# GROWING UP WITH AUTISM:

# THE EDUCATIONAL IMPACT ON NEUROTYPICAL SIBLINGS

## A DISSERTATION SUBMITTED TO THE FACULTY

OF

## THE GRADUATE SCHOOL OF APPLIED AND PROFESSIONAL PSYCHOLOGY

OF

## RUTGERS,

# THE STATE UNIVERSITY OF NEW JERSEY

BY

## ERIN LEIGH HERMAN

# IN PARTIAL FULFILLMENT OF THE

## **REQUIREMENTS FOR THE DEGREE**

OF

## DOCTOR OF PSYCHOLOGY

NEW BRUNSWICK, NEW JERSEY

OCTOBER, 2013

APPROVED:

Kate Fiske, PhD

Nancy Fagley, PhD

Susan Forman, PhD

DEAN:

Stanley Messer, PhD

Copyright 2013 by Erin Leigh Herman

Abstract

A substantial amount of research has focused on the psychological, social, and behavioral impacts of having a sibling with autism on the neurotypical sibling. However, there is a lack of research that focuses on the educational or academic effects that the typically developing sibling may experience as a result of increased responsibility, varying family dynamics, and psychological functioning. This pilot study includes 14 high school students who have a sibling with an autism spectrum diagnosis, and 25 high school students who have a sibling who does not have autism. This study examines three hypotheses, all related to the academic domain of individuals of siblings with autism: (1) siblings of children with autism spend less time on school-related activities (e.g. homework, studying, extracurricular activities) when compared to same-aged peers who do not have a sibling with autism, (2) siblings of children with autism receive less support from their parents or guardians on school-related activities, and (3) siblings of children with autism receive lower grades than students who do not have siblings with autism, and grade point average (GPA) will be predicted by amount of time spent on homework and amount of support received from parents or guardians. Hypothesis 1 and 2 received partial support. (1) Siblings with autism reported participating in fewer extracurricular activities than their peer counterparts who did not have a sibling with autism. (2) High school students with siblings with autism reported needing less help on their homework, and accordingly, receiving less help on their homework from their parents. High school students with siblings with autism reported that their sibling receives more attention from their parents and that they themselves spend less one-on-one time with their sibling when compared to students with typically developing siblings. (3) There was no significant

ii

difference found between the two groups of students' GPAs. Nevertheless, GPA was significantly related to the number of hours spent on studying. An additional finding suggested that students with siblings with autism reported that school was less important to them.

#### Acknowledgments

This dissertation has been such a large part of my life for the past 21 months, and accordingly, so have the people who have helped in the process of it coming to fruition. To Kate Fiske, your patience, selflessness, and optimism made this project possible. Your support and assistance never went unnoticed, and I am so appreciative that you chose my dissertation to be the first one you chaired in your career. To Nancy Fagley, your humor and tolerance for my never-ending list of questions were always admired. Your willingness to work with me well into the evening hours, to print out dozens of sheets of SPSS output, and to understand the anxiety that the results section gave is so very commendable. To Susan Forman, you are the professor I have worked the longest with in my graduate career, and I appreciate all of the support you have provided me. To all of the other faculty and staff at GSAPP, thank you for your encouragement and resourcefulness. Sandra Harris, thank you for the support you have given me in so many ways since I started this dissertation.

To the organizations that gave me the opportunity to recruit—Ocean Township and Toms River School Districts, your openness to allow me to recruit through your high schools made this research possible. To all of the private schools and private practices, your contribution was valued beyond words. Most importantly, thank you to the families that made this research come to life. To the siblings that so willingly gave their time to participate in the research, you made this dissertation happen.

To my family—Mom, Brooke, Blair, Grandma, Judy & the guys—Thank you for your support, your patience, and your enthusiasm as you have watched me on this journey. Thank you for allowing me to grow, to be myself, and above all else, thank you

iv

for the unending amount of love. Brooke and Blair, my interest in sibling relationships is a direct result of our upbringing and the important (and fun) role you have played in my life both individually and together. Mom, thanks for being the most amazing role model there is and instilling the importance of education, love, and sisters. Jared, your patience with me (especially at my nuttiest) always amazes me, and your support is a constant reminder of how lucky I am to have you in my life. Thank you for being by my side from start to finish. To my friends, both old and new—thank you for understanding that I couldn't be everywhere you wanted me to be, couldn't answer every phone call that came my way, was sometimes a little stressed, and for encouraging me along the way. To all of you--You are such a huge part of this success, and I hope you know that each and every one of you helped make it happen.

# TABLE OF CONTENTS

ABSTRAC	ABSTRACTii				
ACKNOWI	ACKNOWLEDGEMENTSiv				
LIST OF TABLESvi					
LIST OF FIGURESix					
CHAPTERS	S				
I.	INTRODUCTION & LITERATURE REVIEW	1			
	Sibling Relationships in the General Population	1			
	Sibling Relationships in the Family with a Child with Autism	4			
	Parent-Child Relationship in the Family of a Child with Autism	.7			
	Impact of Autism on Sibling Psychological Well-Being	9			
	Impact of Autism on the Academic and Educational Experience of Siblings	11			
	Summary	16			
	Hypotheses	17			
	Hypothesis 1: Time Spent on School-Related Activities	17			
	Hypothesis 2: Parental Support	.17			
	Hypothesis 3: Impact of Time Spent on Homework and Parental Support on GPA	.18			
II.	METHOD	.19			
	Design	.19			
,	Participants	.19			
	Procedures	.19			

	Instruments	22
III.	RESULTS	24
	<i>T</i> -Tests and Correlations	24
	Multivariate Analyses	
	Hypothesis 1: Time Spent on School-Related Activities	
	Hypothesis 2: Parental Support	30
	Hypothesis 3: Impact of Time Spent on Homework and Parental Support on GPA	32
	Qualitative Responses	33
IV.	DISCUSSION	35
	General Time for School-Related Activities and Thoughts Surrounding Education	.,35
	Parent Relationships as it relates to Academic Experiences	
	Sibling Relationships as it relates to Academic Experiences	39
	Academic Performance (GPA)	43
	Summary	44
	Limitations	47
	Directions of Future Research	49
	Conclusions	50
REFERENC	CES	51
APPENDIC	ES	60
TABLES		81
FIGURE CA	APTION	90
FIGURE		91

# LIST OF TABLES

Table 1a. Categorical demographic variables	81
Table 1b. Quantitative demographic variables	82
Table 2. Descriptive statistics and independent t-tests for "count" variables	83
Table 3. Descriptive statistics and independent t-tests for rating scale items about frequency of occurrence.	84
Table 4. Descriptive statistics and t-test results for attitude, beliefs, and perception likert scale items	85
Table 5. Descriptive statistics and t-test results of GPA.	86
Table 6. Correlation matrix of variables (N = 39)	87
Table 7. Parental support, time spent on homework, and GPA regression	88
Table 8. Frequency count of participants opting to share more information in open-ended questions	89

# LIST OF FIGURES

Figure 1.	Variable Roles in Hypothesis	1
-----------	------------------------------	---

Growing up with Autism: The Educational Impact on Neurotypical Siblings

In recent years, siblings of children with autism have received increasing attention, as researchers consider the various effects that having a sibling with autism may have on the typically developing sibling. The typically developing sibling may be impacted in the psychological, social, emotional, and academic domains. To date, most research on siblings has looked at the psychological and social effects of having a sibling with autism on the typical sibling; however, there has been a dearth of research focusing on the academic domain. This study will seek to illuminate how having a sibling with autism may affect the typical sibling's academic experience, including performance in school, time on homework, and participation in extracurricular activities. To that end, I will first summarize the literature on the relationship between typical siblings in the general population with regard to their roles in family and in each other's education. I will then examine, based on the literature, how having a sibling with autism affects a typical sibling in psychological and social domains. Finally, I will present my hypotheses regarding how typical siblings' academic performance and involvement is affected by having a sibling with autism.

#### Sibling Relationships in the General Population

Sibling relationships are unique and have many distinctive qualities. Sibling relationships typically last longer than all other human relationships (Orsmond, Kuo, & Seltzer, 2009). The typical sibling relationship is full of rich experiences that, according to Brody (2004), "foster the development of emotional understanding, self-regulation, and a sense of belonging and comfort" (Orsmond & Seltzer, 2007, p. 313). Harris and Glasberg (2003) acknowledge the course of a sibling relationship between typical

siblings and identify "access," coined by Bank and Kahn in 1982, as the factor that creates such a strong emotional bond between two or more siblings. Access increases when siblings are the same gender, are close in age, and spend a lot of time together. Tucker and Updegraff (2009) point out that during younger years, typical siblings play in such a way that enhances their social competencies and joint collaboration skills. Accessibility, which is part of access, is also part of the sibling dynamic, as siblings are always readily available playmates.

Biddle and Thomas (1966) define a role as a set of behaviors associated with a position in a social context. They acknowledge that roles within a family, or kinship, are different than roles held in society because interfamilial roles, unlike others, often involve reciprocal cooperation, loyalty, solidarity, and affection. Biddle and Thomas identified eight different relationships that exist within a family, three regarding siblings: the elder and younger brother, the elder and younger sister, and the brother and sister relationship. They point out that it is likely that the elder sibling often takes on a parental role. Tucker and Updegraff (2009) explored the implications of the inherent role that the older sibling or younger sibling plays in each other's lives, reporting that older siblings often act as the "teacher" or "expert" to their younger sibling, who takes on the role as the learner. This makes the sibling relationship asymmetrical, since the older sibling tends to have more authority over the younger sibling. As would be expected, the younger siblings are likely to comply with the older sibling's directions or guidance (Tucker and Updegraff, 2009). Youngblade and Dunn (1995) acknowledge that the larger the age gap between the two siblings (e.g. the older the older sibling in the dyad is) the more this scenario of the younger sibling modeling the older sibling is likely to play out.

Mendelson, de Villa, Fitch, and Goodman (1997) conducted a study that focused on different role expectations that siblings may have in a family, as viewed by adults (e.g. undergraduate students) who were unfamiliar with the siblings. One of their significant findings indicated that older siblings were expected to take on the roles of teaching, helping, caretaking, considerate behavior, and domination. Younger siblings, on the other hand, had role expectations of respecting, admiring, learning, and deferring to the older sibling. Dunn and Kendrick (1979) and Abramovitch, Corter, and Lando (1979) found that younger siblings are more likely to imitate their older siblings, than vice versa.

The sibling relationship changes as siblings grow older (Harris & Glasberg, 2003; Orsmond et al., 2009). As children get older, their age differences tend to level out, which makes their relationship more symmetrical (Cicirelli, 1982). Thus, they are on an equal playing ground (Buhrmester, 1992; Buhrmester & Furman, 1990). Buhrmester and Furman report that, "[a]s the later born siblings grow older, they become more competent and independent, thereby requiring and accepting less nurturance and direction from older siblings" (p. 1395). The role of the teacher that the older sibling usually plays does not last, nor does the younger sibling's role of the learner. Both the older sibling and younger sibling, regardless of their birth order, assume relatively equal roles by the time they reach adolescence (Buhrmester & Furman, 1990).

It should also be acknowledged that while studies have found that siblings find themselves on equal playing ground as they get older, there are other changes that may be evident in their relationships. Orsmond et al. (2009) found that as siblings enter adolescence, they show decreased satisfaction with their brothers or sisters. This is likely due to the fact that each adolescent is becoming more independent and autonomous, and in the process, may be spending more time in their peer and romantic relationships. During this time, it is also likely that the individual sibling explores their own strengths and passions, and they choose how they want to spend their time. They may seek their own independence from their families, including their parents and siblings. In early adulthood, Orsmond et al. found an even greater decline in sibling relationship satisfaction as the individual sibling establishes and settles into their own lives. The aforementioned studies, however, discuss the sibling roles and sibling relationships when both are typically developing. They do not consider how sibling roles are affected when one sibling has a disability, and more specifically, autism.

## Sibling Relationships in the Family of a Child with Autism

When one of the siblings has a disability, this can change the entire way that a family functions. Typically, it is believed that a child who has a sibling with a disability take on additional childcare roles in their family, especially when compared to peers without a disabled sibling. McHale and Harris (1992) found that in any family, the older sibling usually takes on more household responsibilities than younger siblings; however, this finding was magnified when the younger sibling had a disability. Benderix and Sivberg (2007) conducted a qualitative study in which they interviewed 14 typical siblings in five families where one sibling had autism. They looked for common themes that surfaced from the interviews, and found seven overarching themes: Having a sense of precocious responsibility, feeling sorry for the brother or sister with autism, being exposed to frightening abnormal behavior, having empathetic feelings for the child with autism, hoping that the group home will be a relief for the family, physical violence in the family made siblings feel unsafe and anxious at home, and having a brother or sister with

autism affects relationships with friends negatively. Of particular interest for this study is the theme of "precocious responsibility" (p. 414). Sibling interviewees felt as though they had to look out for, and protect, their siblings with autism. They also assumed the parental role when they felt as though their parents needed to rest. This sense of responsibility grew as the typical sibling got older and was more apparent in close-knit families.

In a past study looking at the role of youngest siblings in families, it was found that in families where one child had a disability, it was likely that the younger child would assume caretaking roles. In a family where none of the children had a disability, the younger child thought it was an "absurdity" to have to provide caretaking for their older sibling (Stoneman, 1991, p. 547). This finding shows that every family develops their own context for what is normal. In families where one child is disabled, roles may be rearranged to accommodate individual family member's needs.

As outlined in the above section, there is an important dynamic that exists between older and younger siblings; however, when one sibling has a disability such as an autism spectrum disorder (ASD), it is likely that the "typical" sibling dynamic no longer exists. Despite where the sibling with a disability fell in birth order, they are likely to assume the role of the younger sibling (Abramovitch, Stanhope, Pepler, & Corter, 1987). Similarly, Knott, Lewis, and Williams (1995) found that children with disabilities were more likely to imitate their sibling than be imitated by their sibling, regardless of birth order. Farber (1960) looked at the nature of relationships in sibling dyads where one had mental retardation, and found that unlike typical sibling dyads, the affected sibling dyads' relationship became less symmetrical as the children got older, regardless of the birth order. In a less symmetrical relationship, the typically developing sibling may take on additional roles and fill a "superordinate position" (p. 78) in the sibling relationship. While no studies have been found that look at whether or not the same patterns take place in a sibling duo with autism, it is possible that, like the duo with mental retardation, the sibling pair with autism becomes less symmetrical as well.

A healthy sibling relationship between siblings when one sibling has a disability either mental or physical—has been described as "one that does not harm the typically developing sibling" (Stoneman, 2005, p. 339). Undoubtedly, healthy relationships can exist between a sibling dyad in which one has autism. While many past researchers hypothesized that the sibling relationship when one child has a disability would be strained in some way, the results of some studies have found just the opposite. In sibling pairs where one child has a disability (not specific to autism), the sibling relationship was found to be closer and more positive than in sibling pairs where neither child had a disability (Abramovitch et al., 1987; Byrne Cunningham, & Sloper, 1988; Gargiulo, O'Sullivan, and Wesley, 1992; Lobato, Miller, Barbour, Hall, and Pezzullo, 1991; McHale and Gamble, 1989; Roevers and Mycke, 1995).

It should be noted, however, that since autism implies inherent social difficulties in the affected sibling, this might affect the sibling relationship when one has autism. When a sibling has autism, typical siblings have been found to spend less time with them, compared to children with typical siblings or siblings with Down syndrome (Knott et al., 1995). Strain and Danko (1995) found that until interventions were put into place to improve frequency of sibling interaction, few positive, and no negative, interactions existed. Because of the social deficits that are a foundational part of the autism diagnosis, the sibling relationship undoubtedly has its differences when compared to a relationship with neurotypical siblings.

Kaminsky and Dewey (2001) looked at sibling relationships in three different groups: when one sibling has autism, when one sibling has Down syndrome, and in a sibling pair where neither has a disability. Typical siblings of a brother or sister with a disability perceived receiving less nurturance from their affected sibling and reported providing more nurturance to their affected sibling when compared to sibling pairs where neither had a disability. Children who had siblings with autism also reported less intimacy in the sibling relationship, as well as fewer prosocial behaviors. They found that, in a sibling pair affected with autism, the typical sibling reported having more admiration for their sibling with autism than did siblings where neither had a disability. A sibling pair where one sibling had autism also engaged in less conflict and arguing than did sibling pairs where neither had a disability. Overall, positive relationships were found among all three groups in the study, including that of the sibling pair where one was diagnosed with autism.

## Parent-Child Relationship in the Family of a Child with Autism

When one child has a disability in a family, it is likely that parental availability will be lessened for the unaffected sibling. Researchers have found that mothers of children with a disability spend more time with that child than with their typically developing children; however, older siblings of children with disabilities spend more time with their mothers than do older siblings with typically developing younger siblings (McHale & Harris, 1992). According to Crocker (1981), differential treatment in a sibling dyad when one is disabled is likely to be a problem faced by the typically developing sibling. Dunn, Stocker, and Plomin (1990) acknowledge that in families who are receive autism treatment based in applied behavior analysis (ABA), much of the family's resources, both monetary and time, are rationed to the child with the disability. Therefore, the typical sibling may feel as though they are not allotted their share of the family resources. Dunn et al. (1990) found that children who have the perception of being treated as "less than" their sibling with a disability may be at an increased risk for having adjustment difficulties. Another study done by Alegre and Benson (2010) found that parental availability, which they operationally defined as the emotional responsiveness to children's feelings, is related to children's adjustment outcomes. More specifically, when a parent is unavailable and lacking in support for their typical child, along with decreased warmth and affection, the child's emotional intelligence is also diminished. If a child or adolescent who has a sibling with autism views their parent as being unavailable to them, it is likely that they will have increased adjustment problems with fewer ways to solve them. Harris (1982) describes four different behavior patterns that she has observed in working with families with a child with autism. One of these patterns that is of particular interest here is the "it's-just-the-three-of-us" pattern (p. 28), in which both parents pay all of their attention to the sibling with autism, and therefore leave out any other siblings that may exist in the family system. In another study, Rodrigue, Geffken, and Morgan (1993) identified some of the sources for negative effects experienced by the typical sibling, which include role changes, structural changes in the home, feelings of guilt and shame, and little parental attention.

While the aforementioned research addressed some of the more negative findings regarding differential treatment and sibling outcomes, not all studies had such bleak

findings. Some studies found that typical siblings do not perceive themselves as receiving less attention from their parents. Kaminsky and Dewey (2001) found that typical siblings did not feel as though their sibling with a disability (in the study, either autism or Down syndrome) received more attention and resources from their parents. McHale and Gamble (1989) found no differences in reported differential treatment between children with siblings with disabilities and siblings without disabilities.

In a different study, Benson and Karlof (2008) sought to see if increased parental attention being aimed at the sibling with autism's education had negative impacts on the typical child. In many interventions for children with autism, their parents are closely tied in with their education. The parents may act as advocates, teachers, or therapists for their child with autism (Benson, Karlof, & Siperstein, 2008). Benson and Karlof's findings (2008) indicated that the typical sibling experiences no adverse affects from their parents being heavily involved in their affected sibling's education. In fact, the typical sibling may even experience positive effects from their parents being a part of their sibling's education. This could be because their sibling is having more beneficial outcomes at school as a function of their parent advocating for them, which in turn may make home life easier for the typical sibling.

#### Impact of Autism on Sibling Psychological Well-Being

Because sibling roles are impacted when one child has autism, as well as the possibility of unequal amounts of parental attention, it is understandable as to why so many past studies have honed in on the psychological well-being of the neurotypical sibling. Past research on the typically developing sibling who has a brother or sister with ASD focuses predominantly on the typical sibling's psychological well-being, adjustment, and socialization. Each of these studies yield mixed reports, with some indicating that the typical sibling may have positive outcomes when their brother or sister has ASD, and others indicating that having a sibling with ASD negatively affects the typical sibling.

A large percentage of past literature reports pessimistic outcomes for the typical sibling in a family where one sibling has autism. Many studies have found that brothers or sister of children with ASD experience elevated levels of depression and internalizing disorders (Fisman, Wolf, Ellison, Gillis, Freeman, & Szatmari, 1996; Gold, 1993). Ross and Cuskelly (2006) looked at adjustment and sibling problems in the typically developing sibling and found that almost half of the typical siblings in their study had elevated scores that placed them in either the borderline or clinical range on the *Child* Behavior Checklist (CBCL), indicating that they were experiencing either internalizing or externalizing symptoms. This proportion is nearly seven times greater than in the general population. Adjustment difficulties were also noted by Fisman, Wolf, Ellison, and Freeman (2000), who found them in siblings of children with Pervasive Developmental Disorder (PDD). Rodrigue et al. (1993) found that siblings of children with autism are more likely to experience internalizing and externalizing symptoms than siblings of individuals without a disability and siblings of individuals with Down syndrome. While this finding was significant, it should be noted that their symptoms were not in the clinical range. In a recent study, Meyer, Ingersoll, and Hambrick (2011) found that siblings of individuals with autism have a greater risk in developing adjustment problems than do their peers without an affected sibling. The typical child's social life was also impeded by their sibling with autism because they were less inclined to bring friends

home (Bendrix & Sivberg, 2007), and they were embarrassed by their sibling with autism (Orsmond & Seltzer, 2007). Hastings (2007) found that siblings of individuals with autism had more problems with peers.

While these studies offer poor outcomes for the typical sibling of a child with autism, other research has identified positive results for the typical sibling growing up with a brother or sister with special needs. Powell and Ogle (1985) found that some typical siblings feel satisfaction in learning to live with their affected brother or sister, even though it is demanding. In addition, the typical sibling experienced pride and delight when they saw their sibling accomplish something that they had been working on. Another positive outcome that Powell and Ogle (1985) found was that the typical sibling often demonstrated empathy to all individuals, regardless of any special needs that they may have. Specific to autism, it has been found that many siblings of children with ASD enjoy spending time with their siblings and appreciate their unique skills. Like children of siblings with various disabilities, siblings of children with autism experience "feeling proud of and even marveling at the achievements of their brother with ASD" (Petalas, Hastings, Nash, Dowey, & Reilly, 2009, p. 390). Kaminsky and Dewey (2002) found that siblings of children with autism indicate decreased levels of arguing than a typicallydeveloping sibling dyad, as well as report less competitiveness.

## Impact of Autism on the Academic and Educational Experience of Siblings

Most research that concerns a child with autism and their sibling focuses on the psychological well-being, social adjustment, and behavioral aspect that this may have on the typically developing child. Little research has focused on how having a sibling with autism affects the academic domain for the typical child. Indeed, there is a lack of research that explores the ways in which siblings—even when both are typically developing—affect each other's academic performance and involvement. According to Zajonc, Markus, and Marcus (1979), among typically siblings, the older sibling may develop a "teaching function" (p. 1328). This teaching function has been found to actually increase the intellectual growth of the older sibling, because they learn by teaching their younger sibling. Research has shown that teaching and caregiving in a sibling relationship can lead to increased cognitive, language, and psychosocial development in both siblings involved (Brody, 2004). This, in turn, may yield greater levels of academic achievement.

Tucker, McHale, and Crouter (2001) sought out to measure sibling support among typical siblings in both familial and non-familial domains. When the participating siblings reported having a more positive relationship with each other, the older sibling was more likely to assist the younger sibling with schoolwork. Similarly, in close sibling relationships, the younger sibling was more likely to provide the older sibling support for school-related issues. It was not found that younger siblings are likely to assist their older siblings in schoolwork. In another study, Bouchey, Shoulberg, Jodl, and Eccles (2010) explored how academic engagement and success in an older sibling affected the academic experience of the younger child in their transition from 7<sup>th</sup> to 8<sup>th</sup> grade. They found that when older siblings had greater academic success and engagement, the younger sibling had greater academic adjustment. However, when the younger sibling reported a decrease in academic adjustment.

In a study done by Smith (1984), children's responsibility for younger siblings was correlated with grades achieved in school. Findings suggested that in the white population, older siblings received highest grades when they were "moderately" (one to four times each week) responsible for their younger siblings. However, a "large" extent of responsibility for younger siblings resulted in declining grades when compared to the rest of the white population. The "teaching function," as outlined above, may only be effective in certain doses and less effective when too much responsibility is put on the older sibling. Smith (1990) looked at the effects that teaching younger siblings had on the older sibling's academic achievement, and he found that there was an increase in the older sibling's verbal performance, but not quantitative performance. The achievement level was lowest for older siblings that did not engage in teaching their younger sibling. The aforesaid studies outline that there is an emerging relationship between older siblings, younger siblings, and their academic experience.

Tucker and Winzeler (2007) sought to examine the effect everyday conversations between typical adolescent siblings may have on their well-being. It was found that adolescent siblings are most likely to talk about extracurricular activities, media, and academics. Interestingly, they found that the more adolescent siblings talk about extracurricular activities, the greater they perceive their competency in these activities. A negative relationship was found between talking about extracurricular activities and academic competence, indicating that the more a sibling pair discussed extracurricular activities, the poorer they perceived their academic competency to be. This study is also notable because it shows the importance that the sibling relationship can have on each of the participants. This type of study required two siblings who verbally communicate with one another. This type of openness between the siblings allowed for richer conversations and more growth that results from the sibling relationship. It is likely, depending on the verbal ability of an individual with autism, that this study would not be as feasible in a sibling pair where one adolescent has autism.

Research has also looked at the effects that parental involvement may have in their typical children's education. Fan and Chen (2001) conducted a meta-analysis looking at these two variables and found mixed results. Parental expectations for student achievement was more strongly related to actual student achievement, whereas parental supervision did not have as strong a relationship with the child's academic achievement. According to Walberg and Paik (2004), students' learning in schools is enhanced when they are intellectually stimulated by parents at home. According to Westmoreland, Rosenberg, Lopez, and Weiss (2009), when family engagement is directly connected to learning, it has the largest impact on the academic achievement of the child. Henderson and Mapp (2002) looked at a variety of studies and found that a common theme was that increased family involvement resulted in increased levels of student achievement (e.g. higher grades, better attendance rates, improved behavior, and motivation to enroll in more challenging programs). No studies have looked at parental involvement when one child has autism and one child is typically developing.

When considering the family in which one sibling has autism, significantly more research focuses on the effects that siblings may have on their sibling with autism's academic experience, than vice versa. An example of this is the siblings' role in the implementation of behavioral and social interventions. It has also been suggested that siblings of individuals with autism take an active role in their brother or sister with autism's education in order to feel more involved and less neglected (Smith, Polloway, Patton, & Dowdy, 2008). This will yield more positive outcomes in the typical sibling. In a sibling pair when one has autism, it is likely that the teaching function is possessed by the typically developing child, even if they are younger in the birth order. It is likely that the typically-developing sibling utilizes the "teaching function" which is a valuable tool in sibling dyads where one child has autism. Past research has shown that siblings of children with ASD can be effective agents in behavioral interventions for their affected siblings (Celiberti & Harris, 1993; Schreibman, O'Neill, & Kogel, 1983) and that they often like to teach their siblings with ASD new skills (Foden, 2009; Taylor, 2001). Celiberti and Harris (1993) refer to sibling relationships as being "less transient" (p. 575) than peer relationships, and cite this factor as one possible reason why siblings can be relatively effective when they are part of interventions. These studies on siblings' roles in behavioral intervention typically examined social and behavioral skills that the typical sibling was able to model for the sibling with autism. The outcomes of such studies are mixed, in that while positive results were achieved when the sibling was implementing the interventions, they were not always generalized to different settings (Reagon, Higbee, & Endicott, 2006; Tsao & Odom, 2006). To date, no studies have examined how typically developing siblings help their sibling with ASD in academic-related activities such as homework, projects, studying.

Fewer studies have been conducted that focus on the academic impact, or educational experience, of the sibling of a child with autism on the typically-developing sibling. Mates (1990) sought to find significant differences in academic and school performance in siblings of children with autism, but he found no such differences. Since then, studies that have found significant results have been mixed. Some studies suggest that having a sibling with autism has little academic impact on their typically-developing sibling, whereas others indicate a larger impact. Macks and Reeve (2007) found that siblings of kids with autism scored higher on intellectual and school status scores than students who did not have a sibling with autism. It is suggested by Macks and Reeve that children with siblings with autism perceived their academic performance and intellectual abilities greater than did children with non-disabled siblings because the former group compared themselves to their sibling with autism, thus giving their own self-esteem a boost.

A more recent, but less uplifting, study found that over half of children with a sibling with autism have academic difficulty (Barak-Levy, Goldstein, Weinstock, 2010). Barak-Levy et al (2010) also found that siblings of a child with autism participate less in extracurricular activities and other activities that take place outside of the home than their peers. Perhaps this could be a result of increased caretaking responsibilities that takes time away from the typically developing sibling, or decreased parental attention and availability that leaves the unaffected sibling with fewer methods of transportation options.

#### **Summary**

To date, little research has explored the academic impact that having a sibling with ASD can have on their neurotypical sibling. As outlined above, most past studies have looked at the adjustment, as well as psychological outcomes, of individuals who have siblings with autism. While these are important on their own, they also can contribute to the academic and educational experiences of the typically developing sibling. Many factors can contribute to academic distress for the typical sibling. These can include, but are not limited to increased responsibility at home, various roles that the sibling may have, decreased parental availability, higher levels of psychological distress, and a genetic vulnerability. The current study aims to look at the academic impact that having a sibling with autism has on the neurotypical sibling.

## **Hypotheses and Research Questions**

Based on the reviewed research, the current study will attempt to answer the following research questions:

Siblings of children with autism spend less time on school-related activities (e.g. homework, studying, extracurricular activities) when compared to same-aged peers who do not have a sibling with autism. Bendrix and Sivberg (2007) found that siblings of individuals with autism felt a "precocious responsibility" (p. 414) to take on parental and protective roles to look after their sibling with autism. If typically developing siblings are taking on additional roles at home, they are likely to have less time to spend on school-related obligations and activities. Additionally, Barak-Levy et al. (2010) found that siblings of children with autism participated less in extracurricular activities and other activities outside of the house. In addition, if siblings are implementing behavioral and social interventions to their sibling with autism (Celiberti & Harris, 1993; Schreibman, O'Neill, & Kogel, 1983), they will have less personal time to spend on homework and studying as well as extracurricular activities.

Siblings of children with autism receive less support from their parents or guardians on school-related activities. Research concludes that siblings of individuals with autism receive less attention from their parents than do siblings who do not have a brother or sister with autism (Crocker, 1981; Dunn, Stocker, & Plomin, 1990; McHale & Harris, 1992). It follows, then, that siblings of children with autism will also receive less support from their parents in the academic domain.

Siblings of children with autism receive lower grades than students who do not have siblings with autism, and GPA will be predicted by amount of time spent on homework and amount of support received from parents. A great deal of past research (Henderson & Mapp, 2002; Walberg & Paik, 2004; Westmoreland et al., 2009) indicates that increased levels of parental involvement are related to increased levels of academic performance in children. Additionally, because of increased caregiving roles, as found in Bendrix and Sivberg (2007), siblings are expected to have less time to tend to their academic responsibilities. If siblings of children with autism have less time to spend on school-related activities (homework, studying, etc.) as suggested by the first hypothesis, and less parent support, as suggested by the second hypothesis, then it is likely that their grades will suffer due to the neglect of their academic obligations. Smith (1984) found that if too much (e.g. a "large" extent of a sibling's time) was spent on caring for their sibling, their academic performance would be compromised. As a result, it is expected that siblings of children with autism will receive lower grades and perform more poorly in the academic domain than will siblings who do not have a brother or sister with autism.

## Method

## Design

A survey design was conducted using two groups, one of which included high school students who had a sibling with autism (focal group), and the other which included high school students that did not have a sibling with autism (comparison group).

## Participants

Thirty-nine high school students from New Jersey participated in this study (25 in comparison group, 14 in focal group). Demographic information and participant breakdown can be found in Tables 1a and 1b. Participants in the comparison group (typically developing high school students who had typically developing siblings, or siblings without autism) were recruited from local high school districts. Those participants in the focal group (those who had siblings with an autism spectrum diagnosis) were recruited from local high school districts, private schools serving students with autism, and outpatient clinics that provide services to children with autism. Informed consent was obtained from each high school student's parent or guardian, in addition to assent being obtained by each participant prior to participating in the study.

## Procedures

Informed consent from parent(s)/guardian(s) and assent from the high school students themselves were obtained differently depending on the recruitment setting. To gain approval to recruit through a public school district, a letter (Appendix A) was first sent to the superintendent, requesting permission to use students in the district high school(s) as potential participants. For both incentive and compensation, the principal researcher offered to present the research findings to the school district once the dissertation is complete. Once approval was gained to conduct the study through a school district, principals at the high school(s) in the district were contacted to seek their approval for using their school (Appendix D). At their discretion, the principal or another staff member appointed by the principal (either a teacher, Child Study Team member, administration, administrative assistant) assisted in finding teachers who would be willing to pass out study materials to students in their homeroom. In addition, the contact person was also asked to help in recruiting assistance from Child Study Team (CST) members (Appendix E). The CST member(s) identified any typically developing high school students who were siblings of students on their caseload with an "Autistic" classification under Individuals with Disabilities Education Improvement Act (IDEIA). By going through the CST, the anonymity and confidentiality of these students were maintained.

Homeroom teachers' duties entailed handing out an envelope to their homeroom classroom. Each envelope contained a cover letter to the study, as well as two copies of informed consent/assent (Appendix F) and an envelope with postage provided. The additional copy of the informed consent/assent had a "copy" stamp on top, indicating that this copy should be retained by the family. The signed informed consent/assent was mailed back to the principal investigator in the envelope provided. Because each high school student was at least 13 years of age, they were able to sign their assent below their parents' signature for consent. Because the informed consent was more than one page, both the parents and students were asked to sign their initials on the bottom of each page in a designated area. In addition to providing their signature for assent, each high school student was asked to provide their e-mail address so that they could be e-mailed the unique internet link, or Uniform Resource Locator (URL) that would direct them to the online survey.

The private schools that served children with autism required a different procedure for recruitment. First, a letter (Appendix B) was sent to the director for approval. The director was asked to write a letter to parents, informing them of the study and stating his/her approval of the research. A staff member disseminated information about the study to parents of students at the school with a typically developing high school-aged sibling. This packet contained a letter signed by the director at the school, informing parents that their typically developing high school-aged children were invited to participate in the study. In addition to this letter, a cover letter to the study, two copies of informed consent/assent, and an envelope with postage provided were included in the packet. The remainder of the procedure for recruiting participants through the private school for autism was the same as that outlined above for the public school district setting.

To recruit participants through outpatient clinics that provide services to a variety of children, many whom have autism, a similar process was used with minor changes. A letter (Appendix C) was sent to the director of the clinic. If he/she approved of the research, each director was asked to identify clients on the autism spectrum who had typically developing high school-aged siblings to whom information about the study could be sent. Each envelope contained the cover letter to the study, two copies of informed consent/assent, and envelopes with postage to return the letter of consent/assent back to the researcher. The remainder of the procedure was the same as that outlined above for the public school district setting. After consent/assent has been obtained for sibling participation and the consent/assent form was mailed back to the principal investigator, each participant received an e-mail containing the URL that directed him or her to the online background questionnaire/survey. The survey can be found in Appendix G. The online program, Survey Monkey, was used to collect the data through an online survey. An upgrade to the program was purchased prior to collecting any data, and this ensured security and encryption of data. This made the data provided secure and unsearchable on the Internet.

The internet-based survey asked participants to complete a background questionnaire and questions regarding their academic experiences. The background questionnaire was designed to take each participant no more than 3 minutes to complete and asked questions regarding demographic information. Once they completed this section, the participants were directed to the remainder of the survey, which should have taken the participants between 10 and 15 minutes to complete. The last required question of the survey asked participants if they would be interested in answering three openended questions regarding their academic experiences with their sibling in mind. Each sibling who completed the survey was entered in a raffle to win one of three \$25 iTunes gift cards that were awarded at the conclusion of the study.

#### Instruments

Participants completed a background questionnaire consisting of demographic variables (gender, birth date, age, grade, high school, race, ethnicity, marital status of parents) and those variables specific to the study (number of siblings and whether or not they have a sibling with autism). The survey asked questions related to the participant's academic experiences. This 33-item survey included both brief open-ended questions (e.g. *How many hours do you spend on homework in the average week?*) and items that required participants to respond using rating scales, of which there were two different types. On the first type, the participant was asked to rate 10 items by indicating how often they are likely to happen, from 1 (Never) to 5 (*Every day*). An example of these items is *My sibling(s) help me with my homework*. The second type of question required parents to endorse their level of agreement with 14 statements on a Likert scale that ranged from 1 (*strongly disagree*) to 7 (*strongly agree*).

The Likert scale mentioned above included four items taken from the Valuing subscale of the *Motivation and Engagement Scale- High School (MES-HS*, Martin, 2001), that required participants to respond on a 7-point Likert scale where 1 indicates strongly disagree and 7 indicates strongly agree. An example of one of these items is *Learning at school is important*. The *MES-HS* is for students aged 12 to 18 years and was normed on over 21,000 high school students. These four items comprise the entire Valuing subscale, which is part of the larger *MES-HS* that includes 11 subscales. The *MES-HS* has shown strong construct validity, particularly within the grade level and gender. In addition, there have been correlations between the *MES-HS* and "cognate constructs," one of which was school resilience, or a student's optimistic attitude towards school (Martin, 2009, p. 794).

There were three optional open-ended questions that asked the participant to describe their academic experiences with their sibling in mind. An example of an openended question asked of the participant was: *Could you tell me a way, if any, that your sibling has positively impacted your education?* 

#### Results

Due to the exploratory nature of this study, the alpha level has been set to .20 to ensure finding even marginally significant results. Prior to data analysis, the data was inspected for invalid responses, as well as outliers. This data cleaning process found no missing data or invalid responses.

Levene's test of equality of variance was significant (at alpha = .05) only for *t*tests of the following six items on the survey: "How much time do you spend one-on-one with your brother or sister outside of school, excluding the time you help them with homework or other skills?", "My sibling helps me with my homework.", "Parents help my sibling study", "I do homework when it is assigned", "I think it is important to do well in school," and "Academically, I feel as though I need to do better than my sibling." The significant differences indicate that the assumption of equal variances was violated for these six items. Consequently, *t*-tests that did not assume equal variances are reported for those six items.

## **T-Tests and Correlations**

Responses of participants that reported having a sibling with autism were compared to responses of those that reported having a typically developing sibling via independent samples *t*-tests. Descriptive statistics and results of independent *t*-tests for variables representing "count" variables (i.e., the number of hours or number of activities) are presented in Table 2. Those participants with siblings with autism reported participating in fewer extracurricular activities (M = 2.14, SD = 1.99) than did those who did not have a sibling with autism (M = 3.20, SD = 1.98). This difference was statistically significant; t(37) = -1.60, p = .119. Participants who had a sibling with autism reported spending fewer hours one-on-one with their sibling (M = 4.86 hours, SD = 4.22 hours) than did those who had typically developing siblings (M = 12.04, SD = 17.35), and this difference was also statistically significant; t(28.749) = -1.97, p = .059. The number of activities outside of school that high school students reported participating in did not differ significantly between the two groups, nor did the number of hours spent on homework each week or the amount of time spent helping their sibling with school-related activities. It should be noted, however, that students with siblings with autism indicated that they are more likely to do their homework (M = 5.00, SD = 0) than their peers with typically developing siblings (M = 4.84, SD = .374), t(23.24) = 2.138, p = .043.

Table 3 presents the descriptive statistics and *t*-test results for the group of questions that were answered on a 5-point rating scale. Participants who had sibling with autism reported receiving less help on homework from their sibling (M = 1.00, SD = .00) than did those who had typically developing siblings (M = 1.72, SD = .98), t(24) = -3.674, p = .001. Participants reported talking to their siblings with autism less about extracurricular activities (M = 1.79, SD = 1.31) than did those who had typically developing siblings (M = 3.92, SD = 1.15), t(37) = -5.283, p < .001. This was also true for conversations about school, where high school students reported they were less likely to speak to their siblings (M = 3.96, SD = 1.14), t(37) = -4.501, p < .001. Those high school students who did not have a sibling with autism (M = 2.24, SD = 1.01) than did those who did have a sibling with autism (M = 1.5, SD = 1.16), t(37) = -2.079, p = .045. Students who did not have a sibling with autism also reported receiving more help on their homework from

their parents (M = 2.40, SD = 1.23) than did students who had a sibling with autism (M = 1.71, SD = 1.27), t(37) = -1.657, p = .106. Students who had a sibling with autism reported that this sibling received more help on their homework than they themselves did (M = 3.79, SD = 1.72) as compared to students who had typically developing siblings (M = 2.36, SD = 1.29), t(37) = 2.939, p = .006.

There were no significant differences between the two groups in the extent to which they helped their siblings learn new skills at home, the amount that they helped their sibling with their homework, the extent to which the high school student's parent helps them study or their sibling study, the extent to which the high school student rated that they participated in extracurricular activities, or the extent to which the participant wishes that they had more time to spend on homework. Some of these items, such as the item regarding the extent to which they participated in extracurricular activities, were asking a question similar to those listed in Table 2 that were asked in a different question format. The purpose of this was to look at the consistency among the participants' responses.

The descriptive statistics for questions that were answered on a 7-point Likert scale are presented in Table 4. High school students who had typically developing siblings more strongly agreed that school is important (M = 6.84, SD = .62) than did students who had siblings with autism (M = 6.43, SD = .94), t(37) = -1.469, p = .158. Siblings of children with autism reported that they were more negatively affected academically by their sibling (M = 2.71, SD = 1.98) than did typically developing siblings (M = 1.84, SD = 1.60), t(37) = 1.504, p = .141, while siblings of children without autism reported that they were more positively affected academically by their sibling (M = 1.84, SD = 1.60), t(37) = 1.504, p = .141, while siblings of children without

= 5.00, SD = 1.96) than did those with autism (M = 3.14, SD = 1.83), t(37) = -2.905, p = .006. High school students who had siblings with autism more strongly agreed that their siblings received more attention at home from parents than they themselves did (M = 4.36, SD = 2.13) as compared to the reports of high school students who had typically developing siblings (M = 3.16, SD = 3.04), t(37) = 1.732, p = .092.

No statistically significant differences between the two groups were detected in their ratings regarding how important their mother, or father, believes it is to do well in school. This was also true for the following variables: being able to use what they learn in school in other parts of their life, feeling as though they have to perform better academically than their sibling, agreeing that it is important to understand what they are taught in school, their belief that learning at school is important, wanting their grades to be higher, believing that what they learn at school will be useful one day, and being satisfied with their grades.

Finally, as indicated in Table 5, no statistically significant difference was found between the GPA reported by the students who had a sibling with autism as compared to students who had typically developing siblings.

The Pearson product-moment correlations for the variables used in this study are presented in Table 6. The correlations in the table provide additional evidence regarding the validity of participants' responses, as responses to items correlate in predicted, sensible ways. For example, as can be seen from Table 6, the extent to which the participant wishes that they had more time for school increased with the number of school-based extracurricular activities that they reported participating in, as well as the number of hours that they reported spending on their homework. The more hours they reported putting into their homework, the higher their reported GPA was. GPA also increased with the amount that students reported their parents helped their sibling with their homework. The extent to which the participants participated in extracurricular activities increased with the amount of time they reported helping their sibling learn new skills at home. The greater number of hours they spent helping their sibling at home with homework and school-related activities was correlated with the extent to which they helped their sibling learn new skills at home, as well as the extent to which they helped their sibling with homework. (This correlation provides some evidence about reliability.) The more that participants helped their siblings also correlated with the amount that their parents helped their siblings both complete their homework and study. It appears that parents that helped the high school student with their homework were also more likely to help their sibling complete their homework. High school participants were more likely to view their sibling as getting more attention than they did the more that their parents helped their sibling with autism with their homework. Regarding sibling diagnosis, those high school students who did not have a sibling with autism reported needing greater help from parents on homework than did students with a sibling with autism, and those high school students who did have a sibling with autism reported that their parents are more likely to help their sibling with homework.

While many correlation matrices only flag significance at the .05 and .01 level, the matrix in Table 6 also includes a .20 alpha level. As stated in the beginning of the results section, this is due to the exploratory nature of this pilot study. The relationships that were significant at this level would be of interest to explore in future studies. One interesting result found that the more frequently a participant helps their sibling at home (learn new skills, do homework, etc.), and the greater frequency with which they help their sibling with homework was positively correlated with the extent to which the participant wished that they had more time to spend on their own homework and studying. The relationship between sibling diagnosis and receiving help on homework from parents was positive, indicating that if the student's sibling was typically developing, they also reported receiving more help on their homework from parents.

#### **Multivariate Analyses**

Time spent on school-related activities. A Multivariate Analysis of Covariance (MANCOVA) was used to analyze responses. The MANCOVA was conducted on three dependent variables representing how involved the high school student is with school (including school-related activities and homework-related activities), while taking into account the extent to which the high school student cares for, or helps, their sibling learn new skills (both related and unrelated to school), and if they are satisfied with the amount of time they spend on homework-related activities. The three dependent variables were: the number of school-based extracurricular activities (including sports) that the high school student reported participating in, the number of hours that the high school student reported spending on homework (including studying) in a typical week, and the extent to which the participant reported participating in extracurricular activities. The four covariates were the extent to which they help their sibling with homework, the extent to which they help their sibling learn new skills at home, the extent to which the high school student wishes that they had more time to spend on homework and studying, and the number of hours each week that the high school student reports helping their sibling outside of school with school-related activities, including homework and self-help skills.

The independent variable was whether the participant's sibling has an autism spectrum diagnosis. All 39 participants' responses were included in this analysis. Refer to Figure 1 for the detailed roles that each variable played in the MANCOVA.

In a MANCOVA, when all of the covariates were controlled for, the composite dependent variate differed significantly depending on whether or not the participant's sibling had an autism diagnosis (Wilks'  $\lambda$ , *F* [3,31] = 2.436, *p* = .084.) Univariate ANCOVA analyses found that when covariates were controlled, the groups differed significantly only in the number of extracurricular activities in which the students participated, *F*(1, 33) = 2.966, *p* = .094). Students with siblings with autism participated in fewer extracurricular activities (marginal *M* = 2.118, *SD* = .505) than students who had typically developing siblings (marginal *M* = 3.214, *SD* = .376).

While the composite variate in the MANCOVA was found to be significant, not all of the univariate ANCOVAs were significant. For the non-significant univariate ANCOVAs, power was estimated as follows: based on 15 participants in each of the two groups, the power of an ANOVA F test from Cohen (1982, Table 8.3.23) would be 39% power to detect a medium effect and 70% power to detect a large effect at an alpha level of .10. Because ANCOVAs were conducted and an alpha level of .20 was used in these analyses, power was increased.

**Parental support.** A Hotelling's  $T^2$  or two-group between-subjects multivariate analysis of variance (MANOVA) was conducted on six dependent variables: the extent to which the participant needed help on their homework from parents, the extent to which they received help from their parents, the extent to which their parents help them study, the extent to which they believe their sibling receives more attention than they do, the extent to which their parents help their sibling with homework, and the extent to which their parents help their sibling study. The independent variable was whether or not the participant's sibling has an autism spectrum diagnosis.

All 39 participants provided valid responses to these items, and therefore all are included in the analysis. Using the Wilks' Lambda criterion, the composite dependent variate was significant, which implies that there was an overall difference between the students who had a sibling with autism and students who had typically developing siblings (Wilks'  $\lambda$ , F [6,32] = 2.52, p < .05, partial  $\eta^2$  = .321). Univariate ANOVAs were conducted on each dependent measure separately to determine which factor, or factor(s) contributes to the overall significance of the analysis. Whether or not the participant's sibling has an autism spectrum diagnosis significantly predicted whether or not the participant needed help on their homework from their parents, F(1,37) = 4.32, p < .05, partial  $\eta^2 = .105$ . About 10.5% of the variance of the extent to which the participant reported needing help on their homework was accounted for by whether or not their sibling had an autism spectrum diagnosis. Participants who had a sibling with an autism diagnosis reported needing less help from their parents on homework (M = 1.5, SD = .29) than participants who had a typically developing sibling (M = 2.24, SD = .21). The extent to which the participant receives help on their homework is also significantly predicted by whether or not their sibling has an autism diagnosis, F(1,37) = 2.74, p = .11, partial  $\eta^2$ = .069. Participants who had a sibling with autism reported receiving less help from their parents (M = 1.71, SD = .33) than did participants who had a typically developing sibling (M = 2.40, SD = .25). Whether their sibling had an autism diagnosis was significantly related to the extent that the participant perceived their sibling as receiving more

attention,  $F(1,37) = 3.00 \ p = .092$ , partial  $\eta^2 = .075$ . Participants who had a sibling with an autism diagnosis perceived themselves as receiving less attention from their parents (M = 4.36, SD = .55) than did participants who have a typically developing sibling (M =3.16, SD = .41). The extent to which the participant perceived their parents as helping their sibling with their homework was also significantly affected by whether or not their sibling had an autism diagnosis, F(1,37) = 8.64, p < .01, partial  $\eta^2 = .189$ . Participants who had a sibling with an autism diagnosis perceived their siblings as receiving more help on their homework (M = 3.79, SD = .39) than participants who had typically developing siblings (M = 2.36, SD = .29). Whether or not the sibling had an autism diagnosis did not have significant effects on the extent to which parents helped the participant study for tests and quizzes, F(1,37) = .15, p > .20, or the extent to which parents helped the sibling study for tests and quizzes, F(1,37) = .121, p < .20.

While the composite variate in the MANCOVA was found to be significant, not all of the univariate ANCOVAs were significant. For the non-significant univariate ANCOVAs, power was estimated as follows: if there had been 15 participants in each group, a rough estimate of the power from Cohen (1988) would be 42% power to detect a medium effect and 59% power to detect a large effect at an alpha level of .10. Because the alpha level was .20 in this analysis, power was increased.

A multiple regression analysis was computed to see if the dependent variable of the extent to which the participant receives help on their homework was a function of the extent to which they *needed* help on their homework from their parents. This analysis indicated that the extent to which the participant received help on their homework from their parents was significantly related to the extent to which they needed help on their homework, F(1, 37) = 90.87,  $p < .001 R^2 adj = .703$ . The beta coefficient for the extent that participants needed help was  $\beta = .843$ , t = 9.53, p < .001, indicating that the more help the participants needed, the more help they received.

Impact of time spent on homework and parental support on GPA. A simultaneous multiple regression was conducted to analyze (a) if sibling diagnosis was significantly related to GPA and to (b) explore if parental support and time spent on homework acted as mediators in the equation. To do this, the procedure introduced by Barron and Kenny (1986) was followed. According to this procedure, a relationship must be established between the predictor variable and the outcome variable, followed by a relationship between the predictor variable and the mediating variables, and lastly, a relationship between the mediating variables and the criterion variables must be established. Then full mediation is demonstrated if the original relationship between the independent variable and dependent variable disappears when the mediator is controlled. It is not until all of these are established that a mediating relationship is demonstrated.

As shown in Table 7, there is no evidence of a relationship between the predictor variable (Sibling Diagnosis, or group membership) and the criterion variable (GPA). Because of this shortcoming, the mediation model is no longer viewed as viable. For documentation, the regression analysis summary beyond step 1 can be found in Phase 2 of Table 7.

# **Qualitative Responses**

The last question of the survey asked participants if they would be interested in sharing more information related to their siblings. If they opted to do so, then they were directed to three open-ended questions, where they could choose to answer whichever questions they were comfortable with. Refer to Table 8 for frequency counts of those who opted to share more information. Because these questions were exploratory and had a limited sample size, no formal theme extraction or analysis of the text was conducted; however, a more casual read through of the responses are presented below.

### Can you tell me a way, if any, that your sibling has positively impacted your

education? The following are sample responses of high school students who had a

sibling with autism. These were chosen because they expressed unique ways that having

a sibling with autism has contributed positively to their various schooling experiences.

"My sibling with autism has made me try harder in school, to get good grades, and get into college."

"He is definitely an influence in a lot of my essays and art assignments..."

"I am able to go to private school because my brother goes to a very good school for him and it is free. My parents could never afford to send more than one child to private school."

Other themes extracted from the responses not listed above were about the acceptance of

others, having a greater perspective of others, and having increased patience.

Themes that were extracted from responses from high school students who had

typically developing siblings were mostly centered about wanting to emulate their

hardworking siblings as well as the close relationships that they have developed.

#### Can you tell me a way, if any, that your sibling has negatively impacted your

education? Participants who had siblings with autism talked about getting less parental

attention and environmental distractions:

"My brother gets much more attention form my parents then I do, so they do not have much time to help me with homework and help me study for my tests. I think that if they help me more, then maybe I would get better grades and be more happier that they care about me." "Sometimes he distracts me when I am trying to study- like he babbles a lot or makes other noises."

"She is constantly making noises and hitting things and basically creating an environment that is extremely hard to study in. She is sitting next to me humming and bouncing on a green ball at the moment."

"People think that I also have autism (students and rare faculty members) and treat me as a lower-class student."

# Are you currently attending the same school as your brother/sister? If not

**now, have you ever before? If so, what is/was your experience like?** Most of the high school students who had siblings with autism responded to this question that they never were in the same school as their sibling with autism because (s)he is in an out-of-district private school to meet their unique needs. The one participant in this group who has been in the same school responded:

"We are currently attending the same school. We greet each other in the hallway. If he does something odd, someone else tells me as if I have control over it."

Many of the high school students with typically developing siblings responded that they either were currently, or had been in previous years, in the same school as their sibling. The extracted themes were positive, many saying that they enjoyed seeing their brother or sister in the hallways, or that they enjoyed knowing more people in the school via their sibling.

### Discussion

### General Time for School-Related Activities and Thoughts Surrounding Education

Participants who had siblings with autism reported participating in fewer extracurricular activities than participants who had typically developing siblings. As suggested by Benderix and Sivberg (2007), these participants may have greater responsibilities at home that do not allow them time to participate in extracurricular activities. Additionally, because parents may be involved in the education and care of the sibling with autism, they may be unable to support the sibling's involvement with the activity, such as by providing transportation. This finding further supports that found by Barak-Levy et al (2010), which also found that siblings of children with autism participate less in extracurricular activities and other activities outside of the home than do their peers.

The lower amounts of participation in extracurricular activities may provide some explanation as to why siblings of children with autism also believed that school was less important than their peers who have typically developing siblings. A study by Marsh (1992) confirmed the commitment-to-school hypothesis, which posits that the greater number of extracurricular activities that a student participates in, the more likely they are to identify with school values, and school in general. Perhaps the lack of participation in extracurricular activities decreases their feelings of belonging, and thus, makes school not as important. Another plausible explanation for the lower level of importance that siblings of children with autism place on school is that these students focus on the larger picture in life, whereas school is not their primary focus. Instead, they may be more aware of situations—especially those related to their sibling—that appear more pressing from moment-to-moment than school. A sibling with autism can create many challenges for their brother or sister in everyday life, therefore causing the typical brother or sister to have different priorities than a high school student with a typically developing sibling. In many of the open-ended responses, siblings of children with autism referred to the greater perspective that they had on life as a result of having a brother or a sister with a

disability, and this broader perspective may have influenced their ratings of the importance of school as compared to their peers.

For both groups of students in the study, the greater number of extracurricular activities in which a student participated, the greater the likelihood that they wished they had more time for school. Similarly, the greater number of hours that they spent on homework, the more they wished that they had more time for school. Also positively correlated was the number of extracurricular activities in which they participated and the number of hours that they spent on their homework. These positive relationships may indicate that participants in this study—both siblings of typical children and children with autism—have the mindset of overachieving. Students with this mentality may believe that they should always be doing better but feel as though they do not have the time to see the desired results. The impact of the potentially overachieving participants in the current study may have decreased the likelihood of finding significant differences between the two groups, since each group is of the overachieving frame of mind. Additionally, it is possible that the sample used in this study is not representative of the general population.

### Parent Relationships as Related to Academic Experiences

Regardless of the whether the high school student had a sibling with autism, no difference was detected in the importance participants reported their parents placed on doing well in school. According to participants, all parents believed that it is of great importance to do well in school.

While there was no difference found in the importance of school performance, however, other significant findings regarding parents emerged. Parental support was conceptualized as comprising six variables: (1) needing help on homework from parents, (2) receiving help on homework from parents, (3) parents helping student study, (4) parents helping sibling with autism study, (5) parents helping sibling with autism with homework, and (6) students perceiving that sibling with autism gets more attention. In this study, those high school students that had a sibling with autism felt that they received less attention from their parents when compared to participants with typically developing siblings. Additionally, they reported that their siblings receive more help from their parents than they do. The extent to which their sibling needs help is unknown, and it is possible that the parents are meeting their sibling with autism's need, or that they are giving them more help than necessary due to their disability. However, because individuals with autism require greater levels of supervision, more support in the home, and increased parental attention, differential amounts of parental treatment among siblings is possible. Services for children with autism (e.g., speech therapy, occupational therapy, applied behavior analysis) often require parental involvement to promote progress and generalization, which can take up a substantial amount of parent's time.

It is also likely that parents view their typically developing child as being more "able" to complete their homework independently and believe that they do not require as much support as the sibling with autism. Indeed, siblings of children with autism report that they need less help on their homework from their parents than did participants who had typically developing siblings. One explanation for their decreased need for help is that they may try to be more independent, self-reliant, and autonomous because they do not have the same disability as their sibling. Further, they may want to show their parents that they are responsible and able to be self-sufficient so as not to cause additional stress for their parents. Reports of the amount of help they need from parents may also be affected by their perception that their sibling with autism needs, and receives, more attention than they do. As a result, siblings of children with autism may have settled into a role where they do not report needing the attention of their parents because they believe their sibling needs it more.

While the participants with siblings with autism did report needing less help on their homework from parents when compared to the participants who did not have siblings with autism, it is important to note that when they did need help, they reported receiving it. This may be evidence that parents are very much aware of all of their children's needs and are able to provide support when their typically developing child expresses that they need it.

#### Sibling Relationships as Related to Academic Experiences

Delayed communication development is one of the primary symptoms of an autism diagnosis. This limited communication is likely to decrease the verbal interaction between siblings when one has autism, and could quite possibly limit non-verbal interactions as well. Participants of the current study reported spending less one-on-one time with their sibling with autism compared to participants who have typically developing siblings, which could be a result of their sibling's limited conversational abilities. Accordingly, participants with siblings with autism spoke to their siblings less about school than did their high school student-counterparts who did not have a sibling with autism. The decreased communication about academics supports Bank and Kahn's (1982) notion of "access," which often exists in a typically developing sibling pair and increases when siblings are close in age, are of the same gender, and have similar interests. When one participant has autism, access is likely to be decreased due to the sibling with autism's difficulty in building intimate relationships with their siblings, as well as having limited communication capabilities. This may result in fewer sibling interactions.

Challenging behaviors that are often exhibited by individuals with autism may also be a factor in the limited interactions between siblings when one has autism. These challenging behaviors can be loud, distracting, and sometimes dangerous. Managing them can be difficult, and a typically developing sibling may not have the proper training, or information, to effectively manage them. This disruptive behavior may also explain why participants feel as though their sibling with autism negatively affects their academics. Extracted from open-ended responses written by participants was a theme of feeling as though their sibling with autism caused a number of distractions in the home environment.

In contrast, participants with typically developing siblings reported feeling that their sibling positively affects their academics. This finding could be because they reported being more likely to receive help on their homework from their siblings than those individuals who have siblings with autism. Additionally, they may look to their older sibling as a role model, or want to be a role model for their younger sibling. Unlike siblings of children with autism, siblings of typically developing children were also more apt to talk to their siblings about their day at school, which Tucker and Winzeler (2007) suggest can have beneficial effects on positive growth for each of the siblings.

While it was expected that high school students with siblings with autism would provide more help to their sibling in the home when compared to their peers with typically developing siblings, this hypothesis was not substantiated. The amount of help that a high school sibling gave their sibling had no relationship with whether or not their sibling had an autism spectrum diagnosis. This is inconsistent with past research, which has found that an individual who has a brother or sister with a disability may develop a "precocious responsibility" (Benderix & Sivberg, 2007, p. 14) and may be more likely to help their sibling at home and fill a parental role, if necessary. It is possible that with the students in this study, their parents typically took on the responsibility is that the children with autism received outside services which removed them from the home for most afternoons. Lastly, if the students' sibling was higher functioning, then this could also be a viable explanation for the finding, because they may not require as much attention as a sibling who is lower functioning.

Of particular interest was the question of whether participants felt they needed to perform better than their sibling academically, because of the commonly assumed notion of sibling competition, where siblings constantly feel the need to perform better than their sibling not only academically, but also athletically and socially. It was hypothesized that perhaps high school students who had a sibling with autism might feel as though they would have to overcompensate for their sibling's deficits, but this was not found to be true. Surprisingly, there was no significant difference between the two groups regarding whether the participant agreed that they had to do better than their sibling academically. This finding is consistent with the research of Kaminsky and Dewey (2001), who found that siblings of children with autism were found to be less competitive with their brother or sister when compared to typically developing sibling pairs. In the current study, it is notable that the participants in the comparison group did not feel the need to outperform their siblings, either.

Open-ended responses yielded additional information that was not captured in the quantitative data. Based on the responses from high school students, it appeared evident that regardless of sibling diagnosis, both groups had input regarding their sibling's influence on their education and chose to answer these optional questions. Many of the participants with siblings on the autism spectrum commented on the fact that their siblings' impact on their own academic performance was negligible, or they commented on their understanding of how their sibling has impacted them emotionally, behaviorally, and in their patience and acceptance of others. Many students with siblings with autism felt as though their behavior in school is impacted by their brother or sister because they do not judge people at first glance. Students with typically developing siblings commented that their brother or sister impacts them academically by helping them study for tests, helping them with their homework, or serving as a role model to succeed in school.

Many of the students, regardless of their group membership, said that their sibling does not negatively impact their education in any way. The few who did think about a way that their sibling has negatively affected them with their schoolwork, regardless of the group, indicated that the negative impact was due to interruptions and distractions caused by their sibling.

The final open-ended question asked students to share experiences they had if they were currently, or had ever, attended the same school as their sibling. Almost all of the students with siblings with autism who responded to this question had never attended the same school, which is intuitive since many of their brothers or sisters were attending private schools that specialized in working with children with autism. Many students in the comparison group had attended the same school as their typically developing sibling. Many responses appeared indifferent to the fact that they shared the same school as their sibling, in that they had attended the same school but seldom saw each other during the school day. Others were positive, stating that they enjoyed the opportunity to share the same hallways, friends, and experiences.

#### **Academic Performance (GPA)**

Considering the aforementioned information regarding the role that students' siblings play in their academics, students' perception of how their parents' attention is divided, and the finding that there is no difference between the amount of time spent on homework between students who have a sibling with autism and those who do not, it is here that we turn to a central question of the study regarding GPA, the most widely known measurement of academic performance. It was hypothesized that those students with siblings with autism would have a lower GPA than their peers based on past research findings of increased responsibility, decreased parental attention, and a possible genetic vulnerability. However, no significant difference was found between the two groups on their grade point average (GPA). In fact, though not significantly significant, participants with a sibling with autism reported slightly higher GPAs than did siblings of typically developing children.

When considering the rationale for the original hypothesis and the lack of support for that rationale in the findings of the current study, the null finding regarding differences in GPA is not surprising. That is, though the students with siblings with autism in the current sample reported receiving less help from their parents than did siblings of typical children, they perceived themselves as receiving the amount of help on their homework that they needed. Sufficient parent help and available time for schoolwork may help partly explain why siblings of children with autism did not report lower GPAs than peers, as was originally expected. Further, findings from past research also suggests that students who have a sibling with a disability score higher on intellectual measures because they compare themselves with their sibling with a disability, thus enhancing their own self-esteem and perception of self-efficacy (Macks and Reeve, 2007). This enhanced self-esteem may have aided the students with siblings with autism in the current sample. On the other hand, the lack of significant differences may be the result of low statistical power. This possibility cannot be ruled out.

### Summary

This pilot study did not detect a difference in GPA, which is the most objective and quantitative measure of academic performance; however, it does have other important implications. The inclusion of a sibling with autism in the family has significant impacts on the academics of the neurotypical sibling, as well as functioning of the family system as a whole.

According to this study, school appears to be something at which both groups of participants succeed. However, the students' underlying cognitions regarding the importance of school and the time allotted to extracurricular activities differentiate siblings of children with autism from siblings of typically developing children. The limited availability of transportation due to parental involvement with their sibling with autism may explain this finding. Additionally, it is possible that they have increased responsibilities at home and have to attend to those, which decreases their available time for extracurricular activities. Perhaps their minimal involvement in extracurricular activities, when compared to students who do not have siblings with autism, lends an explanation to the finding that students who have siblings with autism find school less important than their peer counterparts who do not have a sibling with autism. Sense of belonging can be compromised, and thus, reduces school importance. While certainly not easy, it is important for parents to make sure that their typically developing sibling is involved in activities of their own, participates in social events, and has hobbies that are personal to themselves. School importance may also be of less significance for students who have siblings with autism because they focus on the "bigger picture" in life and are less concerned about day-to-day events and obligations.

Regarding siblings' perceptions of how parents allot their time to their individual children, siblings of autism indicate that their parents spend more time with their brother or sister with autism. While this finding may not be directly related to sibling performance in school, it highlights the sibling perception of parent availability. For these families, parents may be able to utilize the time during which the child with autism has related service appointments (e.g., speech, respite care) to spend one-on-one time with the typically developing child. If finances permit, another option is to hire a babysitter to watch the child with autism and spend the night alone with the typically developing child. Increased dialogue between parents and typically developing children surrounding their sibling's condition, as well as conversation surrounding the possibility of differential levels of attention, could also be beneficial for the sibling. According to Harris and Glasberg (2003), how the typical child understands the discrepant treatment they receive

as compared to their sibling with autism is of great importance in a family. Parents must be in constant communication with their typically developing son or daughter regarding why their sibling with autism may require more attention at specific times.

Because these conversations are not always easy to have, it is necessary that parents are aware of services that they can receive to help facilitate dialogue with their typical child or children. Participating in family therapy so that all family members can speak their mind in a non-judgmental environment can be beneficial to the family system. If it would be counterproductive or inappropriate for the child with autism to attend these family therapy sessions, then perhaps parents can schedule them for a time that their child with autism has one of their service appointments. This would also be an appropriate venue for high school students to voice that they feel as though their siblings with autism negatively impact their academics, if this is the case, and allow for a discussion with parents to take place. Discussing challenges such as these can lead to the development of problem-solving strategies the parents and child may use in the future. These strategies may result from conversations that take place within the family therapy session.

Psychologists and other mental health professionals that work with families with one child with autism should also consider the findings of this study. They should be cognizant of the fact that it is possible that the neurotypical child believes that their sibling has negative impacts on their education and that they are receiving less attention from their parents. Perhaps these factors are some of the reasons that these individuals have been found to have increased levels of depression, as well as the increased likelihood of internalizing and externalizing disorders alike. As Dunn et al. (1990) found, the typically developing child in a family with a child with autism can feel "less than" their sibling. Mental health professionals can help address this cognition with psychoeducation for the typically developing sibling and parents, as well as in a family therapy environment.

### Limitations

This research was not without limitations. The most obvious limitation was the sample size, which was significantly smaller than the desired sample size that was initially established. Because of the limited sample size, the necessary power to detect differences between the groups was significantly compromised, making it challenging to find meaningful results and to interpret nonsignificant differences. The small sample size was the direct result of difficulties in the recruiting process. A related limitation was that the number of participants in each group was not equal. The required permissions in school districts and private schools as well as the cost of recruitment became prohibitive during this project. Additional research to strengthen the results is necessary, and the use of larger sample sizes will provide greater ability to identify findings that may have escaped detection here.

Further, one must always consider in research such as this that the participants that choose to participate are often more motivated, by nature, to complete various tasks and responsibilities than are those who chose not to participate. Students who returned their consent forms to the researcher are likely dependable in other aspects of their life as well, therefore creating a nonrepresentative sample. The participants in this study largely reported that their GPA was between an A and a B and that they wished they had more time to spend on homework. These data indicate that the high school students who agreed to participate in this study may have an overachiever attitude in all realms of life. It is possible that this decreased the likelihood of finding significant differences between the two groups' GPAs, because both groups of children were equally likely to be high-level achievers.

The sibling's severity of autism was not taken into account when analyzing the results, and it is likely that the functioning level of siblings with autism has an effect on their high school-aged sibling. The lower the functioning of an individual with autism, the greater the likelihood that they have limited verbal ability, exhibit challenging behaviors, need to be supervised more intensely by parents and siblings, and receive more services. Therefore, lower functioning siblings with autism may impact their typically developing sibling to a greater extent than higher functioning siblings. Also, this study did not distinguish between sibling diagnoses in the focal group. While some students indicated that their sibling had Asperger's Syndrome or Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS), for the purposes of this pilot study, all participants who had a brother or sister on the autism spectrum were included in the autism group. Combining these diagnoses may have confounded findings because different diagnoses are likely to manifest different symptoms in individuals, and may affect typical siblings differently based on the functioning level of the sibling with an ASD.

### **Direction of Future Research**

Because this research is a pilot study, it would be beneficial to conduct it with a larger sample size to see if significant findings are achieved and supported. Ultimately, the goal of this research is to see if, academically, there is a difference between those high school students who have brothers and sisters with autism, and those who do not. If

future research indicates that those high school students with siblings with autism report struggling academically, interventions should be established and implemented to narrow the gap between these two groups. It should be noted, however, that according to this study, students who have a sibling with autism might do as well as their counterparts who do not have a sibling with autism. The difference of perceived importance of school, however, was significant and can be further investigated to gain insight as to why students who have a sibling with autism feel that school is less important. Interventions that can hone in on school importance and allow students to explore their underlying thoughts surrounding this phenomenon can be utilized.

School psychologists should always consider how factors outside of school may affect school-aged students and develop programs that may effectively support these siblings. One well-established program available for siblings of children with disabilities that has been adapted for those siblings of children with autism is Sibshops (Meyer & Vadasy, 2007). Although originally developed for younger children through age 13, it can be adapted to suit the older child's needs. Alternatively, it may also be worthwhile and advantageous to develop a program solely for the older teenager as they prepare to graduate high school, establish their identity, and begin their adult lives. A program like this would be therapeutic and educational to foster the development of the older teenager.

There are many variables that are of interest when looking at sibling dynamics when one has autism, and this pilot study merely brushed the surface. Looking at the number of siblings in a family, where the sibling with autism falls in the birth order, and the sex of each sibling also has the potential for yielding valuable information about sibling dynamics. Future research should embrace these variables to see if they provide any protective factors or potential risk factors for the typical sibling. For example, it is likely that being the youngest child in a family of four where the second oldest sibling has autism is drastically different from being the oldest child in a family of two where the younger child has autism because having other siblings could act as a buffer to protect some of the impacts that having a sibling with autism may have. Having typically developing siblings in addition to a sibling with autism still allows the high school student to have a relationship in a typical sibling duo. Giving these variables the attention that they deserve was outside of the scope of this pilot study but should be incorporated into future studies.

### Conclusion

When one child in a family has autism, he or she can have various impacts on the immediate family system. The purpose of this study was to explore academic impacts that having a brother or sister with autism may have on their high school-aged sibling. Overall, GPA and academic performance was not significantly affected, but thoughts about school, time allotment outside of school, and routines at home with the family were found to be impacted significantly by the presence of a sibling with autism. The incidence of autism is increasing, and the most recent statistics have showed that 1 in 88 children are on the autism spectrum (CDC, 2012). As the rate of autism increases, so will the number of typically developing siblings. More families, and siblings, will need supports put in place and services made available to them. Even though they do not carry the autism diagnosis, the siblings of children with autism should receive the attention necessary to understand and address their unique position in the family system.

#### References

- Abramovitch, R., Corter, C., & Lando, B. (1979). Sibling interaction in the home. *Child Development*, 50, 997-1003.
- Abramovitch, R., Stanhope, L., Pepler, D., & Corter, C. (1987). The influence of Down syndrome on sibling interaction. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 28,* 865–879.
- Alegre, A., & Benson, M. J. (2010). Parental behaviors and adolescent adjustment: Mediation via adolescent trait emotional intelligence. *Individual Difference Research*, 8(2), 83-96.
- American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.
- Bank, S. P., & Kahn, M. D. (1982). The sibling bond. New York: Basic Books.
- Barak-Levy, Y., Goldstein, E., & Weinstock, M. (2010). Adjustment characteristics of healthy siblings of children with autism. *Journal of Family Studies*, 16(2), 155-164.
- Baron, R. M., & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, 51, 1173–1182.
- Bass, J. D., & Mulick, J. A. (2007). Social play skill enhancement of children with autism using peers and siblings as therapists. *Psychology in the Schools*, 44(7), 727-735.
- Benderix, Y., & Sivberg, B. (2007). Siblings' experiences of having a brother or sister with autism and mental retardation: A case study of 14 siblings from five families. *Journal of Pediatric Nursing*, 22(5), 410-418.

- Benson, P. R., & Karlof, K. L. (2008). Child, parent, and family predictors of latter adjustment in siblings of children with autism. *Research in Autism Spectrum Disorders, 2*, 583-600.
- Benson, P. R., Karlof, K. L., & Siperstein, G. N. (2008). Maternal involvement in the education of young children with autism spectrum disorders. *Autism*, 12, 47–63.
- Biddle, B. J., & Thomas, E. J. (1966). The nature and history of role theory. In Biddle & Thomas (Eds.) *Role theory: Concepts and research* (p. 3-17). New York, NY: John Wiley & Sons, Inc.
- Bouchey, H. A., Shoulberg, E. K., Jodl, K. M., & Eccles, J. S. (2010). Longitudinal links between older sibling features and younger siblings' academic adjustment during early adolescence. *Journal of Educational Psychology*, *102*(1), 198-211.
- Brody, G. H. (2004). Siblings' direct and indirect contribution to child development. *Current Directions in Psychological Science, 13*(3), 124-126.
- Buhrmester, D., & Furman, W. (1990). Perceptions of sibling relationships during middle childhood and adolescence. *Child Development*, 61, 1387-1398.
- Buhrmester, D. (1992). The developmental courses of sibling and peer relationships. In
  F. Boer & J. Dunn (Eds.), *Children's sibling relationships: Developmental and clinical issues* (pp. 19–40). Hillsdale, NJ: Erlbaum.
- Byrne E. A., Cunningham C. C., & Sloper P. (1988.) *Families and their children with Down's syndrome: One feature in common.* London: Routledge.
- Celiberti, D. A., & Harris, S. L. (1993). Behavioral interventions for siblings of children with autism: A focus on skills to enhance play. *Behavior Therapy*, *24*, 573-599.

Centers for Disease Control and Prevention (CDC) (2012). Prevalence of autism spectrum disorders. Retrieved from

http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?s\_cid=ss6103a1\_w

- Cicirelli V. G. (1982). Sibling influence throughout the lifespan. In M. E. Lamb, B.
  Sutton-Smith B, (Eds.) *Sibling relationships* (p 267-284). Hillsdale, NJ: Lawrence Erlbaum.Crocker, A. C. (1981). The involvement of siblings of children with handicaps. In A. Milunsky (Ed.) *Coping with crisis and handicap* (pp 219-223). New York: Plenum Press.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.) Hillsdale, NJ: Lawrence Erlbaum.
- Dunn, J., & Kendrick, C. (1979). Interaction between young siblings in the context of family relationships. In M. Lewis & L. Rosenblum (Eds.), *The child and its family*, (pp. 143-168). New York: Plenum Press.
- Dunn, J., Stocker, C., & Plomin, R. (1990). Non-shared experiences with the family: Correlates of behavioral problems in middle childhood. *Development and Psychopathology*, 2, 113–126.
- Fan, X., & Chen, M. (2001). Parental involvement and students' academic achievement:A meta- analysis. *Educational Psychology Review*, 13(1), 1-22.

Farber, B. (1960.) Interaction between severely mentally retarded children and their normal siblings. In B. Farber (Ed.), Family organization and crisis: Maintenance of integration in families with a severely mentally retarded child. *Monographs of the Society for Research in Child Development, 25*(1). 78-84.

- Fisman, S., Wolf, L., Ellison D., & Freeman, T. (2000). A longitudinal study of siblings of children with chronic disabilities. *Canadian Journal of Psychiatry*, *45*, 369-375.
- Fisman, S., Wolf, L., Ellison, D., Gillis, B., Freeman, T., & Szatmari, P. (1996). Risk and protective factors affecting adjustment of siblings with chronic disabilities. *Journal of American Academy of Child Adolescent Psychiatry*, 35, 1532-1541.
- Foden, T. J. (2009). How do siblings affect autistic kids? *Interactive Autism Network*. Retrieved 2/7/11.
- Gamliel, I., Yirmiya, N., Jaffe, D. H., Manor, O., & Sigman, M. (2009). Developmental trajectories in siblings of children with autism: Cognition and language from 4 months to 7 years. *Journal of Autism and Developmental Discord, 39*, 1131-1144.
- Gargiulo, R. M., O'Sullivan, P. S., & Wesley, K. (1992). Sibling relationships involving school children with acquired/congenital and visible/invisible disabilities. *Special Education and Rehabilitation*, 7(2), 7-23.
- Gold, N. (1993). Depression and social adjustment in siblings of boys with autism. Journal of Autism and Developmental Disorders, 23, 147-163.
- Harris, S. L. (1982). A family systems approach to behavioral training with parents of autistic children. *Child and Family Behavior Therapy*, *4*, 21-35.
- Harris, S. L., & Glasberg, B. A. (2003). Siblings of children with autism: A guide for families. Maryland: Woodbine house.
- Henderson, A., & Berla, N. (1995). A new generation of evidence: The family is critical to student achievement. Washington DC: Center for Law and Education.
- Henderson, A. T., & Mapp, K. L. (2002). *A new wave of evidence: The impact of school, family, and community connections on student achievement.* Austin, TX: National

Center for Family and Community Connections with Schools, Southwest Educational Development Laboratory. Retrieved from http://www.sedl.org/connections/research-syntheses.html.

- Kaminsky, L., and Dewey, D. (2001). Siblings relationships of children with autism. Journal of Autism and Developmental Disorders, 31(4), 399-410.
- Kaminsky, L., and Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry*, 43(2), 225-232.
- Knott, F., Lewis, C., & Williams, T. (1995). Sibling interaction of children with learning disabilities: a comparison of autism and Down's syndrome. *Journal of Child Psychology and Psychiatry*, 36(6), 965-976.
- Lobato, D., Miller C. T., Barbour, L., Miller, C. T., Hall, L. J., & Pezzullo, J. (1991).
   Preschool siblings of handicapped children: Interactions with mothers, brothers, sisters. *Research in Developmental Disabilities*, *12*, 387-399.
- Macks, R. J., & Reeve, R. E. (2007). The adjustment of non-disabled siblings of children with autism. *Journal of Autism and Developmental Discord*, *37*, 1060-1067.
- Marsh, H. W. (1992). Extracurricular activities: Beneficial extension of the traditional curriculum or subversion of academic goals? *Journal of Educational Psychology*, 84(4). 553-562.
- Martin, A. J. (2009). Motivation and engagement across the academic life span: A developmental construct validity study of elementary school, high school, and university/college students. *Educational and Psychological measurement*, 69(5), 794-824.

- Martin, A. J. (2011). *The Motivation and Engagement Scale* (11 Edition). Sydney, Australia: Lifelong Achievement Group (www.lifelongachievement.com).
- Mates, T. E. (1990). Siblings of autistic children: Their adjustment and performance at home and in school. *Journal of Autism and Developmental Disorders, 20*(4), 545-553.
- McHale, S. M., & Gamble, W.C. (1989). Sibling relationships of children with disabled and non- disabled brothers and sisters. *Developmental Psychology*, 25, 421–429.
- McHale, S. M., & Harris, V.S. (1992). Children's experiences with disabled and nondisabled siblings: Links with personal adjustment and relationship evaluations. In F. Boer & J. Dunn (Eds.), *Children sibling relationships: Developmental and clinical issues* (pp. 83-100). Hillsdale, NJ: Erlbaum Associates.
- Mendelson, M. J., de Villa, E. P., Fitch, T. A., & Goodman, F. G. (1997). Adults' expectations for children's sibling roles. *International Journal of Behavioral Development*, 20(3), 549-572.
- Meyer, D., & Vadasy, P. (2007). Sibshops: Workshops for siblings of children with special needs (revised edition ed.). Baltimore, MD: Paul H. Brookes.
- Meyer, K. A., Ingersoll, B., & Hambrick, D. Z. (2011). Factors influencing adjustment in siblings of children with autism spectrum disorders. *Research in Autism Spectrum Disorders* doi:10.1016/j.rasd.2011.01.027.
- Murdock, G. P. (1966). Analysis of kinship. In Biddle & Thomas (Eds.) *Role theory: Concepts and Research,* (p. 81-87). New York, NY: John Wiley & Sons, Inc.

- Orsmond, G. I., & Seltzer, M. (2007). Siblings of individuals with autistic spectrum disorders across the life course. *Mental Retardation and Developmental Disabilities Research Reviews, 13,* 313-320.
- Orsmond, G. I., Kuo, H, & Seltzer, M. M. (2009). Siblings of individuals with an autism spectrum disorder. *Autism*, 13(1), 59-80.
- Petalas, M. A., Hastings, R. P., Nash, S., Dowey, A., & Reilly, D. (2009). "I like that he always shows who he is:" The perceptions and experiences of siblings with a brother with autism spectrum disorder. *International Journal of Disability, Development, and Education, 56*(4), 381-399.
- Powell, T. H., & Ogle, P. A. (1985). Brothers and sisters: A special part of exceptional *families*.Baltimore: Brookes.
- Reagon, K. A., Higbee, T. S., & Endicott, K. (2006). Teaching pretend play skills to a student with Autism using video modeling with a sibling as model and play partner. *Education and Treatment of Children*, 29(3), 517-528.
- Rodrigue, J. R., Geffken, G. K., & Morgan, S. B. (1993). Perceived competence and behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders, 23,* 665-674.
- Ross, P. & Cuskelly, M. (2006). Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual & Developmental Disability*, 31(2), 77-86.
- Roeyers, H., & Mycke, K. (1995). Siblings of children with autism, with mental retardation and with normal development. *Child Care, Health, and Development,* 21, 305–319.

- Schreibman, L., O'Neill, R. E., & Koegel, R. L. (1983). Behavioral training for autistic siblings. *Journal of Applied Behavior Analysis*, 16, 129-138.
- Smith, T., Polloway, E., Patton, J., & Dowdy, C. (2008). *Teaching students with special needs in inclusive settings* (5<sup>th</sup> ed.). Boston: Pearson Education.
- Smith, T. E. (1984). School grades and responsibility for younger siblings: An empirical study of the "teaching function." *American Sociological Review, 49*, 248-260.
- Smith, T. E. (1990). Academic achievement and teaching younger siblings. School Psychology Quarterly, 53(4), 352-363.
- Stevens, J. P. (1980). Power of the multivariate analysis of variance tests. *Psychological Bulletin*, 88(3), 728-737.
- Stoneman, Z., Brody, G. H., Davis, C. H., Crapps, J. M., & Malone, D. M. (1991). Ascribed role relations between children with mental retardation and their younger siblings. *American Journal on Mental Retardation*, 95(5), 537-550.
- Stoneman, Z. (2001). Supporting positive sibling relationships during childhood. *Mental Retardation and Developmental Disabilities Research Reviews*, 7, 134-142.
- Stoneman, Z. (2005). Siblings of children with disabilities: Research themes. *Mental Retardation*, *43*(5), 339-350.
- Strain, P. S. & Danko, C. D. (1995). Caregivers' encouragement of positive interaction between preschoolers with autism and their siblings. *Journal of Emotional and Behavioral Disorders*, 3(1), 2-12.
- Taylor, B. A. (2001). Teaching peer social skills to children with autism. In C. Maurice,G. Green, & R. M. Foxx (eds.), *Making a Difference: Behavioral Intervention for Autism (pp 83-96)*. Austin, TX: Pro-Ed.

- Tsao, L. & Odom, S. L. (2006). Sibling-mediated social interaction intervention for young children with autism. *Topics in Early Childhood Special Education*, 26(2), 106-123.
- Tucker, C. J., McHale, S. M., & Crouter, A. C. (2001). Conditions in sibling support in adolescence. *Journal of Family Psychology*, 15, 254-271.
- Tucker, C. J. & Updegraff, K. (2009). The relative contributions of parents and siblings to child and adolescent development. In L. Kramer & K. J. Conger (Eds.), *Siblings* as agents of socialization. New Directions for Child and Adolescent Development, 126, 13–28. San Francisco: Jossey-Bass.
- Tucker, C. J., & Winzeler, A. (2007). Adolescent siblings' daily discussions: Connections to perceived academic, athletic, and peer competency. *Journal of Research on Adolescence*, 17(1), 145-152.
- Walberg, H. J. & Paik, S. J. (2004). Effective general practices in G. Cawelti (Ed.)
   *Handbook of Research on Improving Student Achievement* (3<sup>rd</sup> ed., pp 25-38).
   Arlington, VA: Educational Research Service.
- Westoreland, H., Rosenberg, H. M. Lopez, M. E., & Weiss, H. (2009). Seeing is Believing: Promising Practices for How School Districts Promote Family Engagement. Harvard Family Research Project.
- Youngblade, L. M., & Dunn, J. (1995). Individual differences in young children's pretend play with mother and sibling: Links to relationships and understanding of other people's feelings and beliefs. *Child Development*, 66, 1472–1492.
- Zajonc, R. B., Markus, H., & Markus, G. B. (1979). The birth order puzzle. *Journal of Personality and Social Psychology*, *37*(8), 1325-1341.

Appendices

# Appendix A

# Dear (superintendent),

My name is Erin Herman, and I am a doctoral student at the Graduate School of Applied and Professional Psychology (GSAPP) at Rutgers University. I am doing a research study to fulfill the dissertation requirement of the doctoral degree in School Psychology.

My dissertation is entitled, "Growing up with Autism: The Educational Impact on Neurotypical Siblings." In this research, I am studying the academic experiences of the typically developing high school student growing up with a sibling with autism, as compared to high school students growing up with siblings who do not have autism. To complete my study, I am currently recruiting **neurotypical high school students** (high school students who do not have a developmental disability, such as autism, PDD-NOS, or Asperger's Syndrome themselves), including those who have a sibling with autism, and those who do not.

The purpose of this letter is to request permission for me to recruit high school students in your district for participation in my study. If you grant me permission, the following steps would take place to recruit participants:

- With your consent allowing me to recruit participants in your district, I would then contact the principals at the high school(s) in your district to obtain their consent as well. I would ask them to recommend a contact person in the high school (either a teacher or a Child Study Team member) that can assist me in finding teachers who are willing to help me recruit participants. Their duties would be to hand out an envelope to each student in their homeroom class. The envelopes will contain the following items: a cover letter to my study, two letters of consent/assent for participation, and a return envelope with provided postage. One of the copies of consent/assent is to be retained by the family. The other is to be mailed back to me in the provided envelope.
- The contact person that is recommended to me will also be asked to solicit assistance from the Child Study Team. The purpose of requesting help from them is because they will have knowledge of students on their caseload with an "Autistic" classification under IDEIA and may be able to identify typically developing siblings who are in the high school. The Child Study Team is not expected to release any names or identifying information to me. They will be given a stack of envelopes as well and will be asked to give one to any target sibling that they are aware of.

Once the envelopes are distributed to the students, the district's and individual high schools' responsibilities in my research are complete. The students who agree to participate will be e-mailed the URL to access my online survey.

If you agree to your district's participation, I would be happy to thank you and the high school(s) in the district by offering a free in-service workshop for your teachers about my study.

# Appendix A

I also CC'd the Director of Special Services in your district, since their help would be appreciated as well.

This study has been approved by the Institutional Review Board (IRB) at Rutgers University. If you have any questions, please do not hesitate to contact me by calling (732)778-0540, or by e-mailing me at <u>erinherm@eden.rutgers.edu</u>. If you agree to have your school district participate in this study, please sign below.

After you have signed below indicating your consent, please mail the portion below the dotted line back in the envelope provided, which is addressed and pre-stamped. When I receive your approval, I will in turn mail you all of my study materials so that you can see exactly what the participants will be doing in helping me conduct my research.

Thank you so much for your consideration in helping me with my research,

Erin L. Herman Principal Investigator Doctoral Candidate in School Psychology Rutgers University

By signing below, I agree to have my school district participate in the study, "Growing up with Autism: The Educational Impact on Neurotypical Siblings."

(Superintendent name, printed)

(Name of District)

(Superintendent signature)

(Date)

## Appendix B

Dear (director),

My name is Erin Herman, and I am a doctoral student at the Graduate School of Applied and Professional Psychology (GSAPP) at Rutgers University. I am doing a research study to fulfill the dissertation requirement of the doctoral degree in School Psychology.

My dissertation is entitled, "Growing up with Autism: The Educational Impact on Neurotypical Siblings." In this research, I am studying the academic experiences of the typically developing high school student growing up with a sibling with autism, as compared to high school students growing up with siblings who do not have autism. To complete my study, I am currently recruiting **neurotypical high school students** (high school students who do not have a developmental disability, such as autism, PDD-NOS, or Asperger's Syndrome themselves), including those who have a sibling with autism, and those who do not.

The purpose of this letter is to request permission for me to recruit participants that are typically developing high school-aged siblings of students at your school. If you grant me permission to recruit participants through your school, the following steps will take place:

• I would ask you to create a letter that would inform parents of the study that is being conducted. This letter would go in an envelope, along with a cover letter to my study, two copies of informed consent/assent, and a return envelope provided with postage. It is requested that the envelope of materials goes home only with students at Search Day Program who have a typically developing sibling that is in high school.

Once the envelopes are sent home with students, your role in my research is complete. Siblings who agrees to participate will provide me with their e-mailed on the inform consent/assent form, and the URL will be e-mailed to them to complete my survey online.

If you are interested, I would be more than happy to present my results at the completion of my dissertation with you and your staff.

This study has been approved by the Institutional Review Board (IRB) at Rutgers University. If you have any questions, please do not hesitate to contact me by calling (732)778-0540, or by e-mailing me at <u>erinherm@eden.rutgers.edu</u>. If you agree to have your school participate in this study, please sign below. Please make a copy of this letter for your records before mailing it back to me in the envelope provided. Thank you!

(Director name, printed)

(Name of School)

(Director signature)

(Date)

## Appendix C

Dear (Director),

My name is Erin Herman, and I am a doctoral student at the Graduate School of Applied and Professional Psychology (GSAPP) at Rutgers University. I am doing a research study to fulfill the dissertation requirement of the doctoral degree in School Psychology.

My dissertation is entitled, "Growing up with Autism: The Educational Impact on Neurotypical Siblings." In this research, I am studying the academic experiences of the typically developing high school student growing up with a sibling with autism, as compared to high school students growing up with siblings who do not have autism. To complete my study, I am currently recruiting **neurotypical high school students** (high school students who do not have a developmental disability, such as autism, PDD-NOS, or Asperger's Syndrome themselves), including those who have a sibling with autism, and those who do not.

The purpose of this letter is to request permission for me to recruit participants that are typically developing high school-aged siblings of clients at your practice. If you grant me permission to recruit participants through your practice, the following steps will take place:

• I will provide therapists at your practice with envelopes that contain materials to my study. Each envelope will contain a cover letter explaining my study to potential participants, two copies of informed consent/assent, and a return envelope with postage provided. The families will be asked to retain one copy of the informed consent/assent, and send the other copy back to me if they choose to participate in the study.

Once the envelopes are sent home with the clients, your role in my research is complete. Siblings who agree to participate will provide me with their e-mailed on the inform consent/assent form, and the URL will be e-mailed to them to complete my survey online.

I would be more than happy to share my results with you at the completion of my dissertation.

This study has been approved by the Institutional Review Board (IRB) at Rutgers University. If you have any questions, please do not hesitate to contact me by calling (732)778-0540, or by e-mailing me at <u>erinherm@eden.rutgers.edu</u>. If you agree to allow me to recruit participants that are siblings of clients in your practice, please sign below. Please make a copy of this letter for your records before mailing it back to me in the envelope provided.

(Director name, printed)

(Name of Practice)

(Director signature)

## Appendix D

Dear (principal),

My name is Erin Herman, and I am a doctoral student at the Graduate School of Applied and Professional Psychology (GSAPP) at Rutgers University. I am doing a research study to fulfill the dissertation requirement of the doctoral degree in School Psychology.

My dissertation is entitled, "Growing up with Autism: The Educational Impact on Neurotypical Siblings." In this research, I am studying the academic experiences of the typically developing high school student growing up with a sibling with autism, as compared to high school students growing up with siblings who do not have autism. To complete my study, I am currently recruiting **neurotypical high school students (**(high school students who do not have a developmental disability, such as autism, PDD-NOS, or Asperger's Syndrome themselves), , including those who have a sibling(s) with autism, and those who do not.

The purpose of this letter is to request permission for me to recruit high school students in your school for participation in my study. If you grant me permission, the following steps would take place to recruit participants:

- I would ask you to recommend a contact person in the high school (either a teacher or a Child Study Team member) that can assist me in finding teachers who are willing to help me recruit participants. Their duties would be to hand out an envelope to each student in their homeroom class. The envelopes will contain the following items: a cover letter to my study, two letters of consent/assent for participation, and a return envelope with provided postage. One of the copies of consent/assent is to be retained by the family. The other is to be mailed back to me in the provided envelope.
- The contact person that you recommend will also be asked to solicit assistance from the Child Study Team. The purpose of requesting help from them is because they will have knowledge of students on their caseload with an "Autistic" classification under IDEIA and may be able to identify typically developing siblings who are in the high school. The Child Study Team is <u>not</u> expected to release any names or identifying information to me. They will be given a stack of envelopes as well and will be asked to give one to any target sibling that they are aware of.

Once the envelopes are distributed to the students, your high school's responsibilities in my research are complete. The students who agree to participate will be e-mailed the URL to access my online survey.

This study has been approved by the Institutional Review Board (IRB) at Rutgers University, as well as the superintendent of your district. If you have any questions, please do not hesitate to contact me by calling (732)778-0540, or by e-mailing me at <u>erinherm@eden.rutgers.edu</u>. If you agree to have your school district participate in this study, please sign below. Please make a copy of this letter for your records before mailing it back to me in the envelope provided.

# Growing up with Autism 67

# Appendix D

(Principal name, printed)

(Name of School)

(Principal signature)

(Date)

#### Appendix E

#### Dear (contact person appointed by principal),

My name is Erin Herman, and I am a doctoral student at the Graduate School of Applied and Professional Psychology (GSAPP) at Rutgers University. I am doing a research study to fulfill the dissertation requirement of the doctoral degree in School Psychology. The principal of your school recommended you as someone who may be able to help me with my research by serving as the contact person in your high school for my study.

My dissertation is entitled, "Growing up with Autism: The Educational Impact on Neurotypical Siblings." In this research, I am studying the academic experiences of the typically developing high school student growing up with a sibling with autism, as compared to high school students growing up with siblings who do not have autism. To complete my study, I am currently recruiting **neurotypical high school students (**(high school students who do not have a developmental disability, such as autism, PDD-NOS, or Asperger's Syndrome themselves), , including those who have a sibling(s) with autism, and those who do not.

The purpose of this letter is to tell you your role as a contact person in helping me recruit participants for my study.

- I would ask you to assist me in finding teachers who are willing to help me recruit participants. Their duties would be to hand out an envelope to each student in their homeroom class. The envelopes will contain the following items: a cover letter to my study, two letters of consent/assent for participation, and a return envelope with provided postage. One of the copies of consent/assent is to be retained by the family. The other is to be mailed back to me in the provided envelope.
- I will also ask you to solicit assistance from the Child Study Team. The purpose of requesting help from them is because they will have knowledge of students on their caseload with an "Autistic" classification under IDEIA and may be able to identify typically developing siblings who are in the high school. The Child Study Team is <u>not</u> expected to release any names or identifying information to me. They will be given a stack of envelopes as well and will be asked to give one to any target sibling that they are aware of.

Once the envelopes are distributed to the students, your high school's responsibilities in my research are complete. The students who agree to participate will be e-mailed the URL to access my online survey.

You would act as a key person in helping me organize and distribute my study materials by finding teachers who may be interested in helping me, as well as Child Study Team members . While this is a responsibility, I would greatly appreciate any help I can get.

This study has been approved by the Institutional Review Board (IRB) at Rutgers University, as well as the superintendent of your district. If you have any questions, please do not hesitate to contact me by calling (732)778-0540, or by e-mailing me at

#### Appendix E

<u>erinherm@eden.rutgers.edu</u>. If you agree to have your school district participate in this study, please complete the information below. If you would kindly cut along the dotted line and send only that portion back to me in the addressed and stamped envelope provided, that would be much appreciated.

Thank you so much for your time and consideration,

Erin L. Herman Principal Investigator Doctoral Candidate in School Psychology Rutgers University

-----

By signing below, I agree to act as a contact person in this school in helping coordinate the research for the study entitled "Growing up with Autism: The Educational Impact on Neurotypical Siblings." I understand that my role would be recruiting teachers who would be willing to hand out study materials to their homeroom classrooms, as well as soliciting assistance from the Child Study Team.

I am a:

	Child	Study	Team	member	(please	specify	which	one:
			)					
	General E	ducation '	Гeacher					
$\Box$ S	pecial Ec	ducation 7	Teacher					
$\square R$	elated Se	ervice Pro	vider (e.	g. speech, O	T, PT)			
C	Other (ple	ase specif	fy:				)	
		General E	General Education 7	) General Education Teacher Special Education Teacher	) General Education Teacher Special Education Teacher Related Service Provider (e.g. speech, O	) General Education Teacher Special Education Teacher Related Service Provider (e.g. speech, OT, PT)	) General Education Teacher Special Education Teacher Related Service Provider (e.g. speech, OT, PT)	General Education Teacher     Special Education Teacher     Related Service Provider (e.g. speech, OT, PT)

(Name, printed)

(Name of School)

(E-Mail Address)

(Signature)

(Date)

Hello,

My name is Erin Herman, and I am a doctoral student at Rutgers University, the Graduate School of Applied and Professional Psychology. I am currently conducting a research study that will fulfill my dissertation requirements for a doctorate in School Psychology.

My dissertation is entitled, "Growing up with Autism: The Educational Impact on Neurotypical Siblings." In this research, I am studying the academic experiences of the typically developing high school student growing up with a sibling with autism, as compared to high school students growing up with siblings who do not have autism. To complete my study, I am currently recruiting **neurotypical high school students** (high school students who do not have a developmental disability, such as autism, PDD-NOS, or Asperger's Syndrome themselves), including those who have a sibling with autism, and those who do not.

I am inviting your high school-aged son or daughter to participate in my study. Attached you will find two copies of the consent form. If you give permission for your child to participate, please initial the bottom of each page, and fill out the information and sign at the completion of the letter. Your high school child must sign this form as well. Please have them initial at the bottom of each page of the letter, in addition to completing the information at the end of the letter. Both you and your high school student's signatures are required. After the signature page, you (the parent or guardian) will be asked to provide some information about your high school student's brother or sister. Please retain one of the copies of the consent form for your records.

This study consists of an online survey. You will notice that your child's e-mail address is requested at the end of the letter. This must be filled out, because it will allow me to e-mail the link to my study to your child so that they can participate.

Please send the completed copy of the informed consent form back to me in the provided envelope, which is pre-addressed and has postage on it already. Your child's participation is entirely optional, but it would be greatly appreciated. I am hoping to get responses from over 100 high school students.

This study has been approved by Rutgers. If you have any questions, please do not hesitate to contact me at <u>erinherm@eden.rutgers.edu</u>.

Thank you for your time!

Erin L. Herman Principal Investigator

#### Growing up with Autism: The Educational Impact on Neurotypical Siblings

Your high school student is invited to participate in a research study that is being conducted by Erin Herman, a doctoral candidate in School Psychology at Rutgers University, the Graduate School of Applied and Professional Psychology. This research is being done to fulfill the dissertation requirement for the doctoral degree. The purpose of this study is to determine if growing up with a sibling with autism has any academic effects on the typically developing sibling.

Approximately 125 subjects between the ages of 13 and 18 years old will participate in the study. All subjects must be in high school (e.g. between 9<sup>th</sup> and 12<sup>th</sup> grade) and have a sibling of any age. Your child does not need to have a sibling with autism to participate in this study. Your high school student cannot participate in this study if (a) they are an only child, (b) they have an autism spectrum diagnosis and/or (c) they have more than one sibling with autism. If you have two or more students in high school, please only have one participate.

Each individual's participation will last no more than 15 minutes. The study procedures include completion of two questionnaires in an online survey. If you consent to your child's participation, I will send him/her an electronic address to access the survey. Participants will first be asked to complete a background questionnaire that includes basic questions about participant age, grade, gender, and family composition. They will then complete a survey that asks them a variety of questions about their academic experience and their involvement in their sibling's academics.

If you agree to have your high school student participate in the study, and your child agrees to participate in the study, they will receive an e-mail with the URL to access the background questionnaire and survey.

There are minimal psychological risks to this study, which include possible shame, guilt, or embarrassment in honestly answering the items on the survey. While it is unlikely, if your high school student is in distress as a result of completing this survey, they can contact the Graduate School of Applied and Professional Psychology (GSAPP) Psychological Clinic to seek counseling. The Psychological Clinic is located at 152 Frelinghuysen Road, Piscataway, NJ 08854, and can be reached at 848-445-6111.

If your high school student completes the survey, their name will be entered in a drawing to win one of three \$25 iTunes gift cards. An additional benefit to this study is that it may give insight as to how having a sibling with autism, as opposed to a sibling without autism, may affect the academic domain of the neurotypical sibling.

Participation in this study is voluntary. Your child may choose not to participate, and they

may withdraw at any time during the study procedures without any penalty to themselves. In addition, they may choose not to answer any questions with which they are not comfortable.

This research is confidential. Confidential means that the research records will include some information about your child, such as their name, school, and age. I will keep this information confidential by limiting individuals' access to the research data and keeping it in a secure location. The research team and the Institutional Review Board at Rutgers University are the only parties that will be allowed to see the data, except as may be required by law. If any information pertaining to child abuse is obtained during this study, it will be reported to the appropriate authorities. If a report of this study is published, or the results are presented at a professional conference, only group results will be stated. The website used is designed to securely collect confidential responses.

If you have any questions about the study procedures, you may contact Erin Herman at (732)778-0540, or e-mail her at <u>erinherm@eden.rutgers.edu</u>. If you have any questions about your rights as a research subject, you may contact the Sponsored Programs Administrator at Rutgers University at:

Rutgers University Institutional Review Board for the Protection of Human Subjects Office of Research and Sponsored Programs 3 Rutgers Plaza, New Brunswick, NJ 08901-8559 Tel: 732-932-0150 ext. 2104 Email: <u>humansubjects@orsp.rutgers.edu</u>

If you and your high school student provide consent to participate in this study, please sign below and return this form in the envelope provided. Please retain the additional copy of this form for your records.

Sign below if you agree to participate in this research study:

Parent/Guardian, please fill out this portion if you give consent for your high school

student to participate in this study:

Т		
	-	

\_\_\_\_\_, give permission for my son/daughter,

(print name here)

\_\_\_\_\_, to participate in this study.

(high school student's name)

(Signature)

(Date)

High school student, please fill out this portion if you give assent to participate in this study:

Ι, \_

\_\_\_\_\_, agree to participate in this study. I know what

(print name here) my participation includes, and *I know that I can withdraw at any point if I choose to do so*. By signing below and providing my e-mail address, I understand that I will be emailed the URL to participate in the study and can withdraw at any time with no penalty.

(Signature)	(Date)
My e-mail address is:	
Principal Investigator	
(Signature)	(Date)

#### **Parent/Guardian:**

Please fill out the following information. This page will be detached from the rest of the informed consent information and will therefore be confidential, in that it will not be able to be linked in any way to you or your child by anyone other than the primary investigator, Erin Herman.

1. Does your high-school aged child participating in this study have a brother or sister with an autism spectrum disorder?

	•	Yes	No	
If	YES, please specify which	ch one:		
	Autistic Disorder	Aspergers Syndrome	PDD-NOS	Other
	, , ,	d child participating in this a those mentioned above?	study have a brother	or sister

	Yes	No
If YES, please specify:		

3. If YES to either of the above questions, what best describes the verbal ability of their sibling?

Can have full conversations
Can speak basic sentences
Can say a few words
Is Non-Verbal

#### FIRST PAGE OF SURVEYMONKEY ONLINE SURVEY:

Thank you for agreeing to participate in this study.

The purpose of this research is to look at factors that affect high school students' education. Specifically, the study is looking at how **siblings** (brothers and sisters) impact high school students' performance in school. We are interested in learning about your involvement in extracurricular activities (sports, after-school clubs, etc.), how you do in school, and how your life at home relates to your performance in school.

It will take you no more than 10 minutes to complete the survey to follow.

Instructions:

- If you have a sibling with autism, please answer the questions on this survey with him/her in mind.
- If you have more than one sibling (none of which have autism), please answer these questions while thinking of the sibling who is *closest in age to you*.
- Please do not participate in this study if your sibling already completed the online portion. This survey is only for ONE sibling per household.

Thank you for your participation in this study. Your involvement is greatly appreciated!

Helpful definitions for this survey:

- A **sibling** is a brother or sister.
- Children and adults with **autism** typically have delays in communication and social skills, and often engage in repetitive behavior.

## **Background Questionnaire**

## **BACKGROUND INFORMATION**

Gender (circle one)	Male	Female	
Date of Birth:/	/	Age:	Grade:
School:			
Race (circle all that apply)			
White			
Black or African An	nerican		
American Indian or	Alaska Nat	ive	
Asian			
Native Hawaiian or	Other Pacif	fic Islander	
Other (please indica	ute):		
Ethnicity (circle one)			
Hispanic			
Non-Hispanic			
Marital Status of Parents	(circle one)	)	
Never Married			
Married			
Separated			
Divorced			
Widowed			
Number of Siblings:	Total		
(brothers	sisters)		
Where are you in the birt Are you a twin? Yes No		<sup>st</sup> , 2 <sup>nd</sup> , 3 <sup>rd</sup> , etc.)	

#### **Survey**

#### **Instructions:**

- If you have a sibling with autism, please answer the questions on this survey with him/her in mind.
- If you have more than one sibling (none of which have autism), please answer these questions while thinking of the sibling who is *closest in age to you*.

The sibling I am thinking about is my:BrotherSisterMy sibling is \_\_\_\_\_\_ years old.years old.Does the sibling you are thinking about have autism? YesNo

- 1. How many school-based extracurricular activities do you participate in? (including sports teams, band, chorus, yearbook, newspaper, key club, etc.)
- 2. How many activities outside of school do you participate in? (e.g. dance lessons, traveling sports teams, karate, piano lessons, art lessons, tennis lessons, etc.)

#### 3. How well do you consider yourself to be doing academically?

Terribly Not so well Kind of well Very well

- 4. How many hours do you spend on homework (including studying), in a typical week? \_\_\_\_\_ hours
- 5. How much time do you spend one-on-one with your brother or sister outside of school, excluding the time you help them with homework or other skills? \_\_\_\_\_\_ hours
- 6. How much time do you spend one-on-one with your brother or sister outside of school helping them with school-related activities? (studying, homework, learning new skills)

\_\_\_\_\_ hours

Please continue to the next page.

Please respond to the following items by circling the extent to which it occurs, indicating never (1) 1 time/month (2) 1 time/week (3) 2-3 times/week (4), or every day (5).

		Never	1 time per month	1 time per week	2-3 times per week	every day
7.	My siblings help me with my homework.	1	2	3	4	5
8.	I help my sibling(s) learn new skills at home (e.g. communication, social, self-help)	1	2	3	4	5
9.	I talk to my sibling(s) about extracurricular activities (including sports)	1	2	3	4	5
10.	I talk to my sibling(s) about school.	1	2	3	4	5
11.	I help my sibling(s) with their homework.	1	2	3	4	5
12.	I need help on my homework from my parent(s)/guardian(s).	1	2	3	4	5
13.	I receive help on my homework from my parent(s)/guardian(s).	1	2	3	4	5
14.	My parent(s)/guardian(s) help my brother(s) and/or sister(s) with their homework.	1	2	3	4	5
15.	My parent(s)/guardian(s) help me study for quizzes and tests.	1	2	3	4	5
16.	My parent(s)/guardian(s) help my brother(s) and/or sister(s) study for tests and quizzes.	1	2	3	4	5
17.	I do my homework (includes studying) when it is assigned.	1	2	3	4	5
18.	I participate in extracurricular activities (INCLUDING sports, after-school clubs, after-school committees, etc.)	1	2	3	4	5

Please respond to the following items by circling the extent to which you strongly disagree (1) or strongly agree (7) with each statement.

		Strongly Disagree			Neutral			Strongly Agree
19.	I think it is important to do well in school.	1	2	3	4	5	6	7
20.	I wish I had more time to spend on studying and homework.	1	2	3	4	5	6	7
21.	My mother/stepmother thinks it is important to do well in school.	1	2	3	4	5	6	7
22.	My father/stepfather thinks it is important to do well in school.	1	2	3	4	5	6	7
23.	I'm able to use some of the things I learn in school in other parts of my life.	1	2	3	4	5	6	7
24.	My sibling(s) negatively affect my performance in school.	1	2	3	4	5	6	7
25.	Academically, I feel as though I have to do better than my sibling(s).	1	2	3	4	5	6	7
26.	It's important to understand what I'm taught at school.	1	2	3	4	5	6	7
27.	My sibling(s) positively affect my performance in school.	1	2	3	4	5	6	7
28.	Learning at school is important.	1	2	3	4	5	6	7
29.	My brother(s) and/or sister(s) get more attention than I do.	1	2	3	4	5	6	7
30.	I would like my grades to be higher.	1	2	3	4	5	6	7
31.	What I learn at school will be useful one day.	1	2	3	4	5	6	7
32.	I am satisfied with my grades.	1	2	3	4	5	6	7

33. You may not be aware, but different schools use different types of grades. What types of grades does your school use?

(pull down bar) a. letter (A, B, C, D, F) b. numbers (0-100) c. Neither of the above

#### THIS QUESTION WILL THEN BRANCH TO WHICHEVER CHOICE THEY PICK SO THEY CAN INDICATE THEIR AVERAGE GRADE ON THE APPROPRIATE SCALE.

34. What is your average grade?

# THIS IS TO BE CONVERTED TO A 4.0 SCALE WHERE 1 INDICATES FAILING AND 5 INDICATES OUTSTANDING PERFORMANCE.

If you are interested in telling me more about your experiences in school with your sibling in mind, please click 'next.' (or the radio button equivalent) If not, you may click 'I'm done.' (or the radio button equivalent) Thank you for your participation!

**35.** Can you tell me a way, if any, that your sibling has positively impacted your education?

**36.** Can you tell me a way, if any, that your sibling has negatively impacted your education?

**37**. Are you currently attending the same school as your brother/sister? If not now, have you ever before? If so, what is/was your experience like?

	Siblings of children with autism	Siblings of typically developing	Total
	(n = 14)	children $(n = 25)$	(N=39)
Gender		· · ·	
Male	6	4	10
Female	8	21	29
Marital Status of Parents			
Never Married	4	6	10
Married	10	14	24
Separated	0	0	0
Divorced	0	5	5
Widowed	0	0	0
Race			
White	14	24	38
Black or African American	0	0	0
American Indian or Alaska Native	0	0	0
Asian	0	0	0
Native Hawaiian or Other Pacific Islander	0	0	0
Other	0	1	1
Ethnicity			
Hispanic	2	1	3
Non-Hispanic	12	24	36
NJ School County			
Monmouth	6	12	18
Ocean	3	13	16
Somerset	2	0	2
Middlesex	2	0	2
Morris	1	0	1

## Table 1a

## Table 1b.

Quantitative demographic variables

		Siblings of children with	Siblings of typically	Total
		autism $(n = 14)$	developing children (n = 25)	(N=39)
	Mean	15.70	(n = 25) 15.28	15.46
Age	SD	15.79	1.37	1.32
	Range	1.19 14-17	13-18	13-18
C 1	Mean	10.57	10.24	10.36
Grade	SD	1.16	1.23	1.20
	Range	9-12	9-12	9-12
# Sibs total	Mean	1.5	2.08	1.87
(not including	SD	.65	1.891	1.58
themselves)	Range	1-3	1-10	1-10
<b>C'11</b>	Mean	13.57	15.28	14.67
Sibling Age	SD	3.11	4.49	4.09
	Range	9-19	7-23	7-23

Table	2
-------	---

Descriptive statistics and independent t-tests for "count" variables

		Siblings of children with autism n = 14	Siblings of typically developing children n = 25	<i>p</i> value
# Extracurricular activities	Mean SD	2.14 1.99	3.20 1.98	.119
# Activities outside of school	Mean SD	1.64 1.15	1.44 1.00	ns
# Hours spent on HW in typical week	Mean SD	13.57 9.51	10.44 7.02	ns
# Hours spent one-on-one with sib, excluding hrs spent helping them with HW	Mean SD	4.86 4.22	12.04 17.35	.059
# Hours spent one-on-one with sib helping them with school-related activities	Mean SD	1.43 2.68	3.76 8.49	Ns

Descriptive statistics and independent t-tests for rating scale items about frequency of occurrence

Survey Item		Siblings of children with autism n = 14	Siblings of typically developing children $n = 25$	<i>p</i> value
My sibling helps me with my	Mean	1.00	1.72	
homework.	SD	.00	.98	.001
	Range	1-1	1-4	
I help my sibling learn new skills at	Mean	2.43	2.36	
home (e.g. communication, social,	SD	.94	1.35	ns
self-help)	Range	1-4	1-5	
I talk to my sibling about	Mean	1.79	3.92	
extracurricular activities (inc.	SD	1.31	1.15	<.001
sports)	Range	1-5	1-4	
I talk to my sibling about school.	Mean	2.00	3.96	
	SD	1.57	1.14	<.001
	Range	1-5	1-5	
I help my sibling with his/her	Mean	2.00	1.96	
homework.	SD	1.66	1.31	ns
	Range	1-5	1-5	
I need help on my homework from	Mean	1.5	2.24	
my parent/guardian.	SD	1.16	1.01	.045
	Range	1-5	1-4	
I receive help on my homework	Mean	1.71	2.40	
from my parent/guardian.	SD	1.27	1.23	.106
	Range	1-5	1-5	
My parent/guardian helps my	Mean	3.79	2.36	
sibling with their homework.	SD	1.72	1.29	.006
<b>5</b>	Range	1-5	1-5	
My parent/guardian helps me study.	Mean	1.93	2.08	
j Friend Standard Friend Standard	SD	1.07	1.22	ns
	Range	1-4	1-4	
My parent/guardian helps my	Mean	2.50	2.32	
sibling study.	SD	1.95	1.28	ns
	Range	1-5	1-5	110
I do my homework (includes	Mean	5.00	4.84	
studying) when assigned.	SD	0.00	.37	
	Range	5-5	4-5	.043
I participate in extracurricular	Mean	4.21	4.36	
activities.	SD	1.19	1.00	ns
	Range	1-5	2-5	
I wish I had more time to spend on	Mean	3.29	3.28	ns
studying/HW	SD	1.59	1.49	
	Range	1-5	1-5	

Note: Responses to these items were answered on a scale where 1=never, 2= 1 time/month, 3= 1 time/week, 4= 2-3 times/week, and 5=every day.

Descriptive statistics and t-test results for attitude, beliefs, and perception likert scale items

Survey Item		Siblings of children with autism n = 14	Siblings of typically developing children n = 25	<i>p</i> value
I think it is important to do well in school	Mean SD	6.43 .94	6.84 .62	.158
	Range	.94 4-7	4-7	.130
Mom thinks its important to do well in school	Mean	6.86	6.92	
won in school	SD	.36	.28	Ns
	Range	6-7	6-7	115
Dad thinks its important to do well in school	Mean	6.79	6.80	
	SD	.43	.65	Ns
	Range	6-7	4-7	
I'm able to use some of the things I learn in school in other	Mean	5.71	5.68	
parts of my life.	SD	1.07	1.38	Ns
	Range	4-7	2-7	
My sibling negatively affects my performance in school.	Mean	2.71	1.84	
	SD	1.98	1.60	.141
	Range	1-7	1-6	
Academically, I feel as though I have to do better than my	Mean	3.79	4.08	
sibling	SD	3.09	2.12	Ns
	Range	1-7	1-7	
It's important to understand what I'm taught in school.	Mean	5.71	6.08	
	SD	1.90	1.32	Ns
	Range	1-7	3-7	
My sibling positively affects my performance in school.	Mean	3.14	5.00	
	SD	1.83	1.96	.006
	Range	1-6	1-7	
Learning at school is important.	Mean	6.50	6.44	
	SD	.65	.92	Ns
	Range	5-7	4-7	
My sibling gets more attention than I do.	Mean	4.36	3.16	
	SD	2.13	3.04	.092
	Range	1-7	1-7	
I would like my grades to be higher.	Mean	5.36	5.68	
	SD	2.13	1.44	Ns
	Range	1-7	2-7	
What I learn at school will be useful one day.	Mean	5.29	5.60	
-	SD	1.73	1.53	Ns
	Range	1-7	2-7	
I am satisfied with my grades.	Mean	5.71	5.64	Ns
	SD	.99	1.35	
	Range	4-7	1-7	

Note: Responses to these items were answered on a 7-point Likert scale where 1=strongly disagree and 7=strongly agree.

Descriptive statistics an	nd t-test resi	ults of GPA		
		Siblings of children with autism n = 14	Siblings of typically developing children $n = 25$	<i>p</i> value
Reported GPA	Mean SD	4.64 .50	4.40 .71	ns

Note. GPA was measured on a scale in which 1 indicated failing and 5 indicated outstanding performance.

Table 6															
Correlation matrix of variables			•		-	c.	-	0	0	10		10	10		
Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Wish I had more time for school	-														
2. I participate in extracurricular activities.	.160	-													
3. Number of school-based extracurricular activities	.406**	.162	-												
4. Time spent helping sibling with their HW and school- related activities	.224*	.213*	.195	-											
5. I help sibling learn new skills at home.	.258*	.360**	.180	.436***	-										
6. Number of hours spent on homework	.415***	.206	.504***	035	.257	-									
7. I help sibling with their homework.	.262*	.198	.281*	.514***	.527***	.151	-								
8. I need help on my homework from my parents.	.020	038	037	.023	110	071	067	-							
9. I receive help on homework from my parents.	120	.141	.093	.120	040	040	.017	.843***	-						
10. Parents help me study.	080	.187	110	.010	.219*	.171	.144	.573***	.607***	-					
11. Parents help sibling study.	.020	.039	.159	034	.302*	.247*	.379**	.284*	.362**	.558***	-				
12. Parents help sibling with their homework.	006	.118	.042	.079	.328**	.319**	.335**	017	.127	.344**	.603***	-			
13. My sibling gets more attention than I do.	.120	130	048	214*	.032	.247*	.153	227*	269*	070	.171	.365**	-		
14. GPA	.181	.161	.352**	190	112	.491***	072	166	062	017	.125	.345**	062	-	
15. Sibling Diagnosis <sup>1</sup>	002	.067	.254*	.161	028	190	014	.323**	.263*	.064	057	435***	.274*	183	-

\* p< .20 \*\*p < .05 \*\*\*p < .01  $^{1}$ Coded 1=sibling with autism; 2=normally developing sibling.

Table 7	
Parental support, time spent on homework, and GPA regression	on

	В	SE B	β	Т	<i>p</i> -value
Does the sibling you are thinking of have autism?	243	.214	183	-1.135	.264
PHASE 2: Regression A	nalysis Sun	nmary for Par	ticipant Variabl	es Predicting	GPA
Does the sibling you are	.111	.220	081	.505	.617
thinking of have autism?					
Parental Support <sup>1</sup>	.046	.111	065	.412	.683
How many hours do you	037	.012	.465**	-2.954	.006
spend on homework					
(including studying), on a					
typical week?					

## PHASE 1 for Regression: Looking at Relationship between Sibling Diagnosis and GPA

<sup>1</sup>Parental support variable was computed with two items on the questionnaire: (1) I receive help on my homework from parents, and (2) My parents help me study. The responses to the items were standardized and then averaged.

\*\* p < .01

Frequency count of participants opting to share more information in open-ended questions

		Does sibling have autism diagnosis		
		YES	NO	
Interested in sharing more information about sibling?	YES	10	19	
0	NO	4	6	

## Figure Captions

Figure 1. Variable roles in hypothesis 1.

Independent Variable Sibling Diagnosis

Dependent Variables

Number of extracurricular activities student participates in (including sports) Number of hours spent on homework (including studying) in a typical week Extent to which student participates in extracurricular activities

#### **Covariates**

Extent to which student wishes they had more time to spend on homework and studying Number of hours that the student reports spending with their sibling outside of school helping them with school-related activities or self-help skills.

Extent to which student reports helping their sibling with homework

Extent to which the student reports helping their sibling learn new skills at home