requests” (p. 507). Inviting over 2,000 individuals to participate in a study and dividing them into 6 groups, each of whom were offered a different level of monetary incentive (no incentive, every participant receiving $20, one out of every 50 participants randomly receiving $100, one out of every 100 participants receiving $100, one out of 200 participants receiving $100, and one out of 300 participants receiving $100), they found that a 1 out of 50 chance at receiving $100 were more most likely to respond to the study (Busby & Yoshida, 2015). This group was two times more likely to respond than the participants being given $20 each, which is promising in terms of keeping the strategy of using monetary incentives cost efficient for researchers (Busby & Yoshida, 2015). However, it is interesting to note that even with an incentive like this, there was a response rate of 10% with almost half of the initial participants being omitted due to invalid email addresses and, thus, no way to gather information from them (Busby & Yoshida, 2015). This issue of low response rate is consistent with the recruitment limitation of my study and speaks to the challenges that online researchers continue to face (Busby & Yoshida, 2015).

Geographic Diversity

For my study, I drew a sample of participants from a population within a specific geographic location. As I recruited families from local organizations and support groups that provide services to children with autism within two particular counties of New York State, the regional boundaries of the sampling procedure is another limitation of my study, especially in terms of the ethnic makeup of my sample. Additionally, as discussed earlier in this chapter, only caregivers of children with autism receiving services or support from their children's schools or other autism organization (i.e., a support group) were informed of the opportunity to participate in my study. Future researchers should seek to recruit with less restrictive and subsequently more diverse geographic parameters which may produce a sample whose demographics and experience is more representative of the population of families of children with autism as a whole.

There are a number of larger organizations from which a more geographically and ethnically diverse sample population can be recruited. For example, the Autism Society of America (ASA), founded in 1965, is an organization that provides information on resources and services to over 120,000 members across the United States (Autism Society, 2016). Rather than limiting recruitment to the local Nassau-Suffolk chapter of the ASA, future researchers with more resources may be more successful in recruiting from this national pool of families of children with autism. Similarly, the National Autism Association, founded in 2003, advocates for the urgent needs children with autism and their families, reaching 25,000 members across the country via email and over one million members via social media (National Autism Association, 2017). They, too, may have the ability to provide access to a more representative sample for the population of interest. Autism Speaks is another large organization that devotes its resources to advocacy, treatment, and awareness of autism across the Unites States and Canada. Very active in autism science as well, Autism Speaks funds research through grants and fellowships around the world (Autism Speaks, 2017). Future researchers may benefit from the research resources that Autism Speaks has to offer.

Conclusion

In conclusion, in this study, I sought to fill a gap in research regarding the familial systemic experience of raising a child with autism while considering the perspective of a secondary caregiver. This research was based upon prior studies that established a relationship between problem behaviors of a child with autism and maternal parenting stress as well as research that explored the interactional effects between children with autism and their siblings. Based on the review of previous literature, I identified the need for more a comprehensive understanding of the familial experience of raising a child with autism was; however, the challenges in recruitment of participants in my study warranted a change in both the variables examined and the analyses utilized. My study explored the relationship between problem behavior of a child with autism and primary caregiver parenting stress specifically within a two-parent household, and I implemented a bivariate correlation. Although my study failed to find a significant relationship between the variables in my sample, future researchers shouldn’t dismiss the potential for significance nor the implications for social change that my original study can offer when the limitations that I acknowledged are accounted for. My study offers value to future researchers seeking to fill the identified gap in literature by highlighting the challenges that may arise in seeking the secondary caregiver perspective and recommending how these challenges may best be proactively addressed to achieve significant results.

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Appendix A: Invitation to Participate in Research

Dear Parent/Guardian:

You are invited to take part in a research study about parenting stress and sibling problem behavior in families of children with autism. The purpose of this study is to explore how maternal parenting stress impacts the relationship between problem behavior of a child with autism and problem behavior of a typically-developing sibling in an effort to support the need for more comprehensive supports and treatments for not only children with autism but their families as well.

Families with two parental figures (may be two parents or one parent and other guardian/caretaker/adult relative),one child with autism under the age of 16, and at least one typically-developing sibling under the age of 16 residing in the household meet criteria to be in this study. *Please Note: This study requires that both the primary and secondary parent participate.*

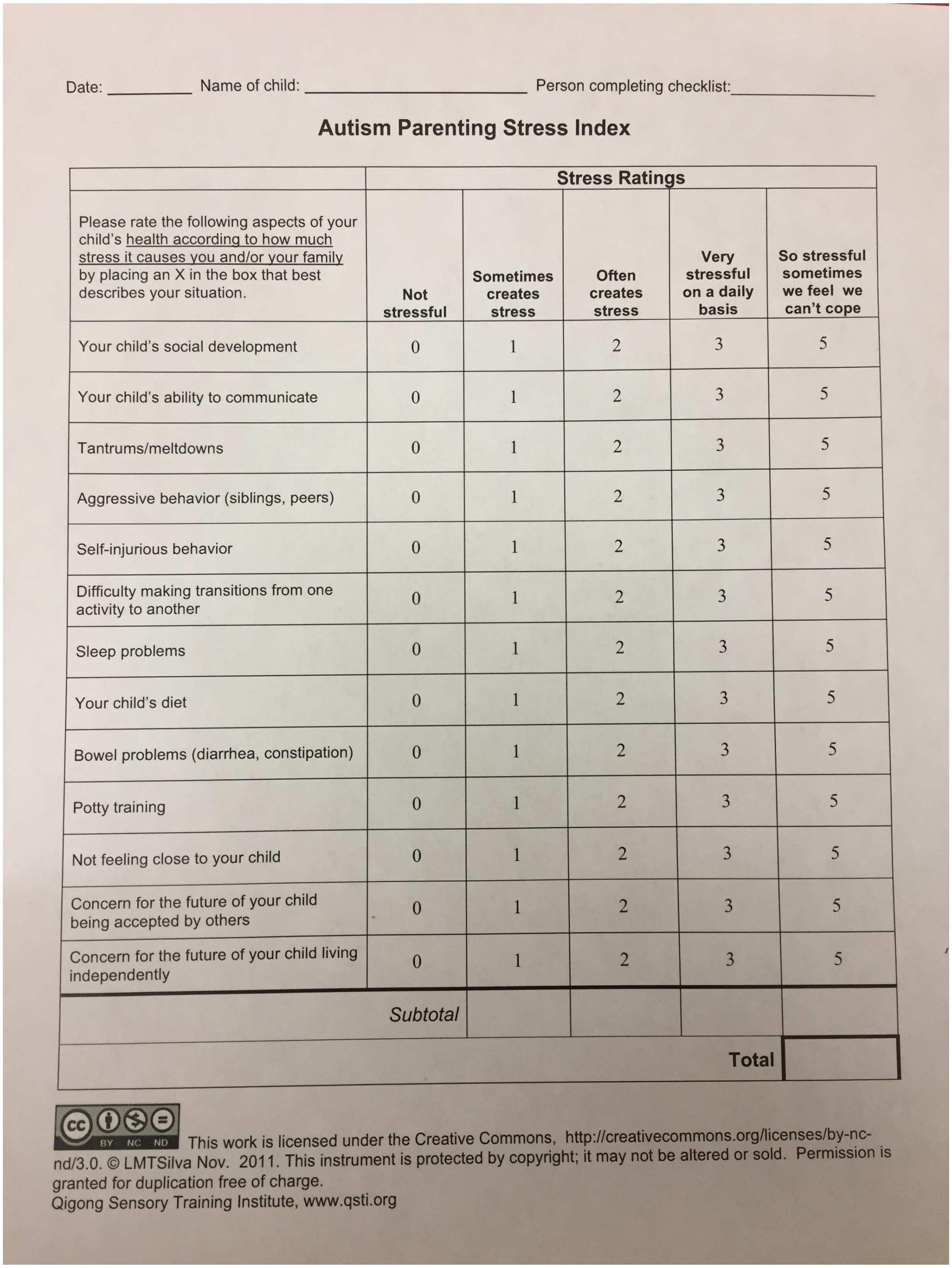
If you are a parent or guardian of a child with autism whose family meets these criteria and would like to know more about this research study, please click on the link below. Any questions or concerns about the study or participation may be directed to Jennifer.torchetti@waldenu.edu.

Thank you in advance for your time and participation,

Sincerely,
Jennifer Torchetti
Ph.D. candidate, Walden University

https://www.surveymonkey.com/r/3GTC587

Appendix B: Autism Parenting Stress Index



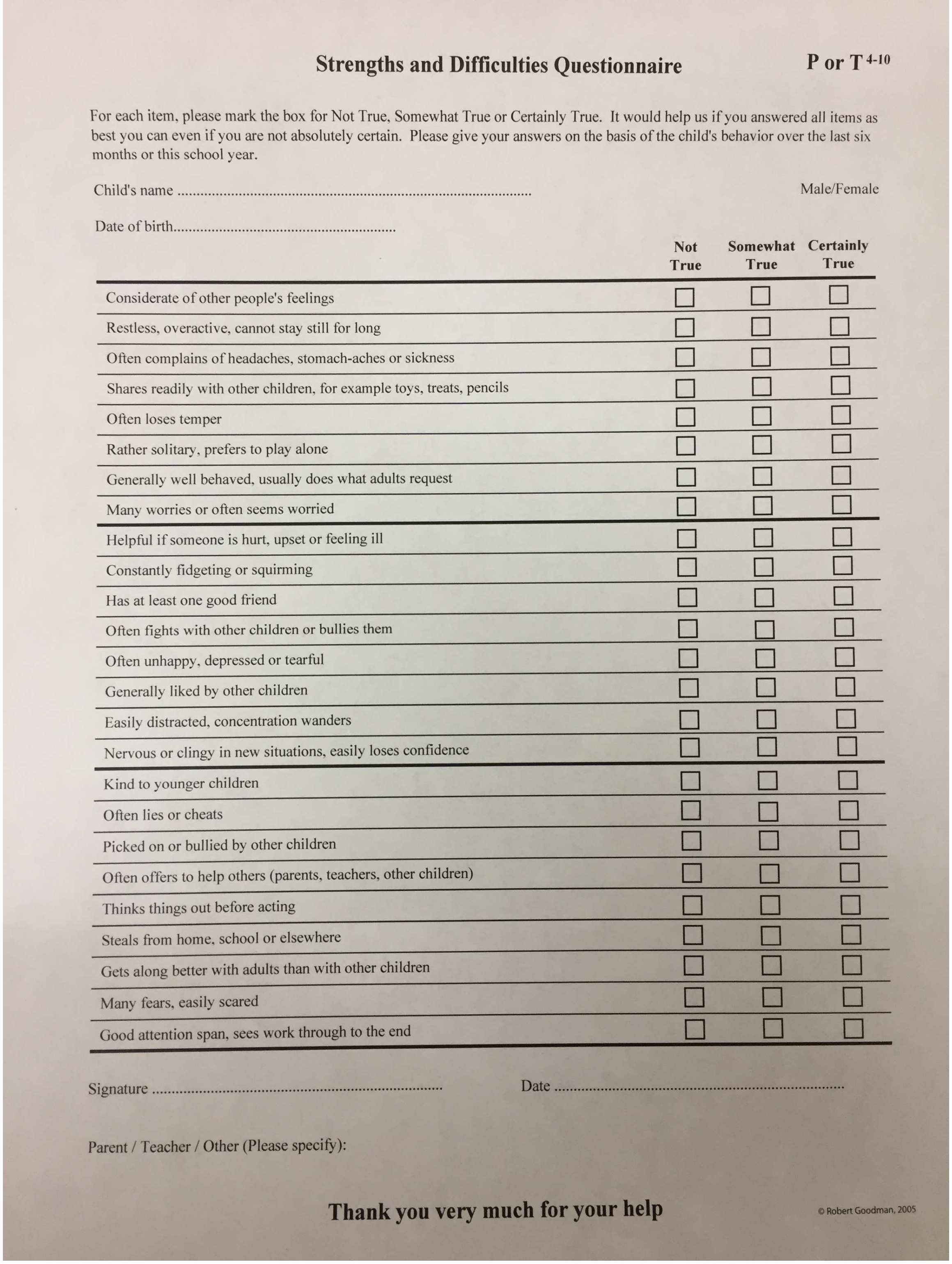
Date: __________ Name of child: ____________________________ Person completing checklist:__________________

Autism Parenting Stress Index

	Stress Ratings				
Please rate the following aspects of your child's health according to how much stress it causes you and/or your family by placing an X in the box that best describes your situation.	**Not stressful**	**Sometimes creates stress**	**Often creates stress**	**Very stressful on a daily basis**	**So stressful sometimes we feel we can't cope**
Your child's social development	0	1	2	3	5
Your child's ability to communicate	0	1	2	3	5
Tantrums/meltdowns	0	1	2	3	5
Aggressive behavior (siblings, peers)	0	1	2	3	5
Self-injurious behavior	0	1	2	3	5
Difficulty making transitions from one activity to another	0	1	2	3	5
Sleep problems	0	1	2	3	5
Your child's diet	0	1	2	3	5
Bowel problems (diarrhea, constipation)	0	1	2	3	5
Potty training	0	1	2	3	5
Not feeling close to your child	0	1	2	3	5
Concern for the future of your child being accepted by others	0	1	2	3	5
Concern for the future of your child living independently	0	1	2	3	5
Subtotal					
				Total	

Qigong Sensory Training Institute, www.qsti.org

Appendix C: Strengths and Difficulties Questionnaire



Strengths and Difficulties Questionnaire

P or T 4-10

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of the child's behavior over the last six months or this school year.

Child's name .... Male/Female

Date of birth..

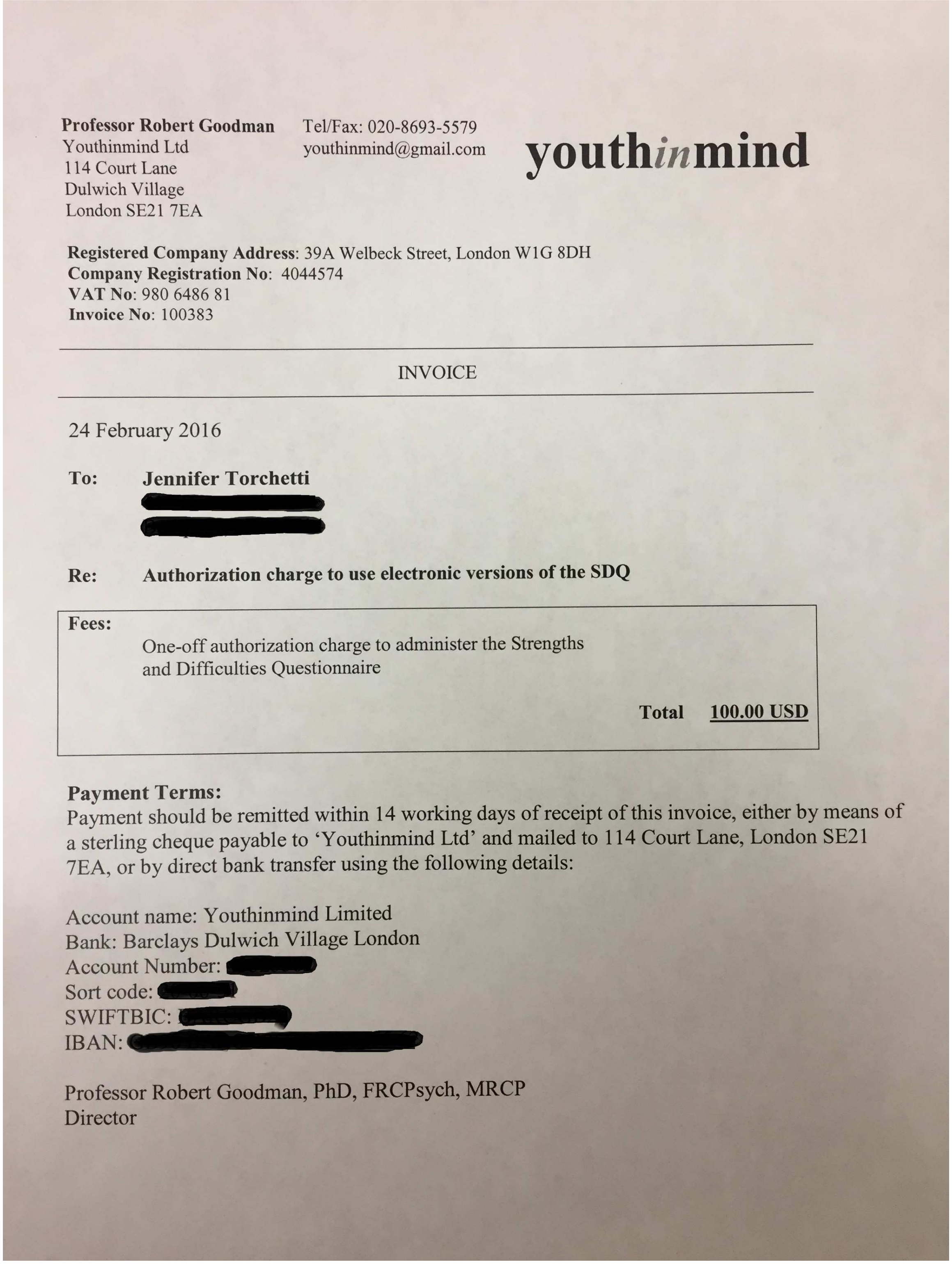
	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	☐	☐	☐
Restless, overactive, cannot stay still for long	☐	☐	☐
Often complains of headaches, stomach-aches or sickness	☐	☐	☐
Shares readily with other children, for example toys, treats, pencils	☐	☐	☐
Often loses temper	☐	☐	☐
Rather solitary, prefers to play alone	☐	☐	☐
Generally well behaved, usually does what adults request	☐	☐	☐
Many worries or often seems worried	☐	☐	☐
Helpful if someone is hurt, upset or feeling ill	☐	☐	☐
Constantly fidgeting or squirming	☐	☐	☐
Has at least one good friend	☐	☐	☐
Often fights with other children or bullies them	☐	☐	☐
Often unhappy, depressed or tearful	☐	☐	☐
Generally liked by other children	☐	☐	☐
Easily distracted, concentration wanders	☐	☐	☐
Nervous or clingy in new situations, easily loses confidence	☐	☐	☐
Kind to younger children	☐	☐	☐
Often lies or cheats	☐	☐	☐
Picked on or bullied by other children	☐	☐	☐
Often offers to help others (parents, teachers, other children)	☐	☐	☐
Thinks things out before acting	☐	☐	☐
Steals from home, school or elsewhere	☐	☐	☐
Gets along better with adults than with other children	☐	☐	☐
Many fears, easily scared	☐	☐	☐
Good attention span, sees work through to the end	☐	☐	☐

Signature .... Date ....

Parent / Teacher / Other (Please specify):

Thank you very much for your help

Appendix D: Authorization to Administer Strengths and Difficulties Questionnaire



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Company Registration No: 4044574
VAT No: 980 6486 81

Invoice No: 100383

INVOICE

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24 February 2016

To: **Jennifer Torchetti**
[redacted]

Re: **Authorization charge to use electronic versions of the SDQ**

Fees:
One-off authorization charge to administer the Strengths and Difficulties Questionnaire

Total **100.00 USD**

Payment Terms:
Payment should be remitted within 14 working days of receipt of this invoice, either by means of a sterling cheque payable to 'Youthinmind Ltd' and mailed to 114 Court Lane, London SE21 7EA, or by direct bank transfer using the following details:

Account name: Youthinmind Limited
Bank: Barclays Dulwich Village London
Account Number: [redacted]
Sort code: [redacted]
SWIFTBIC: [redacted]
IBAN: [redacted]

Professor Robert Goodman, PhD, FRCPsych, MRCP
Director