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**Getting to Know Siblings of Youth with ASD: A Model of Risk and Resilience**

A Dissertation Presented

by

Megan E. Tudor

to

The Graduate School

in Partial Fulfillment of the

Requirements

for the Degree of

**Doctor of Philosophy**

in

**Clinical Psychology**

Stony Brook University

**August 2015**

**Stony Brook University**

The Graduate School

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Abstract of the Dissertation

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Therapy and support programs for siblings of youth with autism spectrum disorders (ASD) are on the rise, indicating a growing demand for specialized sibling services. However, current research findings remain unclear as to what exactly the needs of siblings might be and why those needs might be present. The current dissertation aims to identify what particular risk factors may lead to problematic outcomes that warrant clinical services (e.g., emotional, behavioral, or social problems), while concurrently, examining resilience factors that may lead to positive functioning in these areas. A comprehensive family systems model was created drawing from literature related to relevant predictors for typically developing (TD) youth, including maternal depression and sibling relationship quality. The model also reflected literature regarding family systems affected by ASD, such parental stress and severity of ASD symptoms. A total of 239 mothers of one youth with autism (simplex families) and at least one other youth (ages 6-17) completed online standardized measures of various familial factors and TD youth outcomes. Overall, only a subset of siblings was identified as being in the clinical range in regards to emotional, behavioral, or social functioning (6%-23%). Based on the data, a good-fitting path analysis model including specific pathways that led to both problematic and adaptive outcomes for siblings was created. Both maternal depression and sibling relationship were identified as key components in predicting siblings' functioning. Findings are discussed in terms of moving towards an evidence base for intervention and support for this unique population of children, as well as a more systematic manner of assessing which siblings may be at risk or, conversely, resilient within their family system.

## **Dedication**

For original advisor, Dr. Edward “Ted” Carr (1948-2009). All of my work continues to be inspired by his dedication to improving the lives of children and constant questioning of the status quo. Thank you, Ted.



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## **List of Abbreviations**

ASD – autism spectrum disorder

CFI – comparative fit index

DD – developmental disability

RMSEA – root square mean error of approximation

TD – typically developing

## Acknowledgments

I would like to thank Drs. Allen Butt, Sanders McDougall, Robert Cupp, and, especially, Charles “Chuck” Hoffman, for encouraging me to continue to do research, teaching, and clinical work beyond my college years.

Thank you to Dr. K. Daniel O’Leary for graciously welcoming me into his lab and provide me with expert guidance throughout graduate school. I owe much gratitude to Dr. Matthew Lerner who has provided immeasurable advisorship during my final years of doctoral study – I have succeeded far beyond what I ever thought capable of myself because of his insights and encouragement. After Ted’s untimely passing, I nearly decided to forego a doctoral degree – both of my advisors, Drs. O’Leary and Lerner, make me grateful that I persevered.

The completion of my dissertation would not have been possible without the help of my extraordinary Research Assistant, James Rankin. I owe him my first-born child but stickers and candy will have to suffice. I am also thankful to the other members of Dr. Lerner’s lab – Patricia “Trish” Medina, Sruthi Jonnalagadda, Christine Spaulding, Vladimir Piersaint, Lindsay Bungert, Bianca Marro, Dhara Doshi, Andrea “Andy” Charidemou, and Sora Chenet- who helped with various aspects of the study while I was living across the country. Additionally, the ongoing support of Dr. Steve Edelson and the Autism Research Institute also truly made this work possible – their belief in the importance of this work will always be appreciated.

Thank you to my wonderful Carr labmates that have taught me so much (both professionally and personally) over the years: Drs. Lauren Moskowitz and Caitlin Walsh. My labmate Jessica Salwen also deserves especial thanks for her support as a labmate, cohort-mate, friend, and stats mentor. Two Stony Brook alum, Drs. Jeffrey Foy and Emile Mulder, also provided me with a tremendous amount of meaningful professional insight, especially early in graduate study.

The love and support of several other very important people made this dissertation and the completion of my doctoral degree possible: My mother Nancy “Mim” Tudor for instilling a love of nurturing children and a respect for all other humans within me from a very young age – much of my work is inspired by these philosophies. Thank you to my fiancé, Matthew Heywood, for making the final path to this milestone as peaceful as possible. He deserves several medals for this accomplishment. My best friend, Thang “Flea” Le for making the world a better place and, therefore, making me strive to also make the world a better place through my research. I look forward to congratulating him when he becomes “Dr. Flea” in the near future.

## **Getting to Know Siblings of Youth with ASD:**

### **A Model of Risk and Resilience**

#### **Background and Significance**

The prevalence of Autism Spectrum Disorder (ASD) has been on the rise over recent decades (e.g., Baron-Cohen et al., 2009, Hertz-Picciotto & Delwiche, 2009), with recent Center for Disease Control (CDC) estimates indicating that approximately 1% of the child population may currently meet criteria for an ASD (CDC, 2012). Consequently, the number of brothers and sisters of youth with ASD is also on the rise, indicating an extant need for research into factors contributing to adjustment of these siblings. While research on family members of youth with ASD has recently flourished, it has primarily focused on parental adjustment (e.g., Yirmiya & Shaked, 2005). To a lesser degree, inquiry about siblings of youth with ASD has gained attention (e.g., Orsmond & Seltzer, 2007); however, at present, little is yet known about the potentially distinctive psychological or behavioral well-being of this special population.

Traditionally, early ASD research limited the inclusion of family members, such as parents and siblings, to “using” them as behavior modification trainees that could serve as agents of change for affected children (e.g., Lovaas, 1978). Today, siblings continue to be largely represented as agents of change in ASD-related research, where results often show siblings as useful helpers in promoting behavior change for their brother or sister with ASD (for a review see Ferraioli, Hansford, & Harris, 2011). The study of the unique personal functioning and psychological needs of siblings of youth with ASD, however, demonstrates much less consistency and is characterized by mixed results (see Orsmond & Seltzer, 2007; Meadan, Stoner, & Angell, 2010; Smith & Elder, 2010).

Currently, research suggests that having a brother or sister with ASD puts youth at risk for higher rates of various overall adjustment problems (Bagenholm & Gillberg, 1991; Rodrigue, Geffken, & Morgan, 1993), such as internalizing problems (Gold, 1993; Orsmond & Seltzer, 2009), externalizing problems (Ross & Cuskelly, 2006), and social problems (Hastings, 2003). However, simultaneously, extant research suggests that the majority of these youth are functioning well, with rates of psychological disorders that mirror the general population of children (Howlin, 1988; Kaminsky & Dewey, 2002;

Mates, 1990; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004; Verte, Roeyers, & Buysse, 2003). Together, the overall potential for these youth to be at-risk for psychological, behavioral, or social problems remains unclear. This state of the sibling literature contrasts with a more consistent literature regarding parents of youth with ASD, with various studies providing convergent evidence that these parents are more likely to experience psychological distress (e.g., Piven, Palmer, Jacobi, Childress, & Arndt, 1997; Singer, 2006; Yirmiya & Shaked, 2005). Many potential reasons for these marked inconsistencies in the sibling literature exist (e.g., negative bias, a range of different, often incommensurate, measures and outcomes of interest), which have led to calls for changes in the approach to this area of inquiry (Cuskelly, 1999; Hodapp, Glidden, & Kaiser, 2005; Orsmond & Seltzer, 2007; Stoneman, 2005).

One potential explanation for mixed results regarding sibling outcomes is a bias towards one-sided research questions that consider only negative outcomes for siblings, thereby assuming that being a sibling of a youth with ASD is an inherently negative experience (Stoneman, 2005). Therefore, existing studies may be limited in variability of research questions and the field, as a whole, may be limited in its understanding of sibling needs. Similarly, most sibling studies have narrowly focused on the sole factor of sibling status as a risk factor, without consideration of other factors known to be related to sibling adjustment (Orsmond & Seltzer, 2007; Tudor & Lerner, in preparation). Additional facets of sibling outcomes, for example, family systemic factors which typically impact youth psychosocial functioning, may be particularly affected by the presence of a sibling with ASD. For example, parental functioning (Benson & Karlof, 2008; Giallo & Gavidia-Payne, 2006; Meyer, Ingersoll, & Hambrick, 2011; Quintero & McIntyre, 2010) or socioeconomic status (Macks & Reeve, 2007) may serve as important predictors of siblings' adjustment. Much like all study of youth functioning, multiple factors are more likely to be at play rather a singular predictive factor (e.g., having a sibling with ASD). Furthermore, the outcomes that have been examined for siblings have been largely non-specific, with various definitions of youth "adjustment" (Cuskelly, 1999). This broad and variable category appears to have led to inconsistent research questions, measurements, and outcomes of interest regarding these siblings (Hodapp, Glidden, & Kaiser, 2005).

Overall, many queries about siblings of youth with ASD remain unanswered: are these youth, or at least some of these youth, at risk and, if so, why? What factors may increase risk or, conversely, promote resilience in these youngsters? These unanswered questions become increasingly urgent in light of a growing interest in sibling-focused clinical services, including intervention and support groups. Community-based sibling events, such as SibShops ([www.siblingsupport.org](http://www.siblingsupport.org)), and sibling-based advocacy agencies, such as The Sibling Leadership Network (e.g., [www.siblingleadership.org](http://www.siblingleadership.org)), are on the rise. An increasing number of clinics that serve individuals with ASD now seek to serve their siblings, as well. Indeed, a simple Google search of the terms “siblings”, “autism”, and “groups” yields hundreds of hits for sibling services provided throughout the United States and abroad. The popularity and growing number of these organizations suggest an unmet need for siblings of youth with ASD. However, it may be problematic that services for siblings may grow without a sound evidence-based background about which siblings are in need, what those particular needs are, and how they may best be met (Tudor & Lerner, 2015).

### **Creating a Model of Sibling Outcomes**

In order to better understand the population of siblings of youth with ASD, a model of particular risk and resilience factors that influence these youths’ psychological, behavioral, and social outcomes is warranted. In light of the burgeoning demand for services for these youth, this model is also quite necessary in order to better inform evidence-based practice. Additionally, given the history of mixed findings in this field, it is of great import that such a model approach queries about siblings in an evidence-based and objective manner, with careful consideration of appropriate outcomes and measurement thereof. Furthermore, in order to acquire the most meaningful and generalizable results, this model requires appropriate group comparisons and developmental considerations. The current study proposes such a model with these specific requirements in mind.

**Developmental considerations.** An effective family systemic model of sibling risk and resilience warrants considerations of various developmental stages of the siblings. Indeed, age and developmental factors are more generally an important consideration in predicting youths’ likelihood of developing different psychological or behavioral problems, with the

likelihood of externalizing problems manifesting in younger children (i.e. <12 years) and the presence of internalizing problems increasing with age (e.g., Twenge & Nolen-Hoeksema, 2002). For siblings of youth with ASD, additional considerations may be warranted. Siblings' knowledge of their brother or sister with ASD's condition, as well as concern for their affected sibling, appears to change over time, reflecting the transformation from concrete to abstract thinking (approximately age 5; Glasberg, 2000). As such, siblings may demonstrate differential understanding and, therefore, interactions with their sibling depending on their age. Furthermore, a recent study suggests that birth order may play a special role in understanding sibling behavior problems, with siblings being most likely to exhibit problem behavior if they have an older (rather than younger) brother or sister with ASD with problem behavior (Tomeny, Barry, & Bader, 2012).

As such, the current proposed model will be best initially examined within a specified range of ages in childhood and adolescence. Given the various clinical and social outcomes of interest warranted for this population of children (described further below in the "Outcomes" section), the examined sibling youth should be of the age wherein they have had regular contact and interaction with peers (Howes & Matheson, 1992), thereby allowing for adequate appraisal of social skills ability. These youth should also be able to exercise independence with most self-care tasks and activities (e.g., Eccles, 1999), allowing their mothers to properly report on their self-sufficiency. Also, previous observation by other adults besides parents (Achenbach, McConaughy, & Howell, 1987) will allow mothers to have a heightened sense of any atypical or problematic functioning, per others' report. With these factors considered, it is proposed that the ideal age range for studying these youth begins at the typically-accepted "school age" range and ends before burgeoning adulthood (and a level of child independence which might confound accurate parental measurement): ages 6 to 17 years. Further, these ages will serve to provide sufficient range and variability on all parent-report measures about children.

**Systemic approach.** Family systems theory posits that all members of a family act not only as individuals but also as an interconnected unit, with each family member playing an integral part in the functioning of the rest of the family (Bronfenbrenner, 1979). This ecological approach has proven efficacious in integrating biological, psychological, and social aspects of youth development in relation to a variety of psychological problems (e.g., Granic & Patterson, 2006). Bearing the

most relevance to the proposed model at hand, family systemic models have been implemented in studies of functioning and treatment response in youth with ASD (e.g., Robbins, Dunlap, & Pleinis, 2002) and their parents (e.g., Sivberg, 2002).

A systemic approach also appears ideal for examining the functioning of siblings of youth with ASD. Much like the individual youths with ASD, their mothers, and their fathers, siblings exist within a family context that is distinct from families that are not affected by ASD (to be described further in the “Maternal Depression” and “Sibling Relationships” sections of this monograph). Furthermore, the unique experiences of these families center around an actual member of the family system. Thus, it does not behoove this area of study to examine siblings as separate entities from their family system or to assume consistent family experiences across siblings (Stoneman, 2005). An in-depth family systemic model may better elucidate the various pathways to risk and resilience in these youth and, therefore, the proposed model was developed from a family systemic perspective.

**Group comparisons.** Studies of youth with ASD present with a variety of comparison groups based on contrasting symptomatology (e.g., Down Syndrome) or, most commonly, typically developing (TD) children (Seltzer, Abbeduto, Krauss, Greenberg, & Swe, 2004). Studies of siblings of youth with ASD have rarely included comparison groups but, when present, these groups have invariably been composed of other TD youth with TD siblings (e.g., Kaminsky & Dewey, 2002). Comparison to other TD youth provides an important contrast of family systems and, therefore, provides evidence as to which sibling outcomes, as hypothesized here, are uniquely predicted by being a sibling of a child with ASD.

To best understand the various family context variables that may evince an atypical experience for siblings of youth with ASD, literature will be presented here on the broader population of youth with developmental disabilities (DD). More prominently, research findings regarding families affected specifically by ASD will be presented as a comparison to unaffected families, thereby demonstrating the utility of this comparison when testing the proposed hypotheses presented here. Of note, while research on families affected by various DDs may broadly provide insight about families affected by ASD, it may not provide insight about features that may be unique or specific to families affected by ASD (as compared to other DDs).



A DD comparison group will not be recruited for the current study. This initial study will provide the most meaningful results based upon ASD group versus TD group comparison because 1) these groups are likely to yield a more stark contrast between model pathways and, therefore, provide the most informative results regarding unique risk and resilience for siblings of youth with ASD, and 2) family systems affected by ASD are consistently demonstrated as showing more specific familial risk factors (e.g., maternal stress, maternal depression) than other DD populations (e.g., Abbeduto et al., 2004). Based on the results of this initial investigation, further comparisons between specific DD groups may be warranted.

**Outcomes of interest.** Given the generally mixed and negatively biased outcomes of interest in sibling research (Stoneman, 2005), the current model will examine both psychopathological and social outcomes via standardized measurement. Psychopathological outcomes were chosen to reflect and provide clarity on a composite of outcomes that have been studied previously and, although findings have been mixed, have been evinced as potentially meaningful outcomes for siblings of youth with ASD (see Orsmond & Seltzer, 2007; Meadan, Stoner, & Angell, 2010; Smith & Elder, 2010). Furthermore, social outcomes are of especial significance to this population of siblings, given that social dysfunction is the accepted as the core of ASD symptomatology and impairment for individuals with ASD and, therefore, their family members (White, Keonig, & Scahill, 2007).

Psychopathological outcomes will be examined via a composite of observable behavioral indicators of both internalizing and externalizing symptoms. Additionally, social functioning will be measured via two constructs: actual social skills and functional social contact. Social skills will be measured as a child's ability to effectively interact and communicate with other peers and adults, while functional social contact will be measured by a child's number of friends, play dates, and appropriate play time behaviors. These constructs are described further in the "Measures" section below and, together, create a battery of outcomes that can reflect both potential risk and resilience in important domains of child functioning.

Resilient outcome profiles would consist of low externalizing and internalizing symptoms (i.e., within 1 – 2 SD of normed means), intact social skills abilities, and a high quality of play skills and social contacts. Conversely, at-risk outcomes may be characterized by higher levels of clinical symptoms, lower levels of social abilities, and few social contacts. These

outcomes are predicted differentially across pathways in the proposed model (described further in the “Hypotheses” sections below), given that siblings may show resilient outcomes in some categories and not others, based on their familial context. Of great import to the aims of the current model, these outcomes will be predicted based on the accumulation of findings on ASD family systems as compared to TD family systems, and will not be based on specific findings from previous sibling adjustment research, given the high variability in measurement and mixed findings that characterize this area of study findings (e.g., Cuskelly, 1999; Orsmond & Seltzer, 2007; Stoneman, 2005). The current study will aim to fulfill the suggestions of previous researchers over the past several decades: approach the topic of sibling outcome research in an objective and standardized manner, thereby increasing the chances of results that can be better clinically applied to sibling populations (Hodapp, Glidden, & Kaiser, 2005; Lobato, 1983).

**Theoretical grounding.** The proposed model intends to clarify and re-focus the sibling outcomes research and, therefore, provide information that is applicable to the current demand for clinical services for siblings. As such, the proposed model required a strong foundation in existing, relevant, and evidence-based systemic theoretical frameworks of clinical and social outcomes in TD youth (Kazdin, 2008). The proposed model will represent an integration of the theoretically supported research base on family systems, including TD youth and youth with ASD. Specifically, the existing models that were identified as being most pertinent to understanding risk and resilience for siblings of youth with ASD surround maternal depression (Goodman and Gotlib, 1999) and sibling relationships (Feinberg, Solmeyer, & McHale, 2012), which are described in detail in the following sections.

### **Maternal Depression**

A consistent literature has evinced maternal depression as a predictor of child psychopathology (Downey & Coyne, 1990; Goodman & Gotlib, 1999; Goodman et al., 2011). Approximately 30% of youth who have mothers with depression present with their own affective or behavioral disorder, which exceeds the overall disorder prevalence seen in youth with non-depressed mothers (e.g., Downey & Coyne, 1990; Klein, Lewinsohn, Seeley, & Rohde, 2001). Additionally, youth may be three times more likely remit from DSM-IV disorder diagnoses after their depressed mothers experience remission from

depression. (Weissman et al., 2006), indicating a temporal association and potential causal link between maternal depression and child psychopathology. Conversely, youth are likely to maintain their DSM-IV diagnoses or even show an increased symptom severity as their mothers continue to suffer from depression. In addition, an extensive related theoretical literature (e.g., Beck, 1999; Cummings & Davies, 1994), suggests maternal depression as not only an important predictor of psychopathology in youth, but also a potential cause of psychopathology in youth. While such a link is well-established, the mechanisms underlying how this transmission occurs is a point of ongoing debate, with evidence for both genetic and environmental contributions (e.g., Goodman, 2007).

Several models have examined pathways between maternal depression and youth outcomes with foci on particular potential mechanisms of transmission, such as depression-related marital functioning (e.g. Cummings et al., 2005) and depression-related interpersonal stress (e.g., Hammen, Shih, & Brennan, 2004). One seminal and comprehensive model (Goodman & Gotlib, 1999), suggests various pathways between maternal depression and child psychopathology, including relevant moderators that may make the risk for child psychopathology more or less likely. As seen in Figure 1, this model provides a framework wherein maternal depression does not have one direct effect on a child's psychological functioning but, rather, is part of a complex system wherein depression affects specific mechanisms and vulnerabilities that can lead to psychopathology in children. In the aforementioned alternate models, outcomes are largely based on one specific component of family functioning, which may lead to oversight of other crucial pathways to understanding outcomes in youth. Specifically, these models do not consider the complexities of biopsychosocial pathways known to contribute to psychopathology in family systems more generally (Elgar, McGrath, Waschbusch, Stewart, & Curtis, 2004; Goodman et al., 2011), and which may be especially vital in understanding differences in the context of family systems affected by ASD wherein many of these pathways may be influenced.

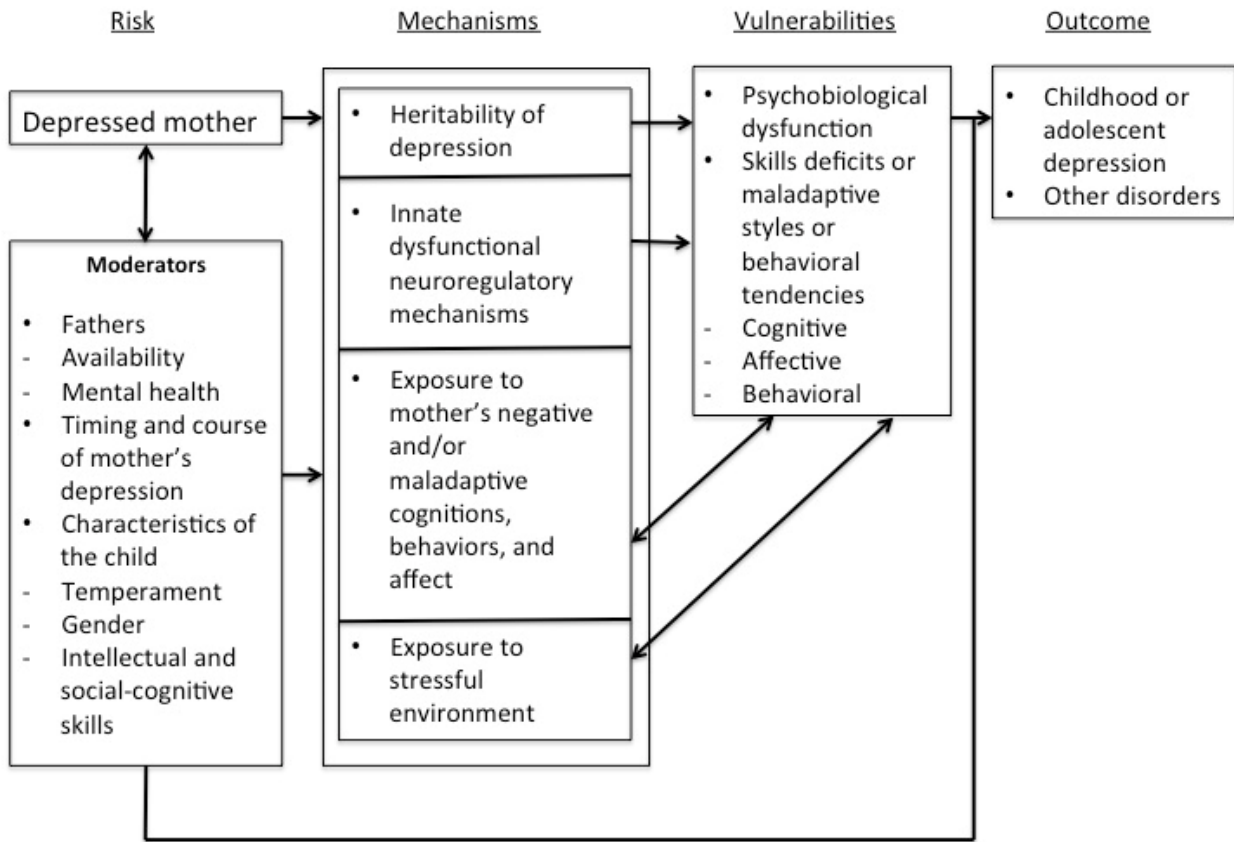


Figure 1. Integrative model of the transmission of risk to children of depressed mothers (Goodman & Gotlib, 1999).

Importantly, the model reflects the evidence that approximately 70% of youth with mothers with depression do not meet criteria for a DSM-IV diagnosis and, therefore, factors that promote resilience amongst certain youth must be considered. As such, this model is ideal for conceptualizing the various effects that maternal depression may have on TD developing youth.

**Mechanisms of transmission.** Goodman and Gotlib's (1999) model describes four different mechanisms of the transmission of maternal depression to psychopathology in youth. Firstly, maternal depression is presented as a highly heritable disorder amongst adult children (e.g., Weissman et al., 2006), while the heritability of depression during childhood may be less clear. While rates of depression and other psychopathology are higher for these children as compared to children with non-depressed mothers, a genetic predisposition alone does not adequately explain children's psychopathology (e.g., Rende, Plomin, Reiss, &

Hetherington, 1993). As such, dysfunctional neuroregulatory mechanisms are also considered, such as innate affective or behavioral disturbances caused by atypical fetal health as a result of the hormonal abnormalities. These abnormalities may include increased cortisol levels or restricted blood flow (e.g., Field, 1995; Bonari et al., 2004) or risky health-related behaviors experienced by the pregnant mother with depression. The model proposed in the present monograph will not directly examine heritability or neuroregulatory functioning. Examination of these factors is beyond the scope of the present investigation, and would be more appropriately studied using differing methodologies (e.g., semi-structured diagnostic interviews with mothers, longitudinal study of youth's functioning in infancy, neuropsychological assessment, genetic assays).

Exposure to mother's negative thoughts, behaviors, and mood is also presented as a potential transmission mechanism. Indeed, various studies show that mothers with depression demonstrate more criticism, conflict, inattention, and inconsistency with discipline with their children (see Lovejoy, Graczyk, O'Hare, & Neuman, 2000). In turn, children may learn to adopt similar affective and behavioral qualities (Hops et al., 1987; Joiner & Wagner, 1995), possibly due to social learning as modeled and shaped by their mother. Similarly, exposure to a stressful environment may also serve as a mechanism of transmission. Psychosocial and sociodemographic factors, such as higher familial conflict and limited financial resources, may create such a stressful environment for these youth. Evidence suggests that mothers with depression concurrently experience elevated levels of stress and higher numbers of specific stressors (e.g., Tisher, Tonge, & Horne, 1994), including family-related stress (Hammen et al., 1987) and marital discord (e.g., O'Leary, Christian, & Mendell, 1994). Overall, it is possible that children of mothers with clinical depression grow up in a more stressful environment, witness more modeling of ineffective coping, live through more of their own personally stressful experiences, and, therefore, may experience more negative outcomes, such as emotion dysregulation and behavioral problems (e.g., Hammen et al., 1987).

According to Goodman and Gotlib's model, the aforementioned mechanisms of transmission then lead to a particular set of vulnerabilities that are experienced by the child. These mechanisms present parallel pathways wherein youth are born with a genetic predisposition to experiencing depression and other psychopathology, which may be related to atypical cognitive and emotional neuroregulation. Besides these biological underpinnings, these youth may also socially learn

maladaptive behavioral tendencies and poor emotional regulation through maternal modeling, in addition to early exposure to high levels of family-related stress. Together, these mechanisms simultaneously present a risk for the child to, in turn, cope with negative emotion through avoidance, experience negative social interactions within and outside of the family, and, throughout their development, receive less support or positive counter-modeling to protect from these particular vulnerabilities. These parallel behavioral, social, and cognitive mechanisms put the child at risk for ultimately developing psychopathological symptoms, including those of depression, anxiety, and externalizing behaviors, in childhood and/or adolescence.

**Relevant moderators.** Goodman and Gotlib's model describes three different clusters of moderators that may ultimately support resilience and promote positive outcomes for youth from families affected by maternal depression. According to Goodman and Gotlib, these factors are categorized as relating to fathers, timing of the depression, and particular demographic characteristics of the child, and are conceptualized as moderators in their transmission model. In the current proposed model, these factors will be examined as covariates, which are described further in the "Covariates" section below.

Youth who have an active father, in addition to their mother with depression, may have different outcomes than youth who do not. Fathers who do not suffer from depression may play a protective role for youth by providing them with another, more functional, model of socialization, problem-solving, and emotional responsiveness (e.g., Belsky, 1984). They may fulfill the child's needs for attention and positive interaction that the mother with depression has difficulty providing to her children. Conversely, a father who also suffers from depression may actually increase the child's likelihood for psychopathology (e.g., Weissman et al., 2006). Having both a mother and father with depression may decrease the child's chances for positive interactions within the family and decrease the amount of one-on-one adult attention that the child receives. Overall, a child with a single mother with depression (Cairney, Boyle, Offord, & Racine, 2003) or a child with two parents that both suffer from depression may have fewer opportunities for positive social modeling and interpersonal experiences within the family. As such, exposure to depressive symptoms and interaction style may be an especially predictive mechanism of transmission for these youth.

Another possible influencing factor includes developmental considerations related to the point in their childhood at which the child's mother has experienced depression. Goodman and Gotlib postulate that youth with later exposure to maternal depression may have had the opportunity to experience part of their childhood with a more responsive and attentive mother, possibly creating a protective period that includes important skills growth. However, youth with early exposure to maternal depression, in infancy and toddlerhood, may not be able to fully recover from these early effects or make up for the important affective or social skills that were difficult for their mothers to nurture (e.g., Cohn, Campbell, Matias, & Hopkins, 1990; Hammen et al., 1987). As such, youth whose mothers suffered from depression only during middle or later childhood may be at lower risk for negative outcomes than youth with mothers with depression during their infancy, toddlerhood, and early childhood.

Lastly, youth demographic characteristics may serve to moderate the links between maternal depression and outcomes. Girls may be more at risk for negative outcomes due to stronger effects of social learning between girls and their mothers (Khajepour, Ghazvini, Memari, & Rahmani, 2011). However, studies generally show mixed evidence regarding gender differences between youth with maternal depression, with some studies showing higher risk for boys and some for girls (e.g., Davies & Windle, 1997; Murray, Fiori-Cowley, Hooper, & Cooper, 1996). It may be the case that maternal depression places each gender group at risk for different problems, such as girls being more likely to develop internalizing problems and boys being more likely to develop externalizing problems, especially in e.g., Twenge & Nolen-Hoeksema, 2002).

**Maternal depression and ASD.** Given that evidence suggests that maternal depression plays an important role in risk for child psychopathology, it is important to note that this risk factor may be more prevalent in families affected by DDs than families that are not. One meta-analysis found that mothers of youth with DDs are more likely to experience depression than mothers of TD youth (Singer, 2006). Across the 18 studies examined, 29% of mothers of youth with DDs experienced elevated depressive symptoms, while the corresponding rate for mothers of TD youth was 19%. Therefore, mothers with youth with DDs were approximately 10% more likely to reach clinical cutoffs on depression self-report measures. Based on these results, Singer (2006) concluded that raising a child with a DD may increase environmental stress and, concurrently, increase risk for

depression. However, Singer also noted that a large majority of mothers were functioning within the typical range of depressive symptoms, thereby raising important questions about the risk or resilience factors influencing outcomes for mothers of youth with DDs.

Extant studies on depression prevalence among mothers of youth with ASD also demonstrate elevated rates of depression when compared to mothers of TD youth (Davis & Carter, 2008; Shu, Lung, & Chang, 2000). In another sample, mothers of youth with ASD self-reported higher levels of depression than mothers of youth with Down Syndrome (Abbeduto et al., 2004), indicating that this risk may not merely be an effect of having a child with a DD but that the particular challenges presented by youth with ASD may affect family systems, including maternal psychological functioning, in unique ways. For instance, the high rates of problem behavior or social difficulties may lead to more family isolation or more stress related to childcare and procuring professional services. Furthermore, evidence shows that anxiety and depressive symptoms in mothers of youth with ASD may remain more stable over time throughout the adolescence and adulthood of their child, especially as care-taking needs also remain stable (Barker, Hartley, Seltzer, & Floyd, 2011). As such, the birth or diagnosis of their child with ASD may not serve as an acute trigger for mothers' depression but a chronic stressor that affects their psychological functioning.

Therefore, TD siblings of youth with ASD may have mothers who are more likely to experience depression. Most importantly, maternal depression amongst mothers of youth with ASD may be a part of a unique framework of risk or resilience transmission to siblings. Potential mechanisms that may be unique to the family affected by ASD and integral to understanding the effects of maternal depression in this population include: differential attention, maternal stress, and social support.

***Differential attention.*** Differential attention, wherein a parent or both parents selectively give more one-on-one attention to a particular child or children and less to another child or children, is somewhat common across multiple child families (McHale, Crouter, McGuire, & Updegraff, 1995). The disfavored youth who receives less attention may experience resentment, less closeness with family members, and less opportunities for familial support during sibling conflict (Brody,



Copeland, Sutton, Richardson, & Guyer, 1998). These processes may result in negative thinking patterns or attention-seeking via inappropriate behaviors; both depressive symptoms (Shanahan et al., 2008) and conduct problems (Richmond, Stocker, & Rienks, 2005) have been evinced among disfavored youth in families who demonstrate differential attention towards children. These associations have, so far, not been examined as an outcome of maternal depression, although a significant amount of research suggests that mothers suffering from depression attend less to their children than non-depressed mothers (Lovejoy et al., 2000).

Youth with a brother or sister with a DD have been shown to consistently receive less parental attention than their affected sibling (Corter, Pepler, Stanhope, & Abramovitch, 1992; Lobato, Miller, Barbour, Hall & Pezzullo, 1991; McHale & Pawletko, 1992; Stoneman, Brody, Davis, & Crapps, 1987). Youth with DDs require more attention in order to assure safety, teach skills, and provide caretaking related to problem behavior, well beyond the age range wherein these parenting needs typically decrease (Barker et al., 2011; Carter, Martinez-Pedraza, & Gray, 2009). Furthermore, mothers of youth with DDs, in comparison with mothers of TD children, are more likely to attribute problem behavior to disability status and possibly demonstrate more helping, rather than disciplinary strategies with their affected child (e.g., Johnson & Patenaude, 1994; Tran & Hodapp, 2002). Therefore, maternal depression may serve as a stronger predictive factor for negative outcomes for youth with a sibling with ASD than youth with TD siblings due to the effects of differential parenting. Differential attention appears to be a standard element of families affected by ASD and, therefore, siblings of youth with ASD may not only be at risk for receiving low levels of attention due to maternal depression but also at-risk for negative outcomes resulting from constant differential parenting associated with their sibling's condition. As such, in the context of families affected by ASD, differential attention may play an important role in determining the association between maternal depression and youth outcomes.

**Maternal stress.** Maternal stress is strongly associated with maternal depression while mothers are raising children and adolescents in the TD population (Hammen et al., 1987) and amongst mothers of youth with ASD (Wang et al., 2013). Goodman and Gotlib (1999) state that maternal stress may, in fact, be another relevant predictor of youth outcomes. While stress and depression are commonly co-occurring, it is also important to view stress as a separate predictor of child outcomes.

Maternal stress reflects an ongoing state of facing difficult challenges related to everyday life, including family, work, and finances. Conversely, maternal depression refers to a mood disturbance wherein mothers experience sadness, negative thinking patterns, and overall lethargy in both interpersonal and daily living activities. As such, maternal stress, as a construct, differs from maternal depression by reflecting various external demands placed on a mother, as opposed to a cluster of clinical mood symptoms that are not directly tied to a specific circumstance. As noted earlier, maternal stress predicts more stress for children and, potentially, negative outcomes such as emotion dysregulation and behavioral problems (e.g., Hammen, 1987). While all parents report some level of stress, mothers of youth with DDs have been shown to experience more stress than mothers of only TD children (Baker et al., 2003).

In the realm of ASD, maternal stress may be an even more salient factor to consider as part of the family system and TD sibling functioning. An abundance of research evinces mothers of youth with ASD as experiencing more stress relative to mothers of TD youth (e.g., McKinney & Peterson, 1987; Rodrigue, Morgan, & Geffken, 1990; Singer, Ethridge, & Aldana, 2002) and of youth with other DDs, such as Down syndrome (Sanders & Morgan, 1997). This stress appears to be associated with the frequent demands of directly caring for their child with special needs, advocating for services, and, overall, rarely getting a “break” or relaxation time in this demanding family context (Abelson, 1999; Kuhn & Carter, 2006). Of note, these elevated stress levels may not affect the family system for a short period of time, but rather remain stably elevated well into the adulthood of the affected sibling (Barker et al., 2011; Carter, Martinez-Pedraza, & Gray, 2009), which could be the entire childhood and adolescence of the unaffected children, as well. Furthermore, parental stress is associated with negative effects on parenting, such as more impulsive and punitive discipline strategies (e.g., Abidin, 1992). For youth, higher levels of parent stress may predict poorer social functioning and increased levels of behavioral problems, both internalizing and externalizing (Anthony et al., 2005).

Of note, a multitude of studies show that parental stress, anxiety, and depression are associated with the severity of their affected child’s ASD symptom severity and problem behavior (Baker, Blacher, Crnic, & Edelbrock, 2002; Barker et al., 2011; Eisenhower, Baker, & Blacher, 2005; Konstantareas & Homatidis, 1989; Lecavalier, Leone, & Wiltz, 2006; Osborne &

Reed, 2009). These mothers may encounter more difficulty in procuring appropriate services for their child, advocating for their child in the school system, and integrating their child into community contexts. These unique challenges may lead to social isolation and a sense of being overwhelmed, as well as feelings of fear and hopelessness, all of which may result in stress, anxiety, and depression-related symptoms.

Together, evidence suggests that the stress of mothers of youth with ASD may be more stable and enduring throughout all of their children's development. Furthermore, given that their unique stress experience may be largely related to the demands of caring for their child with ASD, this stress may further predict differential attention in favor of the child with ASD. In families that are not affected by ASD, maternal stress may wane as children grow older and may be related to a more diffuse set of family factors rather than one particular child. Specifically, parenting stress may be associated with typical developmental patterns and, then, stress may fade as children become increasingly independent (Barker et al., 2011; Carter, Martinez-Pedraza, & Gray, 2009). As such, TD siblings of youth with ASD may be exposed to a longer-term stressful environment and may, again, receive less attention than their sibling with an ASD. This may be especially true for youth who have a brother or sister with ASD with more severe core symptoms or more problem behavior. Therefore, maternal stress may co-occur with maternal depression and, due to potentially higher levels and longer course of stress in ASD families, maternal stress may be a stronger predictor of youth outcomes for siblings of youth with – relative to those without – ASD.

***Social support.*** Various early studies link depression to low levels of social support (see Leavy, 2006). Social support is described as a person's sense of feeling both cared for and valued by others (e.g. extended family, friends, local community) who provide them with emotional or tangible assistance with daily needs and in times of crisis (e.g., Cobb, 1976). More recent models conceptualize social support as consisting of both the actual number of social relationships a person maintains, and that person's participating in supportive interaction via these relationships, such as receiving help in difficult circumstances and being able to enjoy recreational activities that are non-parenting related (Taylor, 2011). Lack of social support is a strong predictor of increased psychological and medical problems (for a review see Uchino, 2006), with higher levels of social support possibly playing a protective role against such problems. For parents, indices of social support include receiving help

with caretaking of children, participating in recreational activities without children, or having any other assistance with child-rearing, as well as perceiving these social connections as being actually helpful or positive. Parents' support may be afforded by partners, their child's other parent, family members, friends, employers, and a variety of other social connections. Additionally, formalized social support for parents, in the form of professional services (e.g., therapy, organized activities) may also serve a protective role for parents. These various forms of family social support may serve as a buffer against familial stressors that are otherwise likely to predict significant maternal psychological problems, such as depression (see Armstrong, Birnie-Lefcovitch, & Ungar, 2005), and thereby may decrease the likelihood of differential attention between children.

A similar buffering effect may be true of social support for families affected by ASD (e.g., Bristol, 1987) and, given the parenting demands of this population, the effect may be particularly relevant. Families affected by ASD are known to receive less actual social support and feel less socially supported than unaffected families, though the positive impacts of social support are probably paramount to those families (e.g., Boyd, 2002; Bromley, Hare, Davison, & Emerson, 2004; Weiss, 2002). Lower levels of social support are purported to be due to social isolation, worries about community inclusion, and a lack of connections with other families in general, as well as other families affected by ASD who may have more empathetic understanding of their family circumstances. While these effects may also be present in populations of families affected by other DDs (e.g., Hassall, Rose, & McDonald, 2005; Weiss, 2002), it is plausible that parents of youth with ASD are especially prone to these outcomes due to the socially inappropriate nature of their child with ASD's behaviors (e.g., Abbedutto et al., 2004). One study has demonstrated formal social support as a meaningful moderator of the relationship between ASD severity and outcomes for siblings (Hastings, 2003). Therefore, the risk for behavioral or social problems posed for TD siblings of youth with ASD may be influenced by family social support, with social support acting as a potential buffer against negative outcomes related to maternal depression and stress and, simultaneously, reducing the risk of differential attention in these families.

As mentioned earlier, a well-functioning second parent may protect TD youth from adverse effects of maternal depression and, similarly, the presence of a social support system may protect youth from the differential parenting associated

with having a brother or sister with ASD. This protective role may consist of the TD sibling gaining more positive one-on-one interactions with others, which may buffer the adverse effects of differential parenting. As such, siblings may be protected from adverse effects of maternal depression (e.g., less attention, increased criticism, social isolation) if their parent receives more social support. This protection may also be afforded by the presence of a second parent who does not suffer from depression. This second parent may be categorized as another social support resource for the mother and, separately, may distinctly influence the family system (discussed further in the “Covariates” section below).

***Maternal depression and special considerations for siblings.*** While the Goodman and Gotlib (1999) model includes many considerations for psychopathology transmission for TD youth, it may not fully capture the pathways to optimal and negative outcomes for a special group of TD youth: siblings of a child or adolescent with ASD. The family systems that these youth belong to may be particularly affected by mothers’ differential attention towards her children (specifically, more attention to her child with ASD), increased maternal stress, and a lack of overall family social support, all of which may be exacerbated by the youth with ASD’s symptom and problem behavior severity.

***Hypotheses related to maternal depression.*** Overall, this literature suggests that the Goodman & Gotlib (1999) transmission model of maternal depression may be uniquely modified among siblings of youth with ASD. Figure 2 presents a model of transmission between maternal depression and youth clinical outcomes with specialized considerations for TD siblings of youth with ASD. Each pathway is numbered in conjunction with the hypothesis list below. Please note, the hypotheses regarding ASD versus TD group comparison (in both mean level and moderation of listed relationships) hypotheses are not visualized in the figure below, but are represented in the hypotheses list.

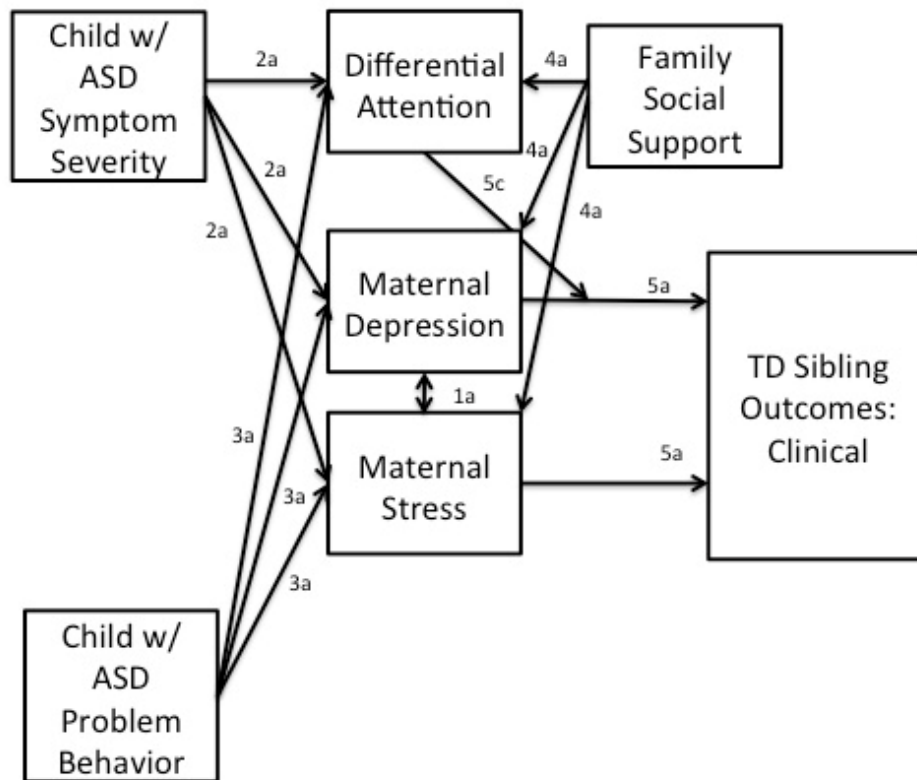


Figure 2. Modified model of maternal depression effects on TD sibling outcomes in families of youth with ASD (ASD versus TD group comparisons not visualized).

**Hypothesis 1: Maternal functioning variables related to each other and study group.**

1a. Maternal stress and depression will be positively correlated across both groups.

1b. Higher mean levels of maternal stress and depression will be evinced in the ASD group, as compared to the TD group.

**Hypothesis 2: Effects of ASD severity (Focus Child 1) on all maternal variables.**

2a. Higher levels of ASD severity will predict higher levels of differential attention, maternal depression, and maternal stress across both groups.

2b. Mean levels of ASD severity, differential attention, maternal depression, and maternal stress will be higher in the ASD group as compared to the TD group.

***Hypothesis 3: Effects of problem behavior (Focus Child 1) on all maternal variables.***

3a: Higher levels of problem behavior will predict higher levels of differential attention, maternal depression, and maternal stress across both groups.

3b. Mean levels of problem behavior, differential attention, maternal depression, and maternal stress will be higher in the ASD group as compared to the TD group.

3c. After accounting for mean level differences, the strength of the relationship between problem behavior and differential attention (but not maternal stress or depression) will be augmented in the ASD group as compared to the TD group.

***Hypothesis 4: Effects of family social support on all maternal variables.***

4a: Higher levels of family social support will predict lower levels of differential attention, maternal depression, and maternal stress in both groups.

4b: Mean levels of social support will be lower, and levels of differential attention, maternal depression, and maternal stress will be higher in the ASD group as compared to the TD group.

***Hypothesis 5: Effects of maternal functioning on sibling (Focus Child 2) outcomes.***

5a. Higher levels of maternal depression and stress will predict poorer psychopathological outcomes for siblings in both groups.

5b. The mean levels of both maternal depression and stress will be higher in the ASD group as compared to the TD group.

5c. Across groups, the relationship between maternal depression (but not stress) and psychopathological outcomes will differ based upon level of differential attention, such that a stronger relationship will be evident under conditions of high differential attention versus low differential attention.

5d. The strength of the relationship between maternal depression and psychopathological outcomes will differ between ASD and TD groups, such that the difference in effect between high versus low differential attention will be augmented in the ASD group.

## **Sibling Relationships**

The relationships between siblings have been described as a model of both intense conflict and intense closeness for children (Stoneman, 2001). Growing up in a multiple child household is very common, with less than 25% of youth growing up as only children (Hernandez, 1997). Siblings share both genetic and environmental history; however, they are nevertheless often quite different due to different life experiences and even different family experiences, including their relationships with one another (e.g., Dunn, Deater-Deckard, Pickering, & Golding, 1999). While sibling relationships are sometimes an overlooked feature of family systems studies, extensive research indicates that sibling relationships may play a pivotal role in outcomes for youth (see Feinberg, Solmeyer, & McHale, 2012; Stoneman, 2001). Multiple studies have demonstrated that sibling conflicts in middle childhood predicts increased levels of both internalizing and externalizing symptoms throughout childhood and adolescence (Kim et al., 2007; Dunn, Slomkowski, Bcardsell, & Rende, 1994; Stocker, Burwell, Briggs, 2002), as well as adulthood (Waldinger, Vaillant, & Orav, 2007), even when other relevant factors such as maternal mood, marital discord, and parental hostility are controlled.

While some theoretical models of sibling relationship quality exist (e.g., Brody, 1998), only one known comprehensive theoretical model examines the youth outcomes in relation to sibling relationship quality (Feinberg et al., 2012). This model attempts to identify and consolidate the various underlying processes that result in sibling relationships as a significant predictor of sibling psychological and behavioral outcomes in childhood and adolescence. While the support for this model is primarily based on delinquent outcomes, it is also designed to encompass pathways towards broader clinical outcomes for youth with brothers and sisters, including both externalizing and internalizing problems. As seen in Figure 3, this model of sibling effects draws links between sibling relations, processes and contexts wherein the child is a participant, ensuring proximal risk factors, and, ultimately, youth problem behaviors. The authors of this model present it as a “third rail of family systems” as it expands upon the typical family systems focuses of parental and individual characteristics. Beyond being the sole model that includes both sibling relationship quality and youth outcomes, this model was also selected as an ideal framework for the current proposed study given its bases in family systems theory. Like the maternal depression model



examined previously, this model includes parallel pathways for interaction between parents and siblings, thus presenting a systemic psychosocial view of multiple mechanism and vulnerabilities that lead to specific outcomes for youth. Such a model allows for multiple empirically-grounded risk and resilience considerations that may be necessary for providing a sufficiently nuanced understanding of how family system factors may affect TD siblings of youth with ASD (Lobato, 1983; Stoneman, 2005).

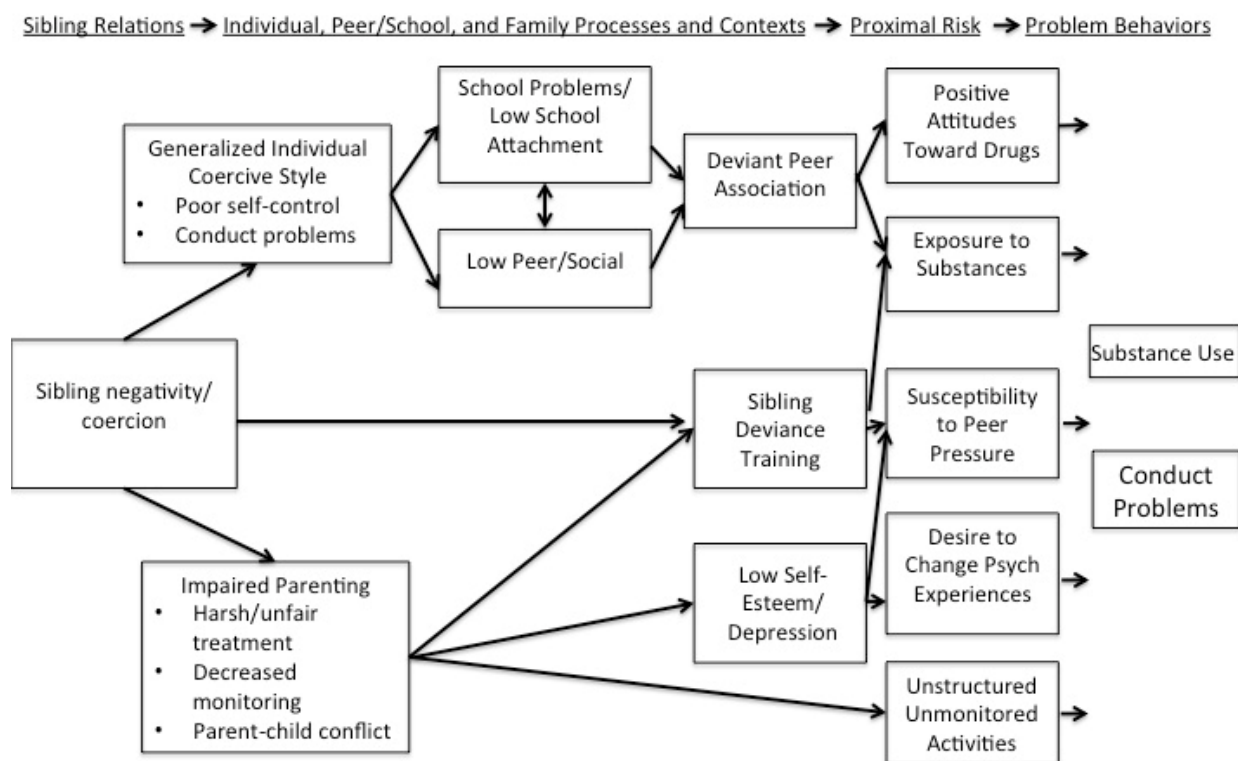


Figure 3. Theoretical model of sibling effects (Feinberg, Solmeyer, & McHale, 2012).

According to Feinberg et al.'s systemic model, conflictual sibling relationships predict a generalized conflictual style with peers (e.g., Natsuaki, Ge, Reiss, & Neiderhiser, 2009), including impulsive behaviors and disruptive behaviors. These outcomes may reflect a negative and coercive interaction style amongst siblings, as well as siblings colluding in deviant behaviors together. Poor sibling relations may also increase stress for parents (McHale & Crouter, 1996), which can affect their parenting style. Increased parent stress may lead to harsher treatment of children (e.g., Abidin, 1992) and less monitoring of sibling activity (e.g., Stocker and Youngblade, 1999). These impairments may then lead to problems in school and social

situations (e.g., Stormshak, Balanti, & Bierman, 1996). The impairments in the youth's family and school contexts are proposed to lead to a desire to distance him/her from the family and school and become more influenced by peer pressure. Ultimately, these proximal risk factors may be associated with depression, anxiety, oppositional defiance, and conduct problems for both siblings.

Conversely, positive, supportive, and warm sibling relationships are proposed to have a positive impact on the family and school environment, thereby protecting youth from negative psychological and behavioral outcomes. Indeed, past studies have shown that positive sibling relationships may improve coping when dealing with stressful life events (Gass, Jenkins, & Dunn, 2007), including marital discord (e.g., Dekovic & Buist, 2005) and bullying (e.g., Milevsky & Levitt, 2005). Overall, the Feinberg et al. (2012) model suggests that these positive impacts create a model of problem solving, frustration tolerance, communication, and social support for youth, which promotes psychological and behavioral adaptation in TD youth and their siblings.

**Sibling relationships and ASD.** While evidence exists for sibling relationships affected by DDs, such as ASD, to be characterized by caring and reciprocal closeness (Stoneman, 2001), there may also be particular negative characteristics of sibling relationships in which one child carries a diagnosis of an ASD. When compared to sibling dyads affected by Down Syndrome, sibling dyads affected by ASD demonstrate less warmth and closeness (Kaminsky & Dewey, 2001) and less social interaction and reciprocity (Knott, Lewis, & Williams, 2006). Nevertheless, mixed evidence exists as to whether sibling dyads affected by ASD experience more negative (e.g., McHale, Sloan, & Simeonsson, 1986) or more positive (e.g., Roeyers & Mycke, 1995) sibling relationships than TD sibling dyads. Sibling relationships may have important effects on outcomes for the TD sibling with a brother or sister with ASD. As described previously, the sibling relationship may be a meaningful model of social and emotional development for youth. For youth with a sibling with ASD, the sibling relationship may be atypically affected by their sibling's social skills deficits (e.g., Stoneman, 2001). For example, social reciprocity may be difficult and engaging in mutually-reinforcing activities may be taxing for the TD sibling. Overall, the severity of the affected sibling's ASD symptoms may predict social outcomes for their TD sibling. For some youth, these peer relationships may be a

maladaptive model for social interaction, which may generalize to problematic social interaction (e.g., poor social skills, minimal functional social contact) outside of the family.

Additionally, the problem behavior exhibited by youth with ASD may affect sibling relationships; they may act aggressively towards their siblings (Farmer & Aman, 2010) beyond what is expected in TD sibling relationships (Hernandez, 1997). Indeed, less problem behavior exhibited by youth with ASD is associated with more positive sibling relationships and more time spent together (Orsmond, Kuo, & Seltzer, 2009). As such, sibling relationships may be characterized by difficult social interactions and more conflict and, as outlined by Feinberg, et al. (2012), these patterns of interaction may generalize to other social settings, lead to peer problems, and elicit higher parental stress. These problems may be especially problematic for these particular siblings, given that they may also present with a broader phenotype of ASD-linked social skills deficit (e.g., Piven et al., 1997) and may already be at risk for negative social outcomes. Furthermore, the problem behavior exhibited by youth with ASD may limit the number of social contacts and play dates that their siblings are able to acquire within the home, thus causing more social isolation. The maternal stress that poor sibling relationships elicit may also be especially salient in families affected by ASD, given that these mothers are already at higher risk for stress (e.g., Koegel et al., 1992). They may also experience ongoing guilt and frustration in managing their children's conflict, given their children's differential needs and abilities (Meirsschaut, Roeyers, & Warreyn, 2010). Overall, strained relationships in sibling dyads affected by ASD may pose unique risks for increased maternal stress, as well as poor psychopathological or social outcomes for TD siblings, above and beyond the risks posed for TD dyads wherein a child exhibits non-ASD social difficulties or externalizing behaviors.

***Hypotheses related to sibling relationship.*** Overall, the sibling relationship may predict psychopathological and social outcomes for TD youth. For siblings of youth with ASD, these relationships may be especially affected by the ASD symptom severity and problem behavior of the affected sibling. Figure 4 presents specialized considerations for the TD sibling of a youth with ASD. All pathways are numbered in conjunction with the specific hypotheses presented below. Please note that hypotheses regarding group comparisons (in both mean level and moderation of listed relationships in ASD versus TD) are not visualized but are presented in the hypothesis list.

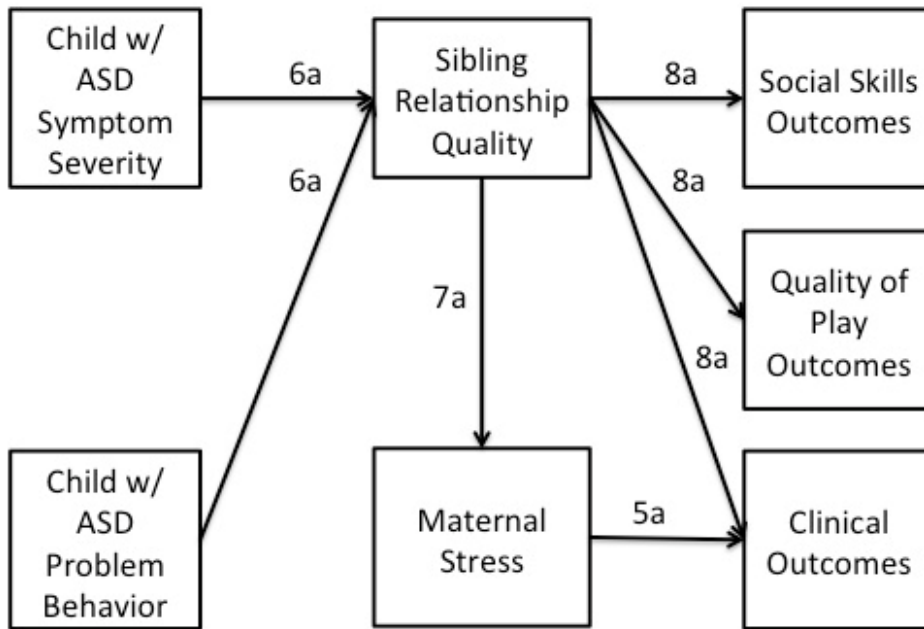


Figure 4. Modified model of sibling relationship quality as a predictor of TD sibling outcomes (ASD versus TD hypotheses not visualized).

***Hypothesis 6: Effects of ASD severity and problem behavior (Focus Child 1) on sibling relationship.***

6a. Higher levels of ASD symptom severity and problem behavior will predict poorer sibling relationship quality across groups.

6b. Mean levels of ASD symptom severity and problem behavior will be higher in the ASD group as compared to the TD group.

6c. After accounting for mean level differences, the strength of the relationships between these predictors (ASD symptom severity and problem behavior) and sibling relationship quality will be augmented in the ASD group as compared to the TD group.

***Hypothesis 7: Effects of sibling relationship quality on maternal stress.***

7a. Poor sibling relationship quality will predict higher levels of maternal stress across groups.

7b. Mean level of maternal stress will be higher in the ASD group as compared to the TD group.

7c. After accounting for mean level differences, the strength of the relationship between sibling relationship and maternal stress will be augmented in the ASD group as compared to the TD group.

***Hypothesis 8: Effects of sibling relationship quality on sibling (Focus Child 2) outcomes***

8a: Poor sibling relationship quality will predict higher levels of psychopathological symptoms and lower levels of social functioning in siblings across both groups.

8b. The strength of the relationship between sibling relationship quality and these outcomes (psychopathological and social) will be augmented in the ASD group as compared to the TD group.

**Full Proposed Model**

The proposed model presented here (see Figure 5) was constructed based on two extant theoretically-driven outcome models of youth psychopathology, one based on maternal depression (Goodman & Gotlib, 1999) and the other framed by sibling relationships (Feinberg et al., 2012). These models were selected for their strong evidence base and multiple pathway structures, which were called for in creating the initial model of risk and resilience for siblings of youth with ASD.

Additionally, evidence-based themes that are unique to this special population were considered and integrated into the proposed model, as it is predicted that the pathways that lead to clinical, adaptive, and social outcomes for siblings of youth with ASD do not exactly mirror those evinced for youth from TD sibling dyads. As such, family social support, maternal stress, and differential attention were considered as unique predictors of outcomes for youth with ASD. Furthermore, the ASD symptom severity and problem behavior of the affected sibling was identified as a potential predictor of all major predictors of interest.

Overall, the proposed model is designed as a novel framework for understanding the particular risk and resilience factors experienced by siblings of youth with ASD. The model is intended to provide a systematic comparison of how 16 risk and resilience pathways differ across this special population and sibling dyads that include only TD youth. Ultimately, the model and its 16 afore-outlined hypotheses will hopefully serve to generate a more cohesive and multi-faceted understanding

of the unique functioning and needs of siblings of youth with ASD, thereby allowing for treatment implications at various levels of the family system.

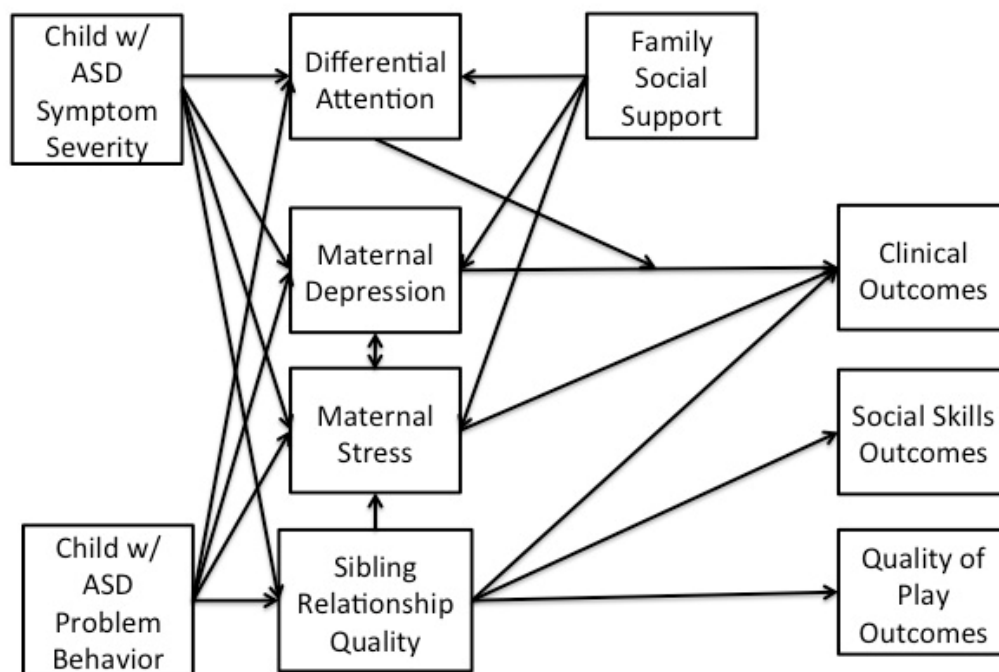


Figure 5. Full proposed family systems model of risk and resilience for siblings of youth with ASD (aggregated from Figures 3 and 4).

### Alternate Single Group Analyses

While group comparisons will be the preferred method of analysis to answer the present research questions, identifying an ASD-specific model and moderators is also of import. ASD represents a vastly heterogeneous phenotypic presentation (Happé, Ronald, & Plomin, 2006). Moreover, the previously described family systems effects of having a child with ASD may differ across these presentations. Understanding how TD sibling outcomes are affected not just by the diagnosis of ASD but, rather, more specific information about ASD presentation may benefit this field of study. Therefore, a model that focuses on both primary pathways to TD siblings outcomes, as well as ASD-specific moderation of such pathways, is proposed here. The following single group (ASD) hypotheses are presented with this rationale and, especially for use in the case that TD group

recruitment is not satisfied within the timeline necessary for the current dissertation. Single group (ASD) hypotheses are presented as a full model (see Figure 6) and, then, subsequent moderation hypotheses related to specifically to ASD severity (see Figures 7-11).

**Main hypotheses.**

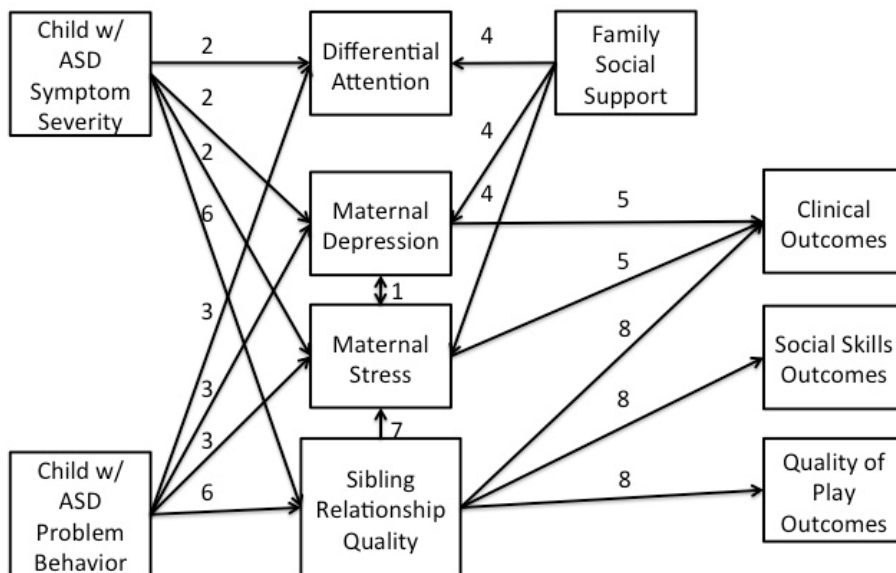


Figure 6. Alternate single group (ASD) hypotheses, full model.

1. Maternal stress and depression will be positively correlated.
2. Higher levels of ASD severity will predict higher levels of differential attention, maternal depression, and maternal stress.
3. Higher levels of problem behavior will predict higher levels of differential attention, maternal depression, and maternal stress.
4. Higher levels of family social support will predict lower levels of differential attention, maternal depression, and maternal stress.
5. Higher levels of maternal depression and stress will predict poorer psychopathological outcomes for siblings.
6. Higher levels of ASD symptom severity and problem behavior will predict poorer sibling relationship quality.

7. Poor sibling relationship quality will predict higher levels of maternal stress.

8: Poor sibling relationship quality will predict higher levels of psychopathological symptoms and lower levels of social functioning in siblings.

**Moderation hypotheses.**

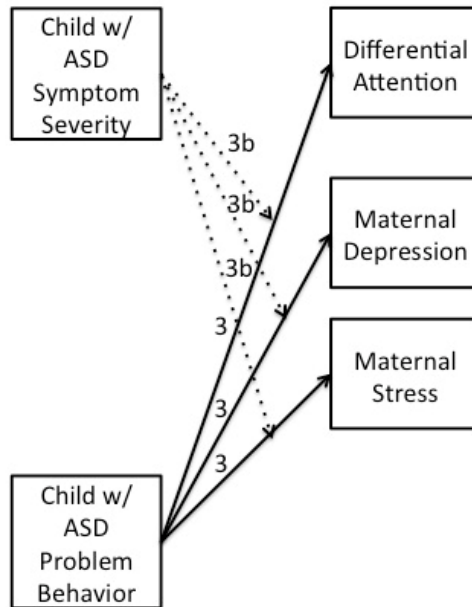


Figure 7. Alternate single group (ASD) hypotheses (3b).

3b. The relationships between ASD problem behavior and maternal variables will differ based upon level of ASD severity, such that stronger relationships will be evident when ASD symptoms are more severe versus when ASD symptoms are less severe.



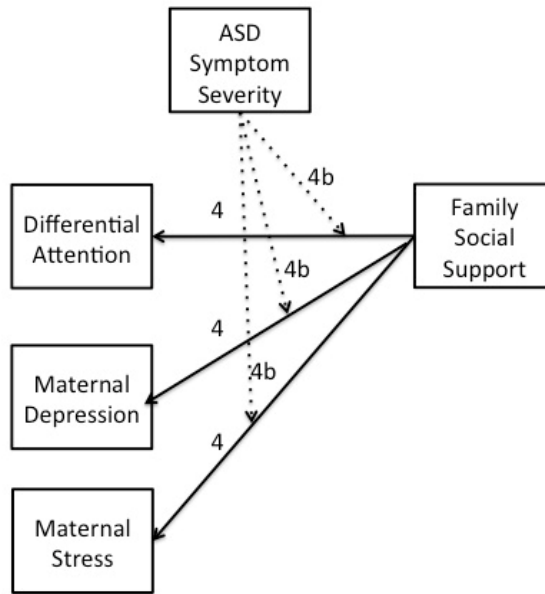


Figure 8. Alternate single group (ASD) hypotheses (4b).

4b. The relationships between family social support and maternal variables will differ upon level of ASD severity, such that stronger relationships will be evidenced when ASD symptoms are more severe versus when ASD symptoms are less severe.

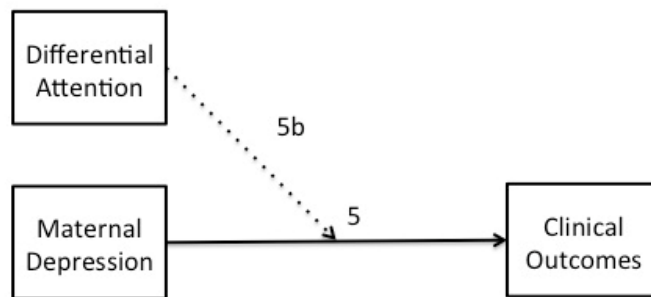


Figure 9. Alternate single group (ASD) hypotheses (5b).

5b. The relationship between maternal depression (but not stress) and psychopathological outcomes will differ based upon level of differential attention, such that a stronger relationship will be evident under conditions of high differential attention versus low differential attention.

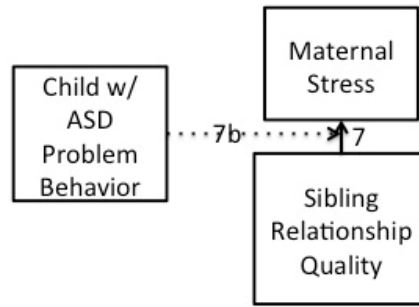


Figure 10. Alternate single group (ASD) hypotheses (7b).

7b. The relationship between sibling relationship quality and maternal stress will differ based upon level of problem behavior of the child with ASD, such that a stronger relationship will be evident under conditions of high problem behavior versus low problem behavior.

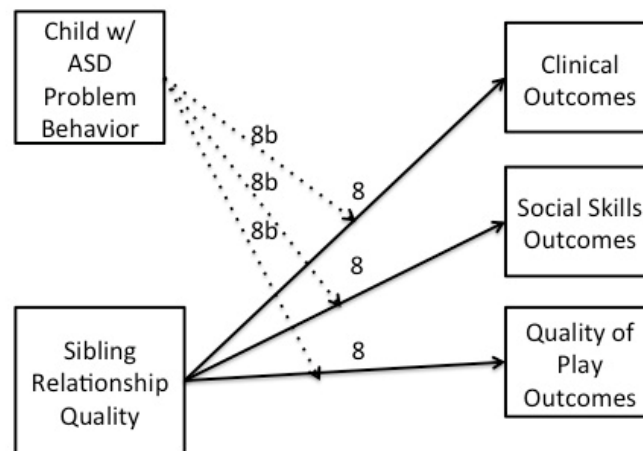


Figure 11. Alternate single group (ASD) hypotheses (8b).

8b. The relationship between sibling relationship quality and sibling outcomes will differ based upon level of problem behavior of the child with ASD, such that stronger relationships will be evident under conditions of high problem behavior versus low problem behavior.

**Covariates**

Several important factors may be considered likely to influence the presence, size, and direction of the pathways proposed in the current model. These factors will be controlled for in the present model. As covariates, specific hypotheses will

not be formulated around these factors, but they may exert undue influence on the modeled variables and relationships, and so must be controlled to limit the possibility that obtained effects are the result of sample bias, restricted range, and other related influences.

Due to potential protective effects of social support and social learning effects, the presence of a father in the family, especially a father without personal psychopathology, may unduly influence the relation of maternal functioning variables to clinical outcome variables; thus, both of these variables (presence of a father, and presence of reported psychopathology in that father) will also be controlled for (Goodman & Gotlib, 1999). Youth are more likely to meet criteria for experiencing a mood or anxiety disorder if a first-degree relative, such as a parent, has a mood disorder (Hirschfeld & Weissman, 2002; Perlmutter, 2002). This may be especially important while examining the current model given that families that include a member with ASD are more likely to have first-degree relatives with other psychopathology (Bolton, Pickles, Murphy, & Rutter, 1998).

Family size, particularly number of other TD siblings, may also serve as a protective factor wherein siblings may have more opportunities for positive sibling relationships, social support, and social learning and more siblings may provide more social support to the mother of the family, thereby influencing the relationship between social support and maternal functioning, as well as the relationships between maternal functioning and youth clinical outcomes (Tanila, Ebeling, Kotimaa, Moilanen, & Jarvelin, 2004). Similarly, family socioeconomic status (SES) may also influence the magnitude and direction of the various family processes studied here, whereby youth of lower SES may be susceptible to more negative peer influence, more stressful life events, and less positive school experiences (for a review see Leventhal & Brooks-Gunn, 2000). Also, in regards to populations of youth with ASD, controlling for SES is relevant in light of evidence that child's problem behavior is associated with the amount of specialized services available or affordable to the family (Mayes & Calhoun, 2011). Therefore, SES may unduly affect all of the pathways leading to youth clinical and social outcomes described here, and so will be controlled.

The difference between TD siblings' and their affected sibling's age may affect the relationships between all the pathways and outcomes presented here. Evidence from the TD population suggests that differential parenting is more

detrimental to disfavored siblings that are older than their favored sibling (e.g., the child with ASD; Feinberg, Neiderhiser, Reiss, Hetherington, & Simmens, 2000). In contrast, other literature suggest that early exposure to maternal depression may yield more negative outcomes for TD youth (Goodman & Gotlib, 1999) and, thus, TD siblings may be at more risk if they are born after their brother or sister with ASD (e.g., Totsika, Hastings, Emerson, Berridge, & Lancaster, 2011). Controlling for sibling age may also be of import due to birth order of siblings, as being younger or older than the child with ASD may influence outcomes. Together, research on sibling age and age differences in the sibling dyad affected by ASD remains unclear, but these variables may nonetheless influence the results of the current proposed model, and so will be controlled.

Additionally, sibling gender may influence the results seen in the proposed model, as research in other clinical populations shows that girls may be at higher risk for negative outcomes due to gender modeling by their mother with depression (Khajehpour et al., 2011) and the effects of differential parenting (Feinberg et al., 2000). Also, evidence shows that boys may be at higher risk for psychopathology in general (Rutter & Quinton, 1984). Thus, controlling for the gender composition of the sibling dyads is also relevant in light of the differences seen in regard to the types of symptom clusters (e.g., internalizing versus externalizing) that girls and boys are each more likely to experience (Twenge & Nolen-Hoeksema, 2002). Lastly, gender composition of the sibling dyad may differ, as dyads including two sisters (as compared to two brothers or a sister and a brother) are evinced as showing the least amount of sibling conflict, as reported by parents (e.g., Kim et al., 2006; Orsmond et al., 2009).

Overall, effects of the following covariates will be controlled for: presence of father in family, psychopathology of father (if present in family), SES, number of siblings in family, sibling age difference, and sibling dyad gender composition.

### **Other Relevant Variables Not Included in the Current Model**

Several variables were considered for inclusion in the current model that, ultimately, were not included. In the interest of ensuring that the current survey-based study was tenable and not cause undue burden to participating families (Spelley, Arnold, & May, 2008), the model attempts to be as parsimonious as possible. As such, the variables described above were chosen for being key to this initial foray into understanding risk and resilience for siblings, and for being especially consonant

with the chosen theoretical models (Goodman & Gottlib, 1999; Feinberg et al., 2012). Based on the findings from the current model, future work would benefit from including the following excluded variables.

Firstly, as pointed out by Goodman and Gottlib (1999), both the onset and clinical severity of mothers' depression may play a key role in understanding how maternal depression leads to youth outcomes. The onset of maternal depression may influence youth outcomes dependent on its temporal association with the child's developmental age. As described earlier in this monograph, maternal depression during pregnancy may influence the developing fetus via neurohormone or blood-flow regulation (Field, 1995; Bonari et al., 2004) and onset in infancy or early development may affect early child-maternal interactions (Lovejoy et al., 2000). Later onset in childhood or adolescence, which may be the case for some siblings of youth with ASD (e.g., older siblings whose mothers experience depression onset after a child with ASD is born), may prove less detrimental to youth development in that they may have experienced a "protective period" wherein they were raised by a mother with significantly less depressive or stress-related symptoms. However, the converse may also be true, wherein mothers with elevated depressive symptoms were actually experiencing these symptoms before having a child with ASD. Indeed, further research is needed to better identify the depression onset and course of mothers of youth with ASD, especially in light of the evidence that a majority of these mothers may not actually experience elevated depressive symptoms (Singer, 2006) even though, on average, these symptoms are more likely in this population of mothers (e.g., Davis & Carter, 2008). Furthermore, the clinical severity of maternal depression (e.g., depressive symptoms versus DSM-vetted depressive disorder diagnoses) may also be of import to interpreting youth outcomes, given that adverse outcomes may only be evidenced when severe and clinically diagnosable depression is present (Goodman & Gottlib, 1999). The proposed study cannot provide verified depression onset or clinical depression diagnosis; as such, future longitudinal and clinical interview-based studies will be able to provide more information on these topics and the current study will provide initial directions for such future work.

Additionally, the current study does not consider how the broader autism phenotype (BAP; Le Couteur et al., 1996) may influence sibling outcomes. The BAP refers to the presence of ASD-like symptoms in family members of individuals with ASD; however, various interpretations of this phenomenon can be found in the literature, with debate as to whether the BAP

should only be considered in first-degree relatives, as well debate as to how to best measure the BAP (e.g., Losh & Piven, 2007; Sasson, Lam, Parlier, Daniels, & Piven, 2013). While the framework for studying the BAP continues to be debated, some evidence does exist showing that TD parents and siblings of youth with ASD may be more likely to show elevated ASD symptoms as compared to TD siblings of TD youth (Le Couteur et al., 1996; Piven et al., 1997). These symptoms may predict a higher likelihood for experiencing depression or anxiety (Bolton, Pickles, Murphy, & Rutter, 1998) or social difficulties (Jobe & White, 2007). The BAP will not be directly studied in either parents or TD siblings in the proposed monograph, but the possibility of clinical and social functioning for these family members will be interpreted with this potentially genetic phenomenon under consideration. As future studies reveal more convergent validity on BAP constructs and measurement, this factor may play an important role in interpreting the initial sibling outcome findings of the proposed study. The current proposed study will not be able to provide a valid BAP assessment (e.g., behavioral tests).

Another potentially relevant variable that was not included in the current model is that of marital discord. Marital discord has been largely evinced as both a predictor and outcome (Beach & O'Leary, 1992) of depression in one partner. This particular phenomenon is also well-evinced as a predictor of poorer clinical outcomes in mothers (e.g., Beach & O'Leary, 1993) and poorer clinical outcomes for youth (Porter & O'Leary, 1980). The conflict and stress associated with marital discord may serve as another poor model of interpersonal relations and source of stress exposure for youth, which may increase the likelihood of depression and anxiety. As such, this variable may be another important mechanism of psychopathology transmission between mothers and youth. In families affected by ASD, such marital discord may indeed be at higher risk, though probably moderately so, than families not affected by ASD (Risdal & Singer, 2004). The current study aims to provide an initial assessment of familial characteristics with a strong emphasis on maternal factors. Future studies that control for family characteristics (e.g., two married parents) may be able to build upon the initial results gathered here and further examine the role that marital discord may play in interpreting TD sibling outcomes.

Lastly, maternal anxiety will not be measured in the current model. While extensive evidence exists for maternal transmission of anxiety (e.g., Moore, Whaley, & Sigman, 2004) and anxiety is evinced as occurring at higher rates in samples

of mothers of youth with ASD, as compared to mothers of only TD children (e.g., Barker et al., 2011). However, these examinations of anxiety are typically presented *in combination* with maternal depression and are not strongly evinced as a distinct factor in mothers of youth with ASD, with depression rates possibly showing a more consistent elevation (Bailey, Golden, Roberts, & Ford, 2007). Therefore, as a novel inquiry into a model of risk and resilience for siblings of youth with ASD, only maternal depression was chosen the primary maternal internalizing symptom of focus.

## Method

### Recruitment

**TD group.** The original recruitment plan (please see Figure 12) was carried out and, eventually, partially modified with the consent of the Dissertation Committee (K. D. O’Leary, M. D., Lerner, J. K. Robinson, & J. M. Wolf, personal communication, 10/21/2014).

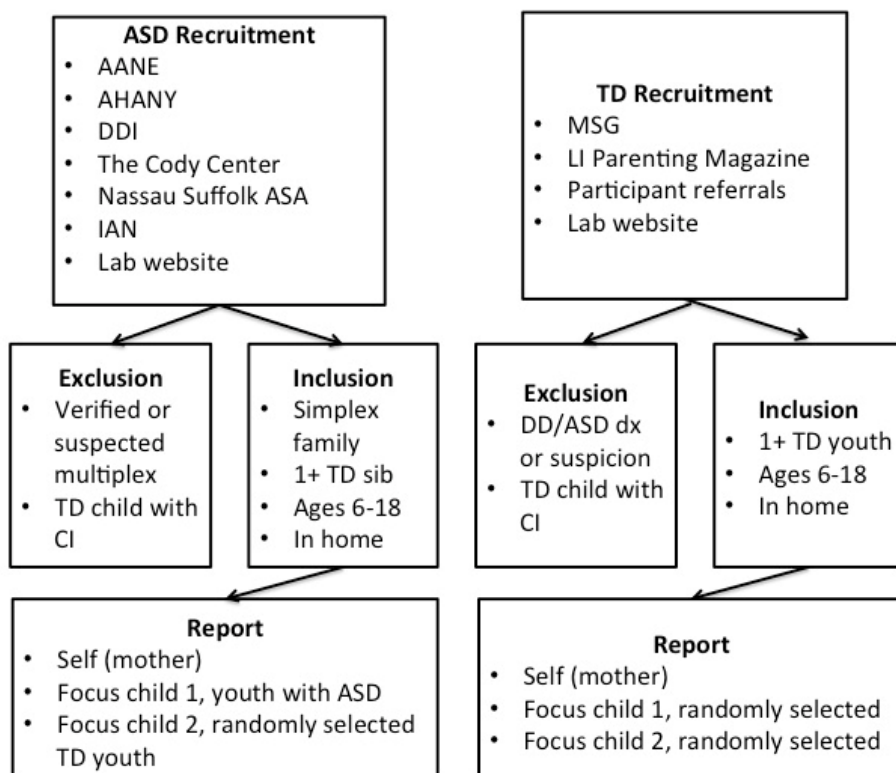


Figure 12. CONSORT flow diagram for both samples. ASD = Autism Spectrum Disorder; TD = Typically-developing; CI = Chronic illness.

Due to insufficient TD sample recruitment despite significant recruitment efforts (e.g., methods outlined in Figure 12, 300+ weekly flyers distributed in the community for a month), the TD group was not analyzed for the current study. Conversely, the ASD group exceeded the original goal of over 200 participants (N=239) for the final dataset included in current analyses. Please see Figure 13 for a CONSORT diagram of actual recruitment outcomes.

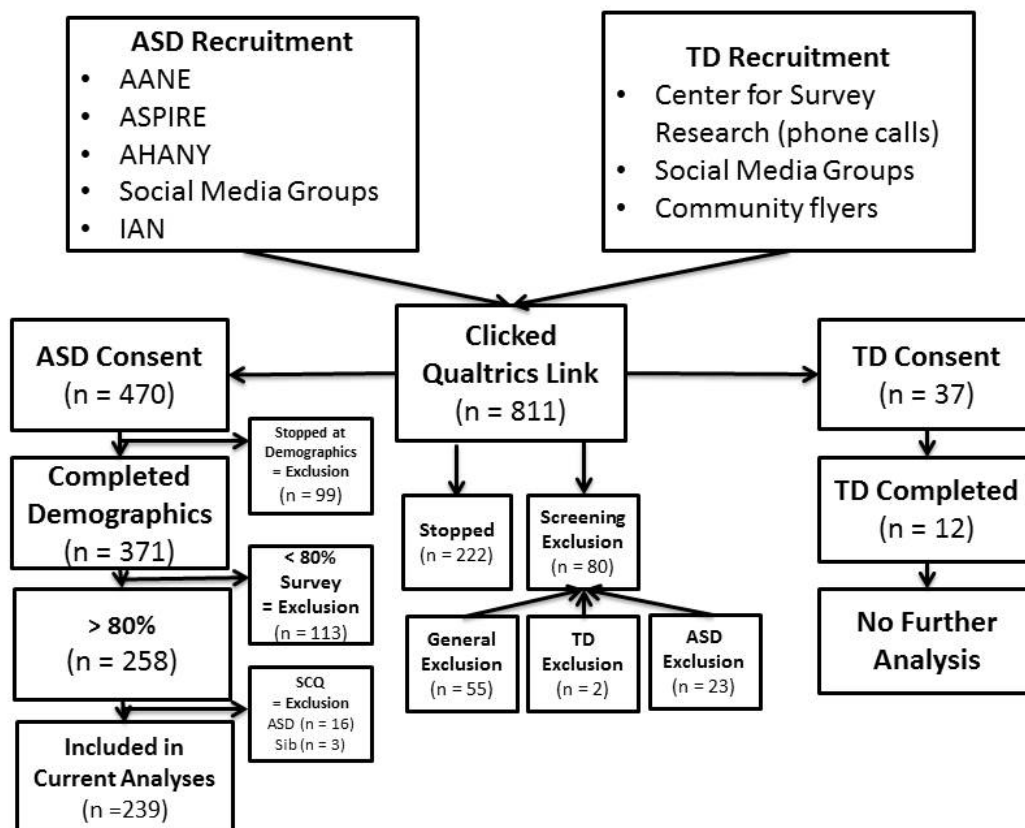


Figure 13. CONSORT diagram of recruitment outcomes for ASD and TD groups.

**ASD group.** ASD sample recruitment initially consisted, as planned, of hard copy and email-based recruitment flyers to be distributed to the following local agencies (both locales and listservs) that provide services to individuals with ASD and their families: Asperger’s Association of New England (AANE; [www.aane.org](http://www.aane.org)), Asperger Syndrome and High-Functioning



Autism Association of New York (AHANY; [www.ahany.org](http://www.ahany.org)); Developmental Disabilities Institute (DDI; [www.ddiny.org](http://www.ddiny.org)), The Cody Center ([www.stonybrookmedicalcenter.org/codycenter](http://www.stonybrookmedicalcenter.org/codycenter)), and The Nassau Suffolk Chapter of the Autism Society of America ([www.nsasa.org](http://www.nsasa.org)). Whenever necessary, separate IRB forms were completed for specific agencies. The lab website ([www.lernerlab.com](http://www.lernerlab.com)) also displayed a link to the current project. After 5 months of lower-than-expected recruitment turnout (approximately 40 participants) via these methods, study funds were used to collaborate with the Interactive Autism Network (IAN; [www.ianproject.org](http://www.ianproject.org)) and recruit families nationally. The IAN collaboration led to a stark increase in sample size and recruitment was closed when an adequate sample was obtained (please see Figure 13). IAN-based recruitment consisted of all mothers with of one youth with autism and at least TD youth on the mailing list receiving the study advertisement via email (along with other research opportunities for that given week). A total of 3,056 mothers received the study email once during recruitment (A. Marvin, personal communication, 04/17/2015).

## **Participants**

**Sample size.** All participating families included in the final analyses (N = 239 of 470 consents) were volunteering mothers who are currently raising and reside with at least two of their biological children. Only mothers were recruited given that the proposed model is primarily based on maternal functioning. Furthermore, previous studies in this research area primarily focus on mothers' report, as mothers tend to be the primary caregivers of children and may have the most insight into children's behavior (Stoneman, 2005). Additionally, only ASD simplex families were included, given that the inclusion of families with multiple children with ASD or other DDs may confound results. Specifically, two or more youth with ASD or other DDs may influence the family system in a manner that is distinct from the influence of a single youth with ASD. Given that the current study aimed to examine the influence of ASD on the family system, inclusion of simplex families allowed for the most clearly interpretable results. Furthermore, the presence of a TD child with a severe chronic illness (diabetes, cystic fibrosis, or pediatric cancer) was excluded, as the lifelong and stressful nature of these illnesses may serve as confounds to the current results (Sharp & Rossiter, 2002). Specifically, family systems affected by chronic illnesses may both present with elevated stress, increased needs for social support, and differential attention towards siblings; therefore, they would complicate

understanding the distinctive systemic factors in the study groups recruited here (e.g., the TD sibling may also require high levels of one-to-one attention for daily healthcare routines). A total of 82 mothers were excluded from study participation based on these various inclusion/exclusion criteria. A subset of those are known to be ASD-group specific (n=23), wherein mothers endorsed having one child with ASD and at least one other child with ASD or another DD.

A proportion of consenting mothers in the ASD group (n=99) did not complete the initial demographic forms and did not reach survey access; as such they were excluded from the final dataset. In order to ensure that estimable models could be produced by the final dataset, the remaining survey sets were included only when at least 80% of survey questions were completed (excluded n = 113). Of note, datasets with <80% completion did not significantly differ from datasets with  $\geq 80\%$  completion on any demographic or obtained data. Lastly, Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2005) scores were examined as screeners for ASD or TD sibling diagnostic validity (described further in the “Measures” section below). SCQ scores resulted in the exclusion of another 19 cases from the final dataset (16 unacceptable ASD scores and 3 unacceptable TD scores).

Overall, the final dataset represents approximately half of the originally-consented ASD families (N=470). Given the length of the current battery, it is suspected that these mothers did not have time to complete the surveys and that discontinuation was not related to survey topics. Please see Figure 13 for a figural representation of dataset finalization for the current study.

**Child characteristics.** Youth age was restricted to children aged 6-12 and adolescents aged 13-17, for the reasons described in the “Developmental Considerations” section above. The final dataset included the full 6-17 year age range for both the ASD youth and TD siblings. The mean age of youth with ASD was 11.74 (SD =2.84) and, similarly, the mean age of TD sibling youth was 11.14 (SD =3.02). In the majority of cases (n=150), the youth with ASD was the older of the two siblings on which mothers reported. Sixteen percent of ASD youth were reported as female; 56% of TD siblings were reported as female. This ratio in the ASD sample is consistent with the approximate 4:1 diagnostic disparity seen in the ASD population

(Fombonne, 2003). Youth reported on in the current sample were predominantly White/Caucasian (87%). Please see Table 1 for more information on child characteristics.

Table 1.  
*Child Characteristics.*

Demographic	Child with ASD	TD Sibling
Age	$M=11.74, SD=2.84$	$M=11.14, SD=3.02$
Sex		
Female	n=38 (16%)	n=105 (44%)
Male	n=201 (84%)	n=134 (56%)
Race/Ethnicity		
White/Caucasian	n=207 (86.6%)	n=208 (87%)
Black/African American	n=2 (.8%)	n=2 (.8%)
Hispanic/Latino	n=7 (2.9%)	n=7 (2.9%)
Native American	n=1 (.4%)	n=1 (.4%)
Asian/Pacific Islander	n=0 (0%)	n=0 (0%)
More than one category	n=22 (9.2%)	n=21 (8.8%)
Presence of IEP	n=212 (88.7%)	n=22 (9.2%)

Notes: ASD = Autism Spectrum Disorder; TD = typically developing; IEP = Individualized Education Plan (special education services).

In regards to gender dyad composition of the two siblings, most were mixed (one boy and one girl, n=118), followed by both boys (n=94), and both girls (n=27). The majority of dyads included the child with ASD as the older sibling (n=150). Please see

Table 2 for more demographic information regarding the sibling dyad.

Table 2.  
*Sibling Dyad Characteristics.*

Demographic	Sibling Dyad
Age discrepancy	
Child with ASD older	n=150 (63%)
TD sibling older	n=39 (37%)
Sex composition	
Mixed	n=118 (50%)
Both boys	n=94 (39%)
Both girls	n=27 (11%)

Notes: ASD = Autism Spectrum Disorder; TD = typically developing.

**Parent and family characteristics .** Mothers self-reported on their own demographic information as well as broader family background factors. Mothers were, on average 42.88 years old ( $SD=5.55$ ) and father age was reported as being, on average, 44.72 years ( $SD=5.72$ ). Both groups represented a wide age range, with mothers ranging from 30 to 57 years and fathers ranging from 30 to 62 years. A subset of parents were reported as having a DSM-5 diagnosis or disorder symptoms:

35.6% and 26.4% of mothers and fathers, respectively. Education history presented a wide range of responses, with “College graduate” as the modal response for both mother and father groups. For more information on parent demographics, please see

Table 3.

Table 3.  
*Parent Demographics.*

Demographic	Mother	Father
Age in years	$M=42.88, SD=5.55$	$M=44.72, SD=5.72$
Presence of DSM-5 disorder diagnosis or symptoms	n=85 (35.6%)	n=63 (26.4%)
Education history		
Eighth grade or less	n=0 (0%)	n=1 (.5%)
Some high school	n=1 (.4%)	n=1 (.5%)
High school graduate or GED	n=10 (4.2%)	n=19 (9.1%)
Some college or post-high school	n=39 (16.3%)	n=32 (13.4%)
College graduate	n=114 (47.7%)	n=92 (38.5%)
Advanced graduate/professional degree	n=75 (31.4%)	n=64 (26.8%)

Note: DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> Edition;  
GED = General Educational Development Degree

In regards to family characteristics, the current sample consisted of predominantly women in heterosexual marriages (87.4%) with total family incomes in the \$101,000 to \$150,000 and over \$150,000 range (48.1%). Participants represented 38 of the contiguous United States, with New York (11.7%), Pennsylvania (9.2%), Massachusetts (8.8%), and California (5.9%) leading in overall distribution. The number of children in the family (including the two reported on for the current study) ranged from 2 to 7 with an average of 2.57 (SD=.89). Further information about family characteristics can be found in Table 4.

Table 4.  
*Family Characteristics of the Study Sample.*

Total number of children in family	$M=2.57, SD=.89$
Mother’s marital/relationship status	
Married (opposite sex)	n=209 (87.4%)
Married (same sex)	n=1 (.4%)
Domestic partnership (opposite sex)	n=1 (.4%)
Separated/divorced	n=21 (8.8%)
Widowed	n=3 (1.3%)
Never married, not living with partner	n=3 (1.3%)
Never married, living with partner	n=1 (.4%)
Total yearly income	
Less than \$10,000	n=6 (2.5%)
\$10,000 to \$20,000	n=7 (2.9%)
\$21,000 to \$ 30,000	n=6 (2.5%)
\$31,000 to \$40,000	n=11 (4.6%)
\$41,000 to \$50,000	n=20 (8.4%)

\$51,000 to \$60,000	n=14 (5.9%)
\$61,000 to \$70,000	n=14 (5.9%)
\$71,000 to \$80,000	n=12 (5.0%)
\$81,000 to \$90,000	n=8 (3.3%)
\$91,000 to \$100,000	n=24 (10%)
\$101,000 to \$150,000	n=62 (25.9%)
More than \$150,000	n=51 (21.3%)
Declined to state	n=4 (1.7%)

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Note: \$ = US Dollars per year.

## Procedure

Participants completed a battery of online questionnaires through the site Qualtrix.com. Before participating in the study, potential participants were presented with an informed consent page (see Appendix A for ASD group and Appendix B for TD group) that explained the specific eligibility requirements for the study, the aims of the study in neutral terms, potential risks and benefits of participation, and the terms for receiving compensation after completing the study. Participants were informed that they would first be asked a set of questions regarding their eligibility for the study and, if they are not eligible, they would not gain access to any further portions of the study. Mothers were further informed that, after completing at least 80% of the questionnaire battery, they would be entered into a 1/10 (10%) chance raffle for a \$200 Amazon.com gift card. Mothers from the TD group were informed that 80% or more completion would enter them into a 1/20 (5%) chance raffle for a \$100.00 Amazon.com giftcard. These differential compensation strategies were implemented based on ethical guidelines of avoiding “undue burden” for research participation by families of youth with significant disorders (Spellecy, Arnold, & May, 2008). If a potential participant did not want to participate in the study after reading the informed consent, then they were directed to the close out of the web browser. Participants that chose to participate indicated that they consented by entering their email address into a specified box on the webpage and, then, gained access to the rest of the questionnaire battery. Email addresses were kept confidential in an encrypted data file that was accessible only to the primary investigator. Besides the email address, no identifying information such as parent names, family surnames, contact information, or any other identifying information was collected in the main data file.

Based on the methodology of past sibling relationship studies (e.g., Furman & Buhrmester, 1985), families that were composed of more than one TD child were asked to only focus on one of these children via random selection (please see Figure 6). All mothers were asked to specify how many youth in their family meet the inclusion criteria for the study. Subsequently, they were prompted to choose one of these particular children to focus upon. To encourage mothers to focus on these particular children, mothers were asked to type the names of the children that they would focus on in the study. For example, prompts appeared as 1) Please type the name of your child with an ASD diagnosis: \_\_\_\_\_, and 2) Please type the name of the other child you will answer questions about: \_\_\_\_\_. Subsequently, prompts with these names will be presented with surveys that focus on specific children (e.g., “When filling out this survey, please focus on Matthew”).

While completing questionnaires, the Qualtrix online survey software employed “skip logic” wherein particular portions of surveys were automatically skipped if they do not apply to that particular participant (e.g., questions about partner were skipped for single mothers). This methodology was employed in order to minimize the amount of time participants were required to spend on the study and, therefore, avoid causing undue burden and reduce response errors. Overall, study completion took approximately 2-2.5 hours. Participants were expected to complete all questionnaires in a single sitting; they were able to save their progress and resume participation at their leisure within a three week time frame. After completing the questionnaire battery, or at least 80% of the battery, participants were thanked for their participation. Raffle winners were told to expect to receive their Amazon.com giftcard via email. All participants had the option to cease participation in the study at any time, without incurring any loss besides the time that they spent on questionnaires. All data was directly stored to the Qualtrix account of the primary investigator. Given that some participants may have been experiencing high levels of distress, all mothers received a link to an online parenting resource site upon study completion (Appendix C).

## **Measures**

Mothers completed measures that related to themselves and their children. Each questionnaire indicated the target individual (e.g. child with ASD vs. child without ASD) on which they were to respond while filling out the questionnaire. Before completing questionnaires, mothers were prompted to enter the first names of the two children that they would be

focusing on for the study. When completing surveys about children, mothers were prompted to fill in the survey about one specific child, based on the selection methods described above. Besides standardized measures (described below), mothers were asked to provide demographic information about themselves, their children, and the broader family (see Appendix D). This form also asked participants to provide information regarding a psychiatric history for themselves and the first-degree relatives of their children. Please see Figure 14 for a depiction of the proposed study model as represented by the following study measures.

**Measure of ASD diagnostic validity.** The following questionnaire was implemented as a measure of ASD diagnostic validity and confirmation of mothers' reported ASD diagnosis (for youth with ASD) or lack thereof (for TD siblings).

***Social Communication Questionnaire, Lifetime Form (SCQ).*** The SCQ was intended as a screener for likelihood of ASD diagnosis (Rutter et al., 2005; Appendix E). The SCQ contains 40 items that relate to the core symptoms of ASD: reciprocal social interaction, communication, and restricted/repetitive behaviors. Each item contains dichotomous "yes" or "no" response, for example: "Can you have a to and fro 'conversation' with her/him that involves taking turns or building on what you have said?" The total score ranges from 0 to 40, with higher scores suggesting a higher likelihood of the presence of an ASD diagnosis within the child's lifetime. As such, the Lifetime Form (as compared to the Current Symptoms form) was used. In the current study, the suggested clinical cutoff of 11 was used as a screen for the validity of mother-reported ASD diagnosis and, in the TD group, a cutoff of 15 was used as a screen for potential ASD diagnosis. These cutoffs have been identified as providing optimal sensitivity and specificity for these distinct screening purposes (i.e. to maximize ASD sensitivity in the putative ASD group, and ASD specificity in the putative TD group; Norris & LeCavalier, 2010). This screener has been identified as a reliable first-level ASD diagnostic tool, with good specificity and sensitivity to differentiating between ASD and non-ASD cases (Chandler et al., 2007). Cronbach's alpha was good for the ASD subgroup (.817) and acceptable for the TD sibling subgroup (.617).

**Measures related to maternal functioning.** The following three measures were reported on by mothers about themselves. These measures assessed depression, stress, and perceived social support.

**Beck Depression Inventory-II (BDI-II).** The BDI-II is a widely used measure of depressive symptoms (Beck, Steer, & Brown, 1996; Appendix F) with evidence for high internal consistency and construct validity (Dozois, Ahnberg, & Dobson, 1998). The measure consists of 21 self-report items that are rated on a Likert scale ranging from 0 to 3, with higher scores indicating higher symptom severity. Items represent specific depressive behaviors or ideations, such as, “Sadness: 0 = *I do not feel sad*; 1 = *I feel sad much of the time*, 2 = *I am sad all the time*; 3 = *I am so sad or unhappy that I can’t stand it*” The total BDI-II score ranges from 0 to 63 and can be compared to clinical cutoffs to determine the clinical severity of current depressive symptoms: minimal, mild, moderate, and severe. Respondents are prompted to report on their past two weeks of functioning. The BDI-II has been used previously in treatment studies (e.g., Blackledge & Hayes, 2006) and descriptive studies (e.g., Dumas, Wolf, Fisman, & Culligan, 1991) of parents of youth with ASD, with these parents typically showing scores within the clinical range of depressive symptoms. The BDI-II was used as a measure of mothers’ current self-reported depressive symptoms and Cronbach’s alpha for this measure was excellent (.925).

**Parenting Stress Index - Short Form (PSI/SF).** The PSI/SF is a 36-item survey of stress commonly experienced by parents of young children (Abidin, 1995; Appendix G). The measure consists of three subscales: Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child Characteristics. As such, the measure yields a score for parenting-specific stress, a score for child-specific stress, and a score for overall stress. Parents rate specific feelings or cognitions relating to their parenting role (e.g., “Since having a child I feel that I am almost never able to do things I like to do.”) on a 1 – 5 Likert scale ranging from *strongly agree* to *strongly disagree*. Total higher scores indicate higher overall parenting stress (ranging from 36 to 180). The PSI/SF has evinced internal consistency and construct validity in a sample of parents of youth with ASD (Zaidman-Zait, et al., 2010) and has been reported on in various samples of parents of youth with ASD (e.g., Davis & Carter, 2008; Lecavalier, Leone, & Wiltz, 2006). The PSI/SF was used as a measure of mothers’ current self-reported parenting stress symptoms and Cronbach’s alpha for this measure was excellent (.935).

**Family Support Scale (FSS).** The FSS is a measure of social support that is provided to parents raising children (Dunst, Jenkins, & Trivette, 1994; Appendix H). The FSS consists of a list of 18 common support resources for parents (e.g.,



specific family members, friends, therapists) and is one of the most widely used scales of social support for samples of mothers of youth with ASD (Boyd, 2002). Support categories include: Partner/Spouse, Informal Kinship, Formal Kinship, Social Organizations, and Professional Services. Parents rate how helpful each particular support resource has been over the past 6 months on a 1 – 5 Likert scale from *not at all helpful* to *extremely helpful*. Total scores indicate how many specific social support resources are relevant to the individual's life (0 - 18) and derives a total score (18 – 90), with higher scores indicating higher levels of overall perceived social support. Overall, the measure has demonstrated internally consistency and retest reliability in samples of parents of youth with DDs (e.g., Frey, Greenberg, & Fewell, 1989). The FSS was used as measure of mothers' self-reported perception of social support and Cronbach's alpha for this measure was good (.761).

**Measures of children's behavior within the family context.** The following two measures pertained to mothers' differential attention and sibling relationships.

***Who Does What? (WDW).*** The WDW questionnaire is designed to measure the division of parenting duties within families (Cowan & Cowan, 1990). For the purposes of the current study, this measure was modified to reflect the division of attention that mothers' give to their children (Appendix I). This particular modification was conceived given that differential attention has not been previously assessed via parental report and is more typically measured via a daily diary (e.g., Quittner & Opiari, 2008), observation (e.g., Brody, Stoneman, & McCoy, 1992), or sibling report (e.g., Brody et al., 1998). The WDW was modified to best reflect specific daily activities related to parent attention that might be reported on in daily diaries, which have been demonstrated to reveal greater levels of differential attention in families than in-person interviews with parents, suggesting that parents may under-report differential attention if asked directly (Quittner & Opiari, 2008). The original WDW focuses on 36 particular behaviors and needs of youth (e.g., bathing, knowing when to eat) and managing a household that are rated in regard to how much responsibility each parent takes in attending to these needs. Here, mothers instead reported on how much they personally attend to 12 specific parenting needs for their children and, conversely, how much their children are able to attend to these items for themselves. For example, mothers were presented with an item such as, "Cleaning up after meals". They responded to items on a 1 - 9 scale ranging from *They do it all alone* to *I do it all*. Total scores ranged from 9 to

108, with higher scores indicating higher levels of mothers attending to their child and, consistently, less independent caretaking. Mothers filled out this measure twice, once for each child. Ultimately, the scores for both administrations (one for each child) were standardized (i.e. Z-scores) and the score of one sibling was subtracted from the other one (TD child's score was subtracted from the ASD child's score) to calculate a standardized differences score (see De Los Reyes & Kazdin, 2004), which was used to represent differential attention. Higher (positive) scores indicated that the child with ASD received more attention and the TD child receives less attention. The traditional form of the WDW has been used in a variety of parenting populations (e.g., Patterson, 1995) and the modification presented here is a novel method of measuring differential attention via parent-report measure. This modified version of the WDW was used as a measure of mother-report of current differential attention towards both children. Cronbach's alpha was good for both sub-groups, youth with ASD (.883) and TD siblings (.842).

***Sibling Inventory of Behavior (SIB).*** The SIB is a 28-item questionnaire that assesses the frequency of specific sibling-related behaviors that can be reported on by either siblings or parents (Schaeffer & Edgerton, 1981; see Appendix J). This scale has been modified to reflect siblings of youth with physical disabilities and DD (McHale & Gamble, 1987) and has been used to reflect the TD sibling's behavior toward their affected siblings. Ratings are presented on a 1 – 5 Likert scale ranging from *never* to *always*, with higher scores indicating a higher frequency of a behavior. The scale reflects both negative (e.g., aggression) and positive (e.g., concern) behaviors that can be demonstrated by one sibling towards the other sibling. Example items include, “Accepts (sibling's name) as a playmate” or “Is embarrassed to be with (sibling's name) in public”. The SIB can either be 1) used for an overall score with reversed scored items (negative) that indicate overall relationship quality, with higher scores indicating better relationship quality or 2) as separate positivity and negativity scores, with respective higher scores indicating higher positivity or negativity in the relationship. Here, the measure was used as an overall total score of relationship quality. Internal consistency and inter-reliability for this measure has been reported to be high in previous samples (McHale & Gamble, 1989) and the measure has been used in multiple samples of siblings of youth with ASD (e.g., Macks & Reeve, 2007). Here, the SIB was used as a measure of mother-report of current sibling relationship quality and

Cronbach's alpha for this measure was good (.700).

**Measures of youths' functioning.** The following four measures reflect various internalizing and externalizing behaviors, as well as overall social skills ability and functional social contact. Two of these measures were completed as assessment of ASD severity and ASD problem behavior. Per the proposed model, three of these measures were implemented as outcome variables for TD siblings.

***Behavioral Assessment System for Children, Second Edition (BASC-2).*** The BASC-2 is a 134-item measure of children's overall psychological and behavioral functioning (Reynolds & Kamphaus, 2004). For the current study, two of the BASC-2 parent report forms were used: child (ages 6-11, Appendix K) and adolescent (ages 12-21, Appendix L). Mothers rated items on a 4-point Likert scale ranging from *never* to *almost always* (e.g., "Is easily upset"). This measure includes Clinical subscales on a variety of internalizing (e.g., anxiety, depression) and externalizing (e.g., aggression, hyperactivity) symptoms. Additionally, the measure includes Adaptive scales such as activities of daily living, social skills, functional communication, and various other domains of children's daily functioning. Higher clinical subscale scores indicate more problematic functioning in that symptom area, while higher Adaptive subscale scores indicate greater independent ability in those specific functioning areas. Higher composite scores on the Behavioral Symptoms Index (BSI) indicate more problematic functioning for youth overall. The BASC-2 shows strong reliability and validity for a wide range of youth (Tan, 2007), including youth with ASD and TD youth (e.g., Mahan & Matson, 2011; Volker et al., 2010). Youth with ASD, in particular, are shown to demonstrate a consistent profile on the BASC-2, which is characterized by high scores on atypicality and withdrawal, and low scores on social skills (Lindner, 2006). Here, the BASC-2 was completed for both focus children, as a measure of problem behavior (externalizing problems subscale) for the child with ASD and as a measure clinical outcomes (externalizing and internalizing subscales with BSI composite) for the TD sibling. NOTE: The BASC-2 data collected for TD siblings was additionally used as a social skills outcome measure (Social Skills subscale of the Adaptive scales) following a researcher error with the originally identified social skills measure (described in the "Social Skills Rating System" subsection). Cronbach's alphas for relevant subscales fell in the good to excellent range for both study subgroups and age groups. For the

TD sibling group Kindergarten-6<sup>th</sup> grade, Externalizing (.927), Internalizing (.944), and Social Skills (.864). For the TD sibling group 7<sup>th</sup>-12<sup>th</sup> grade, Externalizing (.870), Internalizing (.940), and Social Skills (.859). For youth with ASD Externalizing subscale, Kindergarten-6<sup>th</sup> grade (.933), and 7<sup>th</sup>-12<sup>th</sup> grade (.919).

***Social Responsiveness Scale (SRS)***. The SRS is an ASD severity scale for youth that focuses on current impairment in various social behaviors (Constantino & Gruber, 2005; see Appendix M). Parents rate 65 items that relate to their child with ASD's observed social interactions on a 1 - 4 Likert scale ranging from *not true* to *almost always true*. Example items include: "Is awkward in turn-taking interactions with peers (e.g., doesn't seem to understand the give-and-take of conversations)" and "Avoids eye contact or has unusual eye contact". The scale yields five subscales including: Social Awareness, Social Motivation, Social Cognition, Social Communication, and Autistic Mannerisms. Overall, the summed score of this measure yields a representation of overall autism severity. The SRS has been extensively used in both a research and clinical tool in populations with ASD and shows high reliability with diagnostic interviews (e.g., Constantino et al., 2003). In TD youth, the SRS is shown to demonstrate variance across subscales, even when the overall score indicates that a child is not in the ASD diagnostic range (e.g., Pine, Luby, Abbacchi, & Constantino, 2007). The SRS was used as a measure of mother-report of current ASD severity for the youth with ASD. Cronbach's alpha on this measure was excellent (.944).

***Social Skills Rating System (SSRS)***. The SSRS is a parent-report measure of social skills for TD youth, with evidence for internal consistency and validity (Gresham & Elliot, 1990). An Elementary form of the measure was intended to be used for youth in elementary school (Appendix N) and a Secondary form was intended to be used when mothers reported on their children in middle or high school (Appendix O). This scale provides an overall score social functioning and interpretive scores on five categories of positive social behavior: Self-control, responsibility, assertion, empathy, and cooperation. Thirty items are rated on a 0 – 2 Likert scale ranging from *never* and *very often* (e.g., "Answers the phone appropriately"). The SSRS demonstrates high internal consistency in other samples of siblings of youth with ASD (e.g., Quintero & McIntyre, 2010).

However, researcher error resulted in the incorrect versions of the measure being presented to mothers (e.g., the Secondary form presented for elementary school-aged youth). As such, the data was considered invalid and the BASC-2 Social Skills subscale was used as an alternate measure of mother-reported social skills for TD siblings.

***Quality of Play Questionnaire (QPQ)***. The QPQ aims to measure the behaviors that children display during play dates with their peers (Frankel & Mintz, 2010; see Appendix P). The measure includes 19 items regarding common play date activities, as well as the prosocial and conflictual behaviors that the children engaged in during play dates (e.g., “Were bossy with each other”). Items are rated on frequency using a Likert scale of 0 = *not at all* and 3 = *very much*. An additional two items allow parents to report on the number of invitations their child has given or received for one-on-one social activities. Mothers are asked to focus on their child’s one-on-one interactions with the playmate they’ve spent the most time with during the past week. Overall, the scale is reported is described as valid for both clinic and non-clinic samples of youth and has been administered in various studies related to social skills intervention and ASD (e.g., for a review see McMahon, Lerner, Britton, 2013). The current use of the measure as an assessment of siblings’ functional play skills is novel. The QPQ was used as a measure of mother-report of current overall play functioning and social contact for the TD sibling; Cronbach’s alpha was good (.859).

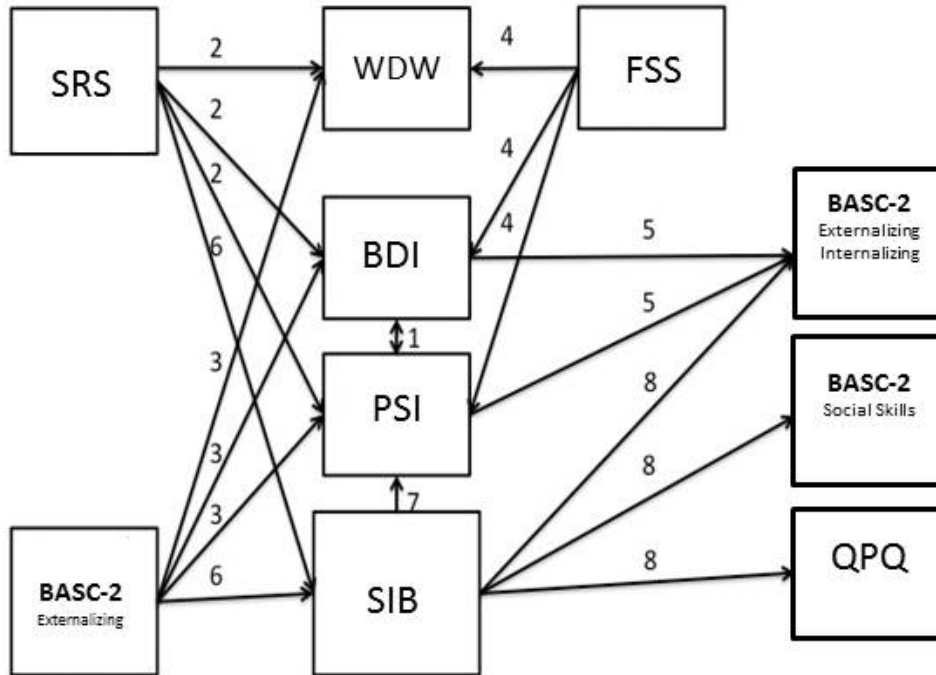


Figure 14. Proposed model as represented by study measures.

### Data Analytic Plan

Based on recruitment outcomes (described above), the alternate single group (ASD) hypotheses were deemed appropriate and implemented for data analysis. As such, the current proposed model was examined as a path analysis given that it proposes directional relationships between a set of observed variables. All data were maintained with IBM SPSS 20 (IBM Corp., 2012) and all analyses were conducted with the IBM SPSS Amos 20 package (IBM Corp., 2011). Missing data was handled with Amos' Full Information Maximum Likelihood (FIML) algorithm. For all analyses, standard goodness of fit parameters were examined: the  $\chi^2$  statistic, Comparative Fit Index (CFI), and Root Mean Square Error of Approximation (RMSEA). A good-fitting model is expected to meet the following cutoffs: CFI >.95, RMSEA <.08 (with a preference of <.05), and, corresponding to the RMSEA value, a non-significant PCLOSE statistic ( $p >.05$ ; e.g., Byrne, 2010). When approaching model respecification, Modification Indices were also examined in the order of largest to smallest, given that larger Modification Indices indicate a larger change to the  $\chi^2$  fit test (Weston & Gore, 2006). As an additional test of how

trimmed or added pathways may influence model fit,  $\Delta\chi^2$  was examined to determine if model changes improved or degraded overall fit. Specific path analysis protocol differed based on requirements of testing particular hypotheses, as described further below.

**Regression and covariation parameters.** The base model (main hypotheses, 1-8) was examined for absolute fit regarding all hypotheses that claim predictive relationships or covariation between variables. The entire model was initially run with all hypothesized pathways included. The exclusion of hypothesized pathways was determined by identifying pathways with potentially poor fit. The pathways related to each hypothesis were examined sequentially with small regression weights that also represented non-significant *p*-values examined first. These pathway regression weights were systematically set to 0. This allowed for the fit indices to be examined with that pathway absent. If the aforementioned fit indices improved in the absence of a specific pathway, that pathway was excluded from the model. Ultimately, the model represented both significant and non-significant pathways that indicated a good fit for the overall model.

Secondly, new regression or covariation pathways that improved overall model fit were added into the model if 1) Modification Indices suggested they would substantially improve model fit and 2) they fit within the theoretical frameworks from which the current model was derived (Anderson & Gerbing, 1988). Improvement in fit based on Modification Indices was measured by improvements to the IFI, CFI, or RMSEA values (according to the cutoff criterion explained above). Besides Hypothesis 1 (correlation between maternal depression and maternal stress), no covariation pathways were included in the original measurement model and no variance parameters were specified. Modification Indices related to covariation of error terms were considered first and, then, suggested regression pathways were examined. Theoretical support was considered in terms of past literature on the topic and, relatedly, if the rationale behind the current study/model included potential relationships between the variables. All variables were entered into the measurement model with respective error terms, allowing modification indices to be suggested for both covariation and regression pathways.

## **Covariates**

After procuring a good-fitting model, all 6 covariates were individually examined for their effect on fit (e.g., Frazier, Tix, & Barron, 2004). Each covariate was modeled as a predictor of all model variables; significant pathways that maintained or improved model fit according to the fit indices were retained, otherwise, these pathways were trimmed.

**Moderation.** After procuring the best-fitting overall model, analysis of moderation hypotheses (3b, 4b, 5b, and 7b) were employed if they remained pertinent to the overall model (i.e. the pathways that they were specified to moderate related in the best-fitting model). Variables of interest were standardized and, then, an interaction term was calculated, using IBM SPSS 20 (e.g., Frazier, Tix, & Barron, 2004). This interaction term was added to the base model and the unconstrained model and run with examination of the appropriate fit indices and statistical significance of the regression weight of the interaction term predicting the dependent variable ( $p < .05$ ). When significant moderation effects were identified, post-hoc probing was performed in order to identify directions of the effect. This was performed by creating “high” and “low” terms (i.e. +/- 1SD) of the relevant moderating variable and comparing regression weights across categories (Holmbeck, 2002).

**Power analysis.** Any given path analysis is recommended to include 10-20 participants per each measured parameter (Klein, 1998). In the proposed model, there are 10 measured variables, 6 covariates, and 1 study group. As such, the recommended sample size for the current study would be 160-320 participants per group. This range of participants would lower the risk of unstable parameters (Kim, 2005), while maintaining a power estimate of .80 and an ability to detect small-medium effect size (Cohen, 1992). Thus the obtained final sample size of 239 is considered adequate for the analyses described above.

## Results

Given the recruitment outcomes described above, all results were examined using the single group (ASD) hypothesis set. Prior to analyses, all data were appropriately screened and prepared for examination. Missing data was handled with Full Information Maximum Likelihood (FIML) in AMOS. Multiple variables were identified as being significantly positively skewed; skewness statistics are presented here: BDI-II (1.00), FSS (1.03), BASC-2 Externalizing subscale (youth with ASD; 1.29), BASC-2 Social Skills subscale (TD sibling; 1.91), and QPQ Conflict (2.35). Appropriate log transformations were



performed for each measure, and normal distributions were obtained. As needed, data relevant to moderation analyses and post-hoc probing were standardized and interaction terms were calculated in order to prepare for the testing of interaction effects.

## **Descriptive Analyses**

Results of descriptive analyses of all study measures are presented in Table 5. The means and standard deviations of all study measures are presented in Table 5. Wherever applicable, scores were examined for the rates of clinical elevations according to the measure's scoring and interpretation protocol. One hundred percent of the ASD sample met the sensitivity clinical cutoff on the SCQ due to study inclusion criteria. Consistently, 0% of the TD sibling group met specificity clinical cutoff on this measure. Similarly, 92% of children with ASD scored in the clinical range on the SRS. In terms of TD sibling-focused measures with clinical cutoffs, sample percentages of elevated scores were as follows (also seen in Table 5): BASC-2 Externalizing 6%, BASC-2 Internalizing 7%, Social Skills 13%, and QPQ Conflict 23%. None of the mean scores on these measures were at or above clinical cutoff. The maternal-focused measures with clinical cutoffs, BDI-II and PSI, demonstrated 34% and 58% of mothers in the clinical range of depression and stress, respectively. Additionally, the group mean for both of these measures were in the clinical range (BDI-II:  $M=11.97$ ,  $SD=9.75$  and PSI:  $M=96.35$ ,  $SD=24.51$ ). On the BDI-II, which differentiates Mild, Moderate, and Severe elevations, the average was in the Mild range.

For the three measures that were completed for both focus children, mean comparisons were examined using paired-sample t-tests. Youth with ASD scored significantly higher than their TD siblings on the SCQ,  $t(238) = 54.71$ ,  $p<.000$ , the BASC-2 Externalizing subscale,  $t(238) = 50.45$ ,  $p<.000$ , and the WDW,  $t(238) = 12.56$ ,  $p<.000$ . As such, the current ASD sample was characterized as having more significant ASD symptoms, externalizing symptoms, and, on average, receiving more maternal attention than TD siblings. As seen in Table 5, the standardized discrepancy of WDW scores, which consists of a Z-score representation of WDW differences between siblings, obtained a mean of .01 ( $SD=1.24$ ). As such, the sibling dyads, on average, lean in favor of the youth with ASD receiving more attention, although a wide range was evidenced (-3.29 – 4.25).

Table 5.  
*Average Scores on Study Measures Grouped by Focus of Report.*

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Focus and Measures	Mean (SD)	Percentage in Clinical Range (When Applicable to Measure)
<i>Child with ASD</i>		
SCQ	22.59 (5.48)	100%
SRS (T-score)	82.85 (14.49)	92%
BASC-2 Externalizing (T-score)	56.63 (11.96)	11%
WDW	63.64 (19.55)	--
<i>TD Sibling</i>		
SCQ	1.78 (1.93)	0%
WDW	46.24 (14.65)	--
BASC-2 Externalizing (T-score)	49.96 (40.62)	6%
BASC-2 Internalizing (T-score)	51.45 (16.31)	13%
BASC-2 Social Skills (T-score)	50.43 (13.85)	7%
QPQ Conflict	2.09 (2.75)	23%
<i>Sibling Dyad</i>		
WDW standardized discrepancy	.01 (1.24)	--
SIB	99.89 (11.44)	--
<i>Mother</i>		
BDI-II Total	11.97 (9.75)	34%
Mild	--	11.7%
Moderate	--	12.6%
Severe	--	8.5%
PSI	96.35 (24.51)	58%
FSS	21.87 (9.69)	--

Note: ASD = Autism Spectrum Disorder; TD = typically developing;  
SCQ = Social Communication Questionnaire; SRS = Social Responsiveness Scale;  
BASC-2 = Behavior Assessment System for Children, Second Edition;  
WDW = Who Does What?; QPQ = Quality of Play of Questionnaire;  
SIB = Sibling Inventory of Behavior; BDI-II = Beck Depression Inventory, Second Edition;  
PSI = Parenting Stress Index

## Correlations

The strength and direction of correlations between all measures was examined (please see Table 6). Many significant correlations were evidenced. Correlations were especially strong amongst subscales of the same measure. For example, TD siblings' BASC-2 Externalizing and BASC-2 Internalizing scales,  $r(239) = .810, p < .01$ , indicating a strong positive correlation between these two subscales.

Table 6.  
Correlations Between Study Measures Included in Model Analyses.

Measures	Child with ASD			TD Sibling		QPQ	Sibling Dyad		Mother		
	SRS	BASC-2 Ext	BASC-2 Ext	BASC-2 Int	BASC-2 SS		WDW	SIB	BDI-II	PSI	FSS
<i>Child with ASD</i>											
SRS	--	--	--	--	--	--	--	--	--	--	--

ASC-2 Ext Sibling	.366**	--	--	--	--	--	--	--	--	--	--
ASC-2 Ex	.006	.124	--	--	--	--	--	--	--	--	--
ASC-2 Int	.046	.066	.810**	--	--	--	--	--	--	--	--
BASC-2 SS	-.014	.005	-.731**	-.613**	--	--	--	--	--	--	--
QPQ Conflict Dyad	-.054	-.027	.291**	.234**	-.123	--	--	--	--	--	--
WDW	.370**	.043	-.256**	-.196**	.166**	-.256**	--	--	--	--	--
SIB Sibling	.079	.127	.143*	.173**	.065	.097	-.201**	--	--	--	--
BDI-II	.339**	.341**	.081	.128*	-.062	.006	.155*	.064	--	--	--
PSI	.469**	.551**	.026	.019	-.062	-.080	.249**	.081	.630**	--	--
SS	-.002	.031	.140*	.097	-.011	.644**	-.046	-.056	.089	-.020	--

Note: ASD = Autism Spectrum Disorder; TD = typically developing;

SCQ = Social Communication Questionnaire; SRS = Social Responsiveness Scale (T-score);

BASC-2 = Behavior Assessment System for Children, Second Edition (T-score) - Ext = Externalizing subscale; Int = Internalizing subscale; SS = Social Skill WDW = Who Does What?

Standardized discrepancy; QPQ = Quality of Play of Questionnaire – Conflict subscale; SIB = Sibling Inventory of Behavior; BDI-II = Beck Depression Inventory, Second Edition;

PSI = Parenting Stress Index

## Initial Measurement Model

Main hypotheses required model fit examination of the full proposed model (Figure 6). The  $\chi^2$  statistic was significant,  $\chi^2(34, N=239) = 705.12, p < .001$ ; however, due to the large sample size, the  $\chi^2$  statistic was deemed inappropriate as a model fit estimate. Fit indices for the base measurement model were IFI (.323), CFI (.305), and RMSEA (.284) and PCLOSE (.000) which all indicated a poor fit. Therefore, model re-specification was pursued in order to improve model fit.

## Model Respecification and Main Hypotheses

To begin model re-specification, model indices related to covariation of error terms were examined first and the model was respecified to include several of these pathways. All TD sibling BASC-2 subscales error terms were covaried with one another. BASC-2 Externalizing subscale error terms were also covaried across the child with ASD and TD sibling versions of the variable. Youth with ASD BASC-2 Externalizing subscale error was additionally covaried with SRS error. These initial modifications improved model fit: IFI (.819), CFI (.814), RMSEA (.164, PCLOSE < .001). Corresponding  $\chi^2(29, N=239) = 111.334, p < .001$ . This represents a large and significant improvement in model fit,  $\Delta\chi^2(5, N=239) = 593.78, p < .001$ .

Next, seven pathways from the original model were trimmed and two new pathways were added. Specifically, the 7 trimmed pathways were: FSS -> WDW, FSS -> BDI-II, FSS -> PSI, SRS -> SIB, SIB -> PSI, SIB -> BASC-2 Social Skills, and BDI-II -> BASC-2 Externalizing (TD sibling). The two pathways that were not reflected in the proposed model but reflected a good fit for the current data were: FSS -> QPQ Conflict and WDW -> QPQ Conflict. These re-specifications to the original measurement model resulted in the following fit indices (all acceptable): IFI (.960), CFI (.959), RMSEA (.07, PCLOSE =.064), and  $\Delta \chi^2 (4, N=239) = 39.38, p < .01$ .

### **Covariates**

Proposed covariates (age discrepancy, gender composition, presence of father, father psychopathology, number of siblings, and family income) were examined as predictors for the full re-specified model of best fit. Specifically, covariates were added as predictors for all of the main variables in the model. The degradation or improvement of fit indices based on the presence of each covariate and specific pathways were trimmed accordingly. Ultimately, 16 covariate-to-model variable pathways were identified.

The overall presence of a father in the family evinced pathways with two variables: a nonsignificant pathway for SRS ( $\beta = -.11, p = .06$ ) and a negative association with QPQ Conflict ( $\beta = -.117, p = .013$ ). TD siblings who lived with their father had lower conflict play scores than those who did not.

Gender composition of the sibling dyad also evinced pathways within the model: a positive association with FSS ( $\beta = .13, p = .05$ ) and a non-significant association with PSI ( $\beta = -.07, p = .11$ ). Higher average family social support was shown for families where both dyads were boys, as compared to mixed dyads or dyads where both siblings were girls.

The other dyadic covariate, age discrepancy between siblings, yielded pathways with maternal/family variables: BDI-II ( $\beta = .14, p = .02$ ), PSI ( $\beta = .15, p = .003$ ), and WDW ( $\beta = .15, p = .01$ ); and three TD sibling outcomes: BASC-2 Externalizing subscale ( $\beta = .13, p = .04$ ), BASC-2 Social Skills subscale ( $\beta = -.12, p = .06$ ), and QPQ Conflict ( $\beta = -.08, p = .09$ ). Larger age discrepancies, therefore, appeared to predict higher depression, stress, and differential attention,

specifically, with more attention paid towards youth with ASD. Further, for TD siblings, it predicted higher externalizing symptoms.

The number of siblings in the family yielded pathways with two variables in the model: WDW ( $\beta = .15, p = .01$ ) and SIB ( $\beta = -.27, p < .001$ ), indicating that number of siblings positively predicted the amount of attention received by the youth with ASD as compared to the TD sibling. More siblings negatively predicted the quality of the sibling relationship.

Total family income predicted three variables: BDI-II ( $\beta = -.21, p < .001$ ), BASC-2 Externalizing (youth with ASD;  $\beta = -.20, p = .001$ ), and SRS ( $\beta = -.22, p < .001$ ). When income was higher, maternal depression and both ASD-specific variables of interest, autism severity and problem behavior, were lower. Lastly, father's psychopathology was not evinced as a meaningful covariate within the current model.

After including covariates, the fit indices of the full model were as follows: IFI (.959), CFI (.957), RMSEA (.048), PCLOSE .554). These indices represent a significant change in model fit from the  $\chi^2$  original measurement model,  $\Delta\chi^2(47, N=239) = 579.34$ , but do not represent a significant change from the immediately previous model.  $\Delta\chi^2(48, N=239) = 53.859, p = .26$ .

### **Re-specified Model**

Overall, the best-fitting model supported some main study hypotheses and nullified others. The full re-specified model and standardized regression weights ( $\beta$ ) are shown in Figure 15; estimated intercepts are shown in Table 6. The main hypotheses and corresponding results are listed here.

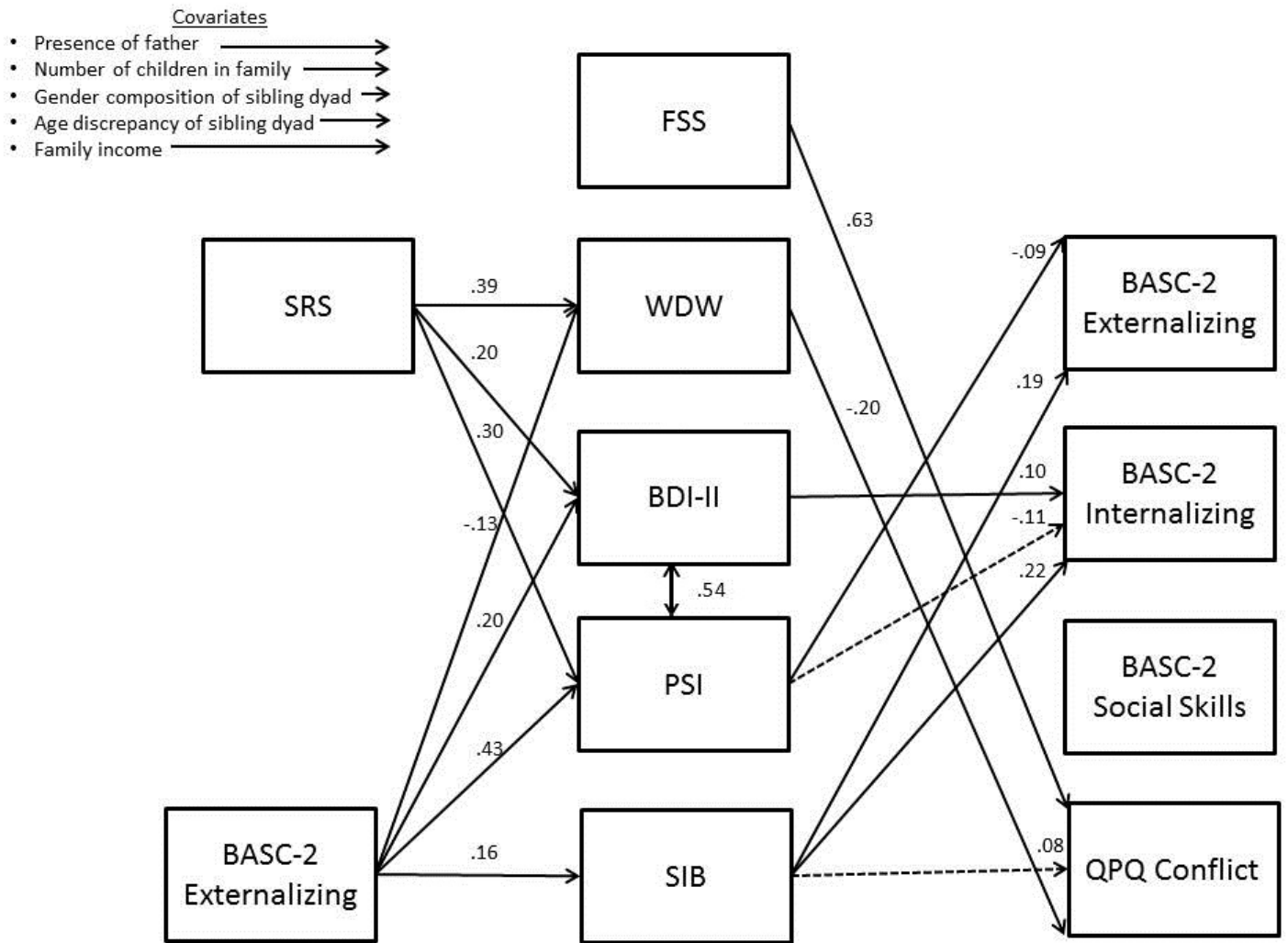


Figure 15. Model of best fit after respecification. Note: Solid lines =  $p < .05$ ; dotted lines =  $p > .05$ .

Table 7.  
Model Intercepts Estimated by AMOS Software.

	Estimate (Standard Error)	<i>p</i> -value
Main variables		
SRS	103.79 (2.84)	<.001
BASC-2 Externalizing - ASD	2.22 (.06)	<.001
BASC-2 Externalizing - TD	79.27 (16.21)	<.001
BASC-2 Internalizing - TD	56.81 (21.58)	.008
BASC-2 Social Skills – TD	1.26 (.02)	<.001
QPQ Conflict	-.38 (.15)	.01
SIB	50.60 (20.46)	.01
WDW	2.71 (2.16)	.21
FSS	.73 (.02)	<.001
PSI	-228.89 (36.25)	<.001

BDI	-.58 (.67)	.02
Covariates		
Presence of father	.92 (.05)	<.001
Income level	.00 (.05)	1.00

Note: ASD = Autism Spectrum Disorder; TD = typically developing;

SCQ = Social Communication Questionnaire; SRS = Social Responsiveness Scale (T-score);

BASC-2 = Behavior Assessment System for Children, Second Edition (T-score) - Ext = Externalizing subscale; Int = Internalizing subscale; SS = Social

Skill WDW = Who Does What? Standardized discrepancy; QPQ = Quality of Play of Questionnaire – Conflict subscale; SIB = Sibling Inventory of

Behavior; BDI-II = Beck Depression Inventory, Second Edition;

PSI = Parenting Stress Index

**Maternal depression and stress.** As predicted (Hypothesis 1), maternal depression and stress were positively correlated in the current model ( $p < .001$ ).

**ASD severity as a pathway predictor.** As expected (Hypothesis 2), higher levels of ASD symptom severity positively predicted higher levels of maternal depression ( $p = .001$ ), maternal stress ( $p < .001$ ), and differential attention across siblings ( $p < .001$ ), specifically with youth with ASD receiving more attention.

**Problem behavior as a predictor of maternal variables.** As expected (Hypothesis 3), higher levels of problem behavior in youth with ASD predicted higher levels of maternal depression ( $p = .001$ ) and maternal stress ( $p < .001$ ). Contrary to expectation, higher levels of problem behavior in youth with ASD negatively predicted the level of differential attention ( $p = .04$ ), with TD siblings receiving more attention.

**Family social support as a predictor of maternal variables.** Contrary to expectations (Hypothesis 4), family social support was not evinced as a meaningful pathway predictor for maternal depression, maternal stress, or differential attention.

**Maternal functioning as a predictor of TD siblings clinical outcomes.** Maternal functioning variables did not predict all of the TD siblings' clinical outcomes, as it was expected to do in the current model (Hypothesis 5). As expected, maternal depression positively predicted internalizing symptoms ( $p = .04$ ); however, it did not predict externalizing symptoms, and that pathway was trimmed from the current model. Maternal stress negatively predicted externalizing ( $p = .04$ ) symptoms, and nonsignificantly predicted internalizing ( $p = .06$ ) symptoms. The directionality of this externalizing effect manifested contrary to expectation. That is, indicating that higher levels of maternal stress predicted less externalizing symptoms for TD siblings.

**ASD factors as a predictor of sibling relationship quality.** As hypothesized (Hypothesis 6), youth with ASD's level of problem behavior predicted sibling relationship quality. Higher levels of problem behavior evinced better sibling relationship quality ( $p = .01$ ). Conversely, ASD symptom severity was not evinced as a meaningful predictor of sibling relationship quality in the current model; the hypothesized pathway was trimmed.

**Sibling relationship quality as a predictor of maternal stress.** Contrary to expectations (Hypothesis 7), sibling relationship quality was not a meaningful predictor of maternal stress in in any direction within the current model; the pathway was trimmed during respecification.

**Sibling relationship quality as a predictor of TD sibling outcomes.** As expected (Hypothesis 8), sibling relationship quality predicted externalizing symptoms ( $p < .001$ ), internalizing symptoms ( $p < .001$ ), and non-significant pathway to quality of play ( $p = .10$ ) for TD siblings within the final model. However, the directionality of findings are counterintuitive, with higher sibling relationship quality scores predicting higher internalizing symptoms. TD siblings' social skills were not predicted by sibling relationship quality as part of the current model and this pathway was trimmed from the final model.

### **Moderation Hypotheses**

All moderation hypotheses were exploratory and examined within the best-fitting model via regression weights and significance testing; model fit change was not evaluated. Some moderation hypotheses were rendered irrelevant by earlier steps of the data analytic plan. Specifically, all of hypotheses 4b and 7b, which proposed ASD symptom severity as a moderator of family social support-predicted pathways and sibling relationship quality as a predictor of maternal stress, were rendered null as none of those pathways were maintained after respecification.

Hypotheses 5b and 8b included pathways that were maintained in the final model. However, none of these moderation analyses yielded significant results ( $p > .05$ ). Therefore, mothers' differential attention was not evinced as a moderator of the relationships between maternal depression and clinical outcomes for TD siblings. Similarly, problem behavior of youth with ASD was not evinced as a moderator of the relationships between sibling relationship quality and TD sibling outcomes (both clinical and social).



Consistent with expectations for Hypothesis 3b, the relationships between ASD problem behavior and maternal variables differed based upon level of ASD severity. All three pathways showed a significant moderating effect on the relationships between BASC-2 Externalizing (youth with ASD) and the following variables: differential attention (WDW standardized discrepancy;  $\beta = -.570, p < .001$ ), maternal depression (BDI-II;  $\beta = -.628, p < .001$ ), and maternal stress (PSI;  $\beta = -.596, p < .001$ ). Post-hoc probing revealed the directionality of these moderation effects. BASC-2 Externalizing of the youth with ASD was identified as having a more positive effect on WDW (i.e. relatively more attention to the ASD vs. the TD child) at *lower* levels of ASD symptom severity (high:  $\beta = -.003, p = .914$ ; versus lower levels of ASD symptom severity:  $\beta = .035, p = .179$ ). That is, when the sibling with ASD exhibited lower levels of ASD symptoms, higher levels of externalizing symptoms were associated with more attention to that sibling (the one with ASD) relative to when the sibling exhibited high levels of ASD symptoms. BASC-2 Externalizing of the youth with ASD was also identified as having a stronger effect on BDI-II (high:  $\beta = .11, p < .001$  versus low:  $\beta = .15, p < .001$ ) and PSI (high:  $\beta = .19, p < .001$  versus low:  $\beta = .22, p < .001$ ) at *lower* levels of ASD symptom severity. These results suggest that lower levels of ASD symptom severity in the presence of higher levels of problem behavior predict poorer maternal functioning and higher levels of differential attention (towards the youth with ASD).

## Discussion

The current dissertation aimed to create a model of risk and resilience for siblings of youth with ASD, thereby answering long-standing questions regarding their overall functioning and, possibly, service needs. The present study fulfilled that aim by generating a model of various family system variables as predictors of clinical and social outcomes for siblings of youth with ASD. Further, a rich set of descriptive findings related to the prevalence of clinical symptoms of siblings of youth with ASD was collected. Of note, the model and other results presented here are, to the knowledge of the author, based upon the largest sibling functioning dataset of its kind. Implications for further research and clinical work based on current findings are discussed here.

### Getting to Know Siblings of Youth with ASD: Characteristics of the Current Sample

Given the history of mixed findings in relation to the adjustment of siblings of youth with ASD (Cuskelly, 1999; Stoneman, 2005; Hodapp et al., 2005), one of the primary aims of the current study was to describe siblings' functioning based on standardized measurement and a large sample of youth. Prior to interpreting these findings, it is important to note that 34% of the current sample of mothers reported depression and 58% reported stress to a clinical degree. These rates are largely consistent with past research (Baker et al., 2003; Davis & Carter, 2008; Singer, 2006).

A small subset of TD siblings was reported to be within the clinical elevation range in terms of externalizing symptoms (6%), internalizing symptoms (7%), and social skills (13%). These numbers are comparable to national estimates for youth aged 3-17: attention and behavioral disorders (10.3%), depression and anxiety (5.1%; CDC, 2013). Further, the mean scores on all of these factors, including social skills, were similar (0-4 point difference) to BASC-2 mean scores obtained from a general sample of TD youth ages 6-13 years (Mahan & Matson, 2011). The highest rate of clinical elevation was observed for quality of play, specifically conflict during play; clinical cutoff was met for 23% of the current TD sibling sample. Clinical cutoff rates for TD youth have not been published elsewhere; however, the overall mean for the sample was not in the clinical range and was, in fact, quite similar to the mean reported for another community TD sample (less than 1 point difference; Frankel & Mintz, 2010). Overall, these results suggest that a subset of siblings may present with clinically relevant challenges, especially in terms of play skills, but, overall, these youth may be functioning similarly to their peers who do not have a brother or sister with ASD.

Interestingly, all of these outcome variables except for internalizing symptoms were influenced by the age discrepancy of the siblings, although only externalizing symptoms demonstrated this effect to a significant degree. Thus, larger age discrepancy may further predict the presence of externalizing symptoms. This finding is consistent with a previous research finding that TD siblings may exhibit more behavioral difficulty when they are significantly younger than their affected sibling (Tomeny et al., 2012). Therefore, birth order may be a dyadic factor that is important when considering risk elevations for behavioral problems amongst TD siblings.

TD siblings, on average, received less attention than their brother or sister with ASD, which replicates a host of previous studies in this area (Corter, Pepler, Stanhope, & Abramovitch, 1992; Lobato, Miller, Barbour, Hall & Pezzullo, 1991; McHale & Pawletko, 1992; Stoneman, Brody, Davis, & Crapps, 1987). This was the first study to utilize the WDW as a measure of differential attention amongst children and, further, in families affected by ASD. The consistent findings with past research and the strong Cronbach's alpha posit this modified measure as a good match for measuring this type of construct. Differential attention in favor of the child with ASD was especially robust when age discrepancies were larger and when more siblings were present within the family. As such, more distance in age may further differentiate siblings and, therefore, make the youth more likely to receive attention. Similarly, more children in the family may result in more caretaking responsibility across siblings and allow for mothers to spend more time attending to the child with ASD.

### **A Model of Sibling Risk and Resilience**

The final model created here represents a model of risk and resilience that fulfills one of the major aims of the current study – to identify how multiple factors, rather than a child's ASD diagnosis alone, act in concert to predict the functioning of TD siblings. Based on the current model, characteristics of the youth with ASD, maternal functioning, and sibling relationship all demonstrate meaningful and specific pathways towards siblings' clinical and social functioning. As suggested by previous work (Cuskelley, 1999; Stoneman, 2005; Hodapp et al., 2005; Tomeny, Barry, & Bader, 2011; Tudor & Lerner, 2015), the current study revealed a multifaceted view of sibling functioning that allows for consideration of a full spectrum of risk and resilience outcomes. Meaningful predictors of sibling outcomes, as evinced by the final model, are presented here separately.

**Youth with ASD.** The problem behavior of the youth with ASD, in particular, predicted all familial variables as hypothesized. ASD symptom severity predicted all of these variables save for sibling relationship quality. These findings suggest that the youth with ASD are an important component of understanding their TD siblings' functioning; however, not as a direct predictor but, instead, as mediated by other familial functioning variables. As seen in past research, higher levels of ASD symptom severity predicted higher levels of differential attention across siblings (with more attention given to the youth with ASD), maternal depression, and maternal stress. Also consistent with past research, ASD problem behavior predicted all

of these variables; however, contrary to expectation, higher levels of problem behavior predicted lower levels of differential attention. This novel finding may reflect how high levels of problem behavior affect the family system as it pertains to mothers' attention to children. For example, problem behavior may encourage mothers to spend more one-on-one time with their respective children or may prompt mothers to engage in one-on-one time with their TD youth following problem behavior episodes. Past research indicates that lower adaptive skills may increase differential attention (in favor of siblings with disabilities; Dallas, Stevenson, & McGurk, 1993; Stoneman & Brody, 1991); the current finding regarding problem behavior may help to elucidate how different kinds of child needs may impact differential attention in families. Interview studies with siblings have indicated that this relationship may be a prominent theme in some siblings' perceptions of life with their brother or sister with ASD (e.g., Benderix & Sivberg, 2007; Petalas, Hastings, & Nash, 2009).

The finding that ASD symptom severity moderated this relationship may further support this interpretation: differential attention was higher when ASD problem behavior was high and ASD symptom severity was low. High levels of both ASD symptom severity and problem behavior may, in fact, influence mothers to give more equal attention to their children, whereas problem behavior accompanied by mild ASD symptoms may divert more attention to youth with ASD alone. Moderation results also showed similar patterns in terms of ASD symptom severity impacting the relationship between ASD problem behavior and maternal functioning. These results interestingly suggest that mothers may experience more depression and stress when problem behavior is high and ASD symptoms are milder. Problem behavior has been evinced as a prominent predictor of maternal stress (e.g., Estes et al., 2009; Hastings, 2003) but this particular moderation finding has not yet been reported. This combination of symptoms may indicate a risk factor for poorer maternal functioning. Further, this pattern of results may reflect social difficulties experienced by mothers. For example, societal understanding may be better when youth with ASD can be more readily perceived as being "different" through the combination of both core symptoms and problem behavior, whereas mothers may feel more isolated when problem behavior alone is significant and others may not perceive the developmental differences of their child and the parenting demands they may face. One prior study demonstrated that mothers of youth with ASD and mothers of youth with behavioral disorders are similar in that both groups experience dysphoria at

levels that far exceed mothers of TD youth or youth with Down Syndrome (Dumas et al., 1991). Such findings may help to interpret the current finding and illuminate the importance of problem behavior in understanding maternal functioning. The depth of the current analytic methodology in examining these relationships here is novel in the ASD and sibling literature and, consistently, these results have not been demonstrated previously.

ASD problem behavior appears to be especially of import in understanding the sibling relationship: higher levels of problem behavior predict a higher sibling relationship quality. These results provide a novel, albeit counterintuitive, insight into the sibling dyad wherein one youth has ASD and one does not. Higher levels of problem behavior may, in fact, create a starker contrast between sibling functioning and, therefore, create more positivity from the TD youth toward their affected sibling. The presentation of problem behaviors may serve as a more concrete and observable form of difficulty (e.g., tantrums, non-compliance) that may be more readily identifiable as development differences to TD youth as opposed to core ASD symptoms (e.g., Glasberg, 2000). As such, TD youth may demonstrate more understanding and demonstrate more positivity to siblings when they are experiencing these difficulties. Further, problem behavior uniquely creates barriers to community integration for families affected by ASD (e.g., Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005). While such barriers may appear to create negativity between siblings, it may, in actuality, promote family unity and solidarity in supporting youth with ASD, which may promote positivity in TD siblings.

**Maternal/family functioning.** As expected, maternal and family functioning were key predictors of sibling outcomes in the final model. However, some of these relationships were different from original expectations. Firstly, maternal depression and stress were highly correlated with one another, consistent with previous research. These two variables, however, demonstrated unique effects on TD siblings' clinical outcomes according to the final model. Maternal depression positively predicted TD siblings' internalizing symptoms (but not externalizing symptoms). This result speaks to the impact that maternal depression may have on the internalizing symptoms of their children, above and beyond the effect it may have on other areas of functioning. Such findings are supported by a vast array of work, including the model by which the current model was partially generated (Goodman & Gotlib, 1999). The degree to which this finding is particular to siblings of youth with ASD

warrants comparison to other groups of children; however, the current analyses indicate that it was *not* moderated by ASD symptom severity, suggesting that the effects are present regardless of the level of ASD symptoms. Here, as with previous studies (e.g., Barnett & Parker, 1998; Cichetti & Toth, 1998; Goodman et al., 2011), the question of intergenerational transmission of depression as an effect of genetic loading, maternal modeling of maladaptive coping, or parentification of youth (or combination of such effects) is raised (Goodman & Gotlib, 1999). Further, the possibility that mothers experiencing depression are wont to perceive their children as having more difficulty is present. However, given that a larger proportion of mothers' self-reported clinical levels of depression than reported clinical levels of internalizing symptoms in their TD children may contraindicate this possibility, at least for a portion of the sample. Overall, the model indicates that ASD characteristics predict maternal depression and maternal depression predicts TD internalizing outcomes – a sequence of family variables that may serve as important in identifying at-risk TD siblings.

Maternal stress presented with more counterintuitive findings. Firstly, unlike maternal depression, maternal stress predicted TD youth externalizing symptoms in the final model; however, this relationship was *negative*. Higher levels of maternal stress predicted lower levels of TD externalizing symptoms. Like the effects demonstrated by maternal depression, maternal stress was predicted by ASD characteristics and appears to influence TD clinical outcomes; however, unlike maternal depression, it appears especially important in identifying a *lower* risk for *externalizing* symptoms. While maternal stress has been characterized as a potential risk factor for youth functioning (e.g., Goodman & Gotlib, 1999; Hammel, 1987), these findings may speak to the truly distinct elements of these highly correlated constructs. Whereas maternal depression may present a higher risk for similar symptoms in youth, maternal stress may serve as a kind of protective factor for these families. Extant research typically approaches the topic of maternal stress as an invariant risk factor. However, stress as a potential predictor of positive outcomes has been elsewhere supported (e.g., as foundation for experiencing resilience and coping, Folkman & Moskowitz, 2000), and Belsky's (1997; 2009) evidence-based concept of stress and "plasticity" speaks to the concept in regards to youths' functioning. More traditionally, youth have been categorized into groups of those that are resilient regardless of adversity and circumstance (dandelions), while others may be especially susceptible to the influence of

their environment and upbringing (orchids; e.g., Luthar, 2006). Belsky & Pluess (2009) propose a model wherein these “orchid children” may not solely represent youth who are sensitive to stress as a predictor of poor outcomes but, alternately, some of these youth may be susceptible to stress in this opposite direction – as a predictor of resilience and adaptation. Siblings of youth with ASD may be “orchids” in this sense and, interestingly, they may demonstrate better outcomes when faced with adversity (e.g., maternal stress). Conversely, the current finding may reflect a reporting effect wherein stressed mothers of youth with ASD under-report behavioral difficulties in their other children, perhaps due to perceptions of behavior being skewed by the behavior of their child with ASD. However, these effects were *not* moderated by the level of problem behavior exhibited by the child with ASD and this may argue against such an interpretation of this result.

Family social support, did not predict any of the familial/maternal functioning variables, while it did, unexpectedly, predict more conflict during play for TD siblings. Given the large amount of past work identifying lack of social support as a predictor of depression and stress (e.g., Leavy, 2006), including within the ASD population (e.g., Boyd, 2002; Duarte, Bordin, Yazigi, & Mooney, 2005; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Weiss, 2002), the lack of meaningful predictions in the final model was surprising. It is possible that the many other meaningful pathways included in the current complex model of ASD family functioning sufficiently explain the processes under investigation, and render the specific pathways between social support and maternal functioning overshadowed by comparison. Further, questions may be raised about the appropriateness of the current measure (Family Support Scale) for the current sample. Specifically, the Family Support Scale consists of ratings of how useful specific common support resources (e.g., partner, friends, community organizations) are for the rater. Other social support measures, such as the Social Support Index (McCubbin, Patterson, & Glynn, 1982) have been used in ASD-related studies (e.g., Luther, Canham, & Cureton, 2005; Boyd, 2002) and focus on specific aspects of social support, such as feelings of being understood and the ability to talk about problems, rather than specific sources of support. Given the high demands of parenting in families affected by ASD, it may be that overall perceptions of support from various sources may be less important than specific feelings of support when predicting maternal depression and stress, as well as differential attention towards the children.

Conversely, perceptions of overall social support from various sources were shown to positively predict conflict during play in the current model. In fact, this was the largest regression weight reported in the overall model. Interestingly, this finding suggests that more support resources for the family predicts more conflict during TD youth's play. It is possible that this wider support network presents with less consistency in responses from adults, thereby lessening the chance to learn about cooperative play skills. Alternatively, members of the expansive support networks may, much like typical home environments, provide more attention to the ASD sibling (assuming they are present) and TD youth may display more conflict with peers as an attention-seeking behavior (e.g., Taylor & Carr, 1992). Families with more supports may also simply provide more chances for peer interaction (e.g., church, community organizations, relatives' homes) and allow for more variability, including conflict, to be observed in peer-interaction behavior. Much like sibling relationships (to be described further below), childhood friendships may benefit from some conflict during play as a chance for practicing assertiveness and compromise (e.g., Hartup, French, Laursen, Johnston, & Ogawa, 1993), but this concept has not yet been studied with the current standardized measure (QPQ). Overall, further investigation is required to examine the potential mediating role that number of social interactions and caretakers may play for this unexpected relationship.

Differential attention also unexpectedly predicted TD siblings' conflict during play. In particular, a higher level of differential attention predicted lower conflict during play. This relationship may be explained by TD siblings who receive less attention as also having less social interaction and, therefore, fewer chances for play conflict. Alternatively, these siblings may have improved play skills, maybe due to responsibility-taking in play conflict with their sibling with ASD. TD siblings often assume more caretaking and dominant roles with their affected sibling (e.g., Stoneman, 2005). Having a sibling that requires more attention from mothers may intensify this common pattern and, ultimately, may reflect an opportunity for an increased strength in terms of play skills.

**Sibling relationship.** Sibling relationship quality was a significant predictor of both clinical outcomes in the final model. All of these relationships were positive in direction, with better sibling relationship quality predicting higher levels of clinical symptoms. Contrary to expectation, this factor was not a meaningful predictor of TD sibling social skills. These



findings may provide a novel insight into how sibling relationship quality may relate to overall sibling functioning and, in a possibly counterintuitive fashion, better relationships may put a TD sibling at higher risk for internalizing and externalizing symptoms. When interpreting this result, it is important to consider the fact that sibling relationships are unique in terms of dyadic relationships in that both positive and negativity can co-occur at high valences, as opposed to one sentiment dominating the other (e.g., Schaeffer & Edgerton, 1981). One study examined the effects of warmth and positivity as the dominant sentiment in sibling dyads (Hetherington, 1988). This characterization was identified as the most rare balance of dyadic sentiment (as opposed to equally negative and positive or mostly negative). This early study found that youth in this category were more likely to come from familial environments where less adult responsiveness was available, purportedly leading to higher alliance between siblings. Further, mostly positive dyads were shown to report less concern with social acceptance (both peers and adults) and, ultimately, were at higher risk for internalizing symptoms. The current study used the SIB composite score, which reflects overall sibling relationship quality by reverse scoring negative relationship items. A higher SIB score reflects more positivity, and may reflect findings that are similar to Hetherington's previous study. Such an interpretation would suggest better clinical functioning for TD siblings whose sibling relationships are less dominated by positive relating. This is not to say, however, that better outcomes are more probable when sibling relationships are more negative but – instead – that sibling relationships consisting of both high positivity *and* high negativity within the dyad are most helpful to the TD sibling. Past research in this area of sibling relationships in dyads affected by DDs is mixed in terms of findings (McHale et al., 1986; Roeyers & Mycke, 1995) and the current results provide a new insight onto the topic of sibling relationships and ASD, as well as the depth of investigation (e.g., levels of co-occurring relationship valences) that may be necessary to identify how these relationships may affect TD siblings.

The lack of a relationship between sibling relationship and TD sibling social skills suggests that social skills may manifest regardless of the positivity or negativity experienced in the sibling dyad. Overall, this may reflect a promising finding wherein TD siblings are not at-risk for poorer social skills in cases of poor sibling relationship. TD sibling social skills may

develop in a fashion largely separate from this specific factor. Again, however, further examination of distinct facets of the sibling relationship (both positivity and negativity) may help yield more results in this specific area.

### **Risk and Resilience in Families Affected by ASD.**

In summary, the model presented here offers unique findings regarding the direct and indirect pathways towards outcomes for siblings of youth with ASD. These findings can be categorized into “risk” (more negative outcomes) and “resilience” implications for these youth. A table representing this categorical breakdown is presented in Table 8. Of note, the directionality of these categorizations (risk versus resilience) is based upon the nature of the measures included in the current study. For example, maternal depression as a risk factor for internalizing symptoms in youth is presented as a risk factor given that the severity of depression was measured; however, these findings may also indicate that the converse is true (e.g., minimal or normative depressive symptoms as a resilience factor for less internalizing symptoms in TD youth). A summary of the ASD-specific findings is briefly presented here.

Consistent with past research (Baker et al., 2002; Barker et al., 2011; Lecavalier et al., 2006; Osborne & Reed, 2009), the ASD symptom severity and problem behavior of youth with ASD were important to understanding the family system. Here, they were especially evinced as initial risk factors that set the model “in motion.” These factors were important predictors of key familial elements of the model: maternal stress, maternal depression, and differential attention. However, these two ASD-specific factors did not have identical effects, suggesting that they are important yet separate constructs in understanding functioning pathways for families affected by ASD and, indirectly, the functioning of TD siblings. Sibling relationship quality, in particular, was positively predicted by ASD problem behavior but not ASD symptom severity. This finding adds to the evidence of the unique role that high levels of problem behavior may play in sibling interactions, including increased conflict and aggression (Farmer & Aman, 2010; Orsmond et al., 2009). As expected, maternal depression and stress were key variables and correlated with one another (e.g., Hammen et al., 1987; Wang et al., 2013) but, like findings regarding the characteristics of the youth with ASD, these maternal functioning factors appeared to differentially affect TD youth outcomes for these families. Specifically, maternal depression was evinced as a risk factor for internalizing symptoms, which

is consistent with research in other TD populations (Downey & Coyne, 1990; Kelin et al., 2001). Maternal stress, on the other hand, played more of a protective role in decreasing externalizing behavioral problems, which is a novel direct pathway that particularly speaks to ASD family functioning. More differential attention in favor of the youth with ASD also appeared to play a protective role in improving quality of play which is, again, a new finding to this area of study.

Additionally, family social support, though shown as prominent resilience factor for maternal functioning when examined in past studies (e.g., Boyd, 2002; Bromley et al., 2004; Leavy, 2006; Weiss, 2002), was more importantly demonstrated as a risk factor for TD siblings' quality of play in the current model. Thus, when considering sibling outcomes, family social support appears to play a uniquely important role. Lastly, both internalizing and externalizing clinical outcomes were also predicted by more positive sibling relationship quality – specifically, as a risk factor for both clinical outcomes, which indicates that a less-balanced (positive and negative) is a risk factor of siblings (e.g., Hetherington, 1988). This finding is novel in the literature related to families affected by ASD.

Table 8.  
*Summary of Predictors in Current Model, Interpreted as Direct Risk or Resilience Factors.*

Variable Constructs	Risk	Resilience
ASD Factors		
ASD Symptom Severity	+ maternal depression + maternal stress + differential attention	
ASD Problem Behavior	+ maternal depression + maternal stress + differential attention - sibling relationship quality	
Maternal/Family Functioning Factors		
Family Social Support	- quality of play	
Maternal Depression	+ internalizing symptoms	
Maternal Stress		- externalizing symptoms
Differential Attention		+ quality of play
Dyadic Factor		
Better Sibling Relationship Quality	+ internalizing symptoms + externalizing symptoms	

### **Implications for Broad Models of Family and Sibling Functioning.**

The current model was adapted from two existing models of youth outcomes, one focused on maternal depression (Goodman & Gotlib, 1999) and one focused on sibling relationships (Feinberg et al., 2011). These models proved meaningful foundations for understanding the processes for this special population of youth, though findings regarding overlapping variables indicate that some processes may differ across populations. Specifically, Goodman and Gotlib's (1999) model presented maternal depression as an invariant risk factor, leading to clinical outcomes (both internalizing and externalizing) due to inherited psychobiological dysfunction, acquired skills deficits in terms of cognitive, affective, and behavioral ability. These vulnerabilities are proposed as outcomes from the genetic loadings and learning history associated with being raised by a mother with depression and, importantly, being exposed to stress. Here, the current model consistently shows that maternal depression leads to similar internalizing symptoms for these siblings. But exposure to maternal stress served as a type of protective factor for youth in terms of externalizing behaviors. As such, the effect of maternal stress on TD sibling outcomes may differ for families affected by ASD versus other families. This effect may, however, may not be particular to ASD but may be present in other family contexts where youth are exposed to ongoing unique experiences (e.g., chronic illness) that affect maternal functioning. Further, these results may speak to other underlying protective variables about the TD sibling, such as resiliency (or even thriving) in adverse circumstances (e.g., Belsky, 1997) or resilience promoted by academic or other external strengths (e.g., Masten, Best, & Garmezy, 1990) that were not a primary focus of the original Goodman and Gotlib model, nor were they a focus of the current study. Such lines of investigation may greatly benefit the general understanding of maternal depression and youth outcomes.

In terms of sibling relationship, families affected by ASD, again, appear to demonstrate a relationship between variables that are not included in the extant sibling relationship model (Feinberg et al., 2011). The extant model conceptualizes sibling negativity as a key predictor that, eventually, leads to behavioral problems. In between these two variables, intermediate pathways are present including impaired family interactions and, subsequently, decreased monitoring and positive attitudes towards defiance. Thus, one may assume that the converse is true – sibling positivity would lead to more favorable clinical outcomes for siblings. Here, however, siblings of youth with ASD were more at risk for poor clinical outcomes when

their sibling relationships were more positive. Some past research in this area (e.g., Hetherington, 1988), suggests that these findings may reflect a unique familial environment wherein youth align more with each other than with their parents; as such, there may be several life circumstances where such an effect could be observed across siblings, including dyads that are not affected by ASD. Overall, the current model suggests ongoing inquiry into the nature of co-occurring positivity and negativity in sibling relationships (e.g., Brody, 1998) and how these valences reflect other areas of youth functioning.

### **Limitations**

While the present study presents several strengths in terms of sample size and depth of information gathered, several aspects may limit generalizability and must be considered when interpreting the current results.

The most notable limitation of this model is the lack of a control sample of families with only TD children. The current study clearly gained little momentum in terms of TD family recruitment, ultimately resulting single group (ASD) analysis of results. As described in the Introduction to this dissertation, a TD comparison group would be ideal for drawing inferences regarding familial patterns that are specific to family systems affected by ASD versus those that are not. Given the immense difficulty that was faced in recruiting TD families despite great effort, it is expected that the raffle prize schedule, in conjunction with the time commitment necessary to complete the battery, was insufficient in motivating these families. Additionally, anecdotal and research evidence suggests that families that feel more in need of benefits from research studies are more likely to participate (e.g., Goodman et al., 2011; Heinrichs, Bertram, Kuschel, & Hahlweg, 2005). TD families are probably less likely to view research studies such as the current one as immediately useful to them, as compared to clinical populations of siblings. These factors should be considered in future studies in this area, with ongoing efforts to recruit comparison samples.

The current sample, though markedly large for the nature of the current investigation, may be limited in terms of what families were represented. It is impossible to know exactly how many mothers of youth with ASD became aware of the current study through various recruitment methods but, assuredly, this number was at least in the 3,000-4,000 range. A total of 470 mothers initially consented, an estimated 12%-16% of mothers who may have received information about the study. The

ultimate dataset (N=239) represents a respective estimate of 6%-8%. These numbers are rather small given the large recruitment effort and, therefore, mothers who did participate in the current study may not reflect a representative sample of mothers of one child with ASD and at least one other child. Demographic information collected on these mothers indicate that they are largely 1) Caucasian/White, 2) married to a man, 3) college-educated, and 4) in a high income bracket. The current study required 2-2.5 hours of participation and, though a chance for a substantial prize was presented, no compensation was guaranteed for their time. Thus, mothers who did complete the study may have been skewed in their ability to devote that amount of time to the current study, maybe due to higher support or financial resources. Further, given that most mothers were recruited through collaboration with IAN, the current sample likely represents families who are very aware of ASD research and are motivated to contribute to such endeavors. As such, the results of the current study may not speak to a broad spectrum of families. The sample is, overall, lacking in diversity on several demographic variables. The results obtained here may be consistent with other samples of families but this could not be examined with the sample that was currently recruited.

Additionally, the current study was limited to cross-sectional survey (maternal report) data collection. Other methods of information gathering could potentially provide more accuracy than mothers' self and parental-report alone. For example, multi-parent reports, teacher reports, and child self-reports could also capture a more informed view of youths' behavior (De los Reyes & Kazdin, 2005). Also, clinical interviews by trained clinicians would be preferable to survey data for some of the information collected here, such as mothers' depression and TD siblings' internalizing and externalizing symptoms, so that clinical diagnoses could be examined. The current dissertation did not possess the resources necessary for undertaking the task of inviting families in to the laboratory and employing trained clinicians to administer, for example, the Structured Clinical Interview for the DSM (SCID; First, 2015) or the Schedule for Affective Disorders and Schizophrenia for School-Age Children (K-SADS; Kaufman et al., 1997). Therefore, the current dataset provides estimates of clinical risk but cannot speak to the actual diagnostic status of the mothers and TD siblings reported upon here. In terms of non-clinical factors, more rigorous methodology could also be employed, For example, when examining sibling relationship quality and differential attention, daily diaries may help mothers give a more nuanced report of sibling interactions or attention towards children (e.g., DeLongis,

Hemphill, & Lehman, 1992). Laboratory-based observations and coding of these familial behaviors may also be useful (Stocker, Dunn, & Plomin, 1989). Similarly, reliance on mother's report disallows for stringent ASD diagnosis confirmation (or lack thereof for TD siblings), which could be better provided through sharing of diagnostic reports or clinician verification. Further, the findings of the current study could be expounded upon with longitudinal study designs as opposed to reports at single time points.

### **Future Clinical Practice (and Related Research)**

The current dissertation suggests that 1) only a small subset of siblings of youth with ASD may be experiencing clinical or social difficulties, and 2) TD sibling outcomes are affected by several familial factors. These findings set the stage for a wealth of future research and research-based clinical practice. Importantly, the results of this study speak to the idea that “sibling” is not a diagnosis (Tudor & Lerner, 2015); having a brother or sister with ASD does not set youth on a singular trajectory of functioning. Such an idea will be important for future research and sibling-focused services.

Most TD siblings may experience a typical level of clinical symptoms and may demonstrate good social skills. Anecdotal reports and the rising interest in sibling-based services indicate that parents of youth with ASD may be quite concerned for their welfare of their TD children, especially in regards to their “sibling” status (Hodapp et al., 2005; Myers, Mackintosh, & Goin-Kochel, 2009; Stoneman, 2005). This concept was certainly supported within the current study, wherein many parents wrote comments to the author that thanked her for embarking on this area of study ([names redacted to protect confidentiality], personal communication, 02-09/2014). These parents may be especially attuned to expecting difficulties or service needs for their children. Clinicians who work with youth with ASD should be prepared to inform parents about the actual rates of risk and resilience for TD siblings – that, in fact, they are likely to function well. For TD sibling where this is not the case, and clinical elevations are demonstrated, consideration of what may help these youth with unique family circumstances is warranted.

**Existing services.** One systematic review has examined the current status of support and intervention services for youth with DDs (Tudor & Lerner, 2015). The majority of such services focus on support for siblings through spending time with other siblings. The current study did not examine the extent to which TD siblings knew or spent time with other sibling

youth and cannot speak to the direct effects of such support. Authors of the aforementioned study noted that clear conclusions on the effectiveness of this approach were precluded by the variability of outcome measurement that has been used in past studies. However, the extant research on services for siblings almost unanimously supports the idea that siblings enjoy groups and find them fun. These groups, such as SibShops, typically consist of social activities, games, and exercises that ask youth to reflect or share about being a sibling. The overall benefits that may be derived from these groups for siblings that are functioning well in emotional, behavioral, and social arenas (e.g., one-on-one adult attention, playtime with peers, time away from sibling, reciprocal support from peers in similar life situations) requires further study. For siblings wherein specific and clinically relevant difficulties are present, these groups will likely *not* be adequate in addressing concerns.

The proportion of youth with high levels of clinical or social problem symptoms may benefit from evidence-based treatment for children that specifically target the outcomes measured here. For example, cognitive behavioral approaches to treating youth anxiety (e.g., Barrett, Duffy, Dadds, & Rapee, 2001) or depression (e.g., Weisz, McCarty, & Valeri, 2006) have a strong evidence base. Parent training and behavioral approaches are strongly evidenced as effective and recommended for the externalizing symptoms measured here (e.g., Chronis, Chacko, Fabiano, Wymbs, & Pelham, 2004; Kazdin, 1997; Serketich & Dumas, 1996). Play skills can also be specifically targeted in terms of decreasing conflict and increasing friendship-making in youth (Frankel & Myatt, 2003). However, the question remains as to whether referring all at-risk siblings to these treatments would be sufficient in light of their unique family system. As the current study demonstrated, multiple factors may lead to symptom outcomes and could be viable focuses of intervention. Further and importantly, questions also remain regarding how siblings might be identified as needing such services in the first place.

**The future of specialized services.** The future of specialized services and related research for siblings will require 1) an effective method of screening siblings for potential difficulties that warrant clinical attention, 2) a re-focus on services not just for the siblings themselves but for specific members and dyads within the family system, and 3) a burgeoning focus on preventing difficulties for siblings, as well as promoting their strengths. The following recommendations are outlined not as



only as suggestions for novel approaches to clinical practice and related research but, additionally, as modifications and supplements to the many existing and growing sibling-focused services that are on the rise in the United States.

**Assessment.** In order to receive effective services, siblings in need will first need to be effectively assessed for those needs. An ever-increasing amount of information is suggested as part of effective evaluations for ASD diagnosis and treatment, such as sleep function (Tudor, Hoffman, Sweeney, 2012) and co-occurring psychiatric symptoms (Simonoff et al., 2008). The amount of information necessary to effectively diagnose ASD and design a useful treatment plan is extensive even before considering additional useful variables. Adding a thorough assessment of sibling functioning to these repertoire is likely not feasible in the typical clinic setting; however, it would behoove clinicians (and, therefore, families) to briefly inquire if parents of multiple children have any concerns about their TD children when they present to clinic regarding their youth with ASD. Due to time, financial, childcare restraints, and other systemic difficulties, parents often report it difficult to access the services recommended for their youth with ASD (e.g., Dymond, Glison, & Myran, 2007), rendering it even more likely that consideration of concern about or services for their TD youth is not always voiced. Should concerns be present following a brief inquiry or observation, it would be beneficial for clinicians to be prepared to provide brief standardized assessment (like the measures used in the current study) surrounding the TD youth's or sibling dyad's functioning or, alternatively, to provide appropriate referral sources. Of most importance, the results of the current study suggest that simply providing a referral to a local sibling group or workshop will be inadequate in addressing specific psychological, behavioral, or social concerns that may be present in a subset of siblings.

Such sibling-focused services could also be, but are typically not currently, an important resource in assessing TD siblings' functioning. In Tudor and Lerner's (2015) systematic review, few services gave pre-intervention or support group assessments to sibling youth. The current study suggests that a small number of siblings in these groups may have actually been experiencing significant clinical or social challenges. While these services may not explicitly offer therapeutic services (e.g., SibShops; Meyer & Vadasy, 2004), many parents may seek these services because of concern and a desire for help regarding the functioning of their TD youth. Future study of the characteristics of siblings and families who seek out these

services is warranted and may reveal interesting information about this topic. Based on the current descriptive findings, it is suggested that such services routinely screen for more pressing concerns that may require additional clinical referrals for families. Of course, in order for the recommendations stated here to be worthwhile for families, it is also of great relevance for this area of study to provide more insight into the validity of singular parent report from parents of youth both with and without ASD, due to potential biases in perceptions of behavior, or limited access to the full range of the child behavior on which they are reporting (e.g., De Los Reyes, 2011).

*A focus on mothers.* Beyond assessing sibling functioning, the current study strongly suggests that the well-being of TD siblings is influenced by maternal functioning. As such, a pivotal change in conceptualizing support or intervention for TD siblings may require focusing support or intervention for *mothers* concurrently or even before focusing on TD youth themselves. One meta-analysis (Singer et al., 2002) demonstrated good outcomes of stress-reduction interventions for mothers of youth with ASD and some evidence for the utility of depression-focused interventions for these mothers exists (e.g., Bristol, Gallagher, & Holt, 1993; Singer & Floyd, 2006). However, anecdote reports of clinical services quickly convey that parent-focused interventions are neither popular nor do they appear much desired (Myers et al., 2009) – quite the opposite of sibling-focused services. Many reasons may explain this discrepancy, such as the high demands that are required to provide care and services for their youth with ASD (e.g., Dymond et al., 2007) in addition to other time-consuming parental demands (Myers et al., 2009). Additionally, self-defeating cognitions surrounding guilt, shame, and lack of self-efficacy may prevent mothers from seeking help (e.g., Kuhn & Carter, 2006; Meirsschaut et al., 2010). A research imperative will be to identify barriers that may preclude mothers from seeking or participating in interventions to improve their overall functioning. The current study suggests that a large proportion of mothers of youth with ASD and at least one other TD child are experiencing clinical depression (34% of sample) or stress (58% of sample). Importantly, depression may directly adversely affect some TD siblings. Maternal stress, in contrast, may not play a similar role but, as mentioned previously, further investigation as to why that may be the case is warranted in order to identify how maternal stress may benefit some siblings. Nevertheless, mothers' personal experience of significant stress remains an important area of clinical need. Overall, improvement of mothers'

functioning may be a key component of improving the likelihood of resilient outcomes for a subset of at-risk siblings and deserves more attention.

***A focus on the sibling relationship.*** Foci for the future of services for siblings should also go beyond individuals, such as the TD youth or mothers, and also consider the sibling dyad. Here, sibling relationship quality was an important predictor of clinical symptoms. Intuitively, targeting sibling relationship quality points to *improving* the quality of the relationship, which might be assumed as making the relationship more *positive*. However, the current study suggests that youth that are highly positive (without balance of negative feelings or interactions) may be especially at-risk for elevated clinical outcomes. Therefore, a focus on the sibling relationship that goes beyond making the relationship better and, instead, focuses on making the sibling relationship resemble a more typical healthy sibling relationship (e.g., high on both positivity and negativity; Brody, 1998) may be more beneficial. Such a focus may include youth receiving more training in how to cooperatively play with their sibling (as opposed to leading or following in play) or training the family in the potential benefits of sharing negative feelings or experiences related to their sibling, thereby making the sibling relationship more of an arena for emotional and behavioral growth (e.g., Brody, 1998; Stoneman, 2001). Subsequently, the absence of the affected sibling in most extant sibling services (Tudor & Lerner, 2015) may actually provide a disservice to youth who are experiencing an atypically positive sibling relationship and, therefore, are more at-risk for clinical outcomes. Given that one child in the dyad has unique development differences and needs; it may be innately difficult to aim for a “typical” type of sibling relationship. Therefore, more information is required as we embark on this area of potential intervention focus, especially in regards to observational study of sibling interaction and how it may be optimized (with optimized representing both negative and positive interaction), as an influence on TD sibling outcomes.

***A positive frame.*** Many voices have emerged to re-conceptualize sibling-hood as an experience, much like any other, that has both negative and positive aspects, rather than an invariant predictor of poor outcomes (Hodapp et al., 2005; Stoneman, 2005; Tudor & Lerner, 2015). While assessing for and treating problems that may be experienced by a subset of TD siblings, it is of utmost importance to also pay attention to the fact, according to the current study, most siblings appear to be

functioning well and this is, at least in part, the result of familial pathways that are promoting their resilience. It will be extremely worthwhile to continue examining their “secrets to success” within themselves and their unique family system - such as what promotes or innately underlies their resilience and, further, how it can further be enhanced. As such, a focus on more adaptive outcomes, academic performance, and a host of other areas of potential success will be an important ongoing area of investigation for this population of children and adolescents (e.g., Masten & Coatsworth, 1998; Orsmond & Seltzer, 2007). Resilient siblings still warrant the attention of professionals and researchers in terms of such ongoing study, as well as awareness that they may desire additional support that speaks to their unique family history. Such supports may be found in the form of existing sibling-focused services or networks (e.g., [siblingsupportproject.org](http://siblingsupportproject.org)), existing community opportunities for youth, or new approaches that may be on the horizon.

**Conclusion.** The current dissertation provides long-needed evidence that TD siblings of youth with ASD present with variable – and largely positive – psychological, behavioral, and emotional functioning. These outcomes, most importantly, are not demonstrated as a direct outcome of their brother or sister’s special needs but, rather, an outcome of many inter-related family systems pathways. Maternal depression, maternal stress, differential attention, family social support, and sibling relationship quality all play an important role in influencing how a sibling may feel, act, or where they may be in need of specialized supports in order to improve problematic – or enhance resilient – functioning. It is hoped that the results obtained here will help to modify and re-conceptualize the current approach to general perceptions of sibling functioning and the provision of specialized services for all youth who have a brother or sister with ASD. According to the current study, there are many reasons to believe that the population of siblings of youth with ASD, as well as the role these children play in their family system, deserves further attention in order to ensure that our field is best serving their needs *and* enhancing their strengths.

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## Appendix A

### Consent Form for ASD Group

#### **RESEARCH ONLINE CONSENT FORM**

**You are being asked to be a volunteer in a research study.**

**Purpose:** We currently know little about the specific experiences and needs of siblings of children and teens with an Autism Spectrum Disorder (ASD). There is reason to believe that many factors may influence the well-being of siblings. These factors might include the way that their brother or sister with autism acts or the way that their parents feel. You are being asked to participate in this study because you are the biological mother of at least one typically developing child, one (and only one) child with ASD, and because these children currently reside in your home.

**Procedures:** If you choose to be in this study, your participation will include completion of a set of online questionnaires that include questions about yourself, how you feel, things you do, and the support you receive as a parent. You will also be asked to complete questionnaires about your child who does not have ASD (if you have only one) or just one of your children who does not have ASD (if you have more than one), and your child with ASD. These questionnaires will relate to your children's feelings and behaviors. In total, these questionnaires should take approximately **2 – 2.5** hours to complete. You may finish study completion within three weeks of beginning participation.

**Payment to you:** If you complete at least 80% of the total questionnaire set, you will be entered into a 1 in 10 chance raffle for a \$200 Amazon.com gift card. If you win the raffle, this gift card will be emailed to you.

**Risks/Discomforts:** The main potential risk of participation is loss of confidential information, which will be guarded against as much as possible (described further in “Confidentiality” section below). Additionally, filling out some of these questionnaires may cause some unpleasant feelings in some individuals. If any of the questions make you feel uncomfortable, you do not have to answer them.

**Benefits:** There will be no direct benefit to you for your participation in this study. More broadly, your participation in this study may help us to better understand the experiences and needs of siblings of children and adolescents with ASD and may help us develop effective ways to help them in the future.

**Confidentiality:** Your responses will only be reviewed by trained research staff. All identifying information (e.g., your name or your children's first names) will be kept in a data file that is separate from your survey responses. Your survey responses will be labeled with a numeric code in order to protect your privacy. Any personal identifying information that we collect online is strictly for the purpose of reimbursing you as thanks for your time (if you win the raffle, as described above).

As part of the study we will be asking you to provide medical information regarding your child. The data we get about his or her health in this study will be accessible to the study team and Stony Brook University's Committee on Research Involving Human Subjects. Again, this information will only be stored separately from identifying information and the file for identifying information will be stored separately by the principal investigator.

**Costs to You:** There is no cost to you for your participation in this study.

**Alternatives and Withdrawal:** Your alternative is to not participate in this study. You may voluntarily stop participating in the study at any time by closing your web browser or choosing not to finish your survey completion. If you have not completed before clicking the surveys after 3 weeks of beginning your participation, your data will be automatically deleted. There are no consequences for discontinuing your participation besides not receiving the \$50 Amazon.com giftcard.

**Participants' Rights:**

- Your participation in this study is voluntary. You do not have to be in this study if you don't want to be.
- You have the right to change your mind and leave the study at any time without giving any reason, and without penalty.
- Any new information that may make you change your mind about being in this study will be given to you.

You do not lose any of your legal rights by signing this consent form.

**Questions About the Study or Your Rights as a Research Participant:**

- The principal investigator conducting this study is Dr. Matthew D. Lerner, [matthew.lerner@stonybrook.edu](mailto:matthew.lerner@stonybrook.edu), (631) 632-7660. A co-investigator conducting this study is Megan E. Tudor, M.A., [megan.tudor@stonybrook.edu](mailto:megan.tudor@stonybrook.edu), (631) 632-7850.
- If you have any questions about your rights as a research participant, you may contact Ms. Judy Matuk, Committee on Research Involving Human Subjects, SUNY at Stony Brook, (631) 632-9036.

**If you type your email address below, it means that you have read the information given in this consent form, and you would like to be a volunteer in this study.**

---

E-mail Address

## Appendix B

### Consent Form for TD Group

#### **RESEARCH ONLINE CONSENT FORM**

**You are being asked to be a volunteer in a research study.**

**Purpose:** There is reason to believe that many factors may influence the well-being of siblings in different families. These factors might include the way that their brother or sister acts or the way that their parents feel. You are being asked to participate in this study because you are the biological mother of at least two typically developing children, and because these children currently reside in your home.

**Procedures:** If you choose to be in this study, your participation will include completion of a set of online questionnaires that include questions about yourself, how you feel, things you do, and the support you receive as a parent. You will also be asked to complete questionnaires about your children. These questionnaires will relate to your children's feelings and behaviors. In total, these questionnaires should take approximately **2 – 2.5** hours to complete. You may finish study completion within three weeks of beginning participation.

**Payment to you:** If you complete at least 80% of the total questionnaire set, you will be entered into a 1 in 20 chance raffle for a \$100 Amazon.com gift card. If you win the raffle, this gift card will be emailed to you.

**Risks/Discomforts:** The main potential risk of participation is loss of confidential information, which will be guarded against as much as possible (described further in “Confidentiality” section below). Additionally, filling out some of these questionnaires may cause some unpleasant feelings in some individuals. If any of the questions make you feel uncomfortable, you do not have to answer them.

**Benefits:** There will be no direct benefit to you for your participation in this study. More broadly, your participation in this study may help us to better understand the experiences and needs of siblings of children and adolescents with ASD and may help us develop effective ways to help them in the future.

**Confidentiality:** Your responses will only be reviewed by trained research staff. All identifying information (e.g., your name or your children's first names) will be kept in a data file that is separate from your survey responses. Your survey responses will be labeled with a numeric code in order to protect your privacy. Any personal identifying information that we collect online is strictly for the purpose of reimbursing you as thanks for your time (if you win the raffle, as described above).

As part of the study we will be asking you to provide medical information regarding your child. The data we get about his or her health in this study will be accessible to the study team and Stony Brook University's Committee on Research Involving Human Subjects. Again, this information will only be stored separately from identifying information and the file for identifying information will be stored separately by the principal investigator.

**Costs to You:** There is no cost to you for your participation in this study.

**Alternatives and Withdrawal:** Your alternative is to not participate in this study. You may voluntarily stop participating in the study at any time by closing your web browser or choosing not to finish your survey completion. If you have not completed

before clicking the surveys after 3 weeks of beginning your participation, your data will be automatically deleted. There are no consequences for discontinuing your participation besides not receiving the \$50 Amazon.com giftcard.

**Participants' Rights:**

- Your participation in this study is voluntary. You do not have to be in this study if you don't want to be.
- You have the right to change your mind and leave the study at any time without giving any reason, and without penalty.
- Any new information that may make you change your mind about being in this study will be given to you.

You do not lose any of your legal rights by signing this consent form.

**Questions About the Study or Your Rights as a Research Participant:**

- The principal investigator conducting this study is Dr. Matthew D. Lerner, [matthew.lerner@stonybrook.edu](mailto:matthew.lerner@stonybrook.edu), (631) 632-7660. A co-investigator conducting this study is Megan E. Tudor, M.A., [megan.tudor@stonybrook.edu](mailto:megan.tudor@stonybrook.edu), (631) 632-7850.
- If you have any questions about your rights as a research participant, you may contact Ms. Judy Matuk, Committee on Research Involving Human Subjects, SUNY at Stony Brook, (631) 632-9036.

**If you type your email address below, it means that you have read the information given in this consent form, and you would like to be a volunteer in this study.**

---

Email Address



## Appendix C

### Parent Resource Link

Thank you for participating in our study!

We are providing the national resource links below for any mothers that may have parenting questions or concerns after participating in our study.

#### **General Parenting Resources**

KidsHealth

<http://www.Kidshealth.org/parent>

The National Parent Helpline

<http://www.nationalparenthelpline.org/find-support>

#### **Autism Parenting Resources**

National Autism Association

<http://nationalautismassociation.org/>

Autism Society of America

<http://www.autism-society.org/a-family-member.html>

# Appendix D

## Demographic Form

### HISTORY FORM

#### IDENTIFYING INFORMATION

All information on this form is confidential and voluntary. It helps us better understand your child and to see if the program works better for some types of children than for others, so that we can improve our services.

Child's sex:                    M        F

Child's age:                    \_\_\_\_\_

Child's primary language:    \_\_\_\_\_

Child's racial/ethnic background:

Caucasian/White non-Hispanic .....1

African American/Black ..... 2

Asian/Asian American ..... 3

Hispanic/Latino ..... 4

Native American/American Indian ..... 5

Mixed (please specify) ..... 6

Your relationship to the child (circle one):

Biologic mother .....1      Adoptive mother .....5      Grandmother ..... 9      Other .....13

Biologic father .....2      Adoptive father .....6      Grandfather ..... 10      Please specify: \_\_\_\_\_

Stepmother .....3      Foster mother .....7      Aunt ..... 11

Stepfather .....4      Foster father .....8      Uncle .....12

#### FAMILY INFORMATION

Information on Primary Household (the one in which child lives most of the time)

City and State of residence: \_\_\_\_\_

Who else lives in the Primary Household with this child?

	Name(s)	Relationship to Child (e.g., biologic mother, adoptive father, grandmother, adoptive sister, step-brother, aunt)	Age(s)
Parent #1			
Parent #2			
Siblings (includes half-siblings and step-siblings)			
Other Children			
Other Adults			

Please answer the questions below about the child's Primary Household, for yourself (Parent #1). If there is a second parent (Parent #2) living with you in the Primary Household, please complete the information for that parent as well.

Parent #1's education (circle one):

Eighth grade or less ..... 1

Some high school ..... 2

High school graduate or GED .....3

Some college or post-high school .....4

College graduate .....5

Advanced graduate or professional degree ..... 6

Parent #2's education (circle one):

Eighth grade or less .....1

Some high school .....2

High school graduate or GED .....3

Some college or post-high school .....4

College graduate .....5

Advanced graduate or professional degree ..... 6

Parent #1's employment status:

- Working full time .....1
- Working part time .....2
- Unemployed, looking for work .....3
- Unemployed, not looking for work .....4
- Stay-at-Home Parent .....5
- Disabled .....6
- Retired .....7
- Student, full-time .....8
- Student, part-time .....9
- Other, please specify: .....10

Parent #1's occupation (please be specific):

\_\_\_\_\_

Total household income (from all sources) for past year:

- Less than \$10,000 ..... 1
- \$10,000 to \$20,000 ..... 2
- \$21,000 to \$30,000 ..... 3
- \$31,000 to \$40,000 ..... 4
- \$41,000 to \$50,000 ..... 5
- \$51,000 to \$60,000 ..... 6
- \$61,000 to \$70,000 ..... 7
- \$71,000 to \$80,000 ..... 8
- \$81,000 to \$90,000 ..... 9
- \$91,000 to \$100,000 .....10
- \$101,000 to \$150,000 .....11
- More than \$150,000 .....12

Current relationship status of parent(s) or parental figures(s) in Primary Household:

- Married (Heterosexual) .....1
- Same sex domestic partnership .....2
- Separated, Divorced, or relationship annulled .....3
- Widowed .....4
- Never married, living with heterosexual partner .....5
- Never married, not living with partner .....6
- Other (please specify) .....7

**Not counting the children being assessed here today, does anyone in this child's family have problems with Developmental Disorders (circle all that apply, if "yes" please specify):**

- Biologic mother .....1 yes, please specify: \_\_\_\_\_
- Biologic father .....2 yes, please specify: \_\_\_\_\_
- Step- or Adoptive parent .....3 yes, please specify: \_\_\_\_\_
- Grandparent .....4 yes, please specify: \_\_\_\_\_
- Biologic full sibling .....5 yes, please specify: \_\_\_\_\_
- Half-sibling .....6 yes, please specify: \_\_\_\_\_
- Step- or adoptive sibling .....7 yes, please specify: \_\_\_\_\_
- First cousin, aunt, uncle .....8 yes, please specify: \_\_\_\_\_
- Other (please specify) .....9 \_\_\_\_\_; yes, please specify: \_\_\_\_\_

**Not counting the child being assessed here today, does anyone in this child's family have problems with psychiatric disorders, such as depression, anxiety, drug/alcohol dependence, etc (circle all that apply, if "yes" please specify):**

- Biologic mother .....1 yes, please specify: \_\_\_\_\_
- Biologic father .....2 yes, please specify: \_\_\_\_\_
- Step- or Adoptive parent .....3 yes, please specify: \_\_\_\_\_
- Grandparent .....4 yes, please specify: \_\_\_\_\_
- Biologic full sibling .....5 yes, please specify: \_\_\_\_\_
- Half-sibling .....6 yes, please specify: \_\_\_\_\_
- Step- or adoptive sibling .....7 yes, please specify: \_\_\_\_\_
- First cousin, aunt, uncle .....8 yes, please specify: \_\_\_\_\_
- Other (please specify) .....9 \_\_\_\_\_ yes, please specify: \_\_\_\_\_

Parent #2's employment status:

- Working full time .....1
- Working part time .....2
- Unemployed, looking for work .....3
- Unemployed, not looking for work .....4
- Stay-at-Home Parent .....5
- Disabled .....6
- Retired .....7
- Student, full-time .....8
- Student, part-time .....9
- Other, please specify: .....10

Parent #2's occupation (please be specific):

\_\_\_\_\_

Current residence:

- Subsidized housing ..... 1
- Mobile home ..... 2
- Rented or leased apartment, condo, house ..... 3
- Self-owned apartment, condo, house ..... 4
- Military quarters ..... 5
- Other, please specify: ..... 6

Any income received from public assistance, welfare, or social security income (SSI)?      Y      N

SCHOOL INFORMATION

Grade: \_\_\_\_\_ (last grade completed)

Type of School: Public.....1  
 Private.....2  
 Parochial/religious.....3

Type of class: Mainstream.....1  
 Self-contained special education...2  
 Inclusion.....3

Does your child have an IEP for the current school year?  
 YES NO

Has the child ever repeated a grade? \_\_\_\_\_ If YES, which grade(s): \_\_\_\_\_

**MEDICAL/DEVELOPMENTAL INFORMATION**

Currently, does your child have significant medical problems? \_\_\_\_\_ If YES, please specify:  
 \_\_\_\_\_

During or after the delivery (optional, please fill out all you can remember):	Yes, no, or don't know		
	Y	N	DK
Baby was born early ( _____ weeks)	Y	N	DK
Baby was born on time ( _____ weeks)	Y	N	DK
Baby was born late ( _____ weeks)	Y	N	DK
Baby had low birth weight ( _____ lbs _____ oz)	Y	N	DK
Baby had normal birth weight ( _____ lbs _____ oz)	Y	N	DK
Baby had high birth weight ( _____ lbs _____ oz)	Y	N	DK
Vaginal delivery	Y	N	DK
Assisted delivery (specify: forceps _____ or vacuum _____)	Y	N	DK
C-section delivery (specify: planned _____ or emergency _____)	Y	N	DK
Baby needed help breathing	Y	N	DK
Baby was born addicted or very exposed to alcohol or drugs (please specify):	Y	N	DK
Baby had to be in an incubator (how long? _____)	Y	N	DK
Baby had extended hospital stay (how long? _____)	Y	N	DK
Baby had other problems (please specify):	Y	N	DK

Please mark primary diagnosis with a "P" and secondary with an "S" (include **only** diagnoses given via previous formal psychological or medical assessment)

- |  |   |
|--|---|
| <input type="checkbox"/> Asperger's Syndrome                         | <input type="checkbox"/> Visual Impairments                           |
| <input type="checkbox"/> PDD/NOS                                     | <input type="checkbox"/> Hearing Impairments                          |
| <input type="checkbox"/> Autism                                      | <input type="checkbox"/> ADD/ADHD                                     |
| <input type="checkbox"/> Non-verbal Learning Disorder                | <input type="checkbox"/> Psychiatric Disorder (please specify): _____ |
| <input type="checkbox"/> Behavioral Disorder (please specify): _____ | <input type="checkbox"/> Learning Disorder (please specify): _____    |
| <input type="checkbox"/> Other: _____                                |   |

**PREVIOUS EVALUATIONS AND INTERVENTIONS**

Please list any medications that the child is currently taking.

Medication	Reason for taking	Date started	Dosage		
			am	noon	pm


If the child has ever received any interventions (for example, psychotherapy or counseling, early intervention) please provide the following information:

Intervention	Date started	Still involved?		If not, date ended	How often?	Type of professional
		Yes	No			
		Y	N			
		Y	N			
		Y	N			
		Y	N			
		Y	N			
		Y	N			



Appendix F

Beck Depression Inventory – Second Edition, Sample

	<b>Beck Depression Inventory</b>	<b>Baseline</b>
V 0477	CRTN: _____ CRF number: _____	Page 14 patient inits: _____
<b>BDI-II</b>		Date: _____
Name: _____ Marital Status: _____ Age: _____ Sex: _____		
Occupation: _____ Education: _____		
<p><b>Instructions:</b> This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the <b>one statement</b> in each group that best describes the way you have been feeling during the <b>past two weeks, including today</b>. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).</p>		
<b>1. Sadness</b>	<b>6. Punishment Feelings</b>	
0 I do not feel sad.	0 I don't feel I am being punished.	
1 I feel sad much of the time.	1 I feel I may be punished.	
2 I am sad all the time.	2 I expect to be punished.	
3 I am so sad or unhappy that I can't stand it.	3 I feel I am being punished.	

Note: Entire measure is not displayed due to copyright protection.

Appendix G

Parenting Stress Index – Short Form

<b>SA = Strongly Agree</b>	<b>A = Agree</b>	<b>NS = Not Sure</b>	<b>D = Disagree</b>	<b>SD = Strongly Disagree</b>
----------------------------	------------------	----------------------	---------------------	-------------------------------

I often have the feeling that I cannot handle things very well. SA A NS D SD

Note: Entire measure is not displayed due to copyright protection.



## Appendix H

### Family Support Scale

#### MODIFIED FAMILY SUPPORT SCALE

Listed below are people and groups that often are helpful to caregivers and to families of a child with cerebral palsy. This questionnaire asks you to indicate how helpful each of the following people or groups of people have been to you and your family.

Please circle the number that best describes how helpful how these people or groups of people have been to you and your family during the past 3 to 6 months. The higher the score, the more helpful the person has been. You may not find a number that exactly describes your feelings or opinions, so you need to circle the number that comes closest to describing how you feel. Your first reaction to each statement should be your answer.

If any of these people or groups of people are unknown to you and your family, then make a tick in the N/A column.

No.	Person	N/A	Not all helpful	Sometimes helpful	Generally helpful	Very helpful	Extremely helpful
1	My parents		1	2	3	4	5
2	My partner		1	2	3	4	5
3	My partner's parents		1	2	3	4	5
4	My relatives		1	2	3	4	5
5	My partner's relatives		1	2	3	4	5
6	My friends		1	2	3	4	5
7	My partner's friends		1	2	3	4	5
8	My other children		1	2	3	4	5
9	Other parents		1	2	3	4	5
10	Co-workers		1	2	3	4	5
11	Parent groups		1	2	3	4	5
12	Social groups / clubs		1	2	3	4	5
13	Church members / minister		1	2	3	4	5
14	My family or child's physician		1	2	3	4	5
15	Early childhood intervention program		1	2	3	4	5
16	School / day-care centre		1	2	3	4	5
17	Professionals (therapists, social workers, nursing staff)		1	2	3	4	5
18	Professional agencies (hospital, clinic, social services)		1	2	3	4	5
19	Other _____		1	2	3	4	5

Appendix I

Who Does What? – Sibling Modification

**WHO DOES WHAT?**

Please show how you and your child divide the caretaking tasks listed here. Using numbers on the scale below, show **HOW MUCH I DO** by choosing one of the ratings below.

1	2	3	4	5	6	7	8	9
<b>My child</b> does it all	we do this about equally				<b>I</b> do it all for my child			

<b>HOW MUCH I DO</b> (1 to 9)	
	Preparing meals for our child
	Deciding the child's feeding schedule
	Dressing our child
	Cleaning or bathing our child
	Calming down after getting upset/crying
	Dealing with getting up in the middle of the night
	Playing
	Doing laundry
	Doing homework
	Entertaining child while in public or on errands: restaurants, visiting, shopping, playgrounds
	Picking up after child
	Dealing with problems with sibling or peers

## Appendix J

### Sibling Inventory of Behavior

*Sibling Inventory of Behavior*

Scale Items	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Accepts (Child 1) as a playmate	1	2	3	4	5
Gets ideas for things they can do together	1	2	3	4	5
Has fun at home with (child 1)	1	2	3	4	5
Treats (child 1) as a good friend	1	2	3	4	5
Makes plans that include (child 1)	1	2	3	4	5
Shares secrets with (child 1)	1	2	3	4	5
Is pleased by progress (child 1) makes	1	2	3	4	5
Wants (child 1) to succeed	1	2	3	4	5
Shows sympathy when things are hard for (child 1)	1	2	3	4	5
Is concerned for (child 1's) welfare and happiness	1	2	3	4	5
Tries to comfort (child 1) when (s/he) is unhappy or upset	1	2	3	4	5
Teaches (child 1) new skills	1	2	3	4	5
Helps (child 1) adjust to a new situation	1	2	3	4	5
Babysits and cares for (child 1)	1	2	3	4	5
Tries to teach (child 1) how to behave	1	2	3	4	5
Tattles on (child 1)	1	2	3	4	5
Is Jealous of (child 1)	1	2	3	4	5
Is nosey and has to know everything about (child 1)	1	2	3	4	5
Takes advantage of (Child 1)	1	2	3	4	5
Blames (Child 1) when something goes wrong	1	2	3	4	5
Is very competitive against (Child 1)	1	2	3	4	5
Resents (Child 1)	1	2	3	4	5
Teases or annoys (Child 1)	1	2	3	4	5
Gets angry with (Child 1)	1	2	3	4	5
Fusses and argues with (Child 1)	1	2	3	4	5
Hurts (Child 1's) feelings	1	2	3	4	5
Has Physical fights with (Child 1) (not just for fun)	1	2	3	4	5
Is embarrassed to be with (child 1) in public	1	2	3	4	5
Stays away from (Child 1) if possible	1	2	3	4	5
Acts ashamed of (Child 1)	1	2	3	4	5
Frowns or pouts when (child 1) has to be with (him/her)	1	2	3	4	5
Tries to avoid being seen with (Child 1)	1	2	3	4	5

# Appendix K

## Behavioral Assessment System for Children – Second Edition, Ages 6-12

<b>Parent Rating Scales— Child</b> Computer-Entry Form		<b>PRS-C</b> Ages 6-11
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# BASC-2

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**Behavior Assessment System for Children, Second Edition**  
Cecil R. Reynolds and Randy W. Kamphaus

Child's Name _____ <small>First Middle Last</small>	Your Name _____ <small>First Middle Last</small>
Date _____ Birth Date _____ <small>Month Day Year Month Day Year</small>	Sex: <input type="checkbox"/> Female <input type="checkbox"/> Male
School _____ Grade _____	Relationship to Child: <input type="checkbox"/> Mother <input type="checkbox"/> Father
Sex: <input type="checkbox"/> Female <input type="checkbox"/> Male Age _____	<input type="checkbox"/> Guardian <input type="checkbox"/> Other _____
Other Data _____	

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**Instructions:**  
On the pages that follow are phrases that describe how children may act. Please read each phrase, and mark the response that describes how this child has behaved recently (in the last several months).

- Circle **N** if the behavior **never** occurs.
- Circle **S** if the behavior **sometimes** occurs.
- Circle **O** if the behavior **often** occurs.
- Circle **A** if the behavior **almost always** occurs.

**Please mark every item.** If you don't know or are unsure of your response to an item, give your best estimate.


**How to Mark Your Responses**  
Be certain to **circle** completely the letter you choose, like this:

N   **(S)**   O   A

If you wish to change a response, mark an X through it, and circle your new choice, like this:

N   ~~(S)~~   **(O)**   A

**Before starting, be sure to complete the information in the boxes above these instructions.**




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PRS-C Ages 6-11

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## Appendix L

### Behavioral Assessment System for Children – Second Edition, Ages 12-21, Sample

<b>Parent Rating Scales– Adolescent Computer-Entry Form</b>		<b>PRS–A Ages 12–21</b>
<h1>BASC-2</h1>		
<b>Behavior Assessment System for Children, Second Edition</b> Cecil R. Reynolds and Randy W. Kamphaus		
Child's Name _____ <small>First Middle Last</small>	Your Name _____ <small>First Middle Last</small>	
Date _____ Birth Date _____ <small>Month Day Year Month Day Year</small>	Sex: <input type="checkbox"/> Female <input type="checkbox"/> Male	
School _____ Grade _____	Relationship to Child: <input type="checkbox"/> Mother <input type="checkbox"/> Father	
Sex: <input type="checkbox"/> Female <input type="checkbox"/> Male Age _____	<input type="checkbox"/> Guardian <input type="checkbox"/> Other _____	
Other Data _____		
<b>Instructions:</b> On the pages that follow are phrases that describe how children may act. Please read each phrase, and mark the response that describes how this child has behaved recently (in the last several months). Circle <b>N</b> if the behavior <b>never</b> occurs. Circle <b>S</b> if the behavior <b>sometimes</b> occurs. Circle <b>O</b> if the behavior <b>often</b> occurs. Circle <b>A</b> if the behavior <b>almost always</b> occurs. <b>Please mark every item.</b> If you don't know or are unsure of your response to an item, give your best estimate. <b>How to Mark Your Responses</b> Be certain to <b>circle</b> completely the letter you choose, like this: N (S) O A If you wish to change a response, mark an X through it, and circle your new choice, like this: N (X) (O) A <b>Before starting, be sure to complete the information in the boxes above these instructions.</b>		
 © 2004 AGS Publishing All rights reserved, including translation. No part of this form may be photocopied or otherwise reproduced. A 0 9 8 7 6 5 4 3 Product Number: 30035		
<b>PRS–A Ages 12–21</b>		<b>1</b>

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## Appendix M

### Social Responsiveness Scale

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<b>SOCIAL RESPONSIVENESS SCALE AUTO-SCORE FORM</b>		John N. Constantino, M.D.	<b>PARENT REPORT</b>
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**DIRECTIONS**  
For each question, circle the number that best describes the child's behavior over the past 6 months.

Child's Name: \_\_\_\_\_ Chronological Age: \_\_\_\_\_  
Gender (required):  Female  Male Ethnicity: \_\_\_\_\_  
Respondent's Name: \_\_\_\_\_ Administration Date: \_\_\_\_\_  
Relationship to Child:  Mother  Father  Other \_\_\_\_\_

PLEASE PRESS HARD WHEN MARKING YOUR RESPONSES.

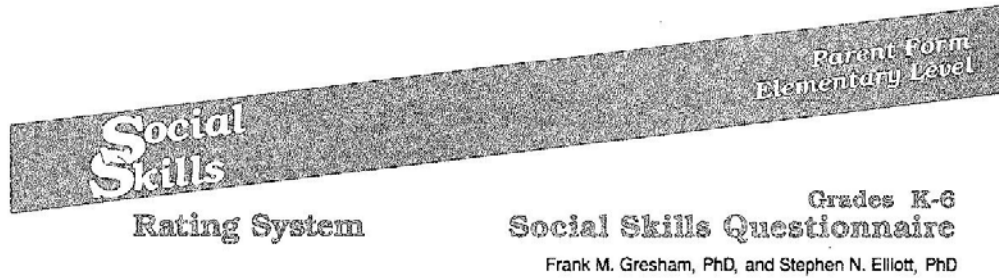
1 = NOT TRUE    2 = SOMETIMES TRUE    3 = OFTEN TRUE    4 = ALMOST ALWAYS TRUE

1. Seems much more fidgety in social situations than when alone. .... 1   2   3   4

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# Appendix N

## Social Skills Rating System – Kindergarten through 6<sup>th</sup> Grade



### Directions

This questionnaire is designed to measure **how often** your child exhibits certain social skills and **how important** those skills are to your child's development. Ratings of problem behaviors are also requested. First, complete the information about your child and yourself.

### Student Information

Name _____	Date _____
School _____	City _____ State _____
Grade _____	Birth date _____ Sex: <input type="checkbox"/> Female <input type="checkbox"/> Male
Teacher's name _____	
Ethnic group (optional)	
<input type="checkbox"/> Asian	<input type="checkbox"/> Indian (Native American)
<input type="checkbox"/> Black	<input type="checkbox"/> White
<input type="checkbox"/> Hispanic	<input type="checkbox"/> Other _____
How many brothers and sisters does this child have at home?	
<input type="checkbox"/> None	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 or more

### Parent Information

Name _____	Telephone _____
Address _____	City _____ State _____
Sex: <input type="checkbox"/> Female <input type="checkbox"/> Male	
How are you related to this child?	
<input type="checkbox"/> Mother	<input type="checkbox"/> Guardian
<input type="checkbox"/> Father	<input type="checkbox"/> Other _____

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Appendix O

Social Skills Rating System – 7<sup>th</sup> to 12<sup>th</sup> Grade

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**Parent Form  
Secondary Level**

**Social Skills Rating System**

**Grades 7-12  
Social Skills Questionnaire**

Frank M. Gresham and Stephen N. Elliott

**Directions**

This questionnaire is designed to measure **how often** your child exhibits certain social skills and **how important** those skills are to your child's development. Ratings of problem behaviors are also requested. First, complete the information about your child and yourself.

**Student Information**

Name _____		Date _____	
<small>First</small>	<small>Middle</small>	<small>Month</small>	<small>Day</small>
School _____		<small>Year</small>	<small>State</small>
Grade _____		City _____	
Birth date _____		Sex: <input type="checkbox"/> Female <input type="checkbox"/> Male	
<small>Month</small>		<small>Day</small>	<small>Year</small>
Teacher's name _____			
Ethnic group (optional)			
<input type="checkbox"/> Asian	<input type="checkbox"/> Indian (Native American)		
<input type="checkbox"/> Black	<input type="checkbox"/> White		
<input type="checkbox"/> Hispanic	<input type="checkbox"/> Other _____		
How many brothers and sisters does this child have at home?			
<input type="checkbox"/> None	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3 or more

**Parent Information**

Name _____		Telephone _____	
<small>First</small>	<small>Middle</small>	<small>City</small>	<small>State</small>
Address _____		_____	
Sex: <input type="checkbox"/> Female <input type="checkbox"/> Male			
How are you related to this child?			
<input type="checkbox"/> Mother	<input type="checkbox"/> Guardian		
<input type="checkbox"/> Father	<input type="checkbox"/> Other _____		



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## Appendix P

### Quality of Play Questionnaire

## Quality of Play Questionnaire: Parent

### Instructions to Parent

We would like information on your child's playmates. We **only** want to know about your child's playmates that you have invited over to your house **in order to play alone with your child**.

**Do not consider** children who only did homework together, or were over only as part of a group, party, or outing or only went to a movie together.

Please fill in the first name of the playmate that has played alone with your child at your house **most often in the past month**. If your child hasn't played with anyone like this for the past month, put the name of the child who **last** played with your child at your house and **you were around to see or hear what was happening**.

Playmate's name \_\_\_\_\_

Please indicate below what you saw the last time they played together.

Circle one number in each row:

How the children spent their time	Not at all	Just a little	Pretty much	Very much
1. Chasing, running, hiding, climbing, sports or physically active	0	1	2	3
2. Cards or board games	0	1	2	3
3. Imaginary or pretend games	0	1	2	3
4. Arts/crafts/making things	0	1	2	3
5. Talk	0	1	2	3
6. Computer or video games	0	1	2	3
7. Watch TV or videos	0	1	2	3

What the children did during this visit:

They...	Not at all	Just a little	Pretty much	Very much
8. played without each other	0	1	2	3
9. didn't share a toy, game, etc.	0	1	2	3

<b>They...</b>	<b>Not at all</b>	<b>Just a little</b>	<b>Pretty much</b>	<b>Very much</b>
10. got upset at each other	0	1	2	3
11. argued with each other	0	1	2	3
12. criticized or teased each other	0	1	2	3
13. were bossy with each other	0	1	2	3
14. had brother or sister into play	0	1	2	3
15. had other children into play	0	1	2	3
16. needed a parent to solve problems	0	1	2	3
17. annoyed each other	0	1	2	3

**18. Play at another child's house:** Please try to recall the times your child was invited to **another** child's house as the **only** invited guest.  
**Number of visits like this (to any child's house) in the last month \_\_\_\_\_**

**19. Play at your house:** Please try to recall the times you invited **another** child to your house as the **only** invited guest.  
**Number of visits like this (by any child) in the last month \_\_\_\_\_**