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Problem and Adaptive Behavior Levels in Children with Autism Spectrum Disorders as Predictors of Sibling Adjustment

Hallie Solarsh

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PROBLEM AND ADAPTIVE BEHAVIOR LEVELS IN CHILDREN WITH AUTISM SPECTRUM DISORDERS AS PREDICTORS OF SIBLING ADJUSTMENT

by

HALLIE M. SOLARSH

A dissertation submitted to the Graduate Faculty in Educational Psychology in partial fulfillment for the degree of Doctor of Philosophy, The City University of New York 2016
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THE CITY UNIVERSITY OF NEW YORK
Abstract

PROBLEM AND ADAPTIVE BEHAVIOR LEVELS IN CHILDREN WITH AUTISM SPECTRUM DISORDERS AS PREDICTORS OF SIBLING ADJUSTMENT

by

Hallie M. Solarsh

Advisor: Professor Marian C. Fish

The purpose of this study was to investigate the relationships among adaptive and problem behaviors in children with autism spectrum disorders (ASDs) and stress, personal adjustment and behavior of typically developing siblings. The participants were 53 sets of parents and typically developing siblings of children with ASDs, recruited from the tri-state New York area. The siblings were between the ages of 8-18 years. Parent participants completed three questionnaires including: 1) The Nisonger Parent Behavior Rating Form, 2) The Vineland Adaptive Behavior Scale-Second Edition, and 3) The Behavior Assessment System for Children-Second Edition, Parent Report. Typically developing siblings completed 1) The Behavior Assessment System for Children-Second Edition, Self-Report, and 2) The Sibling Stress Index. After completing the measures, each participating family was given a $10 gift card.

The results of this study indicated that higher levels of problem behavior in children with ASDs were associated with higher stress ratings in typically developing siblings. While overall adaptive behavior levels in children with ASDs were not associated with sibling outcomes in this
sample, the results revealed a significant relationship between socialization and communication skills in diagnosed children and specific sibling outcomes. Typically developing siblings reported higher levels of stress when their diagnosed sibling had weaker socialization skills. Personal adjustment in typically developing siblings increased as communication skills in diagnosed siblings increased.
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I would like to dedicate this dissertation to my sister, Emily Solarsh. You have enriched my life in so many ways, and although our relationship may be different than the one most sisters
share, I would not trade it for anything. I love you more than I can fully express, and I am here for you always.
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Chapter 1

Introduction

The prevalence of individuals with autism spectrum disorders (ASDs) has increased dramatically over the past decade (Centers for Disease Control and Prevention, 2012). Individuals with ASDs fall along a continuum that represents a wide range of functioning. Prior to the publication of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) in mid 2013, ASDs included disorders such as autism, Asperger’s Syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Although individuals with ASDs may vary in their level of functioning and present very differently from one another, they all exhibit, “severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests and activities” (American Psychiatric Association, 2000). These impairments affect the way individuals with ASDs interact with other people in the environment, including their family members.

Due to the increased prevalence of ASDs, the number of parents and siblings of children with an ASD diagnosis has increased as well. Many researchers have conducted studies on the psychosocial adjustment of siblings of children with ASDs in an effort to identify risk factors and determine the effects of growing up with a brother or sister with an ASD diagnosis. The current research on the impact children with ASDs have on non-disabled siblings is conflicting. One group of studies suggests that children with ASDs can have negative effects on their typically developing siblings (Bagenholm & Gillberg, 1991; Fisman et al, 2000; Gold, 1993; Petalas et al, 2009; Rodrigue, Geffken & Morgan, 1993; Ross & Cuskelly, 2006; Verte, Roeyers & Buysse, 2003), while another group of studies suggests that children with ASD can have either
a positive impact or no impact on their typically developing siblings (Hastings, 2003b, 2007; Kaminsky & Dewey, 2002; Pilowsky et al, 2004).

The inconsistency in the research results may partially be explained by closely examining the methodology of these studies. Most of the researchers who conducted these studies used parent reports to obtain information about the siblings’ psychosocial adjustment. These researchers relied on the parents’ observations of the siblings, and did not obtain information from the siblings themselves with regard to behavior. In addition, while all of the researchers looked at siblings of children on the autism spectrum, some researchers only included siblings of children with a diagnosis of autism in their studies (Bagenholm & Gillberg, 1991; Hastings, 2003a, 2003b, 2007; Kaminsky & Dewey, 2001, 2002; Pilowsky, 2004; Rodgrigue, Gefiiken & Morgan, 1993), while others looked at siblings of children with Asperger’s Sydrome (Ross & Cuskelley, 2006), high functioning autism (Verte, Roeyers & Buysse, 2003) and Pervasive Developmental Disorder (Fisman et al, 2000). This is an important factor, as it is possible that sibling outcomes may vary depending on the type of ASD diagnosis. It is also possible that specific behaviors in children with ASD are more likely to be associated with positive or negative sibling outcomes. All of the prior research was conducted using the diagnostic criteria outlined in the DSM-IV-TR (American Psychiatric Association, 2000).

A recent review of the literature on siblings of children with ASD highlights another important methodological issue: small sample size. Most of the researchers who have studied siblings of children with ASD have used between 20 and 50 participants (Fisman et al, 2000; Hastings, 2003a, 2007; Kaminsky & Dewey 2002; Macks & Reeve, 2007; Petalas et al, 2009; Pilowsky et al, 2004; Ross & Cuskelley, 2006; Verte, Roeyers & Buysse, 2003). These small sample sizes limit the generalization of research results and pose validity threats.
A review of the research on parents of children with ASDs suggests that sibling researchers may gain a clearer understanding of sibling outcomes by focusing on behaviors in children with ASDs, rather than diagnostic criteria. The research on parents indicates that maladaptive or problem behavior in children with ASD is associated with parental stress (Benson 2010; Herring et al, 2006; Konstantares & Homatidis 1989; Lecavalier, Leone & Wiltz, 2006). The research also suggests that weak adaptive behavior skills in this population may contribute to parental stress (Tomanik, Harris & Hawkins, 2004). To date, there is no research on whether problem behavior or adaptive behavior levels in children with ASD has an impact on siblings.

A useful theoretical framework to examine the interrelationships among family members is a family systems model. The family systems model helps researchers better understand the family context within which siblings of children with ASD grow, and the different family factors that can impact them (Bronfenbrenner, 1979). The theory also helps explain how families function and react in response to stressors. A systems approach postulates that the presence of a child with a disability is considered a family stressor; the child affects and is affected by family functioning (Turnbull & Turnbull, 2001).

There are a number of important family factors, unique to families of children with disabilities, that need to be considered by researchers. Seligman and Darling (2007) state that families of children with disabilities can be affected by five types of stress: intellectual, instrumental, emotional, interpersonal and existential. These types of stress, especially emotional and interpersonal stress, can directly or indirectly impact typically developing siblings. Other factors within the family such as communication, caregiving responsibilities, information sharing and thoughts about the future can also affect siblings of children with special needs.
After identifying a gap in the sibling literature, an exploratory pilot study was conducted to explore the relationships between problem and adaptive behavior levels in children with ASD, parental stress and sibling behaviors. The pilot study addressed some of the methodological issues that were brought to light in the review of the sibling literature. The participants included 11 siblings and parents of children with diagnoses across the autism spectrum, and both parent and self-report forms were used to obtain information about the siblings’ levels of internalizing and externalizing behaviors. The study focused on problem and adaptive behaviors, as the research on parents of children with ASDs indicates that these variables are associated with increased parental stress. Given the effects that children with ASD diagnoses can have on the entire family, the relationship between parental stress and sibling behavior was explored.

The results of the pilot study indicated that higher levels of problem behaviors in the children with ASD were associated with elevated levels of stress in parents. The correlation between low adaptive behavior levels in children with ASD and increased levels of parental was just below the threshold for statistical significance. Contrary to the hypotheses, siblings’ internalizing and externalizing behavior levels were not found to be associated with high levels of problem behavior or low levels of adaptive behavior in diagnosed siblings.

It is possible that the initial hypotheses in the pilot study were not confirmed due to the very small sample size. An in-depth analysis of the measures used in the study suggest that in addition to using a measure of internalizing and externalizing behavior, this research should include a measure of sibling stress.

The current study was designed to look at the relationships between adaptive and problem behaviors in children with ASD and stress, personal adjustment and behavior of typically developing siblings. The study addresses the following research questions:
1. Are problem behavior levels in children with autism spectrum disorders associated with personal adjustment, stress and internalizing and externalizing behaviors in typically developing siblings?

2. Are adaptive behavior levels in children with autism spectrum disorders associated with personal adjustment, stress and internalizing externalizing behaviors in typically developing siblings?

The participants in this study included parents and typically developing siblings of children with ASD. The siblings were all between ages of eight and eighteen. Questionnaire packets were mailed to the participants. The parents completed a demographic questionnaire, the Nisonger Child Behavior Rating Form, the Vineland-II Adaptive Behavior Scale and the Behavior Assessment System for Children-Second Edition, Parent Report. The typically developing siblings completed the Behavior Assessment System for Children-Second Edition, Self-Report and the Sibling Stress Index.

The results of this study indicate that higher levels of problem behavior in individuals with ASDs were associated with higher stress ratings in typically developing siblings. This is consistent with the research on parents of children with ASDs. While overall adaptive behavior levels in individuals with ASDs were not associated with sibling outcomes in this sample, the results indicated that sibling outcomes were associated with socialization and communication skills in diagnosed children. Typically developing siblings reported higher levels of stress when their diagnosed sibling had weaker socialization skills. Personal adjustment in typically developing siblings increased as communication skills in diagnosed siblings increased.

It is critical for school psychologists and other professionals in the field to have a better understanding of the impact that children with autism have on their typically developing siblings.
This sibling group is growing as more children are diagnosed with ASDs. It is important to be aware if these children are at-risk for developing internalizing or externalizing behavior problems or experiencing high levels of stress, so that appropriate interventions can be formulated. Professionals should be mindful of the study results, as they highlight factors that can affect sibling outcomes, and suggest interventions and supports that may be beneficial.
Chapter 2

Literature Review

This chapter begins with an overview of the diagnostic criteria for ASDs from both the DSM-IV-TR and the DSM-V. This is followed by a review of the existing literature on typically developing siblings of children with ASDs. One group of sibling studies suggests that typically developing siblings of children with ASDs are negatively affected, while another group of studies suggests that there is no impact, or there is a positive impact. The inconsistency in the sibling research may be due to methodological issues. These issues are presented and discussed.

In the second half of the chapter, the research on parents of children with ASDs is presented. This research indicates that problem behavior and adaptive behavior in children with ASDs are both related to parental stress. A summary of family systems theory is also presented. This theoretical framework is helpful in understanding the structure and needs of families of children with ASDs.

The results from an exploratory pilot study are presented in the last section of this chapter. These results, in conjunction with the methodological issues identified in the prior research, are used to explain the rationale for the current study.

Overview of Autism Spectrum Disorders

Autism spectrum disorders or pervasive developmental disorders, lie along a continuum or spectrum. Until the recent publication of the DSM-V, the diagnosed disorders that fell along this continuum were autism, Asperger’s Syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Other, less prevalent disorders that fell along the spectrum include Childhood Disintegrative Disorder and Rett’s Disorder. The DSM-IV-TR (American Psychiatric Association, 2000), states that although there are specific criteria for each individual
disorder along the spectrum, they are all characterized by, “severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests and activities. The qualitative impairments that define these conditions are distinctly deviant relative to the individual’s developmental level or mental age.” The existing sibling literature is based on the DSM-IV-TR criteria.

The DSM-IV-TR indicates that the onset of autism must occur prior to age three (American Psychiatric Association, 2000). Individuals with autism are often impaired in their ability to use non-verbal and verbal behaviors to interact with those around them. They often have difficulty making eye-contact, interpreting facial expressions and understanding gestures. Children with the disorder are often observed playing by themselves and rarely seek out other children to play with. Reciprocal interactions are challenging for these individuals, and many of them have difficulty empathizing with others.

In terms of communication, many individuals with autism are delayed in their development of language skills, and some never develop the ability to communicate verbally. Those who do communicate verbally, often have difficulty engaging in reciprocal conversations and cooperative play. They may use language in a repetitive or stereotyped manner, and their ability to comprehend language is often impaired. In many cases, individuals with autism also have a comorbid diagnosis of Mental Retardation, as they exhibit deficits in cognition and adaptive behavior (American Psychiatric Association, 2000).

Finally, individuals with autism have restricted interests and often engage in repetitive or stereotyped behaviors. They may be overly focused on certain types of objects or have narrow interests. They may engage in non-functional rituals or routines, and they often have difficulty
adapting to changes in their daily schedules. Their stereotyped body movements may include rocking, swaying or hand flapping.

Individuals with Asperger’s Syndrome exhibit impaired social interactions, restricted interests and repetitive behaviors, but there are two ways in which they differ from individuals with autism (American Psychiatric Association, 2000). Whereas individuals with autism exhibit cognitive deficits and delays in language acquisition, individuals with Asperger’s Syndrome acquire language within normal limits and their cognitive skills are intact. Although individuals with Asperger’s Syndrome often have very strong verbal skills, their pragmatic or social use of language is significantly impaired.

The DSM-IV-TR provides very little information about the diagnostic criteria for PDD-NOS. It states that this diagnosis should be made if individuals do not meet criteria for a specific pervasive developmental disorder, but they present with a severe and pervasive impairment in social interactions, coupled with a deficit in verbal or non-verbal communication or with stereotyped behaviors and interests.

Although the three disorders described above all fall along the “autism spectrum,” the behaviors and impairments associated within each diagnosis vary. Even individuals with the same diagnosis can differ in terms of their communication skills, ritualistic behaviors, interests, cognitive skills and social skills.

The most recent research on the prevalence of ASD indicates that 1 in 68 children has an ASD diagnosis (Centers for Disease Control and Prevention, 2012). This estimate is based on data collected in 2010, and represents an increase in the overall prevalence of ASDs. In 2000, the prevalence estimate was one in 1 in 150, in 2006, the estimate was 1 in 110 children, and in 2008, the estimate was 1 in 88 children. The research also indicates that males are nearly five
times more likely to have a diagnosis of ASD than females. The 2008 data estimate that 1 in 42 males has an ASD diagnosis, compared to 1 in 189 females. While ASDs affect children from all racial and ethnic groups, the estimated prevalence is greater for non-Hispanic white children, than African American and Hispanic children.

With the publication of the DSM-V, the diagnoses of Autism, Asperger’s Syndrome, PDD-NOS, Childhood Disintegrative Disorder and Rett’s Disorder have been eliminated. The manual has moved away from these more narrowly defined disorders, and replaced them with one larger and broader “umbrella” disorder, Autism Spectrum Disorder (ASD). In order to receive a diagnosis of ASD, an individual must evidence “persistent deficits in social communication and social interaction across multiple contexts” (American Psychiatric Association, 2013). In addition, individuals must exhibit restricted, repetitive behaviors or interests, such as stereotypic movements and speech, difficulty adapting to changes in routines, insistence on sameness, highly restricted interests and atypical reactions to sensory stimuli in the environment.

Although all individuals with ASD behaviors now fall into the same diagnostic category, diagnosticians are asked to specify the degree of the impairment by assigning a severity level (American Psychiatric Association, 2013). Individuals with the most severe impairments are classified as “requiring very substantial support.” Individuals with moderate impairments are said to be “requiring substantial support,” while individuals who have more mild impairments are categorized as “requiring support.”

All of the existing research on siblings of children with ASDs was conducted using the DSM-IV-TR criteria, for ASDs. The current study was also conducted using this framework, and the methodology was developed prior to the release of the DSM-V. Interestingly, the current
study looks at patterns of behavior in individuals with ASDs, rather using diagnostic labels, which aligns nicely with the changes made in the DSM-V.

**Research on Siblings of Children with Autism Spectrum Disorders**

Typically developing siblings of children with ASDs are siblings who have not been diagnosed with ASD or any other developmental disability. Early research indicated that when compared to siblings of children with Down syndrome and siblings of typically developing children, siblings of children with autism had higher rates of both internalizing and externalizing behaviors (Rodrique, Geffken & Morgan; 1993). Internalizing behaviors include behaviors that are associated with anxiety, depression and somatic complaints, while externalizing behaviors include behaviors associated with hyperactivity and aggression (Achenbach & Edelbrock, 1978).

In a study that looked specifically at depression, Gold (1993) reported that when compared to controls, adolescent siblings of autistic males evidenced higher levels of depressive symptoms. Early research also found that siblings of children with autism exhibited differences in their socialization with peers and their feelings toward their disabled siblings. Bagenholm & Gillberg (1991) found that siblings of children with autism reported more feelings of loneliness and had more difficulty in their peer interactions when compared to both a control group and to children who had siblings with mental retardation. They also found that the mothers of the children with autism reported higher levels of overall familial stress when compared to mothers in the other groups.

More recent research has also highlighted differences among siblings of children with ASDs. In 2000, Fisman, Wolf, Ellison and Freeman conducted a study designed to assess initial sibling adjustment and adjustment at a 3-year follow-up in siblings ages eight to sixteen of children with Pervasive Developmental Disorder, Down Syndrome and typically developing
children. They obtained behavior ratings from the participants’ parents and teachers on the Survey Diagnostic Instrument, which was adapted from the Child Behavior Checklist. Fisman et. al., also assessed parental stress using the Parenting Stress Index. The results of the study indicated that based on parent ratings, the siblings of children with PDD had higher levels of externalizing behaviors at the time of the initial assessment and at the 3-year follow-up. The parents also indicated higher levels of internalizing behaviors at the initial assessment, but this was not maintained at the follow-up.

Based on teacher ratings, the siblings of the children with PDD exhibited higher levels of internalizing behaviors at the time of both the initial and follow-up assessment. In terms of their own stress levels, the parents of children with PDD reported higher levels of stress over the 3-year period when compared to parents in the comparison and control groups. Parental stress mediated the externalizing behaviors in siblings of children with PDD, such that it accounted for some of the variance in the relationship between having a sibling with PDD and developing high levels of externalizing behaviors.

Verte, Roeyers & Buysse (2003) found that based on parent ratings on the Child Behavior Checklist, siblings of children with high functioning autism had higher levels of internalizing and externalizing behaviors, when compared to controls. While these behaviors did not fall within the clinically significant range, the results suggest that siblings of children with an ASD may be at a greater risk for developing internalizing or externalizing disorders. Verte, Roeyers and Buysse looked at siblings between the ages of 6 and 16, but they divided this larger group into two smaller subgroups: siblings ages 6 to 11 and siblings ages 12 to 16. They found that siblings in the younger age group exhibited more internalizing and externalizing behavior problems, suggesting that siblings may be particularly vulnerable before they reach adolescence.
They also found that based on their own self-reports, sisters of children with high functioning autism in the 12 to 16 year age range reported higher levels of social competence and a more positive self-concept when compared to controls.

In a later study, Ross & Cuskelley (2006), looked at stressors and coping skills in a sample of children who had a sibling with either autism or Asperger’s syndrome. Their results indicated that based on parent reports on the Child Behavior Checklist, 40% of the participants exhibited clinically significant levels of internalizing or externalizing behaviors. Seven of the eight children who had high scores on the internalizing behavior scale, were male, and three of these same children also had clinically significant scores on the externalizing behavior scales. These results suggest that brothers of children with ASD may be at a higher risk for developing elevated levels of behavior problems. The non-disabled siblings in this study identified aggression as the most common stressor in their interactions with their siblings.

Hastings (2003a) also found that brothers of children with autism were at a greater risk of experiencing negative effects when compared to sisters of children with autism. His sample included mothers and siblings ages 4 to 16 of children with dual diagnoses of autism and mental retardation. Based on the mothers’ report on the Strengths and Difficulties Questionnaire (SDQ), the siblings were rated as having more adjustment problems than the normative sample. In addition to gender, Hastings also found an effect for birth order. Siblings who were younger than the child with autism had more adjustment problems than older siblings. Hastings also looked at maternal stress and behavior problems in the child with autism, and found that neither variable was related to adjustment problems in siblings.

In 2009, Petalas, Hastings, Nash, Lloyd and Dowey studied psychosocial adjustment in siblings of children with autism who had an intellectual disability, and siblings of children who
had an intellectual disability only. Parent ratings on the SDQ indicated that the siblings of children who had an autism diagnosis had more emotional problems than siblings of children with an intellectual disability and no autism diagnosis. The siblings of children with autism were more likely to score in the abnormal range in terms of emotional problems and prosocial behaviors. These parent ratings persisted over an 18-month period, suggesting that the behavior in siblings of children with ASD is stable over time.

Petalas et al., (2009) also looked at variables such as gender of the disabled sibling, birth order and socioeconomic status (SES). They found that siblings who had a brother with autism and an intellectual disability had higher emotional problems when compared to siblings who had a sister with the same diagnoses. Children who were younger than the child with autism also had higher emotional problems scores when compared to older siblings. Finally, they found that in lower SES families, siblings had higher total scores on the SDQ.

Kaminsky and Dewey (2001) investigated the quality of sibling relationships and sibling interactions in siblings of children with autism, Down Syndrome and typically developing siblings. The results of their study highlight differences in sibling relationships and interactions, which may play a role in sibling outcomes. Based on the siblings’ ratings on the Sibling Relationships Questionnaire, siblings of children with autism reported that their relationship was characterized by less intimacy and less nurturance. Siblings of children with autism also reported less prosocial behavior in their sibling relationship when compared to siblings of children with Down Syndrome.

Recent research has looked at the role that genetics plays in affecting outcomes for siblings of children with ASDs. Orsmond and Seltzer (2009), evaluated the usefulness of a diathesis-stress model in determining whether adolescent siblings of children with ASD
exhibited higher levels of depression and anxiety when compared to the normative sample. Orsmond and Seltzer adopted the diathesis-stress model that was originally proposed by Bauminger and Yirmiya (2001). In the model, Bauminger and Yirmiya suggest that genetic vulnerability in siblings of children with ASDs may interact with stresses in the siblings’ environment. The interaction of these two variables may affect sibling outcomes. The term “broader autism phenotype,” (BAP) is often used to describe individuals who have impairments in socialization, behavior and/or communication, but the level of impairment is not high enough to warrant a diagnosis of ASD (Bauminger & Yirmiya, 2001 as cited in Orsmond & Seltzer, 2009).

Orsmond and Seltzer (2009), looked at siblings of children with ASDs between the ages of 12 to 18. They used the Center for Epidemiological Studies-Depression Scale (a self-report scale) to assess both sibling and maternal depression. They asked the siblings to complete the Revised Children’s Manifest Anxiety Scale, as well as a Life Events Checklist. The siblings’ mothers completed the social interaction subsection of the Development, Social Interaction and Mood Questionnaire, which was used to measure the siblings’ BAP characteristics, and the mothers’ own BAP characteristics. The mothers also completed the Problem Behavior Scale from the Scales of Independent Behavior-Revised, which was used to measure problem behaviors in the diagnosed sibling, and they were asked questions about the history of ASDs in their family. Orsmond and Seltzer considered the siblings’ BAP, the mothers’ BAP and the family history of ASDs as diathesis variables. The stress variables were the behavior of the child with ASD, sibling life events and maternal depression.

The results of Orsmond and Seltzer’s (2009) study indicated that 36% of the siblings who participated in the study reported clinically significant levels of depressive symptoms and 8.5%
reported clinically significant levels of anxiety symptoms. Overall, these rates were similar to or lower than community samples, but when the results were broken down by gender, Orsmond and Seltzer found that sisters of children with ASDs reported higher levels of depressive and anxiety symptoms when compared to brothers. A family history of ASDs was associated with higher levels of depressive, but not anxiety symptoms. The results also indicated that higher levels of maternal depression were associated with higher levels of depressive and anxiety symptoms in siblings. In terms of the diathesis-stress model, Orsmond and Seltzer found that sibling BAP characteristics were associated with depressive and anxiety symptoms in siblings, only when there were a high number of stressful life events. The same held true for maternal BAP characteristics, which were associated with sibling depressive symptoms, only when there were a high number of stressful life events.

Meyer, Ingersoll and Hambrick (2011) also investigated the relationship between BAP characteristics in siblings of children with ASDs and adjustment in the siblings. They also looked at how maternal depression, severity of ASD and the impact of the disabled child on the sibling affected sibling adjustment. The siblings who participated in the study were between the ages of 6 and 18. Meyer, Ingersoll and Hambrick asked the mothers of the siblings to complete the Autism Behavior Checklist in order to measure the severity of ASD, and a portion of the Family Impact Questionnaire in order to measure the impact of the disabled child on the sibling. The mothers also completed the Social Responsiveness Scale, which the researchers used as a measure of BAP characteristics in siblings, as well as the SDQ, which was used to assess the sibling’s behavioral adjustment. Maternal depression was measured using the Center for Epidemiological Studies-Depression Scale.
The results of the Meyer, Ingersoll and Hambrick’s (2011) study indicated that based on parent reports, the siblings in their sample exhibited higher rates of adjustment problems when compared to the normative sample, with 25.4% of the participants falling in the clinically significant range. The mothers who participated in the study reported higher levels of depressive symptoms when compared to the normative sample. Meyer, Ingersoll and Hambrick also found that siblings of children with more severe ASD symptoms were more likely to have adjustment problems, but the relationship between these variables was mediated by maternal depressive symptoms. Siblings with more BAP characteristics had higher levels of adjustment problems, and this association was moderated by ASD severity.

The studies described above suggest that based largely on parent ratings and reports, having a sibling with an ASD puts typically developing children at risk for negative outcomes, but there is another group of studies involving this population with conflicting results. Kaminsky and Dewey (2002) investigated the psychosocial adjustment of siblings of children with autism, compared to siblings of children with Down Syndrome and typically developing children. Based on parent ratings on the Child Behavior Checklist, the siblings of children with autism were not found to be at-risk for developing behavioral adjustment difficulties. According to self-reports on the Loneliness and Social Dissatisfaction Questionnaire, the siblings of children with autism did not report more loneliness and were as socially competent, when compared to siblings of children with Down Syndrome and typically developing siblings. The results also indicated that larger family size (more children in the family) was associated with better psychosocial adjustment in siblings.

Hastings conducted two studies whose results support the findings of Kaminsky and Dewey (2002). In 2003, Hastings designed a study to examine the adjustment of siblings of
children with autism who were engaged in intensive Applied Behavioral Analysis (ABA) programs. ABA therapists use a variety of behavior modification techniques to teach children with ASDs academic, social, motor and communication skills. Based on parent reports on the SDQ, the siblings of children with autism had fewer behavior problems than the normative sample, and the ABA programs did not have a negative impact on sibling adjustment. Hastings (2003b) also looked at the role of social support, and found that in families where a child’s autism was not that severe (parents endorsed fewer symptoms on the *Autism Behavior Checklist*), the typically developing siblings were at a lower risk for developing behavior problems when the family received high levels of formal social support. (Formal social support was defined as support from outside professionals or agencies, including support available through ABA programs.) In addition, Hastings’ results indicated that based on parent reports, siblings who were older than the child with autism had higher levels of prosocial behavior when compared to younger siblings.

In Hastings’ (2007) second study, he assessed the behavioral adjustment of siblings of children with autism, Down Syndrome and mental retardation. He conducted an initial assessment and a follow-up assessment two years later. The results indicated that based on parent ratings on the SDQ, there were no differences in behavioral adjustment among the three groups. This suggests that when compared to siblings of children with Down Syndrome and mental retardation, siblings of children with autism do not experience more negative effects. While there were no differences initially, Hastings’ results did indicate that behavioral adjustment in non-disabled siblings is temporally related to their siblings’ behavior problems. That is, behavior problems in the children with autism at the initial assessment predicted sibling behavior problems at the two-year follow-up. This finding suggests that disabled siblings with
more behavior problems may place their typically developing sibling at a greater risk of developing behavior problems over time.

Pilowsky, Yirmiya, Doppelt, Gross-Tsur and Shalev (2004) designed a study to investigate the social and emotional impact of having a sibling with autism. The participants’ included siblings of children with autism, mental retardation and developmental language delays. The siblings of children with autism did not differ from the siblings in the other groups on parent ratings on the Child Behavior Checklist, or on self-report scores on the Weinberger Adjustment Inventory. Overall, the siblings with autism were found to be well-adjusted, however, adjustment was found to be related to the verbal ability of the disabled sibling. The more verbal the disabled sibling, the more well-adjusted the non-disabled sibling. Pilowsky et. al., also found that children who were older than their disabled sibling had a more positive view of their sibling.

Macks and Reeve (2007) conducted a study looking at the psychosocial adjustment of siblings of children with autism compared to siblings of typically developing children. The siblings completed the Children’s Depression Inventory-Short Form and the Piers-Harris Children’s Self-Concept Scale. The parents of the siblings completed the Behavior Assessment System for Children-Parent Rating Scale. Macks and Reeve also asked the parents to complete a demographic questionnaire, which they used to create a risk scale. They used the results of previous research to select the factors that were more likely to place a child a risk for experiencing negative social, emotional and academic difficulties. These factors were: being a male, low socioeconomic status, only having one sibling and being older than the child with autism.

When they analyzed their results, Macks and Reeve (2007) found that based on their own self-reports, the siblings of children with autism had more positive self-concept than the siblings
of typically developing children. These siblings also had more positive feelings about their behavior, intelligence, academic performance, anxiety and personal attributes. When Macks and Reeve looked at the effects of the risk factors, they found that an increase in the number of risk factors predicted adjustment in the siblings with autism, but not in the siblings of typically developing children; these results suggest that siblings of children with autism are more negatively impacted as demographic risk factors increase.

Although the results of the current research on siblings of children with ASDs are conflicting, the research does highlight several variables as possible risk factors for elevated levels of internalizing and externalizing behaviors in siblings. In terms of gender, there is some evidence that male siblings of children with ASDs are at a greater risk of developing these behaviors (Hastings, 2007; Ross & Cuskelley, 2006), while one study found that sisters of children with ASDs reported higher levels of depressive and anxiety symptoms (Orsmond & Seltzer, 2009). The results of another study suggest that being female may be a protective factor, as one group of researcher found that sisters of children with an ASD reported higher levels of social competence and a higher self-concept when compared to controls (Verte, Roeyers & Buysse, 2003). The gender of the child with ASD may also play a role, as siblings who had a brother with an ASD reported higher levels of emotional problems when compared to siblings who had a sister with an ASD (Petelas et. al., 2009). It is important to consider birth order, as younger siblings were found to have higher levels of emotional problems, while older siblings exhibited higher levels of prosocial behavior and had a more positive view of their disabled sibling (Hastings, 2003b, 2007; Petelas et. al, 2009; Pilowsky et. al, 2004). In addition, a larger family size (more typically developing children in the family) was found to be associated with better psychosocial adjustment (Kaminsky & Dewey, 2002).
While most of the researchers did not report significant results regarding the age of the typically developing siblings, the results of one study suggest that siblings who are between the ages of 6 and 11 are at a greater risk for developing internalizing and externalizing behavior problems (Verte, Roeyers & Buysse, 2003). Low SES was also identified as a factor that may put typically developing siblings at risk (Petalas et. al., 2009). One study found that as the number of risk factors increases, siblings of children with ASDs are more likely to be negatively affected than typically developing children (Macks & Reeve, 2007).

The research also suggests that the behavior of children with ASD may be related to the behaviors of developing siblings. One study found that ASD symptom severity was related to sibling adjustment (Meyer, Ingersoll & Hambrick, 2011). Another study indicated that higher levels of behavior problems in children with ASD put typically developing siblings at-risk for developing behavior problems over time (Hastings, 2007). Other researchers found that the verbal ability of children with autism is an important factor, as higher verbal skills in children with ASD were associated with better adjustment in typically developing siblings (Pilowsky et. al., 2004).

Recent research suggests that genetics may play a role in sibling outcomes, as siblings with a greater number of BAP characteristics were found to be at a higher risk for developing adjustment problems (Meyer, Ingersoll & Hambrick, 2011; Orsmond & Seltzer, 2009). However, BAP characteristics only affected siblings who were experiencing a high number of stressful life events, or whose disabled sibling had a severe ASD.

In summary, one group of studies suggests that siblings of children with ASD are at risk for negative outcomes, while a second group of studies indicates that siblings may not be at risk, and may even be more likely to have positive outcomes. This variation in results may be
explained, in part, by methodological differences. Most of the researchers who conducted these studies used parent reports to obtain information about the siblings’ internalizing and externalizing behavior levels. These researchers relied on the parents’ observations of the siblings, and they did not obtain information from the siblings themselves with regard to internalizing and externalizing behaviors. In addition, while all of the researchers looked at siblings of children on the autism spectrum, some researchers only included siblings of children with a diagnosis of autism in their studies (Bagenholm & Gillberg, 1991; Hastings, 2003a, 2003b, 2007; Kaminsky & Dewey, 2002 and 2001; Pilowsky, 2004; Rodgrigue, Geffken & Morgan, 1993), while others looked at siblings of children with Asperger’s Syndrome (Ross & Cuskelly, 2006), high functioning autism (Verte, Roeyers & Buysse, 2003) and Pervasive Developmental Disorder (Fisman et al, 2000). Some included siblings of children with any type of ASD (Meyer, Ingersoll & Hambrick, 2011; Orsmond & Seltzer, 2009). This is an important factor, as it is possible that sibling outcomes may vary depending on the type of ASD diagnosis.

It is also possible that specific behaviors in children with ASD are more likely to be associated with positive or negative sibling outcomes. This thinking is in line with the new DSM-V criteria for ASD diagnosis, which moves away from narrower diagnostic categories within the autism spectrum. Diagnosticians are now using a broader diagnostic label, but they are being asked to rate the severity of the individual’s impairment and behavior. The DSM-IV-TR did not account for behavioral symptom severity, and therefore, it was possible for individuals within more than one diagnostic category to present with the same behavioral profile. The new criteria eliminates this possibility, as individuals with ASD are now under the same diagnostic “umbrella,” with different levels of symptom severity.
A recent review of the literature on siblings of children with ASDs highlights another important methodological issue: small sample size. In this literature review, Meaden, Stoner and Agnell (2009), reviewed 12 articles and found that the research results were inconsistent. They applied Hodapp, Glidden and Kaiser’s (2005) themes for studying siblings of children with disabilities, in order to explain the variation in results and to identify ways in which future research could be improved. One of the main themes that Hodapp, Glidden and Kaiser discuss is “methodological challenges,” which includes small sample size. Most of the researchers who have studied siblings of children with ASDs have used between 20 and 50 participants. These small sample sizes limit the generalization of research results and pose validity threats (Fisman et al, 2000; Hastings, 2003a, 2007; Kaminsky & Dewey 2002; Macks & Reeve, 2007; Petalas et al, 2009; Pilowsky et al, 2004; Ross & Cuskelly, 2006; Verte, Roeyers & Buysse, 2003). Meaden, Stoner and Agnell state that larger sample sizes will increase the generalizability of sibling research, and will help to identify risk and resiliency factors in this population.

Several factors may explain why these researchers had a difficult time recruiting parents and siblings of children with ASDs to participate in their research studies. Parents of children with ASDs may have less free time when compared to parents of typically developing children. Children with ASD diagnoses often receive therapy after school hours, participate in specialized programs and need to attend appointments with specialists. All of these activities require parent involvement and participation, and parents of children with ASDs may feel that because of these obligations, they do not have time to participate in research studies. In addition, some parents of children with ASDs may be experiencing high levels of stress, and this may factor into their decision not to participate in research studies.
Research on Parents of Children with Autism Spectrum Disorders

Clearly the research on siblings of children with ASDs is inconsistent. A review of the research on parents of children with autism spectrum disorders suggests ways in which the research on siblings can be viewed and perhaps clarified. Researchers who conducted studies with parents of children with ASDs have identified specific characteristics of the child as being related to higher levels of parental stress. It is possible that these same characteristics may also contribute to increased stress in siblings or impact psychosocial adjustment.

Several researchers have found that behavior problems in children with autism are related to increased levels of stress in parents. Konstantares and Homatidis (1989) conducted a study with 44 parents of children with autism. The researchers rated the children’s symptoms using the Childhood Autism Rating Scale (CARS), and then asked the parents to rate their own level of stress related to each symptom. Konstantares and Homatidis also looked at thirteen independent variables in relation to parent stress. These were: sex, age, cognitive level, verbal ability, hyperirritability, facial oddity, birth order, self-abusive behaviors, seizures and sleep disturbance. When Konstantares and Homatidis analyzed their results, they found that self-abusive behaviors predicted the highest levels of stress in both mothers and fathers. The second best predictor of stress in mothers was hyperirritability, which Konstantares and Homatidis define as, “the extreme end of the difficult temperament dimension.” They listed examples of this behavior including, “aimlessly walking about or running out of the house, vocalizing in an ongoing manner or destroying objects.”

Several years later, Lecavalier, Leone and Wiltz (2006) and Herring, Gray, Taffe, Tonge, Sweeney and Einfeld (2006) conducted further investigation into the relationship between behavior problems in children with autism and parental stress. Lecavalier, Leone and Wiltz
investigated the impact of a child’s level of functioning and behavior problems on parental stress in parents of children with autism. Their sample consisted of 293 children and adolescents with autism. The parents completed the Nisonger Child Behavior Rating Form (NCBRF), a measure of social competence and behavior problems in children and adolescents with developmental disabilities. The parents also completed the Scales of Independent Behavior, which provided information about their child’s level of adaptive behavior, as well as the Parenting Stress Index, which assessed stress in the parent-child relationship. Lecavalier, Leone and Wiltz conducted follow-up ratings with 50 parents, 12 months after the initial assessment.

When they analyzed their results, Lecavalier, Leone and Wiltz (2006) found that high levels of overall behavior problems (measured by the total score on the NCBRF) in the children and adolescents with autism had the strongest association with parental stress. All of the sub-scales on the NCBRF were correlated with high levels of parental stress, but they found the strongest associations with the conduct problems and lack of prosocial behaviors sub-scales. Lecavalier, Leone and Wiltz explain that these sub-scales both contain items related to disruptive, rule-breaking behavior. At the 12-month follow-up, high levels of behavior problems and parental stress were maintained.

Herring et al. (2006) conducted a similar study in which they investigated the impact of behavioral and emotional problems on parental stress in parents of toddlers with and without PDD. They chose to focus on young children because they felt that this population had been somewhat overlooked in the research. Their sample consisted of 84 young children with PDD (who either had a diagnosis of Autistic Disorder or PDD-NOS) and 39 young children with a developmental delay only. The age of the participants ranged from 20 to 51 months.
Herring et al. (2006) included both mothers and fathers in their study. They used the Developmental Behavior Checklist to assess the level of emotional and behavioral problems in the participants. The mothers and fathers of the participants completed this together. In order to assess family functioning, parental mental health and parental stress, each parent individually completed the Family Assessment Device, the General Health Questionnaire and a “stress thermometer scale.” On this last measure, each parent was asked to indicate on a Likert scale, the level of stress associated with parenting his or her child. Herring et al. conducted an intial assessment and then conducted a follow-up, using the same measures, twelve months later.

When Herring et al. (2006) analyzed their results, they found that increased behavioral and emotional problems were correlated with higher levels of parental mental health problems and poor family functioning. High levels of behavioral and emotional problems were also correlated with higher levels of stress in mothers, but not in fathers. Herring et al. found that, on the whole, fathers reported lower levels of stress than mothers, but the fathers of children with PDD reported significantly higher levels of stress at the twelve-month follow-up. This may be due to the fact that at the follow-up assessment, the children with PDD had significantly more emotional and behavioral problems when compared to the children with a developmental delay.

Additional support for the relationship between behavior problems in children with autism and parental stress comes from a study conducted by Benson (2010). In this study, Benson examined coping strategies, distress and well-being in mothers of children with autism. Benson also investigated the impact of autism symptom severity and the impact of problem behaviors on the mothers. His sample consisted of 113 mothers of children with autism who completed a number of self-report scales. Benson used the Brief COPE to assess coping strategies in the mothers, the Center for Epidemiologic Studies-Depression Scale as a measure of
maternal depressed mood and two three-item measures to assess maternal anger and maternal well-being. He asked the mothers to complete the Social Responsiveness Scale, to assess autism symptom severity, and the NCBRF, to assess problem behaviors in the children.

Benson (2010) conducted a factor analysis of the Brief COPE responses, and discovered four distinct coping mechanisms, which he refers to as engagement, distraction, disengagement and cognitive reframing. He found that the increased use of distraction and disengagement coping mechanisms was associated with higher levels of depressed mood and anger in mothers. Disengagement coping mechanisms were also associated with lower levels of maternal well-being. In terms of problem behavior, Benson found that higher levels of problem behaviors in children predicted depressed mood and anger in mothers. The severity of autism symptoms did not predict these negative outcomes in mothers.

While many researchers have investigated the relationship between problem behaviors in children with ASDs and parental stress, few have looked at the relationship between adaptive behavior in these children and parental stress. Tomanik, Harris and Hawkins (2004) designed a study to examine the relationship between both problem and adaptive behaviors in children with pervasive developmental disorder and maternal stress. Their sample consisted of 60 mothers who each had a child diagnosed with PDD. There were 51 boys and 9 girls, all between the ages of two and seven years old.

Tomanik, Harris and Hawkins (2004) asked each mother to complete the Aberrant Behavior Checklist, a measure of problem behavior, and the AAMR Adaptive Behavior Scales-School, a measure of adaptive behavior for school age children who have cognitive impairments, developmental or emotional disabilities. The mothers also completed the Parenting Stress Index.
When Tomanik, Harris and Hawkins (2004) analyzed their results, they found that many of the domains on the aberrant behavior measure were negatively correlated with the adaptive behavior domains. This suggests that higher levels of problem behavior such as social withdrawal, noncompliance and self-stimulatory behaviors are associated with lower levels of adaptive behavior in children with pervasive developmental disorders. In terms of maternal stress, mothers whose children exhibited higher levels of irritability, lethargy/social withdrawal and hyperactivity/non-compliance reported higher levels of stress. Tomanik, Harris and Hawkins found that maternal stress was also related to adaptive behavior. Mothers whose children had deficits in communication and interaction reported higher levels of stress, as did mothers whose children were unable to independently engage in self-care and daily living activities.

The research on parents (although most studies only included mothers) suggests that maladaptive or problem behavior in children with ASD is associated with parental stress. The research also suggests that weak adaptive behavior skills in this population may contribute to parental stress; these variables may play an important role in relationships within the family. To date, there is no research on how problem behavior and adaptive behavior levels in children with ASDs affect siblings, and whether similar relationships can be seen with siblings. This is a relationship that needs to be investigated in order to further the understanding of how siblings of children with ASD are affected.

**Family Systems Theory**

A useful theoretical framework to examine the interrelationships among family members is a family systems model. This model asserts that a family is a collective unit, whose functioning is impacted by its individual members, as well as the relationships that exist between
its members (Turnbull & Turnbull, 2001). Family functioning can be affected by events that occur both within and outside the family. The family systems model helps researchers better understand the family context within which the siblings of children with ASD grow, and the different family factors that can impact them (Bronfenbrenner, 1979). The theory also helps explain how families function and react in response to stressors. A systems approach posits that the presence of a child with a disability is considered a family stressor; the child affects and is affected by family functioning (Turnbull & Turnbull, 2001).

Structural family systems theorists use subsystems to define relationships that exist between two or more members of the family. The subsystems within a family may include the spousal, parental and sibling subsystems. All three of these relationships can be impacted by a child with a disability.

The spousal subsystem refers to the interactions between husbands and wives. As children observe these interactions, they learn about decision-making, conflict resolution and intimacy (Seligman & Darling, 2007). High levels of conflict in the spousal subsystem can increase levels of stress and feelings of worry in children (Seligman & Darling, 2007). The stress that a child with a disability such as an ASD places on a family may result in increased stress and conflict in the parental subsystem. This may impact the children and the sibling subsystem.

The parental subsystem refers to interactions that occur between parents and their children. Through their relationship with their parents, children form ideas about discipline, caretaking, nurturing and limit setting (Goldenberg & Goldenberg, 2003). They also learn how to deal with authority figures (Seligman & Darling, 2007). When the presence of a child with a
disability creates high levels of stress in parents, it is possible that the parents’ parenting style or their interactions with their children may change.

The sibling subsystem refers to interactions that occur between children in the family. By interacting with their brothers and sisters, children develop important social skills. They play, compete, negotiate and support one another (Seligman & Darling, 2007). Because many children with ASD have deficits in communication and socialization, they are likely to play and interact with their siblings in ways that are different than typically developing children. These differences may contribute to increased stress in the siblings relationship, and this impacts the way in which the entire family functions.

Seligman and Darling (2007) identify five types of stress that can affect the family system when a child has special needs. These are: intellectual, instrumental, emotional, interpersonal and existential. Intellectual stress is created as parents try to obtain information about their child’s diagnosis and potential treatments. In some cases, children can be misdiagnosed several times before an accurate diagnosis is provided (Seligman & Darling, 2007). As parents go through this process, they often meet with many doctors and professionals, hear a great deal of information and try to educate themselves about the issues surrounding their child’s disability.

Instrumental stress occurs as parents try to ensure that the child with special needs receives treatment and is cared for, while meeting the needs of the other family members. Brinthaupt (1991) discusses several instrumental stressors for parents of children with special needs. Some of these include allocating financial resources, balancing household chores with caretaking responsibilities and monitoring other family members to determine if they are being negatively impacted by the child’s disability. Seligman and Darling (2007) emphasize that there
is often a tremendous amount of financial pressure and strain on families of children with special needs. They note that parents often spend a great deal of money on therapy, medical expenses, equipment, as well as specialized schools and activities. They also highlight the fact that many parents of children with special needs are often forced to take time off of work or reduce their work schedule in order to care for their child. This can put a tremendous amount of stress on the entire family system.

Emotional and interpersonal stress are the two types of stress that siblings are most likely to experience directly. Emotional stress refers to the impact a child with special needs can have on the mental health of other family members. Parents or siblings may worry, experience high levels of anxiety or feel a sense of loneliness. Emotional stress includes internalizing and externalizing behaviors such as depression, withdrawal and defiance. This type of stress has been studied in much of the existing sibling literature.

Interpersonal stress develops between family members and can negatively impact relationships. The impact of a child with special needs on the family system can create a strain on marriages, sibling relationships and relationships between parents and children. Prior researchers have not measured this type of stress, as questions about relationships within the family are not included on measures that assess internalizing and externalizing behaviors. The last type of stress that Seligman and Darling (2007) discuss is existential stress. Family members experience this type of stress as they begin to ask questions about “why” the child with special needs was born into the family.

In addition to the types of stress described above, Seligman and Darling (2007) describe a number of additional factors which may impact siblings of children with special needs. They state that while parents of children with special needs often obtain a great deal of information
about their child’s disability, they can be hesitant to share this information with their other, typical children. If the information is not shared, siblings may develop their own reasons as to why the disability occurred and what will happen in the future. It is possible for some children to believe that they contributed to their sibling’s disability, or that the disability is contagious and they may “catch” it from their sibling. These types of thoughts can result in negative feelings and increased stress.

Moreover, parents are often required to devote a great deal of time and energy to a child with special needs. If parents are unable to devote an equal amount of time to their typical children, these children may become angry, jealous and resentful (Seligman & Darling, 2007). In some families, parents need help caring for a child with special needs, and they ask their typical children to assume some of the caregiving responsibilities. Siblings who are thrust into the parental role as children or adolescents are referred to as “parentified” (Siegel & Silverstein, 1994). When siblings are put in this position, it alters the typical course of their child development, and this can have negative emotional consequences (Seligman & Darling, 2007). It is important to consider the gender of the typically developing sibling, as parents are most likely to assign caregiving tasks to females, so it is possible that they may be more likely to experience negative effects.

Communication within families can also affect siblings of children with special needs. Seligman and Darling (2007) point out that siblings may feel isolated if they cannot be open and honest about their feelings with their parents and other family members. When parents make decisions on behalf of the child with special needs, these decisions often impact the entire family. Siblings may be upset and resentful if parents do not discuss these decisions with them.
Many siblings of children with special needs become worried about what will happen to their brother or sister in the future, and what their roles and responsibilities will be. Siblings can become fearful or anxious as they think about what will happen when their parents are no longer living, and they become the ones who will be expected to make decisions and possibly care for their brother or sister (Seligman & Darling, 2007).

Sibling researchers who used a family systems approach found a relationship between sibling adjustment, maternal stress and maternal depression (Fisman et. al, 2000; Meyer, Ingersoll & Hambrick, 2011; Orsmond & Seltzer, 2009). Additional support for the use of a family systems approach with families of children with ASDs comes from studies conducted by Hastings et. al. (2005) and Rivers and Stoneman (2003).

Hastings et al. (2005) used a family systems approach to investigate the relationship between behavior problems in children with autism and stress in both mothers and fathers. They considered that parental stress might be a direct result of the child’s behavior problems, but that it also could be due to high levels of spousal stress. This is a systems approach because it looks at the ways in which family members are inter-related and affected by one another’s behavior.

The sample Hastings et al. (2005) used in their study consisted of 48 mothers and 41 fathers of preschoolers with autism, ranging in age from 28 to 45 months. Each parent completed the Developmental Behavior Checklist, a measure of problem behavior, and the Autism Screening Questionnaire, a measure of autism symptom severity. Only the mothers were asked to complete the Vineland Adaptive Behavior Scale, a measure of adaptive behavior in the children. To assess each parent’s mental health, Hastings et al. used the Hospital Anxiety and Depression Scale. They used the Parent and Family Problems sub-scale of the Questionnaire on Resources and Stress to measure parental stress. In order to assess the parents’ view of how their
child with autism impacted them, Hastings et al. used the Kansas Inventory of Parental Perceptions Positive Contributions Scale.

Hastings et al. (2005) analyzed the results obtained on these measures and found that mothers reported more mental health problems when compared to fathers, but there was no difference in the level of stress reported by each group. They found that an increase in maternal stress was related to higher levels of problem behaviors in the children with autism. Adaptive behavior and autism symptom severity were not related to maternal or paternal stress.

In analyzing the family system, Hastings et al. (2005) found that maternal stress was not only related to problem behaviors in the child with autism, but it was also affected by spousal depression. Paternal stress was not related to problem behaviors in the child with autism, but it was predicted by spousal depression (which was likely associated with the behavior of the child). These results support the notion that children with autism can impact other family members both directly and indirectly; they can also affect the ways in which the family system functions as a whole.

Rivers and Stoneman (2003) used a family systems model to study how certain family factors influence sibling relationships when one of the children has an ASD. The family factors that they focused on were marital stress and coping by seeking social support. Rivers and Stoneman used the Sibling Inventory of Behavior and a modified version of the Sibling Relationship Scale to assess the quality of the sibling relationships. Their results indicated that high levels of marital stress were associated with less satisfaction in the sibling relationship. Siblings whose parents had high levels of marital stress also reported that the disabled sibling exhibited more negative behaviors and less positive behaviors towards them. In terms of social support, Rivers and Stoneman found that in families with a high level of marital stress, seeking
informal and formal social support acted as a protective factor for positive behaviors and satisfaction in the sibling relationship. Surprisingly, siblings in families with a high level of marital stress who sought formal social support reported more negative behaviors in the sibling relationship.

Family systems theory assumes circular causality with all members of a family affecting all others; because a child with a disability affects all members of the family, it is essential to use a family systems model to study outcomes in siblings of children with ASDs. Previous studies indicate that in addition to being directly affected by children with ASDs, individual family members can also be affected if other members of the family are experiencing high levels of stress or depression. These findings suggest that in order to obtain a better understanding of sibling outcomes, research on siblings of children with ASD should include measures that assess both siblings and parents, and the relationships that exist within the family unit.

Results from Exploratory Pilot Study

An exploratory pilot study was designed and conducted to address the need for further clarification in the sibling literature. A brief summary of the study is presented below. Please see Appendix A for a more detailed outline of the study and results.

The goal of the exploratory pilot study was to explore the relationships between problem and adaptive behavior levels in children with ASD, parental stress and sibling behaviors. The pilot study addressed some of the methodological issues that were brought to light in the review of the sibling literature. Specifically, internalizing and externalizing behaviors in the siblings were assessed using both parent and self-report forms. In addition, siblings of children with any type of ASD diagnosis were eligible to participate in the study. The primary aim of the study
was to explore whether factors that contribute to increased parental stress, also contribute to increased levels of internalizing and externalizing behaviors in siblings of children with ASDs.

The results of this exploratory study indicated that, consistent with prior research, problem behavior in children with ASDs was positively associated with parental stress, and the results were statistically significant. Adaptive behavior levels in children with ASDs were negatively associated with parental stress, but these results were not statistically significant, as the $p$-value was just above the alpha level threshold of 0.05. In looking at specific aspects of adaptive behavior, the Communication subdomain scores on the Vineland-II were negatively correlated with Total Stress scores on the PSI, such that parental stress increased as communication skills decreased.

There were no statistically significant correlations between the measures of problem and adaptive behavior in children with ASDs and the measures of internalizing and externalizing behavior in siblings. Looking more closely at the measures used in this study, the principal investigator realized that the measures used to assess internalizing and externalizing behaviors in siblings, were not measuring the construct of sibling stress. A measure of sibling stress would be needed to gain a better understanding of whether sibling outcomes are related to problem and adaptive behavior in children with ASDs. By developing a measure of sibling stress, researchers may be able to clarify some of the inconsistency in the sibling research.

**Rationale for the Study**

The rationale, research questions and hypotheses for the current study are presented below.
Rationale

The research on parents of children with ASDs highlights problem behaviors in these children as being related to increased parental stress. The research also suggests that low adaptive behavior levels may contribute to higher levels of parental stress. In light of this, the current study will examine how these same variables impact typically developing siblings.

The research on siblings of children with ASDs suggests that typically developing siblings may be at-risk for developing higher levels of internalizing and externalizing behaviors. Some of the research also suggests having a sibling with an ASD may result in positive outcomes, such as higher levels of adjustment. The results of these studies are conflicting, and it is not clear if there are specific characteristics that may negatively or positively impact siblings.

The inconsistency in the research on siblings of children with autism may be explained by closely examining the methodology used in this group of studies. One of the methodological issues that may have impacted the results is the way in which researchers define the disorder. Some researchers only included siblings of children with a diagnosis of autism in their studies (Bagenholm & Gillberg, 1991; Hastings, 2003a, 2003b, 2007; Kaminsky & Dewey, 2002 and 2001; Pilowsky, 2004; Rodgrigue, Geffken & Morgan, 1993), while others looked at siblings of children with Asperger’s Syndrome (Ross & Cuskelly, 2006), high functioning autism (Verte, Roeyes & Buysse, 2003) and Pervasive Developmental Disorder (Fisman et al, 2000). The researchers who conducted these studies did not look beyond the diagnosis to determine if certain characteristics or behaviors in these children were associated with higher levels of internalizing or externalizing behaviors in siblings.

A review of the research on parents suggests that certain patterns of behavior in children with ASDs, rather than a specific diagnosis, contribute to higher levels of parental stress. Higher
levels of problem behaviors were associated with increased parental stress in parents of children with autism diagnosis (Benson, 2010; Konstantares & Homtidis, 1989; Lecavalier, Leone & Wiltz, 2006), as well as parents of children with a diagnosis of PDD (Herring et al, 2006) and with other autism spectrum disorders (Tomanik, Harris & Hawkins, 2004). Similarly, some research suggests that low adaptive behavior may contribute to parent stress (Tomanik, Harris and Hawkins, 2004).

This study investigated whether high levels of problem behavior and low levels of adaptive behavior are related to stress, internalizing and externalizing behaviors in siblings. Levels of sibling adjustment were also explored. The participants for this study included parents and siblings of children with any disorder that fell along the “autism spectrum.” This included children who had diagnoses of autism, high functioning autism, Asperger’s Syndrome and Pervasive Developmental Disorder. The study examined the problem behaviors, both internalizing and externalizing, as well as adaptive behavior that the children with ASD exhibited, and did not focus on the specific diagnosis.

A second methodological issue is the way in which previous researchers assessed the impact of having a sibling with an ASD. A majority of the researchers used parent reports to assess internalizing and externalizing behaviors in typically developing siblings (Fisman, et al., 2000; Hastings, 2007; Meyer, Ingersoll & Hambrick, 2011; Petalas, et al, 2009; Rodrigue, Geffken & Morgan, 1993; Ross & Cuskelly, 2006; Verte, Roeyers & Buysse, 2003). While parents may be reliable reporters in some cases, it is possible that their ratings of their child may be impacted by their own stress. It is also possible for parents to believe that their typically developing children are or should be experiencing certain problems, when in reality, these problems may not be evident.
In addition to parent reports, the current study used self-report forms, completed by the siblings, to assess the impact of having a sibling with an ASD. Information about the siblings was obtained from the siblings themselves. The information obtained from the parents was compared to the information obtained from the siblings in order to explore whether or not the observations made by parents are in alignment with the siblings’ report of their own thoughts, feelings and behaviors.

In an attempt to clarify the inconsistency in the sibling research, the current study investigated whether the same factors that contribute to an increase in parental stress also contribute to increased levels of stress, internalizing behaviors and externalizing behaviors in siblings. Because there is no published or widely used measure of stress in siblings, stress in siblings was assessed using a measure developed by the principal investigator, which was modeled after the Parenting Stress Index-Fourth Edition (PSI-4). Adjustment levels in typically developing siblings were also explored, to determine if specific patterns of behavior in children with ASDs can lead to positive outcomes for siblings. This was indicated in prior research.

Thus, the current study explored the relationship between both problem and adaptive behavior in children with ASDs and stress, personal adjustment and internalizing and externalizing behaviors in typically developing siblings.

Based on the information presented above, the current study attempted to answer three main research questions:

1. Are problem behavior levels in children with autism spectrum disorders associated with stress, personal adjustment and internalizing and externalizing behaviors in typically developing siblings?
2. Are adaptive behavior levels in children with autism spectrum disorders associated with stress personal adjustment and internalizing and externalizing behaviors in typically developing siblings?

**Hypotheses**

H\(_1\): Adaptive behavior in children with ASDs (as measured by the Vineland Adaptive Behavior Survey Composite score) will be negatively associated with levels of stress, internalizing behaviors and externalizing behaviors in typically developing siblings (as measured by the Sibling Stress Index and the BASC-2).

H\(_2\): Problem behavior levels in children with ASDs (as measured by the Nisonger Child Behavior Rating Form) will be positively associated with stress in typically developing siblings, as well as internalizing behaviors and externalizing behaviors (as measured by the Sibling Stress Inventory and the BASC-2).

H\(_3\): Adaptive levels of adaptive behavior in children with ASDs (as measured by the Vineland Adaptive Behavior Survey Composite score) will be positively associated with personal adjustment scores in typically developing siblings (as measured by the BASC-2).

H\(_4\): Problem behavior levels in children with ASDs (as measured by the Nisonger Child Behavior Rating Form) will be negatively associated personal adjustment scores in typically developing siblings (as measured by the Sibling Stress Inventory and the BASC-2).

H\(_5\): Adaptive behavior levels in children with ASDs (as measured by the Vineland Adaptive Behavior Survey composite score) will predict stress, personal adjustment, internalizing behaviors and externalizing behaviors in typically developing siblings (as
measured by the Sibling Stress Index and the BASC-2) over and above problem behavior levels (as measured by the Nisonger Child Behavior Rating Form).
Chapter 3

Methods

This chapter outlines the methodology and presents the measures used in this study. An overview of the demographic characteristics of the national population of children with ASDs and their families is provided. Demographic information is provided for the sample of parents and typically developing siblings who participated in this study. Next, the measures chosen and developed to assess problem behavior, adaptive behavior, internalizing behaviors, externalizing behaviors, personal adjustment and stress are reviewed. The methods used for participant recruitment are discussed, and the study procedures are outlined.

Participants

Participants for this study were 53 sets of parents and typically developing siblings of individuals with ASD diagnoses. All siblings were between the ages of 8-18 years, did not have any psychiatric diagnoses and were not receiving individual therapy. The participants were recruited from 55 tri-state area agencies, schools, organizations and special recreation programs, all of which provide services or support for individuals with ASDs and/or their families. Although the principal investigator distributed materials just within the tri-state area, snowball sampling was employed, and therefore some of the participants lived in other areas of the county, outside of the tri-state area. Two potential participants were excluded due to psychiatric diagnoses. Three families contacted the principal investigator and were excluded because the sibling did not fall within the age range for the study.

In order to better understand the study sample and how it compares to the national population of children with ASDs and their families, information about the national population is provided below. As stated previously, the most recent research on the prevalence of ASD
indicates that 1 in 68 children has an ASD diagnosis, with males being five times more likely than females to receive an ASD diagnosis (Centers for Disease Control and Prevention, 2012). While ASDs affect children from all racial and ethnic groups, the estimated prevalence is greater for non-Hispanic white children, than African American and Hispanic children.

In terms of socioeconomic status, while ASD is reported to occur in all socioeconomic groups, a 2010 study using data from the Autism and Developmental Disabilities Monitoring Network found that as socioeconomic status increased, ASD prevalence increased in a dose-response manner (Durkin et. al., 2010). The authors note that this relationship may be due to the fact that families with a higher socioeconomic status are likely to have greater access to diagnostic resources and services.

While many believe that the divorce rate is higher for couples that have a child with ASD, recent research suggests that this is not the case. In 2010, Hartley, et. al. conducted a study that compared the divorce rate in couples who had children with ASDs to the divorce rate in couples who had children without any diagnoses. They found that couples who had a child with an ASD diagnosis, had a higher divorce rate (23.5%), than couples in the comparison group (13.8%), but both rates were below the national average. The results also indicated that for couples that had a child with an ASD diagnosis, the divorce rate remained high throughout the child’s adolescence and early adulthood, while the divorce rate decreased after age eight for couples whose children did not have a diagnosis. Freedman, Kalb, Zablotsky and Stuart conducted a study in 2011, where they found that children with an ASD diagnosis were not at a greater risk of living in a household without two biological parents.

The demographic characteristics of this sample were determined by the parents’ responses on the Demographic Questionnaire, and are presented in Table 1.
Table 1

Socio-Demographic Characteristics of the Sample

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N</th>
<th>%</th>
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<tbody>
<tr>
<td>Parent Completing Packet</td>
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<tr>
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<td>51</td>
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<td>Father</td>
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<tr>
<td>Completed Graduate School</td>
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<td>41.5</td>
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<tr>
<td>Marital Status</td>
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<tr>
<td>Married</td>
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</tr>
<tr>
<td>Single</td>
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</tr>
<tr>
<td>Divorced</td>
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<tr>
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</tr>
<tr>
<td>3</td>
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<td>Diagnosis of Child with ASD</td>
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</tr>
<tr>
<td>Autism</td>
<td>28</td>
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<td>Aspergers Syndrome</td>
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<td>High Functioning Autism</td>
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<tr>
<td>Non-Verbal Learning Disability</td>
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<td>1.9</td>
</tr>
<tr>
<td>Gender of Child with ASD</td>
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<td></td>
</tr>
<tr>
<td>Male</td>
<td>44</td>
<td>83.0</td>
</tr>
<tr>
<td>Female</td>
<td>9</td>
<td>17.0</td>
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</table>
The majority of parent participants were mothers (96.2%), and 92.5% of these mothers reported that they had earned a college or graduate degree. In terms of family characteristics, 27.4% of the parents reported that their household income fell below $100,000, 29.4% of parents reported that their income fell between $100,000 and $150,000, and 43.1% of parents reported an income of over $150,000. (Two parents did not report income information on the demographic questionnaire.) Based on these responses, it is clear the majority of study participants have a high socioeconomic status.

With regard to marital status, 83% of parents in this sample were married, 9.4% reported that they were divorced and 5.7% identified as single parents. The majority of parents (60.4%) reported that they had two children, one typically developing child and one child with an ASD diagnosis. Families with three children comprised 24.5% of the sample, and families with four children comprised 15.1% of the sample.
The sample of typically developing siblings consisted of 23 males (43%) and 30 females (57%). With a mean age of 12.22, these children ranged in age from eight to 18 years. Twenty-one (39.6%) of the typically developing siblings were older than the diagnosed child, while 25 (47.2%) of the typically developing siblings were younger. There were seven sets of twins (13.2%) in the sample, where the typically developing sibling and diagnosed child were the same age. The mean age difference between siblings was 2.96 years, with a range of zero to 10 years.

The diagnosed siblings had a mean age of 13 and ranged in age from seven to 21 years. Forty-four (83%) of the diagnosed siblings were male, while nine (17%) were female. Parents reported that 52.8% of these individuals had a diagnosis of autism, 34% had a diagnosis of PDD-NOS and 9.4% had a diagnosis of Asperger’s.

Two parents wrote in a diagnosis for their child with ASD on the demographic questionnaire. One parent indicated that her child had High Functioning Autism, while another indicated that her child had a Non-Verbal Learning Disability. Although these diagnostic categories are not included in the DSM-IV-TR, professionals in the field consider these labels as falling along the autism spectrum. A professional using DSM-IV-TR criteria, would most likely be able to place these participants into one of the three major ASD categories (Autism, Asperger’s Syndrome or PDD-NOS.) For this reason, these participants were not excluded from the study.

Measures

The Nisonger Children Behavior Rating Form-Parent Version (NCBRF) (Aman et al., 1996; Tasse et al., 1996) was used to assess behavior problems in the children with autism spectrum disorders. The NCBRF is a 76-item rating scale that assesses social competence and problem behavior in children and adolescents with developmental disabilities. (The 10 social
competence items were not used for the purposes of this study, as social and adaptive behavior were assessed with the Vineland-II.)

The 66 problem behavior items on the NCBRF load on six subscales: conduct problems, insecure/anxious, hyperactive, self-injury/stereotypic, self-isolated/ritualistic and overly sensitive. Parents rate their child’s behavior over the past month using a Likert scale that ranges from 0 (the behavior did not occur or was not a problem) to 3 (the behavior occurred often or was a severe problem). A score is calculated for each scale, and norms can be used to obtain t-scores and percentile rankings for each scale score. The total score (the score of all of the subscales) on the NCBRF was used to measure problem behaviors in the children with ASDs.

The NCBRF was originally normed on 326 children with mental retardation (Aman et al, 1996; Tasse et al., 1996). Aman et al. (1996) provides details about the reliability and validity of the scale with this population. They found the internal consistency of the problem behavior subscales to be between .77 and .93, with a median value of .85.

To assess convergent validity, the authors of the NCBRF looked at the correspondence between the measure and the Aberrant Behavior Checklist (ABC). The ABC is a rating scale that was designed to assess treatment effects in individuals with mental retardation, but researchers have used it to measure problem behavior with this population (Aman et al., 1985). Aman et al., found that the median correlation between the subscales on the NCBRF and ABC was .72. This suggests that the subscales on these two scales are closely related and seem to measure the same constructs.

In 2004, Lecavalier, Aman, Hammer, Stoica and Matthews, conducted a factor analysis to determine if the NCBRF was a psychometrically valid instrument for use with individuals on the autism spectrum. They explain that while several rating scales have been developed to aid in
the diagnosis of ASDs, there are no rating scales available to measure problem behavior in these individuals. Researchers who wish to measure problem behaviors in this population can either use rating scales that were normed on typically developing individuals, or rating scales that were normed on individuals with mental retardation.

Lecavalier et al. (2004), recruited the parents of 246 children and adolescents with ASDs, ranging in age from 3 to 18 years. After the parents completed the NCBRF, the authors conducted an exploratory factor analysis, which they modeled after the method that Aman et al. (1996) used with the original sample. They also conducted a confirmatory factor analysis. When they compared the results of the two factor analyses, the amounts of explained variance in each were comparable. The indices of fit derived from the confirmatory factor analysis indicated that the fit for the social competence items was “good,” and the fit for the problem behavior items was “acceptable” (p. 719). The authors also found the factor loadings and internal consistencies of the subscales to be “acceptable,” with the exception of the Adaptive/Social subscale of the parent version. In their conclusion, the authors state that their results support the construct validity of the NCBRF.

Cronbach’s alpha for the NCBRF total score in the current study sample was .93, and ranged from .54 to .89 for the subscales.

*The Vineland Adaptive Behavior Scales-Second Edition* (Vineland-II; Sparrow, Cicchetti & Balla, 2005) is a parent and caregiver rating form, which assesses an individual’s adaptive functioning across several areas. It is normed on individuals from birth to age 90. The Vineland-II yields scores in four domains: Communication, Daily Living Skills, Socialization and Motor Skills (this fourth domain is only completed for children under the age of six). These scores are aggregated together to yield an Adaptive Behavior Composite Score. The assessor
computes a standard score, percentile rank, age-equivalent and adaptive level for the domain scores and the Adaptive Behavior Composite. The adaptive levels range from high to low. The Adaptive Behavior Composite was used to measure the adaptive behavior levels of the children with ASDs. The relationship between the individual domain scores and the outcome variables was also explored.

Within each domain, there are two or three subdomains. The Communication Domain consists of the Receptive, Expressive and Written subdomains. Within the area of Daily Living Skills, scores are obtained in the Personal, Domestic and Community subdomains. The Socialization Domain is comprised of the Interpersonal Relationships, Play and Leisure Time and Coping Skills subdomains. The Motor Skills domain (completed by parents of children ages six and younger) consists of the Fine and Gross motor subdomains. Age-equivalents and adaptive levels are available for each subdomain.

In the technical manual, Sparrow, Cicchetti and Balla (2005) provide information about the reliability and validity of the Vineland-II. In terms of reliability, the average split-half reliability coefficients of the domain scores across ages range from .77 to .93. The average test-retest reliability coefficients in the standardization sample are above .80, and the average interrater reliability coefficients are above .70.

In terms of the validity of the Vineland-II, the authors aimed to develop sequential items that measured the behaviors associated with four main areas of adaptive functioning. To establish content validity, the items were evaluated by experts to determine if they were representative of the domain of content. The authors conducted confirmatory factor analysis and found that the data fit best with a three or four factor model.
Sparrow, Chicchetti and Balla (2005), also provide information about the convergent and divergent validity of the Vineland-II. The Vineland-II correlates well with the Adaptive Behavior Assessment System, another rating scale designed to measure adaptive behavior. Correlations between the Vineland-II and the Wechsler Intelligence Scale for Children-Third Edition (WISC-III) are close to zero, which one would expect given that these two assessments measure two very different constructs—one measures adaptive behavior, while the other measures cognitive functioning.

Cronbach’s alpha for the domain scores in the current study ranged from .91 to .93.

The Behavior Assessment for Children-Second Edition, Self-Report Form (Reynolds & Kamphaus, 2004), is a rating scale system designed to aid in the identification of emotional and behavioral issues. The BASC-2, Self Report Form (BASC-2, SRP), is one of the measures used to measure the participants’ internalizing behaviors. The BASC-2, SRP has two forms—one for children ages eight to eleven and another for children ages twelve to eighteen. Both forms were in this study. The child version of the self-report is comprised of 139 items, while the adolescent version is comprised of 176 items. The SRP yields both subscale and composite scores. T-scores and percentile ranks can be obtained for each composite. The composite scores on the BASC-2 Self-Report are: Internalizing Problems, Inattention/hyperactivity, School Maladjustment, Personal Adjustment and the Emotional Symptoms Index.

The Internalizing and Personal Adjustment Composite scores were used in this study. The Internalizing Composite consists of the Atypicality, Locus of Control, Social Stress, Sense of Inadequacy, Anxiety, Depression and Somatization scales. The Internalizing Problems Composite score on the BASC-2, SRP was used to measure the internalizing behaviors of the typically developing siblings. The Personal Adjustment Composite consists of the Relations
with Parents, Interpersonal Relations, Self-Esteem and Self-Reliance scales. This composite score was used to measure adjustment in typically developing siblings.

The reliability and validity data for the BASC-2, Self Report is outlined in the Technical Manual (Reynolds & Kamphaus, 2004). In terms of reliability, the internal consistency of the BASC-2, Self-Report is .83 to .96 for the composite scores and .71 to .86 for the subscales. The test-retest reliability is .74 to .84 for the composites.

To establish content validity of the BASC-2, Self-Report, the authors obtained items from the DSM-IV-TR, parents, teachers and psychologists. The authors claim that individuals with clinical diagnoses have corresponding profiles on the BASC-2, Self-Report. They state that the subscales and composites were created using factor analysis. The Self-Report is correlated with other measures of internalizing behaviors such as the Achenbach System, the Children’s Depression Inventory (CDI) and the Revised Child Manifest Anxiety Scale (RCMAS).

Cronbach’s alpha for the composite scores on the BASC-2 Self-Report scores in the study sample ranged from .70 to .81, and ranged from .44 to .72 for the subscales.

*The Behavior Assessment System for Children-Second Edition, Parent Report Form* (BASC-2 PRS) (Reynolds & Kamphaus, 2004), is the second measure used to measure the siblings’ levels of internalizing behaviors. It was also used to measure the siblings’ levels of externalizing behaviors. The BASC-2, Parent Report has two forms—one for children ages six to eleven and another for children ages twelve to eighteen. Both forms were used in this study. The child version of the Parent Report consists of 160 Likert Scale items, while the adolescent version consists of 150 Likert scale items. Respondents are asked to rate how often the child exhibits each of the behaviors described. The BASC-2, Parent Report yields subscale and composite scores. T-scores and percentile scores can be obtained for each subscale and
composite. The composite scores on the BASC-2 Parent Report are: Internalizing Problems, Externalizing Problems, Behavioral Symptoms Index and Adaptive Skills. The Internalizing Problems Composite is comprised of the Anxiety, Depression and Somatization scales. The Externalizing Problems Composite is comprised of the Hyperactivity, Conduct Problems and Aggression scales. These composites will be used to measure the internalizing and externalizing behavior levels in the typically developing siblings.

In terms of reliability, the internal consistency of the BASC-2, Parent Report is .90-.95 for the composite scores and .77 to .88 for the subscales. The test-retest reliability for the standardization sample is .78 to .92 for the composites and .65 to .87 for the subscales. Interater reliability for this measure is lower, but still adequate, at .68-.77 for the composites and .53 to .80 for the subscales.

To establish content validity of the BASC-2, Parent Report, the authors obtained items from the DSM-IV-TR, parents, teacher and psychologists. The authors claim that individuals with clinical diagnoses have corresponding profiles on the BASC-2, Parent Report. They state that the subscales and composites were created using factor analysis. The Parent Report is correlated with other measures of behavior such as the Achenbach System, the Conners Scale and the Behavior Rating Inventory of Executive Function (BRIEF).

Cronbach’s alpha for the BASC-2 Parent Report scores in the current study sample ranged from .92 to .95 for the composites and .72 to .86 for the subscales.

*The Sibling Stress Index* (SSI) was used to assess stress in siblings. The SSI was created by the principal investigator and consists of 22 Likert scale items. The items are designed to assess aspects of the sibling relationship and characteristics of the child with ASD that may increase stress in typically developing siblings. Seventeen of the items on the SSI were adapted
from the PSI. Thirteen of those items were adapted from the Child Domain, and describe specific traits of the child with ASD. One item was adapted from the Hyperactivity/Distractibility subscale, two items from the Adaptability subscale, five items from the Reinforces Parent subscale, two items from the Demandingness subscale, one item from the Mood subscale and two items from the Acceptability subscale. Five items on the SSI were adapted from the Parent Domain—one item from the Attachment subscale and four items from the Role Restriction subscale. Items from the Depression and Isolation subscales were not included, as these are internalizing behaviors measured by the BASC-2. The BASC-2 also assesses Somatization, which is similar to the items on the Health subscale on the PSI. Items from the Spouse subscale were not included, because they don’t apply to siblings.

The remaining four items on the SSI refer to behaviors that are specific to children with ASD and issues that are unique to siblings of children with disabilities. These included items related to communication, behavior, caregiving responsibilities and embarrassment.

To assess the content validity of the SSI, the questionnaire was presented to four school psychologists, who all currently work with children with ASDs and their families. The school psychologists were asked to review the questionnaire and indicate whether or not each item related to a factor that may contribute to stress in a typically developing sibling. The school psychologists were also asked to indicate if there were any aspects of the sibling relationship or characteristics of children with ASD that may contribute to stress and were not assessed by the SSI. The school psychologists indicated that all of the items were representative of the domain of content, and that no additional items should be added.

In order to test the items on the SSI, the questionnaire was administered to ten children ages eight to fourteen. Four of the children had a sibling with a disability. The questionnaire
was administered to each child individually. The children were instructed to talk out loud about the items as they answered them. They were told to indicate if they had difficulty understanding any of the words or items. The wording of two of the questions was changed based on the children’s responses. The options on the Likert scale were changed to match the options on the BASC-2.

The readability of the questionnaire was calculated in order to determine the ease in which it could be read and understood. *The Flesch Reading Ease* (FRE) score and the *Flesch–Kincaid Reading Grade Level* (FKRGL; Flesch 1973) were chosen to assess readability, because they are widely accepted methods, and they can be calculated with Microsoft Word. The FRE score ranges from 100 (most readable) to zero (least readable). The FKRGL score calculates the US School grade reading level required to read the text. The SSI has a FRE score of 89.7, which falls into the “easy” range. The FKRGL score is 3.2, which suggests that an average third grader will be able to read the questionnaire with ease.

Cronbach’s alpha (α) was calculated for the SSI, as a measure of reliability. A reliability coefficient of 0.7 is an acceptable reliability coefficient, as there is a 95% chance that the true score falls within one standard deviation of the observed score. Using this criterion, the SSI is considered to have adequate reliability, as the α coefficient for the SSI Total Score for the sample is .87. In order to determine how well each individual test item correlated with the overall scale, Corrected-Item Total Correlation values were calculated. Field’s guidelines suggest that correlations below .3 indicate that an item may not correlate well with the overall scale (Field, 2013). Appendix B shows the Corrected-Item-Total Correlation (CI-CT) values for each test item. Values for Cronbach’s Alpha if an Item is Deleted are also presented, which indicate the increase or improvement in alpha if that particular item is removed from the scale. The table in
Appendix B indicates that three out of the 22 items had a CI-CT value below .3. Deleting these items would not result in a sizable increase in reliability, and may result in the loss of valuable information about sibling stress.

**Procedures**

The sample of parents and typically developing siblings of individuals with ASDs was recruited from tri-state area agencies, schools, organizations and special recreation programs, which all provide services or support for individuals with ASDs and/or their families. An informational flyer (Appendix C) was sent via email to school principals, agency directors and special recreation supervisors from over 50 different programs. The principals, directors and supervisors responded to the principal investigator indicating their intent to distribute the flyer to parents of children with ASDs with typically developing children between the ages of eight and eighteen. If the principal investigator did not receive a response from a principal, director or supervisor, a follow-up email was sent two weeks later.

Parents who were interested in participating in the study contacted the principal investigator via email or phone. In her initial response, the principal investigator provided the potential participants with more information about the study, and asked questions to determine if the exclusionary criteria were met. Siblings with psychiatric diagnoses, and/or those who were receiving individual therapy were not eligible to participate.

If the exclusionary criteria were not met, the principal investigator asked the parent to provide an address where she could send the study materials. Immediately after receiving this information, the principal investigator sent out a packet containing a participant consent form (Appendix D), a parental permission form (Appendix E), an assent form (Appendix F) and the study questionnaires. These questionnaires included the NCBRF, Vineland-II, BASC-2, SSI and
the demographic questionnaire (Appendix G). The principal investigator included a self-addressed, stamped envelope for the parent to use to return the completed packet. A separate, smaller envelope was included for the sibling questionnaires. In families that had two or more typically developing siblings who fell within the age range, the parent/family selected which sibling would participate in the study.

The parents were asked to sign the consent form and parental permission form. Once a parent signed these forms, he or she completed the demographic questionnaire, the NCBRF, the Vineland-II, and the BASC-2 Parent Report. The typically developing siblings were asked to sign a separate assent form to indicate that they were participating in the research willingly. Once a sibling signed this form, he or she completed the BASC-2 Self-Report and the Sibling Stress Index. The sibling was instructed to place the questionnaires in a sealed envelope before returning them to his or her parent. The parent was asked to place this envelope along with the completed parent questionnaires in the self-addressed, stamped envelope. Participants were asked to return the completed research packet to the principal investigator within two weeks.

When the principal investigator received a completed packet, she sent a $10 Dunkin Donuts gift card to the family and entered them into a drawing to win an iPad Mini. The principal investigator scored all of the questionnaires in a timely manner. The results were discussed with parents if the results of the BASC-2 Self-Report or Sibling Stress Index suggested that the typically developing sibling was experiencing clinically significant levels of stress, internalizing behaviors or externalizing behaviors. The principal investigator sent out a total of 89 packets and a total of 53 completed packets were returned. The iPad Mini drawing took place in April of 2015, once data collection was complete. The winner of the drawing was contacted via email and the iPad Mini was mailed to the family.
Chapter 4

Results

This chapter outlines the statistical results of this study. The chapter begins with an explanation about the sample size and a description of how the principal investigator handled missing data. Descriptive statistics are presented, followed by the results of an independent samples t-tests and one-way analysis of variance, which were used to examine the relationship of specific demographic variables to the outcome variables. The second half of the chapter contains the results of correlational analysis, and hierarchical regression analyses, which were conducted in order to answer the research questions and hypotheses proposed in this study. An alpha level of 0.05 was used to determine statistical significance for all of the analyses conducted. Unless otherwise noted, all data analysis was conducted using IBM’s SPSS Statistical Software-Version 22 (2013).

Sample Size and Missing Data

Sample size. Prior to data collection, the principal investigator determined her desired sample size using G*Power 3 software (Faul, Erdfelder, Lang & Buchner, 2007). The software package indicated that the principal investigator should aim to recruit 107 sets of parents and siblings in order to detect a medium size effect, an $f^2$ value of 0.15 (Cohen, 1988), with 0.95 statistical power. The recruitment process for this study proved to be quite challenging. (These challenges are described in more detail in the following chapter). The total number of participants recruited for this study was 53 sets of parents and siblings. A post-hoc power analysis using G*Power3 indicated that based on the sample size, the actual statistical power for this study is 0.69, meaning that there is a 69% chance of finding a true effect.
Missing data. The principal investigator received complete research packets, with all of the measures, from 52 of the parents and siblings. One parent did not complete the BASC-2 PRS, but all of the other measures in the packet were complete, and these were included in the data analysis. The BASC-2 Assist (Pearson, 2004) and Vineland-II Assist (Pearson, 2005) software programs were used to score the BASC-2 PRS, BASC-2 SRP and Vineland-II. The program will not compute a score, and will consider a scale or subdomain invalid if there are more than two unanswered items. Composite scores are not calculated if there is an invalid scale or subdomain. In this sample, the BASC-2 and Vineland-II Assist programs computed scale, subdomain and composite scores for all of the participants, which indicates that the missing data threshold for these measures was not met for any of the participants. The principal investigator scored the NCBRF and the SSI by hand. In order to check the scoring reliability, another person scored 10% of the NCBRF and SSI questionnaires. There were no discrepancies in the scoring, which suggests that the scoring method is reliable. The R Package MI (R Core Team, 2015) was used to calculate the frequency of missing observations for these measures. The percentage of missing data was very small, ranging from 0.5% to 1%. Because the percentage of missing data in this study was so low, the missing data was handled using listwise deletion for all analyses.

Descriptive Statistics

Study measures. Table 2 presents the descriptive statistics for the measures used in the study. The Nisonger Parent Behavior Rating Form (NCBRF) was used to assess problem behavior in individuals with ASDs, with higher scores indicating higher levels of problem behaviors. The highest possible score one can obtain on the NCBRF is a 198. Table 2 shows that the mean of NCBRF scores in this sample was 43.64, which is well below the midpoint of total possible scores (99). Further analysis shows that 98.1% of the scores fell below this
midpoint. The distribution of scores is positively skewed, with a skewness of 0.74, such that the right tail of the distribution is elongated.

Table 2

*Means, Standard Deviations and Ranges of Study Variables*

<table>
<thead>
<tr>
<th>Scale</th>
<th>$M$</th>
<th>$SD$</th>
<th>Range of Possible Scores</th>
<th>Range of Observed Scores</th>
<th>Skewness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nisonger Parent Behavior Rating Form</td>
<td>43.64</td>
<td>21.39</td>
<td>0-198</td>
<td>7-105</td>
<td>.74</td>
</tr>
<tr>
<td>Vineland Adaptive Behavior Composite</td>
<td>65.08</td>
<td>13.30</td>
<td>20-160</td>
<td>35-95</td>
<td>-.13</td>
</tr>
<tr>
<td>BASC-2 PRS Internalizing Behavior Composite</td>
<td>48.77</td>
<td>13.36</td>
<td>10-120</td>
<td>34-88</td>
<td>1.10</td>
</tr>
<tr>
<td>BASC-2 PRS Externalizing Behavior Composite</td>
<td>47.00</td>
<td>9.06</td>
<td>10-120</td>
<td>34-74</td>
<td>1.14</td>
</tr>
<tr>
<td>BASC-2 SRP Internalizing Behavior Composite</td>
<td>46.38</td>
<td>8.26</td>
<td>10-120</td>
<td>35-68</td>
<td>.781</td>
</tr>
<tr>
<td>BASC-2 SRP Personal Adjustment Composite</td>
<td>53.45</td>
<td>8.98</td>
<td>10-120</td>
<td>27-67</td>
<td>-.708</td>
</tr>
<tr>
<td>Sibling Stress Index</td>
<td>22.47</td>
<td>8.95</td>
<td>0-66</td>
<td>7-47</td>
<td>.334</td>
</tr>
</tbody>
</table>

The Vineland Adaptive Behavior Scale-Second Edition (Vineland-II) was used to assess adaptive behavior in individuals with ASDs. Standard scores with a mean of 100 and a standard deviation of 15 were calculated using the Vineland-II Assist scoring software. Higher scores indicate greater levels of adaptive functioning. Table 2 shows that the mean Adaptive Behavior Composite score in this sample (65.08) falls more than two standard deviations below the mean of the standardization sample (100). Over half (64%) of the parents in this sample reported that their child with ASD had a significant impairment in adaptive functioning, with an Adaptive Behavior Composite score below 70. This distribution is slightly negatively skewed, with a skewness of -0.13, such that the left tail is slightly elongated.

The BASC-2 PRS and SRP were used to measure internalizing and externalizing behavior in typically developing siblings. T-scores were calculated, which have a mean score of 50, and a standard deviation of 10. Higher T-scores on the BASC-2 Internalizing and Externalizing Behavior Composites indicate a greater level of concern. T-scores above 70 on the internalizing and externalizing behavior composites fall within the Clinically Significant Range. T scores between 60 and 69 fall within the At-Risk Range. Table 2 shows that the mean score on the SRP Internalizing Composite, which was based on sibling self-report was 46.38. This falls within one standard deviation from the mean of the standardization sample (50). The distribution is positively skewed, with a skewness of 0.781, and an elongated right tail. It is important to note that based on the siblings’ self-report of internalizing behaviors, none of the scores fall within the Clinically Significant Range. Only 4 participants reported internalizing behaviors levels within the At-Risk Range with a T score between 60 and 69.

Table 2 also shows that on the BASC-2 PRS, which the parents completed, the mean scores on both the internalizing and externalizing behavior composites (48.77 and 47.00) fell
within one standard deviation from the mean of the standardization sample (50). Both distributions are positively skewed with skewness statistics of 1.10 and 1.14, respectively. This indicates that in both distributions, the right tail is elongated. Three scores fell within the At-Risk Range on the externalizing behavior composite, while two scores fell within the Clinically Significant Range, with T scores above 70. A higher number of parents reported concerns in terms of sibling internalizing behaviors. Five parents reported scores in the At-Risk Range, while 5 parents reported scores in the Clinically Significant Range.

On the BASC-2 SRP Personal Adjustment Composite, higher scores indicate greater levels of positive adjustment. T scores below 20 fall within the Clinically Significant Range, while T scores between 30 and 39 fall within the At-Risk Range. Table 2 shows that the mean personal adjustment composite score in this sample (53.45) fell within one standard deviation from the mean of the standardization sample (50). The distribution is negatively skewed, with a skewness of -0.708 and an elongated left tail. The majority of siblings reported personal adjustment scores within the Average Range (40-60), with only four scores falling within the At-Risk Range. One sibling reported a personal adjustment score in the Clinically Significant Range, with a T score of 27.

The principal investigator constructed the Sibling Stress Index (SSI) to measure stress in typically developing siblings. The lowest possible score one can receive on the SSI is zero, while the highest possible score is 66. Higher scores indicate greater stress in siblings. Table 2 shows that the siblings in the study sample earned a mean score of 22.47, which is below the midpoint of total possible scores (33), with 86.8% of participants reporting scores below the midpoint. The distribution is slightly positively skewed, with a skewness of 0.334, with an elongated right tail.
Relationship of Demographic Variables to Outcome Variables

Independent samples t-tests, and one-way ANOVA were conducted in order to explore the relationship of specific demographic variables to the outcome variables. The demographic variables selected were the gender and age of the typically developing sibling, birth order, the diagnosis of the child with ASD and family size.

**Gender of Typically Developing Sibling.** Table 3 presents the results of independent samples t-tests conducted to compare the mean scores on the outcome measures for male and female siblings.

Table 3

*Independent Samples t-tests Comparing the Mean Scores of Female and Male Siblings on the BASC-2 PRS, BASC-2 SRP and SSI*

<table>
<thead>
<tr>
<th>Scale</th>
<th>Male (n=23)</th>
<th>Female (n=30)</th>
<th>t</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>BASC-2 PRS Externalizing Behavior Composite</td>
<td>48.05 9.52</td>
<td>46.23 8.80</td>
<td>0.71</td>
<td>50</td>
<td>.482</td>
</tr>
<tr>
<td>BASC-2 PRS Internalizing Behavior Composite</td>
<td>44.73 9.70</td>
<td>51.73 14.97</td>
<td>-2.04*</td>
<td>50</td>
<td>.046*</td>
</tr>
<tr>
<td>BASC-2 SRP Internalizing Behavior Composite</td>
<td>44.52 8.00</td>
<td>47.80 8.30</td>
<td>-1.45</td>
<td>51</td>
<td>.154</td>
</tr>
<tr>
<td>BASC-2 SRP Personal Adjustment Composite</td>
<td>54.35 9.33</td>
<td>52.77 8.80</td>
<td>0.63</td>
<td>51</td>
<td>.530</td>
</tr>
<tr>
<td>Sibling Stress Index</td>
<td>21.43 10.78</td>
<td>23.27 7.35</td>
<td>-0.70</td>
<td>51</td>
<td>.489</td>
</tr>
</tbody>
</table>

*Note*. *p < .05, **p < .01*
The results indicate that a statistically significant difference was found between male ($M = 44.73, SD = 9.70$) and female ($M = 51.73, SD = 14.97$) siblings on the BASC-2, PRS Internalizing Behavior Composite, $t(50) = -2.04, p = .046$, such that parents reported higher levels of stress in female siblings. There were no other statistically significant differences between male and female siblings.

**Sibling Age.** Independent samples $t$-tests were conducted to compare the mean scores on the outcome measures for siblings between the ages of 8-11, and siblings ages 12-18. These groupings were chosen because the BASC-2 uses these age ranges to distinguish children from adolescents. Table 4 presents the results of the $t$-tests, which indicate that there are no statistically significant differences between the groups.
Gender of Sibling with ASD Diagnosis. Independent samples $t$-tests were conducted to compare the mean scores on the outcome measures for siblings who had a brother versus a sister with an ASD diagnosis. Table 5 presents the results of the $t$-tests, which indicate that there are no statistically significant differences between the groups.
Birth Order. Independent samples $t$-tests were conducted to compare the mean scores on the outcome measures for siblings who were older than the child with ASD and siblings who were younger than the child with ASD. It is important to note that there were seven sets of twins in the sample, and the siblings from these families were not included in this analysis. Table 6 presents the results of the $t$-tests, which indicate that there is a statistically significant difference
between older ($M = 44.75, SD = 6.46$) and younger ($M = 50.24, SD = 10.59$) siblings on the BASC-2, PRS Externalizing Behavior Composite, $t(43) = 2.03, p = .048$, such that parents reported higher levels of externalizing behavior in younger siblings. There were no other statistically significant differences between older and younger siblings.

Table 6

**Independent Samples t-tests Comparing the Mean Scores on the BASC-2 PRS, BASC-2 SRP and SSI of Siblings who were Older or Younger than the Child with ASD**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Younger ($n=25$)</th>
<th>Older ($n=21$)</th>
<th>$t$</th>
<th>$df$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BASC-2 PRS Externalizing Behavior Composite</strong></td>
<td>$M = 50.24$</td>
<td>$M = 44.75$</td>
<td>2.03</td>
<td>43</td>
<td>.048</td>
</tr>
<tr>
<td><strong>BASC-2 PRS Internalizing Behavior Composite</strong></td>
<td>$M = 50.28$</td>
<td>$M = 48.25$</td>
<td>.493</td>
<td>43</td>
<td>.624</td>
</tr>
<tr>
<td><strong>BASC-2 SRP Internalizing Behavior Composite</strong></td>
<td>$M = 45.12$</td>
<td>$M = 47.95$</td>
<td>-1.16</td>
<td>44</td>
<td>.251</td>
</tr>
<tr>
<td><strong>BASC-2 SRP Personal Adjustment Composite</strong></td>
<td>$M = 54.36$</td>
<td>$M = 54.14$</td>
<td>.081</td>
<td>44</td>
<td>.936</td>
</tr>
<tr>
<td><strong>Sibling Stress Index</strong></td>
<td>$M = 21.08$</td>
<td>$M = 23.14$</td>
<td>-.803</td>
<td>44</td>
<td>.426</td>
</tr>
</tbody>
</table>

*Note*. Total $n=46$ for all scales, except for the BASC-2 PRS, where $n=45$. BASC-2 PRS = Behavior Assessment System for Children, Parent Report Scale; BASC-2 SRP = Behavior Assessment System for Children, Self-Report of Personality.

**Diagnosis of child with ASD**. Table 7 presents the results of one-way ANOVA tests conducted to determine the relationship of the specific ASD diagnosis to sibling stress, personal
adjustment, internalizing behavior and externalizing behavior. It should be noted that on the
demographic questionnaire, two parents wrote in diagnoses of “High Functioning Autism” and
“Non-Verbal Learning Disability.” These participants were not included in the analysis, as there
was only one participant per group.

Table 7

ANOVA Results Comparing the Effect of ASD Diagnosis on Typical Siblings’ Stress, Internalizing
Behavior, Externalizing Behavior and Personal Adjustment

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Autism (n=27)</th>
<th>Asperger’s (n=5)</th>
<th>PDD-NOS (n=18)</th>
<th>F</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scale</td>
<td>M</td>
<td>SE</td>
<td>M</td>
<td>SE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BASC-2 PRS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Externalizing</td>
<td>45.56</td>
<td>1.85</td>
<td>50.80</td>
<td>3.02</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavior Composite</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internalizing</td>
<td>47.70</td>
<td>2.40</td>
<td>48.40</td>
<td>4.59</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavior Composite</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BASC-2 SRP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internalizing</td>
<td>47.18</td>
<td>1.50</td>
<td>41.40</td>
<td>2.86</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavior Composite</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjustment</td>
<td>54.36</td>
<td>1.76</td>
<td>58.00</td>
<td>2.74</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Composite</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling Stress</td>
<td>23.36</td>
<td>1.49</td>
<td>21.40</td>
<td>4.70</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Index</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. BASC-2 PRS = Behavior Assessment System for Children, Parent Report Scale; BASC-2
SRP = Behavior Assessment System for Children, Self-Report of Personality
Table 7 shows that none of the $F$-statistics obtained were statistically significant, indicating that the type of ASD diagnosis had no relationship to the scores calculated on the outcome measures.

**Family Size.** Table 8 presents the results of one-way ANOVA tests conducted to determine the relationship of family size to the siblings’ stress, personal adjustment, internalizing behavior and externalizing behavior.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Group</th>
<th>$M$</th>
<th>$SE$</th>
<th>$M$</th>
<th>$SE$</th>
<th>$M$</th>
<th>$SE$</th>
<th>$F$</th>
<th>$df$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 Children $(n=31)$</td>
<td>3 Children $(n=13)$</td>
<td>4 Children $(n=8)$</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BASC-2 PRS Externalizing Behavior Composite</td>
<td>45.42</td>
<td>1.29</td>
<td>53.31</td>
<td>3.42</td>
<td>42.88</td>
<td>1.28</td>
<td>4.22*</td>
<td>24</td>
<td>.028</td>
<td></td>
</tr>
<tr>
<td>BASC-2 PRS Internalizing Behavior Composite</td>
<td>45.39</td>
<td>1.94</td>
<td>57.92</td>
<td>4.58</td>
<td>47.00</td>
<td>3.94</td>
<td>4.72*</td>
<td>51</td>
<td>.013</td>
<td></td>
</tr>
<tr>
<td>BASC-2 SRP Internalizing Behavior Composite</td>
<td>43.94</td>
<td>1.20</td>
<td>52.31</td>
<td>2.13</td>
<td>46.50</td>
<td>3.70</td>
<td>5.59*</td>
<td>51</td>
<td>.009</td>
<td></td>
</tr>
<tr>
<td>BASC-2 SRP Personal Adjustment Composite</td>
<td>55.69</td>
<td>1.30</td>
<td>46.92</td>
<td>3.23</td>
<td>55.13</td>
<td>1.55</td>
<td>3.12*</td>
<td>22</td>
<td>.066</td>
<td></td>
</tr>
<tr>
<td>Sibling Stress Index</td>
<td>22.38</td>
<td>1.67</td>
<td>21.77</td>
<td>2.21</td>
<td>24.00</td>
<td>3.32</td>
<td>.153</td>
<td>52</td>
<td>.858</td>
<td></td>
</tr>
</tbody>
</table>

*Note. BASC-2 PRS = Behavior Assessment System for Children, Parent Report Scale; BASC-2 SRP = Behavior Assessment System for Children, Self-Report of Personality

*Welch ANOVA test conducted

$p < .05$
The Levene statistic was statistically significant for the BASC-2 PRS Externalizing Behavior Composite \((F = 6.32, p = 0.004)\) and the BASC-2 SRP Personal Adjustment Composite \((F = 4.32, p = 0.02)\), indicating that the variances between the groups were not homogenous, and the assumption of homogeneity of variances was violated. To account for this, a Welch ANOVA test was conducted for these variables. The degrees of freedom were adjusted to 24 for the Externalizing Composite and 22 for the Personal Adjustment Composite.

Table 8 shows that there is a statistically significant difference between the groups on the BASC-2 SRP Internalizing Behavior Composite, the BASC-2 PRS Internalizing Behavior Composite and BASC-2 PRS Externalizing Behavior Composite. Post-hoc tests revealed that siblings who came from families with a total of three children had higher scores than siblings who came from families with two children on the BASC-2 PRS and SRP Internalizing Behavior Composites. Siblings who came from families with a total of three children had higher scores than siblings who came from families with four children on the BASC-2 PRS Externalizing Behavior Composite. Parents with three children reported more externalizing behaviors in their typically developing children when compared to parents of four children.

**Hypothesis Testing**

**Correlations.** Table 9 presents the Pearson correlations between the scales used to assess problem behavior and adaptive behavior in individuals with ASDs and the scales used to assess internalizing behavior, externalizing behavior, personal adjustment and stress in siblings. The Vineland subdomain scores were included in this analysis to determine if specific aspects of adaptive behavior were associated with sibling adjustment.

**Hierarchical Regression Analyses.** In addition to the correlation analyses, hierarchical regression analyses were conducted to test the hypotheses in this study. Regression equations
were generated for each of the outcome variables, using problem behavior and adaptive behavior as the predictors. When conducting a hierarchical regression, one is able to enter the variables one at a time, or in small groups. A regression equation or model is generated at each step, and one is able to examine the change in models as variables are added. The regression analyses were conducted twice—in the first analysis, problem behavior (the NCBRF Total Score) was entered into the model in the first step (Model 1), and in the second analysis, adaptive behavior (Vineland Total Adaptive Behavior Composite) was entered in the model in the first step (Model 2). These equations indicate the strength of each individual variable in predicting the outcome variable. The full model (Model 3) indicates the strength of both predictors, taken together, in predicting the outcome variable. The full model also indicates how well adaptive behavior predicts an outcome over and above problem behavior. The results of the hierarchical regressions are presented in Tables 10 through 14. It is important to note that all of the variables were graphed to confirm that the relationships between them were linear.
Table 9

Correlations between the NCBRF, Vineland-II, BASC-2 PRS, BASC-2 SRP and SSI

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<tr>
<td>2 Vineland Communication Subdomain</td>
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<td>3 Vineland Daily Living Subdomain</td>
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<td>4 Vineland Socialization Subdomain</td>
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<td>5 Vineland Adaptive Behavior Composite</td>
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<td>6 BASC-2 PRS Externalizing Behavior</td>
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Table 9 (Continued)

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<td>-.195</td>
<td>-.063</td>
<td>-.131</td>
<td>-.155</td>
<td>.660**</td>
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<tr>
<td><em>p</em></td>
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<td>8 BASC-2 SRP Internalizing Behavior Composite</td>
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<td>-.126</td>
<td>-.161</td>
<td>-.161</td>
<td>.203</td>
<td>.448**</td>
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<td><em>p</em></td>
<td>.116</td>
<td>.309</td>
<td>.367</td>
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<td>.249</td>
<td>.149</td>
<td>.001</td>
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<td>9 BASC-2 SRP Personal Adjustment Composite</td>
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<td>.303*</td>
<td>.118</td>
<td>.194</td>
<td>.236</td>
<td>-.257</td>
<td>-.356**</td>
<td>-.641**</td>
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<tr>
<td><em>p</em></td>
<td>.382</td>
<td>.027</td>
<td>.402</td>
<td>.154</td>
<td>.089</td>
<td>.066</td>
<td>.010</td>
<td>.000</td>
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</tr>
<tr>
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<td>53</td>
<td>53</td>
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<td></td>
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<tr>
<td>10 Sibling Stress Index</td>
<td>.291*</td>
<td>-.171</td>
<td>-.209</td>
<td>.351**</td>
<td>-.257</td>
<td>.009</td>
<td>.206</td>
<td>.535**</td>
<td>-.419**</td>
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<tr>
<td><em>p</em></td>
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<td>.222</td>
<td>.133</td>
<td>.010</td>
<td>.064</td>
<td>.949</td>
<td>.142</td>
<td>.000</td>
<td>.002</td>
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</tr>
</tbody>
</table>


* _p_ < .05, ** _p_ < .01
Hypotheses 1 and 2. The first hypothesis stated that adaptive behavior in children with ASDs would be negatively associated with stress, internalizing behaviors and externalizing behaviors in typically developing siblings. The second hypothesis stated that problem behavior in children with ASDs would be positively associated with stress, internalizing behaviors and externalizing behaviors in typically developing siblings. Hypothesis one was not supported, while hypothesis two was partially supported.

Sibling Stress. In Table 9, the negative correlation between the Vineland Adaptive Behavior Composite and the SSI Total Score was not statistically significant, $r(51)= -.257, p = .064$, 95% CI [-0.45, -0.05], while a medium sized effect was detected between the Nisonger Total Score and the SSI Total Score ($r(51) = .291, p = 0.035$, 95% CI [0.1, 0.5]).

The results of the hierarchical regression equations presented in Table 10, indicate that on its own, problem behavior was a statistically significant predictor of sibling stress ($b = 0.12$, $t[51] = 2.17$, $p = 0.035$), while adaptive behavior was not. These results should be interpreted with caution, as problem behavior only accounts for 9% of the variance in sibling stress.

Although the Vineland Adaptive Behavior Composite was not a significant predictor of sibling stress, there was a statistically significant negative correlation, with a medium effect size between the Vineland Socialization subdomain score and the SSI, $I(51)= -.351, I = .01$, 95% CI [-0.56, -0.12]. This suggests that as positive social behaviors in children with ASDs decrease, stress in typically developing siblings increases. These results should be interpreted with caution, as the Vineland Socialization subdomain scores only account for 12% of the variance in sibling stress.
### Table 10

**Summary of Regression Analysis Predicting Sibling Stress from Problem Behavior and Adaptive Behavior**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Model 1</th>
<th>Model 2</th>
<th>Model 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variable</td>
<td>$b$</td>
<td>$b$</td>
<td>$b$</td>
</tr>
<tr>
<td>Constant</td>
<td>17.16&quot;&quot;</td>
<td>33.73&quot;&quot;</td>
<td>28.40&quot;&quot;</td>
</tr>
<tr>
<td>Nisonger Parent Behavior Rating Form</td>
<td>.122&quot;&quot;</td>
<td>.122&quot;&quot;</td>
<td>[0.01-0.23]</td>
</tr>
<tr>
<td>Vineland Adaptive Behavior Composite</td>
<td>-0.17</td>
<td>-.173</td>
<td>[-0.35-0.04]</td>
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<tr>
<td>$R^2$</td>
<td>0.09</td>
<td>0.07</td>
<td>0.15</td>
</tr>
<tr>
<td>$F$</td>
<td>4.71&quot;&quot;</td>
<td>3.60</td>
<td>4.42&quot;&quot;</td>
</tr>
<tr>
<td></td>
<td>(1,51)</td>
<td>(1,51)</td>
<td>(2,50)</td>
</tr>
<tr>
<td>$p$</td>
<td>0.04&quot;&quot;</td>
<td>0.06</td>
<td>0.02&quot;&quot;</td>
</tr>
<tr>
<td>$\Delta R^2$</td>
<td></td>
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<tr>
<td>$\Delta F$</td>
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<td></td>
<td>3.86</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(1,50)</td>
</tr>
</tbody>
</table>

*Note. *$p < .05$, **$p < .01$*
**Internalizing Behavior.** In terms of internalizing behaviors, Table 9 indicates that the negative correlation between the Vineland Adaptive Behavior Composite and the BASC-2 PRS Internalizing Behavior Score was not statistically significant, $r(50) = -0.16$, $p = 0.27$, 95% CI [-0.43, 0.12] and neither was the negative correlation between the Vineland Adaptive Behavior Composite and the BASC-2 Self Report, $r(51) = -0.161$, $p = 0.249$, 95% CI [-0.39, 0.07]. A medium sized effect was detected between the Nisonger Total Score and the BASC-2 PRS Internalizing Behavior Composite Scores ($r(50) = .292$, $p = 0.036$, 95% CI [0.04, 0.51]).

The results of the hierarchical regression analyses presented in Tables 11 and 12 indicate that problem behavior, based on parent report, was a statistically significant predictor of internalizing behavior in typically developing siblings ($b = .018$, $t[51] = 2.16$, $p = 0.036$). Although this first model was statistically significant, and a medium effect was calculated, the results should be interpreted with caution, as the model only accounts for 9% of the variance in internalizing behavior. Problem behavior was not a statistically significant predictor of internalizing behavior, based on sibling self-report, and adaptive behavior was not a statistically significant predictor of either outcome.
Table 11

*Summary of Regression Analysis Predicting Internalizing Behavior (on the BASC-2 PRS) from Problem Behavior and Adaptive Behavior*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Model 1</th>
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<th>Model 3</th>
</tr>
</thead>
<tbody>
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<td>$b$</td>
<td>$b$</td>
</tr>
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<td>50.79**</td>
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<td>0.19*</td>
<td>[0.12-0.35]</td>
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<td>Vineland Adaptive Behavior Composite</td>
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<td>-0.15</td>
<td>[-0.42-0.12]</td>
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<tr>
<td>$R^2$</td>
<td>0.09</td>
<td>0.02</td>
<td>0.11</td>
</tr>
<tr>
<td>$F$</td>
<td>4.65 (1,50)</td>
<td>1.22 (1,50)</td>
<td>2.98 (2,49)</td>
</tr>
<tr>
<td>$p$</td>
<td>0.04*</td>
<td>0.27</td>
<td>0.06</td>
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<tr>
<td>$\Delta R^2$</td>
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</tr>
<tr>
<td>$\Delta F$</td>
<td></td>
<td></td>
<td>1.30 (1,49)</td>
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</table>

*Note.* *p < .05, **p < .01*
### Table 12

**Summary of Regression Analysis Predicting Internalizing Behavior (on the BASC-2 SRP) from Problem Behavior and Adaptive Behavior**

<table>
<thead>
<tr>
<th>Variable</th>
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<th>Model 3</th>
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<th>β</th>
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<td>Constant</td>
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<td>52.89***</td>
<td>49.20***</td>
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<td>Nisonger Parent Behavior Rating Form</td>
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<td>[-0.21-0.20]</td>
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<td>-0.10</td>
<td>-0.10</td>
<td>[-0.27-0.07]</td>
<td>-0.16</td>
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<td>$R^2$</td>
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<td>0.03</td>
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<td>0.07</td>
</tr>
<tr>
<td>$F$</td>
<td>2.55</td>
<td>1.36</td>
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<td>1.98</td>
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<td>(1,51)</td>
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<td>(1,51)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>$p$</td>
<td>0.12</td>
<td>0.25</td>
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<td></td>
<td>0.15</td>
</tr>
<tr>
<td>$\Delta R^2$</td>
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<td></td>
<td></td>
<td></td>
<td>0.03</td>
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<td>$\Delta F$</td>
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<td>1.40</td>
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<td></td>
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<td>(1,50)</td>
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</table>

*Note.* *p* < 0.05, **p** < 0.01
Externalizing Behavior. In Table 9, the small negative correlation between the Vineland Adaptive Behavior Composite and the BASC-2 PRS Externalizing Behavior Score was not statistically significant, $r(50) = -.13, p = .355, 95\% \text{ CI } [-0.46, 0.27]$. A non-statistically significant effect was also found between the Nisonger Total Score and the BASC-2 PRS Externalizing Score, ($r(50) = .263, p = .06, 95\% \text{ CI } [-0.05, 0.53]$), however had the sample size been larger, it is possible that these results would have reached statistical significance. The results of Table 13 indicate that neither problem behavior ($b = 0.122, t[51] = 1.92, p = 0.06$) nor adaptive behavior was a statistically significant predictor of externalizing behavior ($b = -0.87, t[51] = -0.95, p = 0.35$).
Table 13

*Summary of Regression Analysis Predicting Externalizing Behavior from Problem Behavior and Adaptive Behavior*

<table>
<thead>
<tr>
<th>Variable</th>
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<td>Vineland Adaptive Behavior Composite</td>
<td>-0.09</td>
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<td>-0.09</td>
</tr>
<tr>
<td>$R^2$</td>
<td>0.07</td>
<td>0.02</td>
<td>0.09</td>
</tr>
<tr>
<td>$F$</td>
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<td>0.87</td>
<td>2.30</td>
</tr>
<tr>
<td>$p$</td>
<td>0.06</td>
<td>0.36</td>
<td>0.11</td>
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<td>0.02</td>
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<tr>
<td>$\Delta F$</td>
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<td>3.71</td>
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</table>

*Note. *$p < .05, **p < .01*
**Hypotheses 3 and 4.** The third hypothesis stated that adaptive behavior in children with ASDs would be positively associated with personal adjustment in typically developing siblings. The fourth hypothesis stated that problem behavior in children with ASDs would be negatively associated with personal adjustment in typically developing siblings.

**Personal adjustment.** Table 9 shows that the positive correlation between personal adjustment and the Vineland Adaptive Behavior Composite was not statistically significant, \( r(51) = .24, p = .089, 95\% \text{ CI } [-0.03, 0.51] \). A small to moderate, non-statistically significant effect was detected, but the results may be inconclusive caution due to the small sample size and low statistical power. Had the sample size been larger, it is possible that these results would have reached statistical significance.

Table 9 shows that there is a positive correlation between the Vineland Communication subdomain score and the Personal Adjustment Composite. This correlation is statistically significant, \( r = .30(51), p = 0.03, 95\% \text{ CI } [0.06, 0.55] \), and suggests that as communication skills in individuals with ASDs increase, personal adjustment in typically developing siblings increases. The effect size suggests that these results should also be interpreted with caution, as the Vineland Communication subdomain scores account for just 9% of the variance in personal adjustment.

The negative correlation between the Nisonger Total Score and the BASC-2 Personal Adjustment Composite score was not statistically significant, \( r(51) = -.123, p = .382, 95\% \text{ CI } [-0.38, 0.15] \). Table 14 indicates that neither problem behavior \((b = -0.05, t[51] = -0.88, p = 0.38)\), nor adaptive behavior was a statistically significant predictor of externalizing behavior \((b = 0.16, t[51] = 1.73, p = 0.09)\). Hypotheses three and four are not supported.
Table 14

*Summary of Regression Analysis Predicting Personal Adjustment from Problem Behavior and Adaptive Behavior*

<table>
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<th>( \beta )</th>
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<td>43.09**</td>
<td>45.34**</td>
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<td></td>
</tr>
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<td>-0.05</td>
<td>[-0.17-0.06]</td>
<td>-0.12</td>
<td></td>
</tr>
<tr>
<td>Vineland Adaptive Behavior Composite</td>
<td>0.16</td>
<td>0.16</td>
<td>[-0.03-0.34]</td>
<td>0.24</td>
<td></td>
</tr>
<tr>
<td>( R^2 )</td>
<td>0.02</td>
<td>0.06</td>
<td></td>
<td>0.07</td>
<td></td>
</tr>
<tr>
<td>( F )</td>
<td>0.78 (1.51)</td>
<td>3.00 (1.51)</td>
<td>1.90 (2.50)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>( p )</td>
<td>0.39</td>
<td>0.09</td>
<td></td>
<td>0.16</td>
<td></td>
</tr>
<tr>
<td>( \Delta R^2 )</td>
<td></td>
<td></td>
<td>0.06</td>
<td></td>
<td></td>
</tr>
<tr>
<td>( \Delta F )</td>
<td></td>
<td></td>
<td>1.90 (1.50)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note. *p < .05, **p < .01*
Hypothesis 5. Hypothesis five stated that adaptive behavior levels in children with ASDs would predict stress, personal adjustment, internalizing behaviors and externalizing behaviors in typically developing siblings over and above problem behavior levels in children with ASDs. Tables 10 through 14 indicate that the full model, with both independent variables as predictors, was only statistically significant for sibling stress ($F(2,50) = 4.42, p = 0.02, R^2 = 0.15$). Although adaptive behavior was not a statistically significant predictor of sibling stress on its own, it added an additional 7% of the explained variance to the full model, and the results also reached statistical significance ($\Delta R^2 = 0.07$) for a total explained variance of 15%.

On its own, problem behavior was a statistically significant predictor of internalizing behavior based on parent report, ($b = .018, t[51] = 2.16, p = 0.036$), but the full model with both predictors was not statistically significant. Adaptive behavior only contributed an additional 2% of the explained variance ($\Delta R^2 = 0.02, F(1,50) = 2.98, p = 0.06$).

The full models were not statistically significant for sibling externalizing behavior, personal adjustment or internalizing behavior, based on sibling self-reports. For these outcomes, adaptive behavior did not contribute a statistically significant amount of explained variance over and above problem behavior. Hypothesis five is partially supported.

Summary of Results

Table 15 presents a summary of the results of hypothesis testing. Two out of the five hypotheses received partial support.
<table>
<thead>
<tr>
<th>Hypothesis</th>
<th>Support</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HO1</strong> Adaptive behavior in children with ASDs will be negatively associated with levels of stress, internalizing behaviors and externalizing behaviors in typically developing siblings.</td>
<td>Not Supported</td>
</tr>
<tr>
<td><strong>HO2</strong> Problem behavior levels in children with ASDs will be positively associated with stress in typically developing siblings, as well as internalizing behaviors and externalizing behaviors.</td>
<td>Partially Supported: Nisonger Total scores were statistically significant predictors of SSI and BASC-2 PRS Internalizing Behavior Composite Scores.</td>
</tr>
<tr>
<td><strong>HO3</strong> Adaptive levels of adaptive behavior in children with ASDs will be positively associated with personal adjustment scores in typically developing siblings.</td>
<td>Not supported</td>
</tr>
<tr>
<td><strong>HO4</strong> Problem behavior levels in children with ASDs will be negatively associated personal adjustment scores in typically developing siblings.</td>
<td>Not Supported</td>
</tr>
<tr>
<td><strong>HO5</strong> Adaptive behavior levels in children with ASDs will predict stress, personal adjustment, internalizing behaviors and externalizing behaviors in typically developing siblings over and above problem behavior levels.</td>
<td>Partially Supported: In terms of sibling stress, Vineland Adaptive Behavior Composite scores explained an additional 7% of the variance over and above Nisonger Total scores.</td>
</tr>
</tbody>
</table>
Chapter 5

Discussion

The goal of the current study was to explore the relationship between both problem and adaptive behavior in children with ASDs and stress, personal adjustment and internalizing and externalizing behaviors in typically developing siblings. The results of this study are discussed below, and the strengths and contributions of the study are presented. After a review of the study limitations, the educational implications and suggestions for future research are outlined.

Problem and Adaptive Behavior in Children with ASDs in Relation to Sibling Adjustment

Problem Behavior. The first research question sought to answer whether problem behavior levels in children with ASDs were associated with stress, personal adjustment and internalizing and externalizing behaviors in typically developing siblings. Previous research indicated that high levels of problem behavior in children with ASDs were associated with higher levels of parental stress (Benson, 2010; Herring et al, 2006; Konstantares & Homtidis, 1989; Lecavalier, Leone & Wiltz, 2006; Tomanik, Harris & Hawkins, 2004), but this relationship had never been explored with typically developing siblings. Based on the prior research, the hypotheses for the current study stated that higher levels of problem behaviors in individuals with ASDs would be associated with higher levels of stress, internalizing and externalizing behaviors in typically developing siblings. The hypotheses also stated that higher levels of problem behaviors in individuals with ASDs would be associated with lower levels of personal adjustment in siblings.

The results of this study partially supported these hypotheses. The findings indicated that there was no relationship between problem behavior in children with ASDs and personal adjustment in typically developing siblings. There was a statistically significant association
between problem behaviors in individuals with ASDs and stress in siblings, as higher levels of problem behavior were associated with higher stress ratings in typically developing siblings. Sibling stress was defined as stress within the sibling relationship, resulting from characteristics of the child with ASD. Practically speaking, typically developing siblings reported more stress in the sibling relationship as problem behaviors in diagnosed siblings increased.

The results of this study suggest that problem behavior in individuals with ASD can be used to predict stress in typically developing siblings. Not only are these results statistically significant, but they are also practically significant for professionals working with siblings and families of children with ASDs. The results suggest that professionals should consider problem behavior in individuals with ASDs as a factor in identifying typically developing siblings who may be at-risk.

There was no association between problem behaviors in individuals with ASDs and externalizing behaviors in typically developing siblings, which was assessed only with parent-reports. There was a statistically significant association between problem behavior in individuals with ASDs and parent-reports of internalizing behaviors in typically developing siblings. However, the association between problem behavior and sibling self-reports of internalizing behavior was not statistically significant. This is an important finding because much of the prior research determined sibling outcomes using parent reports only (Fisman, et al., 2000; Hastings, 2007; Meyer, Ingersoll & Hambrick, 2011; Petalas, et al, 2009; Rodrigue, Geffken & Morgan, 1993; Ross & Cuskelly, 2006; Verte, Roeyers & Buysse, 2003).

The results of this study suggest that parent and sibling reports are not always in agreement. Parent reports should not be used in place of sibling self-reports, as a child may rate his or her own behavior and feelings differently than a parent. The difference in reported ratings
may be due to dynamics within the family system that were not identified in this study. It is essential to include parent reports and sibling self-reports in future research order to obtain a more comprehensive understanding of sibling behavior and the family system as a whole.

**Adaptive Behavior.** The second research question looked at whether adaptive behavior levels in individuals with ASDs were associated with stress, personal adjustment, internalizing and externalizing behaviors in typically developing siblings. Research on parents of children with ASDs indicated that weak adaptive behavior skills in diagnosed children were associated with higher levels of parental stress (Tomanik, Harris & Hawkins, 2004). The current study sought to explore the effect of adaptive behavior skills on typically developing siblings. The hypotheses were in line with the parent research and stated that lower levels of adaptive behavior would be associated with increased stress, internalizing and externalizing behaviors in typically developing siblings, as well as lower levels of personal adjustment. The results of this study did not support these hypotheses, as the Vineland Adaptive Behavior Composite scores were not found to be associated with sibling stress and/or behavior.

Although overall adaptive behavior levels were not related to sibling outcomes, the results suggest that specific aspects of adaptive behavior may affect siblings. The Vineland Socialization Domain score was found to be associated with sibling stress. This is meaningful, as it suggests that typically developing siblings can experience more stress if their diagnosed sibling has weak social skills. In sibling relationships where both children are typically developing, siblings acquire critical social skills by interacting with one another (Seligman & Darling, 2007). In sibling relationships where one sibling has ASD, the quality of the social interaction is not the same as it would be in a typical sibling relationship. One of the hallmarks of ASD is a deficit in socialization, but the degree of deficit varies among individuals. This
study suggests that the level of social impairment in children with ASD is an important factor in determining the level of stress that typically developing siblings report.

In addition to socialization, the results of the current study suggest that the communication skills of the diagnosed sibling may affect typically developing siblings. The Vineland Communication Domain score was positively associated with personal adjustment in typically developing siblings. Personal adjustment in typically developing siblings increased as communication skills in the diagnosed siblings increased. This is consistent with the results of Pilowsky et. al. (2004), who found that adjustment in siblings of children with autism was related to the verbal ability of the disabled siblings. The more verbal the disabled sibling, the more well-adjusted the typically developing sibling.

The diagnosed sibling’s ability to independently perform activities of daily living was not related to any of the sibling outcomes, and this may be explained by a few factors. If typically developing siblings are not asked to take care of their sibling with ASD on an ongoing basis, they may not regularly assist their brother or sister with daily living tasks. Because this sample looked at siblings between the ages of 8 and 18, some of the typically developing siblings who participated in this study may have been too young to act as caretakers, and others may simply not have been required to fulfill that type of role in their family. While daily living skills may not have a direct effect on sibling adjustment, if weak daily living skills increase parent stress, it is likely that this can negatively affect siblings. This relationship was not investigated as part of this study, but should be examined in future research.

Effect of Demographic Variables

**Gender of Typically Developing Sibling.** There were several demographic variables of interest that were explored in this study, the first of which was gender. The results of prior
research on siblings of children with ASDs were conflicting with regard to the effect of gender on sibling outcomes. (Hastings, 2007; Ormond & Seltzer, 2009; Ross & Cuskelley, 2006). Two of the three prior studies that found significant gender effects were based on parent-report only, and did not include sibling self-reports. The results of the current study found that there were no differences between male and female sibling self-reports of stress, personal adjustment or internalizing and externalizing behavior. There was a statistically significant difference in the parent reports of internalizing behaviors, with parents of female siblings reporting higher levels of internalizing behaviors in their children than parents of male siblings. This provides additional support for the need to include both parent and self-report measures in future studies with this population.

The parents in this sample may have rated their daughters highly on this scale because they believed that they were or should be experiencing internalizing problems, such as anxiety or depression. These beliefs may stem from patterns of behavior that the parents have observed within the family, or from assumptions they made about their children’s feelings. The parents’ own level of stress may have also affected these ratings.

**Sibling Age.** While one study found that typically developing siblings who are between the ages of 6 and 11 are at a greater risk for developing internalizing and externalizing behavior problems (Verte, Roeyers & Buysse, 2003), most of the prior research indicates that the age of the sibling is not related to internalizing or externalizing behavior levels. The results of the current study are consistent with these findings, and indicate that while age is not a risk factor, it is also not a protective factor. Some parents may believe that as the typically developing child gets older and moves though adolescence, he or she will be less affected by the child with ASD.
The results of the current study suggest that this is not the case, and that age has no relationship to sibling outcomes.

**Gender of Child with ASD Diagnosis.** Prior research indicated that siblings who had a brother with an ASD reported higher levels of emotional problems when compared to siblings who had a sister with an ASD (Petalas et. al., 2009). The results of the current study indicated that the gender of the child with the ASD diagnosis was not related to outcomes in typically developing siblings. In looking at these findings, it is important to consider that males are five times more likely than females to receive an ASD diagnosis (Centers for Disease Control and Prevention, 2012). Therefore, the population of typically developing siblings who have a sister with an ASD diagnosis is much smaller than the population of siblings who have a brother with an ASD diagnosis. In the current study, 83% of the siblings had a brother with an ASD diagnosis, while only 17% had a sister with an ASD diagnosis. It is possible that because the percentage of siblings who have a sister with an ASD diagnosis is so small, it is difficult to truly determine to the extent to which the gender of the diagnosed child affects sibling outcomes.

**Birth Order.** Prior researchers found that typically developing siblings who were younger than child with ASD, evidenced higher levels of emotional and adjustment problems, while older siblings exhibited higher levels of prosocial behavior and had a more positive view of their disabled sibling (Hastings, 2003; Hastings, 2007; Petalas et. al, 2009; Pilowsky et. al, 2004). The results of this study found that based on parent reports, typically developing siblings who were younger than the child with ASD had higher levels of externalizing behavior, when compared to siblings who were older than the child with ASD. These results are consistent with some of the prior research.
One possible explanation for these results is that siblings who are younger than the child with ASD exhibit higher levels of externalizing behaviors because they have not yet developed coping skills, and they may have difficulty appropriately managing stressful situations that arise at home. It is also possible that the child with the ASD diagnosis acts as a model for younger siblings. In families where the child with ASD exhibits high levels of problem behavior, younger siblings may emulate this behavior because they model the behavior of the older, diagnosed child.

It is important to note that there were seven sets of twins included in the study sample. In each of these dyads, one child had an ASD diagnosis and one child was typically developing. None of the prior sibling research included information about outcomes for typically developing children who have a twin with ASD. This is a unique relationship and should be explored in future research.

**Family Size.** In terms of family size, prior researchers found that larger family size was associated with better psychosocial adjustment in typically developing siblings (Kaminsky and Dewey, 2002). The results of this study found that siblings who came from families with a total of three children, had higher scores than siblings who came from families with two children on both parent and self-reports of internalizing behaviors. In addition, siblings who came from families with a total of three children also had higher scores on parent reports of externalizing behavior. This finding is in contrast to prior research, and may be due to patterns of behavior or family dynamics in families with three children, which were not identified in this study. One possibility is that in families with three children, where one child has an ASD diagnosis, the two typical siblings may be competing for attention from their parents. If this is the case, this may lead to higher levels of internalizing behaviors.
ASD Diagnosis. No differences were found in sibling stress, personal adjustment or behavior based on the specific ASD diagnosis in the disabled sibling. This finding is practically significant because it suggests that simply having a sibling with ASD does not necessarily put typical siblings at risk for negative outcomes. Individuals with ASD diagnoses fall along a continuum that represents a wide range of functioning and behavior, and this was not considered in much of the previous research. Recent changes to the DSM-V (American Psychiatric Association, 2013) encourage thinking about ASDs in this way, as specific diagnostic categories have been eliminated and replaced with a broad “umbrella” diagnosis of ASD.

The current study suggests that certain patterns of behavior, specifically high levels of problem behavior and weak communication and social skills, can put siblings at risk. This helps to clarify some of the inconsistency in the extant literature and also suggests ways in which professionals may be able to proactively identify typically developing siblings who may be at-risk.

Study Strengths and Contributions

The current study contributes to the literature on siblings of children with ASDs in a number of ways. While previous researchers have examined internalizing and externalizing behaviors in typically developing siblings of children with ASDs, a majority of this research has looked at typically developing siblings of children with one specific type of ASD diagnosis (Bagenholm & Gillberg, 1991; Fisman et al, 2000; Hastings, 2003, 2007; Kaminsky & Dewey, 2001, 2002; Pilowsky, 2004; Rodgrigue, Geffken & Morgan, 1993; Ross & Cuskelley, 2006; Verte, Roeyes & Buysse, 2003). It is likely that the diagnosed children in these studies had a wide range of behavioral profiles, but the relationship between behavior in children with ASDs and outcomes in typically developing siblings was not explored. The current study is the first to
explore the relationship between both problem behavior and adaptive behavior in children with ASDs and behavior, stress and personal adjustment in typically developing siblings.

While many researchers have examined internalizing and externalizing behaviors in typically developing siblings of children with ASDs, to date, there have not been any studies that have examined stress in these siblings. Stress has been examined in many studies on parents of children with ASDs, and most of these studies have utilized the Parenting Stress Inventory (PSI) (Abidin, 1995.) This measure is designed to assess aspects of the parent-child system that may increase the level of stress in the parent-child relationship. This researcher felt that it was important to explore stress within the sibling relationship, and because there is no child measure that is comparable to the PSI, she developed the Sibling Stress Index (SSI.) By using the SSI in addition to the BASC-2, this researcher was able to assess internalizing and externalizing behaviors using a broad, normative measure, and sibling stress using a measure that is specific to the sibling relationship. The results of the study, which indicated that increased stress in typically developing siblings was associated with higher levels of problem behavior in siblings with ASDs, suggest that it is important for professionals to assess and address sibling stress in this population.

Another strength of this study, as mentioned previously, is that it used both parent and self-reports to assess behavior in typically developing siblings. Much of the prior research relied solely on parent reports to measure internalizing and externalizing behaviors in siblings, and this may have contributed to some of the inconsistency of the results. While parent reports are an important part of behavior assessment in children, they do not provide a complete and comprehensive picture. Parent reports and self-reports from children may differ, which was indicated in the results of the current study. Differences in these behavior ratings are important
to explore further, as they may be indicative of problematic family functioning patterns, or larger issues within the family system.

The methodology of the current study helps to improve upon the existing sibling literature. As discussed above, the addition of a sibling stress measure, as well as the use of both parent and self-report measures allowed the principal investigator to examine variables and relationships that were not looked at in prior research. In addition, much of the prior research looked at whether simply having a sibling with an ASD diagnosis put typically developing siblings at risk. The current study suggests that this is not the case, but rather, that there are specific patterns of behavior in children with ASDs that can affect sibling outcomes.

**Study Limitations**

Although the current study has a number of strengths, there are several limitations that need to be considered. One of these limitations is the small sample size. Over a nearly two-year data collection period, the principal investigator was able to obtain completed packets from 53 sets of parents and siblings. While the response rate for the study was 59% (53 out of 89 packets completed and returned), information about the study was distributed to potential participants by directors from over 50 different agencies and schools. A large number of families who fit the criteria received recruitment materials, but only a small percentage of these families indicated that they were interested in participating.

The low level of interest and small sample size may be explained by several factors. Parents of children with special needs may have less free time than parents of typically developing children. Many of these parents are overwhelmed with additional responsibilities that may include taking their disabled children to therapies and doctors, and providing assistance to their children at home.
It is important to note that of the 53 families who participated in this study, approximately 70% of these families reported an annual household income over $100,000. Although information about the study was distributed to parents with varying levels of income, most of the parents who responded to the recruitment flyer reported incomes on the higher end of the scale. This is not representative of the larger population of families of children with ASD, which may limit the generalizability of the results. It is possible that the majority of parents who participated in this study had less financial stress and/or greater access to resources and support because of their high socioeconomic status. These parents may have had more time to devote to completing the research packet, when compared to parents with lower socioeconomic status.

The recruitment materials for this study estimated that the time commitment for parents was between 45 and 60 minutes. Parents of children with ASD who received these materials may have seen the time estimate, and chose not to respond because they thought it would be too difficult to find the time to complete the study packet. These reasons may also explain why parents who expressed interest in the study and were sent packets, did not return them, even with several follow-up emails from the principal investigator. In addition, the parents who were sent packets may have been overwhelmed by the number of pages in the packet and the large number of items they were asked to answer.

Small sample size has been a methodological issue for many researchers conducting studies with this population. This issue was highlighted in Meaden, Stoner and Agnell’s (2009) review of the literature on siblings of children with ASDs, as most of the studies cited in this review had between 20 and 50 participants (Fisman et al, 2000; Hastings, 2003a, 2007; Kaminsky & Dewey 2002; Macks & Reeve, 2007; Petalas et al, 2009; Pilowsky et al, 2004; Ross & Cuskelley, 2006; Verte, Roeyers & Buysse, 2003). With 53 sets of parents and typically
developing siblings, the sample size of the current study is slightly greater than many of the previous studies. However, the principal investigator’s initial goal was to obtain at least 107 sets of parent and typically developing siblings in order to have enough power to detect a medium sized effect.

The results of a power analysis using G*Power 3 (Faul, Erdfelder, Lang & Buchner, 2007) indicate that the statistical power of the current study is .69. In other words, there is a 69% chance of detecting a true effect or relationship between variables. Although some of the results were statistically significant, all of these results need to be interpreted with caution due to the small sample size. In all of these cases, the amount of total variance explained was between 9% and 12%. Had the sample size been larger, and the statistical power been higher, one may be able to interpret these results with more confidence. Similarly, the results which were not statistically significant should also be interpreted with caution. It is possible that in reality, an effect exists between these variables, but it was not detected due to the sample size and low statistical power. The small sample size of the current study, as well as the majority of studies on siblings of children with ASDs, suggests that it is particularly difficult to obtain data from this population and future researchers should carefully consider ways in which to increase study participation.

While the development and use of the SSI allowed the principal investigator to assess a construct that has not previously been studied in typically developing siblings of children with ASDs, the scores on the SSI obtained in this study were not compared to siblings of typical children. On the SSI, the typically developing siblings who participated in this study were asked to answer questions about aspects of their sibling relationship and characteristics of their brother or sister that might contribute to an increase in stress. The principal investigator was able to
obtain an average stress score for the participants of this study, but it is not clear how this score compares to the stress levels of siblings of typically developing children.

One can assume that if the SSI were administered to siblings of typical children, they would report some stress within the relationship. It is important for professionals working with families of children with ASDs to be aware of whether having a sibling with ASD puts children at-risk for developing a higher level of stress than what would be expected in a relationship where neither sibling has a disability.

Another limitation of this study is that the parents who participated in this study only provided information about their children’s functioning and behavior, and not their own. The PSI and Family Adaptability and Cohesion Evaluation Scales (FACES) were initially included in this study in order to assess parent stress and family functioning. Using a family systems framework, the principal investigator had hoped to be able to explore the relationship between parent stress and sibling stress in families of children with ASDs. The principal investigator had also planned to measure family functioning in these families in order to better understand the impact that children with ASDs have on the family system as a whole. Including the PSI and FACES in the study packet increased the completion time by 30 minutes for a total of 75 to 90 minutes.

When the principal investigator started collecting data, these two measures were included in the packet. During a five-month period, only 12 families who fit the criteria expressed interest in the study. These families all received packets, but only 4 families completed and returned them. Feedback from the parents who completed the measures, as well as directors of the organizations who distributed the recruitment materials, indicated that the parent packet was
quite lengthy, and that the time estimate of 75 to 90 minutes was most likely a deterrent for many families.

After receiving this feedback, the principal investigator eliminated the PSI and FACES from the research packet. These measures were chosen because they would reduce the total completion time for parents, while still allowing the principal investigator to examine the relationship between behavior levels in children with ASDs and sibling outcomes.

In order to gauge whether future researchers should include parental stress and family functioning in studies about siblings of children with ASDs, the principal investigator included questions about these variables on the demographic questionnaire. Based on the responses to these questions, 43.4% of the parents who participated in this study reported that they were experiencing a high level of stress. These high levels of parental stress may affect the entire family system, and should be studied. Although only 5.7% of parents reported concerns about family functioning, some of the findings of the current study may be explained by family dynamics or functioning patterns, suggesting that family functioning should also be studied with this population.

In addition to the limitations discussed above, some members of the sibling population were excluded from the study, and this may have affected the results. In families where more than one typically developing sibling was eligible to participate in the study, the parent determined which sibling participated in the study. It is possible that the parent chose the sibling who they believed was better adjusted, or the sibling who they had more concerns about. By making this choice, the parents may have excluded at-risk siblings from participating, which may have affected the results.
The principal investigator made a decision to exclude siblings who had a psychiatric diagnosis because she would have been unable to determine if that diagnosis was related to having a sibling with an ASD diagnosis, or if that diagnosis was intrinsic to that child. She also excluded typically developing siblings who were receiving individual therapy because she believed that participating in ongoing therapy might affect a sibling’s behaviors, as well as his or her level of stress and personal adjustment. The results of this study may have been affected because potential participants who fell into one or both of these categories were excluded.

Finally, it is possible that the ratings of sibling stress, personal adjustment and behavior were affected by variables that were not considered in this study. One variable that the principal investigator did not assess was the families’ level of social and extended family support. Prior research has shown that both formal and informal social support can have a positive affect on siblings and families (Hastings, 2003b; Rivers & Stoneman, 2003). No information was obtained about whether the families in this study were accessing informal and/or formal social support, or whether they were receiving support from extended family members. In addition, no information was obtained about the siblings’ level of peer support and their social network. These variables may have affected sibling outcomes in the study sample.

**Educational Implications**

As the prevalence of ASDs continues to increase, the number of typically developing children who have a brother or sister with this diagnosis also continues to increase. It is critical for psychologists, social workers, therapists, doctors and other professionals working with these families to understand how a child with ASD affects the family system. The findings of the current study, which highlight a relationship between problem behaviors in children with ASDs
and stress in typically developing siblings, are important for professionals to consider as they formulate the types of interventions and supports that will be most appropriate for siblings.

With the results of this study in mind, professionals may want to devote some of their work with typically developing siblings to helping them learn strategies and acquire tools that they can use when their diagnosed sibling is engaging in problem behaviors. If typically developing siblings feel more confident in their ability to manage and cope with their diagnosed sibling’s behavior, they may feel less stress within the relationship. Typically developing siblings may need to spend time discussing their feelings in regard to their sibling’s problem behavior, and they may need to reflect on stressful situations during counseling or treatment sessions.

Professionals working with this population should also be aware of the findings with regard to specific aspects of adaptive behavior and their relationship to sibling adjustment. Increased stress in siblings was found to be associated with lower socialization scores on the Vineland, and lower levels of personal adjustment was found to be associated with lower communication scores on the Vineland. The results suggest that professionals working with this population may need to spend some time with the typical sibling and the diagnosed sibling together. Some of this time should be focused on helping the siblings communicate more effectively and interact more positively. While a child with an ASD diagnosis may be limited in terms of his or her communication and social skills, typically developing children can be taught tools and strategies to help them engage with their sibling. Professionals may also need to provide some support to the child with ASD, as he or she may need to utilize alternative communication strategies and/or devices if his or her verbal skills are low.
There is some research on sibling support groups for typically developing siblings of children with a variety of disabilities (D’Arcy, Flynn, McCarthy, O’Connor & Tierney, 2005; Dyson, 1998; Evans, Jones & Mansell, 2001; Smith & Perry, 2005). Many of these groups have included lessons designed to help typically developing siblings develop coping strategies so that they can deal with challenging situations. The results of the current study indicate that typically developing siblings of children with ASDs can certainly benefit from this type of intervention. The results suggest that typically developing siblings whose diagnosed siblings have high levels of problem behavior or low levels of communication and social skills are at-risk for experiencing negative outcomes, and these siblings should be given first priority if a sibling support group is available.

Although this study focused on siblings of children with ASDs, professionals should be mindful of the results when they are working with parents. The family systems model asserts that family functioning impacts both individual members as well as the relationships that exist between members (Turnbull & Turnbull, 2011). Parents may be able to reduce stress in the sibling relationship by modeling and teaching the typically developing sibling how to approach and handle their brother or sister’s problem behavior. Parents may also be able to reduce stress and increase the typically developing sibling’s personal adjustment if they help to model and promote positive social interactions between the siblings. These interventions will not only promote a more positive sibling relationship, but they may affect overall family functioning. If the stress level in the sibling relationship is low, and the typically developing sibling is feeling well-adjusted, this will have a positive impact on how the family functions as a unit.
**Directions for Future Research**

The principal investigator sought to clarify the research on siblings of children with ASDs, by improving upon the methodology and focusing on associations between problem and adaptive behavior and typically developing siblings. Not only do the findings of the current study help professionals gain a better understanding of siblings of children with ASDs, they also indicate directions for future research.

This study was the first to explore the construct of sibling stress in typically developing siblings of children with ASDs. Future researchers should further investigate this construct with the SSI, or consider developing an alternate measure of sibling stress. Because the SSI was modeled after the PSI, it did not assess how having a sibling with ASD would affect a typically developing sibling’s social interactions, or how outside peers might influence a typically developing sibling’s feelings. Researchers should consider including these types of items in future measures of sibling stress.

Any measure of sibling stress that is developed should be administered to siblings of typically developing children so that comparisons in stress levels can be drawn. As mentioned previously, future studies should also examine the relationship between parental stress and sibling stress in order to gain a better understanding of the family system and the impact that a child with ASD has on the family as a whole.

A strength of this study is that it included both parent and self-report measures to assess internalizing behaviors in typically developing siblings. Future researchers should consider including teacher reports in order to obtain information about how siblings behave in their school environment. This would result in a more comprehensive understanding of sibling functioning,
and it may also help practitioners guide their interventions when parent reports and sibling self-reports are not in agreement.

In addition to conducting additional studies on the impact of having a sibling with ASD, future researchers should expand on the studies that assessed interventions for typically developing siblings. This research should measure sibling stress and behavior both pre and post-intervention, and should look at individual and group treatment. As part of the treatment, siblings should learn strategies and be shown tools that they can use when their diagnosed sibling is engaging in problem behaviors. These tools and strategies should be tailored to address the specific problem behaviors that the diagnosed child exhibits.

Future researchers should also aim to obtain a larger sample size in order to increase the generalizability of study results. This may be accomplished by decreasing the amount of time needed to complete the study materials. Future researchers might consider reviewing records and previous evaluations in order to obtain information about adaptive behavior levels in children with ASDs. Online or computerized measures should also be explored, as participants may be more likely to complete these measures, as opposed to writing on hard copies and submitting the information in the mail.

Researchers conducting studies with this population in the future may be able to recruit more participants by offering incentives for study participation that parents feel might be beneficial to their families. Parents may be more willing to participate in research if they were going to receive resources and/or training that would allow them to learn about tools and strategies that they could implement in their households. For example, researchers could offer workshops for parents on handling challenging behaviors at home, or improving social interactions between their diagnosed and typically developing children. Parents may view these
tools and strategies as valuable and potentially necessary, which may increase their interest and participation in research.
Appendix A
Detailed Summary of Exploratory Pilot Study

After a gap in the sibling literature was identified, an exploratory pilot study was designed and conducted. The goal of the study was to explore the relationships among problem and adaptive behavior levels in children with ASD, parental stress and sibling behaviors. The pilot study addressed some of the methodological issues that were brought to light in the review of the sibling literature. Specifically, internalizing and externalizing behaviors in the siblings were assessed using both parent and self-report forms. In addition, siblings of children with any type of ASD diagnosis were eligible to participate in the study. The primary aim of the study was to explore whether factors that contribute to increased parental stress, also contribute to increased levels of internalizing and externalizing behaviors in siblings of children with ASDs. The details of this study are outlined below.

Hypotheses

H1: Low levels of adaptive behavior in children with ASDs (as measured by the Vineland-II Adaptive Behavior Composite score) will be associated with higher levels of parental stress (as measured by the Parenting Stress Index).

H2: High levels of problem behavior in children with ASDs (as measured by the Nisonger Child Behavior Rating Form) will be associated with higher levels of parental stress (as measured by the Parenting Stress Index).

H3: Typically developing siblings of children with ASDs who have lower adaptive behavior (as measured by the Vineland-II Adaptive Behavior Composite) will have higher levels of internalizing and externalizing behaviors (as measured by the BASC-2).
H₄: Typically developing siblings of children with ASDs who have greater problem
behaviors (as measured by the Nisonger Child Behavior Rating Form) will have higher
levels of internalizing behaviors and externalizing behaviors (as measured by the BASC-2).

H₅: Adaptive behavior (as measured by the Vineland-II Adaptive Behavior Composite)
and problem behavior (as measured by the Nisonger Parent Behavior Rating Form) in
children with ASDs will predict internalizing and externalizing behaviors in typically
developing siblings (as measured by the BASC-2).

H₆: High levels of parental stress (as measured by the Parenting Stress Index) will be
associated with greater internalizing and externalizing behaviors in typically developing
siblings (as measured by the BASC-2).

Participants

The participants for this study were eleven sets of parents and siblings of children with
ASD recruited from three special recreation agencies in Westchester, New York. Siblings with
psychiatric diagnoses, or who were receiving individual therapy were not eligible to participate
in the study. None of the participants met the exclusionary criteria for the study. Three fathers
and eight mothers with an average age of 44.8 years completed the questionnaires.

Seven female and four male typically developing children participated in the study. The
average age of these children was 11.54 years. Each child had a sibling with an ASD diagnosis.
Of the eleven siblings with ASD, seven had a diagnosis of autism, and four had a diagnosis of
PDD-NOS. Two were female and nine were male, with an average age of 13.27 years.
Measures

The Nisonger Children Behavior Rating Form-Parent Version (NCBRF) (Aman et al., 1996; Tasse et al., 1996) was be used to assess behavior problems in the children with autism spectrum disorders. The NCBRF is a 76-item rating scale that assesses social competence and problem behavior in children and adolescents with developmental disabilities. (The 10 social competence items will not be used for the purposes of this study, as social and adaptive behavior will be assessed with the Vineland-2.) The 66 problem behavior items load on six subscales: conduct problems, insecure/anxious, hyperactive, self-injury/stereotypic, self-isolated/ritualistic and overly sensitive. Parents rate their child’s behavior over the past month using a Likert scale that ranges from 0 (the behavior did not occur or was not a problem) to 3 (the behavior occurred a lot or was a severe problem). A total score is calculated for each scale, and norms can be used to obtain t-scores and percentile rankings for each scale score.

The NCBRF-Parent Version was originally normed on 326 children with mental retardation (Aman et al, 1996; Tasse et al., 1996). Aman et al. (1996) provides details about the reliability and validity of the scale with this population. They found the internal consistency of the problem behavior subscales to be between .77 and .93, with a median value of .85. To assess convergent validity, the authors looked at the correspondence between the NCBRF and the Aberrant Behavior Checklist (ABC). The ABC is a rating scale that was designed to assess treatment effects in individuals with mental retardation, but researchers have used it to measure problem behavior with this population (Aman et al., 1985). Aman et al., found that the median correlation between the subscales on the NCBRF and ABC was .72. This suggests that the subscales on these two scales are closely related and seem to measure the same constructs.
In 2004, Lecavalier, Aman, Hammer, Stoica and Matthews, conducted a factor analysis to determine if the NCBRF was a psychometrically valid instrument for use with individuals on the autism spectrum. They explain that while several rating scales have been developed to aid in the diagnosis of autism spectrum disorders, there are no rating scales available to measure problem behavior in these individuals. Researchers who wish to measure problem behaviors in this population can either use rating scales that were normed on typically developing individuals, or rating scales that were normed on individuals with mental retardation.

Lecavalier et al. (2004), recruited the parents of 246 children and adolescents with autism spectrum disorders, ranging in age from 3 to 18 years. After the parents completed the NCBRF-Parent Version, the authors conducted an exploratory factor analysis, which they modeled after the method that Aman et al. (1996) used with the original sample. They also conducted a confirmatory factor analysis. When they compared the results of the two factor analyses, the amounts of explained variance in each were comparable. The indices of fit derived from the confirmatory factor analysis indicated that the fit for the social competence items was “good,” and the fit for the problem behavior items was “acceptable.” The authors also found the factor loadings and internal consistencies of the subscales to be “acceptable,” with the exception of the Adaptive/Social subscale of the parent version. In their conclusion, the authors state that their results suggest that the NCBRF is a psychometrically valid instrument with use with individuals on the autism spectrum.

The *Vineland Adaptive Behavior Scales-Second Edition* (Vineland-II) (Sparrow, Cicchetti & Balla, 2005), is a parent and caregiver rating form, which assesses an individual’s adaptive functioning across several areas. It is normed on individuals from birth to age 90. The Vineland-II yields scores in four domains: Communication, Daily Living Skills, Socialization
and Motor Skills (this fourth domain is only completed for children under the age of six). These scores are aggregated together to yield an Adaptive Behavior Composite Score. The assessor computes a standard score, percentile rank, age-equivalent and adaptive level for the domain scores and the Adaptive Behavior Composite. The adaptive levels range from high to low.

Within each domain, there are two or three subdomains. The Communication Domain consists of the Receptive, Expressive and Written subdomains. Within the area of Daily Living Skills, scores are obtained in the Personal, Domestic and Community subdomains. The Socialization Domain is comprised of the Interpersonal Relationships, Play and Leisure Time and Coping Skills subdomains, while the Motor Skills domain consists of the Fine and Gross motor subdomains. Age-equivalents and adaptive levels are available for each subdomain.

In the technical manual, Sparrow, Cicchetti and Balla (2005) provide information about the reliability and validity of the Vineland-II. In terms of reliability, the average split-half reliability coefficients of the domain scores across ages range from .77 to .93. The average test-retest reliability coefficients are above .80, and the average interrater reliability coefficients are above .70. In describing the validity of the Vineland-II, the authors state that they aimed to develop sequential items that measured the behaviors associated with four main areas of adaptive functioning. To establish content validity, the items were evaluated by experts to determine if they were representative of the domain of content. The authors also conducted confirmatory factor analysis and found that the data fit best with a three or four factor model.

Sparrow, Chicchetti and Balla (2005), also provide information about the convergent and divergent validity of the Vineland-II. The Vineland-II correlates well with the Adaptive Behavior Assessment System, another rating scale designed to measure adaptive behavior. Correlations between the Vineland-II and the Wechsler Intelligence Scale for Children-Third
Edition (WISC-III) are close to zero, which one would expect given that these two assessments measure two very different constructs—one measures adaptive behavior, while the other measures cognitive functioning.

The *Parenting Stress Index -Third Edition* (PSI) (Abidin, 1995), was be used to assess parental stress. The PSI is a self-report form completed by parents, and it is designed to assess aspects of the parent-child system that may increase the level of stress in the parent-child relationship. The PSI consists of two domains: the Child Domain and the Parent Domain. The Child Domain assesses the characteristics of the child on the following subscales: Distractibility/Hyperactivity, Adaptability, Reinforces Parent, Demandingness, Mood and Acceptability. The Parent Domain assesses the parent’s functioning on the following subscales: Competence, Isolation, Attachment, Health, Role Restriction, Depression and Spouse. In addition to subscale and domain scores, the PSI also yields a Life Stress Score. The Life Stress Scale assesses situational stress outside the parent-child system. The items from each subscale and domain are summed together and a percentile score is obtained. The PSI also provides a Total Stress Score and percentile.

In the technical manual, Abidin (1995) states that the reliability coefficients for the subscales of the Child Domain range from .70 to .83, while the coefficients for the subscales of the Parent Domain range from .70 to .84. The coefficients for the two domains and the Total Stress scale are all above .90. In terms of validity, Abidin conducted a factor analysis and found that in the Child Domain, 41% of the variance was explained by a six-factor solution. In the Parent Domain, 58% of the variance was explained by a seven-factor solution.

The *Behavior Assessment System for Children-Second Edition, Self-Report* (Reynolds & Kamphaus, 2004), is a rating scale system designed to aid in the identification of emotional and
behavioral issues. The BASC-2, Self Report Form (BASC-2, SRP), is one of the measures that will be used to measure the participants’ internalizing behaviors. The BASC-2, SRP has two forms—one for children ages eight to eleven and another for children ages twelve to eighteen. Both forms were used in this study. The child version of the self-report is comprised of 139 items, while the adolescent version is comprised of 176 items. The SRP yields both subscale and composite scores. The composite scores on the BASC-2 Self-Report are: Internalizing, Inattention/hyperactivity, School maladjustment, Personal Adjustment and the Emotional Symptoms Index. T-scores and percentile ranks can be obtained for each composite. The Internalizing Composite score on the BASC-2 Self-Report will be used in this study. This consists of the Atypicality, Locus of Control, Social Stress, Sense of Inadequacy, Anxiety, Depression and Somatization scales.

The reliability and validity data for the BASC-2, Self Report is outlined in the Technical Manual (Reyonlds & Kamphaus, 2004). In terms of reliability, the internal consistency of the BASC-2, Self-Report is .83 to .96 for the composite scores and .71 to .86 for the subscales. The test-retest reliability is .74 to .84 for the composites. To establish content validity of the BASC-2, Self-Report, the authors obtained items from the DSM-IV-TR, parents, teachers and psychologists. The authors claim that individuals with clinical diagnoses have corresponding profiles on the BASC-2, Self-Report. They state that the subscales and composites were created using factor analysis. The Self-Report is correlated with other measures of internalizing behaviors such as the Achenbach System, the Children’s Depression Inventory (CDI) and the Revised Child Manifest Anxiety Scale (RCMAS).

The Behavior Assessment System for Children-Second Edition, Parent Report Form (BASC-2 PRS) (Reyondls & Kamphaus, 2004), is the second measure that was used to measure
the siblings’ levels of internalizing behaviors. It was also be used to measure the siblings’ levels of externalizing behaviors. The BASC-2 parent rating scale, consists of 160 Likert Scale items that load on various different subscales. Respondents are asked to rate how often the child exhibits each of 160 behaviors described. The subscales are grouped together into several different composites. T-scores and percentile scores can be obtained for each composite. The Internalizing Composite (which is comprised of the Anxiety, Depression and Somatization scales) and the Externalizing Composite (which is comprised of the Hyperactivity, Conduct Problems and Aggression scales) will be used in this study. The BASC-2, Parent Report has two forms—one for children ages six to eleven and another for children ages twelve to eighteen. Both forms were used in this study.

In terms of reliability, the internal consistency of the BASC-2, Parent Report is .90-.95 for the composite scores and .77 to .88 for the subscales. The test-retest reliability is .78-.92 for the composites and .65 to .87 for the subscales. Interater reliability for this measure is lower, but still adequate, at .68-.77 for the composites and .53 to .80 for the subscales. To establish content validity of the BASC-2, Parent Report, the authors obtained items from the DSM-IV-TR, parents, teacher and psychologists. The authors claim that individuals with clinical diagnoses have corresponding profiles on the BASC-2, Parent Report. They state that the subscales and composites were created using factor analysis.

**Procedures**

The directors of the special recreation programs distributed information about the study to parents whose children were enrolled in their programs. Parents who were interested in participating, contacted the principal investigator via telephone or email. Once the principal investigator determined that the interested families were eligible to participate in the study, she
mailed a packet of questionnaires to the family, with a self-addressed, return envelope. The parents completed the NCBRF, Vineland-II, PSI and BASC-2 Parent Report Form. The typically developing siblings completed the BASC-2 Self-Report Form. Fourteen packets were sent out, but only eleven were returned.

Results

Pearson correlations were calculated and regression analyses were conducted in order to explore the relationships between problem behavior, adaptive behavior, parental stress and internalizing and externalizing behavior in siblings.

Hypotheses 1 and 2. Table A1 presents the Pearson correlations calculated between the scales used to assess problem behavior and adaptive behavior in individuals with ASDs and the scales used to assess parental stress and internalizing behavior and externalizing behaviors in typically developing siblings. Table A1 shows that the positive correlation between the NCBRF Total Score and the PSI Total score was statistically significant $r(9) = .57, p = .034$. In terms of adaptive behavior, there was a moderate negative correlation between the Total Adaptive Behavior Composite on the Vineland-II and the PSI Total Score $r(9) = -.51, p = .054$, which fell just above the threshold of the 0.05 alpha level.

In order to explore the relationships between parental stress and specific areas of adaptive behavior in children with ASDs, the Vineland-II subdomain scores were included in the correlation analyses. Table A1 shows that the negative correlation between the Communication subdomain score and the PSI Total Score was statistically significant $r(9) = -0.62, p = .022$. 
Table A1

*Pearson Correlations between the NCBRF, Vineland-II, BASC-2 PRS, BASC-2 SRP and SSI*

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<th>4</th>
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<th>6</th>
<th>7</th>
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<td>.939**</td>
<td>.934**</td>
<td>.921**</td>
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<td>6 BASC-2 PRS Externalizing Behavior</td>
<td>.223</td>
<td>.519</td>
<td>.709**</td>
<td>.554*</td>
<td>.636*</td>
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<td>7 BASC-2 PRS Internalizing Behavior Composite</td>
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<td>.371</td>
<td>.491</td>
<td>.517</td>
<td>.479</td>
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<td>8 BASC-2 SRP Internalizing Behavior Composite</td>
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<td>.555*</td>
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<td>.016</td>
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<td>.371</td>
<td>.076</td>
<td>.038</td>
<td>.135</td>
<td>.060</td>
<td>.488</td>
<td>.481</td>
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<td>9 PSI Total Score</td>
<td>.569*</td>
<td>-.617*</td>
<td>-.405</td>
<td>-.451</td>
<td>-.512</td>
<td>-.310</td>
<td>-.268</td>
<td>-.341</td>
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<td></td>
<td>.034</td>
<td>.022</td>
<td>.108</td>
<td>.082</td>
<td>.054</td>
<td>.177</td>
<td>.212</td>
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*Note. N=11  
*p <.05. **p <.01.
**Hypotheses 3 and 4.** Table A1 shows that the correlation between NCBRF Total Score and the siblings’ self-report of internalizing behavior on the BASC-2 was not statistically significant $r(9) = -.11, p = .37$. The correlation between the siblings’ self-report of internalizing behavior on the BASC-2 and the Total Adaptive Behavior Composite on the Vineland-II, was also not statistically significant $r(9) = .50, p = .060$. The positive correlation was indicates that in this sample, internalizing behaviors in siblings increased as adaptive behaviors increased, which was not consistent with the hypothesis.

Table A1 shows that the Pearson correlations between the NCBRF Total Score and parent ratings of the siblings’ internalizing and externalizing behavior levels on the BASC-2 were not statistically significant. In looking at adaptive behavior, the results indicated several statistically significant positive correlations, which were not consistent with the hypotheses.

**Hypothesis 5.** The results of a multiple regression analysis predicting sibling internalizing behavior (based on the BASC-2 self-report) from problem and adaptive behavior in children with ASDs is presented in Table A2.

<table>
<thead>
<tr>
<th>Multiple Regression Predicting Sibling Internalizing Behavior (on the BASC-2 SRP) from Problem Behavior and Adaptive Behavior</th>
<th>$b$</th>
<th>$SE$</th>
<th>$\beta$</th>
<th>$t$</th>
<th>$p$</th>
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<tbody>
<tr>
<td>Constant</td>
<td>30.03</td>
<td>12.80</td>
<td>2.35</td>
<td>0.05</td>
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<tr>
<td>Nisonger Total Score</td>
<td>-0.06</td>
<td>0.12</td>
<td>-0.16</td>
<td>-0.54</td>
<td>0.61</td>
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<tr>
<td>Vineland Adaptive Behavior Composite</td>
<td>0.35</td>
<td>0.20</td>
<td>0.51</td>
<td>1.69</td>
<td>0.13</td>
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</table>

Note: $N=11$
$R^2 = 0.27$

The regression equation was not statistically significant, ($F(2,8) = 1.495, p = 0.28, R^2 = 0.27$) and neither problem behavior, nor adaptive behavior were statistically significant predictors of
internalizing behavior in siblings. Twenty-seven percent of the variance in the siblings’ ratings of internalizing behavior was accounted for by problem and adaptive behavior levels in children with ASD.

The results of a multiple regression analysis predicting sibling internalizing behavior (based on the BASC-2 parent report) from problem and adaptive behavior in children with ASDs is presented in Table A3.

<table>
<thead>
<tr>
<th>Table A3</th>
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<tbody>
<tr>
<td>Multiple Regression Predicting Sibling Internalizing Behavior (on the BASC-2 PRS) from Problem Behavior and Adaptive Behavior</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>b</th>
<th>SE b</th>
<th>β</th>
<th>t</th>
<th>p</th>
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</thead>
<tbody>
<tr>
<td>Constant</td>
<td>32.24</td>
<td>9.34</td>
<td>3.45</td>
<td>0.01</td>
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<tr>
<td>Nisonger Total Score</td>
<td>0.06</td>
<td>0.09</td>
<td>0.21</td>
<td>0.72</td>
<td>0.49</td>
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<tr>
<td>Vineland Adaptive Behavior Composite</td>
<td>0.23</td>
<td>0.15</td>
<td>0.46</td>
<td>1.51</td>
<td>0.17</td>
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</table>

Note: N=11  
$R^2 = 0.28$

The regression equation was not statistically significant, $(F(2,8) = 1.523, p = 0.28, R^2 = 0.28)$ and neither problem behavior, nor adaptive behavior were statistically significant predictors of internalizing behavior in siblings. Twenty-eight percent of the variance in parent ratings of siblings’ internalizing behavior was accounted for by problem and adaptive behavior levels in children with ASD.

The results of a multiple regression analysis predicting sibling externalizing behavior (based on the BASC-2 parent report) are presented in Table A4.
Although the regression equation was not statistically significant, \( F(2,8) = 3.019, p = 0.11, R^2 = 0.43 \) adaptive behavior was a statistically significant predictor of externalizing behavior in siblings \( (b = .424, t[10] = 2.31, p = 0.05) \). Forty-three percent of the variance in parent ratings of sibling externalizing behavior was accounted for by problem and adaptive behavior levels in children with ASD.

**Hypothesis 6.** Table A1 indicates that the correlations between sibling behavior and parental stress were not statistically significant. The relationships between these variables were negative, which contradicts and does not support the hypothesis.

**Discussion and Limitations**

The goal of the study was to explore the relationships among problem and adaptive behavior levels in children with ASD, parental stress and sibling behaviors. Due to the very small sample size, all results should be interpreted with caution.

The results of this exploratory study confirmed the results of previous research, which indicated that higher levels of problem behaviors in children with ASDs were associated with elevated levels of stress in parents (Benson, 2010; Herring et al, 2006; Konstantares & Homtidis,

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**Table A4**

*Multiple Regression Predicting Sibling Externalizing Behavior from Problem Behavior and Adaptive Behavior*

<table>
<thead>
<tr>
<th>Predictor</th>
<th>( b )</th>
<th>( SE\ b )</th>
<th>( \beta )</th>
<th>( t )</th>
<th>( p )</th>
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<tbody>
<tr>
<td>Constant</td>
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<td>11.45</td>
<td>1.54</td>
<td>0.16</td>
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<td>Nisonger Total Score</td>
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<td>0.10</td>
<td>0.16</td>
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<tr>
<td>Vineland Adaptive Behavior Composite</td>
<td>0.42</td>
<td>0.18</td>
<td>0.62</td>
<td>2.31</td>
<td>0.05</td>
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</table>

*Note: \( N=11 \)  
\( R^2 = 0.43 \)

The correlation between low adaptive behavior levels in children with ASDs and high levels of parental stress was approaching statistical significance. Stress in parents increased as adaptive behaviors in children with ASDs decreased. Had the sample size of this study been larger, it is possible that the correlation would have been statistically significant. The results did indicate that parents reported higher levels of overall stress if their diagnosed children had poor communication skills. This suggests that parents will find it more stressful to raise a child with an ASD diagnosis, if he or she is non-verbal or has significant language impairment. A child with this type of profile is likely to have difficulty comprehending instructions, expressing basic wants and needs and communicating with family members. It is possible that parents of children with these types of deficits feel higher levels of stress because of the time and attention that these children require. Parents may also feel a sense of inadequacy if they are unable to determine what their child needs.

One of the main aims of this exploratory study was to explore whether the factors that contribute to increased stress in parents of children with ASDs are associated with higher levels of internalizing and externalizing behaviors in typically developing siblings. The hypotheses were not confirmed as, siblings’ internalizing and externalizing behavior levels were not found to be associated with high levels of problem behavior or low levels of adaptive behavior in diagnosed siblings. Neither self-report ratings, nor parent ratings of sibling behavior supported the hypotheses. Adaptive behavior was a statistically significant predictor of externalizing behavior in siblings (based on parent report). Adaptive and problem behavior levels in children
with ASD were not found to be statistically significant predictors of internalizing behavior in siblings.

While the results of this exploratory study may suggest that siblings of children with ASD are not at risk for developing internalizing or externalizing behavior problems, study design, including a very small sample size, may have impacted the results. Further, an in-depth analysis of the measures selected for this pilot study suggests considering additional or alternative measures to assess sibling behavior. Prior research on parents of children with ASD used the PSI or other self-report measures to assess parental stress. The PSI was selected for the study, not only because it was used in previous studies, but because it assesses parental stress as it relates to a parent’s feelings about parenting one of his or her children. In this study the parent was instructed to answer the questions on the PSI as they pertained to their child with ASD. The questions on the PSI are very specific to the parent-child subsystem and the parental role.

The BASC-2 was selected for the pilot study because it is a widely used measure of internalizing and externalizing behaviors in typically developing children. Similar measures, such as the Child Behavior Checklist, were used in previous studies. Although the BASC-2 asks a child to answer questions about his or her thoughts and feelings, the questions are very general. They are not specific to how the child feels about his or her sibling or the stress that may be caused by having a sibling with ASD. If these types of targeted questions were asked, typically developing siblings may have indicated high levels of stress in their role as a sibling and within the sibling subsystem.
### Appendix B

Item Reliability for the Sibling Stress Index (SSI)

<table>
<thead>
<tr>
<th>SSI Item</th>
<th>CI-CT</th>
<th>α ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>My sibling has trouble paying attention to things.</td>
<td>.421</td>
<td>.848</td>
</tr>
<tr>
<td>My sibling does things for me that make me feel good.</td>
<td>.407</td>
<td>.848</td>
</tr>
<tr>
<td>I feel like my sibling likes me and wants to be close to me.</td>
<td>.653</td>
<td>.837</td>
</tr>
<tr>
<td>When I do something nice for my sibling, I feel like he or she doesn’t care.</td>
<td>.510</td>
<td>.845</td>
</tr>
<tr>
<td>I feel like my sibling doesn’t like me and doesn’t want to spend time with me.</td>
<td>.479</td>
<td>.846</td>
</tr>
<tr>
<td>My sibling likes to play with me.</td>
<td>.438</td>
<td>.847</td>
</tr>
<tr>
<td>My sibling looks different than other kids, and it bothers me.</td>
<td>.298*</td>
<td>.851</td>
</tr>
<tr>
<td>My sibling doesn’t smile as much as most children.</td>
<td>.351</td>
<td>.850</td>
</tr>
<tr>
<td>When my sibling plays with me, he or she doesn’t laugh or giggle.</td>
<td>.258</td>
<td>.861</td>
</tr>
<tr>
<td>It takes a long time for my sibling to get used to new things.</td>
<td>.152*</td>
<td>.858</td>
</tr>
<tr>
<td>There are things that my sibling does that really annoy me.</td>
<td>.457</td>
<td>.846</td>
</tr>
<tr>
<td>My sibling’s behavior upsets me.</td>
<td>.557</td>
<td>.844</td>
</tr>
<tr>
<td></td>
<td>Description</td>
<td>CI-CT Value</td>
</tr>
<tr>
<td>---</td>
<td>-----------------------------------------------------------------------------</td>
<td>-------------</td>
</tr>
<tr>
<td>13</td>
<td>I feel like my sibling and I aren’t as close as I would like.</td>
<td>.694</td>
</tr>
<tr>
<td>14</td>
<td>There are things that I can’t do because of my sibling.</td>
<td>.509</td>
</tr>
<tr>
<td>15</td>
<td>My sibling controls what my family does.</td>
<td>.466</td>
</tr>
<tr>
<td>16</td>
<td>It is hard to find a place in my house where I can be alone.</td>
<td>.378</td>
</tr>
<tr>
<td>17</td>
<td>Because of my sibling, I am not able to do things that I like to do.</td>
<td>.558</td>
</tr>
<tr>
<td>18</td>
<td>I have to take care of my sibling when I don’t want to.</td>
<td>.336</td>
</tr>
<tr>
<td>19</td>
<td>My sibling embarrasses me.</td>
<td>.431</td>
</tr>
<tr>
<td>20</td>
<td>I wish my sibling were able to talk better.</td>
<td>.195*</td>
</tr>
<tr>
<td>21</td>
<td>I wish my sibling were different.</td>
<td>.566</td>
</tr>
<tr>
<td>22</td>
<td>My sibling gets upset easily, and it bothers me.</td>
<td>.574</td>
</tr>
</tbody>
</table>

*Note: CI-CT = Corrected Item Total Correlation Values; α ID = Cronbach’s Alpha if Item Deleted Value.

Cronbach’s Alpha for the SSI = .868

*Indicates items with CI-CT values <0.3
Appendix C

Families Needed for Research Study on
Siblings of Children with Autism Spectrum Disorders

All participating families will receive a $10 Dunkin Donuts gift card and will be entered into a drawing to win an iPad Mini!!!

Purpose:
- To explore challenges and positive aspects of growing up with a sibling with an Autism Spectrum Disorder.

Your Family Qualifies to Participate if:
- You are the parent of a child with an Autism Spectrum Diagnosis (Autism, PDD, Asperger’s, etc.) and are willing to complete four questionnaires.
- You also have a typically developing child (sibling of the child with ASD) between the ages of 8-18, who can complete two short questionnaires.

Time Commitment:
- The time commitment is approximately 45-60 minutes for parents and 20 minutes for siblings. Questionnaires can be completed in your own home, at your leisure.

Please contact Hallie Solarsh, principal investigator and doctoral student at The CUNY Graduate Center for more information

(914) 275-5308 or hsolarsh@gc.cuny.edu
Appendix D

CITY UNIVERSITY OF NEW YORK
The Graduate Center
Department of Educational Psychology

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Project Title: Problem and Adaptive Behavior Levels in Children with Autism Spectrum Disorders as Predictors of Sibling Adjustment

Principal Investigator: Hallie Solarsh, Graduate Student
The Graduate Center, City University of New York
Department of Educational Psychology
365 Fifth Avenue
New York, NY 10016
(914) 275-5308

Faculty Advisor: Marian Fish, Professor
The Graduate Center, City University of New York
Department of Educational Psychology, Room 3204.02
365 Fifth Avenue
New York, NY 10016
(212) 817-8290

My name is Hallie Solarsh, and I am a doctoral student at the Graduate Center of the City University of New York (CUNY). I am currently conducting a research study under the supervision of Dr. Marian Fish entitled: “Problem and Adaptive Behavior Levels in Children with Autism Spectrum Disorders as Predictors of Sibling Adjustment.” This is a study about the ways in which the behaviors exhibited by children with autism spectrum disorders affect siblings.

The study: The purpose of this study is to gain a better understanding of how problem and adaptive behavior levels in children with autism spectrum disorders affect typically developing siblings. If you and your child choose to participate in this study, I would like for you to complete four questionnaires, which ask questions about your family and your children. These questionnaires will take approximately 45 minutes to complete. There will be approximately 200 participants taking part in this study—100 parents and 100 children. If you choose to participate in this study, you will be given a $10 Dunkin Donuts gift card (one gift card per family). You will also be entered into a drawing to win an iPad Mini.
Risks and benefits: The risks from participating in this study are minimal, but it is possible that the questions you will answer may produce some feelings of anxiety and sadness. The benefits of your participation are that you will provide valuable information about family functioning in families where one child has an autism spectrum disorder. In addition, your participation may help professionals understand how to better support families like yours.

Confidentiality: All information gathered will be kept strictly confidential, and will be stored in a locked file cabinet, to which only I, and my advisor will have access. You do not have to answer any item you do not want to. You may withdraw from this study at anytime without penalty. After you complete the questionnaires, I will only contact you if your responses suggest that you may benefit from following up with an outside service provider(s). I may publish the results of the study, but names of people, or any identifying characteristics will not be used in any of the publications. If you would like a copy of the study, please provide me with your address, and I will send you a copy in the future. I am required to keep that data that I collect for a minimum of three years. All data pertaining to your child will be retained until your child turns eighteen, at which point all data will be destroyed.

Voluntary Participation: Your participation in this study is completely voluntary. You may skip any questions that you don’t feel comfortable answering. You are free to withdraw from the study at any time without penalty.

Contact Information: If you have any questions about this research, you can contact me at (914) 275-5308 or at hsolarsh@gc.cuny.edu, or my advisor, Dr. Marian Fish at (212) 817-8290 or at mfish@gc.cuny.edu. If you have questions about your rights as a participant in this study, you can contact Barbara Lermand, Associate Director, HRPP Office, Queens College, City University of New York, at (718) 997-5415 or at Barbara.Lermand@qc.cuny.edu.

Thank you for your participation in the study. I will give you a copy of this form to take with you.

Participant’s Name (Print)  Participant’s Signature  Date

Investigator’s Signature  Date
Appendix E

CITY UNIVERSITY OF NEW YORK

The Graduate Center
Department of Educational Psychology

PARENTAL PERMISSION TO PARTICPATE IN A RESEARCH STUDY

Project Title: Problem and Adaptive Behavior Levels in Children with Autism Spectrum Disorders as Predictors of Sibling Adjustment

Principal Investigator: Hallie Solarsh, Graduate Student
The Graduate Center, City University of New York
Department of Educational Psychology
365 Fifth Avenue
New York, NY 10016
(914) 275-5308

Faculty Advisor: Marian Fish, Professor
The Graduate Center, City University of New York
Department of Educational Psychology, Room 3204.02
365 Fifth Avenue
New York, NY 10016
(212) 817-8290

My name is Hallie Solarsh, and I am a doctoral student at the Graduate Center of the City University of New York (CUNY). I am currently conducting research under the supervision of Dr. Marian Fish on the impact that children with autism spectrum disorders have on their typically developing siblings. The study is entitled: “Problem and Adaptive Behavior Levels in Children with Autism Spectrum Disorders as Predictors of Sibling Adjustment.” I am asking that your child take part because your child is the sibling of a child with an autism spectrum disorder, and he or she is in the age group that I would like to study. I ask that you read this form and ask any questions you may have before agreeing to allow your child to take part in this research.

The study: The purpose of this study is to gain a better understanding of how problem and adaptive behavior levels in children with autism spectrum disorders affect typically developing siblings. If you agree to allow your child to take part, your child will be asked to fill out two questionnaires. Your child will be asked to answer questions about how he or she thinks, feels and acts. The questionnaires will take about twenty minutes to complete. There will be approximately 200 participants taking part in this study—100 parents and 100 children. Parents
and children who participate in the study will be given a $10 Dunkin Donuts gift card (one gift
card per family). Participants will also be entered into a drawing to win an iPad Mini.

**Risks and benefits:** The risks of this study are minimal, but it is possible that some of the
questions may produce feelings of sadness or anxiety in participants. There are no direct benefits
to you or your child if he or she takes part in the study, however, your child’s participation may
provide valuable information about how typically developing siblings of children with autism
spectrum disorders are affected.

**Confidentiality:** All information gathered will be kept strictly confidential, and will be stored in
a locked file cabinet, to which only I, and my advisor will have access. I will only contact you
regarding your child’s responses, if his or her response pattern suggests that he or she may
benefit from following up with an outside service provider(s). I may publish the results of the
study, but names of people, or any identifying characteristics will not be used in any of the
publications. I am required to keep the data that I collect for a minimum of three years, or until
your child is eighteen years old. At that point, the data will be destroyed.

**Voluntary Participation:** Your child’s participation in this study is completely voluntary. Your
child may skip any questions he or she doesn't feel comfortable answering. If you decide to
allow your child to take part, your child is free to stop at any time. You are free to withdraw your
child from the study at any time without penalty.

**Contact Information:** If you have any questions about this research, you can contact me at
(914) 275-5308 or at hsolarsh@gc.cuny.edu, or my advisor, Dr. Marian Fish at (212) 817-8290
or at mfish@gc.cuny.edu. If you have questions about your rights as a participant in this study,
you can contact Barbara Lermand, Associate Director, HRPP Office, Queens College, City
University of New York, at (718) 997-5415 or at Barbara.Lermand@qc.cuny.edu.

Please write your child's name and sign below if you give consent for your child to participate in
this study. I will give you a copy of this form to take with you.

______________________  ______________________  ________
Child’s Name (Print)     Parent Signature   Date

______________________  ________
Investigator’s Signature  Date
ASSENT TO PARTICIPATE IN A RESEARCH STUDY

**Project Title:** Problem and Adaptive Behavior Levels in Children with Autism Spectrum Disorders as Predictors of Sibling Adjustment

**Principal Investigator:** Hallie Solarsh, Graduate Student

**Faculty Advisor:** Marian Fish, Ph.D., Professor

My name is Hallie Solarsh, and I am a doctoral student at the Graduate Center of the City University of New York. I am asking you to participate in this study because I am trying to gain more information about the ways in which children with autism spectrum disorders affect the other people in their family. The title of my research study is “Problem and Adaptive Behavior Levels in Children with Autism Spectrum Disorders as Predictors of Sibling Adjustment.”

**Purpose:** This research study is being conducted to help professionals better understand what it’s like for families when one child has special needs, like your brother or sister. This study may help professionals learn more about what they can do to help families like yours.

**Description of the Study:** If you choose to participate in this study, you will be asked to complete two questionnaires. This will take approximately twenty to thirty minutes. You will be asked questions about how you think, feel and act.

**Risks:** It is possible that the questions that you will be asked to answer may make you feel uncomfortable. The questions may also ask you about things that make you feel angry, sad or worried.

**Benefits:** Although the study will not benefit you directly, the hope is that your participation will help professionals to better understand families of children with autism spectrum disorders. Your participation will give professionals information about what families like yours need and how they can help!

**Confidentiality:** Your answers to the questions will be kept confidential, unless your answers indicate that the way you think, feel and act may be harmful to you. If this happens, I will tell your parents and give them some suggestions of what they can do to help you. You may feel
embarrassed or worried if I speak with your parents, but it is really important for them to know about anything that may be harmful to you.

**Voluntary Participation:** It is entirely up to you whether or not you take part in this research study. I will be discussing this with your parents too. Your parents are not allowed to have you participate unless you agree. It is okay if you decide to stop once the study has started.

If you decide to participate in the study, you and your parent will be given a $10 Dunkin Donuts gift card to share. You will also be entered into a drawing to win an iPad Mini.

If you have any questions about this research project, you can contact me at (914) 275-5308 or at hsolars@gc.cuny.edu. If you have questions about your rights as a participant in this study, you can contact Barbara Lermand, Associate Director, HRPP Office, Queens College, City University of New York, at (718) 997-5415 or at Barbara.Lermand@qc.cuny.edu.

Please sign your name below if you agree to take part in this study. I will give you a copy of this form to take with you.

_____________________  ______________________ ______________________
Child's Name (Print)   Child’s Signature   Date

____________________  ___________________
Investigator’s Signature   Date
Appendix G

DEMOGRAPHIC QUESTIONNAIRE
(to be completed by parents)

Your Age: ________

Your Gender: Male Female

Highest Level of Education Completed: High School College Graduate School

Marital Status: Married Single Divorced Separated Other: ________

Age of Spouse: ________

Spouse’s Gender: Male Female

Highest Level of Education Completed by Spouse: High School College Graduate School

Annual Household Income (circle one):

Under $25,000 $25,000 - $39,999

$40,000 - $49,999 $50,000 - $74,999

$75,000 - $99,999 $100,000 - $124,999

$125,000 - $149,999 Over $150,000

How many children do you have? ______

What is the age of the child who has an autism spectrum disorder diagnosis? ______

What is this child’s specific diagnosis? Autism Asperger’s Syndrome PDD

PDD-NOS Other: ____________
Where does this child fall in the birth order?  
- Oldest
- Youngest
- In the Middle

What are the ages of your other children? _____________

What is the age of the typically developing sibling who will be participating in this study? ______

Does this child have a diagnosed psychiatric disorder or disability?  
- Yes
- No

If yes, please indicate the disorder or disability: ______________________

Is this child currently receiving any type of counseling?  
- Yes
- No

Is this child currently receiving special education services?  
- Yes
- No

How would you describe this sibling’s level of stress?  
- Low level of stress
- Average level of stress
- High level of stress

How would you describe your own level of stress?  
- Low level of stress
- Average level of stress
- High level of stress

How would you rate your family’s functioning?  
- Not functioning well
- Functioning typically
- Functioning at an above average level
Tell Me About Your Brother or Sister....

These questions are about your brother or sister with special needs. There are a total of 22 questions. Please read each question and circle the best answer. The word “sibling” means brother or sister.

1. My sibling has trouble paying attention to things.
   Never    Sometimes    Often    Almost Always

2. My sibling does things for me that make me feel good.
   Never    Sometimes    Often    Almost Always

3. I feel like my sibling likes me and wants to be close to me.
   Never    Sometimes    Often    Almost Always

4. When I do something nice for my sibling, I feel like he or she doesn’t care.
   Never    Sometimes    Often    Almost Always

5. I feel like my sibling doesn’t like me and doesn’t want to spend time with me.
   Never    Sometimes    Often    Almost Always

6. My sibling likes to play with me.
   Never    Sometimes    Often    Almost Always

7. My sibling looks different than other kids, and it bothers me.
   Never    Sometimes    Often    Almost Always
8. My sibling doesn't smile as much as most children.

   Never    Sometimes    Often    Almost Always

9. When my sibling plays with me, he or she doesn't laugh or giggle.

   Never    Sometimes    Often    Almost Always

10. It takes a long time for my sibling to get used to new things.

    Never    Sometimes    Often    Almost Always

11. There are things that my sibling does that really annoy me.

    Never    Sometimes    Often    Almost Always

12. My sibling's behavior upsets me.

    Never    Sometimes    Often    Almost Always

13. I feel like my sibling and I aren't as close as I would like.

    Never    Sometimes    Often    Almost Always

14. There are things that I can't do because of my sibling.

    Never    Sometimes    Often    Almost Always

15. My sibling controls what my family does.

    Never    Sometimes    Often    Almost Always

16. It is hard to find a place in my house where I can be alone.

    Never    Sometimes    Often    Almost Always
17. Because of my sibling, I am not able to do things that I like to do.

Never  Sometimes  Often  Almost Always

18. I have to take care of my sibling when I don't want to.

Never  Sometimes  Often  Almost Always

19. My sibling embarrasses me.

Never  Sometimes  Often  Almost Always

20. I wish my sibling were able to talk better.

Never  Sometimes  Often  Almost Always

21. I wish my sibling were different.

Never  Sometimes  Often  Almost Always

22. My sibling gets upset easily, and it bothers me.

Never  Sometimes  Often  Almost Always
References


