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The Division of Family Work among Fathers and Mothers of Children with an Autism Spectrum

Disorder: Implications for Parents and Family Functioning

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

by

Paula L. Ogston-Nobile M.S., Virginia Commonwealth University B.A., Michigan State University

Co-Director: Barbara J. Myers, Ph.D. Associate Professor Department of Psychology Co-Director: Geri M. Lotze, Ph.D. Assistant Professor Department of Psychology

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"Tell me, what is it you plan to do with your one wild and precious life?" - Mary Oliver

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List of Abbreviations

Abbreviation	Full Term
ASD	Autism Spectrum Disorder
RRC	Responsibility-Related Caregiving
HLAB	Household Labor
RRC MNG	Management of Responsibility-Related Caregiving
HLAB MNG	Management of Household Labor Satisfaction with the Management of Responsibility-Related Caregiving
HLAB SAT	Satisfaction with the Management of Household Labor
FES	Family Environment Scale
FES RELAT	Family Environment Scale Relationship Dimension
FES FSI	Family Environment Scale Family Social Integration Index
COUP SAT	(Couple's) Relationship Satisfaction
COUP COMM	(Couple's) Communication
COUP CNFRS	(Couple's) Conflict Resolution
QRS-SFA	Questionnaire on Resources and Stress-Short Form Abbreviated
ATEC	Autism Treatment Evaluation Checklist
IV	Independent Variable
DV	Dependent Variable
MeV	Mediating Variable

Abstract

THE DIVISION OF FAMILY WORK AMONG FATHERS AND MOTHERS OF CHILDREN WITH AN AUTISM SPECTRUM DISORDER: IMPLICATIONS FOR PARENTS AND FAMILY FUNCTIONING

By Paula L. Ogston-Nobile

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

Virginia Commonwealth University, 2014

Co-Director: Barbara J. Myers, Ph.D. Associate Professor Co-Director: Geri M. Lotze, Ph.D. Assistant Professor Department of Psychology

An often ignored aspect of parenting and family work is the responsibility-related caregiving (i.e. the monitoring, arranging, and planning) that is done to ensure that a child is cared for. Among fathers and mothers who have a child with an autism spectrum disorder (ASD), the intensity of meeting these needs is greater than for a typically developing child (e.g. additional coordination of schooling, interventions, healthcare, recreation, respite, and after-school services). As is the case for all parents, they must also attend to the demands of household labor (e.g. car maintenance, groceries, laundry, yard care), nurture their relationships (e.g. partner, friends, other family members) and find time to pursue interests outside of the home.

The aim of this study was to examine parents' management of and satisfaction with the division of responsibility-related caregiving and household labor, parenting stress, the couple's relationship quality, and family functioning among parents of children with an ASD.

Fathers (n = 66) and mothers (n = 104) of school-age children with an ASD responded to an online questionnaire. Most parents (mean 41.4 y.) were white (95%) and well-educated (98% had at least some college). All lived in the United States with the child and the child's other parent. Parents provided information about their child (82% boys, mean 8.8 y.), including level of functioning.

Fathers managed less responsibility-related caregiving than mothers, but they did not differ in their management of household labor. Parents were most satisfied with how the family work was shared when they managed less of it; however, when one parent always managed the work, satisfaction with the couple's relationship was lowest and parenting stress was highest. Satisfaction with how the family work was shared was positively associated with overall family functioning.

In general, parents, couples, and families fare better when the management of family work is shared between parents. Findings will further our understanding of the experience of fathers and mothers who have a child with an ASD, and may aid in our efforts to best support families affected by the autism spectrum disorders. The Division of Family Work among Fathers and Mothers of Children with an Autism Spectrum Disorder: Implications for Parents and Family Functioning

Statement of the Problem

Being a parent brings both joys and challenges (Cassidy, McConkey, Truesdale, Kennedy, & Slevin, 2008; Hastings & Taunt, 2002; Hastings, Kovshoff, Ward, et al., 2005; Marcus, Kunce, & Schopler, 2005), and requires a great deal of time and effort (Crnic & Low, 2002; Norton & Drew, 1994). However, fathers and mothers who have a child with an autism spectrum disorder (ASD) encounter additional caregiving demands (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Hutton & Caron, 2005; Sawyer et al., 2010), including those related to education planning, advocacy for receipt of interventions, coordination of healthcare, treatment, transportation, finding and utilizing appropriate recreational activities, respite and after-school services (Sivberg, 2002).

While some of these responsibilities are common to parents of typically developing children, the breadth and intensity of ensuring that these needs are met is greater among parents who have a child with an ASD (Brobst, Clopton, & Hendrick, 2008; Fleischmann, 2004). For example, it is not uncommon for young children on the autism spectrum to receive up to thirty hours a week of services related to their disorder (Kasari, 2002). This level of service provision requires a great deal of management, planning, and organization on behalf of the child's parent (Joosten & Safe, 2014; Nealy, O'Hare, Powers, & Swick, 2012). Beyond arranging and planning for their child, these parents must attend to the demands of caring for their homes (e.g. cooking dinner, yard work, fixing things around the house, managing finances), and contend with the

economic impact of parenting a child on the autism spectrum (Fletcher, Markoulakis, & Bryden, 2012).

In addition to intensified parenting demands (Baker-Ericzen et al., 2005; Hutton & Caron, 2005; Sawyer et al., 2010), fathers and mothers who have a child with an ASD experience greater stress (Baker-Ericzen et al., 2005; Brobst et al., 2008; Cassidy et al., 2008; N. O. Davis & Carter, 2008; Duarte, Bordin, Yazigi, & Mooney, 2005; Dyson, 1997; Ergüner-Tekinalp & Akkök, 2004; Ingersoll & Hambrick, 2011; Marcus et al., 2005; Montes & Halterman, 2007; Olsson & Hwang, 2002; M. J. Weiss, 2002), lower marital satisfaction (Brobst et al., 2008; Gau et al., 2012; Rodrigue, Morgan, & Geffken, 1990), and poorer family functioning (Dumas, Wolf, Fisman, & Culligan, 1991; Gau et al., 2012; Higgins, Bailey, & Pearce, 2005; Rao & Beidel, 2009; Rodrigue et al., 1990; Sanders & Morgan, 2008), when compared with families of typically developing children or those with another kind of disability. However, there is variability within this population. When compared with fathers who have a child with an ASD, mothers experience greater stress (Dabrowska & Pisula, 2010; N. O. Davis & Carter, 2008; Hastings, 2003; Herring et al., 2006; Konstantareas & Homatidis, 1992; Macdonald & Hastings, 2010; Tehee, Honan, & Hevey, 2009), are at greater risk for depression (N. O. Davis & Carter, 2008; Hastings, Kovshoff, Brown, et al., 2005; Olsson & Hwang, 2001), and are more involved in caring for their children and managing their households (Barnett & Baruch, 1987; Baruch & Barnett, 1986a, 1986b; Coltrane, 2000; Craig, 2006; Gray, 2003; Hofferth, 2003; Lamb, 2000; McBride & Mills, 1993; Peterson & Gerson, 1992; J. H. Pleck, 2010; Poortman & Van Der Lippe, 2009; Shelton & John, 1996; Stueve & Pleck, 2003; Tehee et al., 2009).

This study assessed two aspects of family work among parents of children with an ASD: Responsibility-Related Caregiving and Household Labor. Responsibility-Related Caregiving

refers to a domain of parenting involvement termed "responsibility" (Lamb, Pleck, Charnov, & Levine, 1985). Responsibility-Related Caregiving entails monitoring, arranging, and planning for children's lives and day-to-day activities (J. H. Pleck & Masciadrelli, 2004). Household Labor is the unpaid work done to maintain a home (Shelton & John, 1996) and includes household chores that are done inside and outside of the home as well as management of records and finances. The current study will focus on parent's management role in attending to Responsibility-Related Caregiving and Household Labor; both aspects of family work will be described below in greater detail.

Among fathers and mothers of typically developing children, greater father involvement in child related caregiving is associated with higher satisfaction with the parents' relationship (Lamb & Lewis, 2010; McBride & Mills, 1993; J. H. Pleck & Masciadrelli, 2004; J. H. Pleck, 1997). Further, greater parenting involvement and satisfaction with the couple's relationship both have positive implications for the parent-child relationship (Cabrera, Tamis-LeMonda, Bradley, Hofferth, & Lamb, 2000; Hartley, Barker, Seltzer, Greenberg, & Floyd, 2011; Krishnakumar & Buehler, 2000) as well as for family functioning (Cox & Paley, 1997; Davies & Cicchetti, 2004).

Mothers who have a child with an ASD perceive the demands of family work as a source of stress (Gray, 2003), but we know less about fathers' involvement in family work or how they are affected by these demands. Therefore, the current study seeks to better understand the association between parents' management of and satisfaction with the division family work, parenting stress, the couple's relationship, and family functioning among fathers and mothers who have a child with an ASD.

While there is a large literature regarding the experience of parents who have a child on the autism spectrum (Baker-Ericzen et al., 2005; Gray, 2006; Hastings, 2003; Ingersoll &

Hambrick, 2011; Ingersoll, Meyer, & Becker, 2011; King et al., 2006; Kuhn & Carter, 2006; Sawyer et al., 2010; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008), much of what we know about parenting a child with an ASD has resulted from research conducted with mothers (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Flippin & Crais, 2011; Gray, 2006; Higgins et al., 2005; Hines, Balandin, & Togher, 2012; Ingersoll & Hambrick, 2011; Ivey, 2004; Macdonald & Hastings, 2010). Fathers are underrepresented within the general parenting research (Coley & Morris, 2002; Costigan & Cox, 2001; Lamb, 1976; Mikelson, 2008; Minuchin, 1985; Phares, Fields, Kamboukos, & Lopez, 2005; Phares, Lopez, Fields, Kamboukos, & Duhig, 2005; Phares, 1992, 1996; J. H. Pleck, 2012; Silverstein & Phares, 1996), and this is a frequently identified limitation within autism focused research, as well (Altiere & Kluge, 2008; Bekhet, Johnson, & Zauszniewski, 2012; Braunstein, Peniston, Perelman, & Cassano, 2013; N. O. Davis & Carter, 2008; Flippin & Crais, 2011; Hartley et al., 2011; Interactive Autism Network, 2009; Morgan, 1988; Rodrigue, Morgan, & Geffken, 1992; J. A. Weiss, Cappadocia, Macmullin, Viecili, & Lunsky, 2012). To illustrate, a Google scholar search was performed¹ in April of 2014 of articles published between 1975 and 2014 with the words 'autism' and 'father' or 'fathers' in the title, excluding patents and citations. This search yielded 61 articles, 56 of which were published between 2000 and 2013, and 35 of which were published between 2010 and 2014. In contrast, 305 articles were found when the same search was conducted for the terms 'autism' and 'mother' or 'mothers,' 282 of which were published since

¹ Search was conducted by the author.

the year 2000 and 187 of which were published between 2010 and 2014. Since 1975 the number of mother-focused autism articles has outnumbered father-focused articles by five to one.

A number of factors are identified as contributors to the underrepresentation of fathers in research. Historically, mothers have been viewed as having a greater role in children's development (Coley & Morris, 2002; Lamb, 1976; LaRossa & Reitzes, 1995; McBride & Mills, 1993; McBride & Rane, 1997; Ribble, 1943), and have been targeted by researchers to a greater extent. There is also the perception that fathers are more difficult to enroll in research (Phares & Compas, 1992; Woollett, White, & Lyon, 1982) and that mothers have greater availability in their schedule to participate in research (Phares, 1992). Because of these factors, researchers may view mothers as an easier demographic to recruit (Lamb, 2000).

The literature's great emphasis on mothers of children with an ASD is a boon to our understanding of the experience of mothering a child on the spectrum. However, we cannot assume that the same conclusions would have been drawn about "parenting" a child with an ASD if fathers had been equally represented in the extant research. The current literature lays a foundation for our understanding of fathers and mothers who have a child with an ASD. However, the comparative lack of focus on fathers has resulted in an incomplete perspective of the experience of parents who have a child on the autism spectrum.

Neither Responsibility-Related Caregiving nor Household Labor has been well studied in families of children with an ASD. The need for a better understanding of how these parents share the demands of family work and how this division of labor impacts parents and families has been identified in the literature (Karst & Van Hecke, 2012). Relative to other aspects of parenting involvement, Responsibility-Related Caregiving is understudied in both the autism and general parenting literature (J. H. Pleck & Masciadrelli, 2004; J. H. Pleck, 2010). A search was

conducted² in April of 2014 of PsycINFO Psychological Abstracts published in any year that contained the words 'autism' and 'indirect caregiving' in the title; this yielded zero publications. The same search conducted with the words 'autism' and 'responsibility' resulted in two publications, neither of which was relevant to the 'Responsibility-Related Caregiving' construct being assessed in the current study. The same search with 'autism' and 'caregiving' yielded five publications; of these, two took place in Taiwan, three were conducted with mothers only, and one addressed caregiving in the literature review but did not measure it in the study.

The literature on Household Labor in families who have a child with an ASD is similarly scant. A search was conducted in February 2013³ of PsycINFO Publication Abstracts that were published in a peer-reviewed journal and contained the words 'household labor' or 'family work,' with no search restriction regarding publication date. This yielded 1161 publications with at least one of these terms in the abstract, and 315 with at least one in the title. However, 2 publications were found when the same search was conducted for 'autism' and either 'housework' or 'family work' or 'household labor' in the title or abstract. These search results exaggerate the lack of research in this area; there is a small body of research on Household Labor and family work in parents of children with an ASD that was not produced by the search described above. Even so, it can be said that very little focus has been given to either Responsibility-Related Caregiving or Household Labor in parents who have a child with an

² Search was conducted by the author.

³ Search was conducted by the author.

ASD. This omission is problematic, as these facets of family work are salient for parents of children with an ASD, given the greater stress (Baker-Ericzen et al., 2005; Brobst et al., 2008; Cassidy et al., 2008; N. O. Davis & Carter, 2008; Duarte et al., 2005; Dyson, 1997; Ergüner-Tekinalp & Akkök, 2004; Ingersoll & Hambrick, 2011; Marcus et al., 2005; Montes & Halterman, 2007; Olsson & Hwang, 2002; M. J. Weiss, 2002) and intensified demands that are associated with parenting a child on the autism spectrum (Baker-Ericzen et al., 2005; Hutton & Caron, 2005; Sawyer et al., 2010).

Fortunately, there has been a call within the field for a greater focus on fathers in autism research (Flippin & Crais, 2011; Interactive Autism Network, 2009; Ly, Abdullah, Thorsen, Grondhuis, & Goldberg, 2010). Recommendations have been made for improving the inclusion of fathers through such efforts as targeting mothers, who may sometimes be gatekeepers to fathers' participation in research; creating advertisements that are appealing to fathers; providing fathers with a clear reason for why their participation in particular is important; and limiting the time commitment of the study (Flippin & Crais, 2011; Mitchell et al., 2007; West, 2007). Efforts were made to incorporate these recommendations into the current study.

The overarching goal of this study is to further our understanding of what it means for a family to raise a child with an autism spectrum disorder. Results will tell us more about how parents who have a child on the autism spectrum manage their homes and share caregiving responsibilities, the kinds of stress they experience, what their relationship is like with their partner, how their family functions, as well as how these factors influence one another. Research and interventions conducted with family members of children with an ASD may be ineffective if the unique demands associated with the disorder and its impact on family functioning are not

considered. Study findings may aid researchers and professionals in the aim to best support the increasing numbers of fathers and mothers of children on the autism spectrum.

This review of the literature is structured as follows: first, an overview of the ASDs and some of our early misconceptions regarding the disorder, as well a discussion of some characteristics of the ASDs that contribute to a unique parenting experience. Next, family work is introduced, wherein Responsibility-Related Caregiving and Household Labor are described. This is followed by discussions of Parenting Stress, the Couple's Relationship, and Family Functioning.

This literature review focuses on research conducted with parents of children with an ASD, and each section of the review expands upon constructs introduced in preceding sections. For example, the section on Parenting Stress addresses the relationship between family work (preceding section) and Parenting Stress; the section on the Couple's Relationship addresses the associations between family work, Parenting Stress, and the Couple's Relationship. The literature review is followed by the conceptual framework, research questions, and hypotheses. Next, this study's methodology is described, which includes participants, procedures, measures, and results. Lastly, findings are discussed, followed by this study's limitations and directions for future research.

Literature Review

The Autism Spectrum Disorders

In the following subsections, a brief history and definition of the ASDs are provided, along with a review of some of the misconceptions from the early literature on parents of children on the spectrum. Some of the characteristics that contribute to a unique parenting experience for fathers and mothers of children with an ASD are presented.

Definition and history of the ASDs. The ASDs are neurodevelopmental disabilities characterized by persistent deficits in social communication and social interaction, and may be accompanied by repetitive and stereotyped patterns of behavior (American Psychiatric Association, 2013; Volkmar, Chawarska, & Klin, 2005). It is currently estimated that between 1 in 68 and 1 in 88 children are diagnosed with an ASD (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators, 2014; Autism and Developmental Disabilities Monitoring Network, 2012), with males more commonly affected. The male to female ratio of individuals diagnosed with an ASD is approximately 4:1 (Constantino & Charman, 2012). Diagnostic labels were changed in the newest edition of the DSM. Individuals who were previously diagnosed in any of the sub-areas of the autism spectrum are included under the new diagnostic criteria; thus, the current edition of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013) states that "individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder."

Given that individuals on the autism spectrum may also present with impairments in the development of independent living skills, affected individuals may be more dependent on their parents or other caregivers into their adult lives (Krauss, Seltzer, & Jacobson, 2005; Sanders & Morgan, 2008). In 2007, it was estimated that the cost of caring for all individuals with an ASD in the United States is more than 35 billion dollars per year (Ganz, 2007), with recent projections of costs of 126 billion dollars per year (Autism Speaks, 2012). This issue is exacerbated in that families who have a child with an ASD often earn less than families of children with other kinds of special health care needs (Mandell, 2012), as often one parent must stay at home with the

child. Fortunately, parents do not solely bear these expenses, as some of these costs are paid for through public (e.g. supplemental security income, Medicaid waivers) or private funds. It is important that these families and children receive adequate support and understanding. This will help to ensure that these children receive the maximum benefit from any resources, therapy or intervention services they receive.

The disorder that we now know as autism was first described in 1943 by Dr. Leo Kanner, an American child psychiatrist originally from Austria. Through his work, Kanner encountered a number of children who displayed unusual patterns of behavior, with the primary feature being a lack of interest in other people and the social world (Kanner, 1943; Volkmar & Wiesner, 2010). The term 'autism' was not formalized in the DSM as a diagnostic label until 1980 (Feinstein, 2010), and our conceptualization of the ASDs continues to be refined. Contrary to early beliefs that most children on the autism spectrum were of normal intelligence (Feinstein, 2010), current estimates suggest that between 48% (Autism and Developmental Disabilities Monitoring Network, 2012) and 70% of individuals with autism also meet the diagnostic criteria for an Intellectual Disability (ID; Matson & Shoemaker, 2009).

Early misconceptions regarding parents of children with an ASD. Early research conducted with parents of children with an ASD held a number of misconceptions regarding the cause of these disorders. For example, the 'refrigerator mother' theory, which has been used to blame mothers for a range of psychological disorders and mental illnesses, was applied to autism. In the mid-twentieth century, it was theorized that the etiology of autism's social and communication impairments stemmed from cold, emotionally unavailable parents (Bettelheim, 1967). Due to mothers' frequent role as primary caregiver, they received the bulk of this blame (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). However, empirical research has

never implicated parents' behavior as a cause of autism (American Academy of Child & Adolescent Psychiatry, 2008), and in the United States, the refrigerator mother theory has been rejected within the scientific community (Volkmar & Wiesner, 2010). Despite this, the refrigerator mother theory instilled guilt in mothers who were blamed for their child's disorder (Bonnefil, 1976), and the theory's influence has not completely faded. Parents who have a child with an ASD still worry that they might have done something to cause their child's disorder or whether they are doing enough to help their child (Gray, 2003; S. E. Green, 2007; Neely, Amatea, Echevarria-Doan, & Tannen, 2012; Whelan & Hudson, 1987).

Early in the study of autism, many children who were featured in case studies or psychological reports had parents who were highly successful. This led professionals to believe that autism was more common among families of high socioeconomic status (Kanner, 1943, 1949; Volkmar & Wiesner, 2010), and that there were qualities common to successful or educated parents that caused their child's autism (Feinstein, 2010; Macdonald & Hastings, 2010). However, this misconception was a result of self-selection bias (Schopler, Andrews, & Strupp, 1979); parents of high socioeconomic status were better able to seek out resources for their child than were poorer families. Self-selection bias continues to be an issue in autism research. Many studies that are conducted with parents of children with an ASD describe participants' high SES as a limitation to the generalizability of their findings (N. O. Davis & Carter, 2008; Faso, Neal-Beevers, & Carlson, 2013; Hassall, Rose, & McDonald, 2005; Kuhn & Carter, 2006; Ogston, Mackintosh, & Myers, 2011; Smith et al., 2008).

While these misconceptions are unsubstantiated in the literature, their impact on attitudes towards the ASDs continues. For example, literature from the mid-twentieth century indicates that parents who had a child with a disability perceived as psychological in nature (including

autism) received less sympathy than those who had a child with a physical disability or a disorder that was perceived as organic in nature (Feinstein, 2010). Research with families of children with an ASD ought to be conducted with use of an historical lens. This will assist in taking into account lingering negative beliefs and the continued stigmatization of individuals with a disability and their families (Gray, 2002; S. E. Green, 2007; Hinshaw, 2005).

Unique challenges associated with parenting a child with an ASD. Parenting a child with an ASD is associated with unique challenges, relative to parents of typically developing children as well as parents of children with other types of disabilities (Schieve, Blumberg, Rice, Visser, & Boyle, 2007). In addition to experiencing higher levels of stress (Baker-Ericzen et al., 2005; Brobst et al., 2008; Cassidy et al., 2008; N. O. Davis & Carter, 2008; Duarte et al., 2005; Dyson, 1997; Ergüner-Tekinalp & Akkök, 2004; Ingersoll & Hambrick, 2011; Marcus et al., 2005; Montes & Halterman, 2007; Olsson & Hwang, 2002; M. J. Weiss, 2002), lower marital satisfaction (Gau et al., 2012; Rodrigue et al., 1990), and negative adjustment within their family's functioning (Dumas et al., 1991; Sanders & Morgan, 2008), these parents report decreased feelings of parenting competence (Rodrigue et al., 1990), and are at increased risk for depression (Ergüner-Tekinalp & Akkök, 2004; Hastings et al., 2005; Weiss, 2002). These differences suggest that parents who have a child with an ASD experience unique stressors (Marcus et al., 2005), which will be reviewed below.

Unclear etiology. There is a strong genetic component to the ASDs, but neither the cause nor process by which the disorders develop is completely understood (Volkmar, Lord, Bailey, Schultz, & Klin, 2004). This differentiates the ASDs from a disorder like Down syndrome, in which the etiology is more clearly understood (Ghosh, Feingold, & Dey, 2009). In the absence of a clear explanation or theory, parents and other family members are more apt to construct their

own beliefs regarding the cause of the disorder (Gray, 1994; Hines et al., 2012). Consequently, parents may blame themselves for causing their child's ASD (O'Brien, 2007; Rodrigue et al., 1990), either by way of trauma during pregnancy or childbirth, through the effects of parenting, or the transmission of genes (Gray, 1994). The disorder's unclear etiology can be especially difficult for extended family members to understand; those who not have an understanding of the nature of the ASDs or day-to-day experience of living with a child on the spectrum may attribute social and communication impairments to the child's parents (Gray, 1994).

Lack of physical indication of disability. During infancy and early toddlerhood, children who are later diagnosed with an ASD may appear to be typically developing (Bouma, 1990; Marcus et al., 2005; Serbin, Steer, & Lyons, 1983), especially if their motor skills are unimpaired. This differentiates the ASDs from disabilities like Down syndrome or Angelman syndrome. Both of these syndromes present with physical characteristics that are identifiable early in development (Korenberg, 1994), which provide cues to others regarding the presence of a disability. Even as they age, individuals on the spectrum may not display any overt physical indication of their disability. Thus, those who are unaware of a child's ASD may expect them to behave like a typically developing child. This can be difficult for parents, who may feel they are to blamed for their child's behavior (Gray, 2002; Rodrigue et al., 1990).

Sense of loss following child's diagnosis. The age at which children receive a diagnosis on the autism spectrum depends on a number of factors, including a child's symptom presentation, where the family lives (e.g. in many areas, there is a scarcity of professionals trained in the diagnosis of ASD (Siklos & Kerns, 2007), as well as the urgency with which the parent pursues a referral and diagnostic assessment. Regardless, it is unusual for a child to be diagnosed with an ASD before the age of 2 (Bryson, Zwaigenbaum, McDermott, Rombough, &

Brian, 2008; Howlin & Moorf, 1997) and a diagnosis may come later for children who are higher functioning (Howlin & Asgharian, 1999). As our understanding of the ASDs has broadened and both diagnostic techniques and standards have improved, the age at which children are diagnosed may continue to decrease. Regardless, parents may spend the first several years of their child's life believing that he or she is typically developing. Their hopes and expectations for their child's future – as well as their own – may be uprooted once that diagnosis is received (Neely et al., 2012; Wong & Heriot, 2007). Indeed, many parents of children with an ASD describe feeling a sense of grief (Mulligan, MacCulloch, Good, & Nicholas, 2012) or loss upon receiving their child's diagnosis (O'Brien, 2007).

Ambiguous path to the ASD diagnosis. The process by which a child is diagnosed with an ASD can be cumbersome for parents (Neely et al., 2012), due in part to the developmental heterogeneity among individuals on the spectrum (Marcus et al., 2005; Yirmiya & Ozonoff, 2007). The scarcity of professionals trained in the diagnosis and identification of the ASDs is an additional strain on parents. Prior to receiving their child's diagnosis, doctors may be unresponsive to parents' concerns regarding their child's development (Dale, Jahoda, & Knott, 2006; De Giacomo & Fombonne, 1998). Further, the diagnosis that a child receives depends upon the standards in place as well as the experience of the clinician or team of professionals. It can take months or years to obtain a stable diagnosis (Bryson et al., 2008; Goin-Kochel, Mackintosh, & Myers, 2006; Gray, 1994; Howlin & Moorf, 1997), which can be stressful for parents (Howlin & Moorf, 1997). This is very different from a disorder like Down syndrome, which is typically identifiable at birth but can be diagnosed prenatally through genetic testing (Haddow et al., 1992). There are psychological benefits associated with diagnostic certainty; mothers who have a child with an intellectual disability with unknown causes experience greater

anxiety, feelings of guilt, and emotional burden when compared with mothers who have a child with Down syndrome (Lenhard, Breitenbach, Ebert, Schindelhauer-Deutscher, & Henn, 2005).

Wide range of functioning and impairment within the autism spectrum. As the term "spectrum" suggests, there is tremendous variability within the ASD classification (Marcus et al., 2005; Yirmiya & Ozonoff, 2007). This heterogeneity can create a sense of hope for parents; for example, a parent whose child is diagnosed with an ASD may draw on experiences or stereotypes of children on the spectrum whose functioning is at a higher level, or whose autism was 'cured.' However, this can also be a source of confusion and stress for parents (Plant & Sanders, 2007). There is no standardized treatment plan (Dale et al., 2006) for children with an ASD, and the recommended type and frequency of services varies across individuals. This uncertainty creates challenges in education planning, utilizing services, and obtaining appropriate treatments for a child. Parents are responsible for advocating for their child but often lack a guide as to what intervention would be most beneficial. Given that both early diagnosis and prompt delivery of early interventions are key to maximizing gain of skills and developmental outcomes (Dawson et al., 2010; Hume, Bellini, & Pratt, 2005), parents may worry whether or not they are advocating effectively or doing enough for their child (Neely et al., 2012; M. J. Weiss, 2002).

Difficulty in determining child's developmental level. Individuals on the autism spectrum sometimes present with an uneven developmental profile, rather than consistent levels of functioning across verbal, nonverbal and adaptive skills (Marcus et al., 2005). Some children with classic autism demonstrate relative strengths in some nonverbal skills (e.g. visual spatial and gross/fine motor abilities; Volkmar et al., 2005) in conjunction with relative deficits in social and communication skills. It can be stressful for parents when a child is relatively advanced in some areas but lags behind in others, as it makes it difficult to set appropriate expectations as

well as in meeting a child at the right level (e.g. during play, delivering instructions). Further, individuals on the autism spectrum have difficulty generalizing their skills and abilities across contexts. For example, while at school they may do well with toilet training, but then have frequent accidents at home. These unusual patterns are a further challenge to parents in developing appropriate expectations for their child (Rodrigue et al., 1992), and make predicting a child's long-term prognosis or even short-term gains quite difficult (Schuntermann, 2002).

Lack of social relatedness. Among those who have an ASD, there is variability in terms of their social relatedness; however, all affected individuals display impairments in social interaction and communication and the skills that foster social exchanges. Given that any relationship develops through a reciprocal exchange, these behaviors have implications for the parent (N. O. Davis & Carter, 2008; Hoppes & Harris, 1990; Norton & Drew, 1994) and the parent-child relationship. However, these impairments in social relatedness do not preclude a loving, high quality parent-child relationship for fathers and mothers who have a child on the spectrum. Rather, these parents describe strong bonds with their children (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Rutgers, Bakermans-Kranenburg, van Ijzendoorn, & van Berckelaer-Onnes, 2004). Still, individuals with an ASD are more difficult to engage and often lack the communication skills that facilitate a meaningful interaction.

Summary: autism spectrum disorders. The ASDs persist across the lifespan and affect multiple areas of development. Fathers and mothers who have a child with an ASD are faced with a range of unique challenges. Given the high numbers of children with an ASD and the increasing rates of diagnoses, it is crucial that these families be supported and understood as they navigate the path of raising a child on the spectrum. In order to best meet the needs of these parents, we must fully understand their experience and the many roles that they fill (King, King,

Rosenbaum, & Goffin, 1999). By including both fathers and mothers who have a child with an ASD, the current study aimed to help fill a gap in the extant autism literature.

Family Work among Parents who have a Child with an ASD

In the current section, the concept of family work is introduced, followed by a discussion of two aspects of family work: Responsibility-Related Caregiving and Household Labor.

Definition of family work and responsibility. Family work is unpaid labor done by parents or caregivers to care for the home or children (Coltrane, 2000; Shelton & John, 1996). The current study emphasized the management role that parents take in caring for their child and home. Management differs from involvement in that it entails taking responsibility for a task; it is the process of monitoring and ensuring that a given task or activity is taken care of or completed (Lamb et al., 1985; Shelton & John, 1996). For example, if a parent manages or is responsible for his or her child's preventative health care, this means that he or she schedules, keeps track of, and ensures that the child is taken to doctor's appointments. Responsibility for a task may be shared or one parent may be solely or primarily in charge. The following subsections describe the related literature that has been conducted with families of children with an ASD, in addition to gender differences in parents' involvement in these aspects of family work.

Responsibility-Related Caregiving. Responsibility-Related Caregiving is the monitoring, arranging, and planning that is done to ensure that a child is taken care of and that resources are accessible to them (Lamb et al., 1985; Lamb, Pleck, Charnov, & Levine, 1987). Responsibility-Related Caregiving is not a reflection of time spent with one's child or of what a parent does with the child during time spent together. Responsibility-Related Caregiving encompasses activities related to obtaining necessary goods and services for the child, provision of the child's physical environment (Parke, 1995), coordination of health care, facilitating social and

community connections, managing childcare, and some child-related housework activities (Lamb et al., 1985; J. H. Pleck, 1997, 2010). Responsibility-Related Caregiving has a behavioral component (e.g. attending school conferences or Individualized Education Program [IEP] meetings), but much of this work is procedural (e.g. phone calls, meetings, e-mails); all of this requires a great deal of thought and may involve worrisome thinking (L. A. Leslie, Anderson, & Branson, 1991; McBride & Mills, 1993). Management of Responsibility-Related Caregiving can be shared between parents, but this assumes that the demands associated with the management role are divided, as opposed to one parent providing help (J. H. Pleck & Masciadrelli, 2004) or responding to the other parent's request for assistance.

Responsibility was first described by Lamb et al. (1985) in their conceptualization of the three components of parenting involvement, which includes engagement (i.e. parent-child interaction) and accessibility (i.e. availability for interaction with one's child). The value of Responsibility-Related Caregiving is described by Lamb (2000), who wrote that it is important "inasmuch as it reflects the extent to which the parent takes ultimate responsibility for the child's welfare and care" (p. 31).

Responsibility-Related Caregiving does not entail direct interaction with or accessibility to the child (Lamb et al., 1985). When compared with other components of parenting involvement (e.g. engagement and accessibility), a parent's ability to fulfill this family management role is less limited by factors such as the time a parent spends working outside of the home or not living in the same house as one's child. A parent can give thought to his or her child's summer break schedule while at the gym, the office, or while grocery shopping. During a parent's lunch break he or she might be able to work on arrangements for his or her child's birthday party, do online research for a summer program for his or her child, or call the child's

doctor's office to schedule a check-up. A parent can attend to these kinds of activities in the evening while the child is asleep or engaged in an activity that does not require parent supervision.

Responsibility-Related Caregiving has been referred to as the managerial side of parenting (Parke, 1995). While shopping for a child's new clothes or researching summer camp options can be enjoyable, it may be less rewarding than other types of caregiving that allow for direct interaction with the child. The time spent with a child tends to be most meaningful and intrinsically reinforcing to a parent (Bulanda, 2004; Deutsch, Lussier, & Servis, 1993). Fathers and mothers often describe the special moments that are spent with their child as making the work that goes into parenting "all worth it." We do not often hear parents express these kinds of sentiments regarding the time that they spend searching for appropriate childcare arrangements or taking their sick child to the doctor. Further, a parent is unlikely to receive a thank you from his or her child for arranging doctor's appointments or for remembering to pick up diapers from the grocery store on the way home from work. However, these behaviors may be greeted with thanks or appreciation from the spouse or partner; the association between family work and the parents' relationship is addressed later in this review.

The association between the ASDs and Responsibility-Related Caregiving. Responsibility-Related Caregiving has particular salience for parents of children with an ASD. Professionals recommend a range of therapies, services, and strategies for children who are on the autism spectrum, which may include speech and language therapy, physical therapy, occupational therapy, positive behavior support, Applied Behavior Analysis, floor time, social skills groups, visual supports, sensory integration therapy, and special diets (Boyd & Odom, 2010). Many parents seek out additional treatments in hopes of curing or improving their child's condition. Children on the autism spectrum also have a higher number of clinic, pediatric, and psychiatric outpatient visits than children without an ASD (Croen, Najjar, Ray, Lotspeich, & Bernal, 2006).

There is no cure for autism, but we do know that intervention – especially if implemented early in a child's life – is associated with positive outcomes (Dawson et al., 2010) and is key to maximizing developmental gains for children with an ASD (Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Rogers, 1996; Woods & Wetherby, 2003). Mothers who have a child with an ASD describe the increased responsibility for managing their child's medical appointments, referrals, educational planning, and treatment schedules, while fathers are more involved in this aspect of family work during times of greater maternal stress or family crisis (Gray, 2003). Parents must also attend to other Responsibility-Related Caregiving demands that are common to all parents (e.g. finding appropriate recreation activities, arranging for transportation to and from school or daycare, and making sure their child receives preventative dental/medical care). However, due to some of the challenges that are associated with the ASDs (e.g. disruptive behavior, physical disabilities, low functioning in daily living skills, sleep problems, restricted dietary preferences), the task of ensuring that these needs are appropriately met can be frustrating and time intensive.

For parents who have a child with an ASD, the difficulty with which Responsibility-Related Caregiving needs are met may be related to child-related characteristics (e.g. level of functioning, behavior problems, or functioning). For example, arranging for a child's transportation to and from school (i.e. Responsibility-Related Caregiving tasks) may be more challenging for parents who have a child who is lower functioning or displays aggressive behavior on the school bus. Some children on the autism spectrum may be able to ride on a

public school bus, but others may need to ride on a private bus or van and may need to have a one-on-one attendant with them at all times. For children who require the latter, their parent(s) must make these arrangements as well as entrust the individuals who provide assistance with their child's safety.

The association between parents' gender and Responsibility-Related Caregiving. When compared with mothers, fathers are less involved in Responsibility-Related Caregiving (Barnett & Baruch, 1987; Baruch & Barnett, 1986a; Bulanda, 2004; Craig, 2006; Gray, 2003; Hofferth, 2003; McBride & Mills, 1993; Peterson & Gerson, 1992; J. H. Pleck & Masciadrelli, 2004; J. H. Pleck, 2010; Stueve & Pleck, 2003) – even when their wife or partner is employed outside of the home – despite an overall increase in fathers' involvement with their children over the last several decades (Bianchi, 2000; Bonney, Kelley, & Levant, 1999; Cabrera et al., 2000; J. H. Pleck, 1997; Sandberg & Hofferth, 2005). Fathers are less involved than mothers in making health care related matters (e.g. choosing a doctor, keeping track of medical records; Isacco & Garfield, 2010), attending their child's doctor's appointments (Moore & Kotelchuck, 2004), and making child-care arrangements for their child (L. A. Leslie et al., 1991; Peterson & Gerson, 1992; Barnett & Baruch, 1987). The number of hours worked each week by the mother and the father is unrelated to how families share the responsibility for making child-care arrangements (L. A. Leslie et al., 1991) and women who work more hours are more involved in making childcare arrangements for their children, perhaps because greater hours worked leads to greater time spent on making these arrangements (Peterson & Gerson, 1992). Mothers of young children usually stay home with their child when they are sick and also tend to be responsible for taking their child to the doctor or dentist, though fathers are more likely to be involved with their children when their wives are employed outside of the home (Bailey, 1991). Typically, both

fathers and mothers report mothers as being more involved in these aspects of Responsibility-Related Caregiving and fathers more often provide support or assistance to their wives in the area of Responsibility-Related Caregiving as opposed to filling the management role themselves (L. A. Leslie et al., 1991; Stueve & Pleck, 2003; Sunderland, 2000; Wall & Arnold, 2007).

Summary of Responsibility-Related Caregiving. Raising a child with an ASD required that parents fill a number of roles, including that of responsibility-related caregiver. Responsibility-Related Caregiving is important to the well-being of children who have an ASD, and meeting the special needs of children on the autism spectrum is accompanied by a number of challenges. This component of family work has not been addressed in the autism literature, and the current study will broaden our understanding of the roles that are held and the responsibilities that are managed by these fathers and mothers.

Household Labor. Household Labor is the unpaid work that contributes to the maintenance of the home (Coltrane, 2000; Y. Lee & Waite, 2005; Shelton & John, 1996), and includes activities such as preparation of meals, doing the laundry, taking out the garbage, and making sure the bills get paid (Saxbe, Repetti, & Graesch, 2011). This review will address Household Labor from a broad perspective, with coverage of Household Labor activities that occur often or routinely (e.g. cooking, cleaning, doing the dishes), as well as those that arise sporadically or less frequently (e.g. financial paperwork, yard maintenance, household repairs). As described above, the management role that fathers and mothers take in this aspect of family work is emphasized. However, much of the research Household Labor focuses on how the work is divided rather than on how responsibility for this aspect of family work is managed. There is a distinction between the two; for example, if a parent notices that the toaster oven is damaged or broken and then goes online or makes phone calls to inquire about a replacement, it can be said

that this parent is responsible for ensuring that the appliance is fixed or replaced. If the parent then asks his or her spouse to drive to the store to pick up the toaster oven, the spouse is indeed providing support, but they are not bearing responsibility for this task.

The value of managing this aspect of family work is revealed when we consider the consequences of situations in which a parent does not take responsibility for the demands of Household Labor. If parents do not plan ahead in buying groceries, a child may not have appropriate food options available. If a child's laundry is not attended to, a child may not have a clean outfit for school. If a parent does not remember to pay the utility bill on time, a child may wake up to find that there is no heat in their home. While there is more to Household Labor than managing the related tasks, being responsible for this domain of family work home is important to the well-being of the family.

The value that is attached to most kinds of work is related to the payment that is received; that Household Labor is unpaid likely contributes to the perception of it being mundane work (Walters & Whitehouse, 2012). There is an idiom regarding Household Labor that, "a woman's work is never done." Though this phrase is antiquated and it is politically incorrect to refer to family work as "woman's work," the sentiment still prevails. Further, there is truth in this statement: housework is never ending, and a parent's work is never done. A clean bathroom or a freshly mowed yard will remain that way only so long before the job must be done again, and a laundry hamper can go from empty to full very quickly, especially with children in the home. Managing the demands of Household Labor may be overwhelming, especially for parents who face a great deal of other responsibilities.

The association between the ASDs and Household Labor. There is little research on the division of Household Labor in families of children with an ASD; thus, this section is more

theoretically driven. The current study will help to fill this gap in the literature. The factors that are associated with the unique demands and division of Household Labor in families of children with an ASD are discussed.

The demands of Household Labor among families of children with an ASD may differ from families of typically developing children in that children on the spectrum are less likely to take on chores or house related work than are typically developing children. As children develop, parents often assign household chores or ask that children be more independent in things like cleaning their rooms, doing their own laundry, or taking out the recycling. This helps children develop a sense of responsibility and socializes them to the demands of family work (Blair, 1992; Demo & Acock, 1993). Further, as children take on chores and responsibilities around the house, this helps families to better function (Demo & Acock, 1993), and may alleviate some of the demands of Household Labor. However, children who have an ASD may be delayed in the development of independent living skills. Some children on the autism spectrum may never be capable of maintaining responsibility for tasks such as vacuuming the living room or making their own lunches for school. Parents of children with an ASD may remain fully responsible for tasks of Household Labor that parents of typically developing children are able to delegate.

In addition to delays in the development of independent living skills, there are characteristics of children with an ASD that may contribute to intensified demands of Household Labor. Similar to Responsibility-Related Caregiving, a child's functioning, degree of impairment, and the display of problem behaviors can be associated with the difficulty with which the tasks of Household Labor are completed (Sharpe & Baker, 2007). For example, while it is not uncommon for a young child to pull a roll of toilet paper off of its roll, pour the contents of pantry items onto the kitchen floor, or take all of the sheets and blankets off of their beds,

these kinds of behaviors typically subside as children develop and are better able to communicate and comply with behavioral expectations. However, children who have an ASD – especially those whose level of impairment is more severe – may continue to engage in these kinds of behaviors into adolescence or adulthood. This is likely to be a source of frustration and stress for parents, while also creating housework to which parents must attend. If a child's behavior results in broken or damaged goods or materials, this may contribute to added financial costs for the parent (Sharpe & Baker, 2007). For parents of children with an ASD whose functioning is more impaired, fulfilling the demands of Household Labor may feel especially difficult.

The association between parents' gender and the division of Household Labor. Fathers are less involved than mothers in attending to the demands of Household Labor (Barnett & Baruch, 1987; Barnett & Shen, 1997; Poortman & Van Der Lippe, 2009; Saxbe et al., 2011; Shelton & John, 1996; Walters & Whitehouse, 2012). Despite the significant increase in the percent of women in the labor force over the last several decades (Cabrera et al., 2000; Marsiglio, Amato, Day, & Lamb, 2000; Milkie & Raley, 2009), and even in families in which the mother is employed full-time outside of the home, women continue to do a greater share of the housework (Grote, Naylor, & Clark, 2002). Often, couples that have an egalitarian sharing of Household Labor prior to marriage often adopt a more traditional sharing of this work after getting married (S. N. Davis, Greenstein, & Gerteisen Marks, 2007) or having children.

When men perform Household Labor, they tend to engage in tasks that entail working outdoors (e.g. mowing the lawn, emptying the gutters) or repairs around the house (e.g. repairing a broken fence or light switch, fixing a leaky faucet or clogged drain), whereas mothers tend to be more involved with ongoing daily chores such as cleaning and cooking. All of these tasks are important to the maintenance of a home and those who live there, but there is a distinction

between the kinds of activities in which fathers versus mothers tend to be involved. The tasks that fathers are more involved occur less frequently, are more sporadic, and are more flexible as to when they are completed (Barnett & Shen, 1997; Coltrane, 2000; Craig, 2006; Cunningham, 2007). In contrast, the kinds of activities that mothers more typically attend to occur with greater frequency, on a more regular basis, and are associated with greater time constraints (Barnett & Shen, 1997; Craig, 2006) and urgency.

Summary of Household Labor. Parents who have a child with an ASD must manage the care of their home, just as do parents of typically developing children. Meeting their child's needs may be taxing for parents and having a child on the spectrum may be associated with exacerbated demands of Household Labor. Thus, the way in which parents share the management of Household Labor warrants exploration.

Parenting Stress among Fathers and Mothers who have a Child with an ASD

The current section describes parenting stress, with an emphasis on parents who have a child with an ASD. The relationship between parent's gender, Responsibility-Related Caregiving and Household Labor, and Parenting Stress will be addressed.

Definition of parenting stress. Stress arises out of a transactional process between an individual and his environment (Lazarus, 1991) and is based on the appraisal (evaluation) and coping response (efforts to manage) a situation or demand (Krohne, 2002; Lazarus, 1993). Stress occurs when the demands of the environment exceed a person's ability to respond or when demands prevent the pursuit of other objectives (Raina, O'Donnell, Rosenbaum, Brehaut, Walter, Russell, Swinton, Zhu, & Wood, 2005b). While this study focused specifically on parenting stress, this conceptualization still applies. Being a parent is characterized by meeting everyday challenges and demands (Crnic & Low, 2002), and parenting stress arises when the

appraisal of parenting demands exceeds a person's resources or efforts to manage a situation (Deater-Deckard & Scarr, 1996; Webster-Stratton, 1990).

The ASDs and parenting stress. Parents who have a child with an ASD report greater stress than parents of typically developing children, as well as parents who have a child with another kind of special health care need (Baker-Ericzen et al., 2005; Dabrowska & Pisula, 2010; N. O. Davis & Carter, 2008; Duarte et al., 2005; Ergüner-Tekinalp & Akkök, 2004; Ingersoll & Hambrick, 2011; Marcus et al., 2005; Olsson & Hwang, 2002; Rao & Beidel, 2009; Sanders & Morgan, 2008; Watt & Wagner, 2012; M. J. Weiss, 2002). While these parents describe great joy and even contentment in being a father or mother of a child on the spectrum (Fleischmann, 2004; Hutton & Caron, 2005; Joosten & Safe, 2014; Meirsschaut, Roeyers, & Warreyn, 2010; Myers, Mackintosh, & Goin-Kochel, 2009), parents who have a child with an ASD do describe their parenting experience as stressful (Hutton & Caron, 2005) and their lives as characterized by "continual stress, strain, and lack of sleep" (Cassidy et al., 2008). This stress is likely related to the difficult tasks that these parents have in managing their child's treatment and services, special diets, child-care, and adaptive equipment (Autism Speaks, 2012; Cidav, Marcus, & Mandell, 2012; D. L. Leslie & Martin, 2007; Mandell, 2012; Myers et al., 2009; Rodrigue et al., 1992; Sharpe & Baker, 2007), determining how to meet the caregiving needs of their child, as well as managing their home and its upkeep.

While parents who have a child with an ASD typically report greater stress than other groups of parents, there is variability. Some of these parents experience a great deal of stress, while others do not (Hastings, Kovshoff, Ward, et al., 2005; Koegel et al., 1992). Among fathers and mothers who have a child on the spectrum, their child's level of functioning, impairment, or problem behavior are related to their stress (Bebko, Konstantareas, & Springer, 1987; N. O.

Davis & Carter, 2008; Estes et al., 2009; Ingersoll & Hambrick, 2011; Koegel et al., 1992; Walsh, Mulder, & Tudor, 2013). Indeed, these parents' stress is associated with factors that go beyond simply having a child with an ASD. The relationship between parents' gender, family work, and parenting stress in parents of children with an ASD will be discussed below.

The association between parents' gender and parenting stress. Mothers of children with an ASD are typically found to experience greater parenting stress than fathers (Dabrowska & Pisula, 2010; N. O. Davis & Carter, 2008; Hastings, 2003; Herring et al., 2006; Konstantareas & Homatidis, 1992; Macdonald & Hastings, 2010; Tehee et al., 2009), a difference that has been found across parents of children of different ages (Davis & Carter, 2008; Herring et al., 2006; Konstantareas & Homatidis, 1992; Tehee et al., 2009). However, in a recent study of parents who have a child on the autism spectrum, fathers experienced higher levels of parenting related stress than mothers (Rivard, Terroux, Parent-Boursier, & Mercier, 2014).

Much of the autism research on parenting stress has addressed father-mother differences. When compared with fathers, mothers who have a child with an ASD experience greater parenting stress related to limits on family opportunities, child's dependency, management of the child's care giving needs, and personal burden related to caring for the child; this gender difference is less substantial for parents who have a typically developing child or a child with Down syndrome (Dabrowska & Pisula, 2010). On the other hand, fathers describe indirect effects of their child's disorder, through the stress experienced by their wife. This suggests that parents who are more involved in the care of their child may be more likely to experience the effects of their child's functioning or characteristics (Roach & Orsmond, 1999). Fathers may be able to deal more effectively with their partner's mood or child's behavior, because they are less involved in their child's day-to-day care. This discrepancy speaks to the unique challenges

associated with parenting a child with an ASD, and suggests that mothers are particularly vulnerable.

The association between family work and parenting stress. The heightened parenting stress experienced by mothers who have a child with an ASD may be related to the intensified demands of family work that come with having a child with an ASD and the fact that mothers are typically more involved in Responsibility-Related Caregiving (Barnett & Baruch, 1987; Baruch & Barnett, 1986a; Craig, 2006; Gray, 2003; Hofferth, 2003; McBride & Mills, 1993; Peterson & Gerson, 1992; J. H. Pleck & Masciadrelli, 2004; J. H. Pleck, 2010; Stueve & Pleck, 2003) and Household Labor (Barnett & Shen, 1997; Poortman & Van Der Lippe, 2009; Saxbe et al., 2011; Shelton & John, 1996; Walters & Whitehouse, 2012). However, little empirical research has investigated this theory.

Among parents who have a child on the spectrum, mothers often have responsibility for child-related caregiving and domestic tasks (Gray, 2003), and the task of managing their therapies and interventions may be associated with greater stress (Hutton & Caron, 2005; Irvin, McBee, Boyd, Hume, & Odom, 2012). For these mothers, their stress seems to be more strongly affected by child characteristics than is fathers' stress (Hastings, 2003). In addition to experiencing difficulty in maintaining a balance between work and family commitments, mothers describe a great burden associated with always managing some aspects of responsibility-related caregiving (e.g. doctor's appointments), which they feel fathers do not have to deal with (Gray, 2003).

Summary of parenting stress. Parents who have a child with an ASD experience higher levels of stress than parents of typically developing children as well as parents who have a child with another kind of disability (Baker-Ericzen et al., 2005; Dabrowska & Pisula, 2010; N. O.

Davis & Carter, 2008; Duarte et al., 2005; Ergüner-Tekinalp & Akkök, 2004; Ingersoll & Hambrick, 2011; Marcus et al., 2005; Olsson & Hwang, 2002; Rao & Beidel, 2009; Sanders & Morgan, 2008; Watt & Wagner, 2012; M. J. Weiss, 2002), and mothers in these families often experience greater parenting stress than fathers (Dabrowska & Pisula, 2010; N. O. Davis & Carter, 2008; Hastings, 2003; Herring et al., 2006; Konstantareas & Homatidis, 1992; Macdonald & Hastings, 2010; Tehee et al., 2009). These differences may be related to the unique stressors associated with the ASDs and that mothers tend to bear more responsibility for managing their child's caregiving needs and caring for their homes.

The Couple's Relationship among Fathers and Mothers who have a child with an ASD

In the present section, the topic of couple's relationship quality is introduced. This is followed by a discussion of the association between raising a child with an ASD, parenting stress, family work, and the couple's relationship quality.

Definition of couple's relationship quality. Couple's relationship quality reflects several indicators of adjustment in the relationship between partners. One partner's general satisfaction with the other is one component; individuals who are satisfied with the relationship have little desire for the relationship to change a great deal. The couple's relationship quality is also based on the quality of communication between partners. Parents who have a high quality relationship tend to communicate well with one another; they feel comfortable talking about a range of topics and can discuss important issues (Spanier, 1976). A high quality relationship is also characterized by positive attitudes, beliefs, and feelings about conflict and the ability to effectively resolve conflict in the relationship. During a disagreement, partners try to understand each other's perspective and arguments are generally resolved. In contrast, in a low functioning relationship, partners may frequently argue about trivial issues or often consider or talk about the

possibility of divorcing or leaving the other parent (Spanier, 1976). The couple's relationship quality reflects the extent to which partners agree on important issues, their satisfaction with how affection is given and received, and the level of happiness, sadness, or disappointment they feel with regards to the relationship (Fowers & Olson, 1993; Spanier, 1976).

The association between raising a child with an ASD and the couple's relationship. Parents who have a child with an ASD experience lower adjustment in the parent's relationship when compared to parents of children who are not on the autism spectrum (Baker-Ericzen et al., 2005; Brobst et al., 2008; Gau et al., 2012; Higgins et al., 2005; Hutton & Caron, 2005; G. K. Lee, 2009; Rodrigue et al., 1990; Sawyer et al., 2010; Tarabek, 2011). This difference may be related to the greater demands of family work (Baker-Ericzen et al., 2005; Brobst et al., 2008; Cassidy et al., 2008; Hutton & Caron, 2005; Kasari, 2002; Sawyer et al., 2010), the way that family work is shared, as well as the increased stress experienced by parents who have a child on the autism spectrum (Baker-Ericzen et al., 2005; N. O. Davis & Carter, 2008; Duarte et al., 2005; Dyson, 1997; Ergüner-Tekinalp & Akkök, 2004; Ingersoll & Hambrick, 2011; Marcus et al., 2005; Montes & Halterman, 2007; Olsson & Hwang, 2002; M. J. Weiss, 2002).

Among parents who have a child with an ASD, parents' relationship quality is associated with child characteristics. For example, mothers whose children have more severe behavioral problems report lower levels of spousal support, respect for their partner, and commitment to their marriage (Brobst et al., 2008). Similarly, mothers who report more positive perceptions of their child, perhaps because their child displays fewer behavioral challenges, also report higher levels of adjustment in their relationship with their partner (Lickenbrock, Ekas, & Whitman, 2011). This finding indicates that when a parent is faced with overwhelming demands

of caring for their child and do not receive enough help and support from their partners, the couple's relationship may be negatively affected.

The association between parents' gender and the couple's relationship quality. There is a relatively small body of research on the relationship between parents who have a child with an ASD that has included both fathers and mothers. Some research has indicated that mothers of children with an ASD have lower general satisfaction with the marital relationship (Brobst et al., 2008; Gau et al., 2012) as well as lower satisfaction with the expression of affection in the relationship when compared with fathers (Gau et al., 2012), while other research has not found differences between fathers and mothers in their self-reported marital satisfaction (Hartley et al., 2011). Gender differences in other predictors of parents' relationship quality (e.g. involvement in family work) are discussed in subsequent subsections.

The association between family work and couple's relationship quality. Parents' involvement in and management of family work is associated with the quality of the parents' relationship (Barnett & Shen, 1997; Coltrane, 2000; Frisco & Williams, 2003), but fathers' caregiving involvement appears particularly tied to the quality of the couple's relationship (S. M. Allen & Daly, 2002, 2007; Brągiel & Kaniok, 2014; Kalmijn, 1999; Lamb & Lewis, 2010; McBride & Mills, 1993; E. H. Pleck, 2004). Mothers are more involved than fathers in family work, regardless of the quality of the couple's relationship; however, mothers who are more satisfied in the couple's relationship have husbands or partners who are more involved in caring for the children (Doherty, Kouneski, Erickson, & Erickson, 1998). Fathers who are more involved in Responsibility-Related Caregiving also have more favorable perceptions of their marriage (McBride & Mills, 1993); however, a distinction is that when the couple's relationship quality is lower, fathers are more apt than mothers to withdraw from their children (Belsky,

Youngblade, Rovine, & Volling, 1991; Cummings, Goeke-Morey, & Raymond, 2004; Krishnakumar & Buehler, 2000; Sanderson & Sanders-Thompson, 2002).

Fathers acknowledge the positive impact on the spousal relationship of sharing Responsibility-Related Caregiving with their partner (Stueve & Pleck, 2003). In Stueve and Pleck's (2003) qualitative study conducted with fathers of young, typically developing children, one father commented that, "(I)t's just been nice. It really makes a marriage a partnership when you got someone like I do to work with. It also makes life a lot easier." In this study, fathers also indicated that both their perception of and involvement in Responsibility-Related Caregiving were strongly tied to their relationship with their child's mother; greater father involvement in arranging and planning for their child was associated with a better relationship between parents.

Among fathers and mothers of typically developing children (Roxburgh, 2006), most are not completely satisfied with the time that they spend with their spouse. Parents wish that the pace of the time spent with their partner was less rushed and could be uninterrupted by the demands and responsibilities associated with work or children. It is expected that this desire might be even more prevalent among parents of children with an ASD, for whom the demands of family work are exaggerated.

For families of children with an ASD, there are additional ways in which the management of family work may be associated with parents' relationship adjustment. The demands of family work are exacerbated for these families, which may contribute to greater parenting stress as well as decreased functioning in other aspects of the family system (e.g. parents' relationship, family as a whole). In families of typically developing children, women spend the greatest percentage of their time doing Household Labor while men spend the greatest percentage of their time (Saxbe et al., 2011), and women spend less time spent in

leisure or sleep than do men (Milkie & Raley, 2009). This may be problematic; if one parent manages most or all of the Responsibility-Related Caregiving and Household Labor, they may experience frustration or dissatisfaction within their relationship with their child's other parent, especially if it is perceived that the other parent has greater opportunity for personal time, hobbies, etc.

The association between parents' stress and relationship quality. Parenting stress is associated with parents' relationship adjustment (Lavee, Sharlin, & Katz, 1996), a trend that is also found among parents who have a child with an ASD as well as other disabilities (Hartley et al., 2011). Fathers and mothers who have a child on the autism spectrum and experience greater parenting stress report a lower quality relationship between parents (Hartley et al., 2011; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). These parents also indicate that having a child with an ASD puts additional stress on the couple's relationship (Hutton & Caron, 2005; Myers et al., 2009).

Among parents who have a child with an ASD, mothers who report higher parenting stress experienced lower adjustment in the couple's relationship (Brobst et al., 2008). Parents who have a child with an ASD and report lower marital satisfaction tend to experience greater parenting burden (difficulty and distress associated with the parenting role) than those who report higher marital satisfaction (Hartley et al., 2011). The quality of the parents' relationship may either buffer or exaggerate parenting distress among fathers and mothers of children with an ASD (Siman-Tov & Kaniel, 2011), or it may be that parents' level of stress or their satisfaction with how the demands of family work are shared may influence the quality of the parents' couple relationship.

Several studies have examined the link between parents' daily hassles and parents' relationship adjustment. Parenting stress and daily hassles are not one and the same, as daily hassles are not specific to child related care giving. Rather, daily hassles are the accumulation of minor stressors and irritating demands of daily life (Crnic & Booth, 1991; Mazur, 2006). However, findings drawn from research on parents' experience of daily hassles are relevant to the proposed study, as the concept of daily hassles shares overlap with both family work and parenting related stressors. Among families of young children with a disability, parents' report of greater stress related to daily hassles is associated with lower adjustment in the marital relationship (Gavidia-Payne & Stoneman, 2006).

Summary of the couple's relationship quality. A couple's relationship quality is based on overall satisfaction with the relationship, as well as perceptions of the ease of communication and conflict resolution (Olson, Fournier, & Druckman, 1983; Spanier, 1976). Fathers and mothers who have a child with an ASD report lower relationship quality than parents of typically developing children, which may be related to the intense caregiving demands, the way that family work is divided, and high parenting stress. Given the transactional influence between these variables, it is likely that the parent's relationship is just one factor that impacts the parent and family's adaptation to the demands of raising a child with an ASD (Hartley et al., 2011). The current study attempts to elucidate the relationship between these variables.

Family Functioning in Families of Children with an ASD

Family functioning is an indicator of the overall family environment and is affected by each person's characteristics and experiences, as well as the quality of the relationships between family members (e.g. the parents' relationship). The associations between these variables are

complex and transactional; each of these factors impacts family's functioning, which in turn feeds back into each of the variables described above.

For the purpose of the current study, family functioning will be discussed using the Family Environment Scale (R. H. Moos & Moos, 2009), a widely used measure of family functioning, as a guide. In the present section, family functioning and two components, Relationship Quality and Family Social Integration, are described. This is followed by a discussion of family functioning in families of children with an ASD, as well as the association between family work, parenting stress, the couple's relationship adjustment, and family functioning.

Definition of family functioning. Family functioning is a family's ability to successfully respond to stressors and meet the needs of its members, and is based on a family's adjustment in different areas (e.g. cohesion, expressiveness, emphasis on recreation and cultural activities), ranging from low to moderate to high in each area. Within the literature there are multiple definitions and conceptualizations of family functioning that both overlap and differ from one another to some extent (Epstein, Bishop, & Levin, 1978; Olson & Gorall, 2003; Patterson, 1988, 2002; Skinner, Steinhauer, & Sitarenios, 2000). However, broader definitions of family functioning are relatively consistent. In a well-functioning family, family members communicate openly and are able to pursue their own interests. However, it is emphasized that there is no single "best" way for families to function.

Relationship Quality among Family Members. The quality of relationships among family members reflects a family's emotional bond (Olson & Gorall, 2003). Relationship quality is based upon overall cohesion, expressiveness, and conflict, and is an index of overall family support.

A cohesive family is characterized by concern and commitment to other family members; parents and siblings try to help and support one another (Moos & Moos, 1976). For example, older siblings may offer to babysit for their younger siblings so that their parents could attend their high school reunion. Families that are very low on cohesion might be considered disengaged (e.g. unattached, uncommitted). On the other hand, families that are very high on cohesion could be overly enmeshed (e.g. little independence, excessive emotional closeness; Olson & Gorall, 2003).

Expressiveness is the degree of open communication that is encouraged among family members (Moos & Moos, 1976), and includes the respect and empathy that family members display towards one another (Moos & Moos, 1976; Olson & Gorall, 2003). In families that are low on expressiveness, family members may feel inhibited and children may be hesitant to tell their parents about problems they are having at school. In these families, parents and siblings may interrupt one another or not allow one another to share feelings or points of view. In contrast, in families that are moderately high in expressiveness, feelings and thoughts are shared openly and spontaneously but family members are not overwhelmed or bothered by the level of communication. In very expressive families, parents may share inappropriate details of their personal lives with their children.

The way that families engage in and respond to conflict contributes to their overall family functioning (Moos & Moos, 1976). Families that are high in conflict tend to be more aggressive, have serious disagreements with greater frequently, and are critical of one another. In a family that is high in conflict, parents may deliver excessive criticism to one another for minor gaffes or errors in judgment; they may also criticize their children unreasonably. Families that are low on

conflict are not characterized by anger and aggression; during disagreements, family members are respectful to one another and maintain a sense of understanding.

Family functioning: relationships within families of children with an ASD. Some studies have found cohesion to be higher among families of children with an ASD than in families of children with Down syndrome (Rodrigue et al., 1990, 1992) or that cohesion in families of children with an ASD does not differ from comparison families (Rao & Beidel, 2009; Sanders & Morgan, 2008). In other studies, family cohesion has been found to be lower (i.e. family members are less connected) among parents who have a child with an ASD, when compared with parents of typically developing children (Gau et al., 2012) as well as norm groups (Higgins et al., 2005). These findings suggest that families of children with an ASD can maintain healthy, cohesive relationships among family members. While having a child with an ASD can be the source of stress for parents, it may lead to a 'rallying' among family members (i.e. greater cohesion, satisfaction, and communicate). Clearly, there is variability in functioning and adjustment among families who have a child with an ASD, and the current study will help to better understand the factors that are associated with quality relationships within families that have an individual on the spectrum.

Family Social Integration. A family's social integration reflects the connection between the overall family the broader social context; it is the extent to which a family is integrated into their community, and is nested within a broader dimension of family functioning referred to as personal growth. Family social integration is an indicator of family members' overall orientation towards intellectual-cultural interests, the extent to which the family participates in social and recreational activities, as well as the emphasis that is placed on values and ethical or religious issues (Moos & Moos, 2009).

In a family that is oriented towards intellectual-cultural interests, members value learning about new things. For example, a parent may take up learning a new language or a musical instrument. In contrast, within families that are low high on intellectual-cultural interests a great deal of time may be spent watching the television and members rarely attend plays, concerts, or lectures.

Among families that are oriented towards participation in social and recreational activities, children likely take part in school sports and frequently spend time with friends. In contrast, in families that are not oriented towards social and recreational activities, family members likely don't spend a lot of time on hobbies and friends visit infrequently. Aside from work and school, these families may spend most of their time at home.

For families that emphasize moral and religious issues, common values are shared and discussions about religious texts and holidays frequently occur. This is in contrast to other families, in which it is rare to attend church or synagogue and family members may differ in their beliefs.

Family functioning: social integration within families of children with an ASD. Family Social Integration is nested within the dimension of Personal Growth, which has been found to be lower in families of children with an ASD (Rao & Beidel, 2009; Sanders & Morgan, 2008), when compared with families of typically developing children and children with Down Syndrome. Among families who have a child with an ASD, restriction of social integration within their community may be particularly problematic. These families are already under a great deal of stress, and participation in recreation, hobbies, and cultural activities may help to alleviate some of the strain they experience. These findings lend support to the notion that families of children with an ASD experience greater demands on their time, which impacts their

family's opportunities for recreation and leisure activities outside of the home (Cassidy et al., 2008).

Fathers and mothers of children with an ASD describe having little or no time for recreation or family vacations (Hutton & Caron, 2005). These parents describe limits on family opportunities (Dabrowska & Pisula, 2010), experience difficulty in finding recreational activities that are appropriate for their child, and difficulty in securing baby sitters or respite services that would enable them to engage in activities without their child while leaving their child at home (Cassidy et al., 2008; Neely et al., 2012). For families who have a child on the autism spectrum, this decreased opportunity for recreation and activities outside of the home (Koegel et al., 1992; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011) may have implications for their utilization of support services (e.g. if they can't leave their child at home, attendance of a parent support group will be a challenge) as well as engagement in activities that may alleviate stress. Parents of children with an ASD sometimes avoid social settings out of concern that their child may display disruptive or inappropriate behavior, which may be effective in the short term for preventing feelings of embarrassment or stress (Myers et al., 2009). However, the avoidance of social situation may contribute to feelings of isolation sometimes experienced among parents of individuals with an ASD (Altiere & Kluge, 2008; Cassidy et al., 2008; Dunn et al., 2001; Koegel et al., 1992; Walsh et al., 2013).

The inconsistent findings described above suggest that factors beyond the presence of a child on the spectrum contribute to family functioning. Rather than focusing on differences between families of children with an ASD and those without, the current study aimed to help explain the variability that is present among families who have a child on the spectrum. The associations between the variables of interest (e.g. management of family work, parenting stress,

and the couple's relationship quality) and their relationship to family functioning in families who have a child with an ASD is described below.

The association between parents' gender and family functioning. There is little research that has assessed family functioning in families who have a child with an ASD, and an even smaller body of research that has included both fathers and mothers. Several studies on family functioning in fathers and mothers of children with an ASD have failed to find gender differences related to their family's cohesiveness, adaptability, and overall family satisfaction (Altiere & Kluge, 2008; Gau et al., 2012), while other studies have indicated gender differences related the family's personal growth (Sanders & Morgan, 2008). However, it is important to keep in mind that when reporting on family functioning, the respondent is expected to take into account the family's overall adjustment (e.g. family social integration, family relationships), rather than their own personal experience. This may explain why the assessment of family functioning might not yield father-mother differences. Assuming that parents are able to accurately assess their family's functioning and that fathers and mothers are from similar types of families, their reports of family functioning should not necessarily differ. Whether or not fathers and mothers differ in their report of family functioning was explored in the current study.

The association between family work and family functioning. Family functioning is influenced by the demands and responsibilities to which family members must attend (e.g. family work). It is expected that the division of family work has implications for family functioning, regardless of whether or not the family has a child with an ASD. However, the increased and intensified responsibilities associated with parenting a child with an ASD, the role that parents take in arranging and planning for their child's welfare, tending to the care of their home, and otherwise meeting the needs of their child and family all suggest that the demands of

family work may be especially influential to the functioning of these families. However, the degree to which the division of family work has an influence on family functioning may vary across domains of family functioning. For example, the way that parents share the management of family work may have stronger implications for a family's social integration (e.g. a family's interest and involvement in various kinds of activities outside of the home) than for the quality of the relationships (e.g. cohesion, expressiveness, conflict) among family members.

As described in Elder et al. (2003), families of children with an ASD experience less stress when both parents are involved in family work. Therefore, overall strain on the family may be alleviated if fathers and mothers take a coordinated approach to caring for their child with an ASD (Sivberg, 2002). Mothers tend to be more involved in responsibility related care giving (Barnett & Baruch, 1987; Baruch & Barnett, 1986a; Craig, 2006; Gray, 2003; Hofferth, 2003; McBride & Mills, 1993; Peterson & Gerson, 1992; J. H. Pleck & Masciadrelli, 2004; J. H. Pleck, 2010; Stueve & Pleck, 2003) and Household Labor (Barnett & Shen, 1997; Shelton & John, 1996; Walters & Whitehouse, 2012), while fathers assume greater responsibility for their family's financial needs. There is no gold standard regarding the way that parents share family work; an equal division of Responsibility-Related Caregiving and Household Labor is not necessarily the goal for some families. However, the way that parents share the management of family work may influence their family's social integration; parents who share responsibility for the demands of managing Responsibility-Related Caregiving and Household Labor may have families that have greater interest in and opportunities for activities outside of the home.

The association between parenting stress and family functioning. Family functioning is influenced by each family member's experience of stress and their ability to cope with stressors. Among parents who have a child with a developmental disability, parenting stress is

negatively associated with family functioning; fathers who experience lower parenting stress report higher personal growth and system maintenance while mothers who experienced lower parenting stress report higher personal growth, system maintenance as well as higher cohesion, expressiveness and lower conflict (i.e. relationships, Dyson, 1997). Among families of children without a disability, the relationship between stress and family functioning is not significant; this suggests that the effect of stress on family functioning is more pronounced for families who have a child with a disability versus those who do not (Dyson, 1997).

There are a number of explanations for the relationship between parenting stress, family relationships, and a family's social integration. Social integration includes but it not limited to families' interest and involvement in recreation and leisure. Among families of children with an ASD, this area of family functioning tends to be lower than in families of children who are not on the autism spectrum (Rao & Beidel, 2009; Sanders & Morgan, 2008) and these parents report feelings of isolation (Altiere & Kluge, 2008; Cassidy et al., 2008; Dunn et al., 2001; Koegel et al., 1992; Walsh et al., 2013). For any parent, involvement in and enjoyment of leisure and recreational activities can help to reduce stress. However, this may be especially important for parents of children with an ASD, who often experience a great deal of parenting related stress. Their parenting stress may negatively impact their interest in engaging in recreational activities; this feeds in to their family's overall functioning and may become a sort of a chronic stressor to which these parents and families must adjust.

The association between parents' relationship quality and family functioning. The quality of functioning in the relationship between parents sets the precedent for overall family functioning (Cox & Paley, 1997). Thus, it follows that dissatisfaction or discord in this relationship would be negatively associated with family functioning (Davies, Cummings, &

Winter, 2004). Among fathers and mothers of typically developing children, when marital discord (the extent to which couples disagree about important issues) is high, overall family satisfaction is lower (Hostetler, Desrochers, Kopko, & Moen, 2011). Given the increased stress associated with parenting a child on the spectrum, it was expected that this finding would be replicated in research conducted with fathers and mothers of children with an ASD.

The quality of the relationship between parents is important, given speculation that divorce rates are higher among parents who have a child with an ASD. For example, a recent study found that the prevalence of divorce in a sample of middle to high SES parents of children with an ASD was nearly twice that of a comparison group (23.5% vs. 13.8%) that was matched on key characteristics (Hartley et al., 2010). While there are conflicting data regarding risk of divorce in families who have a child with autism (i.e. other findings suggesting that these parents are not at greater risk for divorce; Baeza-Velasco, Michelon, Rattaz, Pernon, & Baghdadli, 2013; Freedman, Kalb, Zablotsky, & Stuart, 2011), it is clear that couples who have a child with an ASD experience added strain in their relationships. Thus, an understanding of the factors that are associated with better adjustment in the marital relationship may contribute to future research designed with the goal of keeping intact the relationship between fathers and mothers who have a child with an ASD.

Summary of family functioning. The family system plays an important role in any child's development (Sameroff, 1990), but given the socio-emotional and communication difficulties that are characteristic of individuals with an ASD and the cognitive and adaptive functioning impairments that are often present, it especially important that we understand the functioning and adjustment of families who have a child on the spectrum. However, we do not yet have a clear understanding of family functioning quality in families who have a child with an

ASD, nor of the factors that contribute to the quality of adjustment in each of the aforementioned areas. Healthy family functioning may help to ensure that we maximize outcomes for individuals with an ASD as well as their families.

Study Aims

The overarching goal of the current study was to investigate the associations among parents' management of and satisfaction with the division of family work, parenting stress, parents' relationship adjustment, and family functioning in fathers and mothers of children with an ASD. To date, there have been no published empirical studies that have examined the associations among these variables, and there is a paucity of research that has assessed these particular aspects of family work – Management of Responsibility-Related Caregiving and Household Labor – in families of children with an ASD. This study will help to describe the experience of fathers and mothers who have a child on the spectrum and will allow for an assessment of how the factors enumerated above contribute to family functioning. An underlying goal was to approach this topic without judgment or an expectation of what these parents should be doing or feeling; the intention was to better understand both fathers and mothers of children with an ASD and the conditions that best support their families.

Conceptual Framework

The current study was informed by Family Systems Theory, which proposes that individuals within the family are interdependent (Minuchin, 1985) and that family members influence one another via their own personalities, the relationships between members, and subsequent feedback loops. The influence between individual family members and the family system is dynamic and bi-directional, much like the process of development that occurs through continuous interactions between individuals and their environment (Sameroff & Fiese, 1993).

Just as parents and typically developing children contribute to their family's functioning (Cox & Paley, 1997), children with an ASD also impact – and are impacted by – their family's functioning (Sanders & Morgan, 2008).

A premise of Family Systems Theory is that family functioning cannot be understood through the examination of individual characteristics, family member dyads, or isolated relationships (Cox & Paley, 1997; Mathijssen, Koot, Verhulst, De Bruyn, & Oud, 1998; Minuchin, 1985). Instead, the understanding of individual development, relationships, and family functioning comes from an exploration of the processes and bi-directional exchanges that occur between the various levels within the family system (Cox & Paley, 1997; Sivberg, 2002). Each person influences the behavior and experience of other family members, as well as the family's overall functioning (Epstein et al., 1978; Sikora et al., 2013). Family systems theory was applied to the present examination of parents' management of family work, parents' stress, the couple's relationship, and family functioning among fathers and mothers who have a child with an ASD.

As illustrated in Figure 1, we took into account the interconnectedness among family members; each variable interacts with the others and ultimately affects family functioning, which subsequently influences family members. In any family, children affect other family members; a child's characteristics (e.g. sociability, communication skills) impact the relationship with his or her family members. A child with an ASD impacts his or her father and mother (e.g. via the stress they experience, the ease with which they are able to attend to family work), as well as the relationship between parents. Both of these family system components (e.g. parents' individual experience, parents' relationship quality) then feed into to overall family functioning.

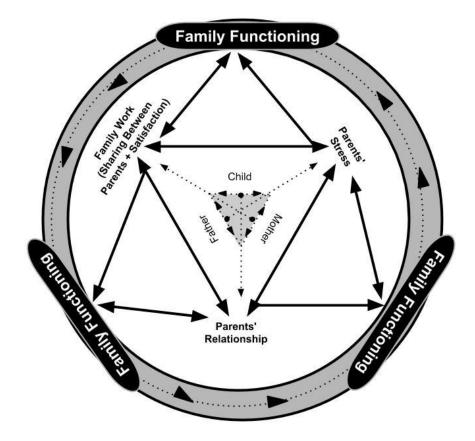


Figure 1. Model for Current Study

The current study was conducted under the premise that the processes and factors described throughout this review (e.g. parents' management of and satisfaction with the division of family work, parents' stress, parents' relationship quality) contribute to family functioning in families of children with an ASD, and that each of these factors ultimately has implications for the development and outcomes of children on the autism spectrum. Individuals who have an ASD experience pervasive delays across areas of development. The ASDs are lifelong disorders, and much like other developmental patterns and processes that are set in place early in life, the impairments they display will persist – to some extent – over the lifespan. However, environmental factors (e.g. family functioning, parents' involvement in family work, parents'

relationship status, parents' stress and relationship quality) have the potential of either maximizing or minimizing children's developmental and social-emotional outcomes (Sameroff & Rosenblum, 2006; Wachs, 2000). Findings from the current study will contribute to our understanding of families who are affected by the autism spectrum disorders and may provide us with insight as to areas of need that are experienced by parents who have a child on the spectrum.

Research Questions and Hypotheses

The current study aimed to address the following research questions and hypotheses.

Research Question 1. What are the relationships between parent's gender, Relationship Satisfaction, and management of family work (Management of Responsibility-Related Caregiving [RRC MNG] and Management of Household Labor [HLAB MNG])?

Hypothesis 1.1a. Fathers will have a lesser role in the Management of Responsibility-Related Caregiving.

Hypothesis 1.1b. Couple's Relationship satisfaction will be highest when the Management of Responsibility-Related Caregiving is distributed more equally between fathers and mothers (i.e., when it is not always performed by just one parent).

Hypothesis 1.2a. Fathers will have a lesser role in the Management of Household Labor.

Hypothesis 1.2b. Couple's Relationship Satisfaction will be highest when the Management of Household Labor is distributed more equally between fathers and mothers (i.e., when it is not always performed by just one parent).

Research Question 2. What are the relationships between children's level of functioning, parent's gender, management of family work (Management of Responsibility-Related

Caregiving [RRC MNG] and Management of Household Labor [HLAB MNG]), and Parenting Stress?

Hypothesis 2.1. Children's level of functioning, parents' gender, and Management of Responsibility-Related Caregiving and Household Labor will predict Parenting Stress (Figure 2).

The direction of these associations are hypothesized to be such that higher child functioning (ATEC), being a father, and a more equal distribution of the Management of Family work (Responsibility-Related Caregiving and Household Labor) will predict lower levels of Parenting Stress.

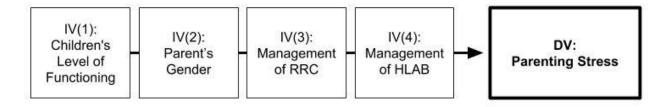


Figure 2. Hypothesis 2.1 – Children's Functioning, Parent's Gender, Management of Responsibility-Related Caregiving and Household Labor, and Parenting Stress

Research Question 3. What are the relationships between parents' Satisfaction with the Management of Responsibility-Related Caregiving and Household Labor, Parenting Stress, and Relationship Satisfaction?

Hypothesis 3.1. Parents' Satisfaction with the Management of Responsibility-Related Caregiving and Household Labor will mediate the relationship between Parenting Stress and Relationship Satisfaction. In other words, it is not that higher Parenting Stress on its own leads to lower Relationship Satisfaction. Rather, parents' satisfaction with how family work is shared will mediate (i.e., explain) the relationship between Parenting Stress and Relationship Satisfaction (Figure 3). The procedure suggested by Baron and Kenny (1986) for testing mediation will be followed, as detailed below.

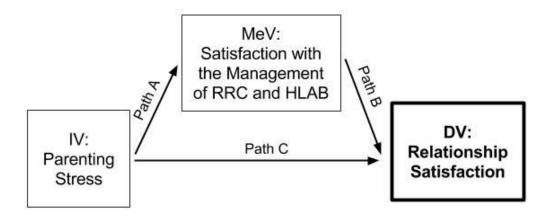


Figure 3. Hypothesis 3.1 - Parenting Stress, Satisfaction with the Management of Family Work, and Relationship Satisfaction

It is expected that Parenting Stress will significantly account for variations in the Satisfaction with the Management of Responsibility-Related Caregiving and Household Labor (Path A) and variations in Satisfaction with the Management of Responsibility-Related Caregiving and Household Labor will significantly account for variations in Relationship Satisfaction (Path B). Lastly, it is expected that a significant relationship between Parenting Stress and Relationship Satisfaction (Path C) will be reduced when Path A and Path B are controlled. Satisfaction with the Management of Responsibility-Related Caregiving (RRC) and Household Labor (HLAB) will be entered simultaneously in order to evaluate whether the mediation of HLAB is independent of the effect of RRC.

Research Question 4. What are the contributions of children's level of functioning, parent's gender, Management of Responsibility-Related Caregiving and Household Labor, Satisfaction with the Management of Responsibility-Related Caregiving and Household Labor, Parenting Stress, and the couple's relationship quality (Relationship Satisfaction, Communication, Conflict Resolution) to Family Functioning?

Hypothesis 4.1. Children's level of functioning, parent's gender, Management of Responsibility-Related Caregiving and Household Labor, and Parenting Stress will be related to a family's Social Integration (Figure 4).

It is expected that children's higher functioning (ATEC), being a mother, a more equal distribution of the Management of Responsibility-Related Caregiving and Household Labor, and lower Parenting Stress will be associated with higher scores on the Family Environment Scale's Family Social Integration Index (Intellectual-cultural, Active-recreational, and Moral-religious Emphasis subscales).

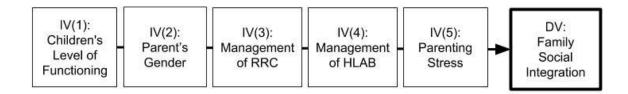


Figure 4. Hypothesis 4.1: Children's Level of Functioning, Parent's Gender, Management of Responsibility-Related Caregiving and Household Labor (*collapsed* variable), Parenting Stress and Family Social Integration

Hypothesis 4.2. Children's level of functioning, parent's gender, Satisfaction with Responsibility-Related Caregiving and Household Labor, and the couple's relationship quality (Satisfaction, Communication, and Conflict Resolution) will be related to the quality of Family Relationships (Figure 5).

It is predicted that children's higher functioning (ATEC), being a mother, greater Satisfaction with the Management of Responsibility-Related Caregiving and Household Labor, lower Parenting Stress, and higher Couple Relationship Quality (Satisfaction, Communication, Conflict Resolution) will be associated with higher scores on the Relationship Dimension of Family Functioning (Cohesion, Expressiveness, and Conflict subscales).

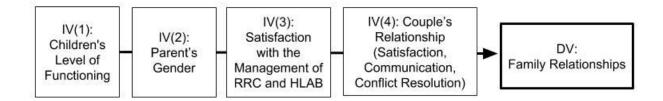


Figure 5. Hypothesis 4.2 - Children's Functioning, Parent's Gender, Satisfaction with the Management of Responsibility-Related Caregiving and Household Labor, Couple's Relationship, and Family Relationships

Methods

Overview

This study took place via an online questionnaire. The following subsections describe this study's participants, measures, design, and procedures. Data preparation and the data analysis plan are described in the Results section.

Participants

Inclusionary Criteria. Our study included Fathers and Mothers who met the following criteria: 1) have a child with an autism spectrum disorder (ASD) who is between the ages of 5 and 12; 2) live with their child's other parent (either married or unmarried); 3) live in the same home as their child with an ASD, 4) live in the United States.

Screener Submissions. A total of N = 369 parents submitted a response to our screener to enroll in the study; however, n = 78 were determined to be potentially suspicious. This suspicion was in regards to a very rapid receipt of screener submissions and unusual trends (e.g. rapid receipt, similar responses) in questionnaire submissions that were received. Within 24 hours of the submission of this unusual data, we disabled our screener and ceased enrollment; additional information regarding these issues is available in Appendix Y. With the suspicious submissions excluded, we were left with n = 291 responses to the screener. Of these, n = 247met the criteria and were enrolled to participate.

Questionnaire Submissions

We received N = 207 total responses to our questionnaire. For a range of reasons, n = 41 of these records were excluded from data analyses (Table 1). Of these 41 excluded cases, n = 16 were fathers and n = 22 were mothers; n = 3 did not provide their relationship to the child. No

differences were found in our variables of interest when comparing parents who were included and those who were excluded from analyses.

Reason	n	%
100% Missing Data across Measures	13	6.3
> 20% Missing Data across measures	17	8.2
Same-Sex Couple	3	1.4
Suspicious Data	6	2.9
ASD Status Uncertain	2	1.0
Total	41	19.8

Table 1. Reason for Exclusion from Data Analyses

Participants (N = 166) include fathers (n = 62) and mothers (n = 104) who are the parent of at least one child with an ASD who is between five and twelve years of age (Table 2). These parents live in the United States with the child and the child's other parent. It was not required that both the mother and father in a family participate.

Most parents were white (95.2%) and had attended college (98%); 72% of parents (n = 119) had a bachelor's degree or an advanced degree. Participants had been married for an average of 13 years. The majority of responding fathers (85.5%) worked full-time, while less than half of responding mothers (41.3%) were employed full-time; 29% of responding fathers (n = 18) reported that their child's mother worked full time and 88.5% (n = 92) of responding mothers reported that their child's father worked full-time. Roughly 30% (n = 50) of responding parents and their partner were both employed full-time. Seventy-nine percent (n = 128) of participants reported that their family's income for the previous year was \$50,000 or greater, and 58% (n = 94) reported an income of \$80,000 or greater; 6% of participants left this item blank (n = 4) or preferred not to say (n = 6). Nearly fourteen percent (n = 40) responded that their

income "somewhat meets," their needs, while 62.1% (n = 103) indicated that their income either "mostly meets" or "meets" their needs.

Four out of five (81.9%) of participants' children were boys (n = 136); boys' average age was 8.7 years and girls' average age was 8.8 years (Table 3). The mode for child's age at diagnosis was 2 years (2 years for males, 3 years for females). Parents were asked if their child with an ASD had been "diagnosed with any other disabilities, diseases, chronic illnesses, or health conditions." More than half (56.6%) of participants responded affirmatively, listing conditions ranging from ADHD to Klinefelter syndrome to asthma.

Table 2.	Participant	Demographics
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	Father		Mother		Total	
	n = 62		<i>n</i> = 104		<i>n</i> = 166	
	М	SD	М	SD	М	SD
Age in Years	44.4	7.2	39.7	6.1	41.4	6.9
Marital Status	n	%	n	%	n	%
Married	61	98.4	100	97.1	161	97.6
Domestic Partner	1	1.6	3	2.9	4	2.4
Race						
White or Caucasian	60	96.8	98	94.2	158	95.2
Black or African American	1	1.6	3	2.9	4	2.4
Asian	2	3.2	2	1.9	4	2.4
American Indian/Alaskan Native	0	-	0	-	0	-
Native Hawaiian/Pacific Islander	0	-	1	1.0	1	0.6
Another race	0	-	1	1.0	1	0.6
Prefer not to say	0	-	1	1.0	1	0.6
Ethnicity						
Mexican/American or Chicano	0	-	1	1.0	1	0.6
Puerto Rican	2	0.0	0	-	2	1.2
Other Hispanic/Latino/Spanish origin	0	3.2	4	3.4	4	2.4
Do not know	0	-	1	1.0	1	0.6
Prefer not to say	0	-	1	1.0	1	0.6
Education						
High School Diploma/GED	1	1.6	1	1.0	2	1.2
Trade School	0	-	1	1.0	1	1.0
Some college but < Bachelors	12	19.7	30	28.8	42	25.5
Bachelors Degree	13	21.3	32	30.8	45	27.3
Some graduate school but < Masters	6	9.8	4	3.8	10	6.1
Masters Degree	22	36.1	33	31.7	55	33.3
Doctoral Degree	2	3.3	0	-	2	1.2
Professional Degree	5	8.2	2	1.9	7	4.2
Other	0		1	1.0	1	0.6
Employment Status						
Employed Full Time	53	85.5	43	41.3	96	57.8
Employed Part Time	2	3.2	24	23.1	26	15.7

Table 2, cont.

Not Employed711.33735.64426.5Laid Off/Unemployed11.621.931.8Full Time Parent58.13028.83521.1On Disability11.611.021.2Student0-11.010.6Other0-32.931.8Employment for Couple Dyad1222.24044.45236.1I FT parent, 1 employed (FT or PT)2851.92932.25739.6IFT Employee, 1 PT Employee1425.92123.33524.3Family Income-11.010.6\$10,000 - \$19,99911.722.031.9\$20,000 - \$24,99911.732.942.5\$30,000 - \$39,99935.076.9106.2\$40,000 - \$49,99946.743.984.9\$50,000 - \$59,999610.098.8159.3\$60,000 - \$69,99923.398.8116.8\$90,000 - \$124,99935.076.9106.2\$90,000 - \$39,99935.076.9106.2\$90,000 - \$69,99935.076.9106.2\$90,000 - \$124,99935.01312.7169.9 </th <th></th> <th></th> <th></th> <th></th> <th></th> <th></th> <th></th>							
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$\begin{array}{c ccccccccccccccccccccccccccccccccccc$	Laid Off/Unemployed	1	1.6	2	1.9	3	1.8
Student0-11.010.6Other0-32.931.8Employment for Couple DyadEquivalent employment1222.24044.45236.11 FT parent, 1 employed (FT or PT)2851.92932.25739.61FT Employee, 1 PT Employee1425.92123.33524.3Family Income< $<$ \$9,9990-11.010.6\$10,000 - \$19,99911.722.031.9\$20,000 - \$24,99911.711.021.2\$25,000 - \$29,99911.732.942.5\$30,000 - \$39,99935.076.9106.2\$40,000 - \$49,99946.743.984.9\$50,000 - \$59,99935.076.9106.2\$60,000 - \$69,99923.398.8116.8\$70,000 - \$79,99935.076.9106.2\$90,000 - \$89,99935.01312.7169.9\$100,000 - \$124,9991321.71413.72113.0> \$150,0001118.398.82012.3Prefer not to say23.343.963.7Does not812.91514.42313.9Somewhat<	Full Time Parent	5	8.1	30	28.8	35	21.1
Other 0 - 3 2.9 3 1.8 Employment for Couple Dyad Equivalent employment 12 22.2 40 44.4 52 36.1 1 FT parent, 1 employed (FT or PT) 28 51.9 29 32.2 57 39.6 1FT Employee, 1 PT Employee 14 25.9 21 23.3 35 24.3 Family Income 1 1.7 2 2.0 3 1.9 \$20,000 - \$19,999 1 1.7 1 1.0 2 1.2 \$25,000 - \$29,999 1 1.7 3 2.9 4 2.5 \$30,000 - \$39,999 3 5.0 7 6.9 10 6.2 \$40,000 - \$49,999 4 6.7 4 3.9 8 4.9 \$50,000 - \$59,999 2 3.3 9 8.8 11 6.8 \$70,000 - \$79,999 3 5.0 7 6.9 10 6.2	On Disability	1	1.6	1	1.0	2	1.2
Employment for Couple DyadEquivalent employment1222.24044.45236.11 FT parent, 1 employed (FT or PT)2851.92932.25739.61FT Employee, 1 PT Employee1425.92123.33524.3Family Income11.722.031.9\$20,000 - \$19,99911.722.031.9\$20,000 - \$24,99911.711.021.2\$25,000 - \$29,99911.732.942.5\$30,000 - \$39,99935.076.9106.2\$40,000 - \$49,99946.743.984.9\$50,000 - \$59,999610.098.8159.3\$60,000 - \$69,99923.398.8116.8\$70,000 - \$79,99935.076.9106.2\$90,000 - \$89,99935.076.9106.2\$90,000 - \$89,99935.076.9106.2\$90,000 - \$124,9991321.71413.72716.7\$125,000 - \$149,999711.71413.72113.0> \$150,0001118.398.82012.3Prefer not to say23.343.963.7Does not812.91514.42313.9	Student	0	-	1	1.0	1	0.6
Equivalent employment1222.24044.45236.11 FT parent, 1 employed (FT or PT)28 51.9 29 32.2 57 39.6 1FT Employee, 1 PT Employee14 25.9 21 23.3 35 24.3 Family Income1 1.7 2 2.0 3 1.9 $< $9,999$ 0-1 1.0 1 0.6 $$10,000 - $19,999$ 1 1.7 2 2.0 3 1.9 $$20,000 - $24,999$ 1 1.7 1 0.6 2.5 $$30,000 - $39,999$ 3 5.0 7 6.9 10 6.2 $$40,000 - $49,999$ 4 6.7 4 3.9 8 4.9 $$50,000 - $59,999$ 6 10.0 9 8.8 15 9.3 $$60,000 - $69,999$ 2 3.3 9 8.8 11 6.8 $$70,000 - $79,999$ 3 5.0 7 6.9 10 6.2 $$90,000 - $89,999$ 3 5.0 7 6.9 10 6.2 $$90,000 - $124,999$ 3 5.0 7 6.9 10 6.2 $$90,000 - $124,999$ 3 5.0 7 6.9 10 6.2 $$90,000 - $124,999$ 3 5.0 7 6.9 10 6.2 $$90,000 - $124,999$ 3 5.0 7 6.9 10 6.2 $$90,000 - $124,999$ 2 3.3 4 3.9 6	Other	0	-	3	2.9	3	1.8
1 I T parent, 1 irmployee, 1 PT Employee28 51.9 29 32.2 57 39.6 3.3 Family Income14 25.9 21 23.3 35 24.3 Family Income 14 25.9 21 23.3 35 24.3 Family Income 1 1.7 2 2.0 3 1.9 $$20,000 - $19,999$ 1 1.7 2 2.0 3 1.9 $$20,000 - $24,999$ 1 1.7 1 1.0 2 1.2 $$25,000 - $29,999$ 1 1.7 3 2.9 4 2.5 $$30,000 - $39,999$ 3 5.0 7 6.9 10 6.2 $$40,000 - $49,999$ 4 6.7 4 3.9 8 4.9 $$50,000 - $59,999$ 6 10.0 9 8.8 15 9.3 $$60,000 - $69,999$ 2 3.3 9 8.8 11 6.8 $$70,000 - $79,999$ 3 5.0 7 6.9 10 6.2 $$90,000 - $89,999$ 3 5.0 13 12.7 16 9.9 $$100,000 - $124,999$ 13 21.7 14 13.7 21 13.0 $$150,000$ $$149,999$ 7 11.7 14 13.7 21 13.0 $$150,000$ $$149,999$ 7 11.7 14 13.7 21 13.0 $$20$ 13 21.7 14.4 23 13.9 90	Employment for Couple Dyad						
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Family Income $< \$9,999$ 0-11.010.6 $\$10,000 - \$19,999$ 11.722.031.9 $\$20,000 - \$24,999$ 11.711.021.2 $\$25,000 - \$29,999$ 11.732.942.5 $\$30,000 - \$39,999$ 35.076.9106.2 $\$40,000 - \$49,999$ 46.743.984.9 $\$50,000 - \$59,999$ 610.098.8159.3 $\$60,000 - \$69,999$ 23.398.8116.8 $\$70,000 - \$79,999$ 35.054.984.9 $\$80,000 - \$89,999$ 35.01312.7169.9 $\$100,000 - \$124,999$ 1321.71413.72716.7 $\$125,000 - \$149,999$ 711.71413.72113.0 $> \$150,000$ 1118.398.82012.3Prefer not to say23.343.963.7Does income meet family's needs? U U 14.42313.9Some what1219.42826.94024.1Mostly meets2337.14341.36639.8	1 FT parent, 1 employed (FT or PT)	28	51.9	29	32.2	57	39.6
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$\begin{array}{cccccccccccccccccccccccccccccccccccc$	Family Income						
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$\begin{array}{cccccccccccccccccccccccccccccccccccc$	\$10,000 - \$19,999	1	1.7	2	2.0	3	1.9
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	\$20,000 - \$24,999	1	1.7	1	1.0	2	1.2
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	\$25,000 - \$29,999	1	1.7	3	2.9	4	2.5
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	\$30,000 - \$39,999	3	5.0	7	6.9	10	6.2
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	\$40,000 - \$49,999	4	6.7	4	3.9	8	4.9
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	\$50,000 - \$59,999	6	10.0	9	8.8	15	9.3
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	\$60,000 - \$69,999	2	3.3	9	8.8	11	6.8
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	\$70,000 - \$79,999	3	5.0	5	4.9	8	4.9
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	\$80,000 - \$89,999	3	5.0	7	6.9	10	6.2
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	\$90,000 - \$99,999	3	5.0	13	12.7	16	9.9
> \$150,000 11 18.3 9 8.8 20 12.3 Prefer not to say 2 3.3 4 3.9 6 3.7 Does income meet family's needs? 0	\$100,000 - \$124,999	13	21.7	14	13.7	27	16.7
Prefer not to say23.343.963.7Does income meet family's needs?Does notSomewhat1219.42337.14341.36639.8	\$125,000 - \$149,999	7	11.7	14	13.7	21	13.0
Does income meet family's needs?812.91514.42313.9Does not812.91514.42313.9Somewhat1219.42826.94024.1Mostly meets2337.14341.36639.8	> \$150,000	11	18.3	9	8.8	20	12.3
Does not812.91514.42313.9Somewhat1219.42826.94024.1Mostly meets2337.14341.36639.8	Prefer not to say	2	3.3	4	3.9	6	3.7
Somewhat1219.42826.94024.1Mostly meets2337.14341.36639.8	Does income meet family's needs?						
Mostly meets 23 37.1 43 41.3 66 39.8	Does not	8	12.9	15	14.4	23	13.9
	Somewhat	12	19.4	28	26.9	40	24.1
Meets 19 30.6 18 17.3 37 22.3	Mostly meets	23	37.1	43	41.3	66	39.8
	Meets	19	30.6	18	17.3	37	22.3

Table 3. Child Demographics

	Male		Female		Total	
	<i>n</i> = 136		n = 30		N =	166
	М	SD	М	SD	М	SD
Age in Years	8.7	2.2	9.1	2.0	8.8	2.2
Age when Diagnosed	3	1.5	3	1.8	3	1.5
ATEC Total Score	59.8	27.6	47.8	25.4	57.6	25.6
ASD Subtype	п	%	n	%	п	%
Autism or Autistic Disorder	101	74.3	15	50.0	116	69.9
Aspergers	17	12.5	4	13.3	21	12.7
PDD-NOS	15	11.0	9	30.0	24	14.5
Specific diagnosis is unclear	3	2.2	1	3.3	4	2.4
Other ^a	0	-	1^{a}	3.3	1	0.6
Other health condition	76	55.9	18	60.0	94	56.6

^aHigh Functioning Autism

ATEC: Autism Treatment Evaluation Checklist; higher score indicates lower functioning

Power analysis and sample size. An *a priori* power analysis conducted using a desired power level of .80, an alpha of .05, and 7 predictors determined that a minimum of N = 103 participants would be required to detect a medium effect size and N = 721 to detect a small effect size (S. B. Green, 1991; Soper, 2013; Tabachnick & Fidell, 2007). A goal was to obtain data from equal numbers of father (n = 100) and mother (n = 100) participants. As anticipated, the recruitment goal for mothers was reached more easily than for fathers.

Procedures

The study utilized an online questionnaire, with data collection occurring at one time point using the REDCap Survey and Database Software^{©4}. Prior to the start of data collection, this questionnaire was piloted and took 25-30 minutes to complete. Data were collected between August and December of 2013. The questionnaire did not contain any items that asked for identifying information, which assured participants' anonymity, and the e-mail address that had been used to invite them to participate was not linked to their responses in any way (Appendix X). After submitting their responses, participants were presented with information about the available compensation options (\$10 Amazon gift card or the chance to win one of 2 iPod shuffles; Appendix U). More detailed information about the compensation options procedures is available in Appendices V and Z. The University IRB approved this study.

Recruitment. Participants were recruited via the Interactive Autism Network (IAN; http://ianproject.org/). IAN is an organization that conducts research, maintains a registry comprised of individuals with an ASD and family members of individuals with an ASD, and advertises autism-focused research on its website (see Appendix 11). IAN does not provide information regarding the number of parents contacted through its registry; however, nearly 80% (n = 131) of participants reported that they heard about this study through IAN. Participants were also recruited from schools, autism resource organizations, autism diagnostic centers, parent support groups, and other autism-related groups, as well as via Facebook (Appendix B). A

⁴ Visit http://ts.vcu.edu/software/2530.html for more information about REDCap.

website (Appendix A) and Facebook page (Appendix B) were created for recruitment purposes. These sources provided general information about the study and the chance to submit screener questions to determine whether participants met criteria for enrollment.

Screening and entry to study. Due to the copyright agreements mandated by several of the measures that were used in the current study, it was not possible to place this questionnaire on the open-web. Parents responded to a brief screener (Appendix F), which was accessible via the study's website. If the parent met inclusionary criteria, the researcher e-mailed a unique hyperlink that allowed for access to the questionnaire. A detailed outline of this process is available in Appendix Y.

Informed Consent. The questionnaire began with a brief set of instructions (Appendix G), followed by the 'Research Subject Information and Consent Form' (Appendix H). Participants indicated their consent by clicking an "agree" button and were taken to the first page of this study's questionnaire (Appendix I).

Measures

The measures that comprised this questionnaire (Table 4) are described below in order of their importance to the research questions, which corresponds to the order of their presentation in the questionnaire.

Table 4. Measures used in study

Name of Measure	Construct	Abbreviation	Appendix
Demographic questionnaire	Demographics		J
Responsibility-Related Caregiving Management Scale	Management of Responsibility- Related Caregiving	RRC MNG	K
Household Labor Management Scale	Management of Household Labor	HLAB MNG	L
Responsibility-Related Caregiving Satisfaction Scale	Satisfaction with Management of Responsibility-Related Caregiving	RRC SAT	М
Household Labor Satisfaction Scale	Satisfaction with Management of Household Labor	HLAB SAT	N
Family Environment Scale - Relationship Dimension	Family Functioning – Relationship Quality	FES RELAT	0
Family Environment Scale - Family Social Integration Index	Family Functioning – Family Social Integration	FES FSI	О
	Relationship Satisfaction	COUP SAT	
(PREPARE/ENRICH) Three Couples Scales	Communication	COUP COMM	Р
	Conflict Resolution	COUP CNFRS	
Questionnaire on Resources and Stress – Short Form (Abbreviated)	Parenting Stress among parents who have a child with a disability	QRS-SFA	Q
Autism Treatment Evaluation Checklist	Autism severity and functioning	ATEC	R

Demographic questionnaire. Demographic information (Appendix J) was collected regarding the participant and child's other parent (e.g. age, sex, race, state of residence, marital status, education level, and employment status), participant's child (e.g. diagnosis, age, sex, race, and other health conditions), and family (e.g. number of children/in home, number of adults in home, total children with an ASD, and household income).

Responsibility-Related Caregiving Management Scale (RRC MNG). The

Responsibility-Related Caregiving Management Scale (Appendix K; Table 5) was created for this study and used to measure parents' Management of Responsibility-Related Caregiving for their child with an ASD. This scale was based on the Parental Responsibility Scale (PRS; McBride & Mills, 1993), which is a 14-item scale that emphasizes child-care tasks common to parents of young children. The PRS has frequently been utilized with modifications (Doherty, Erickson, & LaRossa, 2006; Hofferth, 2003; Nangle, Kelley, Fals-Stewart, & Levant, 2003; Sanderson & Sanders-Thompson, 2002) and is a composite of several other measures of parental responsibility (Barnett & Baruch, 1987; Baruch & Barnett, 1986b; Lamb et al., 1988; McBride, 1990). We obtained the original PRS directly from its author, Dr. Brent McBride.

The PRS was further modified for the purposes of the current study by removing four items and adding twenty-one new items. The range of tasks was expanded, and 7 of these additional items were intended to capture tasks that are specific to parents who have a child with an ASD. In modifying and adding items, a goal was for all items on this measure to be common to all families of children with an ASD in order to preclude a "not applicable" response. These changes yielded a 31-item scale.

Responses were provided on a 5-point Likert scale: (0) 'Other parent always has responsibility for this;' (1) 'Other parent usually has responsibility for this;' (2) Other parent and

I equally share responsibility for this,' (3) I usually have responsibility for this;' and (4) 'I always have responsibility for this.' This scale has a potential range of 124 (min = 0; max =124), where a higher score indicates a greater role in the Management of Responsibility-Related Caregiving on behalf of the responding parent and a lower score indicates greater Management of Responsibility-Related Caregiving on behalf of the child's other parent. A score closer to the middle of the range indicates that overall Management of Responsibility-Related Caregiving is shared equally between parents. The authors of the original study (McBride & Mills, 1993a) reported Cronbach's alpha at .77 for mothers and .79 for fathers. Other studies that have utilized a modified PRS have reported internal consistencies at $\alpha = .70$ (Doherty et al., 2006), $\alpha = .73$ (Hofferth, 2003), and $\alpha = .72$ (fathers), $\alpha = .81$ (mothers; Nangle, Kelley, Fals-Stewart, & Levant, 2003). For the current sample, $\alpha = .98$ ($\alpha = .96$ [fathers], $\alpha = .95$ [mothers].

Table 5. *Responsibility-Related Caregiving Management Scale; Items that were Kept, Modified, Eliminated, and Added; Table is truncated here for copyrite reasons.*

Parental Responsibility Scale (PRS; McBride	
& Mills, 1993)	Modified / Added Item
Clean child's room.	Eliminated
Spend special time at bedtime, e.g., read a story.	Eliminated
Take the child to preventive health care clinic	Making your child's appointments for physicals, vaccinations (i.e. managing routine medical care).
Determine when to take child to pediatrician due to illness.	Deciding whether or not to take your sick child to the doctor.

Responsibility-Related Caregiving Satisfaction Scale (RRC SAT). This scale

(Appendix M) was created for the purpose of the current study and measures parents' satisfaction with how the management of responsibility-related caregiving is shared. This measure's items are drawn directly from the items contained in the Responsibility-Related Caregiving – Management Scale. There are 31 items, and response options were provided on a five-point scale: 0, Dissatisfied; 1, Moderately dissatisfied; 2, Neutral; 3; Moderately satisfied; 4, Satisfied. The potential range is 124 (min = 0; max =124), where a higher score indicates greater satisfaction with how parents share the management of responsibility-related caregiving. For the current sample, Cronbach's alpha = .97.

Household Labor Management Scale (HLAB MNG). The Household Labor Management Scale (see Appendix L) was developed for the purpose of this study and assesses parents' management of household labor. Several household labor measures were reviewed for relevant items and household labor groupings (Barnett & Shen, 1997; Berke & Berke, 1978; Shelton & John, 1996). Goal for this scale were for all items to be relevant to every parent who responded, for there to be items on the scale that both men and women tend to engage in, and for it to contain items that occur both frequently (e.g. planning meals) and infrequently (e.g. ensuring that home repairs are taken care of). This measure is comprised of 17 items, and response options were the same as for the Responsibility-Related Caregiving Management Scale. The potential range is 68 (min = 0; max = 68). A higher score indicates greater management of household labor on behalf of the responding parent and a lower score indicates greater management of household labor on behalf of the child's other parent. A score closer to the middle of the range indicates that management of household labor is shared equally between parents. Two sample items from this scale are 'Ensuring that major home repairs are taken care

of (e.g. furnace/Air conditioner maintenance, leaky roof is fixed, etc.)' and 'Doing the dishes.' In the current study, Cronbach's alpha = .76.

Household Labor Satisfaction Scale (HLAB SAT). This measure (Appendix N) was created for the purposes of the current study and is intended to measure parents' satisfaction with how parents share the management of household labor. This measure's items are drawn directly from the items contained in the Household Labor Management Scale. There are 17 items, and response options were provided on the same five-point scale as for Responsibility-Related Caregiving – Satisfaction Scale. The potential range is 68 (min = 0; max = 68), where a higher score indicates greater satisfaction with how parents share the management of household labor. For the current sample, Cronbach's alpha = .94.

Family Environment Scale (FES; R. H. Moos & Moos, 2009). The FES (Appendix O) measures family functioning across a range of social and environmental characteristics. In the current study, we used an abbreviated 72-item scale to assessed family functioning in two areas: (1) Relationship Quality (cohesion, expressiveness, and conflict); (2) Personal Growth (independence, achievement orientation, intellectual-cultural orientation, active-recreational orientation, and moral-religious emphasis; the latter 3 comprise the Family Social Integration Index). We excluded the 18 items that comprise the FES's System Maintenance and Change Dimension. The FES is available in three versions: 'Real' (family functioning as it is); 'Ideal' (family functioning as it would be in the perfect situation); and 'Expected' (as it will probably be in new situations. For the purpose of the current study, the 'Real' version was used. All responses are provided in a True/False format. Two sample items are: 'We often seem to be killing time at home,' and 'We often talk about political and social problems.'

Cronbach's Alpha for individual subscales, as reported by Moos and Moos (2009) are $\alpha = 0.78$ (Cohesion), $\alpha = 0.69$ (Expressiveness), $\alpha = 0.75$ (Conflict), $\alpha = 0.61$ (Independence), $\alpha = 0.64$ (Achievement), $\alpha = 0.78$ (Intellectual-Cultural), $\alpha = 0.67$ (Active-Recreational), $\alpha = 0.78$ (Moral-Religious). Others have reported $\alpha = .69$ (cohesion) and $\alpha = .70$ (Conflict; Kelly et al., 2008). Given that we our analyses did not address individual subscales, our internal consistency is reported for the Relationship Dimension ($\alpha = .85$) and the Family Social Integration Index ($\alpha = .80$). Internal consistency values for the current sample are: $\alpha = .85$ (Relationship Dimension); $\alpha = .80$ (Family Social Integration Index).

PREPARE/ENRICH Three Couples scales (Olson & Larson, 2008). The

PREPARE/ENRICH Couples Scales is a measure of couples' relationships that includes three subscales: Satisfaction, Communication, and Conflict Resolution (Appendix P). Each of these three scales is comprised of 10 items, for a total of 30 items. Responses are provided on a five-point scale ranging from 1, 'Strongly Disagree' to 5, 'Strongly Agree.' The potential range for each scale is 40 (Minimum = 10, Maximum = 50). The satisfaction subscale is a measure of global satisfaction in the relationship (e.g. role responsibilities, communication, financial concerns, management of leisure time, parental responsibilities, relationships with family and friends, etc.). The communication subscale assesses feelings, attitudes, and beliefs about communication within the relationship. The conflict resolution subscale assesses attitudes, beliefs, and feelings about conflict in the relationship and each partner's willingness to recognize and resolve issues. Two example items include: 'My partner is a very good listener' and 'Sometimes we have serious disputes over unimportant issues.' Internal consistency for these scales was reported by the authors (Fowers & Olson, 1989) at $\alpha = .86$ for Satisfaction; $\alpha = .82$ for Communication, and $\alpha = .84$ for Conflict Resolution. Others have reported Cronbach's Alphas at

 α = .95 for the satisfaction scale (Vanderbleek, Robinson, Casado-Kehoe, & Young, 2011). For the current study, α = .82 (Satisfaction); α = .91 (Communication); α = .88 (Conflict Resolution).

Questionnaire on Resources and Stress – Short Form, Abbreviated (QRS-SFA;

Friedrich, Greenberg, & Crnic, 1983). The QRS-SFA (Appendix Q) is a measure of self-reported stress in parents who have a child with a disability, and is used with parents who have a child with an ASD (Hartley, Seltzer, Head, & Abbeduto, 2012; Hastings, 2003; Hastings, Kovshoff, Ward, et al., 2005; Honey, Hastings, & McConachie, 2005; Osborne, McHugh, Saunders, & Reed, 2008). We used an abbreviated 31-item version of the QRS-SF, comprised of 31 items and two subscales: parent and family problems (e.g. stress that parents and family resulting from impact of child), and pessimism (e.g. negative thinking about the child's future). Responses on the QRS-SF and this abbreviated scale are provided in a True/False format, with a potential range of 31 (Minimum = 1, Maximum = 31). Example items from this scale include, "I worry about what will happen to my child when I can no longer take care of him/her," and "Taking my child on vacation spoils pleasure for the whole family." Internal consistency for the Total Stress Score on the QRS-SF is high ($\alpha = .89$; Osborne, McHugh, Saunders, & Reed, 2008). For the subscales, White and Hastings (2004) reported a Kuder-Richardson coefficient = .88 for parent and family problems, while Honey, Hastings and McConachie (2005) reported a Kuder-Richardson coefficient = .88 for the pessimism, parent and family problems combined. Hartley, Seltzer, Head, & Abbeduto (2012) reported $\alpha = .68$ for pessimism while others reported $\alpha = .70$ (Orsmond, Seltzer, Greenberg, & Krauss, 2006). For the current study's full QRS-SFA Scale, Cronbach's alpha = .88.

Autism Treatment Evaluation Checklist (ATEC; Rimland & Edelson, 1999). The ATEC (Appendix R) is a parent-report measure that is used to evaluate the effectiveness of

treatments for children with autism and to assess autism severity and current functioning (K. A. Allen, Bowles, & Weber, 2013; Magiati, Moss, Yates, Charman, & Howlin, 2011; Moh & Magiati, 2012; Poon, Koh, & Magiati, 2013). The ATEC measures an individual's development across four areas: Communication/Speech, Sociability, Sensory/Cognitive Awareness, and Health/Physical Behavior; however, the total score across areas can also be used as an indicator of overall functioning. Response options are Likert scales with 3 or 4 levels, depending on the subscale. A sample items from the Communication/Speech subscale is, "My child knows own name;" from the Sociability subscale, "My child ignores other people;" from the Sensory/Cognitive subscale, "My child is aware of danger;" and from the Health/Behavior subscale, "My child soils pants/diapers." The range for the total scale is 180 (Minimum = 0, Maximum = 180); a higher score indicates lower functioning/greater severity of symptoms. The Autism Research Institute's website (http://www.autism.com/ari/atec/atec_report.htm) provides score distributions and percentile information on the measure, according to total score as well as subscales. As reported by the authors of the ATEC (Rimland & Edelson, 1999), Cronbach's alpha for the overall scale is $\alpha = .94$; and for individual subscales is $\alpha = .92$ (Communication/Speech), $\alpha = .84$ (Sociability), $\alpha = .88$ (Sensory/Cognitive), and $\alpha = .82$ (Health/Physical behavior). Other studies have reported comparable values for the overall scale: $\alpha = .91$ (Magiati et al., 2011); $\alpha = .95$ (Ogston et al., 2011). For the present study, $\alpha = .95$ (Overall Scale); $\alpha = .93$ (Communication/Speech); $\alpha = .90$ (Sociability); $\alpha = .92$ (Sensory/Cognitive Awareness); and $\alpha = .87$ (Health and Physical Behavior).

Results

Data Preparation

This section describes the data cleaning and preparation procedures. All data cleaning and analyses were conducted using SPSS 22.

Calculating Scale Scores. Items were reverse scored, as necessary. Scale scores for each measure were calculated for those participants who had responded to at least 80% of a measure's items. Not taking into account demographic related items, the average participant was missing .3% of data and the majority of respondents had very little missing data, with n = 134 having no missing data within the measures. Participants who finished the first measure tended to complete the questionnaire in its entirety.

For cases that had no missing data within a measure, the calculated scale score was a sum of item responses within each measure. Among cases that had responded to at least 80% of items but had missing items, scale scores were calculated based on the following method: a 'nonweighted scale score' was calculated, based on a sum of the scores for the items that had received a response. This number was then divided by the number of items completed by the participant for that particular measure. Finally, this value was multiplied by the number of total items in that measure, to yield a 'weighted scale score.' Participants' weighted scale scores for each measure were used in analyses.

Cleaning the data. The data were checked for normality, skewness, and kurtosis; all values were within normal ranges (between -1.00 and 1.00). The presence of univariate outliers was assessed using distributions, boxplots, and standardized values of variable. One case's *z*-score on the ATEC's Health and Behavior subscale was > 3.58; given that we would expect for none of our sample to have a value greater than 3.29, this score was changed to 3 standard

deviations above the mean. Using Mahalanobis distance values, two cases were found to surpass the critical chi-square value (18.47) for several analyses, and were excluded from those analyses. An examination of the residuals plot and a visual check of the data's scatterplot revealed that data were normally distributed with equal variance. The relationship between most variables was found to be linear; those that were not are discussed further below. A check of multicollinearity and singularity was assessed; no bivariate correlations surpassed .80 between any of the variables of interest.

Descriptive Data. Means and standard deviations for all measures are presented in Table 6. Bivariate correlations among study variables are presented in Table 7.

Fathers and mothers were found to differ on several of the measures; fathers reported less of a role in the Management of Responsibility-Related Caregiving, greater Satisfaction with the Management of Responsibility-Related Caregiving and Satisfaction with the Management of Household Labor, lower Family Social Integration, and that their child's functioning was lower. Parents' Satisfaction with the Management of Responsibility-Related Caregiving and Household Labor was negatively correlated with the extent of their role in these aspects of family work; satisfaction with how this work was shared was higher when parents had less of a role and lower when parents had more of a role.

Measures	Fathers Mothers		iers	Tot	al	Potential Range	
	M	SD	M	SD	M	SD	
RRC MNG***	50.7	21.3	99.2	16.2	81.0	29.8	0-124
HLAB MNG	40.9	8.7	40.3	10.1	40.6	9.6	0-68
RRC SAT***	105.0	18.5	89.9	28.6	95.6	26.3	0-124
HLAB SAT ***	57.8	10.7	46.2	15.4	50.5	14.9	0-68
FES RELAT	18.0	5.4	18.8	5.1	18.5	5.2	0-27
FES FSI*	14.1	5.0	15.9	4.0	15.2	5.0	0-27
COUP SAT	32.6	7.2	31.5	7.6	32.0	7.5	10-50
COUP COMM	33.0	9.5	33.3	9.4	33.2	9.4	10-50
COUP CNFRS	31.8	8.0	33.3	8.3	32.8	8.2	10-50
QRS-SFA	15.3	6.8	13.9	6.6	14.4	6.7	0-31

* p < 0.05. ** p < 0.01. *** p < .001 (comparing fathers and mothers)

RRC MNG: Responsibility-Related Caregiving (Management Scale); Raw Score; higher score indicates greater management

HLAB MNG: Household Labor (Management Scale); Raw Score; higher score indicates greater management

RRC SAT: Responsibility Related Caregiving (Satisfaction Scale); higher score indicates greater satisfaction

HLAB SAT: Household Labor (Satisfaction Scale); higher score indicates greater satisfaction

FES RELAT: Family Environment Scale-Relationship Dimension; higher score indicates better relationships

FES FSI: Family Environment Scale-Family Social Integration Index; higher score indicates greater social integration

COUP SAT: Couples Relationship Satisfaction; higher score indicates greater relationship satisfaction

COUP COMM: Couples Communication; higher score indicates better communication

COUP CNFRS: Couples Conflict Resolution; higher score indicates less conflict/greater resolution

QRS-SFA: Questionnare on Resources and Stress-Short Form Abbrev (Parenting Stress);

higher score indicates higher stress

ATEC: Autism Treatment Evaluation Checklist; higher score indicates lower functioning

Variable	1	2	3	4	5	6	7	8	9	10	11
(1) RRC MNG	-	.29***	•37**	44**	04	.06	16*	08	.01	.00	13
(2) HLAB MNG	-	-	09	29**	13	11	20**	16*	16*	.20*	.12
(3) RRC SAT	-	-	-	.73**	.39**	.27**	.41**	.32**	.27**	.30**	20*
(4) HLAB SAT	-	-	-	-	.37**	.18*	.48**	.39**		28**	09
(5) FES RELAT	-	-	-	-	-	.43**	.68**	.69**	.63**	59**	26**
(6) FES FSI	-	-	-	-	-	-	.28**	.22**	.25**	39**	35***
(7) COUP SAT	-	-	-	-	-	-	-	.86**	.80**	46**	08
(8) COUP COMM	-	-	-	-	-	-	-	-	.87**	40**	12
(9) COUP CNFRS	-	-	-	-	-	-	-	-	-	45**	23**
(10) QRS-SFA	-	-	-	-	-	-	-	-	-	-	.55**
(11) ATEC	-	-	-	-	-	-	-	-	-	-	-

Table 7. Bivariate Correlations among Study Variables

* p < 0.05. ** p < 0.01. *** p < 0.001.

RRC MNG: Responsibility-Related Caregiving (Management Scale); Raw Score; higher score indicates greater management

HLAB MNG: Household Labor (Management Scale); Raw Score; higher score indicates greater management

RRC SAT: Responsibility Related Caregiving (Satisfaction Scale); higher score indicates greater satisfaction

HLAB SAT: Household Labor (Satisfaction Scale); higher score indicates greater satisfaction

FES RELAT: Family Environment Scale-Relationship Dimension; higher score indicates better relationships

FES FSI: Family Environment Scale-Family Social Integration Index; higher score indicates greater social integration

COUP SAT: Couples Relationship Satisfaction; higher score indicates greater relationship satisfaction

COUP COMM: Couples Communication; higher score indicates better communication

COUP CNFRS: Couples Conflict Resolution; higher score indicates less conflict/greater resolution

QRS-SFA: Questionnare on Resources and Stress-Short Form Abbrev (Parenting Stress);

higher score indicates higher stress

ATEC: Autism Treatment Evaluation Checklist; higher score indicates lower functioning

Transforming and Collapsing Variables. In examining the relationships among some of our variables (i.e. Management of Responsibility-Related Caregiving and Relationship Satisfaction; Management of Household Labor and Relationship Satisfaction) a non-linear relationship was discovered, which violated an assumption of multiple regression. Therefore, we *transformed* our Responsibility-Related Caregiving Management Scale *original* (raw) Scores and Household Multiple Management Scale *original* (raw) Scores into categorical variables, each with 5 levels: *Other Parent Always MNG, Other Parent Usually MNG, Parents Equally MNG, I Usually MNG*, and *I Always MNG*. This allowed for assessment of differences in our variables of interest based on parents' level of management of these two aspects of family work.

The mean scores and standard deviations for the management of the *transformed* Responsibility-Related Caregiving variable are presented in Table 8; Table 9 presents this information for the Management of Household Labor.

Using the *transformed* variables, group differences in Relationship Satisfaction based on parents' role across the 5 levels of Management of Responsibility-Related Caregiving and Household Labor are illustrated in Figure 6 and Figure 7, respectively.

An examination of these *transformed* variables suggested that the distribution of the management of family work within the couple dyad was important to assessment of our research questions. For example, there were no mean differences in Relationship Satisfaction between parents who "Always Managed RRC' and those who indicated that the "Other Parent Always Managed RRC." Therefore, the decision was made to further *collapse* these *transformed* variables into 3 levels (Group 1: 1 Parent Always manages; Group 2: 1 Parent Usually Manages; Group 3: Parents Equally Manage) to serve as an indicator of the distribution of the management

of either Responsibility-Related Caregiving or Household Labor within the couple dyad. Note that zero fathers or mothers indicated that the "Other Parent Always Manages" Household Labor.

	Other A	lways	Other U	Jsually							
	MN	IG	MN	IG	Equally	MNG	ING I Usually MNG			I always MNG	
Measure	М	SD	М	SD	М	SD	М	SD	М	SD	
RRC SAT	117.17	4.26	107.36	19.11	103.93	15.70	93.95	24.37	84.44	31.96	
HLAB SAT	62.16	4.78	57.72	11.71	57.39	9.51	50.37	12.99	42.06	16.87	
FES RELAT	15.83	7.17	18.46	5.50	18.97	4.45	19.95	4.85	17.29	5.49	
FES FSI	14.50	5.89	14.96	4.95	14.36	4.44	16.10	4.54	15.04	5.68	
COUP SAT	29.33	7.09	32.44	7.64	34.00	6.87	33.79	6.70	29.11	7.75	
COUP COMM	28.33	8.36	33.12	10.28	35.48	8.22	35.08	9.40	30.73	9.28	
COUP CNFRS	28.17	7.73	31.56	9.66	33.57	6.83	34.86	8.14	31.46	8.24	
QRS-SFA	17.17	8.04	15.34	6.83	13.85	7.15	12.91	6.13	15.52	6.60	
ATEC	57.83	35.92	64.70	28.14	61.20	28.12	57.84	29.41	52.65	24.03	

Table 8. Descriptives Based on Parent's Role in the Management of Responsibility-Related Caregiving (transformed variable)

RRC SAT: Responsibility Related Caregiving (Satisfaction Scale); higher score indicates greater satisfaction

HLAB SAT: Household Labor (Satisfaction Scale); higher score indicates greater satisfaction

FES RELAT: Family Environment Scale-Relationship Dimension; higher score indicates better relationships

FES FSI: Family Environment Scale-Family Social Integration Index; higher score indicates greater social integration

COUP SAT: Couples Relationship Satisfaction; higher score indicates greater relationship satisfaction

COUP COMM: Couples Communication; higher score indicates better communication

COUP CNFRS: Couples Conflict Resolution; higher score indicates less conflict/greater resolution

QRS-SFA: Questionnare on Resources and Stress-Short Form Abbrev (Parenting Stress);

higher score indicates higher stress

ATEC: Autism Treatment Evaluation Checklist; higher score indicates lower functioning

	Other	Always	Other U	Jsually						
	M	NG	MNG		Equally	Equally MNG		MNG	I always MNG	
Measure	М	SD	М	SD	М	SD	М	SD	М	SD
RRC SAT	-	-	93.88	26.12	97.73	24.65	94.02	26.85	93.99	34.45
HLAB SAT	-	-	56.21	11.20	52.52	13.32	49.05	15.60	40.67	19.14
FES RELAT	-	-	18.21	5.10	19.02	5.49	18.54	5.06	16.08	4.93
FES FSI	-	-	16.27	4.04	16.17	4.63	14.15	5.21	14.83	6.21
COUP SAT	-	-	32.34	6.67	33.30	7.10	31.27	7.47	27.67	9.09
COUP COMM	-	-	34.64	9.20	33.98	9.49	33.11	9.24	27.75	9.12
COUP CNFRS	-	-	34.97	6.46	33.48	8.38	32.05	8.29	30.20	8.88
QRS-SFA	-	-	13.95	5.24	13.41	7.01	15.02	6.56	17.55	6.29
ATEC	-	-	59.22	18.34	53.40	28.01	61.23	28.90	58.44	25.48

Table 9. Descriptives Based on Parent's Role in the Management of Household Labor (transformed variable)

RRC SAT: Responsibility Related Caregiving (Satisfaction Scale); higher score indicates greater satisfaction

HLAB SAT: Household Labor (Satisfaction Scale); higher score indicates greater satisfaction

FES RELAT: Family Environment Scale-Relationship Dimension; higher score indicates better relationships

FES FSI: Family Environment Scale-Family Social Integration Index; higher score indicates greater social integration

COUP SAT: Couples Relationship Satisfaction; higher score indicates greater relationship satisfaction

COUP COMM: Couples Communication; higher score indicates better communication

COUP CNFRS: Couples Conflict Resolution; higher score indicates less conflict/greater resolution

 $QRS\text{-}SFA\text{: }Questionnare \ on \ Resources \ and \ Stress\text{-}Short \ Form \ Abbrev \ (Parenting \ Stress);$

higher score indicates higher stress

ATEC: Autism Treatment Evaluation Checklist; higher score indicates lower functioning

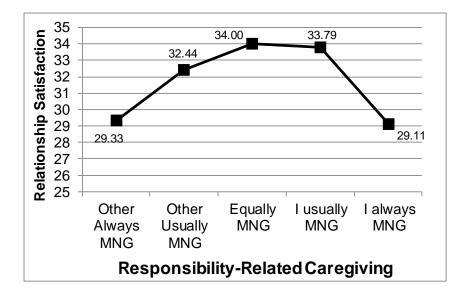


Figure 6. Relationship Satisfaction Based on Parent's Role in the Management of Responsibility-Related Caregiving (*transformed* variable)

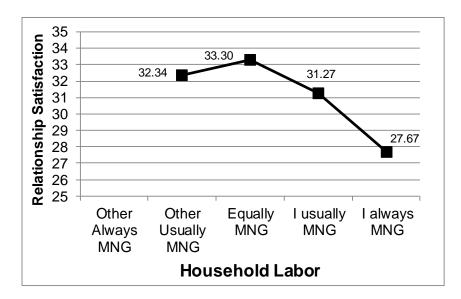


Figure 7. Relationship Satisfaction based on Parent's Role in the Management of Household Labor (*transformed* variable)

Figure 8 provides a breakdown of the percentage of fathers, mothers, and total parents in each of the 5 levels of the RRC MNG *transformed* variable. Mothers and fathers reporting on themselves differed in who they thought performed this work. Approximately half of mothers (50.5%) reported always managing Responsibility-Related Caregiving, while 9.6% of fathers reported that the mother always managed Responsibility-Related Caregiving. A greater percentage of fathers (37.1%) than mothers (7.8%) indicated that Management of Responsibility-Related Caregiving was equally shared between parents.

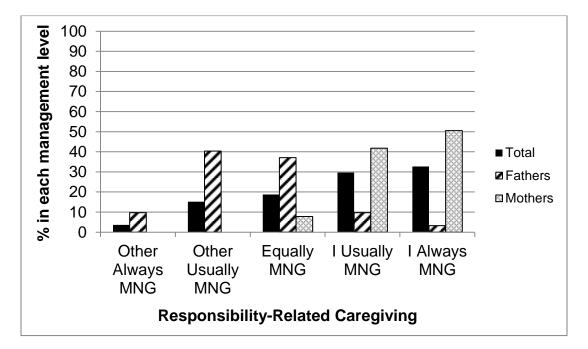


Figure 8. The Percent of Parents in each of the 5 levels of the Management of Responsibility-Related Caregiving (*transformed* variable)

Figure 9 provides a breakdown of the percentage of fathers, mothers, and total parents in each of the 5 levels of the HLAB MNG *transformed* variable. The percent of fathers and mothers in each level was similar; 45.2% of fathers and 40.4% of mothers indicated that the Management of Household Labor was equally shared between parents, 43.5% of fathers reported usually managing Household Labor compared with 41.6% of mothers.

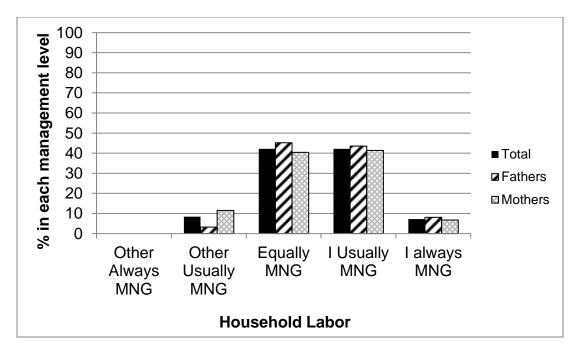
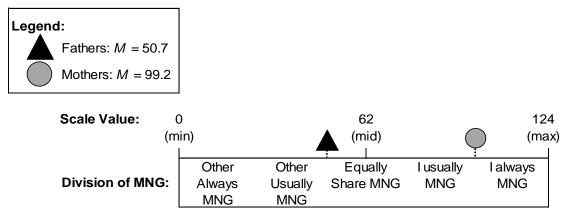


Figure 9. The Percent of Parents in Each of the 5 levels of the Management of Household Labor (*transformed* variable).

Hypothesis Testing

Hypothesis 1.1a. Using *original* Management of Responsibility-Related Caregiving (RRC MNG) scale scores, an independent samples *t*-test was conducted to compare fathers and mothers reported management of RRC. There was a significant difference between the scores for fathers (M = 50.7, SD = 21.3) and mothers (M = 99.2, SD = 16.2); t (163) = 16.49, p < .001. Fathers managed less Responsibility-Related Caregiving than mothers.

Figure 10 depicts the difference between fathers' and mothers' mean scores, as well as where their scores fall on the division of Management of Responsibility-Related Caregiving. These scores indicate that on average, mothers report usually/always managing Responsibility-Related Caregiving; fathers' scores indicate that Responsibility-Related Caregiving is usually managed by the other parent or equally shared.



Management of Responsibility-Related Caregiving

Figure 10. Mothers' and Fathers' Reports of their Role in the Management of Responsibility-Related Caregiving (*original* variable)

Hypothesis 1.1b.

Using the *collapsed* Management of Responsibility-Related Caregiving (RRC MNG) variable, a one-way between-groups ANOVA was used to examine differences in Relationship Satisfaction across the three groups. There were statistically significant group differences in Relationship Satisfaction (COUP SAT) scores, F(2, 162) = 7.19, p < .001; these differences are illustrated in Figure 11. Data for fathers and mothers is included in this figure for descriptive purposes only; parent's gender was not included in the analysis as we did not expect differences in Relationship Satisfaction between fathers and mothers.

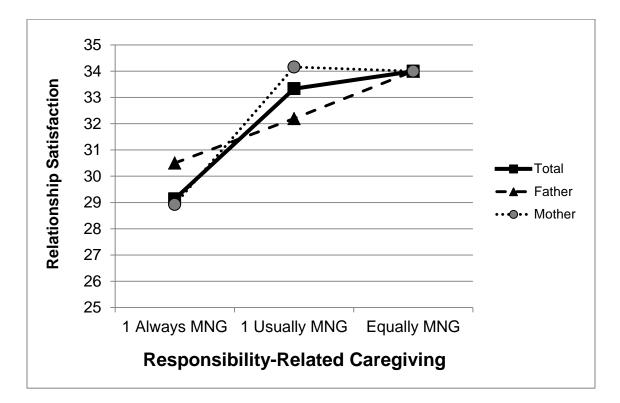


Figure 11. The Association between Parents' Gender, the Distribution of the Management of Responsibility-Related Caregiving (*collapsed* variable), and Relationship Satisfaction

Post-hoc comparisons using the Tukey HSD test revealed significant differences in Relationship Satisfaction between Group 1 (1 parent always manages RRC; M = 29.13, SD =7.6) and Group 2 (1 parent usually manages RRC; M = 33.34, SD = 7.01, p = .003) as well as when comparing Group 1 with Group 3 (Parents equally manage RRC; M = 34.00, SD = 6.87, p =.008). Parents in Group 1(1 parent always manages RRC) reported less relationship satisfaction than those in Group 2 (1 parent usually manages RRC) and Group 3 (Parents equally manage RRC). Group 2 did not differ significantly from Group 3, p = .903.

These results show first that fathers manage a lesser share of Responsibility-Related Caregiving (RRC) than mothers. Further, both fathers and mothers experience greater Relationship Satisfaction when the Management of RRC is shared by the parents, whether management is equally shared or usually done by one parent. Parents had the lowest Relationship Satisfaction when one parent always managed Responsibility-Related Caregiving, regardless of whether it was the participant or his or her partner who was always responsible. However, it is noted that when one parent "always" managed RRC, it was nearly always the mother (50.5%; n = 52) who took this role; n = 2 (3.2%) fathers reported that they always managed RRC.

Testing hypothesis 1.2a. Using *original* Management of Household Labor Caregiving (HLAB MNG) scale scores, an independent samples *t*-test was conducted to compare fathers and mothers reported management of HLAB. Fathers (M = 40.9, SD = 8.7) and mothers (M = 40.3, SD = 10.1) did not differ in their Management of Household Labor; t(164) = .370, p = .712.

Figure 12 depicts fathers' and mothers' mean scores, as well as where their scores fall on the division of Management of Household Labor. Fathers and mothers mean scores were very similar; these scores indicate that on average, both fathers and mothers feel that they equally share or usually manage Household Labor.

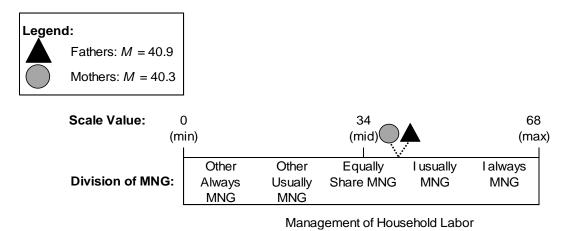


Figure 12. Mothers' and Fathers' Reports of their Role in the Management of Household Labor (*original* variable)

Testing hypothesis 1.2b. Using the *collapsed* Management of Household Labor variable (HLAB MNG) variable, a one-way between-groups ANOVA was used to examine differences in Relationship Satisfaction across the three groups (HLAB MNG; Figure 13). Data for fathers and mothers is included in this figure for descriptive purposes only; parent's gender was not included in the analysis as we did not expect differences between fathers and mothers in terms of their Relationship Satisfaction.

There were statistically significant group differences in Relationship Satisfaction scores, F(2,163) = 3.40, p = .036. Post-hoc comparisons using the Tukey HSD test indicated that the Relationship Satisfaction mean score for Group 1 (1 parent always manages HLAB; M = 27.67, SD = 9.08) differed from Group 3 (Parents equally share MNG; M = 33.30, SD = 7.10, p = .040). Group 2 (1 parent usually manages RRC; M = 31.45, SD = 7.32) did not differ from Group 1(1 parent always manages HLAB; p = .221) or Group 3 (Parents equally MNG; p = .269).

These results show that both fathers and mothers report that the Management of Household Labor is shared between parents, and that both fathers and mothers experience higher levels of Relationship Satisfaction when the Management of Household Labor is distributed



more equally. Parents are least satisfied in the couple's relationship when one parent always manages Household Labor.

Figure 13. The Association between Parents' Gender, the Distribution of the Management of Responsibility-Related Caregiving (*collapsed* variable), and Relationship Satisfaction

Testing hypothesis 2.1. A hierarchical linear regression was used to predict Parenting Stress (QRS-SFA; Table 10). The independent variables were entered in 4 steps): 1) Children's level of functioning (Autism Treatment Evaluation Checklist [ATEC]); 2) parents' gender; 3) Management of Responsibility-Related Caregiving (RRC MNG; *collapsed* variable [entered as dummy coded variables]); and 4) Management of Household Labor (HLAB MNG; *collapsed* variable [entered as dummy coded variables]). Results of an ANOVA indicate that the overall model predicted Parenting Stress (QRS-SFA), *F* (6, 155) = 14.67 (p < .001). The R^2 for the full model was .36. For the ATEC, $R^2 = .30$ (p < .001), and for parent's gender, $\Delta R^2 = .00$ (p = .843). The addition of RRC-MNG explained an additional 5% of the variance in parenting stress, $\Delta R^2 =$.05 (p < .01); for HLAB-MNG, $\Delta R^2 = .01$ (p = .508).

Parenting stress was higher when a child's functioning was lower and when one parent always managed Responsibility-Related Caregiving, regardless of whether it was the responding parent or their partner. Neither parents' gender nor Management of Household Labor added to the prediction of Parenting Stress.

 Table 10. Hypothesis 2.1 - Hierarchical Regression Analysis Predicting Parenting Stress

				ß in final		
Predictor	В	SEB	ß	model	R^2	ΔR^2
Step 1: ATEC	.14	.02	.55***	.56***	.30	.30***
Step 2: Parent's Gender	18	.93	01	10	.30	.00
Step 3: RRC MNG ^a					.36	.05**
1 parent always MNG	3.94	1.37	.28**	.26*		
1 parent usually MNG	.62	1.23	.05	.05		
Step 4: HLAB MNG ^a					.36	.01
1 parent always MNG	2.08	1.79	.08	.08		
1 parent usually MNG	.35	.91	.03	.03		

* p < 0.05. ** p < 0.01. *** p < 0.001.

^aParents Equally Share MNG used as reference group for both RRC and HLAB

QRS-SFA: Questionnare on Resources and Stress-Short Form Abbrev (Parenting Stress);

higher score indicates higher stress

ATEC: Autism Treatment Evaluation Checklist; higher score indicates lower functioning RRC-MNG: Responsibility-Related Caregiving (Management Scale); higher score indicates greater management HLAB-MNG: Household Labor (Management Scale); higher score indicates greater management

Hypothesis 3.1. A series of regression analyses were conducted to first establish a significant relationship between Parenting Stress (IV), Satisfaction with the Management of

Responsibility-Related Caregiving and Satisfaction with the management of Household Labor

(MeV) and Relationship Satisfaction (DV). As recommended by Baron and Kenny (1986), these

significant relationships must be confirmed in order for a mediator to be assessed. Given that

significant relationships were found, we ran the final analysis to test for mediation, with Satisfaction with the Management of Responsibility-Related Caregiving and Household Labor entered in the 1st step and Parenting Stress (IV) entered in the 2nd step (Table 11). The proportion of variability accounted for by each variable (R^2) in these initial analyses is indicated in Figure 14; the ΔR^2 between Parenting Stress and Relationship Satisfaction after controlling for Satisfaction with the Management of Responsibility-Related Caregiving and Household Labor is in parentheses.

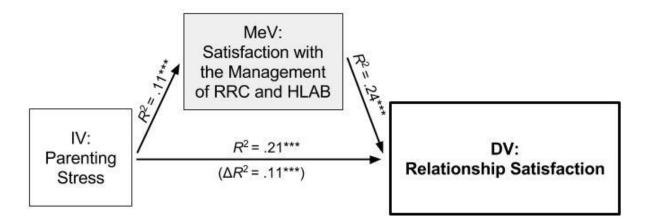


Figure 14. R^2 for Parenting Stress, Satisfaction with the Management of Responsibility-Related Caregiving and Household Labor, and Relationship Satisfaction

Results of an ANOVA indicate that the overall model predicted parenting stress, *F* $(3,160) = 28.6 \ (p < .001)$. The R^2 for the full model was .35. In the final model, Satisfaction with the Management of RRC HLAB accounted for 24% of the variance associated with Relationship Satisfaction ($R^2 = .24$; p < .001); the variance in Relationship Satisfaction accounted for by Parenting Stress was reduced from 21% ($R^2 = .21$; p < .001) to 11% ($\Delta R^2 = .11$; p < .001).

Parents experienced greater Relationship Satisfaction when they were more satisfied with the Management of Responsibility Related Caregiving and Household Labor, and when they experienced less Parenting Stress. After controlling for parents' Satisfaction with the Management of Responsibility-Related Caregiving and Household Labor, Parenting Stress was still found to significantly predict parent's Relationship Satisfaction, though its influence was reduced; this demonstrates the partial mediation effect of Satisfaction with the Management of Responsibility-Related Caregiving and Household Labor. This suggests that parents' satisfaction with the management of family work helps – but does not fully explain – the association between parenting stress and couple's relationship satisfaction.

 Table 11. Hypothesis 3.1 - Regression Analysis Predicting Relationship Satisfaction and Test for

 Mediation

				ß in final		
Predictor	В	SEB	ß	model	R^2	ΔR^2
Step 1:					.24	.24***
RRC SAT	.04	.03	.14	.04		
HLAB SAT	.19	.05	.38	.35***		
Step 2: QRS-SFA	39	.08	35	35***	.35	.11***

* p < 0.05. ** p < 0.01. *** p < .001.

RRC SAT: Responsibility Related Caregiving (Satisfaction Scale); higher score indicates greater satisfaction HLAB SAT: Household Labor (Satisfaction Scale); higher score indicates greater satisfaction COUP SAT: Couples Relationship Satisfaction; higher score indicates greater relationship satisfaction QRS-SFA: Questionnare on Resources and Stress-Short Form Abbrev (Parenting Stress);

higher score indicates higher stress

Testing Hypothesis 4.1. A hierarchical linear regression was used to predict Family Social Integration (FES FSI; Table 12). The independent variables were entered in 5 steps: 1) children's level of functioning (Autism Treatment Evaluation Checklist [ATEC]); 2) parents' gender; 3) Management of Responsibility-Related Caregiving (RRC MNG; *collapsed* variable [entered as dummy coded variables]); 4) Management of Household Labor (HLAB MNG; *collapsed* variable [entered as dummy coded variables]), and 5) Parenting Stress (QRS-SFA). Results of an ANOVA indicate that the overall model predicted Family Social Integration, F(7, 154) = 6.38 (p < .001). The R^2 for the full model was .23. Children's level of functioning (ATEC) explained 13% of the variance in Family Social Integration, $R^2 = .13$ (p < .001), and for parent's gender, $\Delta R^2 = .02$ (p = .062). With the addition of RRC-MNG, $\Delta R^2 = .02$ (p = .195); HLAB-MNG, $\Delta R^2 = .01$ (p = .320); Parenting Stress explained an additional 5% of the variance ($\Delta R^2 = .05$; p = .003).

Parents reported higher Family Social Integration when the child's level of functioning (ATEC) was higher and when Parenting Stress (QRS-SFA) was lower. There was a trend in which fathers reported lower Family Social Integration, approaching significance (p = .075) in the final model, while neither the Management of Responsibility-Related Caregiving nor the Management of Household Labor were significantly related to a family's Social Integration.

				ß in final		
Predictor	В	SEB	ß	model	R^2	ΔR^2
Step 1: ATEC	07	.01	36***	19*	.13	.13***
Step 2: Parent's Gender	1.43	.77	.14	.14	.15	.02
Step 3: RRC MNG ^a					.17	.02
1 parent always MNG	56	1.16	05	.02		
1 parent usually MNG	.94	1.04	.09	.10		
Step 4: HLAB MNG ^a					.18	.01
1 parent always MNG	45	1.51	02	00		
1 parent usually MNG	-1.17	.77	12	11		
Step 5: QRS-SFA	20	.07	27**	27**	.23	.05**

 Table 12. Hypothesis 4.1 - Hierarchical Regression Analysis: Predicting Family Social Integration

* p < 0.05. ** p < 0.01. *** p < .001.

^aParents Equally Share MNG used as reference group for both RRC and HLAB

FES FSI: Family Environment Scale-Family Social Integration Index; higher score indicates greater social integration ATEC: Autism Treatment Evaluation Checklist; higher score indicates lower functioning

RRC MNG: Responsibility-Related Caregiving (Management Scale); higher score indicates greater management

HLAB MNG: Household Labor (Management Scale); higher score indicates greater management

QRS-SFA: Questionnare on Resources and Stress-Short Form Abbrev (Parenting Stress);

higher score indicates higher stress

Testing Hypothesis 4.2. A hierarchical linear regression was used to predict Family Relationship Quality (FES RELAT; Table 13). The independent variables were entered in 4 steps: 1) Children's level of functioning (Autism Treatment Evaluation Checklist [ATEC]); 2) parents' gender; 3) Satisfaction with the Management of Responsibility-Related Caregiving (RRC SAT) and Household Labor (HLAB SAT); 4) the Couple's Relationship (Satisfaction [COUP SAT], Communication [COUP COMM], and Conflict Resolution [COUP CNFRES]). Results of an ANOVA indicate that the overall model predicted Family Relationship Quality, *F* (7, 155) = 28.83 (p < .001). The R^2 for the full model was .57. Results indicate that child's level of functioning ($R^2 = .07$; p = .001) contributes to the model, but parent gender did not, $\Delta R^2 =$.001(p = .618). The addition of Satisfaction with the Management of Responsibility-Related Caregiving and Household Labor resulted in a significant increase in the variance explained ($\Delta R^2 = .18$; p < .001), as did the Couple's Relationship quality (COUP SAT, COUP COMM, COUP CNFRES), $\Delta R^2 = .32$ (p < .001).

Both fathers and mothers reported better quality Family Relationships among family members when the child's level of functioning was higher, when parents were more satisfied with the management of family work, and when the overall quality of the Couple's Relationship was higher.

Table 13. Hypothesis 4.2 - Hierarchical Regression Analysis: Predicting Family Relationships

				ß in final		
Predictor	В	SEB	ß	model	R^2	ΔR^2
Step 1: ATEC	05	.02	27***	15**	.07	.07***
Step 2: Parent's Gender	.42	.84	.04	.12	.07	.00
Step 3:					.25	.18***
RRC SAT	.05	.02	.24*	.13		
HLAB SAT	.09	.04	.27*	.02		
Step 4:					.57	.32***
COUP SAT	.21	.08	.29*	.29*	-	-
COUP COMM	.24	.07	.42*	.42**	-	-
COUP CNFRES	04	.07	06	06	-	-

* p < 0.05. ** p < 0.01. *** p < .001.

FES RELAT: Family Environment Scale-Relationship Dimension; higher score indicates better relationships ATEC: Autism Treatment Evaluation Checklist; higher score indicates lower functioning RRC SAT: Responsibility Related Caregiving (Satisfaction Scale); higher score indicates greater satisfaction HLAB SAT: Household Labor (Satisfaction Scale); higher score indicates greater satisfaction COUP SAT: Couples Relationship Satisfaction; higher score indicates greater relationship satisfaction COUP COMM: Couples Communication; higher score indicates better communication COUP CNFRES: Couples Conflict Resolution; higher score indicates less conflict/greater resolution

Discussion

Findings from this study suggest that among parents who have a child with an autism spectrum disorder, fathers manage less Responsibility-Related Caregiving than mothers. Beyond gender differences, results indicate that the distribution of the Management of Responsibility-Related Caregiving and Household Labor, as well as parents' satisfaction with the how this work is shared, have implications for Parenting Stress, the Couple's Relationship, and Family Functioning. In general, the couple and family seem to fare better when family work is shared between parents.

Family Work

Parents reported that fathers manage less Responsibility-Related Caregiving than mothers; both father and mother participants indicated that this was the case, lending support to Hypothesis 1.1a. Nearly 50% of mothers reported always managing Responsibility-Related Caregiving. Regardless of whether a parent's child has an ASD or is typically developing, a number of factors may help to explain why we find that fathers are less involved in the Management of Responsibility-Related Caregiving.

Among American parents, the paternal role is less scripted than the maternal role (Belsky et al., 1991; Dyer, McBride, & Jeans, 2009; Hoff, Larsen, & Tardif, 1995; McBride et al., 2005; Parke, 2002; Saxbe et al., 2011). When compared with mothers, fathers report lower parenting efficacy and competence (Leerkes & Burney, 2007) and fathers' feelings of parenting competency may be less related to their identity as a parent than mothers (Gray, 2003). Traditionally, men have less practical hands-on experience with children and less frequently engage in child-care activities such as babysitting, working at a child care facility, or helping to care for a younger sibling (Kilmartin, 1994). While providing direct care for a child is certainly a

different skill set than management of responsibility related caregiving, it is preparation for the parenting role. In truth, prior to becoming a parent, neither women nor men typically have had the experience of managing a child's responsibility-related caregiving. Among partners who both work outside the home, men are less likely than women to take leave from work when their children need extra care (e.g., snow days, sick days). Men are also less likely to take paternity leave when a child is born than women are to take maternity leave. If the mother stays home while the father works outside of the home, it makes practical sense – at least in the short term – that mothers might take the primary role for managing Responsibility-Related Caregiving (e.g. taking their child in for doctor's appointments, shopping for the baby, etc.), and established behavioral patterns tend to persist. Together, these factors may influence fathers' and mothers' motivation and comfort in involving themselves in the Management of Responsibility-Related Caregiving.

This difference was not found for the Management of Household labor; 91.9% of fathers and 93.3% of mothers reported that this work was shared to some extent. It is important to note that in creating the Household Labor Management Scale, we were purposeful in including a range of items; some tend to apply primarily to men (e.g. Remembering that the garbage needs to be taken out), some primarily to women (e.g. Making sure the house gets swept/vacuumed), and some that were more gender neutral (e.g. Making sure the bills get paid (e.g. mailing out bills, submitting payment online). It is possible that fathers compensate for their lesser role in the Management of Responsibility-Related Caregiving by taking on a greater share of the Management of Household Labor.

Overall, fathers reported greater Satisfaction with the Management of Responsibility-Related Caregiving and Household Labor than mothers. Notably, parents' Satisfaction with the

Management of Responsibility-Related Caregiving and Household Labor was highest when they were *least* involved in these aspects of family work. This differs from the association that was found between involvement in the management of family work and Relationship Satisfaction, in which couple's relationship satisfaction was lowest when one person *always* managed of the family work and highest when this work was shared. This suggests that there is a difference between *personal* satisfaction with one's role in the management of family work (e.g., parents were happy when they were not doing the work) and *couple's* Relationship Satisfaction, which is affected by the distribution of work, rather than just one partner's role. In other words, a parent might be quite happy to not be scheduling the child's doctors' appointments or researching afterschool transportation options, but the couple's relationship is impacted nonetheless.

While the current study did not assess parents' time spent on the management of responsibility-related caregiving or household labor, we can say with certainty that there is a time cost associated with this family work. When one parent assumes a primary role in the management of family work, the corollary is that this parent experiences a loss of time that the child's other parent does not. If a parent manages all of the Responsibility-Related Caregiving and Household labor, she is likely to feel some resentment (Feldman, 2000; Stueve & Pleck, 2003). The fact is, ensuring that the home and child are taken care requires a great deal of time and effort. Most parents – those with and without a child with an ASD – attest to feeling that there is not enough time to get everything done. A great deal of the work that goes into raising a child is unseen, and this is especially true for parents who have a child on the autism spectrum. Autism is talked about a great deal in the media, and public awareness and understanding of the disorder is growing. However, these parents still report feelings of isolation, judgment, and difficulties in connecting their child and families with their communities.

Parenting Stress

Prior to the current study, the Management of Responsibility-Related Caregiving and Household Labor had not been explicitly examined among parents who have a child with an ASD, though several studies had found that parents reported stress associated with fulfilling this management role (Gray, 2003; Hutton & Caron, 2005; Karst & Van Hecke, 2012; Saxbe et al., 2011). Parenting Stress was higher when one parent always managed Responsibility-Related Caregiving, while the Management of Household Labor was unrelated to parenting stress. It may be the case that the demands of managing Responsibility-Related Caregiving are impacted differently by having a child with an ASD than is the Management of Household Labor, and that this work is especially stressful when one parent manages all or most of the work.

Parenting stress was higher for fathers and mothers whose children exhibited lower functioning, which supported Hypothesis 2.1 as well as prior research suggesting that among parents of children with an ASD, parenting stress is associated with child-related variables (Bebko et al., 1987; Brobst et al., 2008; N. O. Davis & Carter, 2008; Ingersoll & Hambrick, 2011; Koegel et al., 1992; Lickenbrock et al., 2011). Many of the items on the QRS-SFA tap into ways that parents' other family members have adapted to their child with a disability, as well as concerns related to a child's ability to live independently, have successful relationships, etc.; thus, it makes sense that parents of children who are lower functioning would experience greater parenting related stressors.

Couple's Relationship

Among both fathers and mothers, Relationship Satisfaction was at its highest when the Management of Family Work was distributed equally between parents; this finding held for both the Management of Responsibility-Related Caregiving and the Management of Household

Labor. While we had expected for Relationship Satisfaction to be lower among parents who always managed Responsibility-Related Caregiving (generally the mother) or Household Labor, an unanticipated finding was that Relationship Satisfaction did not differ between parents who always managed the work and those whose partner always managed the work. The extent to which the management of Responsibility-Related Caregiving or Household Labor is distributed unequally is important. When one parent always managed these aspects of family work – regardless of which parent – Relationship Satisfaction was lower. However, parents' Relationship Satisfaction did not differ between those who reported that one parent *usually* managed Household Labor or Responsibility-Related Caregiving or that management was *equally* shared. When it comes to the management of family work, even a little bit of sharing of the work goes a long way in benefiting the couple.

This finding supports prior research that suggests that fathers are more involved in childrelated caregiving when their relationship satisfaction is higher (S. M. Allen & Daly, 2002, 2007; Doherty et al., 1998; Lamb & Lewis, 2010; McBride & Mills, 1993; E. H. Pleck, 2004). Conceptually, this makes sense; a person's experience as part of a couple is not independent of the other partner's experience. If one parent assumes the role of fully managing family work, he or she may feel unsupported and less satisfied in the relationship. At the same time, the parent who does not share a role in the management of family work may feel guilty or detached from the inner workings of the family. Beyond querying degree of satisfaction, our study did not fully explore questions such as "how did you feel about having to do everything?" or "how did you feel about not helping?"

Conversely, parents who are satisfied in their relationship may be more likely to contribute to these aspects of family work. In this view, the couple's relationship precedes the

development of how parents' divide the management of family work (i.e. without the couple, there is no division of family work). The direction of effect cannot be assumed in this correlational finding; regardless, it is expected that the relationship among these variables is transactional rather than causal in either direction. Using family systems theory as a guide, it is understood that the parents' relationship and parents' management of family work influence each other over time (Belsky et al., 1991). Family members' habits and relationship dimensions develop and progress through bi-directional exchanges (Feldman, 2000; Minuchin, 1985). Prior research suggests that fathers who report a higher quality relationship with their partners tend to be more involved in various kinds of family work; their wives/partners likely appreciate this involvement and thus are more satisfied in the relationship. Or, it may be that fathers who are more satisfied in the marital relationship feel more invested in the parenting role and thus are more likely to engage in the Management of Responsibility-Related Caregiving.

Within couples, parents who receive greater support from their spouses report greater satisfaction with their marriage, their spouse, and the couple's relationship (Ehrenberg, Gearing-Small, Hunter, & Small, 2001). It is likely that there is a transactional exchange between a parent's satisfaction in the couple's relationship, his or her satisfaction with how family work is shared, and the ways parents adapt to the challenges of raising a child with an ASD (Hartley et al., 2011). When this work is shared, each parent may have more time to engage in leisure, recreation, and alone time; further, both parents may feel like they are contributing to the care and welfare of the family, while receiving help and support from one another.

Fathers and mothers with lower levels of Parenting Stress and who were more satisfied with the Management of Household Labor had higher Relationship Satisfaction. This finding supports prior research suggesting that relationship satisfaction among parents of children with

an ASD is affected by parenting-related stress (Baker-Ericzen et al., 2005; Brobst et al., 2008; Crnic & Booth, 1991; N. O. Davis & Carter, 2008; Duarte et al., 2005; Dyson, 1997; Ergüner-Tekinalp & Akkök, 2004; Gavidia-Payne & Stoneman, 2006; Hartley et al., 2011; Hutton & Caron, 2005; Ingersoll & Hambrick, 2011; Kersh et al., 2006; Lavee et al., 1996; Marcus et al., 2005; Mazur, 2006; Montes & Halterman, 2007; Olsson & Hwang, 2002; M. J. Weiss, 2002) as well as the division of family work (S. M. Allen & Daly, 2002, 2007; Baker-Ericzen et al., 2005; Barnett & Shen, 1997; Brobst et al., 2008; Cassidy et al., 2008; Coltrane, 2000; Doherty et al., 1998; Frisco & Williams, 2003; Hutton & Caron, 2005; Kasari, 2002; Lamb & Lewis, 2010; McBride & Mills, 1993; E. H. Pleck, 2004; Roxburgh, 2006; Sawyer et al., 2010; Stueve & Pleck, 2003). In line with our hypotheses, Satisfaction with the Management of Responsibility-Related Caregiving and Household Labor was found to partially account for the effect of Parenting Stress on Relationship Satisfaction; it seems that the extent to which parents are satisfied with how the management of family work is shared helps to explain the relationship between Parenting Stress and Relationship Satisfaction. Regardless, parents who experience fewer stressors and concerns related to their child with an ASD may be better able to cultivate a good quality relationship with their partners. Further, parents who are more satisfied with how the Management of Family Work is shared between parents likely feel supported by their partners, which feeds into their feelings of satisfaction with the relationship overall.

Family Functioning

Among these parents, their family's Social Integration – the connectedness between the family and the larger social context (Moos & Moos, 2009) – was lower when their child's functioning was lower and when parents experienced higher Parenting Stress. This supports prior findings that parents of children with an ASD experience difficulty in finding viable activities

outside of the home for their family to engage in as well as difficulty in making time for recreation (Cassidy et al., 2008; Hutton & Caron, 2005; Koegel et al., 1992; Rao & Beidel, 2009; Sanders & Morgan, 2008; Schaaf et al., 2011). Parents who have a child with an ASD experience challenges in finding qualified babysitters or respite care providers (Cassidy et al., 2008; Neely et al., 2012), as well as in finding activities for the child and family to do together (Sivberg, 2002). It follows that these difficulties would be exacerbated among parents whose children are lower functioning, as well as those who experience heightened concerns and stressors related to their child. Contrary to our expectations, neither parents' gender nor the distribution of the Management of Responsibility-Related Caregiving predicted Family Social Integration. It seems that in responding to the questions that comprised the Family Environment Scale, fathers and mothers were able to effectively report on their family as a whole – as they were instructed to do – and they had a similar picture of their family's overall functioning.

Parents who reported better quality relationships (i.e. FES Relationship Quality) among family members had a child whose functioning was higher; this is in line with prior research, which suggests that the demands of attending to the needs of a child who is lower functioning can be a strain on family relationships. Family relationship quality was also higher among parents who were more satisfied with the Management of Responsibility-Related Caregiving and Household Labor, and who reported higher Relationship Satisfaction and Communication with their partners. Satisfaction with the Management of Responsibility-Related Caregiving and Household Labor are general indicators of the extent to which parents are pleased with their role in the management of family work. While this type of satisfaction is not necessarily an indicator of parents' feelings of being supported in this role, a sense of support in this role is likely tied to general feelings of support within the family overall. Further, the parents' relationship sets the

precedent for overall family functioning (Cox & Paley, 1997); thus, it follows that relationships among family members would be of higher quality when parents have higher Relationship Satisfaction and better communication. We know that families of children with an ASD can maintain positive relationships (i.e. good cohesion, communication/expressiveness and conflict resolution) among family members (Rao & Beidel, 2009; Rodrigue et al., 1990, 1992; Sanders & Morgan, 2008); however, there is variability.

Commentary on Findings

Among fathers and mothers who have a child with an ASD, parents' management of and satisfaction with the division of family work have implications for parents' stress, the couple's relationship, their overall family functioning, and presumably for the child with an ASD, as well. Parents put a great deal of time and effort into managing their home and ensuring that their child is cared for; all of this work combined – making sure that their child sees the doctor and is ready for school in the morning, that the house gets cleaned, that the latest appliance malfunction gets attended to - is greater than the sum of its parts. A parent's role in the Management of Responsibility-Related Caregiving and Household Labor entails more than helping out around the house or even spending time with the children; it is the mental exertion, the persistence, the never-ending commitment that goes into making sure that children and home are cared for. Managing these components of family work can be exhausting for any parent, but for parents who have a child with an ASD, there is added pressure. The consequences of forgetting an IEP meeting or neglecting to communicate with a child's ABA therapist or forgetting to get the washer repaired may be exacerbated for these parents. These parents might think about all that they must juggle and wonder what would happen if they dropped the ball; it is very likely that

they have faltered at times, and experienced the upheaval that ensued. These fathers and mothers may feel that everyone's well-being rests on their shoulders.

These parents have many roles to fill: they must advocate for and attend to the needs of their child, care for their homes, and fulfill their employment-related responsibilities. They have to go to work and earn a living to support the family, including the extra expenses that go along with having a child on the autism spectrum. At the same time, they are to find time to nurture their relationship with their partner or spouse, friends and other family members, and – if any time is still available – pursue hobbies, responsibilities, and other interests outside of the home. Parenting a child who is on the autism spectrum is more than an everyday stressor, and the intensity of ensuring that their child's needs are met may impact parents' stress and their ability to successfully attend to the demands of family work. Among mothers who have a child with an ASD, the perception of the ability to set and reach goals is associated with lower levels of parenting stress, even after accounting for the effects of child's impairment (Ogston, Christon, Carr, Myers, & Mackintosh, 2009). A parent's role in the management of family work, in combination with the increased intensity of family work, has implications for the parent and their level of stress, as well as the couple and family.

While it was expected that fathers would be less involved in the Management of Responsibility-Related Caregiving, we were cautious in hypothesizing the relationship between this division of family work and other aspects of the parent's and family's experience. Our intention was to broach this topic without judgment or presumption of how parents ought to divide the work that goes into caring for their child and home. However, it is clear that the distribution of family work has implications for the parent, the couple, and the family. Regardless of how this family work is shared, these findings serve to increase our appreciation of

the effort that parents put into caring for their families, allowing for a more complete picture of what it means to raise a child on the autism spectrum. Further, it is hoped that findings will be utilized by other researchers, clinicians, and practitioners in our efforts to best support families that are affected by the autism spectrum disorders.

Limitations

Our sample was a disproportionately white, well-educated, middle to high socioeconomic status families; this is in line with other parenting focused research publications that cite a homogenous sample as a limitation to the generalizability of findings (Altiere & Kluge, 2008; N. O. Davis & Carter, 2008; Hassall et al., 2005; Johnson & Simpson, 2013; Kuhn & Carter, 2006; Ogston et al., 2011; Smith et al., 2008). Unfortunately, family research samples are often nonrepresentative of the population of interest. Even when random sampling methods are attempted, samples are often biased in some way (Braver & Bay, 1992). The issue of self-selection bias may be of particular concern with regards to fathers (Costigan & Cox, 2001) and for research conducted with parents of children with an ASD. Families who are experiencing high levels of distress may be less likely to participate in a study of this sort (Kelly et al., 2008). Further, our sample intentionally included only parents who live in the United States; the way that couples share family work is rather culture-specific, and it was expected that the division of family work and its impact on parents, the couple, and family would vary across countries. It is not possible to say whether these findings would be upheld within a different or more diverse sample. Future research must continue to wrestle with diversity and representativeness of samples. This will allow for better understanding and provision of support for all parents who have a child on the autism spectrum, rather than those who are easier to reach.

The current findings are rather specific to the time period in which this study took place; if we had conducted this study in 1950, we undoubtedly would have found different trends in how parents share the management of family work. Parenting beliefs and practices continue to evolve, and thus a similar study conducted 20 years from now may also yield different results.

The findings in this study, as with any non-experimental study, are correlational; thus causal statements cannot be made. We did not have the benefit of a control group to determine whether our findings would be similar in families with children without an ASD. A further limitation of this study was that child's diagnosis and level of functioning were provided through parent report and not through direct assessment.

While fathers and mothers both that report mothers have a greater role in the Management of Responsibility-Related Caregiving, more than 50% of mothers reported that they always managed Responsibility-Related Caregiving while only 9.6% of fathers reported that the other parent (mother) always managed this work. While we did not collect data from parents within the same family, we are assuming that fathers and mothers came from similar families; therefore, the differences between fathers' and mothers' reports is an indicator of informant discrepancy. It may be the case that both fathers and mothers wrongly estimated their partner's role in this aspect of family.

Directions for Future Research

Future research could include fathers and mothers in the same family, which would help elucidate parents' perceptions of their own and their partner's role in the management of family work. However, given what we know about the challenges that are associated with family research – studies that include fathers, in particular – it may be the case that families who have a child with an ASD in which both parents are willing to participate may differ from the average

family that has a child with an ASD. For example, such families may hold more egalitarian beliefs about parenting or have greater free time that allows for both parents to participate in research.

It was decided *a priori* that data collected from fathers and mothers in same-sex relationships (i.e., gay and lesbian parents) would be excluded from data analyses as we anticipated a small number of reporters. While we would have liked to have included same-sex parents in this study, the small number who participated made this not possible. This topic was beyond the scope of the current study but ought to be explored further.

Future research could examine the Management of Responsibility-Related Caregiving among non-residential parents; this aspect of parenting is important to consider in relation to the growing numbers of families in which fathers or mothers do not live with their children. Not living in the same home as one's child is a barrier to managing Responsibility-Related Caregiving, but parents can share this role (e.g., make their child's dentist appointment, buy child new shoes), regardless of whether they live with their child. Among divorced or never married parents who live with their child with an ASD, not having a spouse or partner to share in the family work would likely intensify the effort of attending to these demands; this would likely be associated with heightened parenting stress and would have implications for family functioning, as well. This could be examined in future research.

This study did not take into account the influence parental employment or hours worked on how family work is shared. Parents of children with an ASD are faced with added (and seemingly unending) costs related to services, treatment, and healthcare. Further, given the value that some men place on their role as an economic provider (Fox, Bruce, & Combs-Orme, 2000; Isacco, Garfield, & Rogers, 2010), these fathers perceptions of themselves as a successful parent

may be dependent on their ability to meet their family's financial needs. Future research ought to address the importance that these fathers and mothers place on each parent's role as an economic provider, as well as whether the Management of Responsibility-Related Caregiving and Household Labor differs between families in which both parents are employed and those in which one parent does not work outside of the home.

While results from the current study suggest that the way that parents share the demands of family work has implication for parenting-related stress, the couple's relationship, and overall family functioning, we know little about the impact of the division of family work on children themselves. We do not know how or whether the parents' division of work might play a role in their young children's progress in social, communication, and behavior goals or their older children's educational, vocational, and independence goals. Further, the amount of work that goes into arranging a child's interventions and services is considerable, and fathers and mothers are ultimately left in the position of sorting through treatment and therapy options that are available (Marcus et al., 2005) and managing the delivery of services that their child receives (Mulligan et al., 2012). These demands are a heavy load to carry, even when they are shared between parents. However, when just one always manages the Responsibility-Related Caregiving, a further question is whether the child with an ASD is vulnerable. Given the unique characteristics that are associated with the autism spectrum as well as the importance of interventions and services in maximizing developmental gains, the success with which these parents attend to their Responsibility-Related Caregiving demands – and the extent to which they are satisfied with how the family work in their home is shared – may be especially important.

Conclusion

The way that parents share family work is a neglected and undervalued aspect of the lives of families. Managing the demands of responsibility-related caregiving and household labor is particularly salient for fathers and mothers whose child has an ASD. The unseen effort that goes into caring for a child (e.g. the phone calls, the e-mails, the arranging and planning for treatment and services) and home is important in its own right and deserves to be acknowledged; beyond that, these aspects of family work have clear implications for parents, the parents' relationship, and family functioning. The primary goal for this study was not to recommend any particular formula for how fathers and mothers share the management of family work. Rather, the intention was to contribute to our understanding of how parents who have a child with an ASD manage to get everything done, and to make their story more complete.

If there is a one-sentence finding from this study, it is that parents and families are better off when the family work is shared. It is expected that this is true regardless of whether or not parents have a child on the autism spectrum. The degree of sharing between parents can vary, but for couples to be satisfied in their relationship and for families to function well, it cannot be just one parent's job to do everything. A discussion of how to share the work that goes into caring for the family may be beneficial to parents as well as their families; this is a conversation that couples ought to have.

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Appendix A

Information regarding study's website

http://www.parentsasd.com/

Website Heading (present on all pages): Research Study with Parents who have a Child on the Autism Spectrum

Facebook icon present on all pages, which links to study's Facebook page (Appendix B).

Page: Home: http://www.parentsasd.com/index.html

Photo (photo credit: Paula L. Ogston-Nobile)



Thank you for your interest in this research study being conducted with fathers and mothers who have a school-aged child with an autism spectrum disorder (ASD).

- This is a web-based study conducted in the Department of Psychology at Virginia Commonwealth University.
- This online questionnaire will take approximately 30 minutes to complete.

- Parents will be asked questions about themselves, their child, spouse/partner and family.
- Findings will tell us more about how parents share housework and caregiving responsibilities, the kinds of stress they experience, what their relationship is like with their partner, and how their family functions.
- We know less about fathers who have a child with an ASD, and we want to make sure that both dads and moms are represented in this research. However, it is not necessary that both parents in your family take part.
- Parents who participate may receive a \$10 Amazon gift card or enter for a chance to win one of two portable mp3 players!

Want to know more? For more information about this study, click here⁵.

Would you like to participate in this study? Click here⁶ for information on how you can take part.

The project coordinator for this study is Paula Ogston-Nobile⁷; you can contact her at ogstonpl@vcu.edu or 804.396.4387. Please feel free to pass this site along to other fathers and mothers who may be interested in participating. Thanks!

Page: About the Study: http://www.parentsasd.com/about-the-study.html

What is the purpose of this study?

- We want to better understand what it is like to be a parent of a child with an ASD.
- We know less about fathers who have a child with an ASD, and we want to make sure that they are represented in this research.
- Findings from this research will tell us more about how parents manage their homes and share caregiving responsibilities, the kinds of stress they experience, what their relationship is like with their partner, and how their family functions.

What are parents asked to do?

- Fathers and mothers will fill out an online questionnaire, which will take approximately 30 minutes.
- Parents will be asked questions about themselves, their child, partner and family.

⁵ Will link to: http://www.parentsasd.com/about-the-study.html

⁶ Will link to: http://www.parentsasd.com/to-participate.html

⁷ Will link to: http://www.parentsasd.com/about-the-researcher.html

• Parents who participate may receive a \$10 Amazon gift card or enter for a chance to win one of two portable mp3 players!

Who can participate?

- Fathers and Mothers who:
 - have a child with an autism spectrum disorder (ASD) who is between the ages of 5 and 12, AND
 - live with their child's other parent (either married or unmarried), AND
 - live in the same home as their child with an ASD, AND
 - live in the United States.

Note: all of the criteria listed above must be met in order to participate.

Any other details?

- Parents will not be contacted again regarding future studies.
- No identifying information will be collected.
- This study is being conducted as part of my⁸ doctoral research at Virginia Commonwealth University⁹

Please feel free to pass this site along to other fathers and mothers who may be interested in participating. Thanks!

Page: To Participate: http://www.parentsasd.com/to-participate.html

Are you interested in participating in this study? Here is how you can get involved:

- 1. Read about the study and the kinds of parents we are looking for.
- **2.** Click on the link below.
 - Respond to the questions and submit your responses.
 - You must provide an e-mail address in order to participate.
- **3.** Within 5 business days of submitting your responses, you will receive an e-mail from the researcher in charge of this study.
- **4.** If you fit the criteria we are looking for, the e-mail you are sent will include a link for the online questionnaire.
- 5. You can then fill out the online questionnaire! This can be done in one sitting or you can save your info and login to finish it another time. In all, it should take about 30 minutes.

⁸Will link to: http://www.parentsasd.com/about-the-researcher.html

⁹ Will link to: http://www.vcu.edu/

Please note:

- Your e-mail address will only be used to contact you regarding the current study.
- Your e-mail address and responses will only be accessible to the project coordinator in charge of this study, as well as her faculty advisors (Dr. Barbara Myers, Dr. Geri Lotze).

Screener Link (Appendix F).

Text for link: (Click here to enroll in the study. This will take approximately 2 minutes.)

Page: About the Researcher page: http://www.parentsasd.com/about-the-researcher.html

Paula L. Ogston-Nobile

Photo (credit: Paula L. Ogston-Nobile)



I am a graduate student studying development in the Department of Psychology at Virginia Commonwealth University. For the past 8 years, I have been working with children on the autism spectrum and their families.

I am originally from Michigan, and completed my undergraduate work in Psychology and Art at Michigan State University. Following that, I worked for three years as a research assistant with the Yale Autism Program. I moved to Richmond in 2007 to attend graduate school at VCU. I enjoy spending time with my husband and our two dogs, as well as rock climbing and doing yoga whenever I can.

I can be reached at ogstonpl@vcu.edu.

You may view my curriculum vitae here.

Appendix B

Description of Study's Facebook Page

Facebook Page Title: Research Study with Parents who have a Child on the Autism Spectrum

Link: https://www.Facebook.com/parentsasd

Cover Photo (photo credit: Paula L. Ogston-Nobile)



Profile Photo (photo credit: Paula L. Ogston-Nobile)



Name: Research Study with Parents who have a Child on the Autism Spectrum

"About" section of Facebook page:

Start Date: 2013

Short Description

This is the Facebook page for a web-based research study with fathers and mothers who have a child with an autism spectrum disorder.

If you would like more information or are interested in participating in this study, please visit http://www.parentsasd.com/

This is a web-based study conducted in the Department of Psychology at Virginia Commonwealth University.

•This online questionnaire will take approximately 30 minutes to complete.

• Parents will be asked questions about themselves, their child, spouse/partner and family.

• Findings will tell us more about how parents share housework and caregiving responsibilities, the kinds of stress they experience, what their relationship is like with their partner, and how their family functions.

• We know less about fathers who have a child with an ASD, and we want to make sure that both dads and moms are represented in this research. However, it is not necessary that both parents in your family take part.

• Parents who participate may receive either a \$10 Amazon gift card or enter for a chance to win one of two portable mp3 players!

Note: Fans of this page will not be contacted regarding this or any other study. This page will be used only for the purpose of providing information regarding the current research study.

Website: http://www.parentsasd.com

Appendix C

Advertisement(s)/Flyer(s) used for Recruitment. Both were printed at full page at full resolution.



Are you a father or mother of a child on the autism spectrum?

You are invited to participate in a research study with parents who have a child with an ASD.

- This is a web-based study conducted in the Department of Psychology at Virginia Commonwealth University.
- This online questionnaire will take approximately 30 minutes to complete.
- Parents will be asked questions about themselves, their child, spouse/partner and family.
- Findings will tell us more about how parents share housework and caregiving responsibilities, the kinds of stress they experience, what their relationship is like with their partner, and how their family functions.
- We know less about fathers who have a child with an ASD, and we want to make sure that both dads and moms are represented in this research. However, it is not necessary that both parents in your family take part.

visit www.parentsasd.com for more info.

You may also contact this study's project coordinator, Paula Ogston-Nobile, MS; Paula may be contacted at ogstonpl@vcu.edu or 804.396.4387.

Research Study parentsasd.com (804)396-4387 Research Study parentsasd.com (804)396-4387 (804)396-4387 (804)396-4387 (804)396-4387 (804)396-4387 Research Study parentsasd.com (804)396-4387 (804)396-4387 (804)396-4387 (804)396-4387 (804)396-4387	Research Study parentsasd.com (804)396-4387 (804)396-4387 Research Study parentsasd.com (804)396-4387	Research Study parentsasd.com (804)396-4387	Research Study parentsasd.com (804)396-4387	Research Study parentsasd.com (804)396-4387
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Appendix D

Letter for Recruitment via the Interactive Autism Network (IAN)¹⁰

Dear IAN Research participant,

When you joined the Interactive Autism Network (IAN Research Project), we promised to inform you about research projects that might be of interest to you. Below is an invitation from a team of researchers seeking IAN Research Project participants to join a new study. If you think that you qualify for this study and are interested in joining, please click on the study link or contact the study team directly using the information provided. You do not have to participate in this study and your non-participation will neither affect the care you receive from any health provider nor your standing as a participant in IAN Research.

Please note that IAN Research is serving as a resource linking the autism community and researchers. This study is not endorsed by or performed under the auspices of the IAN Research project at Kennedy Krieger Institute/Johns Hopkins.

Name of Study: The Division of Family Work among Fathers and Mothers of Children with an Autism Spectrum Disorder (ASD)

Institution: Virginia Commonwealth University; Richmond, Virginia

Location: Online survey; no geographic limitation within the United States

Eligibility Criteria:

Fathers and Mothers who:

- have at least one child with an ASD who is between the ages of 5 and 12 AND
- live with their child's other parent in the same home as their child

Principal Investigator: Barbara J. Myers, PhD

Contact Information: Paula L. Ogston-Nobile, Research Coordinator; Paula may be contacted at <u>ogstonpl@vcu.edu</u> or <u>804.396.4387</u> **Study Link**: http://www.parentsasd.com/

Dear Parent,

I am writing this letter to offer you an opportunity to participate in a research study that is being conducted by the Department of Psychology at Virginia Commonwealth University in Richmond, Virginia.

¹⁰ Letter was distributed by an IAN representative to parents registered with IAN.

We want to learn about how both fathers and mothers who have a child with an ASD share the work that goes into caring for their home and child, their parenting stress, the parents' relationship, and how their family functions. We know less about fathers who have a child with an ASD, and we want to make sure that they are represented in this research.

This study will take place via an online questionnaire, which you may complete at your convenience. This questionnaire will take approximately 30 minutes to complete and may be filled out in more than one sitting, so long as your computer accepts cookies.

As a thank you for your participation, you can receive a \$10 gift-card (sent via mail) for use on <u>www.amazon.com</u> or enter for a chance to win one of two portable mp3 players, approximate value \$50. You may also choose to receive information (via e-mail) regarding findings that result from this study.

If you would like to participate, please click on the following link: http://www.parentsasd.com/

If you have any questions, you may contact Paula L. Ogston-Nobile, our research coordinator, at ogstonpl@vcu.edu or 804.396.4387.

Thank you in advance for your time and assistance.

Sincerely,

Dr. Barbara J. Myers Associate Professor Department of Psychology Virginia Commonwealth University

and

Dr. Geri Lotze Assistant Professor Department of Psychology Virginia Commonwealth University

Appendix E

Text used in solicitations for recruitment assistance

- 1. Template Text used for contacting schools/organizations affiliated with the autism spectrum disorders.¹¹ All will be sent via e-mail.
 - a. Dear (Name of Contact) *or* To Whom it May Concern (if no contact information available),

I am a graduate student in psychology at Virginia Commonwealth University, and I am conducting a study with parents who have a child on the autism spectrum as part of my dissertation research. I am writing to ask for permission to send to your school/organization fliers that advertise for my study; I have attached a .pdf of this flier¹². Are you willing to allow this? If so, I can offer two options:

- i. I can mail or deliver 5-10 fliers to you to be posted at your school/facility where parents are likely to see them. Or,
- ii. I can mail or deliver enough fliers so that one could be sent home with every child who is between age 5 and 12.

Please be in touch via e-mail (<u>ogstonpl@vcu.edu</u>) or phone (804.396.4387) if you have questions. Thanks, and I look forward to your response!

Paula Ogston-Nobile

2. Text used for status updates via study's Facebook page: <u>https://www.Facebook.com/parentsasd</u>

A preview of the website will be included with all posts.

- a. We are conducting research study with fathers and mothers who have a child with an autism spectrum disorder (ASD) who is between age 5 and 12. If you have a child who is on the autism spectrum, we would love to hear from you! Visit http://www.parentsasd.com/ for more information.
- b. Are you a father or mother of a child with an autism spectrum disorder who is between age 5 and 12? If so, we'd love for you to participate in our online research study. Visit <u>http://www.parentsasd.com/</u> for more information.
- c. Please visit <u>http://www.parentsasd.com/</u> for information about a web-based research study with fathers and mothers who have a child with an autism spectrum disorder.

¹¹ Individual e-mails were tailored to each site/school/organization/group.

¹² See Advertisement(s)/Flyer(s) used for Recruitment in Appendix C.

- 3. Text used for sharing of Facebook page and website via current author's personal Facebook page:
 - a. Hello! As part of my dissertation research, I am conducting a study with parents who have a child with an autism spectrum disorder who is between age 5 and 12. If you have a child on the autism spectrum, please visit my study's webpage for more information: <u>http://www.parentsasd.com/</u>
 - b. Hello! As part of my dissertation research, I am conducting a study with parents who have a child with an autism spectrum disorder who is between age 5 and 12. Feel free to share my study's Facebook page or website with fathers and mothers who may be interested. Thanks! <u>http://www.parentsasd.com/</u> and <u>https://www.Facebook.com/parentsasd</u>
- 4. Template Text used for sharing Facebook page and website with other autism related pages on Facebook. Manager of page was first contacted to ask for permission to post. The following text will be sent:
 - a. Hello, I am a graduate student at Virginia Commonwealth University and I am conducting an online study with parents who have a child with an autism spectrum disorder as part of my dissertation research. I am writing to ask for your permission to post a link on your Facebook page to the website associated with my study (http://www.parentsasd.com/). Are you willing to grant this permission? Alternatively, you could post this link yourself on behalf of your page. I look forward to your response. Thank you,

Paula L. Ogston-Nobile

- 5. Link to the study's website and/or Facebook page was occasionally shared elsewhere on Facebook without first contacting the page's manager.
 - a. For example, if a news source/media outlet posts an article about autism, I occasionally posted information about the study under the 'comments' section of the post. Posts will contain text from one of the following options:
 - i. We are conducting research study with fathers and mothers who have a child with an autism spectrum disorder (ASD) who is between age 5 and 12. If you have a child who is on the autism spectrum, we would love to hear from you! Visit <u>http://www.parentsasd.com/</u> for more information.
 - ii. Are you a father or mother of a child with an autism spectrum disorder? If so, we'd love for you to participate in our online research study. Visit <u>http://www.parentsasd.com/</u> for more information.
 - iii. Please visit <u>http://www.parentsasd.com/</u> for information about a webbased research study with fathers and mothers who have a child with an autism spectrum disorder.
 - iv. Are you a father or mother of a child with an autism spectrum disorder who is between age 5 and 12? If so, we'd love for you to participate in our online research study. Visit <u>https://www.Facebook.com/parentsasd</u> for more information.
- 6. Procedures for recruitment via the Interactive Autism Network

- a. A representative with the Interactive Autism Network sent an e-mail to fathers and mothers registered with IAN on behalf of the researchers in charge of the current study.
- b. This e-mail contained the text contained in the supporting document: Letter for Recruitment via the Interactive Autism Network (IAN; Appendix D).
- c. IAN twice distributed this information.
 - i. In mid-August 2013, this information was sent to all fathers registered with IAN and a portion of mothers.
 - ii. In mid-October 2013, this information was again sent to all fathers registered with IAN and a portion of mothers.
 - 1. IAN does not provide specific numbers re: registered parents, the number of parents who were contacted, or if the same mothers who were contacted in the first e-mailing were also contacted in the second distribution.

Appendix F

Online Screener (REDCap) - Questions

Survey Instructions

Are you interested in participating in this study? Here is how you can get involved:

- Make sure that you have read about the study and the kinds of parents we are looking for.

- Respond to the questions below.

Within 5 business days of submitting your responses, you will receive an e-mail from this study's project coordinator.

If you fit the criteria we are looking for, the e-mail you are sent will include a link for the online questionnaire.

- 1. What is your e-mail address?
- 2. Please confirm your e-mail address by entering it again here:
- 3. Are you a parent of a child with an autism spectrum disorder who is between the age of 5 and 12?

(Multiple Choice Response Options)

- Yes, I have a child on the autism spectrum who is between age 5 and 12^{*13}
- No, I do not have a child on the autism spectrum who is between age 5 and 12
- 4. What is your relationship to your child?
 - \Box Mother (adoptive, biological/birth)*
 - \Box Father (adoptive, biological/birth)*
 - □ Stepmother
 - \Box Stepfather

Other: write in _____

¹³ Response options that meet study criteria are marked with a *. A response must be provided for all questions; one cannot submit their responses unless each item is filled out.

5. Does your child who has an ASD live in yo	your home?
--	------------

(Multiple Choice Response Options)

		-		-		
Yes,	my child	lives	with	me all	of the	time*

Yes, my child lives with me some of the time

No, my child and I do not live in the same home

Other____(write in)

6.	Which of the following best describes the adult(s) living in your home? ¹⁴
	(Multiple Choice Response Options)

2 parents (both are child's adoptive or biological/birth parents)*

	1	parent	(ado	ptive	or	biol	ogical	/birth)) +	1	step-pa	arent
--	---	--------	------	-------	----	------	--------	---------	-----	---	---------	-------

1 parent

Other____(write in)

7. Do you currently live in the United States?	7.	Do you	currently	live in	the	United	States?
--	----	--------	-----------	---------	-----	--------	---------

] Yes*] No

- 8. How did you hear about this study?
 - \Box Through my child's school
 - \Box From a friend
 - \Box From another parent
 - □ Through IAN (Interactive Autism Network)
 - \Box Other_____

Survey Acknowledgment Text

Thank you for responding to these questions.

Within 5 business days, you will receive an e-mail from this study's project coordinator.

¹⁴ It was required that both child's parents live in the home; however, the presence of other adults living in the home (e.g. a grandparent) did not exclude parents from being enrolled.

Appendix G

Initial Instructions at Start of Questionnaire

Thank you for your interest in this study.

Due to technology issues, we ask that you respond to this questionnaire using a laptop or PC, rather than using a smartphone or tablet.

After your initial viewing of this page, you will have 24 hours to complete this survey. If you need more time, click the "Save & Return Later" button at the bottom of the page and follow the instructions.

Please review the information below.

Appendix H

RESEARCH SUBJECT INFORMATION AND CONSENT FORM

TITLE: The Division of Family Work in Fathers and Mothers of Children with an Autism Spectrum Disorder: Implications for Parents and Family Functioning

VCU IRB NO.: HM15207

This section includes information about the study as well as the option for you to consent to participate.

PURPOSE OF THE STUDY

The purpose of this study is to learn about how parents who have a child with an ASD share the work that goes into caring for their home and child, the kinds of stress they experience, what their relationship is like with their partner, and how their family functions.

You are welcome to participate in this study if you:

- have a child (biological/birth or adopted) on the autism spectrum who is between age 5 and 12, AND
- live with your child's other parent (either married or unmarried), AND
- live in the same home as your child with an ASD, AND
- live in the United States.

It is expected that a minimum of 200 parents and no more than 720 parents will participate in this study.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT

If you decide to take part in this research study, you will be asked to indicate that:

- you have read this information
- you understand what the study entails
- you understand the study's risks and benefits.
- This is a web-based study conducted in the Department of Psychology at Virginia Commonwealth University.
- This online questionnaire is comprised of several sections and will take approximately 30 minutes to complete. You may fill it out in more than one sitting.
- Findings will tell us more about how parents share housework and caregiving responsibilities, the kinds of stress they experience, what their relationship is like with their partner, and how their family functions.

• We know less about fathers who have a child with an ASD, and we want to make sure that both dads and moms are represented in this research. However, it is not necessary that both parents in your family take part.

If you participate in this study, you will be asked a number of questions. You will be asked about:

- Your family members' demographics (age, education, race/ethnicity, etc)
- Your child's skills in different areas
- How you and your partner/spouse share housework and caregiving responsibilities
 Your satisfaction with how this work is shared
- Stress related to parenting
- Your relationship with your spouse/partner
- Family functioning

BENEFITS TO YOU AND OTHERS

You may not get any direct benefit from this study, but the information we learn from people in this study may help us to understand and better meet the needs of fathers and mothers who have a child on the autism spectrum.

RISKS AND DISCOMFORTS

There are no expected risks. However, it can be upsetting for people to think about some of the topics that will be asked about in this study.

COSTS

There are no costs for participating in this study, other than the approximately 30 minutes it will

take to fill out this questionnaire.

PAYMENT FOR PARTICIPATION

If you decide to submit your responses, you may elect to receive a \$10 Amazon gift card (sent via mail) for use on www.amazon.com or you may enter for the chance to win one of two iPod® shuffles. In order to receive the gift card, you must provide a mailing address. The gift card will be sent to you, along with a self-addressed stamped envelope and a Research Participation Form. The form will ask for your name, address, and Social Security Number. You must provide an e-mail address in order to enter to win the iPod® shuffle. If you win the shuffle, you must provide your name and a mailing address.

CONFIDENTIALITY

Your responses are being collected for the purpose of the current study and will be used only for research purposes. You will not be required to provide first or last names or birthdates, and no

other identifying information will be required of you or connected to your responses. Data will be encrypted and stored on a secure server using REDCap data management system (http://project-redcap.org/). Access to all data will be limited to study personnel.

We will not share your responses with anyone; however, information from the study and the consent that you submit may be looked at or copied for research or legal purposes by Virginia Commonwealth University.

What we learn from this study may be presented at meetings or published in papers. However, since your responses are anonymous your name will never be connected to the information contained in these presentations or papers.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may choose not to answer particular questions that are asked.

QUESTIONS

If you have any questions, complaints, or concerns about your participation in this research, contact a member of this research team:

Paula L. Ogston-Nobile, MS; Graduate Student and Study Coordinator (<u>ogstonpl@vcu.edu</u>; 804.396.4387). and/or
Barbara J. Myers. PhD; Principal Investigator leading study (bmyers@vcu.edu; 804.828.6752).
Geri M. Lotze, PhD: Faculty member supervising this study (<u>glotze@vcu.edu</u>; 804.827.1862).

The researchers named above are the best people to call for questions about your participation in this study.

If you have any general questions, concerns, or complaints about your rights as a participant in this or any other research, you may contact:

Office of Research Virginia Commonwealth University 800 East Leigh Street, Suite 3000 P.O. Box 980568 Richmond, VA 23298 Telephone: (804) 827-2157

You may also call this number if you cannot reach the research team or if you wish to talk with someone else. General information about participation in research studies can also be found at http://www.research.vcu.edu/irb/volunteers.htm.

If you would like to wait to decide whether to participate, you may sign out of REDCap and log back in at a later time.

CONSENT

If you consent to participate in this study, you indicate the following:

- I have been given the chance to read this consent form.
- Any questions that I have asked about the study have been answered.
- I understand what the study entails
- I understand the study's risks and benefits.

Do you consent to participate in this study?¹⁵

 \Box Yes, I consent to participate in this study.¹⁶

 \square No, I do not consent to participate in this study.¹⁷

¹⁵ The questionnaire was formatted so that the respondent was required to respond to this question in order to move forward.

¹⁶ Upon clicking "Yes," the participant was taken to the first page of the study's questionnaire.

¹⁷ If the respondent chose "no," they were presented with a dialogue box that said:

[&]quot;You have selected an option that triggers this survey to end right now. To save your responses and end the survey, click the button below to do so. If you have selected the wrong option by accident and do not wish to leave the survey, you may click the other button below to continue, which will also remove the value of the option you just selected to allow you to enter it again and continue the survey." REDCap does not allow this text to be customized.

Appendix I

Introduction and Information Regarding Focus Child

Throughout this questionnaire, you will be asked a number of questions about **your family and the people who live in your home: you, your child(ren), and your partner/spouse**.

9. Are you a parent of a child with an autism spectrum disorder who is between the age of 5 and 12?¹⁸

 \Box Yes, I have a child on the autism spectrum who is between age 5 and 12^{*19}

No, I do not have a child on the autism spectrum who is between age 5 and 12

Many questions will ask specifically about your child with an ASD, who will be referred to throughout as your **Focus Child**.

The questions below will help you decide which of your children is your Focus Child:

Do you have more than one child with an ASD between the age of 5 and 12? Yes

• If parent responds 'yes' \rightarrow You have indicated that you have more than one child with an ASD between age 5 and 12).

¹⁸ Due to the use of the online screener that will be used to recruit potential participants, it was expected that only parents who met the study's inclusionary criteria would reach this point in filling out the questionnaire. However, due to the importance placed on meeting the criteria, this information was re-verified.

If a parent's response does not fit the inclusionary criterion (* above), he or she was presented with a message, which was built in to the REDCap platform, that read "You have selected an option that triggers this survey to end right now. To save your responses and end the survey, click the button below to do so. If you have selected the wrong option by accident and do not wish to leave the survey, you may click the other button below to continue, which will also remove the value of the option you just selected to allow you to enter it again and continue the survey." REDCap does not allow this text to be customized.

¹⁹ Response options that meet study criteria are marked with a *. The asterisk will not be included in the questionnaire.

• Please use this criteria for identifying your Focus Child: Of your children who have an ASD and are between age 5 and 12, please identify the child whose birthday is coming up next. This is your Focus Child.

- No
 - If parent responds 'no' → You have indicated that you have only one child with an ASD who is between 5 and 12 years old. This one child will be your Focus Child.

Throughout this questionnaire, when asked a question about your "child," please refer to your Focus Child. 20

10. Does your focus child live in your home? (Multiple Choice Response Options)

Yes, my child lives with me all of the time*

Yes, my child lives with me some of the time

No, my child and I do not live in the same home

Other____(write in)

11. What is your relationship to your child?

 \Box Mother (adoptive, biological/birth)*

 \Box Father (adoptive, biological/birth)*

□ Other: write in _____

12. Which of the following best describes the adult(s) living in your home? (Multiple Choice Response Options)

2 parents (both are child's adoptive or biological/birth parents)*

] 1 parent (adoptive or biological/birth) + 1 step-parent

1 parent

Other____(write in)

If other \rightarrow Please describe the adults who live in your home. This study requires that both of the focus child's parents (adoptive or biological/birth) live in the home.

²⁰ For pages of the questionnaire that contain questions that are intended to be answered with the parent's Focus Child in mind, the following message will be included: *Please think about your Focus Child when answering the questions below.*

13. Do	you currently live in	the United State	s?
Yes*			
No			

14. How did you hear about this study? □ Through my child's school

 \Box From a friend

 \Box From another parent

Through IAN (Interactive Autism Network)

□ Other_____

Appendix J

Demographic Survey

Questions about your Child

Please think about your Focus Child when answering the questions below.

- 15. How old is your child? (drop-down). Will contain integers 5 through 12, inclusive.
- 16. What is your child's diagnosis?
 - \Box Autism or autistic disorder
 - □ Asperger's Syndrome
 - \Box PDD-NOS
 - \Box Rett's Disorder²¹
 - □ Childhood Disintegrative Disorder

 \Box On the autism spectrum disorder or has Pervasive Developmental Delay but specific diagnosis is unclear

- \Box other _____ (write in)
- 17. How old was your child (in years) when he/she first received a diagnosis on the Autism Spectrum?

(drop-down). Will contain values: <1, and 1-12 (with 1 year intervals).

²¹ The most recent DSM (V) specifies that the autism spectrum disorder does not include Rett's Disorder. This is a change from the last edition of the DSM. Thus, in order to adhere to new DSM-V specifications, data collected from parents who indicate that their child has Rett's will not be included in analysis. An alternative would be to present parents who indicate that their child has Rett's Disorder with a message stating that they did not meet the inclusionary criteria for this study. However, given that this information may be new and potentially upsetting for some parents, it was determined that it would be inappropriate to deliver this information in this manner.

18. Has your child been diagnosed with any other disabilities, diseases, chronic illnesses, or health conditions?

Please describe them here:

19. Is your child	male or female?
-------------------	-----------------

 \Box Male

□ Female

20. What is your child's race? Check **all that apply:**

White or Caucasian	American Indian or Alaskan Native
Black or African American	Asian
Native Hawaiian or Other Pacific Islander	Another race (write in)
Prefer not to say	

21. Is your child of Hispanic, Latino, or Spanish origin?

No, not of Hispanic, Latino or Spanish origin.
Yes, Mexican/Mexican American or Chicano
Yes, Puerto Rican
Yes, Cuban
Yes, other. Write in:
Do not know
Prefer not to say

Questions about Yourself

22. Are you male or female?

 \Box Male \Box Female

- 23. What is your age (in years)? Write in.
- 24. In what state do you live? (Drop-down). Contained all U.S. states and territories.
- 25. What is the highest level of education that you have completed?
 - \Box Less than a high school diploma
 - \Box High school diploma/GED

 \Box Trade school

- □ Some college/university, but less than a Bachelor's degree
- \Box Bachelor's degree (B.A or B.S.)
- \Box Some graduate school, but less than a Master's Degree
- □ Master's Degree (M.A. or M.S.)
- □ Doctoral Degree (PhD)
- □ Professional Degree (medicine, law, dentistry, veterinary, etc.)
- \Box Other____(write in)

26. What is your race?

Check all that apply:

White or Caucasian	American Indian or Alaskan Native
Black or African American	Asian
Native Hawaiian or Other Pacific Islander	Another race (write in)
Prefer not to say	

27. Are you of Hispanic, Latino, or Spanish origin?

No, not of Hispanic, Latino or Spanish origin.
Yes, Mexican/Mexican American or Chicano
Yes, Puerto Rican
Yes, Cuban

Yes, other. Write in:
Do not know
Prefer not to say

28. What is your employment status?

Employed full-time in one or more paid positions (35 hours a week or more)

□ Employed part-time in one or more paid positions (less than 35 hours a week) □ Not employed

- Laid off/unemployed
- Work inside the home as a full-time parent
- \circ Retired

□ Other____(write in)

29. If you are employed, how many hours do you work during the average week? *Please include all hours from paid employment. If you do not work outside of the home, leave blank.*

Please think about your Focus Child when answering the questions below.

30. What is your marital/relationship status?

- □ Currently married to child's other parent
- □ Currently in a relationship/domestic partnership with child's other parent
- Other_____(write in)
- 31. If you are married, for how many years have you been married? Write in.

Questions about your spouse/partner

When answering questions below that refer to your 'child,' please think about your <u>Focus</u> <u><i>Child.</u>

- 32. Is your spouse/partner male or female?

□ Female

- 33. What is the relationship of your spouse/partner to your child? □ Mother (biological/birth or adoptive)
 - \Box Father (biological/birth or adoptive)

□ Other: write in _____

- 34. What is your spouse/partner's age (in years)? Write in.
- 35. What is the highest level of education that your spouse/partner has completed?
 - \Box Less than a high school diploma
 - □ High school diploma/GED
 - \Box Trade school
 - □ Some college/university, but less than a Bachelor's degree
 - \Box Bachelor's degree (B.A or B.S.)
 - □ Some graduate school, but less than a Master's Degree
 - \Box Master's Degree (M.A. or M.S.)
 - □ Doctoral Degree (PhD)
 - □ Professional Degree (medicine, law, dentistry, veterinary, etc.)
 - \Box Other____(write in)
- 36. What is your spouse/partner's race? Check **all that apply:**

White or Caucasian	American Indian or Alaskan Native
Black or African American	Asian
Native Hawaiian or Other Pacific Islander	Another race (write in)
Prefer not to say	

37. Is your spouse/partner of Hispanic, Latino, or Spanish origin?

No, not of Hispanic, Latino or Spanish origin.
Yes, Mexican/Mexican American or Chicano
Yes, Puerto Rican
Yes, Cuban
Yes, other. Write in:

Do not know.
Prefer not to say.

38. What is your spouse/partner's current employment status?

Employed full-time in one or more paid positions (35 hours a week or more)

Employed part-time in one or more paid positions (less than 35 hours a week)

- \Box Not employed
 - o Laid off/unemployed
 - Work inside the home as a full-time parent
 - Retired
- \Box Other_
 - 39. If your spouse/partner is employed, how many hours does he or she work during the average week?

Please include all hours from paid employment. If your child's other parent does not work outside of the home, leave blank.

- 40. What was your household's approximate pre-tax income for the previous calendar year? Please include you and/or your spouse/partner's earned wages, tips, investment income, as well as income from child support, properties, public assistance, estates and trust. □ Less than \$9,999
 - □ 100,000 \$19,999 □ \$10,000 - \$19,999 □ \$20,000 - \$24,999 □ \$25,000 - \$29,999 □ \$30,000 - \$39,999 □ \$40,000 - \$49,999 □ \$50,000 - \$59,999 □ \$60,000 - \$69,999 □ \$70,000 - \$79,999 □ \$80,000 - \$89,999 □ \$90,000 - \$99,999 □ \$100,000 - \$124,999 □ \$125,000 - \$149,999 □ Greater than \$150,000
 - \Box Prefer not to say
- 41. What percent of your household income from the previous calendar year came from wages/salary earned from your own paid employment?

Please use this slider scale to indicate the approximate percentage. If you did not earn wages/salary from the previous calendar year, set this to "0%." (slider is precise to 1 percentage point) 42. What percent of your household income from the previous calendar year came from wages/salary your spouse/partner earned from paid employment?

Please use this slider option to indicate the approximate percentage. If your spouse/partner did not earn wages/salary from the previous calendar year, set this to "0%."

(slider is precise to 1 percentage point)

43. Approximately what percent of your household income from the previous calendar year came from non-wage sources? Include earnings from investments, properties, public assistance, child support, etc.

Please use this drop-down option to indicate the approximate percentage. If none of your income from the previous calendar year came from non-wage sources, set this to "0%."

(slider is precise to 1 percentage point)

Before moving on to the next section, please check whether the percentages indicated in the previous 3 questions add up to 100.

Do they add up to 100? Yes No

44. How well does your household's income meet your family's needs?

Please respond using the following rating system.

Scale of 0 to 3, where 0 = family's needs are not at all met by household income and 3 = family's needs are very well met by household income.

- 0. Not at all met
- 1. Somewhat met
- 2. Mostly met
- 3. Very well met

Questions about your Family

45. How many children (adopted, biological, or step-) who are 18 years old and under live in your home?

Please write this in this here:

46. How many adults in total live in your home (e.g. parents, grandparents, other adults)? Please include you and your partner/spouse. Do not include adult children. Please write this in this here: ______

Please think about your Focus Child when answering the questions below

47. Including your **Focus Child**, how many of your children have ever been diagnosed with an autism spectrum disorder?

Please write this in this here: _____

- 48. Do you have a home-aide, baby-sitter, nanny or respite care provider who helps care for your child on a regular basis?☐ Yes
- 🗌 No
 - 49. Do you have a maid or housekeeper who helps care for your home on a regular basis? □ Yes

Appendix K

$Responsibility\text{-}Related\ Caregiving-Management\ Scale^{\textcircled{0}}$

Note: The items contained on this page are a part of the Responsibility-Related Caregiving Management Scale (Ogston-Nobile, Myers, & Lotze, 2014). You may e-mail ogstonpl@vcu.edu or paulaogston@gmail.com for more information or if you are interested in using this scale as a part of your own research or evaluation. You may not use this scale or the items above without the permission of the author.

Additional instructions were provided but are omitted here.

How do you and your Focus Child's other parent usually share the responsibility for____?²²

Response Options

Other parent	Other parent	Other parent and I equally	I usually	I always
always has	usually has	share	have	have
responsibility	responsibility	responsibility	responsibility	responsibility
for this.	for this.	for this.	for this.	for this.

Making your child's appointments for physicals, vaccinations (i.e. managing routine medical care).
Making sure that your child's routine hygiene needs are met (e.g. bathed/showered, teeth are brushed, hair is washed).
Arranging and planning for your child's treatments and/or services that are related to his/her autism spectrum disorder
Making child care arrangements for your child (e.g. babysitting/respite care).

²² Items were presented in a 'Matrix Format,' and response options were the same for all items in this scale.

Appendix L

Household Labor – Management $Scale^{\odot}$

Note: The items contained on this page are a part of the Household Labor Management Scale (Ogston-Nobile, Myers, & Lotze, 2014). You may e-mail ogstonpl@vcu.edu or paulaogston@gmail.com for more information or if you are interested in using this scale as a part of your own research or evaluation. You may not use this scale or the items above without the permission of the author.

Additional instructions were provided but are omitted here.

How do you and your spouse or partner usually share the responsibility for_____?²³

Response Options

Other parent always has responsibility	Other parent usually has responsibility	Other parent and I equally share responsibility	I usually have responsibility	I always have responsibility
for this.	for this.	for this.	for this.	for this.

Planning meals.
Remembering that the garbage needs to be taken out.
Making sure the bathrooms are cleaned.
Attending to minor household repairs and maintenance (e.g. replacing
light bulbs, replacing the bag on the vacuum, putting in the storm
windows).

²³ Items were presented in a 'Matrix Format,' and response options were the same for all items in this scale.

Appendix M

Responsibility-Related Caregiving - Satisfaction Scale[©]

Note: The items contained on this page are a part of the Responsibility-Related Caregiving Satisfaction Scale (Ogston-Nobile, Myers, & Lotze, 2014). You may e-mail ogstonpl@vcu.edu or paulaogston@gmail.com for more information or if you are interested in using this scale as a part of your own research or evaluation. You may not use this scale or the items above without the permission of the author.

Additional instructions were provided but are omitted here.

How satisfied are you with how you and your child's other parent share the responsibility for 2^{24}

Response Options

	Moderately		Moderately	
Dissatisfied	Dissatisfied	Neutral	Satisfied	Satisfied

Making your child's appointments for physicals, vaccinations (i.e. managing routine medical care).
Making sure that your child's routine hygiene needs are met (e.g. bathed/showered, teeth are brushed, hair is washed).
Arranging and planning for your child's treatments and/or services that are related to his/her autism spectrum disorder
Making child care arrangements for your child (e.g. babysitting/respite care).

²⁴ Items were presented in a 'Matrix Format,' and response options were the same for all items in this scale.

Appendix N

Household Labor - Satisfaction $Scale^{\odot}$

Note: The items contained on this page are a part of the Household Labor Satisfaction Scale (Ogston-Nobile, Myers, & Lotze, 2014). You may e-mail ogstonpl@vcu.edu or paulaogston@gmail.com for more information or if you are interested in using this scale as a part of your own research or evaluation. You may not use this scale or the items above without the permission of the author.

Additional instructions were provided but are omitted here.

How satisfied are you with how you and your spouse/partner share the responsibility for___?²⁵

Response Options

	Moderately		Moderately	
Dissatisfied	Dissatisfied	Neutral	Satisfied	Satisfied

Planning meals.				
Remembering that the garbage needs to be taken out.				
Making sure the bathrooms are cleaned.				
Attending to minor household repairs and maintenance (e.g. replacing				
light bulbs, replacing the bag on the vacuum, putting in the storm				
windows).				

²⁵ Items were presented in a 'Matrix Format,' and response options were the same for all items in this scale.

Appendix O

Family Environment Scale²⁶

Additional instructions were provided but are omitted here. Example items are omitted here; subscales and dimensions included only.

Response Options27TrueFalse

Relationship Dimensions²⁸

Cohesion subscale Expressiveness subscale Conflict subscale

Personal Growth Dimensions

Independence subscale Achievement Orientation Subscale Intellectual-Cultural Orientation Subscale Active-Recreational subscale Moral-Religious Emphasis

Note: The content on this page is copyright protected by Mind Garden and the items make up a part of the Family Environment Scale. For more info about this measure visit www.mindgarden.com.²⁹

²⁶ Moos, R. H., & Moos, B. S. (2009). Family Environment Scale Manual, 4th Edition. Palo Alto, CA: Mind Garden.

²⁷ Items were presented in a 'Matrix Format,' and response options were the same for all items in this scale.

²⁸ Dimensions and subscales were not labeled in questionnaire.

²⁹ The publisher of the Family Environment Scale (FES), Mind Garden, Inc., requires that every page of this questionnaire that contains any material from the FES contain the instrument copyright and <u>www.mindgarden.com</u>.

Appendix P

PREPARE/ENRICH - Three Couples Scales³⁰

Instructions:

Indicate how strongly you agree or disagree.³¹ Example items are omitted here; subscales included only.

Response Options

Disagree				Agree
strongly	Disagree	Undecided	Agree	Strongly

Satisfaction Subscale³² **Communication Subscale Conflict Resolution Subscale**

Note: The items contained on this page comprise the Three Couple Scales (Olson & Larson, 2008); copyright Life Innovations. You may e-mail cs@prepare-enrich.com for more information.

³⁰ Olson, D. H., & Larson, P. (2008). PREPARE/ENRICH: Customized Version. Life Innovations, P.O. Box 190, Minneapolis, MN 55440. ³¹ Items were presented in a 'Matrix Format,' and response options were the same for all items in

this scale.

³² Subscales were not labeled in the questionnaire.

Appendix Q

Questionnaire on Resources and Stress – Short Form Abbreviated (QRS-SFA)³³

Additional instructions were provided but are omitted here.

Response Options34TrueFalse

Example items

Other family members have to do without th	nings because of
The family does as many things together nov	w as we ever did.
I worry about what will happen to care of him/her.	_ when I can no longer take

Note: the items contained on this page are a part of the Questionnaire on Resources and Stress - Short Form (Friedrich, Greenberg & Crnic, 1983).

³³ Friedrich, W. N., Greenberg, M. T., & Crnic, K. A. (1983). A short-form of the Questionnaire on Resources and Stress. *American Journal of Mental Deficiency*, 88(1), 41–48.

³⁴ Items were presented in a 'Matrix Format,' and response options were the same for all items in this scale.

Appendix **R**

Autism Treatment and Evaluation Checklist (ATEC)^{35, 36}

This section is about your child's speech, language, and communication abilities. Please indicate the extent to which each item is true for your child.

Response Options³⁷

1 1		
	Somewhat	
Not True	true	Very True

1	Knows own name
2	Responds to 'No' or 'Stop'
3	Can follow some commands
4	Can use one word at a time
5	Can use 2 words at a time
6	Can use 3 words at a time
7	Knows 10 or more words
8	Can use sentences with 4 or more words
9	Explains what he/she wants
10	Asks meaningful questions
11	Speech tends to be meaningful/relevant
12	Often uses several successive sentences
13	Carries on fairly good conversation
14	Has normal ability to communicate for his/her age

³⁵ The ATEC is comprised of four subsections, which are presented separately.

³⁶ Rimland, B., & Edelson, S. M. (1999). Autism Treatment Evaluation Checklist (ATEC). Autism Research Institute.

³⁷ Items were presented in a 'Matrix Format,' and response options were the same for all items in this scale.

This section is about your child's sociability. Please indicate the extent to which each item describes your child.

Response Options³⁸

Not	Somewhat	Very
Descriptive	Descriptive	Descriptive

1	Seems to be in a shell - you cannot reach him/her
2	Ignores other people
3	Pays little or no attention when addressed
4	Uncooperative and resistant
5	No eye contact
6	Prefers to be left alone
7	Shows no affection
8	Fails to greet parents
9	Avoids contact with others
10	Does not imitate
11	Dislikes being held/cuddled
12	Does not share or show
13	Does not wave 'bye-bye'
14	Disagreeable/not compliant
15	Temper tantrums
16	Lacks friends/companions
17	Rarely smiles
18	Insensitive to other's feelings
19	Indifferent to being liked
20	Indifferent if parent(s) leave

³⁸ Items were presented in a 'Matrix Format,' and response options were the same for all items in this scale.

This section is about your child's sensory/cognitive awareness. Please indicate the extent to which each item describes your child.

Response Options³⁹

Not	Somewhat	Very
Descriptive	Descriptive	Descriptive

1	Responds to own name
2	
2	Responds to praise
3	Looks at people and animals
4	Looks at pictures (and T.V.)
5	Does drawing, coloring, art
6	Plays with toys appropriately
7	Appropriate facial expression
8	Understands stories on T.V.
9	Understands explanations
10	Aware of environment
11	Aware of danger
12	Shows imagination
13	Initiates activities
14	Dresses self
15	Curious, interested
16	Venturesome - explores
17	Tuned in - Not spacey
18	Looks where others are looking

³⁹ Items were presented in a 'Matrix Format,' and response options were the same for all items in this scale.

This section is about your child's health, physical symptoms, and behavior. Please indicate the extent to which each item is a problem for your child.

Respo	nse Opti	ions ⁴⁰			
No	ot a	Minor	Moderate	Serious	
pro	olem	problem	problem	Problem	
1	Bed-w	-			
2	_	ants/diapers			
3		ants/diapers			
4	Diarrhe				
5	Consti	-			
6	Sleep p	problems			
7	Eats to	o much/too little	e		
8	Extrem	nely limited diet			
9	Hypera	active			
10	Lethar	gic			
11	Hits or	injures self			
12	Hits or	injures others			
13	Destru	ctive			
14	Sound-	-sensitive			
15	Anxiou	us/fearful			
16	Unhap	py/crying			
17	Seizure	es			
18	Obsess	sive speech			
19		outines			
20		or screams			
21	Deman	nds sameness			
22	Often a	agitated			
23	Not ser	nsitive to pain			
24		ed' or fixated on	certain objects/	topics	
25	Repetit	tive movements	•		

⁴⁰ Items were presented in a 'Matrix Format,' and response options were the same for all items in this scale.

Appendix S

Open-Ended Questions

1. What is the most important thing that you do for your family? (open-ended)

2. What is the most important thing that your partner/spouse does for your family? (open-ended)

3. Do you have any feedback or comments about this study? (open-ended)

Appendix T

Additional Questions

You are almost finished with this questionnaire!

Will you respond to 6 additional items?

 \Box Yes ⁴¹ \Box No

- Prior to this, have you ever participated in a research study?
 □ Yes □ No □ Not Sure
- Prior to this, have you ever participated in a research study about parents/parenting?
 □ Yes □ No □ Not Sure
- 3. In the future, would you participate in another research study about parenting? □ Yes □ No □ Not Sure

For each of the following 3 items below, please indicate the extent to which each statement sounds like you.

Response Options

Not at all	A little like	Somewhat	A lot like
like me.	me.	like me.	me.

1	I will tell other parents I know who have a child with an ASD about this research study.
2	If my spouse/partner sent me an email about another research study that was being done with parents like me, I would participate.
3	If I came across a flier for a research study that was recruiting parents like me, I would get in touch for more information.

⁴¹ Participant was presented with the following six questions only if they responded 'Yes.'

Appendix U

End of questionnaire

Survey Acknowledgement Text:

Congratulations! You have completed this questionnaire. Thank you for your participation!

In recognition of your time and effort, we have a few options available. You can receive a \$10 Amazon gift-card for use on www.amazon.com, which will be sent via mail, OR you can enter for a chance to win one of two iPod shuffles. We can also provide you with information (via email) regarding findings that result from this study.

In the next several weeks, we will send you an e-mail (sent by ogstonpl@vcu.edu) that will allow for you to indicate your preference for the options above. This information is being collected separately from the current questionnaire in order to ensure the anonymity of your responses.

You can contact this study's project coordinator, Paula Ogston-Nobile (ogstonpl@vcu.edu) if you have any questions.

Thanks again!

Appendix V

Survey Regarding Compensation Options

Thank you for participating in our research study!⁴²

You have been sent this survey because you recently participated in a research study conducted with parents who have a child with an autism spectrum disorder (www.parentsasd.com).

In recognition of your time and effort, we have a few options available. You can either:

- receive a \$10 Amazon gift card for use on www.amazon.com, which will be sent via mail OR - enter for a chance to win one of two iPod© shuffles.

We can also provide you with information (via e-mail) regarding findings that result from this study.

After accessing the current link, you have 24 hours to complete this survey.

Due to technology issues, please do NOT fill out this survey using a smartphone or tablet.

Are you interested in any of these options?

 \Box Yes⁴³ \Box No⁴⁴

Here's how this will work:

If you'd like to receive the \$10 Amazon gift card, you must provide a mailing address. You will be asked to provide an e-mail address so that we can confirm your address in the event that the gift card is returned to us. Within 30 days of submitting your gift card request, the gift card will be mailed to you. The gift card mailing will include a self-addressed stamped envelope and a 'Research Participant Form,' which you will be asked to mail back to this study's project coordinator. The form will ask for your name, address, and Social Security Number. In order to enter to win one of the 2 iPod[©] shuffles, you must provide a mailing address. You will be asked to provide an e-mail address so that we can confirm your address in the event that the iPod[©] shuffle is returned to us. If you are selected as one of the winners, the iPod[©] shuffle will be shipped to you via USPS priority mail.

We bear no responsibility for gift cards or iPod[©] shuffles that are lost during or after shipment. In order to receive information regarding study results, you must provide your e-mail address.

⁴² This survey was sent to all of those who completed or partially completed the questionnaire.

⁴³ Survey would only proceed past this point if participant selects 'Yes.'

⁴⁴ Survey would not advance past this point if participant selects 'No.'

Your contact information (e.g. mailing address, Social Security Number, e-mail address) will be kept confidential and will not be connected to any of the responses you previously provided during your participation in this research study.

Would you like to receive information regarding study findings? \Box Yes \Box No

Please choose from the following three options.

(You may select only one.)

 \Box I would like to receive the \$10 Amazon gift card.

□I would like to enter for the chance to win an iPod© shuffle.

□I do not want to receive the gift card or enter to win the iPod© shuffle.

What is your e-mail address?⁴⁵ Please confirm your e-mail address by typing it in again here.

What is your first name?⁴⁶ What is your last name? What is your street address? (Please provide complete your street address.) What city do you live in? What state do you live in? (dropdown) What is your zip code?

Thank you again for participating!⁴⁷

If you have any questions, you can contact this project's study coordinator, Paula Ogston-Nobile(ogstonpl@vcu.edu) or visit www.parentsasd.com.

⁴⁵ All responding participants were asked for their e-mail address.

⁴⁶ Only those who elected to receive the gift card or to enter in the drawing were asked for their contact information (e.g. name, address).

⁴⁷ Survey Acknowledgement Text (Displayed after survey is completed)

Appendix W

Process for Delivery of Incentives

Participants in this study were given the option of electing to

1. Receive information (via e-mail) regarding findings that result from this study and/or one of the following:

- \$10 gift-card that can be used on www.amazon.com
- A chance to win one of two iPod® shuffles.

Procedures for the delivery of the \$10 Amazon gift-card

Notes re: procedures for the distribution of \$10 Amazon Gift Cards.

The intention was to send the \$10 amazon gift card to those who had requested in within 30 days of submitting their request. For the first 69 participants who requested the gift card option, this procedure was adhered to. In October 2013, we sent out our first batch of gift cards to those who had completed the study and indicated that they wanted to receive the \$10 amazon gift card. We had received guidance and advice from designated staff both within the Department of Psychology and VCU's Office of Procurement and had developed our IRB approved gift card distribution procedures based on these communications. However, in December 2013 it was determined by representatives within the Office of the Dean, College of Humanities and Sciences that our procedures were not in compliance with VCU requirements for the distribution of gift cards. Specifically, we learned that it was mandatory for us to first send a copy of VCU's Research Participation Form (http://www.treasury.vcu.edu/w9.pdf) to those participants who had requested a \$10 gift card, and for this form to be returned to us prior to the distribution of the \$10 amazon gift card. Therefore, two sets of procedures will be described:

Gift Card Distribution: Batch 1

Within approximately 30 business days of submitting their request to receive the \$10 amazon.com gift card, the participant was mailed: a letter (Appendix Z), 1 gift card, 1 self-addressed stamped envelope, and Research Participation Form.

- These items were mailed in an envelope with Virginia Commonwealth University Department of Psychology as the return address
- Thank you for your participation in our research study with parents who have a child with and autism spectrum disorder.
- Per your request, we've sent you a \$10 Amazon gift card. In addition, we have included a Research Participation Form. Please fill out this form and mail it to us using the self-addressed stamped envelope that has been provided. We request that you mail it back within 5 days of receiving your gift card.
- There is no expiration date associated with this gift card.

• Thank you again for participating in this study!

Barbara J. Myers, PhD Geri Lotze, PhD Paula L. Ogston-Nobile

www.parentsasd.com

After learning that our procedures were not in compliance with VCU's requirements for the distribution of gift cards, it was demanded by the Office of the Dean, College of Humanities and Sciences that we contact those participants who had been sent the gift card but who had not returned the Research Participation Form. We sent these participants a REDCap survey that asked for confirmation of their receipt of the gift card as well as of their understanding of the Research Participation Form.

Gift Card Distribution: Batch 2

We experienced difficulty in obtaining a definitive response from representatives from the Office of the Dean, College of Humanities and Sciences regarding our procedures for distribution of our 2^{nd} batch of gift cards. Therefore, there was a delay in this process.

- In early March 2014, we mailed an explanatory letter (Appendix Z) and Research Participation Form to remaining participants who requested the \$10 Amazon Gift Card.
- After this signed Research Participation Form is received, the Department of Psychology's Service Center Director of Operations will mail the gift card to the participant(s).

Procedures for the delivery of information regarding study findings:

- 1. The data collected for the current study will contribute to the current author's doctoral dissertation.
- 2. Within 6 months of successfully defending her dissertation, the current author will prepare a summary of study findings that is no more than one page in length.
 - a. The summary will be posted on this study's website under: http://www.parentsasd.com/results-of-study.html
 - b. The summary will be sent via e-mail from the current author's e-mail address to those parents who requested that they receive information regarding findings that result from this study.
 - c. The e-mail will include the following message:
 - You are receiving this e-mail per your request for information regarding findings from a research study that was conducted in 2013 with parents who have a child with an autism spectrum disorder.
 - The summary will be embedded in the text of the e-mail.
 - You may also review the results of this study at:

http://www.parentsasd.com/results-of-study.html

Procedure for choosing the winner of and delivering the two iPod® shuffles

1. The winner of the two iPod® shuffles was chosen approximately 30 days after the compensation survey (Appendix V) was closed.

- a. Using Microsoft excel, the current author compiled a list of the e-mail addresses of participants who elected to enter to win one of two iPod® shuffles.
 - These e-mail addresses were compiled in a Microsoft excel spreadsheet, in Column A.
 - Using the "RAND()" function, a random value between 0.0 and 1.0 were generated in Column B, next to each e-mail address.
 - These values were copied and pasted using paste \rightarrow values into Column C.
 - Using the Data→ Sort feature, the data were sorted according to Column C, ascending.
 - The 2 e-mail addresses that were at the highest and lowest ranking value (i.e. top and bottom of the list) were chosen as the winners.
- b. Within 10 business days of choosing the winners of the iPod® shuffles, an e-mail was sent to the 2 winners.
 - i. This e-mail was sent from the current author's e-mail address and contained the following text:
 - 1. You are receiving this e-mail in relation to your recent participation in a research study with parents who have a child with an autism spectrum disorder. We are writing to notify you that you have been chosen as a winner of an iPod® shuffle.

In order to successfully deliver this iPod® shuffle to you, we ask that you verify:

- Your first and last name
- Mailing address⁴⁸

Please respond to this e-mail and verify your mailing address within 5 days of receiving this message.

• If you do not respond within 5 days, we will choose another winner and you will not receive the iPod® shuffle.

Once your mailing address is received, the iPod® shuffle will be sent in a padded box via USPS using delivery confirmation. We bear no responsibility for a package that is lost in shipment.

Thank you again for participating in this study!

Paula Ogston, MS Barbara Myers, PhD Geri Lotze, PhD

⁴⁸ The participant provided this information when filling out the request for compensation preferences, and will be included here.

Appendix X

Clarification of Confidentiality and Privacy - REDCap

REDCap has several options available for the administration of an online questionnaire, including use of a public survey link, which we did not utilize. Parents who were eligible to participate were invited via REDCap's 'Participant List and Email Survey Invitation.' Per REDCap's description, "The Participant List option allows you to send a customized email to anyone in your list and track who responds to your survey. It is also possible to identify an individual's survey answers, if desired, by providing an Identifier for each participant (this feature must first be enabled by clicking the 'Enable' button in the table below). Unless an Identifier is used, all survey responses collected are considered anonymous."

With the options that we utilized, the REDCap system only indicated IF the individual associated with each e-mail address responded; we were able to connect an individual's e-mail address to their data. We will not provide an identifier for each participant; therefore, survey responses are considered anonymous. Figure 15 and Figure 16 provide a visual clarification of the information that REDCap provides regarding participant responses. Figure 15 displays the information that is available regarding e-mail addresses to which an invitation to participate have been sent. Note that: the participant identifier option has been 'disabled;' that a link has been sent to that e-mail address; the green circular symbol with the white horizontal line indicates that the participant began but did not complete the survey.

This feature was utilized for several reasons. First, it allowed for us determine the percent of parents who were enrolled in the study that eventually started/completed the questionnaire. It was also essential for the purpose of sending the compensation/thank you survey to those who completed/started the questionnaire; this feature enabled us to query participants regarding their preference for the compensation options <u>without</u> connecting their questionnaire response to their contact information.

survey. It is also possible to identify an in	send a customized email to anyone in your li- ndividual's survey answers, if desired, by provi he 'Enable' button in the table below). Unless ore details	ding an Ide	entifier for ea	ach participan	
				(n	
Participant List				Remove all par	ticipants
	Add participants	ations		Exp	
Participant List Displaying 1 - 10 🔷 of 10 🔒 A Email	Add participants Compose Survey Invi Participant Identifier Enable	ations Link	Sent Msg?	S Exp	

Figure 15. Screenshot of REDCap Interface

Figure 16 provides the message that is given when the REDCap user clicks on the participant's 'responded?' box. For participants who have responded, the message reads "Response cannot be viewed: When clicking the 'Responded' icon, you may only view responses that have a Participant Identifier defined. Thus you will not be able to view this participant's response by clicking this icon. This is done in order to preserve this response as anonymous."

survey. It is also possible to identify	ou to send a customized email to anyone in your list and track who responds y an individual's survey answers, if desired, by providing an Identifier for each p king the 'Enable' button in the table below). Unless an Identifier is used, all sur- us. <u>More details</u>	articipan	nt (this
Participant List	Ren	move all par	rticipants
		land m	
Displaying 1 - 10 of 10	Add participants Compose Survey Invitations	34 Exp	ortlist
	Participant Identifier Enable Link Sent Msg? Res		
Email	Participant Identifier Enable Link Sent Msg? Res Response cannot be viewed:		
Email	Participant Identifier Enable Link Sent Msg? Res Response cannot be viewed: When clicking the 'Responded' icon, you may only view responses that have a Participant Identifier defined.	ponded?	
Email bmyers@vcu.edu Additional e-mail	Participant Identifier Enable Link Sent Msg? Res Response cannot be viewed: When clicking the 'Responded' icon, you may only view responses that have a Participant Identifier defined. Thus you will <u>not</u> be able to view this participant's response by clicking this icon. This is done in order to	ponded?	removi
Displaying 1 - 10 of 10 Email bmyers@vcu.edu Additional e-mail addressed 'blocked' out here.	Participant Identifier Enable Link Sent Msg? Res Response cannot be viewed: When clicking the 'Responded' icon, you may only view responses that have a Participant Identifier defined. Thus you will not be able to view this participant's	ponded?	remove remove

Figure 16. REDCap Interface - Message Regarding Participant Response

Appendix Y

Enrollment Procedures

Through various avenues (e.g. Interactive Autism Network, fliers that advertise the study, via Facebook) fathers and mothers who have a child with an ASD were directed to this study's website:

http://www.parentsasd.com/index.html49

- 2. Enrollment in the study required that parents filled out the screener (Appendix F)
 - a. Every time a parent filled out the screener, I received an e-mail notification via REDCap.
 - b. I checked my e-mail throughout the day during weekdays and at least once on most weekend days during the data collection period.
 - c. Within a week of submitting the screener, responses were transferred into a Microsoft excel spreadsheet that was formatted with formulas that automatically calculate whether each respondent met the study criteria.
 - d. If it was determined that the respondent met the study's criteria, I invited him or her to participate via REDCap's invitation tool.
 - i. Sender: ogstonpl@vcu.edu; Subject: Followup: Research Study with Parents who have a child on the Autism Spectrum):
 - ii. The following message was included in the body of the e-mail:

Thank you for your interest in our research study with parents who have a child on the autism spectrum. We would like to invite you to participate. Please click on the link below, which will take you to this study's online questionnaire. This link can only be accessed by one person, so please do not forward this e-mail to anyone else. Please note that once you click on this link, you have 24 hours to complete the survey. However, if you need more time than that you may choose to save your responses and return to the survey at any time.

Thank you,

Paula Ogston-Nobile (ogstonpl@vcu.edu) Barbara J. Myers, PhD (bmyers@vcu.edu)

⁴⁹ This page no longer contains a link to the screener.

Geri Lotze, PhD (lotzegm@vcu.edu) http://www.parentsasd.com/

e. If it was determined that the parent did not meet the study's criteria, I sent the following e-mail from my e-mail address (ogstonpl@vcu.edu; subject: Followup: Research Study with Parents who have a child on the Autism Spectrum):

Thank you for your interest in our research study with parents who have a child on the autism spectrum. In order to participate in this study, we have critera that must be met, which can be viewed here: http://www.parentsasd.com/who-can-participate.html Based on the information you provided, we are unable to invite you to participate. Please let me know if you have any questions.

Thanks again,

Paula Ogston-Nobile (ogstonpl@vcu.edu) Barbara J. Myers, PhD (bmyers@vcu.edu) Geri Lotze, PhD (lotzegm@vcu.edu) http://www.parentsasd.com/

- 3. A recruitment goal was to obtain valid data from n = 100 mothers and n = 100 fathers.
 - a. Participation for mothers was capped once approximately n = 100 complete records were submitted, which around October 20, 2013.
 - i. After this point, mothers who filled out the screener and fit the criteria were sent this e-mail:
 - 1. Thank you for your interest in our research study with parents who have a child on the autism spectrum. While you have met the criteria for participating in this study, we are currently only enrolling fathers. We have had a great response from mothers, and have finished our enrollment of mothers who have a child on the spectrum. We apologize for any inconvenience this might have caused.

Again, thank you again for your interest.

Paula Ogston-Nobile (ogstonpl@vcu.edu) Barbara J. Myers, PhD (bmyers@vcu.edu) Geri Lotze, PhD (lotzegm@vcu.edu) http://www.parentsasd.com/

- b. Upon completion of data collection, the link to the screener questionnaire was disabled and removed from the "How to Participate" section of this study's website and replaced with the following text:
 - i. Thank you for your interest in this study with fathers and mothers who have a child with an autism spectrum disorder. We are not currently recruiting participants. Please check back with this site in the future, as we

will be posting information regarding the results of this study with fathers and mothers who have a child on the autism spectrum.

- 4. Reminder e-mails were sent to those who had either enrolled and not responded or enrolled and only partially completed the questionnaire.
 - a. Reminder e-mail sent via REDCap to those who enrolled but did not respond/start the questionnaire:

Thank you again for your interest in our research study with parents who have a child on the autism spectrum. We would like to invite you to participate. Please click on the link below, which will take you to this study's online questionnaire. This link can only be accessed by one person, so please do not forward this e-mail to anyone else. Please note that once you click on this link, you have 24 hours to complete the survey. However, if you need more time than that you may choose to save your responses and return to the survey at any time.

Thank you,

Paula Ogston-Nobile (ogstonpl@vcu.edu) Barbara J. Myers, PhD (bmyers@vcu.edu) Geri Lotze, PhD (lotzegm@vcu.edu) http://www.parentsasd.com/

b. Reminder e-mail sent via REDCap to those who partially completed the questionnaire:

Hello,

You are receiving this message because you recently enrolled in a research study with parents who have a child on the autism spectrum (http://www.parentsasd.com/). Our records indicate that you began but did not complete the questionnaire associated with this study. An option was available for you to save your responses and complete the questionnaire at a later time. If you chose this option, a code would have been provided that will allow you to access and complete the questionnaire. However, due to the confidential nature of this data collection, we do not have access to this code and are unable to provide this code to you. Just as a reminder, your email address is not linked to any of the responses that you provide to this questionnaire.

Thank you for your participation in this study, and please let me know if you have any questions about how to complete this questionnaire.

Paula Ogston-Nobile (ogstonpl@vcu.edu) Barbara J. Myers, PhD (bmyers@vcu.edu) Geri Lotze, PhD (lotzegm@vcu.edu) <u>http://www.parentsasd.com/</u>

- 5. Change in enrollment procedures due to suspicious data and screener submissions
 - a. In mid-November, 2013 I noticed some unusual similarities among data I received from 5 records participants; the questionnaires were all submitted within a roughly 10 minute span, which was very unusual.
 - b. Further, I reviewed the data as it came in, and I noticed that the responses were very similar among these 5 respondents, with slight differences in the demographic items; all 5 left blank the 3 open-ended questions at the end of the survey, and all 5 declined to answer the optional questions at the end of the survey.
 - c. Soon after these responses were submitted, I received roughly 60 responses to my screener for enrollment.
 - i. I use a google app called 'Google Analytics' with my study's website, which allows me to see information about the demographics/location of those who access my site; in mid-November I had quite a few viewers from India and China access my webpage, but not prior to that.
 - ii. I assume that these viewers were among those who attempted to enroll, that they use multiple e-mail address for doing so, and that expected for the \$10 gift cards to be delivered electronically.
 - d. The day after these 5 records came in, I disabled my enrollment screener and put a message up on my webpage stating that interested parents to contact me directly if they wanted to participate.
 - i. I did not invited anyone to participate who filled out the screener after the suspected 'scamming' began.
 - ii. There was one additional record that came in that showed a similar trend to what I described above; I am confident that I have identified the respondents within my dataset whose data are suspected of being scammers (n = 6).
 - e. At the point that this issue arose, roughly 300 parents had filled out the initial screener to enroll in the study (not including the 60 mentioned above); about 171 parents had completed the survey (not including the invalid data).
 - f. Given the issued I experienced and the fact that I was fairly close to my recruitment goal, the decision was made to stop enrolling new participants.
 - i. Those who had already been invited to participate were still able to access the questionnaire.

Appendix Z

Letter(s) included in mailing for Gift Cards

Batch 1 Letter; printed on Department of Psychology letterhead.

Hello,

Thank you for your participation in our research study with parents who have a child with and autism spectrum disorder.

Per your request, we've sent you a \$10 Amazon gift card. In addition, we have included Virginia Commonwealth University's Research Participation Form. Please fill out this form and mail it to us using the self-addressed stamped envelope that has been provided. We request that you mail it back within 5 days of receiving your gift card. There is no expiration date associated with this gift card.

Thank you again for participating in this study!

Paula L. Ogston-Nobile, MS Barbara J. Myers, PhD Geri Lotze, PhD

www.parentsasd.com

Batch 2 Letter; printed on Department of Psychology letterhead.

Hello,

You have received these materials because you recently participated in a research study with parents who have a child on the autism spectrum (http://www.parentsasd.com/) and you requested the \$10 amazon gift card compensation option that was offered.

As mentioned at the time of your gift card request, participants who receive the \$10 Amazon gift card are asked to fill out a 'Research Participation Form,' which is enclosed. Virginia Commonwealth University policy requires that this form be filled out for all of our participants who receive the gift card. Your Social Security Number is appreciated but <u>not</u> required. Please <u>sign and return</u> this 'Research Participation Form,' using the enclosed self-addressed stamped envelope.

After we have received your signed 'Research Participation Form,' we will mail you the \$10 amazon gift card. Your gift card will not be sent until your 'Research Participation Form' is returned to us. We have adopted this procedure in order to comply with VCU requirements, and apologize for any inconvenience.

We ask that this signed form be returned **as soon as possible, but no later than Friday, April 4th**. Your contact information (e.g. name, mailing address, Social Security Number) will be kept confidential and will not be connected to any of the information you have previously provided. Please contact Paula Ogston-Nobile (804.396.4387; ogstonpl@vcu.edu) if you have any questions. Thanks again for participating in this study,

Paula L. Ogston-Nobile, MS Barbara J. Myers, PhD Geri Lotze, PhD Paula L. Ogston-Nobile was born in 1981 in Lansing, Michigan. She graduated in 1999 from Haslett High School in Haslett, Michigan. In 2004, Paula graduated with honors from Michigan State University in East Lansing, Michigan, where she received a Bachelor of Arts in Psychology and a Bachelor of Arts in Studio Art. Paula received her Masters of Science in Psychology from Virginia Commonwealth University in 2010. While at VCU, Paula completed the Virginia Leadership and Education in Neurodevelopmental Disabilities (VA-LEND) Program, in which she received advanced training for working with individuals who have a disability and their families. Paula's research and applied work has focused on children and families affected by the autism spectrum disorders, at-risk preschool age children, as well as program evaluation.