

Family Functioning and School Variables in Typically-Developing Siblings of Children with  
Autism Spectrum Disorders

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## ABSTRACT

Findings related to the adjustment of typically-developing (TD) siblings of children with Autism Spectrum Disorder (ASD) have been inconsistent, but suggest that most function well over time. The current mixed methods study investigated the relationship between family factors, especially disruptions to family routines, and academic functioning of TD siblings. Measures of family functioning, parenting stress, and parenting daily hassles were collected from parents ( $n = 20$ ); an additional 19 families also completed semi-structured interviews (total  $n = 39$ ). Teacher reports on classroom functioning ( $n = 25$ ) and report cards were also collected. All parent participants (92% Caucasian, 90% married, 79% college-educated) had a child with an ASD diagnosis (80% male,  $M$  age = 11.74) and a TD child (62% male,  $M$  age = 10.31 years). Seventy-two percent of TD siblings ( $n = 18$ ) had scores above the mean on the Academic Performance Rating Scale (DuPaul, Rapport, & Perriello, 1991), and 91% ( $n = 32$ ) had grade averages of B or higher. Ninety-six percent ( $n = 24$ ) of TD siblings had scores within the normative range on the Learning Problems and School Problems scales of the Behavior Assessment System for Children, Second Edition (BASC-2; Reynolds & Kamphaus, 2004). Daily hassles were not significantly correlated with any school measures for the TD siblings. Families with children with more severe ASD symptoms discussed greater frequencies of emotional outbursts in the child with ASD and missed social opportunities as a family. Families of children with externalizing behaviors may particularly benefit from targeted support.

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## ABSTRACT

Research on the adjustment of typically-developing (TD) siblings of children with Autism Spectrum Disorder (ASD) spans more than 30 years. Findings have been mixed; while earlier studies suggest that TD children have worse psychosocial functioning, more rigorous recent research suggests this may not be the case. Most siblings function well over time. Our study investigated the relationship between family variables, especially disruptions to family routines, and the academic functioning of TD siblings. Thirty-nine parents of children with ASD completed forms about family functioning, parenting stress, and parenting daily hassles. Nineteen of these parents and their TD children also completed interviews. Teachers reported on the classroom functioning of TD children; report card data were also collected. Most parents were Caucasian (92%), married (90%), and college-educated (79%). The children with ASD were 80% male, with an average age close to 12 years old. Their TD siblings were 62% male and had an average age of 10 years old. The majority of TD children (91%) had at least a B average on their most recent report card. On a rating of classroom behavior, 72% of TD siblings had scores above the mean; 96% had scores within the normative range on an assessment of school and learning problems. Daily hassles were not correlated with any school measures for the TD siblings. Families with children with more severe ASD symptoms discussed emotional outbursts in the child with ASD and missed social opportunities as a family more often. Families of children with externalizing behaviors (e.g., aggression) may particularly benefit from targeted support.



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Current estimates from the Centers for Disease Control and Prevention (CDC, 2014) indicate that 1 in every 68 children has a diagnosis of Autism Spectrum Disorder (ASD). Characterized by deficits in social communication and restricted behaviors or interests (American Psychological Association [APA], 2013), ASD has increased in prevalence by 30% in the past two years. As 90% of Americans have siblings (Cicirelli, 1982), the number of typically-developing (TD) children who have a sibling with an ASD has also increased. Thus, it is worth investigating the experiences of the TD siblings of individuals with ASD.

Sibling relationships have the potential to be the longest-lasting relationship of one's life, ending only in death. Additionally, being a sibling is a uniquely egalitarian role, in that it cannot be earned (Cicirelli, 1982). Broadly speaking, sibling support research has existed for at least 40 years, and has grown extensively since the 1980's (Stoneman, 2005). More recently, sibling research has developed an international focus, such as in the United Kingdom (e.g., work of Richard Hastings), Australia (Giallo & Gavidia-Payne, 2006; Cridland, Jones, Magee, & Caputi, 2014), and Greece (Stampoltzis et al., 2014).

However, researchers agree that the sibling literature continues to be contradictory in its findings regarding sibling adjustment, both in the literature examining TD siblings of children with chronic illnesses (CI; Drotar & Crawford, 1985) as well as in the ASD-specific sibling literature (Hastings, 2003; Orsmond & Seltzer, 2007; Meadan, Stoner, & Angell, 2010; Cridland et al., 2014; Tomeny, Barry, & Bader, 2014). Some studies have shown that siblings of children with disabilities are at risk for adjustment and behavior difficulties (Lavigne & Ryan, 1979; Lobato, 1983; Drotar & Crawford, 1985; Bendor, 1990; Leonard, 1991; Strohm, 2001), but outcomes vary (Wallander & Varni, 1998; Stoneman, 2005) and positive outcomes may not appear until later in the lifespan (McKeever, 1983; Williams, 1997; Sharpe & Rossiter, 2002).

## **The Importance of Siblings**

Sibling relationships are multi-faceted and dynamic, and must be observed within the social context of family and peers (Buhrmester, 1992). These unique relationships take on additional importance when considering that more children in the United States will grow up with a sibling than with a father (McHale, Kim, & Whiteman, 2006). Additionally, Caucasian children have been found to spend more of their free time playing with their siblings than with anyone else (McHale & Crouter, 1996).

Siblings can fulfill a variety of roles: friends, confidantes, teachers, caregivers, competitors, and role models (Buhrmester, 1992). Additionally, siblings take on different responsibilities over time, such as emotional support in interactions with parents or other extended family members, physical protection, and loans of money or other resources (Cicirelli, 1982; Goetting, 1986). In families where a child has a CI or developmental disability (DD), the sibling relationship may have additional value. For example, siblings of children with ASD are uniquely positioned to model appropriate social behaviors, and can even be used as co-therapists (e.g., Celiberti & Harris, 1993; Bass & Mulick, 2007; Castorina & Negri, 2011). Additionally, many individuals with disabilities now outlive their parents, and living with a sibling can be a less-restrictive option than living in an institution (Dew, Balandin, & Llewellyn, 2008). An increased understanding of this dynamic relationship may allow us to better support individuals with disabilities and their siblings over the lifespan (Dew et al., 2008).

## **Adjustment of Siblings of Individuals of ASD**

Initial studies posited that TD siblings of children with ASD were at higher risk for behavioral, emotional, or psychological problems than peers who do not have a sibling with ASD (e.g., Gold, 1993; Bågenholm & Gillberg, 1991). Williams' (1997) review of 40 studies of

siblings of children with CIs, including ASD, found that 26 studies showed an increased risk for sibling difficulties, whereas five showed both positive and negative effects of being a sibling of a child with a CI, and 12 studies showed no difference between children with ill siblings as compared to children with healthy siblings. In this review, Williams noted that most of the studies that indicated increased risk for siblings were more rigorous methodologically (e.g., larger sample sizes, used standardized assessment tools, control groups, less sampling bias) than the studies finding mixed or null results. Other meta-analyses also found that siblings of individuals with CIs were slightly more likely to have negative outcomes than siblings of persons without CIs (Lavigne & Faier-Routman, 1992; Sharpe & Rossiter, 2002).

Other studies, however, suggest that TD siblings do *not* suffer from more psychological problems as compared to children who do not have a sibling with ASD. A meta-analysis of 18 studies (Yirmiya, Shaked, & Erel, 2001), for example, found that weak methodologies (e.g., few comparable studies, small sample sizes, lack of comparison groups) prevent us from concluding that having a sibling with ASD has either a negative or positive effect on cognitive or psychiatric outcomes (excluding the higher genetic likelihood of having the broad autism phenotype [BAP]). Stoneman (2005) agrees that differences in reporters, measures, and use of control or comparison groups have added to these discrepancies.

Neely-Barnes and Graff (2011) studied a diverse population of siblings of children with and without siblings with a disability. More problems were found for the siblings of a child with a disability, but effect sizes were small and researchers concluded no greater risk for the target population. Similarly, in studying specifically siblings of children with ASD, Dempsey and colleagues (2012) and Shivers, Deisenroth, & Taylor (2013) used large samples and found no between-groups differences. Hastings and Petalas (2014) supported these findings with self-

report data from British siblings of children with ASD, which indicated slightly elevated behavioral problems on the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997, 1999), but no group differences that were statistically significant and most had very small effect sizes ( $<.20$ ).

Alternatively, having a sibling with a disability may not necessarily be a risk factor in and of itself, but as other psychosocial risk factors increase, adjustment outcomes for the sibling are likely to worsen (Macks & Reeve, 2007; Tsao, Davenport, & Schmiege, 2012). The severity of ASD symptoms and comorbid behavioral problems have consistently been the most compelling factors related to TD sibling maladjustment (Benson & Karlof, 2008; Meyer, Ingersoll, & Hambrick, 2011). Overall, the TD siblings of children with disabilities are usually able to function well across the lifespan (Sanders & Morgan, 1997; Meyer & Vadasy, 2008), suggesting a form of resilience (Grant, Ramcharan, & Flynn, 2007; Bellin & Kovacs, 2006).

The consensus in the field, if any, is that this population is at risk for adjustment and behavior difficulties (Lavigne & Ryan, 1979; Lobato, 1983; Drotar & Crawford, 1985; Bendor, 1990; Leonard, 1991; Strohm, 2001), but that outcomes vary (Wallander & Varni, 1998; Stoneman, 2005). There are still *many* areas that remain open to investigation in the ASD sibling literature. Specifically, little research has explored the impact of having a sibling with ASD on the TD sibling's school functioning. To our knowledge, only one study (Mates, 1990) examined academic achievement in TD siblings of children with ASD. Research on other areas of school functioning in TD children with a sibling with ASD is lacking or non-existent. We propose that having a sibling with ASD, especially if he/she exhibits challenging behaviors, may present additional strain on family resources. As a result, the homework, dinner, sleep, and morning routines of the TD sibling may be disrupted due to the influence of the child with ASD. TD

siblings thus may be at heightened risk for tardiness, poor attendance, lack of homework completion, and fatigue and distraction in the classroom.

### **Theoretical Foundation**

Since the early development of the literature on siblings of individuals with disabilities, a family systems approach has been used to explore the impact and adjustment of an individual's symptoms of ASD on his/her family (e.g., Morgan, 1988). Today, this theoretical foundation remains relevant, and will serve as the conceptual basis for this investigation. For example, in a family with an individual with ASD, a number of bidirectional relationships exist (e.g., sibling-sibling, parent-child, parent-parent). However, most research on these families has focused on the relationship between parents and the reference child (Glasberg, 2000; Tomeny et al., 2014), at the exclusion of siblings, who are also affected and are an integral part of the family unit.

Relatedly, a transactional model of stress and coping (Lazarus & Folkman, 1987) may help us explore the relationship between a TD child and their sibling with ASD. This orientation, whereby "child and caregiver behaviors impact each other," was used in a study of maternal stress, behavior problems, and social competence of children with ASD (Lecavalier, Leone, & Wiltz, 2006, p. 174). As seen in literature regarding family stressors, siblings exchange resources and stressors as part of their daily interactions. For example, this theory has been used in other health and psychopathology studies regarding the impact of certain diseases on the family system, such as when a child has sickle cell disease (Thompson, Gil, Burbach, Keith, & Kinney, 1993), congenital heart disease (Davis, Brown, Bakeman, & Campbell, 1998), or cystic fibrosis (Thompson, Gustafson, Hamlett, & Spock, 1992).

### **Disruptions to Daily Family Routines**

While certain aspects of behavior and emotional regulation have been studied, the impact that a child with ASD may have on daily family routines has not been considered. There are a number of ways that a child with ASD may disrupt the family's daily life due to their specific set of needs.

**Morning.** In the morning, children with ASD may become upset at changes in their routines, or may experience anxiety leading to school refusal. In a study of Japanese children and young adults (Kurita, 1991), 27.3% of those with pervasive developmental disorders (PDD) had a history of school refusal. Individuals with PDD showed more frequent school refusal than those with intellectual disability and no PDD, although significance was not reached. Reasons for school refusal noted in this study included anxiety, physical illness, wanting to avoid teasing, changes in routine, and harsh discipline from the teacher, despite parent encouragement to attend school.

TD siblings are likely to be affected when their sibling refuses to go to school; parents must attend to the child with ASD at the exclusion of their other child or children. TD siblings may have greater responsibility for getting themselves prepared for the school day, making breakfast or preparing school lunches, and completing morning chores. Additionally, reference children who refuse to ride the bus or get into the family car may impact the TD sibling who shares the same mode of transportation, and who may be tardy as a result.

Positively, in 25 individuals from the Kurita study (1991), the school fears of reference children in the study had resolved by an average age of 12 (ranging from ages 4 to 19). Additionally, 60% of children reporting school refusal missed less than 3 weeks of school total, leading the author to call most cases of school refusal "mild" (p. 7). Interestingly, of 30 children with PDD who refused to attend school, all 9 students whose parents did *not* consult with a

teacher or psychologist for help on the school fears missed more than 3 weeks of school - significantly more school absences compared to the 21 children whose parents *did* seek help. This suggests that, in this instance, the majority of parents were aware of the school fears, felt that they were problematic, and sought ways to cope or change the behavior. However, it is unknown what behavioral or coping strategies on the part of the parents or educators may have caused children with PDD to return to school. Information is also missing as to how this school refusal or its resolution might affect siblings.

**After school.** For all families, school nights can be full of a number of commitments, such as completing homework and attending extracurricular activities. For families with a child with ASD, additional time is likely to be used towards extra therapy outside of school (e.g., speech, occupational, or psychological therapies), tutoring, or other skill-building opportunities. For example, a number of interventions are recommended by the American Academy of Pediatrics to enhance a child with ASD's communication and social skills, and to decrease disruptive behaviors (Myers & Johnson, 2007; reaffirmed in 2010).

TD siblings may have their personal time for homework, extracurricular activities, or recreation disrupted by the needs of their sibling, such as travel to therapy sessions or doctor visits. Parent attention may be more focused on the child with ASD during this time, especially if extra help is needed to complete homework, chores, and self-care tasks. Outbursts, aggression, and family conflicts are also likely to be disruptive to the TD sibling, and may affect their performance in school the next day.

**Evening.** Children with ASD who have difficulty going to bed or sleeping during the night may negatively impact the sleep hygiene of their family members. In a study of 38 children with autism and Asperger's disorder and 36 matched controls, parents completed a 14-

day sleep diary regarding a number of sleep variables (Patzold, Richdale, & Tonge, 1998). Significantly more children with ASD showed problematic sleep behaviors than children in the control group. Parents from either group who perceived their child as having sleep difficulties reported that one reason was due to their own stress level, which was increased due to their own lack of sleep and sleep disruptions of their other children.

Liu, Hubbard, Fabes, and Adam (2006) described the sleep patterns of 167 children with autism and Asperger's disorder and found that 86% had at least one sleep problem. More than half of the children (54%) had difficulties at bedtime (e.g., afraid of the dark, need parent in room to fall asleep, behaviorally resistant), while nearly half (45%) had trouble upon waking in the morning (e.g., irritable in the morning, slow to rise). Other sleep difficulties included insomnia, parasomnias, breathing difficulties while sleeping, and bed-wetting. According to parent report, 15.6% of participants ( $n = 26$ ) shared a room (but not a bed) with their sibling, while 3.6% ( $n = 6$ ) shared a bed with their sibling. Siblings of children with ASD may be affected by their sibling's problematic behaviors at bedtime and in the morning, or roused by their sibling's disorder sleep during the middle of the night.

In general, the TD child might also miss more school due to traveling with the family to appointments that are geographically distant (e.g., specialists in a larger city or another state) or other special needs of the child with ASD. Overall, a number of factors may place demands on the TD sibling due to the behaviors and symptoms of their sibling with ASD, which include sleep difficulties, anxiety, aggression, and difficulty with transitions and change, all of which have the potential to disrupt daily routines for the family and siblings. Difficulty getting to school, increased personal responsibility during daily routines, less attention from parents, and disruption to after-school activities and sleep are likely to place a burden on the TD sibling.

Previous research has neglected to explore the environment of a sibling of a child with disability; as such, research and treatment approaches that incorporate family and school contexts are encouraged (Giallo & Gavidia-Payne, 2006). Identifying risk factors for siblings of children with ASD will move the field forward (Meadan et al., 2010). Consequently, we are investigating whether there is a relationship between having a sibling with ASD and worse school functioning for TD siblings. Mates (1990) explored academic achievement of TD siblings of children with ASD, and found no difference as compared to normative scores on an achievement test. However, as we will describe below, his methodology leaves room for improvement.

### **Family Functioning**

Previous research suggests that a number of variables influence family functioning, and that families with a child with ASD function worse overall than families without a child with ASD. Due to the specific symptoms associated with an ASD diagnosis, a number of potential burdens are placed on the family (Herring et al., 2006), leading families to rearrange their lives and forfeit social opportunities that they would otherwise take (Kelly, Garnett, Attwood, & Peterson, 2008). Additionally, siblings of children with ASD who had greater expression of the Broad Autism Phenotype (BAP) had greater adjustment difficulties - even more so as the symptoms of the child with ASD increased in severity (Meyer, Ingersoll, & Hambrick, 2011). These findings emphasize the need for examination of the entire family context, suggesting that investigating each member is insufficient to provide an accurate view of how the system is functioning as a whole. Many families raising a child with ASD function well, and further investigation into factors that contribute to this success highlight ways to help other families cope.

**Parenting stress.** Parents of children with ASD or Down syndrome (DS) have been found to have more stress than parents of TD children (Sanders & Morgan, 1997; Dabrowska & Pisula, 2010). Additionally, parents of children with ASD had more total stress in comparison to parents of children with DS (Sanders & Morgan, 1997), and more parenting stress than both other groups in the domains of life span care, limits on family opportunities, and dependency and management (Dabrowska & Pisula, 2010). Another study found that mothers of children with ASD had overall higher levels of parenting-related stress than mothers of TD children or children with DD (Estes et al., 2013).

Potential explanations for this increased stress are that parenting a child who is socially aloof may be emotionally difficult, or that the reactions of strangers who do not know about ASD to public meltdowns may be distressing to parents (Estes et al., 2009). In the broader DD literature, stress has been found to stem from a number of sources, such as a parent's difficulty accepting the diagnosis, social stigma, financial burden, and fatigue and loss of leisure time (Sanders & Morgan, 1997). A large epidemiological study found that, as compared to children with CI without ASD, families with a child with ASD had less access to appropriate health care or family support services (Kogan et al., 2008). Additionally, parents of children with ASD were more likely to report financial burden, need extra financial support to cover medical care, spend greater than 10 hours per week providing or coordinating their child's care, and decrease or quit working to care for their child. Parents of children with ASD appear to be at higher risk for parenting-related stress, even when compared to parents of children with other DDs.

A common predictor of parental stress in this population is problem behaviors. Child externalizing behaviors, but not maternal psychological distress, predicted parenting-related stress for both mothers of children with ASD and mothers of children with DD (Estes et al.,

2013). Further, teachers and parents agree that behavior problems (especially conduct problems) in children with ASD cause them the most stress (Lecavalier et al., 2006), and child behavior problems appeared to have a bidirectional relationship with parental stress.

**Parenting self-efficacy/competency.** In a recent study, behavior problems in children with ASD were associated with greater parental stress, which was then associated with decreased parenting self-efficacy (Rezendes & Scarpa, 2011). Decreased parenting self-efficacy as a result of parent stress was also related to increased parent anxiety/depression in this study.

**Family cohesion & adaptability.** In a study of 26 mother-father pairs who had a child with ASD, families who described their cohesion style as enmeshed used more coping skills than families who endorsed separated or disengaged cohesion styles (Altieri & von Kluge, 2009). The authors suggested that over-involvement and protectiveness, family characteristics that might otherwise restrict a child's development of autonomy, may be adaptive for a family with a child with ASD (Altieri & von Kluge, 2009).

Overall, research suggests that families with a child with ASD are at-risk for worse family functioning; as such, we explored family adaptation and functioning as related to school variables in TD siblings.

### **Mixed Methods Data Collection**

Mixed methods research approaches have emerged as the middle ground between the historically opposing quantitative and qualitative paradigms (Leech & Onwuegbuzie, 2009). Advocates argue that consideration and use of mixed methods as a new third paradigm in research will move research beyond the 'either-or' of quantitative versus qualitative methodologies (Burke Johnson & Onwuegbuzie, 2004). In the current study, a mixed methods design was preferred over a monomethod design primarily to improve the interpretation of our

findings (i.e., significance enhancement, one of Collins, Onwuegbuzie, and Sutton's [2006] four principles for rationale of mixed methods research for special education researchers).

Concurrent mixed analyses (i.e., waiting until all data are collected to begin analyses) allowed us to use qualitative findings to further explain significant quantitative results (Collins et al., 2006). A fully mixed, sequential, dominant status design was used to explore the life experience of the family members of an individual with ASD (Leech and Onwuegbuzie, 2009). According to this typology, in order to be "fully mixed," a study must involve both qualitative and quantitative aspects in one or more of the following: 1) research questions, 2) type of data and operations, 3) type of analysis, and 4) type of inference. Our study used mixed research in the research questions, type of data, and type of analysis. Additionally, this study is considered to be a sequential design because it was temporally structured in two phases (quantitative data collection [Phase I], followed by qualitative data collection [Phase II]), and it is a dominant status design because quantitative methods are weighted more heavily than qualitative methods. Finally, our mixed methods study differs from a mixed model study in that qualitative and quantitative philosophies were integrated and used from start to finish across the study (e.g., forming objectives, collecting data, interpreting data), rather than different paradigms being used in isolation for each of those three different stages of the project (e.g., quantitative objectives leading to quantitative data collection and qualitative data analyses; Burke Johnson & Onwuegbuzie, 2004).

Mixed methods approaches to study family functioning in ASD-affected families have been successfully used in the past. An investigation into the resilience of families of individuals with ASD, for example, used a mixed method approach through content analysis of written responses to survey questions, in combination with quantitative data (Bayat, 2007). The author

found that responses from the parents and caregivers of children with autism were overwhelmingly positive in regards to the experience of raising a child with ASD, although fewer responses related directly to resilience than expected. Mixed methods approaches have also been used in the development of interventions for children with ASD (Ostmeyer & Scarpa, 2012). Similarly, the current study used both qualitative and quantitative methods to examine the needs of siblings of children with ASD; our findings have the potential to change how TD siblings are supported at home and in school.

**Quantitative data collection.** Collection of quantitative data allowed us to have concrete information regarding the potential relationships between our variables of interest. This data allowed a more thorough and dynamic investigation of how family, parent, and sibling variables are connected in families raising a child with ASD. Above and beyond the qualitative data we collected, the use of standardized assessments with validated psychometric properties provided us with data that was compared between participants and to normative data. Additionally, statistical testing was used to test our hypotheses. Thus, the ability to integrate findings between both sets of data allowed for a richer understanding of the experience of a child who has a brother or sister with ASD.

**Qualitative data collection.** Qualitative data were used to assess the impact of children with ASD on daily family routines, through both focus groups and individual interviews (see Appendices A and B for topic guides). The parent topic guide was adjusted to be more developmentally appropriate for the child interviews, but content remained generally the same.

Mascha and Boucher (2006) collected similar qualitative data in individual interviews with 14 siblings of children with ASD, aged 11-18 years. However, the current study expanded upon this design by also including qualitative data from parents. Another qualitative study

investigated the experiences of TD siblings aged 5 to 29 years old (Benderix & Sivberg, 2007). In contrast, the current study, (similar to Petalas, Hastings, Nash, Dowey, & Reilly, 2009), collected qualitative data from children aged 7 to 15, which allows more specific conclusions to be drawn about school-aged children's adjustment, as compared to children ages 5 to 29.

### **Gap in the Literature**

In a 2010 review of the literature of sibling adjustment when the child had a sibling with ASD, only 12 studies were found (Meadan et al., 2010). Little to no information regarding school variables in TD siblings of children with ASD has been collected, indicating that the findings of this study will fill a gap in the literature. While one study explored academic achievement in this population (Mates, 1990), studies targeting the broader construct of school functioning are missing from the literature. For example, measures of classroom behaviors are neglected when only grades are considered. Mates (1990) found that academic achievement of TD children with siblings with ASD was not worse than TD peers without a sibling with ASD. However, the study was limited by a small sample size ( $n = 33$ ) and a broad age range (5-17 years). Additionally, TD siblings in the Mates study were recruited through their siblings with ASD, who were all receiving intensive treatment (TEACCH). Therefore, the sample is skewed towards families who are proactive and successful in procuring treatment for their children. The current study is innovative in that it has a slightly larger sample size and smaller age range than the Mates study, and used mixed methods analyses to add depth to quantitative findings about school functioning. Results may influence the current discussion on siblings' need, or lack thereof, for structured support or treatment.

### **Hypotheses**

There are four hypotheses for this study. In Hypothesis 1, it was expected that siblings of children with ASD would have lower than average/normative school functioning, such as lower grades, increased learning difficulties, and worse behavior in the classroom. In Hypothesis 2, disruptions to the family's after school, evening, and morning routines were expected to impair TD sibling school functioning. In Hypothesis 3, parent stress was expected to be positively correlated to disruption to family routines as well as to worse grades and classroom behaviors in TD siblings. Additionally, in Hypothesis 4, we expected that parent stress would be negatively correlated to family functioning variables (i.e., flexibility, cohesion, parenting satisfaction, and parenting efficacy), and that these family variables would be positively correlated to TD sibling grades and classroom behavior. Qualitative data were used in mixed methods analyses in an exploratory, rather than predictive, fashion in order to enrich findings from the quantitative data.

## **Method**

### **Participants**

Questionnaire packets were sent to 49 families; 39 were returned. Ten families did not return packets, with four families indicating that their packets had been lost in the mail. Recruitment will continue until May 2016 or until funding ends, whichever comes first, in order to increase sample size for publication. Thus, 39 TD children in grades 1 through 9 and their primary caregivers were included in final analyses. Demographic information for parents, children with ASD, and TD siblings is summarized in Table 1.

TD children were required to attend public or private school (i.e., not homeschooled), to live in the same household as their sibling with ASD, and to have previous knowledge of their sibling's diagnosis. The participating TD sibling was the child in the family who was closest in age to the child with ASD, while still being in grades 1 through 9. Previous mental health

diagnoses such as a learning disability, anxiety disorder, or Attention-Deficit/Hyperactivity Disorder [ADHD] did not exclude the TD sibling from participation, as long as the TD sibling did not have an ASD diagnosis. Siblings with ASD were not required to meet a specific age requirement, and parents were not required to provide documentation of the child's ASD diagnosis.

TD participants were 62% male, 85% Caucasian, and ranged in age from 7 to 15 ( $M = 10.31$ ,  $SD = 2.68$ ). Six TD siblings (15%) had their own mental health diagnoses. Siblings with ASD were 80% male, 87% Caucasian, and ranged in age from 4 to 18 ( $M = 11.74$ ,  $SD = 3.36$ ). Eighty percent ( $n = 31$ ) of the children with ASD attended public school. The average time elapsed since diagnosis was 82 months ( $SD = 51$  months), with the average age at diagnosis being 57 months ( $SD = 36$  months). Sixty-one percent ( $n = 24$ ) had an additional mental health diagnosis. Of the nine children with ASD aged 15-18, only one had a part-time job.

Our sample is not ethnically representative of the ASD population; the most recent epidemiological data from the CDC indicated a Caucasian to African American prevalence ratio of 1.3 (CDC, 2014). In contrast, the prevalence ratio in Phase I was 16 to 1, and was even larger in families who also completed Phase II (18 to 1). However, our sample's gender and median age of diagnosis were more similar to population data. Eighty percent of our sample of children with ASD was male, as compared to 78% of children with ASD across the CDC's 11 data collection sites (prevalence ratio of 4.5). The median age of diagnosis in our sample was 47 months, which is also similar to the population median of 53 months.

Ninety-two percent of parents were biological mothers, with the other reporters being adoptive mothers ( $n = 2$ ) or a biological father ( $n = 1$ ). For ease of reporting, all parent participants will be referred to as 'mothers.' Mothers were predominantly Caucasian (92.31%;  $n$

= 36), married (89.74%;  $n = 35$ ), well-educated (79.49% [ $n = 31$ ] had at least a college degree), and well-off (51.28% [ $n = 20$ ] earned at least \$80,000 per year as a family). Two-thirds of participating mothers worked outside the home (66.67%;  $n = 26$ ). Most families had two or three children living in the home (76.92%;  $n = 30$ ), and 89.74% ( $n = 35$ ) of TD and ASD siblings were full biological siblings. Participants lived in various states across the U.S., with a majority living in the South (76.92% South [ $n = 30$ ], 2.56% West [ $n = 1$ ], 10.26% Mid-West [ $n = 4$ ], 10.26% Northeast [ $n = 4$ ]).

Participants were recruited for this study through flyers, email listservs, and word-of-mouth. Individual chapters nationwide of the two major autism advocacy organizations in the United States (Autism Speaks, Autism Society of America) were contacted via email and social media to help with recruitment. Additionally, autism schools and community agencies in the Mid-Atlantic were contacted directly to assist with recruitment.

After participating parents completed the battery of measures, teachers were contacted directly by the researcher to complete the consent process and questionnaires. Twenty-five teachers (64% of the 39 returned packets) completed measures by mail and were compensated.

## **Procedure**

This study was conducted in two phases: completion of measures by the parent (Phase I) and completion of a focus group or interview by the parent and TD sibling (Phase II). While 39 families participated in Phase I, Phase II was only completed by a subset of families ( $n = 19$ ; 48.7%). Compensation was provided to families for both phases, and children completing a focus group or interview received a small prize.

Chi-square testing found no significant differences between families who completed only Phase I ( $n = 20$ ) and families who also completed Phase II ( $n = 19$ ) on mother's ethnicity ( $X^2$  (2,

$N = 39$ ) = 2.85,  $p = .24$ ), mother's education level ( $X^2$  (4,  $N = 39$ ) = 3.84,  $p = .43$ ), mother's marital status ( $X^2$  (2,  $N = 38$ ) = 1.31,  $p = .52$ ), annual household income ( $X^2$  (6,  $N = 39$ ) = 2.89,  $p = .82$ ), or child with ASD's severity category ( $X^2$  (3,  $N = 36$ ) = 2.51,  $p = .47$ ). No significant differences were found between participants who did and did not complete phase II in regard to parenting stress ( $F(1, 37) = .19, p = .67$ ), parenting self-competency ( $F(1, 37) = .09, p = .77$ ), parenting daily hassles ( $F(1, 36) = 1.26, p = .27$ ), family communication ( $F(1, 37) = 1.66, p = .21$ ), and family satisfaction ( $F(1, 37) = .65, p = .43$ ). Finally, there were no significant differences between these groups on academic measures, including average report card grades ( $F(1, 33) = .95, p = .34$ ), learning problems ( $F(1, 23) = 1.66, p = .21$ ), school problems ( $F(1, 23) = 2.80, p = .11$ ), or classroom performance ( $F(1, 23) = 1.15, p = .29$ ).

**Phase I (Quantitative data collection).** Local participants completed a phone screen prior to their clinic visit; long-distance participants also completed consent procedures by phone prior to receiving the questionnaires. Parents completed pencil-and-paper measures either during an in-clinic visit or by mail. Parents provided the names of three of their child's teachers from the current or past school year, and gave consent for the researcher to contact these teachers. Teachers were sent two questionnaires by mail (see below for more detail) and received a gift card upon returning them to the researcher. To protect the privacy of all families involved, the study was presented to teachers as a study about siblings, not a study relating to the Autism Spectrum. By signing the consent form and returning measures to the researcher, teachers indicated their consent to participate in the study.

**Phase II (Qualitative data collection).** Focus groups were considered the optimal setting for qualitative data collection, in the hopes that participants' interactions with each other would cultivate deeper discussion and yield more nuanced data above and beyond the topic guide.

Children were expected to find the group setting more comfortable, and perhaps more enjoyable, than a formal one-on-one interview with an adult. Rossman and Rallis (2012) suggest that “people often need to listen to others’ opinions and understandings to clarify their own” (p. 189). Indeed, parents in the focus groups seemed to talk more, and with less strict adherence to the topic guide, as compared to parents in the individual interviews. This may also be related to the in-person versus phone or video call formats.

After completing Phase I, 20 TD siblings and their 19 parents participated in Phase II. When the study was expanded geographically, families were given the option for individual interviews via phone or video call. As such, 35% ( $n = 7$ ) of child interviews were completed through three in-person focus groups, and 26% ( $n = 5$ ) of parent interviews were completed through two in-person focus groups. In families with multiple TD children, additional TD siblings were welcome to participate in focus groups or interviews; only one additional TD sibling chose to do so. The remainder of families completed one-on-one interviews via phone or video call. One family completed Phase I but did not respond to multiple contact attempts to schedule Phase II interviews. Two families participated in Skype interviews but their packets were not received. All parents were compensated and offered a summary of the research project after its completion.

Parent and child focus groups and interviews were similar in theme, regarding the impact of the child with ASD on the family’s functioning as related to everyday routines. Open-ended questions were asked in a semi-structured format based on the Topic Guide (Appendices A and B). One father participated in a focus group, while the remaining participants were mothers. All participants’ names have been changed to pseudonyms throughout this paper.

Phase II was concluded when qualitative data saturation was reached. Qualitative researchers agree on the concept of “diminishing return;” that is, after a certain number of interviews have been conducted, the likelihood of finding novel results decreases rapidly (e.g., Morse, 1995; Bradley, Curry, & Devers, 2007; Mason, 2010). However, there is great debate on how to find that specific threshold, and what the contributing factors to practical data saturation are. While other studies cite a recommended sample size for theoretical saturation (e.g., five to 25 [Creswell, 1998] or at least six [Morse, 1994] for phenomenological studies; at least 15 for any qualitative study [Bertaux, 1981]), only Guest, Bunce, and Johnson (2006) provide a recommendation based on the analysis of the creation of their own codebook. Specifically, data they had collected regarding women’s health care in Africa revealed that 94% of the most frequently used codes were found with  $n = 6$ , and 97% were found with  $n = 12$ . Additionally, these codes remained relevant throughout multiple rounds of analysis (Guest et al., 2006). Overall, the authors suggest that six to twelve interviews are sufficient to reach data saturation, in studies where the research topic is not too wide, the participants are relatively homogenous, the data quality is high, and there are not obvious sub-groups within participants. Considering Guest et al.’s and the other recommendations for data saturation cited above, Phase II was concluded after 19 parents and 20 children were interviewed.

Qualitative data from focus groups and interviews were analyzed using QSR International’s NVivo 11 for Mac text analysis software (2010). Audio tapes of interviews were transcribed and documents were imported into NVivo from the word-processing program. NVivo software was preferred over manual coding to allow faster and more thorough analysis of the large volume of qualitative data.

## **Power**

Power analyses for correlations, ANOVAs, and linear regressions were calculated using G\*Power 3 software (Faul, Erdfelder, Lang, & Buchner, 2007). Small, medium, and large effect sizes for each type of analysis were based on Cohen's (1988) estimates.

**Correlations.** An a priori power analysis ( $\alpha = .05$ ) for a two-tailed correlation at 95% power showed that a sample size of 134 would be needed to detect a medium effect size of 0.30, and a sample size of 71 would be needed to detect a medium-large effect size of 0.40. A sample size of 42 would detect a large effect size of 0.50. With a sample size of 39, the current sample is under-powered; however, sample size of 42 is expected to be reached prior to submission for publication. Effect sizes will be examined in order to estimate magnitude of effects, despite low power.

## **Measures**

**Parent measures.** To determine eligibility, a member of the research team conducted a phone screening with the parent prior to enrollment, to confirm that both children meet inclusion criteria and to explain the study procedures. The researcher confirmed the following information: 1) that the parent had a child with an ASD diagnosis, 2) that the TD child was in grades 1-9 in a public or private school, 3) that the parent is the children's primary caregiver, and 4) that the children lived in the same household. The researcher also confirmed that the TD child was aware of his/her sibling's diagnosis. The researcher then explained the procedures of the study and answered any questions the parent had.

Parents completed a number of measures, either during a clinic visit or at home prior to returning measures by mail. Online completion of measures was not feasible, due to copyright laws. Completion of the battery of questionnaires was estimated to take approximately 60 minutes. Several measures were used to measure potentially disruptive behaviors of the child

with ASD (e.g., measures of sleep difficulties, anxiety, and externalizing behaviors), while other measures were used to assess routine disruptions (Parenting Daily Hassles Questionnaire; PDHQ), family adaptability and functioning (Family Adaptability and Cohesion Evaluation Scales [FACES-IV]; Parenting Sense of Competence Scale [PSOC] and maternal stress (Parenting Stress Index, Short Form; PSI-SF). Parents were compensated for their time.

1). *Parental permission form.* Before beginning the survey, parents reviewed a parental permission form that described the general purpose of this study and the inclusion criteria. Parents were also asked to sign a Consent for Release of Information form allowing the researcher to contact the child's teacher and for the teacher to complete the requested forms.

2). *Demographics form.* The demographic measure collected basic identifying information such as the mother's ethnicity, educational level, profession, and income level and the children's gender, age, ethnicity, and grade in school. Information regarding the child with ASD's previous diagnosis (e.g., when was the child diagnosed, at what age, who was the child diagnosed by, and what other mental health diagnoses the child might have) was also included. Other information collected included the number and birth order of all siblings, how siblings are related to each other (i.e., biologically, through adoption or marriage, etc.), and whether the siblings live together and attend the same school.

3). *Social Responsiveness Scale (SRS; Constantino, 2002).* The SRS is a 65-item questionnaire used to measure the severity of social communication difficulties, especially as related to ASD. This parent report uses a 4-item Likert scale (0 = Never true to 3 = Almost always true) to collect information related to a child's difficulties within five domains: Receptive, Cognitive, Expressive, and Motivational Aspects of Social Behavior, and Autistic Preoccupations, as well as an overall score (Constantino, 2002). The SRS is completed within

15-20 minutes (Constantino & Todd, 2003) and is frequently used in research settings with children. Higher scores indicate more severe symptoms of ASD.

In studies on over 1,900 children aged 4 to 15 years, the SRS was found to be continuously distributed, and was able to distinguish between children with pervasive developmental disorders and other psychiatric disorders test-reliability (Constantino & Todd, 2000; 2003). Test-retest reliability over three months was 0.88 (Constantino & Todd, 2000; 2003). A later study used 15 participants from the previous sample and found 0.83 test-retest reliability over a 27-month period (Constantino et al., 2003). The SRS also has appropriate reliability with the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994; greater than 0.64 between the SRS score and all DSM-IV algorithm scores of the ADI-R), the gold standard interview for ASD diagnosis.

The parent was asked to complete the SRS for both of their children, to confirm that the TD child was not showing symptoms of ASD, and that the child with ASD did in fact have current ASD symptomatology.

4). *Parenting Daily Hassles Scale* (PDHQ; Crnic & Greenberg, 1990; Crnic & Booth, 1991). The PDHQ is a self-report measure of everyday parenting stresses, including daily events and interactions between parent and child. Parents rate 20 ‘hassles’ (e.g., meal-time difficulties, sibling arguments, getting privacy, children being demanding or complaining often) on both frequency and intensity. Frequency is rated on a 4-point Likert scale (‘rarely,’ ‘sometimes,’ ‘a lot,’ ‘constantly’) and intensity is measured through a 5-point Likert scale, where 1 indicates “no hassle” and 5 indicates a “big hassle.” The frequency and intensity indices are highly corrected ( $r = 0.78$ ), and each has appropriate internal reliabilities as well (0.81 for the frequency index and 0.89 for the intensity index). The intensity score, which is considered a better indicator of a

parent's perceived stress, had an average reliability of 0.90 across several studies (Crnic, Gaze, & Hoffman, 2005). Factor analysis produced two subscales from the PDHQ – Parenting Tasks (typical parenting duties, such as cleaning up after a child) and Challenging Behaviors (problem behaviors, such as complaining, resisting bedtime, or interrupting). Analyses can be used based upon frequency and intensity scores, or through calculations of the subscales. Higher scores indicate more overall daily hassles related to parenting. The PDHQ was used here as a proxy for disruptions to the family routine.

5). *Family Adaptability & Cohesion Evaluation Scales* (FACES-IV; Olson, 2008). The Family Adaptability & Cohesion Evaluation Scales, Fourth Edition (FACES-IV; Olson, 2008) is a self-report tool used to assess the both dimensions (balanced and unbalanced) of cohesion and flexibility of the Circumplex Model of Marital and Family Systems (Olson, 2000). This model states that families with healthy functioning show a balance between their levels of flexibility and cohesion (Olson, 2000).

A validation study (Olson, 2011) confirmed the presence of two Balanced scales (Cohesion and Flexibility) and four Unbalanced scales (Disengaged, Enmeshed, Rigid, and Chaotic). Higher scores on balanced cohesion and balanced flexibility are related to positive family functioning, while higher scores on the four unbalanced scales are related to negative family functioning. Scores are also provided which measure the quality and quantity of family communication (Family Communication Scale) and the level of satisfaction a parent has with his/her family (Family Satisfaction Scale). Analyses were conducted on the Family Communication and Satisfaction scales; exploratory analyses also used the Unbalanced scales. Internal consistencies for the six scales ranged from 0.77 to 0.89. Two other measures of family functioning were used to separate 87 college-aged participants into “problem” and “non-

problem” groups (top and bottom 40% of the groups). The discriminant validity of the FACES-IV ranged from 84% to 99% when all six scales were used together, with an average of 94%, demonstrating good validity (Olson, 2011).

6). *Parenting Sense of Competence Scale* (PSOC; Johnston & Mash, 1989). The 17-item Parenting Sense of Competence Scale (PSOC; Johnston & Mash, 1989) is answered on a 6-point Likert scale, ranging from “Strongly Agree” to “Strongly Disagree.” The PSOC measures Satisfaction and Efficacy related to parenting, such that parents with higher scores are those who feel satisfied and effective in their parenting skills (Ohan, Leung, & Johnston, 2000). Internal consistency was found to be 0.75 for the Satisfaction scale and 0.76 for the Efficacy scale. A more recent study confirmed the two-factor structure and found internal consistencies of 0.80 for mothers on both scales (Ohan et al., 2000). Internal consistencies for fathers were 0.77 for the Efficacy scale and 0.80 for the Satisfaction scale.

The PSOC has been used previously to measure parenting self-competence in parents of children with ASD (Rezendes & Scarpa, 2011) and in a study of children with autism, externalizing behaviors, or no problem behaviors (Donenberg & Baker, 1993), among other studies. The overall parenting competency score, as well as scores of parental satisfaction and parental efficacy, were used in this study.

7). *Parenting Stress Index, Third Edition, Short Form* (PSI-SF; Abidin, 1995). The PSI-SF consists of 36 items taken from the original version of the PSI-3 (101 items), and takes 10 minutes to complete. Subscale scores are provided for Parental Distress, Parent-Child Dysfunctional Interaction, Defensive Responding, and Difficult Child, as well as a Total Distress score (Abidin, 1995); all scores except the Defensive Responding score were used in this study. The PSI-SF is highly correlated with the PSI, Third Edition ( $r = 0.95$ ; Abidin, 1995). In a

sample of 21 parents of children aged 4 - 10 who had documented physical abuse histories towards their children, one-year test-retest reliability was good (0.61-0.75; 0.75 on Total Distress score; Haskett, Ahern, Ward, & Allaire, 2006). The PSI has been used previously in studies of the stress of parents of children with ASD (e.g., Lecavalier et al., 2006). Higher scores indicate greater levels of parenting stress.

### **Child measures.**

1). *Assent script/form.* Children who were at least 12 years of age were given an assent form to read, sign, and return. Children between the ages of 5-11 were asked to read the assent form, but were not required to sign or return it. Children participating in Phase II interviews were read the assent form, given the opportunity to ask questions about the project, and then asked for verbal assent. Child participants picked a prize from a prize box to thank them for their time.

2). *Report card.* The TD child's most recent report card was provided by the parent, and used as a measure of academic performance. Although other studies have utilized statewide standardized assessments or in-clinic achievement testing, the report card was used here as an easily accessible measure of performance. Grades across four main subject areas (Math, Language Arts, Science, and Social Studies) were averaged; higher grades were weighted more heavily (e.g., 2 points for an 'A,' 0 points for a 'C,' and -2 points for an 'F').

Attendance data were collected from these report cards; however, these data could not be analyzed, due to notable differences in reporting between school districts. Additionally, parents had difficulty remembering how many days their child missed due to 'excused' absences, rendering these data unusable.

**Teacher measures.** Teachers were contacted by mail, offered the opportunity to participate in the study, and provided with a copy of the parent release form. Upon receipt of measures, teachers were compensated with a small gift card.

1). *Consent form.* Teachers completed a consent form regarding their participation in the study. The study was purposefully presented as a study of siblings, and not of siblings of children with ASD, in order to protect the family's right to disclose.

2). *Academic Performance Rating Scale (APRS; DuPaul, Rapport, & Perriello, 1991).* The APRS is a 19-question measure that helps identify students who need extra support in the classroom. Scores for three subscales are provided: Academic Success, Academic Productivity, and Impulse Control. Questions probe for work completion, accuracy, and quality, following teacher directions, and being organized. A subsample of 50 children randomly selected from a larger sample was used to test the APRS against observational measures (DuPaul et al., 1991). Internal consistency was high for the Academic Success and Academic Productivity (0.94 for each subscale) and for the Total APRS score (0.95), but less for Impulse Control (0.72). Test-retest reliability over a 2-week period yielded high reliability across scales, ranging from 0.88 to 0.95. The Academic Success, Academic Productivity, and Total APRS score were correlated with achievement test scores and with students' percentage of assignments correctly completed. Higher scores on the APRS represent better classroom performance; total APRS score was used in this study.

3). *Behavior Assessment System for Children, Second Edition, Teacher Rating Scales (BASC-2; Reynolds & Kamphaus, 2004).* The BASC-2 was used to measure behavior and adaptive skills. Teachers completed either the child (ages 6-11) or adolescent (ages 12-21) version; composite and subscale domains are the same between versions, with questions

changing slightly to reflect development. Regarding problem behaviors in the school setting, four composite scale scores are created: Externalizing Problems (Hyperactivity, Aggression, and Conduct Problems subscales), Internalizing Problems (Anxiety, Depression, and Somatization subscales), School Problems (Attention Problems and Learning Problems subscales), and Behavioral Symptoms Index (Atypicality and Withdrawal subscales). The Adaptive Skills composite is composed of Adaptability, Social Skills, Leadership, Study Skills, and Functional Communication subscales. Only the School Problems subscales were used in the current study.

Teachers responded to 139 questions, based on a 4-point Likert scale ('never,' 'often,' 'sometimes,' or 'almost always'). Raw scores were converted into standard scores ( $M = 50$ ,  $SD = 10$ ). Lower t-scores (i.e., less than 60) in the Attention Problems and Learning Problems subscales indicate normative behavior. Scores falling between 60 and 69 indicate borderline significant difficulties, which scores above 70 representing clinically significant attention or learning problems.

In combined gender, non-clinical samples, during an interval of 8 to 65 days, TRS internal reliabilities across all five composite scores ranged from 0.88 to 0.97 (ages 6 to 11) and 0.91 to 0.97 (ages 12 to 18; Reynolds & Kamphaus, 2004). Across ages in combined gender, non-clinical samples, internal reliabilities for the School Problems composite score range from 0.92 to 0.94, and from 0.85 to 0.89 for the Learning Problems subscale. Adjusted test-retest reliabilities for composite scores in a non-clinical sample ranged from 0.84 to 0.93 (0.91 for School Problems) on the child version, and 0.81 to 0.92 (0.90 for School Problems) on the adolescent version. Test-retest reliability on the Learning Problems subscale was 0.88 on the child version and 0.89 on the adolescent version. Finally, in a combined clinical and non-clinical

sample, the Attention Problems and Learning Problems subscales both have inter-correlations of 0.90 (child version) and 0.91 (adolescent version) with the School Problems composite.

**Focus groups.** Two parent focus groups were facilitated by Clinical Psychology graduate students. All individual parent interviews, child focus groups, and individual child interviews were conducted by the first author. Topic guides (Appendices A and B) were used to structure the conversations. Of parents who participated in a focus group or interview, 18 out of 19 (94.7%) were the same parent who had completed Phase I paperwork. One mother was not able to attend the focus group and her husband attended in her place. One additional sibling who was not the focus of Phase I paperwork participated in a focus group.

## Results

### Quantitative

Descriptive analyses were conducted to characterize the sample (Table 2). Correlational analyses were considered primary analyses, as sample size did not support multiple regression or moderation analyses.

### Comparisons to Normative Scores on Academic Performance (Hypothesis 1)

The report cards of 35 child participants were received. Grades averaged 1.56 ( $SD = 0.58$ ), or approximately a B+ average across subject areas. Grades ranged from -.89 (nearly all Ds) to 2.00 (all As). Thirty-two children (91%) had grade averages of B or higher, and fourteen of those (40%) had A averages. On the BASC-2, scores were categorized based on clinical cut-offs. Twenty-four out of 25 (96%) child participants whose teachers returned measures had Learning Problems and School Problems scores within the normative range; one child had a clinically significant score on both the subscales and the composite score.

Normative comparisons are less clear on the APRS, as mean scores were broken down by grade and gender, not as a whole. Across groups (DuPaul, 1991), a mean Total Score on the APRS was found to be 69.46. In the current study, 72% ( $n = 18$ ) of TD children had APRS scores equal to or above 69, indicating that approximately one-quarter of the sample had below average scores on this measure of classroom behavior. The APRS measures both performance outcomes in the classroom (i.e., percentage of work that is completed accurately) as well as ratings of more abstract processes, such as how a student pays attention, follows directions, or completes work. Attentional difficulties are subsumed in both BASC-2 and APRS scores. Five TD siblings (12.82%) were reported by their parents to have ADHD diagnoses; one of these five also had a learning disability. Average report card grades and APRS scores were slightly higher, and Learning and School Problems scores were slightly lower, when the scores of TD siblings with ADHD were removed.

### **Correlational Analyses**

Two-tailed bivariate correlations were conducted in order to determine whether ASD severity was related to any main constructs. ASD severity as measured by SRS-2 T-score was not correlated with any of the primary variables of interest (e.g., overall scores and subtest scores of the PSI-SF, PSOC, PDHQ, or FACES-IV), except for the Challenging Behavior subscale of the PDHQ ( $r = .36, p = .02$ ), where higher scores indicate more troublesome daily behaviors from all children in the family. As such, ASD severity was controlled in analyses involving the PDHQ Challenging Behavior subscale. ASD severity was not significantly related to total score on the APRS ( $r = -.06, p = .39$ ), average report card score ( $r = .07, p = .35$ ), Learning Problems on the BASC-2 ( $r = -.10, p = .32$ ), or School Problems on the BASC-2 ( $r = -.01, p = .49$ ).

One-tailed bivariate correlations were conducted according to the four main hypotheses, and are detailed below. Outliers were examined by identifying scores three standard deviations above and below the mean scores. In all of the main variables, one participant's scores were outliers in the domains of report card grades and BASC-2 scores (both School and Learning Problems scores). However, removal of this participant from the data did not significantly affect any of the main outcomes. Regarding the Defensive Responding scale of the PSI-SF, no participant's scores fell three standard deviations below the mean score; however, two participants' scores fell below the clinical cutoff of 10. Main outcomes were not significantly affected by removing these participants' data.

### **Family Routine Disruptions and TD School Performance (Hypothesis 2)**

No significant correlations were found between school outcomes and the subscales or overall score on the PDHQ, a proxy to measure for disruptions in family routines (see Table 3 for correlations). Total PDHQ score was not significantly correlated with academic performance score on the APRS ( $r = .11, p = .30$ ), BASC-2 Learning Problems ( $r = -.12, p = .29$ ), BASC-2 School Problems ( $r = -.11, p = .31$ ), or report card grades ( $r = -.20, p = .11$ ).

Controlling for SRS severity, the PDHQ Challenging Behavior subscale score was not significantly correlated with APRS score ( $r = .27, p = .96$ ), Learning Problems ( $r = -.02, p = .95$ ), School Problems ( $r = .02, p = .94$ ), or report card grades ( $r = .27, p = .22$ ). However, correlations with APRS score and report card grades were moderate in effect size; these relationships may have been significant with a larger sample size. These trends suggest that parents who are distressed by their children's problem behaviors might have TD children with better academic performance and grades.

The PDHQ Parenting Tasks subscale score was also not significantly correlated with APRS score ( $r = .09, p = .34$ ), Learning Problems ( $r = -.03, p = .44$ ), School Problems ( $r = -.06, p = .40$ ), or report card grades ( $r = -.17, p = .15$ ). Effect sizes were small here, suggesting a minimal relationship between stress about parenting duties and TD academic functioning.

### **Relationship of Parenting Stress with Family Routine Disruption and TD Sibling School Outcomes (Hypothesis 3)**

Correlations were conducted to examine the relationship between parenting stress (overall PSI-SF score and sub-domain scores) with disruption to family routines (PDHQ intensity score and subscale scores; Table 4) and school performance (APRS, report card grades, BASC-2 school behavior problems; Table 5).

The correlation between the Total Stress scale of the PSI-SF and the intensity scale of the PDHQ ( $r = -.02, p = .46$ ) was non-significant with a small effect size. This result indicates no substantial relationship between parenting stress and family routine disruptions.

The PSI-SF Difficult Child subscale score was significantly negatively related to the BASC-2 School Problems composite ( $r = -.35, p = .05$ ), where lower scores indicate fewer problems) and report card grades ( $r = -.40, p = .01$ ), suggesting that heightened child-related stress was associated with fewer school behavior problems but also lower grades. Higher overall parenting stress also was significantly correlated with lower grades on the TD child's report card ( $r = -.31, p = .03$ ).

### **Relationships of TD Sibling School Outcomes and Parenting Stress with Family Functioning and Parenting Self-Competence (Hypothesis 4)**

**TD sibling school outcomes (Table 6).** We hypothesized that TD sibling grades and classroom behavior would be positively correlated with family flexibility and cohesion, and

parenting satisfaction and efficacy. No significant relationships were found between family cohesion and average report card grades ( $r = .22, p = .09$ ), APRS score ( $r = .01, p = .48$ ), BASC-2 Learning Problems ( $r = -.15, p = .24$ ), or BASC-2 School Problems ( $r = -.16, p = .22$ ), although the relationship with grades approached a moderate effect size. Additionally, no significant correlations were found between family flexibility and report card scores ( $r = -.19, p = .12$ ), APRS score ( $r = -.25, p = .12$ ), BASC-2 Learning Problems ( $r = .20, p = .17$ ), or BASC-2 School Problems ( $r = .16, p = .22$ ). The relationship between family flexibility and APRS score was close to moderate.

Parenting satisfaction was not significantly related to grades ( $r = -.07, p = .34$ ), learning problems ( $r = .09, p = .34$ ), school problems ( $r = .17, p = .21$ ), or academic performance ( $r = -.17, p = .22$ ) in the TD child. Similarly, parenting efficacy was not significantly correlated with grades ( $r = -.12, p = .24$ ), learning problems ( $r = .24, p = .13$ ), school problems ( $r = .33, p = .06$ ), or classroom performance ( $r = -.28, p = .09$ ). Overall parenting self-competency was similarly not significantly correlated with report card grades ( $r = -.11, p = .25$ ), school problems ( $r = .33, p = .06$ ), learning problems ( $r = .21, p = .16$ ), or academic performance ( $r = -.29, p = .08$ ). Effect sizes for the relationships between parenting efficacy and parenting self-competency were moderate for the BASC-2 and APRS scores, indicating that correlations may have been significant with a larger sample size.

**Parenting stress and self-competence (Table 7).** Additionally, we expected that parenting stress would be negatively correlated with family flexibility and cohesion, and parenting satisfaction and efficacy. Total Stress scores on the PSI-SF were not significantly related to parenting efficacy ( $r = -.18, p = .14$ ) or satisfaction ( $r = .00, p = .50$ ) on the PSOC, nor to family flexibility ( $r = .22, p = .09$ ) or cohesion ( $r = .10, p = .28$ ) on the FACES-IV. Parental

Distress scores on the PSI were not significantly related to efficacy ( $r = -.22, p = .09$ ), satisfaction ( $r = .04, p = .40$ ), cohesion ( $r = .06, p = .35$ ), or flexibility ( $r = .08, p = .31$ ). The measure of parent-child dyadic difficulties on the PSI-SF was also not significantly correlated with parenting efficacy ( $r = -.17, p = .15$ ) or satisfaction ( $r = -.11, p = .25$ ), or family cohesion ( $r = .09, p = .30$ ) or flexibility ( $r = .21, p = .10$ ). Finally, Difficult Child scores were also not significantly correlated to efficacy ( $r = -.10, p = .27$ ), satisfaction ( $r = .05, p = .38$ ), or cohesion ( $r = .11, p = .25$ ). Difficult Child scores were positively correlated with family flexibility ( $r = .30, p = .03$ ), with a moderate effect size.

### **Exploratory Analyses**

**Correlations with measures of academic performance.** Two-tailed correlations were performed on the measures of academic performance. APRS scores were negatively correlated with school ( $r = -.93, p = .00$ ) and learning ( $r = -.85, p = .00$ ) problems (BASC-2), such that students with better academic performance were rated as having fewer school behavior problems. APRS scores were positively correlated to report card grades ( $r = .69, p = .00$ ), with a large effect size. The BASC-2 Learning Problems and School Problems scales were significantly positively correlated with each other ( $r = .91, p = .00$ ), with a large effect size. Both the BASC-2 School Problems composite and the Learning Problems subscale were significantly negatively related to report card grades ( $r = -.70, p = .00$  and  $r = -.80, p = .00$ ), with large effect sizes. In all cases, higher grades were associated with better classroom performance and fewer learning and school problems.

In summary, the majority of TD participants did not have academic difficulties; 91% had at least a B average, 96% had normative scores on the Learning Problems subscale and the School Problems composite of the BASC-2, and 72% fell above an approximate cut-off on the

APRS. Daily parenting hassles, a proxy for routine disruptions, was not significantly related to school outcomes. Overall parenting stress (Total PSI-SF score) and endorsements of child-related stress (Difficult Child scale of the PSI-SF) were related to lower report card grades. However, child-related stress was also related to *fewer* academic problems as reported by teachers on the BASC-2 School Problems composite. Parenting self-competency measures were not related to parenting stress, or to TD child academic performance. Parents who reported more child-related difficulties on the PSI-SF reported themselves to be less flexible as a family.

A few correlations were noted that trended towards significance, and may have been significantly correlated given more power. For example, the relationships between parenting efficacy (PSOC) and Parent Distress (PSI-SF;  $r = -.22, p = .10$ ), parenting self-competency (PSOC) and academic performance (APRS;  $r = -.29, p = .08$ ), and parenting self-competency (PSOC) and school problems (BASC-2;  $r = .33, p = .06$ ) approached significance. However, this is contradictory in the fact that as parenting self-competency increases, school problems decrease but classroom performance worsens.

### **Mixed Methods**

Mixed methods data analyses were completed based on Onwuegbuzie and Teddlie's (2003) seven-step conceptualization. Classical content analysis was used, whereby descriptive pieces of data were coded, and codes were then counted to determine which ones were used most often (Leech & Onwuegbuzie, 2007). Codes were determined inductively (i.e., emerged from the data, also known as *grounded theory*; Glaser & Strauss, 1967), rather than being determined prior to analysis.

The subgroup of participants who completed Phase II interviews was overwhelmingly comprised of parents who were Caucasian (94.7%), female (94.7%), and the child's biological

parent (89.5%). As such, qualitative comparisons were not conducted based on race, parent gender, or marital status. Additionally, only one child in Phase II met clinical cut-offs for Learning and School Problems on the BASC-2; this child was also the only child who had average grades less than A's or B's. As such, comparisons between children were not completed based on grades or school performance.

Across parents and children, six main categories emerged from the data: Emotions (28.0% of all codes), Family Concerns (23.2%), Child with ASD (19.1%), "The ASD Process" (11.1%), TD Child (10.8%), and Coping (7.8%; see Table 8 for summary of frequencies). Separate categories were made specifically for research questions on family routines and parents' experiences of feeling most and least competent.

**1) Emotions.** Statements describing the emotional experience of having a family member with ASD made up the most frequently coded category. Emotion-based codes comprised 34.1% of sibling codes and 25.8% of parent codes. TD siblings often described their sibling with ASD as 'annoying' (33.5%), 'challenging' (18.9%), and 'stressful' (14.1%). Siblings also reported having both positive and negative emotions towards their sibling with ASD ('conflicted,' 8.6%) and caring about their sibling (7.0%).

Parents also reported that their child with ASD was often 'challenging' (19.0%) and 'stressful' (14.7%), but that their child with ASD often brought a unique perspective (14.4%) and a sense of resiliency (8.2%) to the family's life.

**2) Family Concerns.** Topics related to general family concerns and running a household were coded here, such as marriage, work, and sibling bonding or discord. 'Family Concerns' codes comprised 13.8% of sibling codes and 22.5% of parent codes. Nearly half (43.7%) of TD sibling codes in this category were related to normative concerns between sibling pairs, such as

arguing, breaking promises, doing chores, and sharing, borrowing, or stealing personal possessions. TD siblings reported more frequently about difficulties getting along with their siblings (20.7%) as compared to bonding experiences (1.5%).

Parent concerns in this area were also predominantly about typical parenting concerns (10.9%), such as breaking up arguments, enforcing house rules, being fair, dealing with health issues, and handling the stresses of puberty. Parents also reported feeling that they were missing out on ‘typical’ family experiences (9.8%), such as going on vacations and family outings, hosting social gatherings, and having more “carefree” leisure time. Parents also expressed regret about often having to leave events early due to their child with ASD and having less ability to pay for fun activities due to the cost of therapies.

**3) Child with ASD.** A number of parent and sibling concerns were focused on how ASD-related behaviors impact the family’s everyday life. ‘Child with ASD’ codes comprised 16.9% of sibling codes and 19.9% of parent codes (19.1% of all codes). Siblings were particularly concerned with their sibling with ASD’s emotional outbursts (22.8%) and behavioral rigidities (16.3%). Parents also discussed behavioral rigidities (23.5%), emotional outbursts (18.6%), improvements in their child with ASD’s behavior over time (6.3%), and the child with ASD’s difficulties in the morning (6.3%).

**4) “The ASD Process.”** Discussions about ASD-related issues (e.g., diagnosis, services, advocacy, future planning) were rare among TD siblings (6.8% of codes), but were sometimes discussed by parents (12.7%) of codes. For siblings, these codes predominantly consisted of discussions of strategies to deal with their siblings’ disruptive behaviors (75.7%). Parents also discussed these types of strategies (25.3%), as well as services their child was receiving (13.2%) and their initial reaction to hearing of their child’s diagnosis (11.0%).

**5) TD Child.** Many responses discussed the impact having a sibling with ASD had on the TD child. TD Child codes made up 13.8% of sibling codes and 9.6% of parent codes. Twenty-eight percent of sibling codes in this area discussed feeling responsible for their sibling, while 21.3% discussed their own everyday difficulties, such as being easily distracted, having homework problems, or not following directions. Another 17.3% of these codes represented the TD child feeling “on the outside,” either in regard to their family being busy taking care of their sibling with ASD, or missing out on experiences such as having friends over for play dates. Feelings of being jealous or embarrassed, which have been highlighted in previous literature of siblings with chronic illnesses (Minagawa, 1997; Herrman, 2010; Read, Kinali, Muntoni, Weaver, & Garralda, 2011), were reported relatively few times (9.3% and 8.0%, respectively).

Parents were also most concerned about 1) the amount of responsibility falling on the TD child’s shoulders (18.2%) and 2) the TD child’s own difficulties (19.7%), such as ADHD, behavioral difficulties, or emotional problems. Four mothers (23.5%) specifically indicated that their TD child was currently more stressful to parent than their child with ASD. The other commonly cited experiences were of TD children being disappointed by their sibling with ASD (7.3%), not getting as much attention as the child with ASD (7.3%) and therefore feeling jealous (10.2%), and being protective of their sibling with ASD (9.5%).

**6) Coping.** Coping-related codes were one of the two least mentioned categories for parents (9.5%), despite parents specifically being asked how they coped with their parenting stress. Specific coping strategies were rated here, including division of labor (20.1%), parents having their own hobbies (7.4%), social support (28.9%), and having respite care (12.6%). Statements about coping in general made up 30.4% of these codes.

As children were not asked about coping directly, only 3.5% of all TD child codes were coping-related. Of these, 63.2% of codes were related to their parents' division of labor, and 26.3% discussed social support, such as having another TD sibling or one of the parents that they were able to share their problems with.

### **Mixed Methods Analyses Related to Research Questions**

**Family routines (Hypothesis 2).** A higher percentage of parent codes (24.8%), as compared to sibling codes (18.5%), discussed routine disruptions stemming from the child with ASD, although both groups were asked directly about this topic. This may be due to the fact that TD siblings have their own difficulties with daily routines, and that parents have more insight into the ideal routine, given their position in the family. Many routine disruptions were tied to the child with ASD's rigidities, although some parents noted that a propensity for routine actually helped their child with ASD complete chores and self-care tasks more smoothly than their TD children. For example:

*“Grace also is good about getting herself ready, and with routines. Once you get a good routine it’s fantastic. So once she gets home from school if she hasn’t finished her homework, I mean we never have to tell her, she’ll sit down and do her homework. She’ll ask, her job is the dishwasher, “do I need to do the dishwasher?”, she’ll go up and take a shower.”*

*“Liam really loves routines, so for him, routine is easy, so if anything, he’s more of a role model for the younger ones. He is, once he has his routine down, he knows what it is, he doesn’t need to be reminded, he knows the routine and he’s gonna follow it.”*

**Parenting daily hassles (Hypothesis 2).** Regarding the PDHQ, specific cut-off scores do not exist for the Challenging Behaviors and Parenting Tasks subscales. As such, participant’s

total PDHQ scores were separated at the median into “High Hassles” ( $n = 8$ ) and “Low Hassles” ( $n = 9$ ) groups. “High hassles” families reported more often about the child with ASD’s meltdowns (4.80% vs. 3.00%), rigidity (5.52% vs. 3.21%), and less often about his/her strengths (3.24% vs. 5.80%). Parents with higher PDHQ scores also discussed using social support (3.12% vs. 1.66%) and respite care (1.44% vs. 0.41%) as coping strategies more often. In the Emotions category, parents with lower PDHQ scores described their child with ASD as less challenging (3.62% vs. 6.36%), and described themselves as less stressed (3.21% vs. 5.28%). They also reported more instances where they used their sense of humor to cope (1.24% vs. 0.36%). Finally, families with more hassles discussed missing out on more activities as a family (2.16% vs. 1.04%), experiencing more routine disruptions (6.12% vs. 5.28%), and using fewer behavioral strategies with their child with ASD (2.52% vs. 4.76%).

These qualitative findings on parents who experienced high levels of hassles are surprising when compared to our quantitative finding of a trending moderate effect size between higher Challenging Behavior scores on the PDHQ and better TD sibling academic outcomes. It would follow that “high hassles” parents who are more stressed and experience more routine disruptions than “low hassles” parents would have difficulty monitoring their TD child’s homework routine. However, this may indicate that the TD children in our sample are proficient at separating their potentially chaotic home life from their in-class performance

**Parenting stress (Hypothesis 3).** Total Stress scores on the PSI-SF were separated according to normative scores (15<sup>th</sup> to 80<sup>th</sup> percentile) and high scores (at or above the 85<sup>th</sup> percentile). Only two parents reported Total Stress scores within the normative range; another parent reported an unusually low score in the 1<sup>st</sup> percentile. This parent also had an unusually low PDHQ score, and was the only parent (in Phase II) who had a significant Defensive

Responding score, indicating that these scores are likely outliers. However, for the purposes of this analysis, despite unevenness, groups were considered to be high ( $n = 14$ ) or low ( $n = 3$ ).

The lower stress group spoke more frequently about the specific stresses associated with high-functioning ASD (1.74% vs. 0.51%), such as their child's ASD diagnosis being doubted by others, or their teenager with ASD having dating difficulties. This group also had higher percentages of difficult mornings (2.49% vs. 1.40%), annoying instances (6.72% vs. 2.23%), and sibling discord (4.73% vs. 1.91%). Lower stress parents and TD siblings spoke more frequently about the child with ASD's strengths (5.72% vs. 4.14%), whereas high stress parents spoke more frequently about their TD children's strengths, both when asked directly and spontaneously throughout the interview (1.97% vs. 0.75%). This group surprisingly spoke more often about feeling stressed (4.73% vs. 3.89%); many of these specific examples revolved around the difficulties of creating and updating Individualized Education Programs (IEPs). Additionally, in both categories, some of these frequencies stemmed from children responding to the question about whether their family was more stressed than other families, or not. Thus, TD child report about their family's stress level may be different than the parent report on the PSI-SF. This group spoke more frequently about typical sibling concerns (7.21% vs. 2.74%); lower stress parents spoke more often about the TD child's own current difficulties (4.23% vs. 1.66%). The lower stress group spoke more often about the types of strategies that they as parents and siblings use with the child with ASD (5.47% vs. 3.31%).

In contrast, the higher stress group spoke more frequently about the stressors of having a child with little to no verbal language (0.45% vs 0%). This group also spoke more about having emotional outbursts (4.08% vs. 2.49%), difficulty ending a preferred activity (1.02% vs. 0.25%), and coping strategies (2.48% vs. 1.00%). This group discussed more frequent examples of

challenging behavior from the child with ASD (5.92% vs. 2.99%), the family being in crisis (1.53% vs. 0.25%), and the family missing out on social opportunities (2.04% vs. 1.00%). TD siblings in this category were discussed more often as taking responsibility in the family (2.74% vs. 0.75%).

Our quantitative data suggested that parents with more child-related stress had TD children with fewer problem behaviors in the classroom, but also lower grades. When compared to qualitative data, these findings suggest that TD children whose parents report high levels of stress may have more responsibility at home, as well as more ‘crises,’ outbursts, and challenging behaviors from their sibling with ASD. As such, these TD children may be able to generalize this level of responsibility to self-monitor their in-class behavior. However, there may be more distractions and less parental attention at home, leading to poorer studying skills, less homework completion, and therefore worse grades.

**Family communication and satisfaction (Hypothesis 4).** Families were separated according to their scores on the Family Communication and Satisfaction scores on the FACES-IV. Based on categories provided by the scoring manual, families were separated into groups of ‘High,’ ‘Very High,’ ‘Moderate,’ ‘Low,’ and ‘Very Low.’ For qualitative analyses, the highest two categories and lowest two categories were grouped together and compared.

**Family communication.** Ten families (58.82%) fell within the High/Very High range for Family Communication, while four (23.53%) fell within the Low/Very Low range and three (17.65%) within the Moderate range. Families with High/Very High communication scores spoke more frequently about their child with ASD’s strengths (4.67% vs. 3.17%). TD siblings and parents in this category spoke more often about normative concerns between siblings (4.77% vs. 2.20%) and the TD child’s own difficulties (2.29% vs. 1.71%). Families with Low/Very Low

communication scores spoke more often about their use of respite care (1.71% vs. 0.27%) and their need for social support (4.15% vs. 1.47%). Families with lower communication scores also spoke much more often about the challenges of raising a child with ASD (8.54% vs. 3.67%), feeling conflicted towards their child (2.68% vs. 1.65%), and feeling stressed (5.37% vs. 3.48%).

**Family satisfaction.** Seven families (41.18%) fell in the High/Very High range in the Family Satisfaction domain. Eight families (47.06%) fell in the Low/Very Low range, and two families (11.76%) fell in the Moderate range. Highly satisfied families spoke more often about the child with ASD's behavior improvements (1.12% vs. 0.76%) and their own use of various coping skills (2.47% vs. 1.26%). However, parents who fell in the Low/Very Low range of satisfaction scores reported using respite care (1.64% vs. 0.34%) and social support (3.16% vs. 1.80%) more often. TD siblings whose parents reported higher satisfaction spoke more frequently about their sibling with ASD being annoying (4.05% vs. 3.03%), but less often about their sibling being challenging (3.49% vs. 6.57%). Families with less satisfaction discussed being more stressed (5.44% vs. 3.26%) and less resilient (0.76% vs. 1.35%) than highly satisfied families. Highly satisfied families spoke more frequently about the importance of advocacy (1.24% vs. 0.25%), symptoms of high-functioning ASD (1.12% vs. 0.38%), a child with ASD 'passing' as TD (0.79% vs. 0.25%), and normative concerns between siblings (4.39% vs. 3.41%).

### **Exploratory Qualitative Analyses**

**Parenting competency.** Parents were asked specifically about the situations in which they felt most and least competent as a parent. These codes were coded within the 'Family Concerns' category; feelings of competency comprised 5.6% of that category, while feeling incompetent made up 7.5% of the category. One-third of the reported feelings of incompetency

stemmed from a child (TD or with ASD) having an emotional outburst in public (33.3%), while 8.3% mentioned that sibling arguments were when they felt least on top of their parenting. Other concerns included co-parenting difficulties, advocating for their child, helping their child academically, and handling personal and parenting stress.

Parents cited a variety of times when they felt most competent, especially when their children were not having arguments, emotional outbursts, or academic difficulties. Nearly a quarter of codes (22.2%) reported that parents felt most competent before the start of the day, or “when [my kids] go to bed at night!” Having fun as a family (22.2%), meeting a therapy goal (11.1%), or getting a compliment on a child’s behavior (11.1%) were also important to parents.

**Parent vs. child reports.** Parents discussed behavioral rigidity (4.69% of all codes) almost twice as often as their TD children (2.76%). Emotionally, the most common words used by parents were ‘challenging’ and ‘stressful,’ followed by ‘conflicted,’ ‘grateful,’ ‘resilient,’ ‘sad,’ and ‘tired.’ Parents additionally described the perspective their experience had given them the importance of having a sense of humor and the unpredictability of life with a child with ASD. TD siblings primarily used the word ‘annoying’ to describe their siblings with ASD (11.42%), but also used the words ‘challenging,’ ‘conflicted,’ and ‘stressful.’ TD siblings described instances of sibling discord (5.16%) much more often than their parents did (1.47%), although this could be related to any of their siblings, not just their sibling with ASD. They also reported feeling more responsible (3.87%) and protective (1.84%) than their parents reported for them (1.75% and 0.91%, respectively). Jealousy was not a commonly discussed emotion by either parents or TD siblings. However, more feelings of being left out were endorsed by TD children (2.39%) than their parents reported for them (0.70%).

Although TD siblings used fewer positive adjectives than their parents did to describe their sibling with ASD, TD siblings were able to discuss their sibling with ASD's positive traits when asked about them specifically (e.g., "What is your favorite thing about your siblings with ASD?"). Although both parents and TD siblings were asked to report on their child/sibling with ASD's strengths, child participants did so (6.26%) nearly twice as often as their parents (3.78%). Both parents and TD siblings discussed mutual care and love within their families.

TD siblings discussed a variety of concerns that affect many families, such as having privacy, doing chores, house rules, traveling, helping each other when hurt, arguing, and losing each other's belongings. These normative sibling concerns constituted 10.87% of all TD sibling codes. Parents also shared a number of 'typical' parenting concerns (2.45%); these included discipline, play dates, extracurricular activities, self-care skills, health issues, balance, and weekend outings. Parents reflected about their child's initial diagnosis, their own and others' knowledge of ASD, and planning for the future (ASD Process codes; 12.74%) much more frequently than their TD children did (6.81%). Parents also discussed helpful behavioral strategies slightly more than their TD children; however, it was notable that many children had a basic awareness of their sibling with ASD's therapies or calming techniques (5.53% combined).

**ASD severity.** Families were compared based on their ASD child's severity on the SRS. Eleven of 17 families (64.7%) had children with ASD who met the clinical cut-off for "severe symptoms of ASD." These parents spoke more frequently about emotional meltdowns (4.54% vs. 1.54%), behavioral rigidity (4.54% vs. 3.74%), and sibling discord (2.74% vs. 0.88%). Higher levels of being in crisis (1.01% vs. 0.44%) and the family missing out on social opportunities (1.73% vs. 0.88%) were also reported. Parents of children whom they rated as having more severe ASD symptoms also talked more extensively about coping (2.31% vs.

1.32%). However, they spoke less about division of labor within the home (1.66% vs. 3.52%) and more about respite care (1.15% vs. 0%). Siblings of children with ‘severe’ ASD were described as responsible more often (2.67% vs. 1.54%).

**Maternal work status.** Ten of 17 parents (58.8%) worked outside the home, although information on part- versus full-time status was not collected. Families with working mothers spoke of meltdowns more often (5.56% vs. 2.58%), but also discussed coping more frequently (3.44% vs. 1.10%). Working mothers spoke about division of labor (2.52% vs. 1.84%) and respite care (1.19% vs. 0.64%) more often, but spoke about their own hobbies (0.53% vs. 0.46%) and social support (2.38% vs. 2.30%) with the same frequency as stay-at-home-mothers. Stress was also reported roughly equally between both groups (4.42% [stay-at-home-mothers] vs. 3.84% [working mothers]). Working mothers discussed more instances of their child with ASD being unpredictable (1.59% vs. 0.28%). Stay-at-home-mothers, and their TD children, spoke about sibling discord more often (2.94%) than families with a working mother (1.32%). Families with a working mother spoke more often about the TD child taking on responsibility in the household (3.58% vs. 1.56%).

**Sibling support group access.** Seven out of 17 (41.2%) families had a TD child who had accessed a sibling support group or workshop, either in the past, currently, or on a waitlist. Families who had support group access reported more meltdowns in the child with ASD (5.95% vs. 3.83%) and slightly fewer strengths in the child with ASD (5.24% vs. 6.64%). Families who had not accessed a support group for their TD child discussed using social support as a coping tool more (3.83% vs. 2.41%), but also had nearly double the number of statements regarding challenging behaviors in the child with ASD (9.73% vs. 5.10%). Sibling bonding, sibling discord, and the family missing out on social opportunities were relatively similar between

groups. Descriptions of families ‘in crisis’ (e.g., having a child with ASD with significant amounts of aggression towards siblings), were tripled in the families who had not accessed a sibling support group (2.65% vs. 0.85%).

### **Discussion**

This study was guided, broadly, by the overarching question, “*What subsets of TD siblings are better-adjusted, and what factors contribute to that adjustment?*” This question persists across researchers in the field, and the search for answers has been painstaking and slow. The study aimed to explore academic outcomes of TD siblings of children with ASD and their relationship with a variety of family variables, including parent stress, daily hassles, flexibility, cohesion, and parenting self-competency. Positively, most TD child participants did not have significant academic problems compared to the norm, as found in report card grades as well as through teacher reports.

### **Quantitative Findings**

A particular emphasis of our hypotheses was that routine disruptions throughout the day might impact a TD child’s ability to perform well in school (Hypothesis 2). Daily routine, as measured on the PDHQ, was not significantly related to school outcomes, suggesting that our hypothesis was not supported. However, within our qualitative findings, parents noted that a child with ASD’s routine-oriented nature sometimes helped him/her complete tasks in a timely manner, which could generalize to the whole family. Qualitative reports about routine disruptions were only different between parents who reported high and low levels of daily hassles. This provides support for the use of the PDHQ as a measure of routine disruption. While only one PDHQ question is directly related to changing plans (“Having to change your plans because of unprecedented child needs”), it follows that having children who ‘are hard to

manage in public,' 'struggle with you over bed-time,' and 'are constantly underfoot' would make it difficult to stick to a schedule.

We had hypothesized that parents with greater stress would also report more daily hassles (Hypothesis 3). This was not supported by our results, and indeed was correlated in the opposite direction of what was predicted (although with a small effect size). Higher parenting stress and more challenging child behaviors were related to lower report card grades for the TD child, as predicted, but were also related to fewer problems within the classroom. It is possible that parents who are more overwhelmed by their parenting duties are less able to monitor their TD child's homework and test preparation, but that their child still behaves appropriately in school.

In a trend approaching significance, parents who described themselves as more efficacious parents were less distressed by parenting challenges. This finding suggests that parents who feel confident and well-equipped to handle the nuances of parenting may be buffered against these stressors. Parenting efficacy and overall self-competency also approached significance in regards to classroom behavior and academic performance, although not report card grades.

Results of the current study should be interpreted cautiously, due to low power. Although many correlations were found to be non-significant, it is possible that actual relationships exist which would not be detected because of the small sample size. In these cases, it is especially important to consider effect sizes. A number of our findings, despite not reaching significance, had moderate effect sizes, suggesting clinical significance, if not statistical significance. For example, the relationships between parenting self-competency, academic performance, and school problems may have reached significance with a larger sample size. This also applies to the potential relationship between parenting efficacy and parenting-related

distress. However, our findings do appear to support Mates' (1990) findings that TD siblings of children with ASD are, overall, functioning well within the classroom. This is especially seen in comparisons to normative scores on the academic measures.

### **Qualitative Findings**

Emotionally-based codes were the most frequently referenced, across parents and TD siblings. Sibling codes were frequently negative, such as describing their sibling with ASD as annoying, and discussing sibling discord more than bonding moments. However, without a comparison group, it is difficult to know if these codes are unusual. Rather, many siblings did discuss 'typical sibling concerns,' suggesting that autism is a minor piece of their family identity. Common ASD-related behaviors that did emerge from codes across reporters included emotional outbursts and behavioral rigidities. These may have a particularly negative impact on sibling relationships and family harmony. Parents felt especially incompetent in the face of public meltdowns or sibling arguments. In therapy, clinicians could discuss the impact of stigma on the family, and help provide parents with ways to handle other people's comments, which could improve their own parenting confidence.

TD siblings and their parents also discussed weaknesses of the TD child, such as attentional problems or not doing their chores well. Several parents noted that their child with ASD was not currently their 'most troublesome' child. As such, clinicians who work with parents in a family therapy setting should not assume that the child with ASD is the source of the family's stress. Treatment of or support for the TD child's difficulties should take precedence over autism-related support groups; in other words, support should be provided to the TD sibling, but having a sibling with ASD should not automatically indicate that the support group needs to be autism-related.

Parents and siblings both expressed disappointment in the family missing out on social opportunities. For TD siblings who raise these issues, it may be helpful for parents to seek out one-on-one time that allows the sibling to feel special. Additionally, families could attend autism-friendly events in the community together, or seek respite care when they need a break from parenting duties.

It is interesting to examine our results in the context of our reporters, which is a developing area in the family and sibling adjustment field. Previous research suggests that in siblings of children with chronic illnesses, reports from the parent and TD sibling about the TD sibling's quality of life (QOL) do not always match. A review of nine studies demonstrated that parents often rated the well sibling's QOL better than the well sibling rated his/her own QOL (Limbers & Skipper, 2014). The authors suggest that this could be due to actual differences in perception, or to the fact that parents must pay more attention to the ill child. In the current study, parents did not complete quantitative measures about their TD child's well-being. However, when comparing parent and TD child responses to the same qualitative questions, dyads appeared in agreement on issues that were most important to them (i.e., most frequently coded). For example, when talking about themselves, TD children talked most about feeling responsible for their sibling with ASD, or about their own difficulties. Parent answers also reflected these themes, as well as additional themes of their TD child being disappointed, feeling jealous, and acting protectively. Parents may be overly sensitive to their TD child's needs, even to the extent of mentioning problems that most TD children did not perceive or actually have.

Families of children with more severe symptoms of ASD reported more meltdowns in their child with ASD, more social isolation due to these behaviors, and a greater need for coping, especially respite care. These TD siblings were also described as "responsible" more than TD

siblings of children with less severe symptoms. Families who were “in crisis” were much less likely to have accessed a sibling support group; treatment for their child with ASD likely takes precedence. However, these siblings are likely those who could benefit most from a support group, and may represent a subset of TD siblings who are more at-risk for adjustment difficulties. These findings are supported by results from comparisons of “high stress” and “low stress” families based on PSI-SF scores. Parents who reported being less stressed spoke more often about less severe parenting challenges, such as IEPs and dating problems, as compared to parents and siblings who discussed instances of physical aggression or intense sibling rivalries. Parents who reported fewer daily hassles on the PDHQ were more likely to use their sense of humor as a coping tool, as compared to parents who reported high levels of daily hassles.

### **Theoretical and Clinical Implications**

A framework based on the concepts of resilience and traumatic growth (Cridland et al., 2014) may best capture the current findings on the daily ‘hassles and uplifts’ (Giallo & Gavidia-Payne, 2006) of parenting and being a sibling to a child with ASD. Findings from the trauma, acute stress, and bereavement literatures may be applied to the process families go through during and after receiving an ASD diagnosis. Eleven percent of all codes emerged as related to the ASD diagnosis and a family’s processing of related emotions. Predictability and a sense of control are helpful to families who have gone through traumatic events; similarly, this framework may be helpful to parents as they accept the diagnosis and integrate its meaning into their daily lives. Clinicians, especially those providing an ASD diagnosis, should bear in mind the elements of grief that a family may experience.

TD siblings of children with more severe ASD symptoms, especially externalizing behaviors, should be carefully screened in regard to their adjustment to determine possible

support needs. This finding is supported by prior research; Sikora et al. (2013) found poorer family functioning in families whose child with ASD had higher levels of externalizing behaviors, but not in those with higher levels of internalizing behaviors.

Additionally, more diverse coping tools should be explored with families, such as helping families make meaning out of their child's ASD diagnosis and use humor to cope with challenges. Working mothers, parents of children with more severe ASD, and parents who reported higher daily hassles also discussed respite care more often; these families may particularly benefit from taking a break from their children to engage in self-care.

**Clinical meaningfulness.** Given the intentional small-sample design of this study, it is important to couch our findings within the context of clinical meaningfulness. Although definitions vary, clinical significance can be examined as a construct's impact on an individual, or on the population (Lydick & Epstein, 1993). Effect size is a common tool to assess the magnitude of change, and has been used to interpret our quantitative findings. Measuring impact on individuals is less precise, and definitions on how to do so vary; Jaeschke, Singer, and Guyatt (1989) suggest that clinical significance in a variable balances both the benefits and costs to a consumer, at the smallest level needed to observe a change.

In studying siblings of children with ASD, clinical meaningfulness could be considered the point at which 1) a factor (e.g., academic, psychosocial, behavioral, emotional) has become troublesome to the TD sibling or parent, *and* 2) intervention would be maximally beneficial, and costs or risk to the family would be minimized. As the majority of TD siblings sampled are not experiencing academic problems, our findings were not clinically meaningful. Future analyses will further examine TD siblings on a case-by-case basis, with particular attention paid to those who *did* fall below clinical cut-offs on academic measures. Quantitative and qualitative data will

be integrated in these analyses to determine potential risk factors that set these children apart from those who are more successful in the school setting.

### **Limitations and Future Research**

**Demographics.** When considering the limitations of this study, it is important to consider the demographic make-up of participants. Parents self-selected into the study and were generally highly educated and with a high socio-economic status (SES), suggesting that these parents may have been better able to attend to their children's interpersonal and psychological needs, as they were not preoccupied with providing for their children's more basic needs. This demographic of parents may also have more free time to complete research measures, and most parents had a spouse or partner. Some parents also discussed having additional caregivers, such as a nanny or babysitter, in the qualitative data; lower SES families may not have the financial resources for outside help. While state-funded opportunities may be available to the lowest-SES families (e.g., transportation to appointments subsidized by insurance), middle class families may have the fewest resources (i.e., the 'doughnut hole' in healthcare; Rosenthal [2004], Shrank & Choudhry [2011]). More variability in SES would have shed light on the relationship between income, parenting stress, and family functioning in this sample.

Additionally, our sample was heavily Caucasian, which does not reflect the racial diversity of children with ASD (although gender and age at diagnosis demographics were more similar to the population) and impairs the generalizability of the study. Minority families, families with lower SES, and families with lower levels of education level are generally less likely to participate in research (Perez et al., 2007; Henderson et al., 2008). Barrera, Chung, and Fleming (2004) found that families lost to attrition at follow-up were more likely to have a lower SES, which was attributed to these families feeling more overwhelmed by daily life demands. If

more of these families had been included in this study, we expect that there would have been greater variance on the PDHQ.

Families with more pressing needs, such as those who were dealing with school suspensions, inpatient hospitalizations, or medication management difficulties, also were not well-represented in this study. By broadening the study's scope beyond a mother's perspective (e.g., to fathers, extended family members, in-home therapists), we may gain new insights. It is vital that we find ways to locate more diverse families and incorporate their experiences into research, as suggested by previous research (e.g., (Wallander & Varni, 1998; Hodapp, Glidden, & Kaiser, 2005). Additional supports and funding may be necessary to attract and keep socially disadvantaged and minority families as research participants (Hilton et al., 2010). For example, research teams may need to conduct home visits or provide more substantial compensation to make the research time worthwhile for parents.

Mothers in the current study were comfortable having a detailed, emotional discussion about their child's diagnosis and behaviors with the researcher, and allowed their TD child to have a similar conversation with an interviewer. In contrast, there may be untapped families where the ASD diagnosis is not well accepted and is not discussed within the family or to others outside the family unit. These families are unlikely to step forward to discuss their experiences, especially if they feel distrust or animosity to healthcare providers, and researchers as an extension. Families who do not agree with their child's ASD diagnosis also are not likely to join a study about ASD, or to discuss ASD with their TD children. Additionally, though all parents were asked to confirm that their TD child knew about their sibling's ASD diagnosis, the level to which ASD was discussed commonly and considered part of the family varied greatly and was

not measured quantitatively. All families had come to terms with their child's diagnosis; even though some families had been diagnosed within the past year.

**Methodological limitations.** One drawback to this study involves the use of report card data, especially the transformation of categorical grades (e.g., "Needs Improvement," "Satisfactory," "Above Expectations") into numerical data. This is particularly salient for children in or below 3<sup>rd</sup> grade, most of whom receive these categorical grades, which are often more based on behavior and effort. Additionally, although a "C" grade is still considered to be average, it is not statistically the average grade (i.e., many more children receive A's and B's than D's and F's). There were also differences by grade, state, and school on the types of classes children took; for example, sometimes Reading and Writing skills received separate grades, as compared to one Language Arts grade. Finally, only grade data from the most recent marking period were used, which may or may not have been representative of the child's actual school performance throughout the year. These limitations make the report card data more difficult to generalize as compared to the standardized scores from the BASC-2 and APRS.

Future studies should consider using online methods of data collection, which would have been more convenient for many families and may have decreased our amount of missing data. However, copyright laws make online completion of some measures difficult, and it would be hard to follow-up on missing data if questionnaires were completed anonymously. Studies that will move the field forward will need to include increased depth (i.e., larger batteries) and/or breadth (i.e., longitudinal designs). More data, and in turn, more sophisticated analyses, will help clarify the needs of this population as a whole, especially any mediators or moderators of well-adjustment.

In the future, it will be important to examine sibling reports of their own well-being, in addition to parent reports. Additionally, the youngest child participants in this study gave interviews that were noticeably shorter and less fluent than older children. Future studies may find interviews with older elementary schoolers or middle schoolers to be more productive and insightful.

## **Conclusions**

In the field, there continues to be a lack of generalizable conclusions as to the impact of a sibling with ASD on a TD child; this is also seen in the literature of TD children with siblings with chronic illnesses other than ASD (e.g., McClellan & Cohen, 2007). TD siblings of children with various disabilities are usually able to function well across the lifespan (Sanders & Morgan, 1997; Meyer & Vadasy, 2008), suggesting a form of resilience (Grant, Ramcharan, & Flynn, 2007; Bellin & Kovacs, 2006). Having a sibling with special needs may serve as a type of inoculation effect, whereby the TD sibling receives a boost in self-esteem and feelings of competence as a result of defending, teaching, and interacting with their sibling with special needs (Grant et al., 2007). As studies with stronger methodologies than those used previously are published, we will better be able to identify which TD siblings, if any, are most at-risk for adjustment difficulties. In addition, we will be more informed as a field as to which areas of functioning are most important for continued study.

Despite the power limitations of this study, TD siblings were found to be performing well in the classroom. Daily hassles have been found to be a good predictor of overall parenting stress and future parent-child relationships (Crnic & Booth, 1991), and should be further explored within the ASD parenting field. Additionally, parenting competency was potentially related to decreased parenting stress and better academic performance in TD siblings, suggesting

that parent confidence could be a target of intervention. A number of methodological improvements may contribute to more satisfying answers within the sibling adjustment literature. In the meantime, clinicians should work to support parents and siblings of children with more severe ASD and more externalizing behaviors, as these families may be particularly in need of additional resources.

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Table 1  
*Demographic Characteristics of Sample*

Mother and child characteristics	Total Sample ( <i>n</i> = 39)
Child with ASD age in years (SD)	11.74 (3.36)
Child with ASD gender (male)	31 (79.49%)
TD child age in years (SD)	10.31 (2.68)
TD child gender (male)	24 (61.54%)
Mother ethnicity	
Caucasian	36 (92.31%)
African American	2 (5.13%)
Other	1 (2.56%)
Annual income	
Less than \$20,000	1 (2.56%)
\$20,000 - \$39,000	3 (7.69%)
\$40,000 - \$59,000	7 (17.95%)
\$60,000 - \$79,000	7 (17.95%)
\$80,000 - \$99,000	3 (7.69%)
\$100,000 or greater	17 (43.59%)
Not reported	1 (2.56%)
Mother's highest level of education	
High school degree	1 (2.56%)
Some college education	7 (17.95%)
College degree	16 (41.03%)
Some graduate education	4 (10.26%)
Graduate degree	11 (28.21%)
Mother's marital status	
Married	35 (89.74%)
Separated/Divorced	2 (5.13%)
Never Married	1 (2.56%)
Did not report	1 (2.56%)
Maternal work status	
Works outside the home	26 (66.67%)
Stay-at-home-mother	12 (30.77%)
Did not report	1 (2.56%)

Table 2  
*Means and Standard Deviations of Main Variables*

Measure	<i>n</i>	Mean (SD)
Total PDHQ score	38	22.74 (10.60)
PDHQ Challenging Behavior	38	8.79 (4.06)
PDHQ Parenting Tasks	38	9.03 (4.10)
FACES-IV Family Communication	39	63.74 (24.13)
FACES-IV Family Satisfaction	39	45.08 (29.56)
FACES-IV Balanced Cohesion	39	73.77 (9.40)
FACES-IV Balanced Flexibility	39	60.36 (12.50)
Total PSOC	39	70.90 (14.34)
PSOC Satisfaction	39	37.85 (7.93)
PSOC Efficacy	39	32.79 (8.18)
Total PSI-SF	39	111.03 (28.37)
PSI Parental Distress	39	38.97 (10.97)
PSI Parent-Child Dysfunctional	39	
Interaction		38.59 (12.10)
PSI Difficult Child	39	33.23 (10.39)
Average report card score	35	1.56 (0.58)
BASC-2 Learning Problems	25	46.24 (6.99)
BASC-2 School Problems	25	47.04 (8.28)
APRS	25	77.12 (11.40)

Table 3  
*Correlations Between the PDHQ and School Measures (Hypothesis 2)*

	1.	2.	3.	4.	5.	6.	7.
1. Overall PDHQ Score	---						
2. Challenging Behavior	.94***	---					
3. Parenting Tasks	.91***	.75***	---				
4. BASC-2 School Problems composite	-.11	-.08	-.06	---			
5. BASC-2 Learning Problems	-.12	-.11	-.03	.91***	---		
6. APRS	.11	.06	.09	-.93***	-.85***	---	
7. Report card grades	-.20	-.18	-.17	.34*	.25	.25	---

*Note.* \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ .

Table 4  
*Correlations Between the PDHQ and PSI-SF (Hypothesis 3)*

	1.	2.	3.	4.	5.	6.	7.
1. Overall PDHQ Score	---						
2. Challenging Behavior	.94***	---					
3. Parenting Tasks	.91***	.75***	---				
4. PSI-SF Total Stress Score	-.02	.01	.00	---			
5. Difficult Child Score	-.05	-.06	-.02	.81***	---		
6. Parent-Child Dysfunctional Interaction Score	.09	.08	.14	.90***	.59***	---	
7. Parental Distress Score	-.06	.04	-.10	.86***	.52***	.70***	---

Note. \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ .

Table 5  
*Correlations Between the PSI-SF and School Measures (Hypothesis 3)*

	1.	2.	3.	4.	5.	6.	7.	8.
1. PSI-SF Total Stress Score	---							
2. Difficult Child Score	.81***	---						
3. Parent-Child Dysfunctional Interaction Score	.90***	.58***	---					
4. Parental Distress Score	.86***	.52***	.70***	---				
5. BASC-2 School Problems composite	-.29	-.35*	-.16	-.27	---			
6. BASC-2 Learning Problems	-.24	-.22	-.17	-.22	.91***	---		
7. APRS	.20	.23	.14	.17	-.93***	-.85***	---	
8. Report card grades	-.31*	-.40**	-.25	-.14	.34*	.25	-.25	---

Note. \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ .

Table 6  
*Correlations Between FACES-IV, PSOC, and School Measures (Hypothesis 4)*

	1.	2.	3.	4.	5.	6.	7.	8.	9.
1. FACES-IV Family Flexibility Scale	---								
2. FACES-IV Family Cohesion Scale	.26	---							
3. PSOC total score	.41	.55*	---						
4. PSOC Parenting Satisfaction	.34	.40	.88***	---					
5. PSOC Parenting Efficacy	.44	.63	.91***	.62***	---				
6. BASC-2 School Problems	.20	.12	.33	.17	.33	---			
7. BASC-2 Learning Problems	-.01	-.11	.21	.09	.24	.91***	---		
8. APRS	-.22	-.16	-.29	-.17	-.28	-.93***	-.85***	---	
9. Report card grades	-.01	.21	-.11	-.07	-.12	.34*	.25	-.25	---

*Note.* \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ .

Table 7  
*Correlations Between PSI-SF, FACES-IV, and PSOC (Hypothesis 4)*

	1.	2.	3.	4.	5.	6.	7.	8.	9.
1. PSI-SF Total Stress Score	---								
2. Difficult Child Score	.81***	---							
3. Parent-Child Dysfunctional Interaction Score	.90***	.58***	---						
4. Parental Distress Score	.86***	.52***	.70***	---					
5. FACES-IV Family Flexibility Scale	.22	.30*	.21	.08	---				
6. FACES-IV Family Cohesion Scale	.10	.11	.09	.06	.74**	---			
7. PSOC total score	-.11	-.04	-.15	-.12	.41	.55*	---		
8. PSOC Parenting Satisfaction	.00	.05	-.11	.04	.34	.40	.88***	---	
9. PSOC Parenting Efficacy	-.18	-.10	-.17	-.22	.44	.63	.91***	.62***	--

*Note.* \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ .

Table 8  
*Main Codes from Qualitative Data*

Codes	Sample Codes	Overall Codes	Parent Codes	TD Sibling Codes
1. Emotions	Conflicted, sad, challenging, caring, scared	28.04%	25.75%	34.07%
2. Family Concerns	Family in crisis, family missing out on social opportunities, sibling bond, sibling discord, typical parenting concerns	23.17%	22.53%	24.86%
3. Child with ASD	Comorbidity, immaturity, behavioral rigidity, meltdowns, sensory sensitivities	19.12%	19.94%	16.94%
4. "The ASD Process"	Differential diagnosis, future planning, 'passing' as TD, behavioral strategies	11.11%	12.74%	6.81%
5. The TD Child	Protective, responsible, confident, disappointed, embarrassed	10.75%	9.59%	13.81%
6. Coping	Social support, respite, division of labor, parent hobbies	7.81%	9.45%	3.50%

## Appendix A: Parent Topic Guide

*Please introduce yourself and tell us a little bit about your children.*

1. One reason you were asked to join our group today is that you have a child with autism or an Autism Spectrum Disorder. What is it like parenting a child who has autism?

*Today we will be talking about family routines, especially getting your kids ready for school in the morning, helping them afterschool, and their time before going to bed.*

1. Tell us about one of your ordinary routines.
2. What disrupts your family routines, and why do they get disrupted?
3. Does having a child with autism affect your family routines? How so?
4. How do you think your other kids are affected by having a sibling with autism?
5. Regarding all of your kids, when do you feel most competent as a mom? Least competent?
6. How do you cope with your parenting stress? Do you think you cope better or worse compared to moms who don't have a child on the spectrum?

*Thank you for chatting with us today. Before we leave, I would like everyone to share their favorite thing about their children.*

7. What is your favorite thing about your children?

## Appendix B: Child Topic Guide

*Please introduce yourself and tell us one thing about yourself and how old you are.*

1. One reason you were asked to join our group today is that you have a brother or sister with autism. What is it like living with someone who has autism?

*Today we are going to be talking about routines. These are things that you do everyday, like eating breakfast, brushing your teeth, and getting dressed before school. You also might have a routine of things that you do everyday when you get home from school, or at bedtime.*

2. Tell us about one of your routines that you do on a regular, ordinary day.

3. Do your sibling with autism do anything that makes your routines easier or harder than usual?

*Prompt:* How about in the morning/after school/in the evening?

4. Does your mom or dad do anything to help you if there is a problem with one of your routines?

5. Do you think your family is more stressed out than other families?

*Thank you for chatting with us today. Before we leave, I would like everyone to share their favorite thing about their sibling with autism.*

6. What is your favorite thing about your brother/sister with autism?