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# Associations Between Stress and Resourcefulness Among Parents of Children at Risk for Autism Spectrum Disorder and Developmental Delays

Meena Khowaja  
*Georgia State University*

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ASSOCIATIONS BETWEEN STRESS AND RESOURCEFULNESS AMONG PARENTS OF  
CHILDREN AT RISK FOR AUTISM SPECTRUM DISORDER AND DEVELOPMENTAL  
DELAYS

by

MEENA KHOWAJA

Under the Direction of Diana L. Robins, PhD & Erin C. Tully, PhD

ABSTRACT

Parents who are rearing a child with a developmental disability have higher stress than parents raising typically developing children. Protective factors, such as optimism and social support, are associated with psychological well-being among parents of children with and without disabilities. However, little is known about when this pattern of elevated stress among parents with developmental disabilities emerges; associations between parents' level of stress and resilience prior to their child's initial diagnostic evaluation has yet to be thoroughly researched. Resourcefulness refers both to internal processes to handle stress and external help-seeking behaviors that contribute to resilience. It is related to psychological adjustment in adults,

but it has never been examined among parents whose children demonstrate risk for developmental disability prior to a clinical evaluation. This study utilizes a strengths-based approach to investigate how parents' resourcefulness relates to child functioning and parent stress during the time leading up to an evaluation. The sample included 119 parents of toddlers at-risk for autism spectrum disorder and other developmental delays who were referred for diagnostic evaluation. Parents completed the Perceived Stress Scale (Cohen, Kamarch, & Mermelstein, 1983) and Resourcefulness Scale (Zauszniewski, Lai, & Tithiphontumrong, 2006). Diagnostic outcomes included autism spectrum disorder ( $n=37$ ), language disorder and other developmental delays ( $n=55$ ), and no diagnosis ( $n = 27$ ). Specifically, moderation analyses were conducted to examine whether resourcefulness moderates the relation between child functioning (i.e., adaptive behavior, autism symptom severity) and parents' stress, as well as to assess whether child's diagnostic outcome moderated the relation between parents' resourcefulness and stress. Results indicated a significant moderating effect of resourcefulness on the relation between children's autism symptom severity and parents' stress, such that among parents with low levels of resourcefulness, high severity of autism symptoms was associated with high stress. Clinical implications, including future screening to detect parents who might be at risk for elevated stress and poor mental health functioning following diagnosis of their child's developmental disability, are discussed, as well as considerations for parent-directed stress management interventions. Limitations regarding study methodology are also explored.

**INDEX WORDS:** Autism, Developmental delay, Parent, Stress, Resourcefulness

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MEENA KHOWAJA

A Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree of

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in the College of Arts and Sciences

Georgia State University

2017

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by

Meena Khowaja

Committee Chairs: Diana L. Robins

Erin C. Tully

Committee: Lauren B. Adamson

Wing Yi Chan

Electronic Version Approved:

Office of Graduate Studies

College of Arts and Sciences

Georgia State University

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## 1 INTRODUCTION

Research has consistently shown that compared to parents who are raising typically developing children, parents who rear a child with developmental disabilities have higher parenting stress (Baker, Blacher, Crnic, & Edelbrock, 2002; Emerson, 2003; Innocenti, Huh, Boyce, 1992; Roach, Orsmond, & Barratt, 1999). Several factors may contribute to parents' stress, such as impaired functioning level of the child or perhaps the diagnostic process itself; however, the emergence of elevated stress among parents of very young children with developmental disabilities has not yet been well studied. After receiving a diagnosis of developmental disability for their children, parents have to learn to navigate a very complex system of resources and services in order for their children to receive the necessary intervention. This can be a very challenging process that leads to frustration and disappointment for many reasons, such as limited availability of or difficulty accessing services, and contributes to heightened stress among parents. On the other hand, not everyone experiences life events in the same way, and some may possess strengths that allow them to more effectively adapt. Little is known about potential stress-buffering qualities in parents of very young children at-risk for developmental disabilities. It is important to recognize such qualities, as they can inform interventions to improve parent coping or modifications to early intervention services. The initial diagnostic evaluation is one of the first steps in child's long-term healthcare and an important opportunity to prepare and support parents for the journey ahead. There is a great need to identify ways in which to better support and reduce the stress of these families beginning with the evaluation process, in order to better facilitate the process of implementing early and effective intervention. Therefore, this study focused on the relatively unexplored time period leading up to a diagnostic evaluation for children exhibiting risk for developmental disability in

order to better understand the relation between between child functioning and parents' stress at this stage, as well as the potential buffering role of resourcefulness.

## **1.1 Stress among Parents of Children with Developmental Disabilities**

Although the stress of parenting is part of normative life experiences, it is well documented that raising children with developmental delays is associated with significantly elevated levels of stress among parents (Baker et al., 2002; Emerson, 2003; Innocenti et al., 1992; Roach et al., 1999). Research has identified a number of correlates that relate to parents' stress in this population.

### ***1.1.1 Child's Symptoms, Functioning, Behavioral Presentation***

Several studies have demonstrated the relation between the behavioral presentation of children with developmental disabilities and parents' stress. Specifically, some researchers have identified that clinical presentation specific to a particular disorder contributes to parents' stress; for example, greater severity of autism symptoms is associated with heightened maternal stress (Hastings, Daley, Burns, & Beck, 2006). More general challenges or impairments across a range of developmental disabilities, such as behavioral problems (e.g., hyperactivity, sleep issues, and other externalizing behaviors), difficulties with social relatedness, communication difficulties, and lower cognitive functioning, have been identified as factors associated with higher stress among parents raising children with developmental disabilities (Baker et al., 2002; Davis & Carter, 2008; Lecavalier, Leone, & Wiltz, 2006; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014; Norton & Drew, 1994; Tomanik, Harris, & Hawkins, 2004). Findings regarding the effects of adaptive functioning of children with developmental disabilities on parents' stress have been equivocal. Whereas some investigators did not find significant correlations between parents' stress and the child's adaptive behavior (Davis & Carter, 2008, Hastings et al., 2005;

Lecavalier et al., 2006), others demonstrated associations between adaptive functioning and parents' stress (Secco et al., 2006; Tomanik et al., 2004; Weiss, Sullivan, & Diamond, 2005).

The majority of these studies use samples that span a large age range, making it difficult to infer patterns early in the child's life. It will be important to examine whether child functioning is related to stress in parents of children exhibiting risk for developmental disability prior to the diagnostic evaluation. Moreover, having a greater understanding of these relations during this time can help inform how best to support parents during the evaluation process and following diagnosis.

### ***1.1.2 Receiving a Diagnosis***

Research on correlates of parents' stress and other aspects of functioning has identified differentiating factors pertaining to receiving a diagnosis, such as the type of diagnosis and age at diagnosis for their child with developmental disability. When children exhibit signs of abnormal development but are not diagnosed until later, parents may potentially experience more confusion or lack of clarity about their child's well-being (Lauchlan & Boyle, 2007). For example, qualitative analysis suggested that mothers of children with Fragile X reported more distressed emotional reactions due to uncertainty related to their child's developmental difficulties, less social support, and more frequent use of self-blame or depressive emotional coping strategies than mothers of children with Down syndrome (Poehlmann, Clements, Abbeduto, & Farsad, 2005). The authors attributed these differences to timing of diagnosis, with Down syndrome being diagnosed at birth and Fragile X between 2 to 16 years of age, suggesting that longer periods of concern and uncertainty may have negatively impacted mothers' stress level after learning of their child's diagnosis. It was also argued that the early diagnosis of Down syndrome may allow for social support to start at an earlier age; moreover, the increased body of

knowledge regarding etiology and prognosis, availability of professional support, and early intervention for families with Down syndrome may facilitate coping compared to families of children with Fragile X syndrome for whom such information, support, and services are more limited. Differences in symptom presentation or severity may also impact parent coping. Moreover, disorders like autism spectrum disorder (ASD), in which there are high levels of perceived societal stigma, mixed parent perceptions regarding the causes, and high levels of parent pessimism may also contribute to stress (Abbeduto et al., 2004; Fischbach, Harris, Ballan, Fischbach, & Link, 2016; Hebert & Koulouglioti, 2010; Milačić-Vidojević, Gligorović, & Dragojević, 2014). In contrast, it has been suggested that the common etiology-related personality traits of being cheerful and pleasant among children with Down syndrome may contribute to parents perceiving their children's language difficulties to be less severe (Smith, Romski, Sevcik, Adamson, & Barker, 2014).

Together, these findings suggest that the diagnosis of developmental disorders that are more often identified during childhood or have an unclear etiology may be more difficult for parents to cope with than those more commonly diagnosed at birth, and this requires further investigation (Glidden, Billings & Jobe, 2006). In the current study, children participating in an ongoing screening study are being evaluated for disorders that fall into the former category (e.g., ASD, developmental language disorders), indicating that their parents may be at risk for elevated stress and problems coping.

Research examining parents' experience of the evaluation process has noted a substantial amount of dissatisfaction (Crane, Chester, Goddard, Henry, & Hill, 2016; Goin-Kochel, Mackintosh, & Myers, 2006; Howlin & Moore, 1997). In addition, parents have been shown to have a mix of both positive and negative reactions about their child's diagnostic outcome. For



example, in a survey study, 90% of families were relieved to learn about their child's diagnosis of ASD, whereas 73% were also more worried about their child's future (Mansell & Morris, 2004). Based on open-ended comments about parents' initial reactions to diagnosis, some felt shocked, devastated, or upset, and others felt that their concerns had been confirmed. However, the generalizability of these views is limited, given the 50% response rate of parents and use of a convenience sample. It is likely that parents' reactions may depend on a variety of different factors, such as the reason for diagnostic referral and whether parents had initial concerns or were referred by a provider who had concerns. Although these and similar studies illustrate the reactions to the diagnostic experience, the majority of this area of research, including the described studies, relies on retrospective data that were collected long after diagnosis (often years later). This can be problematic in that it relies on the memories of parents.

To our knowledge, there is no published research investigating the stress level of parents leading up to a diagnostic evaluation for children at-risk for developmental delay. The evaluation is the first step in a child's continuous intervention and healthcare needs, and is a good time point to screen for psychosocial risk that may hinder parent and child functioning. In order to provide support that specifically benefits each family with a newly diagnosed child, it will be especially important to assess parent functioning around the time of the evaluation, rather than use retrospective data collection.

For very young children at-risk for developmental delays, parents' stress levels and initial concerns about their child's development may be more similar than different across developmental delay conditions. For example, in evaluating parenting-related stress in mothers of toddlers with typical development, developmental delays, and ASD, Estes and colleagues (2013) found that severity of behavior problems in the child was a significant predictor of

parenting-related stress and psychological distress. This was true for both mothers of children with ASD and other developmental delays. Herring et al. (2006) similarly found that more so than child's diagnosis, the emotional and behavioral problems related significantly to stress in mothers of children with varying developmental disabilities. Additionally, a common first concern parents have for children diagnosed with ASD, for example, is communication delays. However, concerns about language skills are common for many other developmental or intellectual disabilities in children. Specifically, Kozlowski and colleagues (2011) found that parents report communication concerns 74% of the time for children with ASD and 81% of the time for children with non-ASD developmental delays. Therefore, in investigating parents' stress at an early stage in the child's development it will be helpful to study all children who exhibit risk for delay, regardless of diagnostic outcome.

### ***1.1.3 Why Stress Matters***

High parental stress may be associated with parents' effectiveness in obtaining services for their child because it is also associated with other negative outcomes, including poorer physical and mental health of parents (Anastopoulos, Guevremont, Shelton, & DuPaul, 1992; Deater-Deckard, Dodge, Bates, & Pettit, 1998; Eisenhower, Baker, & Blacher, 2009; Hastings et al., 2006; Oelofsen & Richardson, 2006; Sawyer et al., 2010; Yirmiya & Shaked, 2005) and marital problems (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Suárez & Baker, 1997). Moreover, the stressors and challenges related to raising children with special needs are presumed to be related to negative child outcomes in a reciprocally escalating pattern. For example, high parental stress is associated with less effective parenting and more negative parenting styles (Coldwell, Pike, & Dunn, 2006; Crnic, Gaze, & Hoffman, 2005; Deater-Deckard, Scarr, McCartney, & Eisenberg, 1994), which may be related to a child's coping

competence and ability (Cappa, Begle, Conger, Dumas, & Conger, 2011). Parental stress has also been linked to high levels of child behavior problems (Baker et al., 2003; Davis & Neece, 2017; Donenberg & Baker, 1993; Johnston & Mash, 2001; Neece, Green, & Baker, 2012), separation anxiety (Deater-Deckard et al., 1994), attention problems (DuPaul, McGoey, Eckert, & VanBrakle, 2001), and depression (Anastopoulos et al., 1992). Finally, researchers have identified parental mental health problems (i.e., stress, depression) to be associated with an attenuated effect of early interventions on the intellectual, adaptive, behavioral, educational, and developmental functioning of children with ASD (Osborne, McHugh, Saunders, & Reed, 2008; Reyno & McGrath, 2006; Robbins, Dunlap, & Plienis, 1991). These findings describe the important relation between parent functioning and child outcomes and how parents' stress can be a risk factor for poor functioning (e.g., greater symptom severity, reduced adaptive skills) among children with developmental disabilities. It suggests that parents' stress may play an important role in the effectiveness of intervention and may be an integral component to implementing successful early intervention programs for children with developmental disabilities.

It is important to note that within the literature on stress among parents of children with developmental disabilities, there has been a recent focus on the unique experience of parenting children with ASD, perhaps resulting from empirical evidence suggesting particularly high levels of stress among caregivers of this population (e.g., Estes et al., 2013). Although not the case for all parents, difficulties navigating resources, experiences of grief, and increases in stress over time are potential outcomes for parents who learn that their child has been diagnosed with a significant developmental disorder, regardless of specific diagnosis. In other areas of research, the process of screening itself, although it has many benefits, has been found to be related to elevated stress. For example, newborn metabolic screening research has demonstrated elevated

parent stress and anxiety response following screen positive results (and awaiting follow-up), relative to parents of screen negative children; researchers have identified clear communication between providers and parents and shortening delays between screening and final diagnostic testing as potential methods to alleviate parents' stress (Gurian, Kinnamon, Henry, & Waisbren, 2006; Rueegg et al., 2016; Tluczek, Kosciak, Farrell, & Rock, 2005). For ASD, however, the period leading up to diagnostic evaluation is relatively unexplored. Assessing protective and risk factors for parenting stress prior to the evaluation may inform providers about how best to help parents cope and move forward with interventions, thereby affecting the outcome for parents and children (Wachtel & Carter, 2008). It is important to first understand stress levels in parents during this key developmental period, given the negative outcomes associated with higher levels of stress. As will be described further, the current study seeks to address this gap in the literature by assessing parent functioning (i.e., stress, resourcefulness) prior to the evaluation among parents whose children demonstrate risk for delay.

On one hand, although parents of children with special needs experience greater burden or stress and poor outcomes compared to parents of typically developing children, over time, many parents may gain resilience and better adjustment to challenges faced. Employing a strengths based model to better understand what factors relate to resilience in parents and families is important, as this can inform ways to best help families. Given what is known about the transactional relationship between parent and child outcomes (i.e., parent health is a large part of child well-being) in addition to the importance placed on early intervention for children with disabilities, it is also crucial to identify the strengths and skills that could best help parents early on.

## 1.2 Resilience and Resourcefulness

Resilience is defined as demonstrating good outcomes in spite of serious threats to adaptation or development (Masten, 2001). People have a remarkable ability to adapt and cope with adverse events across the life span (DiRago & Vaillant, 2007; Gralinski-Bakker, Hauser, Stott, Billings, & Allen, 2004; Hildon, Smith, Netuveli, & Blane, 2008). In addition to understanding elevated stress levels, it is even more important to understand what factors may promote resilience to overcome challenges, as this can better inform strategies to help people manage and cope with stressors.

Much research exists on various personal protective factors that prevent negative outcomes (e.g., significant increase in stress levels that can lead to poor mental health) and supply the resources or qualities that help set a positive trajectory for outcome, adaptation, and resilience. These include, for example, positive affect, self-efficacy, life satisfaction, optimism, social support, and self-esteem (for review see Lee et al., 2013). Learned resourcefulness (or personal resourcefulness) is another personal attribute that can promote resilience. It has been conceptualized as a repertoire of thoughts, behaviors, and a set of coping skills that have been acquired from one's life experiences that are used to respond to adverse events and manage daily life hassles independently (Rosenbaum, 1983; Rosenbaum, 1990; Zauszniewski, 1995). According to Rosenbaum (1980, 1990), there are three underlying dimensions to personal resourcefulness: redressive self-control (use of positive self-instructions for thought, mood, and pain control in order to resume normal functioning that has been disrupted), reformative self-control (problem-solving strategies and postponement of the need for instant gratification in order to adopt a new behavior), and belief in coping effectiveness (perceived self-efficacy or self-evaluation of the ability to attain a desired goal).

Personal resourcefulness is of particular interest in the proposed study as it allows people to better regulate their emotions, sensations, and cognitions in order to effectively carry out tasks. Higher levels of learned resourcefulness have been associated with higher levels of social self-efficacy (Bilgin & Akkapalu, 2007), less avoidant and more problem-solving and positive appraisal coping strategies (Akgün, 2004), higher maternal sense of competence and satisfaction (Ngai, Chan, & Ip, 2010), better management of academic stress (Akgün & Ciarrochi, 2003), fewer depressed cognitions and better quality of life (Huang, Sousa, Tu, & Hwang, 2005; Zauszniewski & Bekhet, 2011; Zauszniewski, Picot, Debanne, Roberts, & Wykle, 2002), and better adaptive functioning and more positive beliefs among depressed adults (Lai et al., 2014). Moreover, resourcefulness is learned through one's life experiences and can be improved through instruction or intervention.

In addition to the learned (or personal) resourcefulness, which emphasizes an individual's ability to be self-sufficient, a complementary concept is social resourcefulness, which accounts for one's ability and willingness to effectively seek help from other sources (formal or informal). Social resourcefulness, or help-seeking behavior, focuses on the interpersonal or external rather than the intrapersonal aspect of coping when managing stress (Nadler, 1990). When faced with stress, although individuals may utilize their internal resources to overcome a problem (i.e., personal or learned resourcefulness), they may alternatively seek assistance through external resources (i.e., social resourcefulness). As a construct, social resourcefulness has been correlated with measures of instrumental social support seeking as a problem-focused coping strategy, availability of social coping resources during times of stress, and social self-efficacy (i.e., confidence in ability to initiate social contact; McCarthy, Lambert, Bead, & Dematitis, 2002). Social resourcefulness is related to perceived social support and has been associated with

wellbeing in caregivers of individuals with dementia, as indicated by, for example, lower levels of depression, better quality of life, and self-report ratings of personal health (Rapp, Shumaker, Schmidt, Naughton, & Anderson, 1998). As such, social resourcefulness is an indicator of effective coping through the help of others.

Zauszniewski and colleagues (2006) sought to better understand resourcefulness by measuring it as a construct inclusive of both self-help and help-seeking strategies. They created the Resourcefulness Scale that consists of two subscales for both personal and social resourcefulness. It has been argued that both personal and social resourcefulness should be measured in conjunction as complementary constructs, given that together they contribute to better daily functioning outcomes than either construct alone (Zauszniewski, 1996). Although resourcefulness is a construct that seems to be a foundation for adaptive outcomes or adequate coping in response to stressors, it has not been well-studied among parents of children with developmental disabilities. Only Bekhet and her colleagues have investigated the role of the Resourcefulness Scale among caregivers of individuals with developmental disabilities (specifically, ASD). They found that higher levels of resourcefulness among caregivers is associated with positive thinking skills, psychological/general wellbeing, lower levels of burden, and fewer symptoms of depression (Bekhet, Johnson, & Zauszniewski, 2012; Bekhet & Zauszniewski, 2013; Bekhet & Zauszniewski, 2014). Notably, the age range of individuals with ASD across these samples was variable and extended into adulthood; they were also assessed up to 19 years after a diagnosis was received.

To date, resourcefulness in parents has not yet been researched at the time of the child's initial diagnosis of developmental disability. It is therefore unconfirmed that it serves as a buffer to the potential stress response during this early phase. Resourcefulness is a variable of particular

interest among caregivers of children with developmental disabilities, as it is an all-encompassing concept incorporating the efficiency of seeking the necessary help, strength, and motivation within the self and through others, which could potentially benefit parents during the post-diagnosis process and promote better outcomes. If shown to be a significant contributing factor, it is, although a relatively stable or learned construct, a teachable skill set (e.g., Ronen & Rosenbaum, 2010) that can be targeted as an aspect of early intervention.

In order to identify the best steps to support parents after diagnosis and achieve optimal outcomes for both children and parents, we must also further explore and understand parents' experience around the time of the initial evaluation and the early impacts of raising children demonstrating risk for developmental delays at this early stage. That is, it is known that disproportionately higher stress levels among parents of individuals with versus without delays persist across various developmental stages (e.g., preschool, adolescence, etc.), and that families benefit from stress-reduction intervention. It is not known, however, if parents of young children exhibiting risk for developmental disability experience elevated stress prior to the initial diagnostic evaluation. There is also a clear gap in the literature on whether higher resourcefulness is related to positive outcomes in this particular population of parents by serving as a buffer against the link between children's symptoms and heightened parent stress. If these research and clinical questions can be answered, they can help inform effective early intervention practice and support for parents.

### **1.3 Current Study**

Parents of children with a developmental disability tend to have higher parenting stress than parents of typically developing children (Baker et al., 2002; Emerson, 2003; Innocenti et al., 1992; Roach et al., 1999); however, prior research has not addressed the question of whether



these parents experience elevated stress early on, prior to learning of their child's diagnostic outcomes. High levels of child developmental and behavioral problems are associated with poor parental well-being (Baker et al., 2002; Davis & Carter, 2008; Lecavalier et al., 2006; McStay et al., 2014; Norton & Drew, 1994; Tomanik et al., 2004). In turn, poor mental health (e.g., stress, depression, etc.) in parents is associated with negative outcomes in children and can impact implementation of early intervention (Baker et al., 2003; Davis & Neece, 2017; Donenberg & Baker, 1993; Johnston & Mash, 2001; Neece et al., 2012; Osborne et al., 2008). Although protective factors (e.g., social support, appropriate coping skills) among parents of children with developmental disabilities have been found to be correlated with more positive parent functioning (e.g., subjective well-being; Glidden et al., 2006), parents' stress and resilience leading up to the child's assessment for developmental delay have yet to be studied. The diagnostic evaluation is an important point of contact regarding the child's healthcare in that it provides an opportunity to assess parents' need for support and to respond accordingly.

In evaluating parents' stress level early in the child's life, when he or she is first demonstrating risk for developmental difficulties (Barbaro & Dissanayake, 2009; Shattuck et al., 2009), it is important to also understand parents' effective skills and resources that can be utilized to manage challenges with raising a child with developmental disabilities.

Resourcefulness relates to good adjustment in terms of problem-solving skills, positive cognitions, adaptive functioning, and life satisfaction, and it has been shown to have a negative relation with poor mental health (e.g., depression; Huang et al., 2005; Zauszniewski et al., 2002). However, resourcefulness has never been examined in parents prior to receiving a diagnosis of developmental disability for their child. It is a construct of particular interest for this population, given its focus on one's utilization of adaptive skills (e.g., positive cognitions, support-seeking)

to promote resilience. Before conducting intervention studies that aim to increase the resourcefulness of parents receiving their child's first diagnosis, it is essential to better understand the construct within such a sample.

This study assessed parents' stress and resourcefulness via self-report measures prior to a diagnostic evaluation for their child who is at risk for developmental delay. Participants were recruited from a larger ASD screening study, in which they screened positive on a parent questionnaire and subsequently completed a diagnostic evaluation. A significant portion of the child participants are diagnosed with ASD as well as developmental delays other than ASD. Analyses included the entire sample of at-risk toddlers regardless of final diagnostic outcome, given that different developmental disabilities often share similar first concerns and symptoms during this young age range (e.g., delayed speech as a symptom of language disorder, global developmental delay, or autism spectrum disorder). Moreover, the variety of behavioral challenges in children that correlate with parents' stress are present across different developmental disabilities (Baker et al., 2002; Lecavalier et al., 2006; McStay et al., 2014).

More specifically, in addition to exploring basic sample characteristics and correlations regarding parent and child factors, this study sought to understand whether parents' resourcefulness buffers the relation between poor child functioning and parents' stress in the early phase between screening and diagnostic evaluation. Given the equivocal findings regarding the relation between child adaptive functioning and parents' stress, there is a need to expand on this literature in order to better understand this dynamic, particularly at this young age and phase of development. Therefore, child adaptive functioning was a variable of particular interest. Moreover, because the sample was recruited based on demonstrating risk on an ASD screening measure, ASD symptom severity was another important predictor variable in the analyses.

Lastly, given the lack of research regarding these parent constructs in this population and time frame, this project explored the relation between these parent factors while also evaluating interacting effects of child's diagnosis; this is consistent with the developmental disabilities literature, which tends to compare findings by diagnostic groups.

The specific hypotheses are outlined below and illustrated in Figure 1:

- Hypothesis 1: It was predicted that lower adaptive functioning skills (Vineland-II composite score) in the toddler would be associated with higher parent stress (Perceived Stress Scale), but the relation between these variables would be moderated by level of parents' resourcefulness (Resourcefulness Scale). Specifically, when parents' resourcefulness was high, the relation between child adaptive functioning at the time of the evaluation and parents' stress after screening but before the evaluation was expected to be weaker.
- Hypothesis 2: It was predicted that child's greater ASD symptom severity (Autism Diagnostic Observation Scale, First and Second Editions; ADOS(-2)) would be associated with higher parent stress, but the relation between these variables would be moderated by level of parents' resourcefulness. Specifically, when parents' resourcefulness was high, the relation between ASD symptom severity and parents' stress was expected to be weaker.
- Hypothesis 3: It was predicted that higher self-reported resourcefulness would be associated with lower stress in parents, but this relation would be moderated by child's diagnosis. Specifically, for parents of children who received a diagnosis of some type of developmental delay, the relation between parents' resourcefulness and stress was

expected to be stronger relative to parents of children who did not receive any diagnosis at the evaluation.

- Exploratory Analyses: The three main hypotheses utilize the total scores for the predictor variables from the Resourcefulness Scale and ADOS(-2). Although these total scores are robust measures of parent and child functioning, it is important to additionally examine the roles of their underlying constructs to detect possible differentiating factors contributing to participant functioning (Hus, Gotham, & Lord, 2014; Zausniewski, 1996). Therefore, for exploratory purposes, the hypotheses were also tested examining the specific subscales of the Resourcefulness Scale (Personal and Social Resourcefulness scale scores) in all three hypotheses and ADOS(-2) (Social Affect and RRB domain severity scores) in the second hypothesis. For the third hypothesis, the moderating effect of diagnosis was reevaluated with different diagnostic groupings: 1) ASD vs. children with other developmental delays or no diagnosis, 2) ASD vs. children without any diagnosis, and 3) ASD vs. other delays vs. no diagnosis.

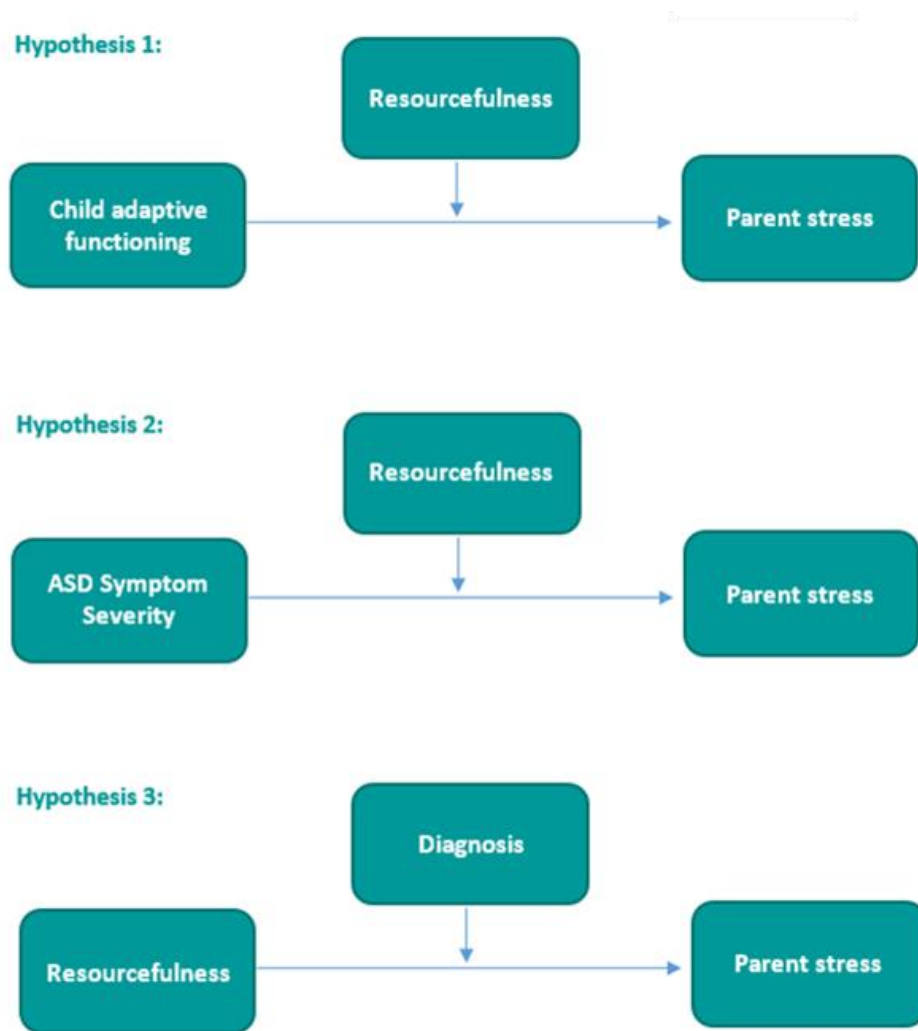


Figure 1.1. Moderation models for three primary hypotheses

## 2 METHOD

### 2.1 Participants

Participants were a subset of participants from an ongoing research study in the metro-Atlanta and metro-Philadelphia area investigating the early detection of autism and other developmental disabilities. In the larger study, parents completed an ASD screening measure (Modified Checklist for Autism in Toddlers, Revised with Follow-Up; Robins, Fein, & Barton, 2009), and children who exhibited at-risk scores were invited for a free diagnostic evaluation. Families in the larger sample were eligible for the current study if (1) the child had not been previously diagnosed with a DSM-5 developmental disorder, and (2) the toddlers were 36 months or younger at the time of the initial evaluation. Extreme outliers were removed, which included 5 children who were older than the remaining sample. A total of 119 children screened positive on an ASD-specific parent report questionnaire, completed a subsequent diagnostic evaluation, and were included in this study.

Diagnostic outcome was categorized into three groups: ASD ( $n=37$ ; autism spectrum disorder diagnosis), LD/DD ( $n=55$ ; language disorder or global developmental delay diagnoses), and TD/ND ( $n = 27$ ; typical development or no diagnosis). Autism spectrum disorder, language disorder ( $n = 20$ ; receptive and/or expressive delays), and global developmental delay diagnoses were based on DSM-5 diagnostic criteria. Specifically, global developmental delay included performance at least one and a half standard deviations below average on verbal and nonverbal domains of functioning. “Typical development” ( $n = 14$ ) refers to children who did not exhibit performance significantly below the average range on any cognitive, language, or motor domains, and did not meet criteria for any other DSM-5 disorder. “No diagnosis” ( $n = 13$ ) includes children who scored out of the average range on one or more domains, but were

subthreshold from meeting criteria for any DSM-5 diagnosis; this included children with subclinical symptoms of ASD (or Broader Autism Phenotype,  $n=4$ ) or of other developmental disorder ( $n = 10$ ).

## 2.2 Measures

### 2.2.1 *Perceived Stress Scale*

The Perceived Stress Scale (PSS; Cohen, Kamarch, & Mermelstein, 1983) is the most widely used self-report measure of one's perceived stress. It indicates the degree to which an individual appraises her life as stressful by assessing how unpredictable, uncontrollable, and overloaded one experiences life to be. Research utilizing the PSS has found that perceived stress is associated with other negative outcomes, such as anxiety and depression, which is consistent with literature on stress; it has also been used to evaluate efficacy of stress-reduction interventions (e.g., Lane, Seskevich, & Pieper, 2007).

The original PSS consists of 14 items; however, in a study comparing its performance to 10-item and 4-item alternative versions, although all version were shown to be valid and reliable, the 10-item version was recommended for use in future research given its relatively stronger psychometric properties (Cohen & Williamson, 1988). Responses are made on a 5-point Likert scale, ranging from 0 to 4 (i.e., 0 = never, 1 = almost never, 2, = sometimes, 3 = fairly often, 4 = very often), to measure an individual's frequency of experiencing each item in the past month. Six items are negatively worded (e.g., "How often have you found that you could not cope with all the things that you had to do?"), and four items are positively worded (e.g., "How often have you felt that you were on top of things?"). The PSS is scored by reversing scores for the positively worded items and then calculating a summative total score across all items (ranging 0 to 40); higher scores indicate higher stress. The dependent variable in all three primary analyses

used the 10-item total score. Although this measure does not have clinical cut-off scores, population-based means and standard deviations have been published using the 10-item PSS, which have been used for comparative purposes (Cohen & Janicki-Deverts, 2012).

Evaluation of the psychometric properties of the PSS raw total score has yielded adequate internal reliability with alpha coefficients ranging from .78 to .85 (Cohen & Williamson, 1988; Kupper, van den Broek, Widdershoven, & Denollet, 2013; Ezzati et al., 2014; Smith, Rosenberg, Haight, 2014) among adults and older adults. To demonstrate construct validity, Cohen & Williamson (1988) identified moderate correlations between the PSS and stress frequency within the past week ( $r = .39, p < .0001$ ) and the number of significant life events experienced ( $r = .32, p < .0001$ ). It was also strongly correlated with a measure of stress arousal (i.e., cognitive-affective experiences of worry and rumination) in young adults ( $r = .68, p < .001$ ; Smith et al., 2014). The PSS has also demonstrated divergent validity in comparison to measure of workload demand ( $r = .03, n.s.$ ; Cohen, 1988), and to a bodily pain measure, which showed a weak, albeit significant, relation ( $r = .18, p < .001$ ; Ezzati et al., 2014). Cohen et al. (1983) posited that perceived stress should be sensitive to daily life stressors and other changes, and thereby it should not have a strong test-retest reliability. The PSS has demonstrated test-retest reliability of .86 after seven days, .77 after two weeks, and .53 to .61 after one year (Golden-Kreutz, Browne, Frierson, & Anderson, 2004; Reis, Hino, & Añez, 2010; Remor, 2006). Results from the 14-item PSS mapped on very similarly to the 10-item version, with coefficients of .85 after two days and .73 after two weeks. Also, as a comparison, the 14-item version has demonstrated the same decline at only a six-week interval with a coefficient of .55 (Cohen et al., 1983). Given this drop in predictive ability after a few weeks, it is thought to be a helpful measure that can capture the fluctuations in stress based on recent events.



### ***2.2.2 Resourcefulness Scale***

The Resourcefulness Scale (RS; Zauszniewski et al., 2006) is a self-report questionnaire that assesses the tendency to utilize both personal (self-help) and social (help-seeking) resourcefulness when faced with adversity. It has been argued that both internal and external coping skills are equally important to measure (Zauszniewski, 1996), and the RS is the only measure that broadly captures both constructs into one single measure. Therefore, the RS allows for a complete measure of parents' resourcefulness in terms of overall skills and behaviors as well as the effects of individual constructs. It consists of 28 items on a 6-point Likert scale, with 0 indicating "not at all like me" and 5 indicating "very much like me." Sixteen items yield a Personal Resourcefulness scale score (0 to 80), and the remaining 12 produce a Social Resourcefulness scale score (0 to 60). Total scores range from 0 to 140, with higher scores indicating higher levels of resourcefulness. This measure does not have clinical cut-off scores. Given that resourcefulness has not been well studied in this population, this study used the total score as an overall measure of resourcefulness in the primary analyses, but the two scale scores were used in the exploratory analyses in order to detect potential specific underlying differences.

The RS was developed by combining the Help-Seeking Resource Scale (HSRS; Zauszniewski, 1998) and a subset of items from the Self-Control Scale (SCS; Rosenbaum, 1980) for the social and Personal Resourcefulness scales, respectively. The HSRS (used to create Social Resourcefulness scale) captures help-seeking behaviors from both formal (i.e., professional), and informal (i.e., family, friends) sources. The items in the SCS (used to create Personal Resourcefulness scale) measure concepts of redressive self-control (using positive thoughts or mood to resume normal functioning), reformative self-control (modifying methods of functioning to adopt a new approach), and perceived self-efficacy (belief in one's ability to reach

a goal). It has been associated with locus of control, ways of coping with stress, higher self-esteem, and increased ego strength (Rosenbaum, 1990). The correlation between personal resourcefulness with the 36-item SCS was shown to be .85 ( $p < .001$ ). Cronbach alphas for internal consistency were .83 to .92 for total score, .85 for Social Resourcefulness scale, and .79 for personal resourcefulness (Bekhet et al., 2012; Zauszniewski et al., 2006). Construct validity was demonstrated by confirmatory factor analysis, which indicated that each scale loaded on separate factors. Personal and social resourcefulness are theoretically related concepts, and this was supported through correlational analysis of the two scales ( $r = .41, p < .001$ ). However, the scale evaluates diverse aspects of personal and social resourcefulness, given its average inter-item correlation of .18, indicating that personal and social resourcefulness are associated, complementary, and both are important for the measurement of resourcefulness. The RS has been studied among the elderly, caregivers of children with ASD, and grandmothers caring for children.

### ***2.2.3 Vineland Adaptive Behavior Scales, Second Edition***

The Vineland Adaptive Behaviors Scales, Second Edition (Vineland-II; Sparrow, Cicchetti, & Balla, 2005) is a widely used parent interview scale that assesses four domains of adaptive functioning (Communication, Daily Living Skills, Socialization, and Motor Skills); these domain scores are combined to derive a composite score of overall adaptive behavior, which was used for analyses in the present study. Psychometric properties across domains included: split-half reliability correlations ranging from .77 to .93, test-retest reliability ranging from .76 to .92, inter-rater reliability ranging from .71 to .81, convergent validity of .70 with Adaptive Behavior Assessment System, Second Edition (Harrison & Oakland, 2003), and strong discriminant validity against measures of IQ.

#### ***2.2.4 Autism Diagnostic Observation Schedule, First and Second Editions***

The Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000) and its second edition (ADOS-2; Lord et al., 2012a, 2012b) involve a play session with the child using one of five modules based on the child's current developmental and expressive language level. It assesses current behavior in the social communication and the restricted and repetitive behaviors domains, and is part of the "gold standard" assessment of ASD. The ADOS modules are selected based on age and verbal ability. For each module, the scoring algorithm generates Social Interaction, Communication, Social Interaction + Communication, Restricted and Repetitive Behaviors (RRB), and Total scores. Published data indicate strong inter-rater reliability for domain scores (.82-.93; Lord et al., 2000), as well as strong sensitivity (.90-.97) and specificity (.87-.94) for detecting a child on the autism spectrum. The ADOS-2 yields algorithm scores for Social Affect (i.e., Communication + Reciprocal Social Interaction), RRB, and Total. Psychometric properties of ADOS-2 include: high internal consistency for Social Affect (.87-.92) and moderate internal inconsistency for RRB (.50-.66), test-retest reliability ranging from .68 to .92, inter-rater reliability ranging from .79 to .98, sensitivity ranging from .60 to .95 for detecting ASD, and specificity of .75 to .100 (McCrimmon & Rostad, 2014). In this study, 4 participants completed the first edition ADOS, whereas the remaining 115 were administered the second edition.

In efforts to create a standardized severity score that could be interpreted across modules and editions, calibrated severity scores were developed. These scores were derived from the ADOS-2 algorithm, but they can retrospectively be applied to the ADOS algorithm, given that they rely on specific items that are common across both versions. In the current study, calibrated severity scores were computed based on published score conversion tables (Gotham, Pickles, &

Lord, 2009; Gotham, Risi, Pickles, & Lord, 2007; Hus et al., 2014) for the total score, as well as for each domain – Social Affect and RRB. The primary analysis in Hypothesis 2 utilized the total calibrated severity score as a measure of overall symptom severity, whereas exploratory analyses investigated the effects of each domain.

### ***2.2.5 Sociodemographic Variables***

Maternal educational attainment was measured by forced choice response: no high school diploma (with highest grade completed noted), GED, high school diploma, vocation or technical degree (e.g., beauty/barber school), associate degree (completed 2 years of college, bachelor's degree (completed 4 years of college), master's degree, and doctoral degree (PhD/MD/JD). Annual income was completed via forced choice responses, which were collapsed into the following categories: \$10,000 or less, \$10,001 to \$50,000, \$50,001 to \$96,000, over \$96,000. Occupation was measured by employment status: unemployed, employed full-time, and employed part-time. Racial/ethnic background data were collected utilizing government census categories for race: White, Black or African American, American Indian and Alaska native, Asian, native Hawaiian and other Pacific Islander, other, bi/multiracial. In addition, membership in one's ethnic categories (i.e., Hispanic or Latino, not Hispanic or Latino) was specified. Based on the variance in the distribution of this variable, data was further collapsed into groups. Sociodemographic variables were correlated with outcome variable to determine inclusion as covariates.

## **2.3 Procedures**

Parents provided informed consent and completed an electronic version of an autism-specific screening questionnaire during pediatric well-child pediatric visits for the larger study. Those who demonstrated risk on the scored measure were contacted by research staff who

explained that the results indicated that their child may be at risk for developmental delay; families were told that the screening measure itself is not confirmation of a diagnosis, and that we recommended that the child receive a free diagnostic evaluation. The evaluation consisted of cognitive testing, parent interview of adaptive functioning, and autism-specific play observation and parent interview measures. Testing was completed by a licensed psychologist and a graduate student clinician. Based on the results from assessment measures, clinical judgment, and DSM-5 diagnostic criteria, the clinicians classified children in one of the following non-overlapping groups: autism spectrum disorder, language disorder, global developmental delay, typical development, or no diagnosis. The sample in this study included children who screened positive on the questionnaire and completed a diagnostic evaluation as well as the child's primary caregiver.

As part of the procedures in the larger study, a packet of background questionnaires assessing early child development and sociodemographic variables, as well as a measure of children's behavioral, emotional, and social functioning were mailed to parents 1 to 2 weeks prior to the evaluation. For the current study, the Resourcefulness Scale and Perceived Stress Scale were included in the packet. Parents were asked to complete all questionnaires before arriving and bring them to the evaluation.

#### **2.4 Data Analysis**

All data (e.g., background history questionnaire, stress and resourcefulness measures, evaluation outcome measures, etc.) were entered and stored in an electronic database. All relevant data were imported into a database using IBM SPSS Statistics V22.0 software with identifying information removed. All analyses were completed via SPSS, with an alpha level of .05.

### ***2.4.1 Power Analysis***

G-Power, V3.1 software was used to conduct power analysis. Effect sizes were calculated for each hypothesis in a preliminary subsample of data ( $n = 102$ ). Corresponding effect sizes (Cohen's  $f^2$ ) for Hypotheses 1, 2, and 3 were computed to be .166, .170, and .136, respectively. A sample of 117 participants were required for sufficient power ( $1 - \beta = .95$ ) at  $\alpha = .05$  to detect the expected effect for Hypothesis 3, whereas Hypothesis 1 and 2 required 97 and 94 participants, respectively.

### ***2.4.2 Preliminary Analysis***

Descriptive statistics were computed for all variables. Correlational analyses were conducted across primary child and parent functioning variables. Additionally, statistical analyses were conducted across main test variables and other sociodemographic variables to identify potential covariates for major analyses, including annual household income (categorical), research site (categorical; Atlanta vs. Philadelphia), and for the participating parent, educational attainment (categorical), employment status (categorical), and race/ethnicity (categorical). Tests included Pearson correlation,  $t$ -test, ANOVA, and Chi-square analyses, or their nonparametric counterparts, depending on level of measurement for each variable.

### ***2.4.3 Test of Hypotheses***

A series of moderation analyses were conducted using hierarchical multiple linear regression analysis with tests of simple slopes following significant interaction effects. Continuous predictor variables were sample mean centered and categorical variables were dummy coded prior to computing interaction terms. The following statistical analyses were conducted to test hypotheses for the proposed project.

- Hypothesis 1: Multiple linear regression analysis was used to assess if parents' resourcefulness (RS) moderates the relation between child's adaptive functioning (Vineland-II; predictor variable) and parents' stress (PSS; outcome variable).
- Hypothesis 2: Multiple linear regression analysis was used to assess if parents' resourcefulness (RS) moderates the relation between child's autism symptom severity (ADOS(-2); predictor variable) and parents' stress (PSS; outcome variable).
- Hypothesis 3: Multiple linear regression analysis was conducted to examine whether a child receiving any diagnosis vs. no diagnosis moderates the relation between parents' resourcefulness (RS; predictor variable) and stress (PSS; outcome variable).
- \*Exploratory Analyses: The main hypotheses were separately reanalyzed with the subscales of the Resourcefulness Scale (Personal and Social Resourcefulness) instead of the total score for all three hypotheses, and the scale severity scores of the ADOS(-2) (Social Affect and RRB) instead of the total severity score in Hypothesis 2. For Hypothesis 3, exploratory analyses were also conducted to examine the effect of different groupings of diagnostic outcome as the moderating variable.

### 3 RESULTS

For each analysis, test of statistical assumptions were checked. To assess multivariate normality, Kolmogorov-Smirnov and Shapiro-Wilk tests were examined, but given that these tests are conservative, they were interpreted in the context of skewness and kurtosis z-scores





*Note.* \*indicates statistical significance at  $\alpha = .05$ , \*\*indicates statistical significance at  $\alpha = .01$

Autocorrelations were evaluated via Durbin-Watson statistic (critical values of  $1.5 < d < 2.5$  indicates no auto-correlation). All three hypotheses met assumptions for no autocorrelation in the analyses. Regarding the assumption of homoscedasticity, standardized residuals were plotted against the predicted Y values to examine whether points were equally distributed across all values of the predictor variables for each hypothesis. Hypothesis 1 and 3 met assumptions for homoscedasticity; visual inspection of plots from Hypothesis 2 variables demonstrated a potential pattern (i.e., funnel shape) of increasing variance across residuals. However, a Glejser test for heteroscedasticity was performed and indicated no significant heteroscedasticity.

### 3.1 Sample Characteristics and Preliminary Analyses

Chi-square analyses revealed no significant differences in child race/ethnicity, educational attainment, or child sex across the three diagnostic groups,  $ps > .05$ .<sup>1</sup> One-way ANOVA indicated no significant differences in child age by diagnostic outcome<sup>2</sup> but identified differences in child ability and functioning level (i.e., cognitive, adaptive behavior, ASD symptom severity) across diagnostic groups,  $ps < .05$  (see Table 3.2). Sidak-Bonferroni post hoc tests specified significantly higher cognitive ( $\eta^2 = .446$ ) and adaptive functioning ( $\eta^2 = .357$ ) for the TD/ND group than both the ASD and LD/DD groups,  $ps < .001$ . One-way ANOVA was used to compare ADOS(-2) severity scores (Total, Social Affect domain, RRB domain) across diagnostic outcome groups; the analysis examining difference in RRB was completed with adjusted *F* statistic (Welch test) and Games-Howell post hoc tests, due to violation in equal

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<sup>1</sup> With diagnostic groups collapsed into two groups (i.e., ASD vs all other children), a significant difference was found in proportion of boys and girls across diagnostic groups, as would be expected given higher rates of ASD in boys. That is, 86.5% of participants with ASD were male compared to only 67.1% being male among the non-ASD participants ( $\chi^2(1) = 4.89, p = .027$ ).

<sup>2</sup> Independent samples *t*-test with collapsed diagnostic groups indicated children with ASD ( $M=22.21, SD=3.85$ ) to be older at time of evaluation compared to non-ASD children ( $M=20.56, SD=4.14; t(117) = -2.06, p = .042$ )."

variance assumption. As expected, ADOS(-2) Total ( $\eta^2 = .596$ ), Social Affect ( $\eta^2 = .565$ ), and RRB ( $\eta^2 = .337$ ) severity scores were significantly higher for the ASD group relative to the LD/DD and TD/ND groups,  $ps < .001$ . ADOS(-2) Social Affect was also higher for the LD/DD group compared to the TD/ND group ( $p = .040$ ).

Table 3.2 *Sample Demographics of Children*

	Total (N = 119)		ASD (n=37)		LD/DD (n=55)		TD/ND (n = 27)	
	N	%	n	%	n	%	n	%
<b>Child Sex</b>								
Female	32	26.9	5	13.5	17	30.9	10	37.0
Male	87	73.1	32	86.5	38	69.1	17	63.0
<b>Child Race/Ethnicity</b>								
Black, not Hispanic	47	39.5	14	37.8	26	47.3	7	25.9
White, not Hispanic	42	35.3	11	29.7	17	30.9	14	51.9
Hispanic	13	10.9	4	10.8	8	14.5	1	3.7
Multiracial/Other	17	14.3	8	21.6	4	7.3	5	18.5
	M	SD	M	SD	M	SD	M	SD
Child Age at Screen (mo.)	19.0	3.4	19.9	3.2	18.9	2.9	18.1	4.2
Child Age at Evaluation (mo.)	21.0	4.0	21.9	3.6	20.7	3.7	20.3	5.0
Screen-to-Evaluation Time (mo.)	2.0	1.8	2.0	1.9	1.8	1.6	2.2	2.1
ADOS(-2) Total <sup>a,b</sup>	4.4	3.0	7.8	1.9	3.2	2.0	2.3	1.7
ADOS(-2) Social Affect <sup>a,b,c</sup>	4.7	3.0	8.0	1.8	3.6	2.2	2.5	1.7
ADOS(-2) RRB <sup>a,b</sup>	4.2	2.8	6.6	2.2	3.3	3.5	2.8	2.1
Mullen Composite <sup>a,b</sup>	69.4	17.0	61.1	14.7	64.8	10.3	88.5	15.8
Vineland-II Composite <sup>a,b</sup>	84.8	13.0	78.4	11.8	82.2	10.7	97.9	9.4

*Note.* ADOS(-2): Autism Diagnostic Observation Schedule, First and Second Editions (calibrated severity scores; possible range 1-10) with Total severity score and Social Affect and RRB domain severity scores; Mullen Composite: Mullen Scales of Early Learning, Early Learning Composite (standard score); Vineland-II Composite: Vineland Adaptive Behavior Scales, Second Edition, Adaptive Behavior Composite (standard score).

<sup>a</sup> indicates significant difference ( $p < .05$ ) between ASD and TD/ND, <sup>b</sup> indicates significant difference ( $p < .05$ ) between ASD and LD/DD, and <sup>c</sup> indicates significant difference ( $p < .05$ ) between LD/DD and TD/ND

No differences in parents' stress or resourcefulness were found across diagnostic groups,  $ps > .05$  (see Table 3.3 for summary of parent demographics). The primary outcome variable of parent perceived stress was compared across levels of the sociodemographic variables to detect differences. Parents' stress did not significantly differ across levels of: maternal education ( $F(3,114) = .558, p = .624, \eta^2 = .015$ ), household income ( $F(3,101) = 2.511, p = .063, \eta^2 = .069$ ),

primary caregiver occupational status ( $F(2,102) = 1.672, p = .193, \eta^2 = .031$ ), marital status ( $F(2,109) = 1.011, p = .367, \eta^2 = .018$ ), child race ( $F(3,115) = 2.280, p = .083, \eta^2 = .056$ ), or recruitment site,  $t(117) = 1.085, p = .280, d = .009$ . It is notable that of the sample of 119 participants, only 88% reported income and occupational status. Chi-square analyses with comparison of adjusted standardized residuals (greater than  $\pm 1.96$ ) indicated that compared to the rest of the sample, a larger proportion parents of children who were Hispanic/Latino, multiracial, or other racial/ethnic background ( $\chi^2(3) = 8.698, p = .034, V = .270$ ) did not report income. Also, a greater proportion of parents with the lowest levels of education ( $\chi^2(3) = 8.622, p = .035, V = .270$ ) did not report occupational status, whereas a larger proportion of parents of Hispanic/Latino children did not report the primary caregiver's occupational status ( $\chi^2(3) = 11.956, p = .008, V = .317$ ); however, more than 20% of the cell counts were less than 5, thereby limiting validity and interpretation of chi-square analyses of occupational status (Yates, Moore, & McCabe, 1999, p. 734).

Table 3.3 *Sample Demographics of Parents*

	Total ( <i>N</i> = 119)		ASD ( <i>n</i> = 37)		LD/DD ( <i>n</i> = 55)		TD/ND ( <i>n</i> = 27)	
	<i>N</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
<b>Parent Relationship</b>								
Mother	103	86.6	33	89.2	46	83.6	24	88.9
Father	11	9.2	3	8.1	5	9.1	3	11.1
Legal Guardian	5	4.2	1	2.7	4	7.3	0	0.0
<b>Parent Race/Ethnicity (<i>n</i> = 110)</b>								
Black, not Hispanic	40	33.6	13	35.1	21	38.2	6	22.2
White, not Hispanic	46	38.7	11	29.7	21	38.2	14	51.9
Hispanic	13	10.9	5	13.5	7	12.7	1	3.7
Multiracial/Other	11	9.2	6	16.2	1	1.8	4	14.8
<b>Parent Education (<i>n</i> = 116)</b>								
High School/GED or less	34	28.6	11	29.7	17	30.9	6	22.2
Some College/Associates/Trade	33	27.7	12	32.4	17	30.9	4	14.8
Bachelor's Degree	32	26.9	6	17.1	15	27.3	11	40.7
Graduate Degree	17	14.3	6	17.1	6	10.9	5	18.5

**Parent Occupational Status (n = 105)**

Not Employed	32	26.9	10	27.0	14	25.5	8	29.6
Employed Part-time	16	13.4	5	13.5	7	12.7	4	14.8
Employed Full-time	57	47.9	16	43.2	27	49.1	14	51.9

**Maternal Education (n = 118)**

High School/GED or less	34	29.4	10	27.0	19	34.5	5	18.5
Some College/Associates/Trade	29	24.4	13	35.1	12	21.8	4	14.8
Bachelor's Degree	35	29.4	7	18.9	15	27.3	13	48.1
Graduate Degree	20	16.8	6	16.2	9	16.4	5	18.5

**Annual Household Income (n = 105)**

Less than 10K	20	16.8	6	16.2	11	20.0	3	11.1
~10K to 50K	25	21.0	5	13.5	16	29.1	4	14.8
~50K to 96K	18	15.1	7	18.9	6	10.9	5	18.5
Over 96K	42	35.3	13	35.1	15	27.3	14	51.9

**Marital Status (n = 112)**

Single	42	35.3	13	35.1	23	41.8	6	22.2
Married/Partnered	68	57.1	20	54.1	28	50.9	20	74.1
Separated/Divorced	2	1.7	1	2.7	1	1.8	0	0.0

**Sought Early Intervention Services**

Yes	60	50.4	21	56.8	34	61.8	5	81.5
No	59	49.6	16	43.2	21	38.2	22	18.5

	M	SD	M	SD	M	SD	M	SD
Parent Age at Evaluation (yr.)	32.3	6.1	32.6	1.2	31.5	0.8	33.5	1.3
PSS Total	15.9	7.5	17.5	8.2	15.3	7.5	14.9	6.5
RS Total	89.0	17.2	84.6	17.5	91.9	16.5	89.3	17.7
RS Personal	55.2	11.2	53.5	12.0	56.8	10.9	54.3	10.7
RS Social	33.8	10.0	31.1	10.2	35.1	9.5	35.0	10.4

*Note.* PSS: Perceived Stress Scale (raw score total; possible range 0-40); RS: Resourcefulness Scale (raw score total; possible range 0-140) with Total score and Personal and Social Resourcefulness scale scores.

Although sociodemographic variables were not directly related to parents' stress, there may have been insufficient power to detect effects. It is important to account for any variance that could be explained in the model, given the extensive body of literature documenting a negative association between socioeconomic status and stress (e.g., Conger & Donnellan, 2007; Emmen et al., 2013). In the primary analyses, maternal education and child race were included as control variables. Maternal education is commonly utilized indicator of socioeconomic status in research studies (Desai & Alva, 1998), and it has been shown to largely account for effects of socioeconomic status in child outcomes (Bornstein, Hahn, Suwalsky, and Haynes, 2003). Maternal education was also used as a control variable instead of the respond parent's education

because a greater proportion of the sample reported maternal education, which ensures adequate power to detect effects based on a priori power analysis and because the majority of respondents were mothers. Additionally, because the relation between socioeconomic variables is complex and may vary between racial/ethnic groups (Shavers, 2007), child race was also included as a control variable. Child race was controlled for because it captures racial/ethnic identity of both biological parents. Annual income and occupational status were not included as control variables due to only 88% of families reporting these data; however, income ( $r_s = .505, p < .001$ ) and occupational status ( $r_s = .294, p = .002$ ) were significantly correlated with the control variable of maternal education.

The inclusion criteria indicated no prior diagnosis of a DSM-5 developmental disorder in order to assess experience of parents involved in initial diagnostic process. However, 50.4% of the sample indicated on the background history questionnaire that the family had previously sought early intervention services for their child. Additionally, parents were asked in an open-ended format to identify their first concerns about their child's development as part of the history questionnaire completed prior to the evaluation. A total of 35.3% of parents indicated some type of concern, 5% explicitly stated no concerns, and the remaining 59.7% left the response blank, which was inferred to mean "no concerns." More parents of children who received a diagnosis of ASD and LD/DD sought early intervention services than parents of TD/ND children  $\chi^2(1) = 14.218, p < .001, V = .346$ . Parents' stress and resourcefulness scores (total and scales) did not differ based on whether parents sought services prior to participation in this study,  $ps \geq .05$ . No differences in parents' stress, parents' resourcefulness, or diagnostic outcome were found for parents who had prior concerns about their child's development compared to those who did not. Nonetheless, to assess whether these factors significantly influenced the moderation models, the

three primary analyses were retested while controlling for previous service-seeking and prior parent concern. Significance of results was the same with and without the inclusion of service-seeking and prior concern in the analyses; results presented below do not include these control variables.

### 3.2 Hypothesis 1: Does Resourcefulness Moderate the Relation between Adaptive Functioning and Parents' Stress?

Regression analyses assessed whether parents' resourcefulness (RS Total) moderates the relation between child adaptive functioning (Vineland-II) and parents' stress (PSS Total), with results summarized in Table 3.4. The first step of the model included control variables of parent education and race/ethnicity; the second step included main effects of adaptive functioning and resourcefulness and accounted for a significant amount of variance in parents' stress. The main effect of parents' resourcefulness was also significant. The interaction term between child adaptive functioning and parents' resourcefulness was added in the next step of the regression model. The overall effect for all variables in the third step was significant, but the interaction term only accounted for .1% additional variance in parents' stress and was not significant. Therefore, resourcefulness was not found to be a significant moderator of the relation between child adaptive functioning and parents' stress.

Table 3.4 *Results of Hypothesis 1: Examining Moderating Effect of Resourcefulness on Relation between Adaptive Functioning and Parents' Stress (n = 116)*

	<i>b</i>	SE	$\beta$	<i>p</i>	<i>F</i>	<i>R</i> <sup>2</sup>	$\Delta R^2$
<b>Step 1</b>							
Maternal Education (0=HS or less)	--	--	--	--	1.495	.075	.075
Some college	2.225	1.914	.128	.248	--	--	--
Bachelor's degree	1.874	1.897	.114	.325	--	--	--
Graduate degree	1.299	2.224	.065	.560	--	--	--
Race (0=Black)							
White	-3.485	1.713	-.223	.044	--	--	--
Hispanic	2.183	2.452	.088	.375	--	--	--
Other	-3.016	2.226	-.138	.178	--	--	--

<b>Step 2</b>	--	--	--	--	2.697*	.167	.091
Vineland-II	.045	.055	.078	.419	--	--	--
RS Total	-.132	.039	-.304	.001	--	--	--
<b>Step 3</b>	--	--	--	--	2.388*	.167	.001
Vineland-II	.047	.056	.081	.403	--	--	--
RS Total	-.129	.041	-.296	.002	--	--	--
Vineland-II x RS Total	.001	.003	.029	.758	--	--	--

\*  $p < .05$

### 3.2.1 Exploratory Analyses

As part of exploratory analyses, these moderation analyses were rerun examining the Resourcefulness Scale subscale scores separately as moderators: Personal Total (RS-Personal) and Social Total (RS-Social); see results in Table 3.5. Results from each analysis indicated that neither personal resourcefulness nor social resourcefulness were significant moderators. However, higher levels of personal resourcefulness were significantly associated with lower levels of parents' stress.

Table 3.5 *Exploratory Analyses for Hypothesis 1: Examining Subscales of Resourcefulness Scale (Personal, Social) as Moderators of Relation between Adaptive Functioning and Parents' Stress (n = 116)*

<i>Exploratory Analysis 1: RS-Personal as Moderator</i>							
	<i>b</i>	<i>SE</i>	$\beta$	<i>p</i>	<i>F</i>	<i>R</i> <sup>2</sup>	$\Delta R^2$
<b>Step 2</b>	--	--	--	--	3.224*	.193	.117
Vineland-II	.035	.054	.060	.522	--	--	--
RS-Personal	-.232	.059	-.348	< .001	--	--	--
<b>Step 3</b>	--	--	--	--	2.932*	.198	.005
Vineland-II	.037	.054	.064	.498	--	--	--
RS-Personal	-.214	.063	-.321	.001	--	--	--
Vineland-II x RS-Personal	.004	.004	.077	.413	--	--	--
<i>Exploratory Analysis 2: RS-Social as Moderator</i>							
	<i>b</i>	<i>SE</i>	$\beta$	<i>p</i>	<i>F</i>	<i>R</i> <sup>2</sup>	$\Delta R^2$
<b>Step 2</b>	--	--	--	--	1.452	.097	.022
Vineland-II	.041	.058	.070	.484	--	--	--
RS-Social	-.109	.072	-.146	.131	--	--	--
<b>Step 3</b>	--	--	--	--	1.322	.100	.003
Vineland-II	.035	.059	.061	.554	--	--	--
RS-Social	-.115	.073	-.155	.116	--	--	--
Vineland-II x RS-Social	-.003	.005	-.057	.557	--	--	--

*Note.* Results for main effects of control variables in Step 1 of each exploratory analysis are not listed above, as they are the same as results in primary Hypothesis 1 analysis. See Table 3.4 for results for Step 1.

\*  $p < .05$

### 3.3 Hypothesis 2: Does Resourcefulness Moderate the Relation between ASD Symptom Severity and Parents' Stress?

Parents' resourcefulness (RS Total) was examined as a moderator of the relation between child's ASD symptom severity (ADOS(-2) Total) and parents' stress (PSS Total); see Table 3.6. Controlling for education and race in the first step, main effects of ASD symptom severity and parents' resourcefulness were entered in the second step of the analyses and explained a significant amount of variance (16.0%) in parents' stress, with a significant main effect of resourcefulness. When the interaction term between ASD symptom severity and resourcefulness was added to the third step, it accounted for significantly more variance (21.2%) than the individual variables, indicating significant moderation.

Table 3.6 *Results of Hypothesis 2: Examining Moderating Effect of Resourcefulness on Relation between ASD Severity and Parents' Stress (n = 118)*

	<i>b</i>	SE	$\beta$	<i>p</i>	<i>F</i>	<i>R</i> <sup>2</sup>	$\Delta R^2$
<b>Step 1</b>							
Maternal Education (0=HS or less)	--	--	--	--	1.412	.071	.071
Some college	2.384	1.909	.137	.214	--	--	--
Bachelor's degree	2.075	1.888	.127	.274	--	--	--
Graduate degree	1.432	2.222	.072	.521	--	--	--
Race (0=Black)							
White	-3.523	1.713	-.225	.042	--	--	--
Hispanic	1.567	2.383	.065	.512	--	--	--
Other	-3.049	2.227	-.139	.174	--	--	--
<b>Step 2</b>					2.602*	.160	.089
ADOS(-2) Total	.164	.231	.065	.480	--	--	--
RS Total	-.124	.040	-.285	.002	--	--	--
<b>Step 3</b>					3.232*	.212	.052
ADOS(-2) Total	.072	.227	.029	.753	--	--	--
RS Total	-.106	.039	-.244	.008	--	--	--
ADOS(-2) Total x RS Total	-.034	.013	-.241	.009	--	--	--

\*  $p < .05$



Tests of simple slopes were used to probe the significant interaction. Simple slopes for the association between ASD symptom severity and parent perceived stress were tested for low (one and a half standard deviations below the mean) and high (one and a half standard deviations above the mean) levels of parents' resourcefulness. For parents with low resourcefulness, higher levels of ASD symptom severity were significantly associated with higher parent stress,  $b = .954$ ,  $p = .012$ . The simple slope for parents with high resourcefulness was not significant  $b = -.810$ ,  $p = .063$ . Figure 3.1 illustrates the moderation interaction plot, with *low* indicating one and a half standard deviation below the mean, and *high* indicating one and a half standard deviation above the mean.

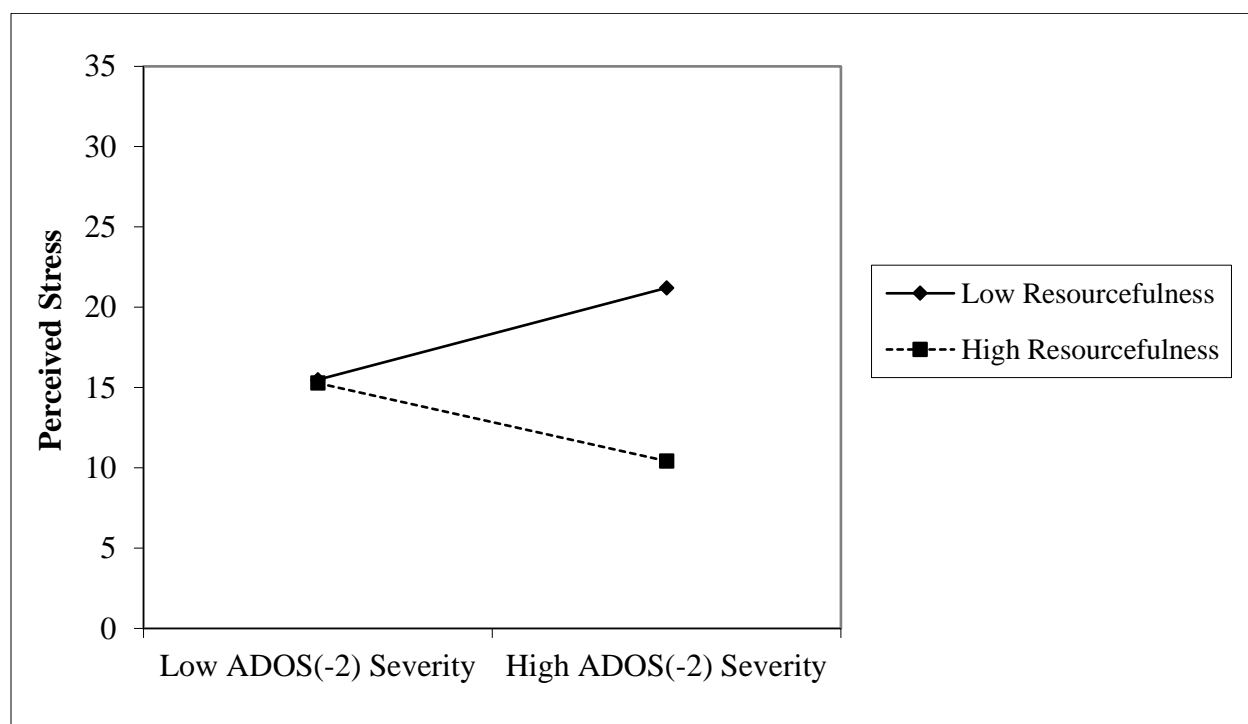


Figure 3.1. Resourcefulness moderates the relation between ASD severity and stress

### 3.3.1 Exploratory Analyses

This moderation model was explored examining the Personal and Social scale scores of the Resourcefulness Scale as moderators (see Table 3.7). For both analyses, control variables

were entered in the first step. In the first exploratory analysis, main effects of ADOS(-2) Total and RS-Personal were entered in the second step of the model, which accounted for a significant amount of the variance in parents' stress. The third step included the addition of interaction term between ASD total symptom severity and RS-Personal, which accounted for significantly more variance in parents' stress with a significant interaction effect. Simple slope analyses at low and high levels of personal resourcefulness were conducted. Results indicated a similar pattern of results as total resourcefulness, with a significant simple slope at low levels of personal resourcefulness,  $b = .919$ ,  $p = .026$ . That is, higher levels of ASD symptom severity was associated with higher stress for parents who endorsed low levels of personal resourcefulness. The simple slope for high personal resourcefulness was not significant,  $b = -.567$ ,  $p = .143$ . This analysis was repeated with RS-Social as the moderating variable, and no significant interaction effects or main effects were found,  $ps \geq .05$ .

The ADOS(-2) severity scores for Social Affect and Restricted and Repetitive Behaviors (RRB) domains were also each explored as predictor variables with RS Total as the moderating variable (see Table 3.7). In each analysis, the main effects of the predictor variable and moderator were entered in the second step, and both accounted for a significant amount of variance in parents' stress. Significant interaction effects in the third step indicated that RS Total significantly moderated the relation between ADOS(-2) Social Affect and parents' stress, as well as ADOS(-2) RRB and parents' stress. Tests of simple slopes for the association between ADOS(-2) SA severity and parent perceived stress was significant at low levels of resourcefulness,  $b = .977$ ,  $p = .009$ , and also reached significance at high levels of resourcefulness,  $b = -.839$ ,  $p = .049$ , demonstrating a buffering effect against stress associated with greater impairments in child social communication skills. Regarding the association

between ADOS(-2) RRB severity and parent perceived stress, tests of simple slopes were significant at low levels of resourcefulness,  $b = .925$ ,  $p = .048$ , but did not reach significance at high levels of resourcefulness,  $b = -.839$ ,  $p = .059$ .

Table 3.7 *Exploratory Analyses for Hypothesis 2 (n = 118)*

<i>Exploratory Analysis 1: RS-Personal as Moderator</i>							
	<i>b</i>	<i>SE</i>	$\beta$	<i>p</i>	<i>F</i>	<i>R</i> <sup>2</sup>	$\Delta R^2$
<b>Step 2</b>	--	--	--	--	3.234*	.192	.121
ADOS(-2) Total	.215	.223	.086	.339	--	--	--
RS-Personal	-.226	.060	-.337	< .001	--	--	--
<b>Step 3</b>	--	--	--	--	3.549*	.228	.036
ADOS(-2) Total	.171	.220	.070	.426	--	--	--
RS-Personal	-.195	.060	-.291	.002	--	--	--
ADOS(-2) Total x RS-Personal	-.044	.020	-.201	.026	--	--	--
<i>Exploratory Analysis 2: RS-Social as Moderator</i>							
	<i>b</i>	<i>SE</i>	$\beta$	<i>p</i>	<i>F</i>	<i>R</i> <sup>2</sup>	$\Delta R^2$
<b>Step 2</b>	--	--	--	--	1.459	.097	.026
ADOS(-2) Total	.244	.241	.097	.313	--	--	--
RS-Social	-.086	.073	-.115	.242	--	--	--
<b>Step 3</b>	--	--	--	--	1.589	.117	.020
ADOS(-2) Total	.187	.242	.074	.442	--	--	--
RS-Social	-.059	.075	-.080	.428	--	--	--
ADOS(-2) Total x RS-Social	-.035	.023	-.152	.119	--	--	--
<i>Exploratory Analysis 3: ADOS(-2) Social Affect as Predictor Variable</i>							
	<i>b</i>	<i>SE</i>	$\beta$	<i>p</i>	<i>F</i>	<i>R</i> <sup>2</sup>	$\Delta R^2$
<b>Step 2</b>	--	--	--	--	2.604*	.160	.090
ADOS(-2) Social Affect	.162	.226	.065	.475	--	--	--
RS Total	-.124	.040	-.285	.002	--	--	--
<b>Step 3</b>	--	--	--	--	3.316*	.217	.056
ADOS(-2) Social Affect	.069	.222	.028	.758	--	--	--
RS Total	-.108	.039	-.248	.007	--	--	--
ADOS(-2) Social Affect x RS Total	-.035	.013	-.250	.006	--	--	--
<i>Exploratory Analysis 4: ADOS(-2) RRB as Predictor Variable</i>							
	<i>b</i>	<i>SE</i>	$\beta$	<i>p</i>	<i>F</i>	<i>R</i> <sup>2</sup>	$\Delta R^2$
<b>Step 2</b>	--	--	--	--	2.528*	.156	.086
ADOS(-2) RRB	.011	.245	.004	.965	--	--	--
RS Total	-.129	.039	-.297	.001	--	--	--
<b>Step 3</b>	--	--	--	--	2.918*	.196	.039
ADOS(-2) RRB	.043	.240	.016	.859	--	--	--
RS Total	-.112	.039	-.257	.005	--	--	--
ADOS(-2) RRB x RS Total	-.034	.015	-.213	.024	--	--	--

*Note.* Results for main effects of control variables in Step 1 of each exploratory analysis are not listed above, as they are the same as results in primary Hypothesis 2 analysis. See Table 3.6 for results for Step 1.

\*  $p < .05$

### 3.4 Hypothesis 3: Does Diagnostic Outcome Moderate the Relation between Parents'

#### Resourcefulness and Stress?

The final moderation analysis examined the effect of child's diagnostic outcome on the relation between resourcefulness (RS Total) and parents' stress (PSS Total); results are summarized in Table 3.8. The diagnosis variable was dummy coded to compare children who

received *any* diagnosis (collapsed ASD and LD/DD groups) to the TD/ND group, and was entered in the second step with resourcefulness (first step consisted of control variables), which explained a significant amount of variance in parents' stress. The main effect of parents' resourcefulness on stress was significant. Inclusion of the interaction terms in the third step did not account for significantly more variance than the previous step.

Table 3.8 *Results of Hypothesis 3: Examining Moderating Effect of Diagnostic Outcome (Any Diagnosis vs. TD/ND) on Relation between Resourcefulness and Parents' Stress (n = 118)*

	<i>b</i>	SE	$\beta$	<i>p</i>	<i>F</i>	<i>R</i> <sup>2</sup>	$\Delta R^2$
<b>Step 1</b>							
Maternal Education (0=HS or less)	--	--	--	--	1.412	.071	.071
Some college	2.384	1.909	.137	.214	--	--	--
Bachelor's degree	2.075	1.888	.127	.274	--	--	--
Graduate degree	1.432	2.222	.072	.521	--	--	--
Race (0=Black)							
White	-3.523	1.713	-.225	.042	--	--	--
Hispanic	1.567	2.383	.065	.512	--	--	--
Other	-3.049	2.227	-.139	.174	--	--	--
<b>Step 2</b>	--	--	--	--	2.544*	.157	.086
RS Total	-.129	.039	-.297	.001	--	--	--
Diagnosis (0=TD/ND)	.552	1.642	.031	.737	--	--	--
<b>Step 3</b>	--	--	--	--	2.420*	.168	.011
RS Total	-.049	.079	-.113	.534	--	--	--
Diagnosis (0=TD/ND)	.704	1.645	.039	.669	--	--	--
RS Total x Diagnosis	-.106	.091	-.212	.246	--	--	--

\*  $p < .05$

### 3.4.1 Exploratory Analyses

This moderation analysis was recomputed to separately examine the moderating effect of diagnostic outcome on the relation between Personal Resourcefulness and parents' stress, and on the relation between Social Resourcefulness and parents' stress. In both analyses, there was no significant interaction suggesting, no moderating effect,  $ps > .05$ . Also, the main effect of RS-Personal was significant ( $b = -.231$ ,  $t(109) = -3.898$ ,  $p < .001$ ), whereas RS-Social was not,  $b = .651$ ,  $t(109) = .381$ ,  $p = .704$ .

The analyses were rerun comparing different groups of diagnostic outcomes as the moderator: 1) ASD vs. all other, 2) ASD vs TD/ND with LD/ND excluded, and 3) all three groups. No significant interaction effect was found in these analyses ( $ps \geq .05$ ), but the main effect of resourcefulness on stress was significant for all analyses,  $ps < .05$ . It is important to note that, given the 54 cases that were removed in the second analysis to compare ASD and TD/ND, this analysis was underpowered.

#### 4 DISCUSSION

The purpose of this study was to better understand parent functioning during the time period leading up to a diagnostic evaluation for children at risk for autism spectrum disorder and other developmental delays. High stress among parents of children with developmental disabilities has been well-documented, including its negative consequences in parent and child outcomes. On the other hand, many parents of children with developmental disabilities report positive experiences (Hastings & Taunt, 2002), and parents with resilient characteristics (e.g., use of problem-focused coping or social support) exhibit better adjustment (Glidden et al., 2006; Stoneman & Gavidia-Payne, 2006). These associations, however, have not been examined during a child's early years when signs of atypical development are first detected. Having greater understanding of parent functioning in the context of child functioning during this relatively unexplored time period can help inform what supports may be needed for parents during and following the diagnostic evaluation in order to promote optimal family outcomes. In a sample of 119 families with toddlers at-risk for developmental delays, this study sought to explore associations between child functioning (i.e., adaptive behavior, ASD symptom severity, diagnostic outcome) and parent functioning (i.e., stress, resourcefulness), with a particular

interest in investigating the potential buffering role of parents' resourcefulness on poor parent and child functioning.

Preliminary analyses examining correlations across test variables indicated that parents' resourcefulness and perception of general stress were negatively related, which was expected given that they measure opposing constructs. Interestingly, this negative association was observed with the Personal Resourcefulness scale, but not the Social Resourcefulness scale. This suggests that in this sample of parents, use of adaptive internal coping mechanisms (e.g., positive appraisals) is associated with lower perception of stress, whereas use of external resources (e.g., seeking social support) is not related to stress. As described by Zausniewski and colleagues (2006), the "cognitive-behavioral skills constituting personal resourcefulness facilitate the performance of daily activities despite the presence of disturbing thoughts, feelings, sensations, or impulses" (p. 58). Results suggest that the characteristics of personal resourcefulness, which is linked with constructs like cognitive hardiness or flexibility, locus of control, self-esteem, and ego strength, are particularly adaptive for parents during this early period as a child is receiving an initial evaluation for possible developmental delay (Kobasa, 1979; Rosenbaum, 1990).

Additionally, stress level in this sample of parents with children at risk for developmental delay was similar regardless of children's diagnostic outcomes. This is inconsistent with the literature documenting group differences, for example, higher stress in parents of children with ASD versus other developmental delays (Estes et al., 2009; Estes et al., 2013; Griffith, Hastings, Nash, & Hill, 2010; Schieve, Blumberg, Rice, Visser, & Boyle, 2007). It is noteworthy that all families in this sample shared the same referral question of parent-reported screening indicating risk for developmental delay. This may explain why, despite their children not meeting criteria for any diagnosis, the parents of the TD/ND group exhibited similar stress levels to parents

receiving a diagnosis of developmental disability for their child. Additionally, stress did not differ across different levels of sociodemographic variables, whereas the literature has shown factors such as income, education level, and racial/ethnic background to contribute to stress.

One important consideration for interpreting the lack of variation of stress across groups is the level of stress these parents were reporting. The average PSS score was 15.9 ( $SD = 7.5$ ) in this sample and, compared to mean PSS scores ( $17.5 \pm 7.3$ ) in national survey data of adults in the same age range, yields a z score of  $-.219$  (Cohen & Janicki-Deverts, 2012). At this early phase, when children are identified as at-risk by professionals prior to completing a comprehensive diagnostic evaluation, parents' perception of their general stress level was within a normative range, indicating that the widely reported elevated level of stress among parents with children with developmental disabilities in the literature was not apparent. Of course, not every child in this sample received a diagnosis of a developmental disability at the evaluation; however, even the means for both the ASD ( $17.5 \pm 8.2$ ) and LD/DD ( $15.3 \pm 7.5$ ) groups were similar to national norms. It is also unknown if and how the screening and referral process itself may have affected parents' stress in this study, which is further discussed in the Limitations and Future Directions section. This is the first study examining parents' stress at this time period via prospective report. If future studies replicate findings of average level stress and equal stress levels across different diagnostic outcome groups, this may indicate the diagnostic and treatment process to be a good point of preventative intervention efforts for parents.

#### **4.1 Hypothesis 1: Resourcefulness as a Moderator of Relation between Adaptive Functioning and Parents' Stress**

In the first primary analysis, there was no evidence for a buffering effect of resourcefulness on the relation between child adaptive behavior and parents' stress while



controlling for race and maternal education. Moreover, the main effect of adaptive functioning on parents' stress was also not significant. In this study, child's adaptive functioning had almost no correlation with parents' stress ( $r = .033$ ); Vineland-II domain scores also did not significantly correlate with parents' stress ( $r_s = -.036$  to  $.105$ ). On one hand, it seems very plausible that impairments in adaptive functioning, which is typically indicative of greater parent assistance with a range of daily activities (e.g., hygiene, feeding), would relate to caregiver stress or burden. However, the research examining this relation has found mixed results, with some supporting this association among children with developmental disabilities and their parents (e.g., Secco et al., 2006; Tomanik et al., 2004), and some indicating no relation (e.g., Estes et al., 2009; Estes et al., 2013; Lecavalier et al., 2006).

Based on the results in the present study, it is possible that, at this young age in particular, there may perhaps be lower expectations regarding a child's level of independence in day-to-day activities compared to older children, especially given the often-anticipated period of "terrible twos" among parents in western culture. Therefore, a toddler's degree of adaptive functioning, even when significantly below average, might not have as strong of an influence on parents' perceived stress or burden as it would in other developmental periods. In other words, parents may be resilient to demands required for toddlers with adaptive functioning impairments at this very young age. Interestingly, the one study examining the relationship between parents' stress and adaptive functioning of children with ASD and other developmental disabilities in a similar age range to the children in the present study also did not find these constructs to be related (Estes et al., 2013). This may also explain why the strength of the relation between children's adaptive functioning and parents' stress does not depend on parents' resourcefulness and no moderation effect was found. Similar to resilience, resourcefulness involves the use of skills to

overcome adverse events and manage daily life hassles. However, it may be that poor adaptive functioning is not a threatening or distressing concern requiring defeat, which is why no buffering effect of resourcefulness was found.

Consistent with correlation analyses, the main effect of resourcefulness on stress was significant, after controlling for race, education, and adaptive functioning, and in exploratory analyses with scale scores, only the main effect of personal resourcefulness (but not social resourcefulness) was significant. In addition to the explanation above regarding importance of internal coping mechanisms, this finding may also be related to the type of stress measured. Much of the literature regarding caregiver stress has utilized measures specific to parenting-related stress. Several studies have found parenting stress to remain stable over time (Crnic et al., 2005; Gray et al., 2015; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Willard et al., 2016). In the present study, the PSS was selected as a measure of general perceived stress to the individual, as it captures fluctuations in stress relative to recent events. Therefore, it was expected that any potential stress related to the common experience of initiating the diagnostic process would be captured. Moreover, the PSS could lend to appropriate measurement of tracking stress trajectory across different developmental phases of the child and/or across different systemic transition points, such as shifting services from early intervention to school. On a similar note regarding type of stress measure, the current measure of perceived stress was not elevated in this sample compared to national means, but parenting-related stress has also not yet been studied in this pre-evaluation period. This would be an important point of comparison in order to better understand patterns of generalized perceived stress versus parenting-specific stress.

## 4.2 Hypothesis 2: Resourcefulness as a Moderator of the Relation between ASD Symptom Severity and Parent Stress

It was found that the effect of ASD symptom severity on parents' stress was moderated by parents' resourcefulness after controlling for race and maternal education. Specifically, ASD symptom severity was positively associated with stress among parents with low levels of parents' resourcefulness. This pattern of results was replicated with personal resourcefulness as the moderator in a separate analysis with Social Affect severity score as the predictor, and also when RRB severity was the predictor. These findings suggest that parents with low levels of resourcefulness, especially personal resourcefulness (i.e., internal coping skills), may be vulnerable to stress related to severity of child's symptom presentation, whereas parents with high resourcefulness do not exhibit high stress in association with high symptom severity.

However, only when Social Affect severity score was the predictor variable of parents' stress was high symptom severity significantly related to lower stress for those parents with higher levels of resourcefulness, indicating a stress-buffering effect. This suggests greater resourcefulness to be a protective factor against parent stressors associated with their child's impairments in reciprocal social interaction and communication skills in particular, which are the cluster of symptoms that comprise the Social Affect domain of the ADOS(-2). It is noteworthy that, although simple slopes test were not statistically significant ( $\alpha = .05$ ) at high levels of resourcefulness when examining total symptom severity ( $p = .063$ ) and RRB severity ( $p = .059$ ) as a predictors, the models approached significance.

The negative association between symptom severity and parents' stress is not surprising. For example, the severity of behavior symptoms among youth with ASD, Down Syndrome, or Fragile X has been found to be a consistent predictor of maternal outcomes, as measured by an

ASD-specific behavior checklist (Abbeduto et al., 2004). However, this is the first study to demonstrate a stress-buffering effect for parents of very young children with developmental concerns in this early time period.

#### **4.3 Hypothesis 3: Diagnostic Outcome as a Moderator of the Relation between Parents' Resourcefulness and Stress?**

Whereas previous analyses examined all participants together as one sample of at-risk children and their parents, this particular analysis sought to identify potential group differences in parent functioning by dividing the sample based on diagnostic outcomes of the children. This was completed to reflect previous research in the area of developmental disabilities, which has traditionally examined group differences by diagnosis. The expected result was that the negative relation between parents' resourcefulness and stress would be stronger in parents of children who receive a diagnosis at the evaluation. However, findings indicated that whether or not the child received a diagnosis of any type of developmental delay (i.e., ASD, LD/DD) did not moderate the relation between parents' resourcefulness and stress, after controlling for race and maternal education. That is, higher total (and personal) resourcefulness was associated with lower stress regardless of diagnostic outcome of children. This may likely be explained by the nature of the screening sample, which consisted of very young children at-risk for developmental disabilities. It is possible that at this age, behavioral presentation is not characteristically distinct enough across diagnostic groups to yield a significant effect on the resourcefulness-stress relation. This idea is supported by literature documenting similarities in first concerns and symptoms in children at this age across with different developmental disabilities (Kozlowski et al., 2011).

No diagnosis-based group differences were found for parents' stress or resourcefulness in preliminary analyses, which is inconsistent with previous research in the area of parent stress

among children with developmental disabilities. One reason for this may be that the TD/ND group in this sample was not truly a “typically developing” control group as has been utilized in previous research, given that these toddlers also demonstrated risk on the initial screening questionnaire. Furthermore, parents’ stress level overall across the sample of parents was not significantly elevated. Therefore, there is insufficient evidence to support the emergence of differential stress levels at this early time period prior to diagnostic evaluation.

#### **4.4 Clinical Implications**

This study is the first to prospectively investigate parents’ perceived stress and resourcefulness in the context of child functioning during the time period leading up to a diagnostic evaluation among toddlers at-risk for developmental delay. Certainly, additional research in this area and time period is necessary to inform clinical practice; however, implications regarding the meaningfulness of findings in this area of research are offered. The data suggest that parents with low levels of resourcefulness may be disproportionately more greatly impacted by stressors related to more impaired ASD symptoms, especially social communication skills, and that high levels of resourcefulness may protect against high parent stress.

The current study utilized a strengths-based approach of identifying how resourcefulness may contribute to reduced stress in parents of children at-risk for developmental disabilities. The findings provide additional support for the movement towards more parent-directed early intervention efforts and services. The presence of relatively average levels of stress in this sample suggest that this is an opportune time period to intervene and capitalize on preventive intervention efforts. Such efforts might help circumvent negative parent outcomes related to parenting children with developmental disabilities and instead promote psychological well-being.

Parent mental health is related to many child outcomes, including the level of gains made from early intervention efforts. For example, parents of children with ASD with high stress made significantly fewer adaptive, educational, and intellectual gains despite more than 15.6 hours of weekly intervention (Osborne et al., 2008). It is important to not only educate and empower parents for the journey ahead following a diagnosis of developmental disability but also support them in a way that effectively manages stress and mental health. Based on findings in this study, it also seems especially important to improve skills related to personal resourcefulness among parents.

Traditionally, early intervention efforts following diagnosis for developmental delay have focused on individual therapy to boost children's functioning level. However, there has recently been a greater focus on the role of parents in terms of improved child functioning, such as parent-mediated behavioral intervention therapies, parent education or support groups, and supportive services, such as use of patient navigators (Budd, Hella, Bae, Meyerson, & Watkin, 2011; Reichow, Barton, Boyd, & Hume, 2012; Roth et al., 2016; Steiner, Koegel, Koegel, & Ence, 2012). Given the challenges parents experience navigating therapy and support resources for their children, it is important to identify ways to help parents cope during and following evaluations in a way that may facilitate seeking early intervention, such as improving resourcefulness skills.

Findings from the current study provide support for resourcefulness, particularly personal resourcefulness, as a protective factor against stress among parents with children with developmental concerns, and it may be beneficial to incorporate resourcefulness training as part of parent-directed intervention efforts. Resourcefulness is shaped through life experiences, but can also be modified via intervention. Resourcefulness training has found to improve cognition,

affect, and self-perception of health and functioning among elderly with and without chronic illness (Zauszniewski, Bekhet, Lai, McDonald, & Musil, 2007; Zauszniewski, Eggenschwiler, Preechawong, Roberts, & Morris, 2006), as well as reduce stress and depressive symptoms and improve quality of life among grandmothers raising grandchildren (Zauszniewski, Musil, Burant, & Au, 2014). Moreover, Ronen and Rosenbaum (2010) aimed to reduce aggression among adolescent students by improving their personal resourcefulness (e.g., modifying negative cognitions and enacting self-control) through cognitive-behavioral intervention strategies. Their intervention study found that from baseline, those who participated in the program had significantly increased resourcefulness and managed their anger significantly better than students who did not participate. However, because randomized control assignment was not utilized, it could not be concluded the resourcefulness-boosting intervention was the sole contributor to reductions in aggression.

The efficacy of resourcefulness training has not yet been investigated among parents of children with developmental disabilities. However, mindfulness-based stress reduction interventions, which may be considered a distinct yet complementary approach to personal and social resourcefulness skill building, have demonstrated promising findings. Mindfulness interventions focus on improving intrapersonal processes (e.g., thoughts, feelings) and has indications for targeting interpersonal processes that impact parenting (e.g., closeness; Coatsworth, Duncan, Greenberg, & Nix, 2009). Studies have shown preliminary support for such intervention in parents of children with ASD and developmental disabilities, yielding increased satisfaction with parenting skills, increased satisfaction parent–child interactions, decreased parenting stress and overall stress, and decreased parent report of child behavioral problems (Gika et al., 2012; Singer, Irving, & Hawkins, 1988; Singh et al., 2006; Singh et al., 2007).

Similar to personal resourcefulness training, these studies utilized techniques drawn from cognitive behavioral theory and mindfulness practice in order to improve parents' internal coping and self-regulation skills. Continued research in the area of improving personal resourcefulness and adaptive coping strategies, as well as decreasing stress among caregivers of developmental disabilities, is needed.

It is not recommended that every newly-diagnosed family necessarily undergo parent-directed intervention to improve resourcefulness and reduce stress, given that many parents possess protective factors that promote resilience. Moreover, not all parents exhibit psychological distress, and many even identify positive aspects associated with rearing children with developmental disabilities (Hastings & Taunt, 2002; Minnes, Perry, & Weiss, 2015). Therefore, in order to identify parents and families in greatest need of support, it would be important to screen parents at this time period for any risk factors, such as low resourcefulness and high stress. For example, in the pediatric cancer population, the Psychosocial Assessment Tool has been used to flag parents of children newly diagnosed with cancer who exhibit elevated psychosocial risk that may contribute to negative outcomes (Pai et al., 2008). This is a popular tool that has resulted in increased referrals and utilization of social work and psychological services (Alderfer et al., 2009). Such an approach could be applied to parents of children newly diagnosed with autism or other developmental disabilities as part of the diagnostic process in order to inform appropriate follow-up referrals for family-based intervention services.

#### **4.5 Limitations and Future Directions**

There are several important limitations to note. First, the sample included in this study was heterogeneous in terms of whether parents had previous concerns and whether they sought services for their child prior to the evaluation. These factors impact parents' awareness of



atypical development and level of concern, which can potentially influence stress levels and self-report of resourcefulness ratings. Inclusion criteria for this study included no prior diagnosis of a DSM-5 developmental disorder as reported by parents. However, data from background history questionnaires indicated that 50.4% of the parents sought services for their child prior to the diagnostic evaluation, and 35.3% of parents indicated having concerns about their child's development prior to the evaluation. Prior services primarily included participation in state-funded early intervention services (e.g., speech therapy); these services typically do not involve comprehensive evaluations resulting in DSM-5 diagnoses, but they do include eligibility testing to identify skills deficits. This indicates that the screening and evaluation in the study was not an entirely novel experience, and that concerns may have been previously identified. Theoretically, the parent experience for those who had no concerns and/or no prior early intervention experience may be distinct from those who had concerns and/or sought intervention for their child even prior to formal diagnosis. For example, parents who sought early intervention services could perhaps exhibit higher levels of social resourcefulness (i.e., utilization of external resources). Or, perhaps, parents who had previous concerns may be more stressed due to feelings of uncertainty about their child's development relative to parents who did not have concerns about their child's development (Lauchlan & Boyle, 2007). In contrast to these expectations, exploratory analyses indicated that whether or not a family sought services or had concerns prior to the evaluation was not related to parents' stress or resourcefulness (including personal and social resourcefulness), and when controlling for these factors, results from the primary three hypotheses did not differ.

Despite the relatively average levels of stress in the study sample, the potential stress response to screening itself is unknown. It is possible that for the families in this study, or any

other family who has experienced the screening and diagnostic process, parent perception of stress may have differed from before to after screening positive on an ASD questionnaire during a routine well-visit at their pediatrician's office, and thereafter being informed that their child may be at risk for developmental delay. Retrospective report from mothers of children with developmental disabilities has indicated experiencing stress when faced with the suspicion of possible developmental problems (Bingham, Correa, & Huber, 2012).

In other areas of research, stress related to screening and diagnosis has been explored. For example, parents who receive false positive results from newborn screening exhibit higher stress than parents who receive normal results (Baroni, Anderson, & Mischler, 1997; Waisbren et al., 2003). Similarly, when women receive clear results immediately after completing mammographic screening, no elevations in anxiety is reported, whereas those who require further investigation experience significant anxiety (Brett, Bankhead, Henderson, Watson, & Austoker, 2005). However, in this study, comparative baseline data prior to screening were not collected in the present study to understand whether stress increased after screening positive, or if stress and resourcefulness among parents in this study differed from those whose children screened negative and did not require additional follow-up.

Another important gap is the lack of data from families who did not participate in the evaluation. Data from the larger screening study suggest that 33-39% of children who screen positive (i.e., demonstrate risk) on the initial ASD-specific questionnaire do not continue on to participate in follow-up, which is, in part, related to lower maternal education and factors associated to economic challenges, such as invalid/disconnected phone numbers (Chlebowski, Robins, Barton, & Fein, 2013; Khowaja, Hazzard, & Robins, 2015). There may be potential bias or important characteristic differences among families who do and do not participate. For

example, it may be possible that the families who elected to participate had higher levels of resourcefulness or problem-focused coping skills, which also may be correlated with lower stress in this sample. This could be a possible explanation for the average level of stress in this sample. In contrast, given that families who do not participate in the evaluation tend to have lower levels of maternal education, which is a rudimentary marker for socioeconomic status, this may perhaps be indicative of increased economic pressure (e.g., difficulty taking off work) that prevented participation. Additional data are needed to draw conclusions about parent perceptions and functioning among those who do and do not follow-up with referrals for evaluation.

On a similar note, most children (92.6%; Robins et al., 2014) do not exhibit risk on the initial screening questionnaire and no follow-up data are collected from these families, indicating no control comparison group. In the present study, group differences were assessed based on diagnostic outcome. However, the TD/ND group in the current study sample is likely characteristically distinct from the typically developing children who screen negative on the initial screening questionnaire and do not later go on to receive any diagnoses. Therefore, we cannot infer how these families' ratings of stress, resourcefulness, and child functioning may or may not differ from families who did participate in the study. It will be important for future research during this time period to include a control group of parents of children who do not exhibit any risk at screening.

Further clarification is still needed regarding the factors influencing parent and child functioning over time, and what leads to adaptive versus maladaptive outcomes. This study used self-report questionnaires from the same participants for both predictor and outcome variables, which introduces potential common method bias. With common method bias, associations found regarding parent functioning may be due to a measurement method issue rather than the actual

constructs measured. This, coupled with the cross-sectional study design, limits the inferences that can be made about associations found in this study, particularly in regard to causal inferences. Future research should take a multi-informant, longitudinal approach to better understand the trajectory of parents' stress and resilience at each phase of the diagnostic and treatment process, such as prior to initial screening, between screening and evaluation, shortly after the evaluation, and long-term follow-up. It is likely that parent concerns at each phase of development may vary over time (Missiuna, Moll, King, King, & Law, 2007). Moreover, additional intervention studies evaluating the efficacy parent-focused interventions are needed. Ideally, this would involve random assignment to treatment groups (e.g., control group without formal intervention, and treatment group participating in personal resourcefulness skill building intervention), with baseline and follow-up measures of stress, resourcefulness, and service utilization.

Finally, this was the first study to retrospectively examine relations between child and parent functioning in the early time period leading up to diagnostic evaluation when children are very young, but the study only examined certain aspects of child functioning (i.e., adaptive behavior, ASD symptom severity) and parent functioning (i.e., resourcefulness, stress). Previous research on these relations in older children across a range of developmental disabilities have also examined other factors, such as depression and anxiety in parents and behavioral challenges in children. To expand on the literature on parent and child functioning during this early period, broader measures of social, emotional, and behavioral functioning of parents and children should be used in future research, as this will help further identify protective and risk factors.

## **4.6 Conclusions**

This study was a first step towards better understanding of parents' experience of the screening and diagnostic process, in order to inform improvements in service provision for families following diagnosis of ASD or other developmental disability, including preventative intervention efforts that promote optimal family outcomes. Findings from the present study provided support for a potential stress-buffering effect against the impact of severe social communication impairments on parents with high levels of resourcefulness. However, continued research in this area is needed, particularly longitudinal research beginning with initial screening or when first concerns arise.

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