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Parenting Stress in Parents of Young Children with Autism Spectrum Disorders: The Role of Child Characteristics and Social Support

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ABSTRACT

The current study drew on the Double ABCX model of stress to explore the relationship between parenting stress in parents of children with an autism spectrum disorder (ASD) and factors contributing to heightened levels of stress. Specifically child characteristics, pile-up demands, external resources and parent perception were examined in cross-sectional samples of parents of children 2 (Time 1), 4 (Time 2) and 8 (Time 3) years of age. Additionally a comparison sample of parents of 2 year olds with a developmental delay (DD), and two longitudinal subsamples (2-4 and 4-8) were utilized. Prior to the child's diagnosis (Time 1), parenting stress was associated with the parent's perceptions, specifically concerns about the child's development. In the comparison DD sample, parenting stress was most related to social support. Changes in parenting stress over time were found to be associated with changes in adaptive skills, specifically parent-reported daily living and social skills. Contrary to hypotheses, social support was not found to be related to parenting stress at any time point in the ASD groups. Potential explanations for the varied contributors to parenting stress, as well as clinical implications are addressed.

Parenting Stress in Parents of Young Children with Autism Spectrum Disorders: The Role of Child Characteristics and Social Support

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by a behavioral profile present in early childhood. ASD is defined by deficits in communication and socialization, as well as the presence of restricted interests and repetitive behaviors. Social deficits include diminished nonverbal communication (e.g., eye contact, gestures, pointing), and a failure to share experiences with others, both of which result in an inability to form reciprocal relationships. Young children with an ASD demonstrate an inability to engage in joint attention, a lack of spontaneous imitation, limited reciprocal and imaginative play, and difficulty understanding social cues such as facial expressions. Deficits in social interaction are intrinsically related to difficulties with communication. Many children with ASD experience a delay in language acquisition, and some never acquire verbal communication. Other individuals will develop structural aspects of language typically, yet still demonstrate deficits in pragmatics, or the social use of language.

Individuals with ASD demonstrate repetitive behaviors, and/or restricted areas of intense interest. Some individuals with ASD may exhibit repetitive motor movements (hand flapping, jumping, rocking, toe-walking, etc.), or become transfixed by a part of an object (e.g., spinning the wheels of a toy car). At a higher cognitive level, individuals with ASD may fixate on a circumscribed topic or object of interest (e.g., construction signs, train schedules, types of cars). Similarly, individuals with ASD may rigidly adhere to routines or specific daily schedules. Finally, individuals with ASD frequently exhibit hyper- or hypo- sensitivity to sensory stimuli including certain textures (clothing, food, etc.), sounds, smells and motions. The term autism-

specific characteristics, used later in the paper, refer to the above symptoms. Sensory concerns are not really autism specific.

Under the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV) the broader ASD classification included specific disorders such as autistic disorder, Asperger's Syndrome and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS; APA, 2000). DSM-5 subsumed each of these diagnoses under a single Autism Spectrum Disorder classification (APA, 2013). Among individuals with ASDs, there is great heterogeneity in the severity and presentation of these symptoms. In May 2012, the Center for Disease Control and Prevention (CDC) released prevalence data that 1 in 88 children in the United States had an ASD (CDC, 2012), suggesting that a large number of families in the United States are grappling with the daily struggles of caring for a child with an ASD.

Although clinicians are able to diagnose children with an ASD reliably by around 2 years of age, the average age of diagnosis in the United States remains approximately 4-5 years, depending on the child's specific symptom profile (CDC, 2012; Mandel, Novak, Zubritsky, 2005). However, parents often have concerns within the first two years of life, well before an official diagnosis is made (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; Hess & Landa, 2012; Chawarska et al., 2007). Parents' most common concerns are related to communication, followed by concerns over the child's social skills (Chawarska et al. 2007; Hess & Landa, 2012, Young et al. 2003). In a study of younger siblings of children with an ASD, Hess and Landa (2012) found that parents demonstrated good specificity when asked about their concerns, meaning that when they indicated concerns, standardized tests and clinical judgment corroborated those concerns. However parents did not demonstrate good sensitivity, frequently missing delays in communication and social skills. Additionally, parents report concerns earlier

if the child has an older sibling, and even earlier if that older sibling has an ASD (Herlihy et al., 2013). Family studies have revealed that if a child has ASD, a sibling is 20 times more likely to have the disorder than siblings of children without ASD (Lauritsen, Pedersen, & Mortensen, 2005). The deficits in social relatedness and communication that parents notice at such a young age can be stressful for parents on many levels.

Parenting Stress

Parenting stress is the incidence of distress or discomfort related to the experience of parenting (Deater-Deckard, 1998). While some amount of parenting stress is typical, and even beneficial, significant levels of parenting stress can lead to lower parental self-efficacy, poor quality of life and distressed parent-child relationships (Rodrigue, Morgan, & Geffken,1990; Donnenberg and Baker, 1993; Hastings and Brown, 2002; Guralnick, 2006). Many factors can contribute to parenting stress including the parent's perceptions of the child's characteristics and behavior, as well as a parent's perceived competence, and his or her experience of support (Abidin, 1983). The double ABCX model suggests that three domains (each divided into two more specific subdomains; see Figure 1) contribute to a parent's experience of stress: specific stressors (a) and the accumulation of parenting demands (aA); individual resources (b) and external resources (bB); and the appraisal of the stressor (c) and subsequent coping strategies (cC). Each of these domains contributes to the family's ability to cope with a given stressor and their ultimate adaptation (X; McCubbin & Patterson, 1983). In families affected by ASD, this model may include the child's symptoms (a) and the number of siblings requiring daily care (aA), the parent's mental health (b), social support (bB) and parental stress (X). Previous research on stress in families affected by ASD has utilized the double ABCX model as a helpful

framework for quantifying and describing the factors contributing to a family's experience of negative stress (Hall & Graff, 2010; Manning, Wainwright, Bennett, 2011).

Parenting Stress in Families of Children with an ASD

Over the past 30 years, parenting stress has been a topic of substantial interest in families of children with developmental delays (Baker et al., 2003; Gupta, 2007; Webster, Majnemer, Platt, & Shevell, 2008). As one would expect, parents of children with developmental delays experience higher levels of stress than parents of typically developing children. In line with the double ABCX model, children with developmental delays may have more difficult behaviors and fewer adaptive skills, contributing to greater specific stressors and parenting demands, and thus leading to higher levels of parenting stress. Based on this understanding, we can hypothesize that families with a child affected by ASD may experience similar challenges.

Parenting stress has been well documented in families of children with an ASD. Consistently research has shown that these parents experience higher levels of stress than parents of typically developing children (Eisenhower, Baker, Blacher, 2005; Hodapp, Ricci, Ly, Fidler, 2003; Johnston et al., 2003; Hayes & Watson, 2013). Additionally parents of children with ASD experience higher levels of stress than parents of children with other disorders and medical conditions including Down syndrome, intellectual disability, fragile X syndrome, cystic fibrosis, cerebral palsy and developmental delay (Blacher & McIntyre, 2006; Bouma & Schweitzer, 1989; Estes et al., 2009; Hayes & Watson, 2013). However some studies have shown more equivalent levels of stress in parents of children with an ASD and parents of children with externalizing behaviors, ADHD and fetal alcohol syndrome (Donnenberg and Baker, 1993; Dumas et al., 1991). In a recent meta-analysis Hayes and Watson (2013) reported large combined effect sizes when comparing stress levels in parents of children with ASD versus other disorders and

disabilities; however they cautioned that these large effect sizes were driven by comparing families affected by ASD and those affected by Down Syndrome.

Not only does parenting stress have deleterious effects on parent mental health and self-efficacy, it also influences the child's level of functioning. Sensitive parenting practices have been shown to foster cognitive and behavioral development (Landry, Smith, Miller-Loncar & Swank, 1997). Increased parenting stress however is associated with less parental involvement, poor communication and less limit setting (Osborne & Reed, 2010). Baker and colleagues (2003) found a transactional relationship between parenting stress and behavior problems in children with developmental delays. In a sample of toddlers and their parents, child behavior problems predicted higher levels of stress, which in turn contributed to increasing child behavior problems. Notably parenting stress has been shown to influence a child's gains in intervention (Osborne, McHugh, Saunders, and Reed, 2008; Robbins, Dunlap, and Plienis, 1991). A 2010 study by Shine and Perry addressed the relation between intervention gains, adaptive behaviors and parenting stress in families affected by ASD. The researchers found an inverse trend between Intensive Behavioral Intervention (IBI) gains and level of parental distress. This is notable as the intervention was *not* parent-directed. The study also found a significant inverse relationship between adaptive functioning level and parental distress. Although few studies have looked at the relationship between parenting stress and a child's gains in intervention, the initial results suggest the need to address a parent's experience of stress as part of a child's intervention plan.

Based on the findings discussed above, it is important to understand what causes these higher levels of stress in parents of children with ASD. At this time it is unclear as to what developmental stage is most stressful for parents, as research has demonstrated inconsistent results. Lounds and colleagues (2007) found that maternal distress lessened as the child

transitioned from adolescence into young adulthood, while Smith et al. (2008) demonstrated no difference in depressive symptoms between mothers of toddles and adolescents with ASD. However few studies have examined parenting stress longitudinally across early and middle childhood. In one nationally representative sample, younger child-age (under 6 years of age) was associated with higher levels of parent "aggravation" (Schieve et al., 2011). The only study examining stress across the toddler to preschool years (approximately 28 to 52 months) found no significant change in parenting stress or maternal depression (Carter, Martínez-Pedraza, & Gray, 2009; Green & Carter, 2011). As more children are receiving earlier diagnoses and intervention services, it will become increasingly important to understand how parents experience stress in relation to their newly diagnosed child.

Predictors of Parenting Stress for Parents of Children with ASD

Due to the higher level of parenting stress in parents of children with ASD, one might hypothesize that ASD-specific symptoms are contributing to this higher level of stress. To a certain extent, the literature has demonstrated this link; higher levels of parenting stress have been associated with ASD-specific symptoms such as lower levels of social relatedness (Davis & Carter, 2008; Kasari & Sigman, 1997), poor communication skills (Bebko, Konstantareas & Springer, 1987; Tomanik, Harris & Hawkins, 2004), the presence of repetitive behaviors (Gabriels et al., 2005), and overall ASD symptom severity (Estes et al., 2009; Hastings & Johnson, 2001; Hoffman, et al., 2008; Ingersoll & Hambrick, 2010). However higher levels of parenting stress have also been consistently linked to non-ASD specific symptoms such as the presence of more problem behaviors (Davis & Carter, 2008; Estes et al., 2009; Hastings et al., 2005). Problem behaviors include a wide and varied range of behaviors including aggression, irritability, noncompliance, being easily distressed, among others. However, questionnaires

assessing "behavior problems" such as the Aberrant Behavior Checklist (ABC; Aman and Singh, 1986) and the Developmental Behavior Checklist (DBC; Einfeld & Tonge, 1995) also include ASD-related domains such as social withdrawal, stereotypic behavior and poor communication skills. Therefore it may be difficult to tease apart what specific behaviors under the umbrella term "problem behaviors" are contributing to parenting stress. Estes and colleagues (2009) described that when preschoolers' problem behaviors were accounted for, ASD-specific symptom severity no longer significantly contributed to the experience of parenting stress. In a similar population, Davis and Carter (2008) found that stress was predicted by both social relatedness and behavioral problems. Thus these problem behavior measures may be picking up on the most stressful behaviors related to an ASD diagnosis. It will be important to tease these two domains apart in future research.

Research findings on the influence of a child's daily living skills on the level of parenting stress have been mixed. Estes and colleagues (2009; 2013) found that after problem behaviors were accounted for, daily living skills also no longer contributed to higher levels of parenting stress. However, Green and Carter (2011) reported that the relationship between daily living skills and parenting stress grew stronger over time (from 28 to 52 months), and that a positive change in the child's daily living skills was related to a decrease in parenting stress after accounting for child age, developmental level, autism severity, and problem behaviors. Therefore it may be that daily living skills contribute more to parenting stress as children get older and are expected to be more independent in their personal care. Thus, a synthesis of the literature suggests that ASD-specific symptoms, as well as problem behaviors and potentially daily living skills, significantly contribute to the experience of parenting stress in early childhood. In terms of

the double ABCX model, these child characteristics would be classified as individual level stressors that may be either acute or chronic (a or aA).

Social Support as a Buffer for Parenting Stress

Since it is well established that parents of children with an ASD experience a higher level of stress, and that increased parenting stress may relate to a child's ability to make developmental gains, it is important to understand factors that buffer this increased stress. As previously discussed, most research has focused on the child factors contributing to parenting stress (aA in the double ABCX model). Other studies have also suggested that external factors such as SES and social support may play a role in the experience of parenting stress. Social support is especially important to study, due to its potential role as a safeguard against stress. Social support is defined as a multidimensional construct that encompasses the emotional and psychological support, as well as the instrumental and physical assistance that an individual can receive from others (Boyd, 2002; Dunst, Trivette, & Cross, 1986). Social support can be further broken down into two sources: formal (community resources, parenting groups, therapy, etc.) and informal (family, friends, partner). Both sources of social support have been found to increase positive mood in this population of parents (Pottie et al., 2009). However, studies have shown that most parents reported lower parenting stress with increased informal, but not necessarily formal social support (Boyd, 2002; Bishop et al., 2007; Hastings & Johnson, 2001; Ekas, Lickenbrock & Whitman, 2010). This finding may be because parents receive more informal than formal support (Bromley, Hare, Davison, & Emerson, 2004). Hall and Graff (2011) and Hastings (2001) reported that parents of young children found professional organizations and parenting groups only minimally helpful, and that they did not ameliorate their experience of stress. Additionally, most studies addressing formal social support quantify

support in terms of child-directed services. Fewer studies have examined the relationship between formal parent support (therapy, parent groups, etc.), and the experience of parenting stress. This is a gap in the literature that the current study plans to address.

Parenting Stress and Appraisal of Child's Needs/Development

Most studies have looked at parenting stress within families of children in middle-childhood. Although recent studies have begun to address parenting stress in families of newly diagnosed children, this remains an area in need of further exploration, particularly in light of increasing early diagnosis and implementation of early intervention. As previously stated, parents regularly notice issues with their child's development in the second year of life yet do not receive an official diagnosis until years later (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; Hess & Landa, 2012; Chawarska et al., 2007), this experience may lead to increased levels of stress. Goin-Kochel et al. (2006), reported higher parent satisfaction the earlier his/her child received a diagnosis, and the fewer professionals that s/he saw prior to receiving the diagnosis. Similarly, in the only study directly assessing parent's stress level in connection with diagnostic process, Moh and Magiati (2011) found that the duration of the diagnostic process (from first concerns to final diagnosis) was not associated with increased parenting stress in a sample of parents in Singapore. On average, this sample was able to consult with a professional within 6 months and attain a diagnosis within 12 months of their first concerns. This is a considerably shorter period than that found in the United States (Howlin & Asgharian, 1999; Siklos & Kerns, 2007; Wiggins et al., 2006). Therefore, similar research should be conducted in the United States, and is another gap this paper attempts to fill.

Current Study

As previously stated, little research has been conducted looking at the experience of parents with newly diagnosed children. One study (Estes, 2013) found that parents of toddlers diagnosed for the first time with an ASD were already experiencing higher levels of parenting stress than parents of typically developing children or children with a developmental delay. It is important to understand what contributes to the experience of parenting stress prior to a child's diagnosis in order to support parents appropriately during the process. Therefore the current study assessed parenting stress directly prior to a child's first autism diagnosis.

Similarly, few studies examine parenting stress across a child's development. Lecavalier, Leone and Wiltz (2006) found that parenting stress remained stable across a one year period. However, their sample included parents of children ages 3-18, and therefore did not highlight the differences in parenting stress at different times in development. Eisenhower, Baker and Blacher (2005) reported that parenting stress remained relatively stable when children were 3, 4, and 5 years of age, and that stress was related to both problem behaviors and having an ASD diagnosis. In contrast Green and Carter (2011) found that change in parenting stress from 28-52 months was not related to autism symptom severity or behavior problems, but to the change in daily living skills. The current study attempts to add to this literature by examining parenting stress between 2-4 years of age.

The current study seeks to address the following questions:

1. What contributes to the experience of parenting stress in parents of children with an ASD at 2, 4 and 8 years of age? The current study will examine the following domains:

   a. **Specific Stressors ("a" in the Double ABCX model):** what child characteristics (age, social skills, language skills, ASD symptom severity) predict parenting stress?
   b. **Pile-up Demands (aA):** Do parents of multiple children with an ASD experience higher levels of parenting stress?
   c. **External Resources (bB):** How does social support (both formal and informal) affect parenting stress? Does financial support affect parenting stress?
   d. **Appraisal of Stressor (C):** Does the timing of the parent's initial concerns relate to the level of parenting stress? Does the parent's perception of the child's development or need for services relate to parenting stress?
2. Do sources of parenting stress differ between parents of children with a DD and those with an ASD prior to the child's diagnosis?
3. Do changes in the above domains (a-c) relate to changes in parenting stress over time?
   a. Changes when the child is 2-4 years of age.

To address Question 1 the current study will examine the stated areas of inquiry within three cross-sectional samples: Time 1(24 months of age), 2 (50 months of age) and 3 (96 months of age). In order to address Question 2, this study will compare the results from the Time 1 ASD sample, to a sample of parents with children who have a DD. Finally the current study will answer Question 3 by using a subsamples of children with sets of scores at both Time 1 and 2 and Time 2 and 3.

Based on the proposed questions, previous research, and the Double ABCX model of stress, we have generated the following hypotheses:

1. Autism specific symptoms and specifically social skills will contribute to the experience of parenting stress at 2, 4, and 8 years of age; this relationship will be stronger for older children, as their ASD symptoms will be more apparent. ASD symptoms and social skills will not be related to parenting stress in the DD control group. The association between daily living skills and parenting stress will increase over time.
2. Parents with more than one child on the autism spectrum will have greater "pile-up demands," therefore it is hypothesized that these parents will have higher levels of parenting stress.
3. Social support will be associated with lower parenting stress after accounting for the child's ASD symptom severity at 2, 4, and 8 year time points.
4. Based on research suggesting that parents notice issues with their child's development long before a diagnosis is made, and that the diagnosis process can be stressful, it is hypothesized that parenting stress at the 2 year time point will be related to the amount of time between the parent's first concerns and the diagnosis.

Methods

Participants

Participants in the current study were part of a larger screening study assessing the psychometric properties of the Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al., 2001), and its revision the MCHAT-Revised (Robins et al., 2014). Parents were invited to participate at their pediatrician's office during the child's 18 or 24 month well-child visit. Additionally, some children were referred to the study by an Early Intervention service provider (28% Time 1, 46% Time 2 and 74% Time 3) or rarely, were directly referred by their concerned parent. If children screened positive for early signs of autism, families were invited for a free

developmental and diagnostic evaluation at the University of Connecticut (procedure detailed in full below). Children were evaluated at around 24 months of age (Time 1), and then re-evaluated at 48 months (Time 2). Some children received an evaluation at 8 years of age (Time 3) as part of a follow-up study.

In order to be included in the current study, the child had to receive an Autism Spectrum Disorder diagnosis, which included a diagnosis of autistic disorder, Asperger's syndrome, or Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS) at all time points s/he was evaluated. The children in the Time 1 comparison group had to have a diagnosis of Developmental Delay and no siblings with an ASD (4 families were excluded based on this criterion). The parent also had to have filled out the Parenting Stress Index- Short Form (Abidin, 1995) before the child's visit. The resulting cross-sectional ASD samples are comprised of 88 parents at Time 1, 102 parents at Time 2, and 35 parents at Time 3. The Time 1 Developmental Delay comparison group included 43 parents. Two subsamples of children received an evaluation and the PSI-SF at two time points: Time 1 and Time 2 (n = 45) and Time 2 and Time 3 (n= 21). Only two children received an evaluation and the PSI-SF at Time 1, 2 and 3, therefore analyses were not conducted at three time points. Please refer to Table 1-3 for demographic data on the parents and children in the Time 1, Time 2 and Time 3 cross-sectional samples.

Procedures

As described above, parents entered the study through their pediatrician, early intervention provider, or infrequently via self-referral. Parents filled out either the M-CHAT (Robins, Fein, Barton & Green, 2001) or the M-CHAT-R Robins, Fein & Green, 2014). If the child screened positive on the questionnaire, the parent was administered a follow-up interview over the phone in order to confirm their screener responses. If the child continued to screen

positive on the measure, the family was offered a free developmental and diagnostic evaluation at the University of Connecticut. If the family was unable to provide their own transportation, a taxi service was provided or the evaluation was conducted at their pediatrician's office. The evaluations were performed by a licensed clinical psychologist or a developmental pediatrician, and a graduate student in the clinical psychology Ph.D. program. Prior to the family's visit, they were sent a packet with the Parenting Stress Index-Short Form, a Caregiver Information form (including the Social Support Index), and a developmental history form.

During the evaluation, the graduate student conducted the Mullen Scales of Early Learning and the Autism Diagnostic Observation Schedule (ADOS) with the child. The parent was given the Vineland Adaptive Behavior Scales and the Toddler Autism Screening Interview (TASI), both in interview form. Based on their observations of the child, the examiners completed a Childhood Autism Rating Scale (CARS). A diagnosis was determined by clinical judgment, in conjunction with results from the Mullen, ADOS, TASI and Vineland, and according to DSM-IV-TR criteria. A diagnosis of developmental delay was given if the child scored 1.5 standard deviations below the mean on two of the four Mullen domains, including one of the two language domains (detailed below).

Regardless of diagnosis at Time 1, children seen at 24 months of age were invited for a re-evaluation around 48 months of age (Time 2). The same evaluative procedure was repeated, except the TASI was replaced by the Autism Diagnostic Interview (ADI). Additionally, a second round of 48 month screeners were sent out to families whose children had screened negative on the MCHAT/MCHAT-R at the child's original 18 or 24-month well-child visit in order to identify children with an ASD that the screener originally missed. Children who screened positive on this follow-up screener were invited for an evaluation and classified as "potential

misses." Finally, 40 children who had received an ASD diagnosis at both Time 1 and Time 2 were invited for a Time 3 evaluation at 92 months.

Measures

Modified Checklist for Autism in Toddlers (M-CHAT) / M-CHAT-Revised. The Modified Checklist for Autism in Toddlers (M-CHAT) is a parent-report questionnaire designed to assess for the risk of autism spectrum disorders (ASDs) in young children (Robins, Fein, Barton & Green, 2001). Parents read and respond to 23 yes/no questions regarding their child's current behavior. A child screens positive for ASD concerns if s/he "fails" three of the 23 total items, or two of six critical items. If the child screens positive on the questionnaire, then a follow-up phone interview is administered to ensure the accuracy of a parent's responses. The M-CHAT is a modified version of the original Checklist for Autism in Toddlers (CHAT; Baron-Cohen, Allen, & Gillberg, 1992; Baron-Cohen, Cox, & Baird, 1996). The measure has demonstrated good internal reliability both for the whole measure, as well as for the six critical items (α= .85 and α= .84 respectively; Kleinman et al., 2008). Studies have estimated the M-CHAT's sensitivity to be between .77 and .92 (Eaves, Wingert, Ho & Mickleson, 2006; Kleinman et al., 2008; Robins et al., 2001; Wong et al., 2004). Specificity has been estimated at .85 with the follow-up phone interview (Robins et al., 2001).

The Modified Checklist for Autism in Toddlers-Revised (M-CHAT-R; Robins et al., 2014) is a revision of the M-CHAT containing 20 yes/no questions. Similar to the M-CHAT, a child screens positive if s/he "fails" 3 of the 20 total items or 2 of the critical 6 items. Again, if their child meets either of these criteria, a follow-up phone interview is administered. A recent publication validating the MCHAT-R and follow-up interview, reported that children who failed at least 3 items on the screener, and then at least 2 items on the follow-up interview had a 47.5%

risk of being diagnosed with an ASD and a 94.6% risk of any developmental delay or concern. The measure with the follow-up interview demonstrated good sensitivity (0.83) and specificity (0.99).

Autism Diagnostic Observation Schedule-General (ADOS-G). The Autism Diagnostic Observation Schedule-Generic (ADOS-G; Lord et al., 2000) is a semi-structured play assessment that probes for behaviors within five domains: Communication, Reciprocal Social Interaction, Repetitive Behaviors and Play. There are four modules, which are selected based on the child's language skills (Preverbal/single words/simple phrases, Flexible phrase speech, fluent speech child/adolescent, fluent speech adolescent/adult); modules 1, 2 and 3 were used in the current study. The measure provides an algorithm and cut-off scores for three diagnostic classifications: no autism spectrum disorder, autism spectrum disorder (ASD) and autistic disorder. The inter-rater reliability has been reported as adequate across all domains: social (r = .93), communication (r = .84), social communication (r = .92), and restricted repetitive behaviors (r = .82). Inter-rater agreement for autism versus non-spectrum diagnostic classification based on the ADOS-G algorithm was 100% for Module 1 and 3, 91% for Module 2, and 90% for Module 4 (Lord et al., 2000). Validity of the entire measure and for each domain has been found to be adequate, with less consistency observed for Stereotyped and Repetitive Behaviors (Lord et al., 2000). Cronbach's alpha was highest for the Social domain (.86-.91 for each module), followed by Communication (.74-.84) and then Stereotyped Behaviors and Restricted Interests (.63-.65 for Modules 1 and 2, .47-.56 for Modules 3 and 4).

Childhood Autism Rating Scale (CARS). The Childhood Autism Rating Scale (CARS; Schopler, Reichler & Renner, 1988) is an observer-report questionnaire assessing a child's behavioral functioning within 15 subdomains including imitation, emotional responsiveness,

verbal and nonverbal language, visual response, use of body, and social reciprocity. The scale is meant to identify the severity of ASD behaviors, as well as differentiate those with an ASD from other developmental delays. The observer, in the current study a clinical psychologist or developmental pediatrician, rated a child's behavior in each subdomain on a scale from 1 (Typical) to 4 (Severely Abnormal). A total score is calculated ranging from 15 to 60, with cutoffs for non-autistic, mildly-moderately autistic, and severely autistic ranges. Higher scores indicate more severe ASD symptoms. An initial study on the psychometric properties of the CARS suggests acceptable inter-rater reliability at 0.71 and internal consistency at 0.94 (Schopler, Reichler & Renner 1988).

Mullen Scales of Early Learning. The Mullen Scales of Early Learning (Mullen, 1994) is a standardized test of cognitive abilities used with children from birth to age 68 months. It consists of five subtests: Gross Motor, Visual Reception, Fine Motor, Expressive Language, and Receptive Language. The Gross Motor domain was not administered in the current study. The measure offers T-scores, percentile ranks, and age equivalents for each domain. The measure demonstrated good inter-rater reliability (.94 to .98) and internal consistency using the split-half method (from .75 to .83 for each scale and .91 for the composite; Mullen, 1994). Additionally, the Mullen demonstrated adequate test-retest reliability in a sample of younger (1 to 24 months; .82 to .84) and older (25 to 56 months; .71 to .79) children.

A recent study by Bishop and colleagues (2011) validated the use of this cognitive measure on a population of toddlers with ASDs. The Mullen was determined to have good convergent validity with the Differential Ability Scales (DAS; Elliott, 1990, 2007) with Verbal IQ and Nonverbal IQ scores correlating at .74 and .83 respectively. Neither NVIQ nor VIQ

scores on the DAS and Mullen were significantly different from one another (t (50) = 0.56, p = 0.58; t (61) = 1.34, p = 0.19, respectively; Bishop, Guthrie, Coffing, Lord, 2011).

Differential Ability Scales-II. The Differential Ability Scales-II (DAS-II, Elliott, 2007) was used to measure intellectual ability at Time 3. Unlike the four domains produced by the Mullen, the DAS produces verbal, nonverbal and spatial reasoning scores. The test-retest reliabilities for all subtests range from 0.54 to 0.94 (Elliott, 2007). The DAS-II can be used with children whose mental ages range from 2 years, 6 months through 17 years 11 months. When a participant's developmental level fell below 2 years, 6 months, the *Stanford-Binet Intelligence Scales, Fifth Edition* (Stanford-Binet; Roid, 2005) was used to measure of verbal and nonverbal ability.

Stanford-Binet Intelligence Scales, Fifth Edition. The Stanford-Binet (Stanford-Binet; Roid, 2005) is another measure of cognitive functioning and extends down to the developmental age of 2 years, and therefore was used at Time 3 when the DAS-II was not appropriate. The Stanford Binet also give a Verbal and Nonverbal domain scores. The test has good psychometrics with internal consistency composite reliability for both verbal and nonverbal reasoning scores are above 0.95. Test-retest reliability for 8-10 year olds ranged from 0.76 to 0.91 for all subtests (Roid, 2005).

Vineland Adaptive Behavior Scales- Interview Edition. The Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984) is a standardized caregiver-report interview designed to assess a child's level of adaptive functioning. The measure includes four domains: Communication, Daily Living, Socialization, and Motor domains. The measure yields domain scores, standard scores, and an overall Adaptive Behavior Composite (ABC). In a sample of

children under 3, the Vineland-II demonstrated good internal consistency, with split half coefficients ranging from .90 to .97 for individual domains and .98 to .99 for the ABC.

Parenting Stress Index-Short Form (PSI-SF). The Parenting Stress Index- Short Form (PSI-SF- Abidin, 1995) is a 36-item self-report questionnaire assessing the level of relative stress in a parent-child relationship. The questionnaire is meant for parents of young children, and can be used for the parents of children 0-12 years of age. Each item requires the parent/caregiver to rate the degree to which s/he agrees with a statement on a five-point Likert scale (1 = Strongly Agree, 2 = Agree, 3 = Not Sure, 4 = Disagree, and 5 = Strongly Disagree). The questionnaire's 36 items are divided into three subscales: Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI), and Difficult Child (DC). Items are scored and added together to establish a total score as well as three subscale scores.

In 1995, Abidin created a model of parenting stress based on data collected from his original 120-item Parenting Stress Index (Abidin, 1983). A factor analysis revealed three factors or dimensions which Abidin labeled Parent Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI), and Difficult Child (DC). The Parent Distress subscale assesses the distress a parent experiences due to personal factors related to parenting, such as depression or conflict with a partner, and from life restrictions because of the demands of parenting, ("Since having a child I feel that I am almost never able to do things I like to do.''). The Parent-Child Dysfunctional Interaction subscale assesses how the parent perceives the relationship with his/her child, either positive (fulfilling and reinforcing) or negative (unsatisfying and unacceptable; "Most times I feel that my child does not like me and does not want to be close to me."). The Difficult Child subscale assesses child characteristics that would make him/her more

challenging to parent, such as self-regulatory abilities, temperament and defiance (“My child seems to cry or fuss more often than most children.’’).

The PSI-SF produces subscale raw scores ranging from 12 to 60 and an overall Parenting Stress (PSI-PS) total score that ranges from 36 to 180; a higher score indicates a greater level of stress. A PSI-PS score above 85 (at the 90th percentile) indicates clinically significant parenting stress (Abidin, 1995). The PSI-SF also includes a Defensive Responding (DR) scale to identify parents who might be attempting to minimize or deny problems.

The PSI-SF demonstrates good validity and reliability in populations of parents with typically developing children. Abidin (1995) reported internal reliability (Cronbach’s alpha) ranging from .80 to .87 for each of the subscales, and .91 for the measure overall. Other studies have found similar results (Deater-Deckard & Scarr, 1996; Haskett, Ahern, Ward, & Allaire, 2006). Adequate test-retest reliability has been demonstrated in several studies of typically developing children, with correlations for the overall scale of 0.70 to 0.80 (Deater-Deckard & Scarr, 1996; Haskett et al., 2006). The PSI-SF has demonstrated good convergent and divergent validity (Bigras, LaFreniere, & Dumas, 1996; Eyberg, Boggs, & Rodriguez, 1992; Haskett et al., 2006; Teti, Nakagawa, Das, & Wirth, 1991).

Despite the measure’s wide use in research on families affected by ASDs, fewer studies have explicitly examined the psychometric properties of the PSI-SF with this population. Many studies have reported good internal reliability for the measure, reporting Cronbach’s alphas ranging from .84 to .92 for the subscales and the total score (Davis & Carter, 2008; Herlihy, 2010; Zaidman-Zait et al, 2010). Zaidman-Zait et al. (2010) examined the utility of specific items, conducting analyses based on item response theory on data from parents of 141 children with an ASD. Factor analyses supported the presence of three distinct factors within the PSI-SF.

The item response analyses suggested that the PD subscale items contributed to the overall score, while on their own, the P-CDI and DC subscales should be used with caution, as items within these scales were frequently too easy or too difficult for parents to endorse. Therefore this study focused more on the overall parenting stress score, rather than placing too much importance on any single scale.

Although in previous literature the PSI-SF is treated as a continuous measure, the questionnaire only reports raw (as opposed to standardized) scores. Therefore it is unlikely that a parent who scores a 45 is experiencing exactly half the stress that a parent who scores a 90; we took this method of measurement into account and considered the PSI-SF as closer to an ordinal measure in many ways, as opposed to an interval measure. Therefore when presenting correlations both Spearman's correlations were computed, as well as Pearson's correlations in order to be in line with previous research. Unless noted, the Pearson's correlations were not significantly different from the Spearman's correlations, and thus the Spearman's correlations were reported.

Social Support Index (SSI). The Social Support Index (SSI; McCubbin, Patterson, & Glynn, 1982) is a 17-item; self-report questionnaire that assesses an individual's perceived support from both his/her family and the community. On each item the individual indicates his/her level of agreement with a statement on a 5-point Likert scale from 0 (strongly disagree) to 4 (strongly agree). Items 7, 9, 10, 13, 14, 15 and 17 are reverse scored, (4 = strongly disagree to 0 = strongly agree). All items are totaled with higher scores indicating higher levels of social support. Internal consistency has been reported as $\alpha = .83$, with a test-retest correlation of .83 (Fischer & Corcoran, 2007). The same study found that the SSI predicted family resilience, and was related to family efficacy in dealing with difficult situations.

Power Statement

For the purposes of this study, power calculations were estimated for each sub-sample separately (Time 1 sample, Time 2 sample, Time 3 sample). The Time 1 (n = 88) and Time 2 (n = 102) samples provide sufficient power ($1-\beta = .80$, alpha = .50) to detect a medium to large correlation ($r \geq .30$) between characteristic variables and parenting stress, and to detect a medium to large main effect ($d \geq .60$). The Time 3 (n = 35) sample is only sufficient for detecting large correlations and main effects ($r \geq .50$; $d \geq .70$).

Results

Child and Parent Demographic Characteristics at Time 1, 2, and 3

Demographic data for each ASD sample, children and parents, are presented in Tables 1-3.

Two children were excluded from the original Time 1 ASD sample, due to their Parenting Stress Total scores being greater than three standard deviations from the mean (Keppel & Wickens, 2004, pp.145). In the Time 1 cross-sectional sample (n = 88) the children were an average of 25.26 months of age (SD = 4.98) and 78% male, which is consistent with the ratio reported by epidemiological studies (Fombonne, 2003). Two children were adopted. Due to the small sample size, and previous research suggesting that involved mothers and fathers experience similar levels of parenting stress, the data from mothers and fathers were combined (Davis & Carter, 2008). Seventy-seven (88%) of the parents who participated were mothers. This sample of parents was 64% Caucasian and had an average yearly income of $ 58,976 (SD = 33,201). Twenty-one (24%) parents had two or more children with an ASD, while 67 (76%) had one child with an ASD.

In the Time 2 cross-sectional sample (n = 102) the children were an average of 50.75 months of age (SD = 6.77) and 85% male. Ninety-eight (96%) of the parents who participated

were female; there was one grandmother, and four fathers. This sample of parents was 78% Caucasian and had an average yearly income of $ 72,128 (SD = 31,026). Eighteen children were classified as "potential misses" meaning that they were identified in a second round of screening at 48 months. Eighty-eight (86%) parents had only one child with an ASD, and 14 (14%) had two or more.

In the Time 3 sample (n = 35), the children were an average of 117.29 months old (SD =11.04), and 83% male. The sample of parents was 91% female, including two adoptive mothers. Parents were 91% Caucasian and had an average yearly income of $74,412 (SD = 27,846). Eight parents (23%) had two or more children with an ASD.

Time 1 Sources of Parenting Stress

At Time 1, the total average level of Parenting Stress was 76.41, however scores varied widely with a standard deviation of 20.02 (see Table 4 for PSI-SF data). Although the average was below the "clinically significant stress" cutoff of 90, this score was within a single standard deviation of that score, suggesting that these parents were experiencing an elevated level of stress. It should be noted that the variable Difficult Child was positively skewed, in the ASD group, and thus a square root transformation was performed; however the mean and standard deviation reported in the table represent the original data. Correlations were conducted in order to assess the relationship between child characteristics and Total Parenting Stress. Specifically the relationships between child age, ADOS severity score, CARS total, Mullen age equivalents (visual reception, fine motor, expressive language, receptive language), and adaptive skills (Vineland Social and Daily Living Skills) were assessed. Mullen t-scores were highly positively skewed, therefore ratio IQ scores were calculated using Age Equivalents and the following formula: (Mullen Age Equivalent/ chronological age) * 100. There were no differences in

significant predictors between Pearson's and Spearman's correlations when examining Total Parenting Stress. There was a significant positive relationship between Total Parenting Stress and CARS total (r_s (86) = .237, p = 0.027) and Vineland Social Skills (r_s (86) = -.286, p = 0.007). There were no other significant relationships between Total Parenting Stress and child characteristics at Time 1 (see Table 5). It should be mentioned, the current sample only has sufficient power to accurately detect correlation coefficients ≤ .30. When examining the three PSI-SF subscales, only the Parent-Child Dysfunctional Interaction was significantly correlated with the CARS total (r_s (86) = .347, p = 0.001), and thus based on the Zaidman-Zait et al. (2010) article previously discussed, this result should be interpreted with caution. The Vineland Social Skills domain was associated with all three subscales at the trend level or stronger, but only with Parent-Child Dysfunctional Interaction at a significant level (see Table 5).

In order to further probe informal social support's effect on parenting stress and its interaction with ASD symptoms, a partial correlation was conducted controlling for CARS and Vineland Social scores. This analysis was not significant, suggesting no relation between child ASD symptoms, social support and parenting stress (r = -.170, p =.132).

Next, Spearman's correlations were computed to assess the relationship between Total Parenting Stress, pile-up demands, and external resources; specifically parent age, number of children, number of children with an ASD, yearly income, informal social support (SSI total score), and the time since initial concern were assessed. Number of children was operationalized as the number of children, including half-siblings, which the parent noted to be living in the home. Total Parenting Stress was significantly correlated with the number of children in the home, and there was a trend for the number of children with an ASD (r_s (86) = .255, p =.016; r_s (86) = .201. p = .060 respectively). There was also a significant correlation between the amount

of time between the parents' initial concern and the child's diagnosis and Total Parenting Stress (ρ (75) =.314, p =.005). Social support, parent age and yearly income were not significantly related to Total Parenting Stress (Table 5).

A Mann-Whitney U test was conducted in order to assess whether parents who received formal social support (therapy, parenting group or respite care) experienced different levels of stress than parents who did not. Twenty-three parents reported receiving some form of formal social support, while 65 did not. The null hypothesis was maintained, parents who received formal social support did not experience significantly different levels of parenting stress than those who were not enrolled in formal social support (z = -.36, p = .722). Parents were asked about informal support related to childcare, specifically whether his/her spouse or other family/friends helped with childcare. Two Mann-Whitney U tests were conducted to assess whether a parent's perception of informal help with childcare from their spouse and/or other friends/family affected Total Parenting Stress levels. There was no significant difference between distributions of total stress scores in parents who reported receiving equal help with childcare from their spouse versus those who received less help from their spouse (z = -.059, p = .953), or those who reported daily help from other individuals (family/friends) versus those who do not (z = -.998, p = .318).

Two Mann-Whitney U tests were conducted to assess the parent's perception of the child, and whether it affected Total Parenting Stress levels. First we examined whether parents who perceived that his/her child "stopped gaining skills" experienced higher levels of stress than those who did not. Forty-six parents denied that his/her child had stopped gaining skills with an average Total Parenting Stress score of 70.78 (SD = 18.64), while 40 parents indicated that his/her child had stopped gaining skills and indicated an average Total stress score of 82.85 (SD

= 20.29). The Mann Whitney Test confirmed that there was a significant difference in the distribution of Total Parenting Stress scores between these two groups of parents ($z = -2.88$, $p = .004$). Second, we examined whether parents who stated that his/her child "needed more services" experience higher levels of parenting stress. Only 68 parents responded to this question. The forty-six parents who denied that his/her child needed more services had an average Total Parenting Stress score of 72.62 (SD =18.74), while the 24 parents who indicated that his/her child required more services reported an average Total Parenting Stress score of 82.71(SD = 21.12). The Mann Whitney U test reported no significant difference between these two groups ($z = -1.83$, $p = .067$).

Based on the previous results examining the relation of Total Parenting Stress to child characteristics, parent perception, pile-up demands and social support, a set of significant predictors was determined: CARS total symptom severity, Vineland Social Skills, number of children, time since initial concern, and an indication that the child stopped gaining skills. The predictors were entered into a hierarchical linear regression in the following order: child characteristics, pile-up demands and appraisal of stressor. The model was assessed for collinearity, Tolerance was between .805-.997 with VIF ranging between 1.003-1.226, well within accepted assumption limits. The overall model was significant $F(5,70) = 5.31$, $p < .001$, and accounted for 28% of the variance in Total Parenting Stress. Block 1 (CARS and Vineland Social Skills) was significant and explained 10% of the variance with Vineland Social Skills reaching significance. Block 2 (Number of Children) was significant and explained an additional 6% of the variance, Vineland Social Skills maintained trend-level significance, with Number of Children reaching significance. Finally Block 3 (Time Since Initial Concern and Stopped Gaining Skills) was significant and explained an additional 11% of the variance, with Time

Since Initial Concern and Stopped Gaining Skills each significantly contributing to the model (Table 6).

ASD specific symptoms, and specifically social deficits, were related to higher levels of parenting stress in the Time 1 sample. Additionally the number of children in the parent's home was associated with higher parenting stress. However, the parent's perception of the child's development, specifically whether the child stopped gaining skills and how long the parent has had developmental concerns, accounted for variance above and beyond both child characteristics and pile-up demands. Contrary to our hypothesis, social support was not related to parenting stress at Time 1.

Demographic Characteristics of Time 1 ASD and DD Samples

Next we examined the DD comparison group (see Table 7 and 8 for demographic comparisons). There was no difference in age between children given an ASD diagnosis (M = 25.26, SD=4.98) and those given a DD diagnosis (M= 24.69, SD = 4.13) at Time 1 (t(129) = -.665, p = .507). Similarly there were no gender differences between the two groups of children. Parents in the ASD group were older (M = 33.65, SD = 5.86) than the parents in the DD group (M = 30.21, SD = 6.90; t(122) = -2.93, p= .004). Of those parents who provided yearly income data (n = 113), there was no difference between the ASD (M = 59,487, SD = 32,259) and DD groups (M = 49,571, SD = 37,286; t(111) = -1.44, p=.153).

Parenting Stress in ASD and DD samples

Means, standard deviations and t-scores are presented in Table 9. There was no difference between Total Parenting Stress in the ASD (M = 76.41, SD = 20.02) and the DD (M =82.54, SD = 23.77) groups (t(129) = 1.55, p = .13). As previously stated a score above 90 indicates the presence of clinically significant stress. A Pearson's chi-square analysis was

conducted to examine whether the number of parents who scored above 90 differed by group. Thirty-five percent of parents in the DD group, and 30% of parents in the ASD group scored within this "clinically elevated" range; this is not a statistically significant difference, X^2 (1, 131) = .383, p = .536. Parents in the DD group were not included if they also had a child with an ASD.

Time 1 Sources of Parenting Stress in ASD versus DD families

The same analyses as conducted in the Time 1 ASD group, detailed above, were repeated for the Time 1 DD group. Spearman's correlations were conducted to assess the relationship between child age, ADOS severity score, CARS total, Mullen ratio IQ scores (visual reception, fine motor, expressive language, receptive language), and adaptive skills (Vineland Social and Daily Living Skills) were assessed. There were no significant correlations between Total Parenting Stress and any of the measured child variables.

Next, Spearman's correlations were calculated to assess the relationship between Total Parenting Stress, pile-up demands, and external resources; specifically parent age, yearly income, informal social support (SSI total score), and the time since initial concern were assessed (Table 9). Total Parenting Stress was significantly negatively correlated with the parent's score on the SSI ((41) = -.440, p =.003); importantly SSI was not associated with yearly income in this group ((33) = -.050, p =.776). Surprisingly there was a negative trend between number of children and Total Parenting Stress ((41) = -.290, p =.059). Only 35 parents supplied information regarding their yearly income; the negative correlation was not significant ((33) = -.308, p =.072).

Only 8 parents in the DD group indicated being involved in formal social support, with a mean Total Parenting Stress score of 94.13 (SD = 27.24), suggesting that these parents are

experiencing significant levels of stress, which may be why they sought out formal support. The other 35 parents had an average Total Parenting Stress score of 79.86 (22.51). However the difference between these groups was not significant ($p = .109$). Similar to the ASD group, whether the other parent was equally involved in child care or whether the parent had daily help from outside individuals, did not make a significant difference in the distribution of Total Parenting Stress scores ($z = -.884, .399$; $z = -1.182$, $p = .237$ respectively).

Twenty-three parents denied that his/her child had stopped gaining skills with an average Total Parenting Stress score of 80.22 ($SD = 24.32$), while 11 parents indicated that his/her child had stopped gaining skills and indicated an average Total Parenting Stress score of 82.85 ($SD = 23.48$). The Mann Whitney U Test reported no significant difference in Total Parenting Stress scores between these two groups of parents ($z = -.416$, $p= .682$). Nineteen parents confirmed that his/her child needed more services; they had an average Total Parenting Stress score of 81.36 ($SD = 22.99$), while fifteen parents denied that his/her child required more services, and reported an average Total Parenting Stress score of 77.90 ($SD = 24.52$). The Mann Whitney U test reported no significant difference between these two groups ($z = -.514$, $p = .612$).

Based on these findings, similar to the Time 1 ASD group, a linear regression was conducted in order to test the amount of variance accounted for by number of children and SSI score. VIF was 1.032 for both variables included. The predictors number of children (step 1), and SSI score (step 2), were entered into a hierarchical linear regression. The overall model was significant $F(2,40) = 3.60$, $p = .037$, and accounted for 15% of the variance in Total Parenting Stress. Block 1 (number children) explained 4% of the variance, however, it was also not significant. Block 2 (SSI) explained an additional 11% of the variance. SSI was the only significant contributor in the final model (see Table 10). The model confirms the hypothesis that

even after accounting for the number of children, informal social support from family, friends and the community significantly affects parenting stress in the DD group.

We hypothesized that ASD specific symptoms would not affect level of parenting stress, and this proved to be true within our sample. Parenting stress, in a sample of parents of children who went on to be diagnosed with a DD, was most related to the level of informal social support, however this only accounted for 11% of the variance in Total Parenting Stress.

Time 2 Sources of Parenting Stress

For the Time 2 cross-sectional sample, the average Total Parenting Stress was 84.59 (SD = 19.29). As noted previously, 18 children in this sample were "potential misses," meaning that they were picked up by an autism screener (MCHAT, MCHAT-R, SCQ) at Time 2, but not at Time 1. There was no significant difference in Total Parenting Stress between the "potential miss" group (M = 83.06, SD = 17.54) and the other parents (M = 84.92, SD = 17.54; z = -.307, p = .759). There were no significant differences between these two groups across measures of autism symptoms (ADOS or CARS) or social support (SSI). However, parents of "potential miss" children consistently reported higher Vineland scores across domains (social, daily living skills, communication and motor), suggesting that these children have generally higher adaptive skills. Additionally "potential miss" children had higher Mullen Visual Reception and Fine Motor skills. These results are to be expected, as these higher skills likely contributed to them being missed in the first round of screening. All statistical procedures were conducted with the groups separately to assess differences, and then with the combined sample.

Examining child characteristics, there were no significant correlations between any domains on the Mullen, child age, ADOS severity score, Vineland domains or CARS total. However, the CARS total score, Mullen Visual Reception and both Vineland scales were

significantly associated with the Parent Child Dysfunctional Interaction subscale (see Table 11). As cautioned by Zaidman-Zait et al. (2010), this subscale may be particularly elevated when children have greater ASD related symptoms, which is likely reflected in these correlations. There were no significant correlations between Total Parenting Stress and pile-up demands, SSI, or external resources (Table 11). It should be noted, that when the Time 2 sample was separated into "potential miss" and "not," the "potential miss" group demonstrated a significant association between yearly income and Total Parenting Stress ($r_s(16) = -.504$, $p = .033$), as well as Mullen Visual Reception ($r_s(16) = -.537$, $p = .026$). These differences suggest that parents of children with a later diagnosis may experience parenting stress differently than those whose children were diagnosed at 24 months; thus this is an area in need of further exploration. Mann-Whitney tests were not performed on the "potential miss" group separately, as the groups within this subsample were too small ($n < 10$). A Mann-Whitney test on the entire sample demonstrated a trend; parents enrolled in formal social support experienced higher levels of parenting stress than those who were not ($z = -1.886$, $p = .056$). There was no difference in total stress between parents who received help with childcare from family/friends, and those who did not ($z = -.315$, $p = .752$). Parents who reported receiving "no" or "little" help from a spouse ($M = 91.77$, $SD = 16.77$) did not demonstrate higher levels of stress than those who receive "some" or "equal" help in caring for their children ($M = 83.01$, $SD = 19.99$; $z = -1.787$, $p = .074$).

As no predictors reached the level of significance for the entire group, a regression model was not completed. Contrary to hypotheses, ASD specific child characteristics were not associated with higher levels of parenting stress, nor were any measures of informal social support. It is likely that other, unmeasured variables, such as problem behaviors and parent mental health, contribute to the experience of parenting stress that this age. Additionally, there

was a difference between the small "potential miss" subsample and those parents who came in for a Time 1 visit. Therefore there may be differences in parenting stress depending on diagnostic timeline and the characteristics that lead a child to be evaluated.

Time 1 and Time 2 Subsample Demographics

A subsample of mothers completed the PSI-SF at both Time 1 and Time 2 evaluations. All of the children in this subsample had an ASD diagnosis at all time points assessed. The Time 2 evaluation took place an average of 23.86 months (SD = 5.19) after the Time 1 evaluation. For complete demographic data see Table 13 and 14. A series of Wilcoxon Signed-Rank Tests were completed to assess changes in parenting stress over time. There was a significant increase in Total Parenting Stress, and specifically the Difficult Child subdomain between Time 1 and Time 2; see Table 14.

Time 1-2 Factor Changes Related to Changes in Parenting Stress

In order to assess whether changes in child characteristics were associated with changes in Total Parenting Stress, change scores were calculated by subtracting the Time 1 scores from Time 2 scores on any given domain (CARS total, Mullen scores, etc.). Spearman's correlations were then conducted to assess whether changes in child characteristics were related to changes in Total Parenting Stress (Table 15). Change in Total Parenting Stress was significantly associated with Vineland Daily Living (ρ (41) = -.427, p = .004) and Social Skills (ρ(41) = -.304, p = .048). The less a child's adaptive skills improved, the more a parent's stress level increased over time. Changes in Total Parenting Stress were not related to change in child age, ASD severity or cognitive scores.

Additionally, partial correlations were calculated controlling for Time 1 Total Parenting Stress as well as the specific Time 1 child characteristic (Table 16). Based on these analyses, the

only child characteristic associated with Time 2 Total Parenting Stress was Vineland Daily Living Skills ($r(41) = -.336$, $p = .032$).

Next, changes in pile-up demands and external resources were assessed for their relationship to changes in Total Parenting Stress. Changes in yearly income, informal social support and the mother's age were not associated with a change in parenting stress; neither were the number of siblings or siblings with ASD at Time 2. When examining the same domains controlling for Time 1 Total Parenting Stress and the Time 1 score of interest, parent age, SSI and yearly income were not significantly associated with Time 2 Total Parenting Stress. Additionally, we examined whether Time Since Initial Concern was related to Time 2 Total Parenting Stress when controlling for Time 1 Total Parenting Stress, however, this was not significant; suggesting that the effect of Time Since Initial Concern on parenting stress is limited to Time 1.

Using the items associated with a change in parenting stress over time, a hierarchical linear regression was conducted. In the first step Time 1 Total Parenting Stress, Vineland Daily Living and Social scores were entered into the model predicting Time 2 Total Parenting Stress (Table 17). In the second step, Time 2 Vineland Daily Living and Social Scores and in step three, Time 2 yearly income. VIF ranged from 1.203-1.859. This model was also significant $F(5, 37) = 6.658$, $p < .001$, accounting for 47% of the variance in Time 2 Total Parenting Stress. Aside from Time 1 Total Parenting Stress, Time 2 Daily Living Skills was the only other significant contributor ($\beta = .330$, $t(37) = -2.031$, $p = .050$. Time 2 Vineland Daily Living and Social scores explained an additional 7% of the variance, although this was not a significant change. In accordance with the partial correlations and change score correlations, changes in daily living

skills appear to be most associated with changes in parenting stress, although its contribution is limited.

Total Parenting Stress increased between Time 1 and Time 2. This increase in stress was associated with lower daily living skills in the 4 year old children after controlling for the child's daily living skills at Time 1. Parents expect their 4 year old children to be able to accomplish more daily living activities on their own, such as feeding themselves, getting dressed and using the bathroom, than they expected from their 2 year old, and thus deficits may be more noticeable as well as stressful for these parents.

Time 3 Cross-sectional Sample Sources of Parenting Stress

The average Total Parenting Stress for the Cross-Sectional Time 3 sample was 90.09 (SD = 24.79); on average the parents were reporting clinically significant levels of stress (Table 4).

Examining child characteristics, Spearman's correlations demonstrated a significant association between Total Parenting Stress and both Vineland Daily Living ($\rho(33) = -.505$, p = .002) and Social skills ($\rho(33) = -.498$, p = .003). Due to their advanced age, the Mullen was not used to evaluate cognitive scores, and instead either the Stanford Binet or the DAS was used to calculate both a Verbal and Nonverbal cognitive score. There was a significant correlation between Verbal cognitive scores and Total Parenting Stress ($\rho(33) = -.384$, p = .025). There were no significant correlations with child age, Nonverbal cognitive scores, or ADOS severity. The CARS total score was significantly associated with Total Parenting Stress using Pearson's correlation, but not Spearman's correlation ($r(32) = .360$, p = .043, $\rho(32) = .285$, p = .113). Correlations were generally consistent across subdomains, however Nonverbal cognitive skills were significantly correlated with the Parent Child Dysfunctional Interaction subscale ($\rho = -.384$,

p = .025). There were no significant correlations between Total Parenting Stress and pile-up demands, SSI, or external resources (Table 18).

A Mann-Whitney test demonstrated no significant difference in Total Parenting Stress between parents enrolled in formal social support and those who were not (z = -1.196, p = .232). There was no difference in Total Parenting Stress between parents who indicated that they received help with childcare from family/friends, and those who indicated that they did not (z = -.150, p =.882). Only 5 parents indicated receiving "no" or "little" help from their spouse, and these parents did not report experiencing significantly different levels of parenting stress than those that indicated receiving "some" or "equal" help (z = -.377, p = .706).

The first regression model generated included Vineland Daily Living and Social Skill scores and the child's Verbal cognitive score. The model was assessed for collinearity, Tolerance was between .286-.499 with VIF ranging from 2.002-3.500, which is outside generally accepted cutoffs. It was noted that the two Vineland subscales were highly correlated (r =.830, p < .001), which violates the assumptions necessary for linear regression. Although the Daily Living and Social subscales represent theoretically separate skills, as children develop, there may be greater overall deficits leading to less distinct factors. Thus for the purposes of our model, Vineland Social Skills subscale was used, as it was more highly correlated with the dependent variable. The VIF for this model was 1.85 and tolerance was at 0.54, within accepted limits. The overall model was significant (F(2,30) = 6.334, p = .005) and explained 30% of the variance in Total Parenting Stress. Verbal scores were entered first and accounted for 14% of the variance, followed by Vineland Social Skills which accounted for an additional 16% of the variance in Total Parenting Stress. In the final model, Vineland Social Skills was the only significant contributor (t(30) = -2.60, p = .014).

At Time 3, Total Parenting Stress was associated with the child's verbal skills, as well as social and daily living skills. Vineland Daily Living and Social subscales were highly correlated with one another and suggest that in middle childhood, children with ASD may demonstrate a general level of deficit across adaptive skill domains, causing the Vineland to be less useful in differentiating between symptom factors. As the Vineland represents the only parent-completed symptom questionnaire included in the study, parents may experience increased stress due to the wide-spread deficits they observe in their child across adaptive domains.

Time 2 and Time 3 Subsample Demographics

A subsample of mothers (n = 21) completed the PSI-SF at both Time 2 and Time 3 evaluations. All of the children in this subsample had an ASD diagnosis at Time 2, clinical diagnoses were not given at Time 3 as evaluations were completed by graduate students. The Time 3 evaluation took place an average of 62.13 months (SD = 9.90) after the Time 2 evaluation. For complete demographic data see Table 19 and 20. A series of Wilcoxon Signed-Rank Tests were completed to assess changes in parenting stress over time. There were no significant changes in Total Parenting Stress or other PSI-SF subscales (Table 21). On average parents in this subsample experienced clinically significant levels of parenting stress at both Time 2 and Time 3, therefore these parents may experience a ceiling effect in the level of stress experienced, or stress may stabilize over time as parents become more used to particular challenges relating to their child's development and behavior.

Although on average Total Parenting Stress only changed 2.33 points between Time 2 and Time 3, there was variability within the subsample (SD =25.58). Therefore correlations were completed to further understand what factors are associated with these changes. Similar to the Time1-Time 2 sample, change scores were calculated. There were no significant associations

between change in parenting stress and change in child or external factors (Table 22). There was a significant correlation between Number of ASD Children and Total Parenting Stress (r = .595, p = .002). Controlling for the Time 2 scores, there was a significant correlation between Time 3 Total Parenting Stress and both Time 3 Daily Living and Social Skills on the Vineland (r = -.549, p = .022; r = -.624, p = .007).

Due to high collinearity between the Vineland subdomains, the assumptions for a regression model were not met, therefore similar to the Time 3 sample, Vineland Social Skills was used in the model. Additionally Number of ASD Children was not included in the final model as Time 2 and Time 3 ASD Children were highly collinear with one another, and the small sample size made this an untenable variable. The VIF for this model ranged between 1.05-1.25, with Tolerance between .80-.95. The overall model was significant (F(3,15) = 5.99, p = .007; Table 20) and accounted for 55% of the variance in Time 3 Total Parenting Stress. Interestingly after adding Time 3 Vineland Social Skills to the model, Time 2 Total Parenting Stress was no longer a significant contributor. This may indicate that there is a shift in parenting stress between Time 2 and Time 3 as deficits in domains such as daily living and social skills become more pronounced and parents become more aware of these deficits. However, the results from this sample should be interpreted with caution due to the limited sample size.

Discussion

The current study sought to understand the experience of parenting stress in parents of children with an ASD beginning before the diagnosis and across multiple stages of development. Drawing upon the Double ABCX model of stress, this study was interested in how child characteristics, external factors, pile-up demands and parent perception affect levels of parenting stress.

At Time 1, parenting stress in parents of two years olds who received an ASD diagnosis was associated with ASD symptoms (CARS total and Vineland Social Skills), the number of children in the home, and the parent's perception of the child's development. Specifically parents who indicated that their child had stopped gaining skills and those who had waited longer for a diagnosis experienced higher levels of parenting stress. Social support both formal and informal, were not significant in ameliorating the experience of parenting stress.

On average parents waited 12.37 months (SD = 7.11) from their initial concern to the child's diagnosis through the study. This is a similar time frame to Moh and Magiati (2011) who found that parents did not experience heightened levels of stress related to the diagnostic process in a sample of parents in Singapore. The differing results may be due to the differences in the diagnostic process between the United States and Singapore, or cultural differences in the role parents play in the process. As these are the only two studies to date that have looked at parenting stress and parent perceptions around the diagnostic process, clearly more research needs to be conducted focusing on this area.

Parents at Time 1 whose children received a DD diagnosis experienced similar levels of parenting stress to those whose children were diagnosed with an ASD. Previous research has consistently shown that parents of children with an ASD experience higher levels of stress than those whose children have a DD (Estes et al., 2009; Hayes & Watson, 2012). In this study, children were evaluated at a younger age, and parents filled out the PSI-SF prior to the diagnosis; each of these could have contributed to the incongruity between our study and other published work. Future research should measure stress prior to and soon after the child's diagnosis in order to further elucidate this finding. In line with our hypothesis, parenting stress in the DD group was not affected by ASD specific symptoms such as social skills or ASD symptom severity.

Parenting stress in this sample was most related to level of informal social support from family, friends and the community (as measured by the SSI).

Taken together the results from Time 1 present an interesting picture. It may be that parents of children with an ASD are noticing that something is "different" with their child, such as social deficits and that they stop gaining skills. The longer the time between the parent's first concern and the child's diagnosis, the greater the uncertainty and stress around what the future holds for the child. Parents of toddlers with an ASD may wish for more formal support for their child, and thus informal social support does not have beneficial effects as it does for parents of children with a DD. For example, parents may feel that they need the formal support of a pediatrician and early interventionists more than the advice of a friend.

Contrary to our predictions, ASD specific symptoms and daily living skills were not associated with parenting stress at Time 2. Nor did social support, informal or formal, play a role in the experience of parenting stress in this group. It is likely that variables not measured in this study are the main contributors to parenting stress; specifically we did not include a measure of child behavior problems or parent mental health concerns. Child behavior problems have consistently been shown to play a significant role in parenting stress across other studies (Davis & Carter, 2008; Estes et al., 2009; Hastings et al., 2005), and therefore were notably missing from the current design.

Another consideration for the Time 2 sample is the presence of 18 "potential miss" children in the sample. These children were picked up by a developmental screener at age 4, as opposed to age 2. Although parents of these children did not differ on reported levels of parenting stress, parents did describe their children as having greater adaptive functioning (Vineland Social and Daily Living skills), and the children were found to have higher scores on

the Mullen Fine Motor and Visual Reception domains. Parents of "potential miss" children indicated higher levels of stress associated with lower Mullen Visual Reception scores and lower yearly incomes. The differences between sources of stress in these two subgroups suggest that parents who go through different diagnostic processes, and whose children are "higher functioning" may experience stress from different sources. However, due to the small sample size of "potential miss" children and the heterogeneity among this group, it is difficult to draw conclusions based on our sample alone.

In looking at how changes from Time 1 to Time 2 affect parenting stress, we found that changes in both parent-reported adaptive skills, both social and daily living, were associated with higher levels of parenting stress. Time 2 daily living skills significantly accounted for variance above and beyond that accounted for by Time 1 parenting stress and Time 1 daily living skills. Thus our results mirror those of Green and Carter (2011) who found that a positive change in the child's daily living skills was related to a decrease in parenting stress after accounting for child age, developmental level, autism severity, and problem behaviors. However, Time 2 Daily Living Skills only accounted for 7% of the variance in Time 2 Total Parenting Stress, therefore it is likely that other non-measured variables such as problem behaviors have a greater contributory effect on the increase in parenting stress.

When children were in middle childhood (Time 3), parents in our sample were, on average, experiencing clinically significant levels of parenting stress. In our sample, higher Verbal skills were associated with less parenting stress. Although other studies have consistently shown that parenting stress is not related to cognitive abilities, these studies examined younger children or high functioning populations (Davis & Carter, 2008; Rao & Beidel, 2009). Both at Time 3 and from Time 2 to Time 3, parenting stress appeared most related to adaptive skills as

measured by the Vineland questionnaire. Deficits in adaptive skills, including social and daily living skills, have consistently been shown to be a major component of the ASD phenotype. Individuals with ASD frequently have deficits in adaptive skills that go beyond what would be expected based on their cognitive level (Anderson, Oti, Lord & Welch, 2012; Klin et al., 2007). Additionally, adaptive skills have been shown to be predictive of a child's prognosis (Gilham, Carter, Volkmar & Sparrow, 2000), and thus an important component of the overall diagnostic picture. It also appeared that parents who had multiple children with an ASD experienced an increase in Total Parenting Stress, as compared to those with only one child with an ASD, although the sample was too small to make any definitive conclusions.

Our original hypothesis that ASD symptoms would be associated with parenting stress, and that the association would become stronger over time was partially supported. Although examiner-completed measures such as the CARS and the ADOS were not more strongly related to parenting stress at later time points, parent-reported ASD symptoms, specifically social skills, were. Thus it may be that parents are noticing social deficits in the child's daily life that the examiner is not able to identify during the evaluation. For example, the examiner does not see the child interact with other peers. Also the CARS and the ADOS are more general measures of symptom severity, therefore it might be social symptoms specifically that are most related to parenting stress. Another hypothesis was that parents of more than one child with an ASD would experience higher levels of stress than parents with only one child who has an ASD, due to the greater "pile-up demand." Overall this was not supported in our study. Parents may gain skills and competence at working with their children who have an ASD, and thus multiple children with an ASD do not add to their experienced levels of stress. Studies of parenting stress

generally exclude multiplex families, thus more research should be conducted to understand the experience of these families.

The current study did not support the beneficial effects of social support found in some previous research (Boyd, 2002; Bishop et al., 2007; Hastings & Johnson, 2001; Ekas, Lickenbrock & Whitman, 2010). The current study addressed general informal social support using the SSI, and then probed whether parents had instrumental help with childcare from their spouses, as well as other family and friends. These data were not found to be related to parenting stress at Time 1, Time 2 or Time 3 in the ASD groups. The results of this study were similar to previous research suggesting that formal support does not help to lessen parenting stress. However, few parents in each of our samples were engaged in formal social support such as parenting groups or respite care, and therefore we cannot draw firm conclusions. Additionally, it is likely that parents who do receive formal social support are experiencing heightened distress from their own mental health concerns or the child's heightened level of need.

Clinical Implications

The current study demonstrated the importance of parent perceptions on the experience of parenting stress. Before the child is even diagnosed, parents are experiencing heightened levels of stress due to their concerns for their children's development. This finding in combination with the literature suggesting that parents consistently have concerns prior to the child's diagnosis (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; Hess & Landa, 2012; Chawarska et al., 2007), suggests that pediatricians and other healthcare professionals should pay particular attention when a parent voices concerns about their child's development, especially those that are social in nature. Concerns may not only be an indication of an issue in the child's development, but also a heightened level of parenting stress that could go on to affect both the parent's mental

health as well as the child's development. Our study suggests that parents might benefit from added support and attention after endorsing concerns. Although Time Since Initial Concern no longer predicted Time 2 parenting stress in the longitudinal sample, Time 1 Total Parenting Stress continued to predict 40% of the variance in Time 2 parenting stress. Thus early stressors may initiate a trajectory that continues on into the child's preschool years. Based on our study this trajectory may change as the child enters middle childhood; after accounting for a child's adaptive skills, Time 2 parenting stress did not significantly predict Time 3 parenting stress.

Although the current study had a limited sample of parents at Time 3, it appears that parents experienced heightened levels of stress due to their child's limited adaptive skills. Of course, adaptive skills should be an integral piece of any child's intervention work, but these skills take on increased importance as they seem to impact the level of stress in the family. Parents may understand that with lower adaptive skills, it is less likely that children will go on to be independent adults, which may in turn increase parenting stress. Also if parents have to help their children with routine activities of daily living, they have less time and resources for other activities. It is discouraging that parents in our study did not appear to benefit from the added assistance of formal social support, however this is likely in part due to the limited sample size. Our study adds to the work by others suggesting that parents do not receive high levels of formal social support (Bromley, Hare, Davison, & Emerson, 2004). Therefore, additional research should be conducted in order to assess what interventions might ameliorate parenting stress caused by the child's adaptive skill deficits, as external resources were not found to be significant contributors in our study.

Study Limitations and Future Work

There were several limitations to the current study. One significant limitation mentioned throughout the paper was the size of our longitudinal and Time 3 samples. Despite larger effect sizes than in our Time 1 and Time 2 samples, it is difficult to draw conclusions based on such limited samples. Additionally, the limited sample size contributed to the collinearity seen in the Time 3 and Time 2 – Time 3 samples. Larger sample sizes would allow us to tease apart whether different adaptive skills contribute uniquely to the experience of parenting stress.

Another limitation of this study was that it did not include a measure of child problem behaviors. Problem behaviors, such as externalizing behaviors and poor impulse control, have been shown to be highly related to parenting stress across studies, therefore it is data notably lacking from this paper. It is likely that part of the reason we did not see any significant results at Time 2 is because parenting stress is more highly related to these types of externalizing behaviors so frequently seen at the preschool age. The study would have additionally benefited from a measure of parent mental health, specifically anxiety and depression.

Although our data captured snapshots of parenting stress from several points along a child's development, the study would have benefitted greatly from an entirely longitudinal design. Future studies should measure parenting stress prior to a child's diagnosis, and then every one to two years after that through adolescence. This type of longitudinal study would be able to more accurately depict how parenting stress changes as a child with ASD develops.

Many of the significant results in the current study were based on parent report. Therefore it might be that parents experience heightened levels of stress because of a third, unmeasured variable, and in turn report greater concerns and heightened child symptom levels. For example, parents who have heightened levels of stress may report having concerns for their

child at an earlier age, or may report lower adaptive skills because they feel overwhelmed. Thus future work would benefit from multiple reporters, such as both parents and a teacher. Multiple reporters would help to provide corroborating evidence for retrospective information and current symptom levels.

Finally, based on the results from this paper, future work should more closely examine the contribution of the diagnostic process and child interventions to parenting stress. Anecdotally it has been claimed that parenting stress is associated with increased child intervention hours, however there is no research to corroborate this claim. Instead of focusing on child characteristics, future research should focus on the process of receiving a diagnosis, enrolling children in services and helping with intervention. Research examining these practices would show health care workers areas for improvement and change.

Conclusion

The current study corroborates data from previous work suggesting that deficits in social and daily living skills contribute to the experience of parenting stress in older children with ASD. This research added new information to the field by suggesting that the parent's early perception of their child, prior to diagnosis, contributes to parenting stress over and above child symptom level or external resources. As we establish a firm understanding of how parenting stress arises, we need to focus our attention on what we can do to help parents adjust to the demands of parenting a child with an ASD. As we demonstrated, parents in this population will require greater support than what the broader community, family and friends are able to offer.

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Table 1
Time 1 Child and Parent Demographic Data

Child Demographics	**Time 1 n = 88**
Age (months)	M = 25.13, SD=4.98
Gender	
Male	68 (78%)
Female	20 (22%)
Diagnosis	
Autism	36 (40%)
ASD Low MA	15 (17%)
PDD-NOS	37 (42%)
Referral Source	
Pediatrician	61 (70%)
Birth to Three	25 (28%)
Parent	2 (2%)
Parent Demographics	
Age (years)	M =33.44, SD = 5.88
Gender	
Female	78 (89%)
Male	10 (11%)
Ethnicity	
Caucasian	56 (64%)
Hispanic/Latino	18 (20%)
Black/African American	7 (8%)
Asian	6 (7%)
Other	1 (1%)
Marital Status	
Married/ Together	74 (84%)
Separated/Divorced	10 (16%)
Maternal Education	
Some High School	6 (7%)
High School Diploma	34 (39%)
Some College/ Special Training	23 (26%)
College Degree	7 (8%)
Graduate/Professional Degree	16 (18%)
Missing Data	2 (2%)
Yearly Income	n = 78 59,487 (32,259)

Table 2
Time 2 Child and Parent Demographic Data

Child Demographics	**Time 2 n = 102**
Age (months)	M = 50.75 SD = 6.77
Gender	
Male	87 (85%)
Female	15 (15%)
Diagnosis	
Autism	61 (60%)
ASD Low MA	3 (3%)
PDD-NOS	36 (35%)
Aspergers	2 (2%)
Referral Source	
Pediatrician	45 (44%)
Birth to Three	47 (46%)
Parent	4 (4%)
Unknown	6 (6%)
Parent Demographics	
Age (years)	36.42 (5.68)
Gender	
Female	98 (96%)
Male	4 (4%)
Ethnicity	
Caucasian	27 (63%)
Hispanic/Latino	10 (23%)
Black/African American	2 (5%)
Asian	3(7%)
Marital Status	
Married/ Together	36 (84%)
Separated/Divorced	7 (16%)
Maternal Education	
Some High School	7 (16%)
High School Diploma	12 (28%)
Some College/ Special Training	15 (35%)
College Degree	2 (5%)
Graduate/Professional Degree	6 (14%)
Missing Data	1 (1%)
Yearly Income	n = 101 72,129 (31,027)

Table 3
Time 3 Child and Parent Demographic Data

Child Demographics	**Time 3 n = 35**
Age (months)	M = 117.29, SD =11.04
Gender	
Male	29 (83%)
Female	6 (17%)
Diagnosis	
Autism	30 (86%)
ASD Low MA	0 (0%)
PDD-NOS	5 (14%)
Referral Source	
Pediatrician	8 (23%)
Birth to Three	26 (74%)
Unknown	1 (3%)
Parent Demographics	
Age (years)	44.31 (5.76)
Gender	
Female	32 (91%)
Male	3 (5%)
Ethnicity	
Caucasian	32 (91%)
Hispanic/Latino	0 (0%)
Black/African American	2 (6%)
Asian	1 (3%)
Marital Status	
Married/ Together	31 (89%)
Separated/Divorced	3 (9%)
Missing	1 (3%)
Maternal Education	
High School Diploma	6 (18%)
Associate's/Technical Degree	9 (27%)
College Degree	10 (30%)
Graduate Degree	8 (14%)
Yearly Income	n = 34 74,412 (27,846)

Table 4

Parenting Stress Index-Short Form Total and Subdomain Raw Score Means and Standard Deviations: Time 1, Time 2 and Time 3 Cross-Sectional Data

	Time 1 n = 88	**Time 2 n = 102**	**Time 3 n = 35**
Parenting Stress Total	76.41 (20.02)	84.59 (19.29)	90.09 (24.79)
Difficult Child	26.82 (9.23)	33.28 (9.28)	35.54 (10.05)
Parent-Child Dysfunctional Interaction	23.65 (6.62)	24.51 (6.60)	25.49 (8.04)
Parental Distress	25.94 (8.51)	27.06 (7.95)	29.09 (9.79)

Table 5

Time 1 Spearman ASD Group Correlation Table: Child Characteristics, Pile-Up Demands, External Resources and Perception, and Parenting Stress

Child Characteristics	**ρ Total Parenting Stress**	**ρ Difficult Child**	**ρ Parent-Child Dysfunctional Interaction**	**ρ Parent Distress**
Age	.188	.189	.021	.187
ADOS	-.112	-.114	-.063	-.125
CARS	.237*	.123	.347**	.136
Mullen Visual Reception	.109	.150	-.039	.152
Mullen Motor	-.021	-.029	-.094	.044
Mullen Expressive	.086	.129	-.029	.132
Mullen Receptive	.034	.084	-.118	.127
Vineland Daily Living Skills n = 87	-.143	-.035	-.152	-.181
Vineland Social n = 87	-.286**	-.201	-.344**	-.183
Pile-Up Demands, External Resources and Perception				
Parent Age	.072	-.117	.154	.166
Number Children	.255*	.088	.348**	.251*
Number Children ASD	.201	.112	.173	.289**
Yearly Income n = 83	-.114	-.206	-.046	-.011
SSI n = 84	-.054	.093	.027	-.254*
Time Since First Concern n = 77	.314**	.267*	.163	.349**

*p<.05, **p<.01

Table 6

Linear Regression Total Parenting Stress Time 1

	ΔR^2	B (SE)	β
Step 1	0.10*		
CARS Total		0.52 (0.47)	0.14
Vineland Social Skills		-0.44 (0.26)	-0.22
Step 2	0.06*		
CARS Total		0.58 (0.46)	0.16
Vineland Social Skills		-0.42 (0.24)	-0.21
Number Children		4.48 (1.95)	0.25*
Step 3	0.12**		
CARS Total		0.60 (0.45)	0.16
Vineland Social Skills		-0.13(0.26)	-0.06
Number Children		3.61 (1.86)	0.20
Time Since Initial Concern		0.80 (0.32)	0.28*
Stopped Gaining Skills		9.51 (4.18)	0.24*

* $p \leq .05$. ** $p \leq .01$.

Note. The overall model was significant $F(5,70) = \pm 5.31, p < .001$

Table 7
Time 1 Child Demographic Data: ASD and DD groups

	ASD (n=88)	DD (n=43)	t or χ^2
Age (months)	M = 25.26, SD=4.98	M= 24.69, SD = 4.13	t(129) = -.665, p = .507
Gender			
Male	68 (78%)	32 (74%)	χ^2 (1,131) = 0.13,
Female	20 (22%)	11 (26%)	p = .718
Diagnosis	Autism: 36 (40%) ASD Low MA: 15 (17%) PDD-NOS: 37 (42%)	N/A	
Referral Source			
Pediatrician	61 (70%)	38 (88%)	χ^2 (1,131) = 5.92,
Birth to Three	25 (28%)	5 (12%)	p = .052
Parent	2 (2%)		

Table 8

Time 1 Parent Demographic Data: ASD and DD group

	ASD (n = 88)	DD (n = 43)	
Age (years)	n = 81 33.65 (5.86)	30.21 (6.90)	t(122) = -2.93, p= .004
Gender			
Female	78 (89%)	36 (84%)	χ^2 (1,131) = 0.62, p = .432
Male	10 (11%)	7 (16%)	
Ethnicity			
Caucasian	56 (64%)	27 (63%)	
Hispanic/Latino	18 (20%)	10 (23%)	
Black/African American	7 (8%)	2 (5%)	χ^2 (4,131) = 0.84, p = .933
Asian	6 (7%)	3 (7%)	
Other	1 (1%)		
Unknown		1 (2%)	
Marital Status			
Married/ Together	74 (84%)	36 (84%)	χ^2 (1,131) = 0.47, p = .493
Separated/Divorced	10 (11%)	7 (16%)	
Missing	4 (5%)		
Maternal Education			
Some High School	6 (7%)	7 (16%)	
High School Diploma	34 (39%)	12 (28%)	
Associate Degree/Special Training	23 (26%)	15 (35%)	χ^2 (5,131) = 5.08, p = .406
College Degree	7 (8%)	2 (5%)	
Graduate/Professional Degree	16 (18%)	6 (14%)	
Unknown	2 (2%)	1 (2%)	
Yearly Income	n = 83 58,976 (33,201)	n = 35 49,571 (37,286)	t(118) = -1.44, p= .153

Table 9

Time 1 Spearman DD Group Correlation Table: Child Characteristics, Pile-Up Demands, External Resources and Perception, and Parenting Stress

Child Characteristics	**ρ Total Parenting Stress**	**ρ Difficult Child**	**ρ Parent-Child Dysfunctional Interaction**	**ρ Parent Distress**
Age	.284	.250	.281	.208
ADOS	.001	.074	-.106	-.091
CARS	.165	.161	.042	.115
Mullen Visual Reception	.068	.058	.125	.046
Mullen Fine Motor	-.067	.098	-.089	-.186
Mullen Expressive	.017	.117	.029	-.058
Mullen Receptive	.076	.094	.139	.051
Vineland Daily Living Skills	-.189	-.165	-.198	-.132
Vineland Social	-.192	-.201	-.151	-.171
Pile-Up Demands, External Resources and Perception				
Parent Age	-.164	-.156	-.125	-.105
Number Children	-.290†	-.146	-.350*	-.253
Yearly Income n = 35	-.308	-.314	-.191	-.259
SSI	-.440**	-.354*	-.425**	-.383*
Time Since First Concern n = 39	.084	.074	.050	.145

† p<.06, *p<.05, **p<.01

Table 10
Linear Regression Total Parenting Stress Time 1: DD Sample

	ΔR^2	B (SE)	β
Step 1	0.04		
Number Children		-4.03 (3.07)	-0.20
Step 2	0.11*		
Number Children		-2.83 (2.97)	-0.14
SSI		-1.48 (0.65)	-.034*

* $p \leq .05$. ** $p \leq .01$.
Note. The overall model was significant $F(2,40) = \pm 3.60$, $p = .037$

Table 11

Time 2 Spearman ASD Group Correlation Table: Child Characteristics, Pile-Up Demands, External Resources and Perception, and Parenting Stress

Child Characteristics	**ρ Total Parenting Stress**	**ρ Difficult Child**	**ρ Parent-Child Dysfunctional Interaction**	**ρ Parent Distress**
Age	.146	.177	.039	.168
ADOS	.152	.133	.183	.146
CARS n = 92	.166	.101	.286**	.012
Mullen Visual Reception n =95	-.099	-.003	-.245*	.040
Mullen Fine Motor n = 94	-.087	-.061	-.183	.062
Mullen Expressive n = 94	-.044	.046	-.166	.069
Mullen Receptive n = 95	.010	.095	-.146	.118
Vineland Daily Living Skills n = 99	-.172	-.167	-.255*	-.001
Vineland Social n = 99	-.184	-.106	-.358**	.025
Pile-Up Demands, External Resources and Perception				
Parent Age	.039	.015	.064	-.005
Number Children	.129	.039	.114	.110
Number Children with ASD	.025	.028	.035	-.029
Yearly Income n = 101	-.094	-.134	-.040	-.038
SSI	-.057	.062	-.008	-.161

$^{\dagger}p<.06$, $*p<.05$, $**p<.01$

Table 12
Time 1-2 Child Demographic Data

N= 45	Time 1	Time 2
Age (months)	M = 25.04, SD=4.43	M= 48.90, SD = 4.76
Gender		
Male	38 (84%)	38 (84%)
Female	7 (16%)	7 (16%)
Diagnosis		
Autism	20 (44%)	26 (58%)
ASD Low MA	7 (16%)	3 (7%)
PDD-NOS	18 (40%)	16 (36%)
Referral Source		
Pediatrician	26 (58%)	26 (58%)
Birth to Three	16 (35%)	16 (35%)
Parent	3 (7%)	3 (7%)

Table 13

Time 1-2 Parent Demographic Data

N = 45	Time 1	Time 2	t-test
Age (years)	n = 43 34.05 (5.26)	35.62 (5.67)	N/A
Gender			N/A
Female	45 (100%)	45 (100%)	
Ethnicity			N/A
Caucasian	34 (75%)	34 (75%)	
Hispanic/Latino	7 (16%)	7 (16%)	
Black/African American	3 (7%)	3 (7%)	
Asian	1 (2%)	1 (2%)	
Marital Status			N/A
Married/ Together	39 (87%)	39 (87%)	
Separated/Divorced	4 (9%)	6 (13%)	
Missing	2 (2%)		
Maternal Education			N/A
High School Diploma/GED	23 (51%)	23 (51%)	
Associate Degree/ Special Training	1 (2%)	1 (2%)	
College Degree	11 (24%)	11 (24%)	
Graduate/Professional Degree	10 (22%)	10 (22%)	
Yearly Income	n = 43 66,628 (28,944)	73,667 (29,124)	t(42) = -3.129, p = .003

Table 14

Time 1 – 2 Change in Parenting Stress Index- Short Form

	Time 1	Time 2	Wilcoxon t-test
Parenting Stress Total	77.31 (19.82)	82.27 (18.83)	z = -1.975, p = .048
Difficult Child	26.80 (9.79)	32.16 (9.11)	z = -4.822, p < .001
Parent-Child Dysfunctional Interaction	24.29 (6.11)	24.36 (5.62)	z = -.436, p = .663
Parental Distress	26.22 (8.09)	25.76 (7.83)	z = -.370, p = .712

Table 15

Spearman's Correlation Table: Child Characteristics and Parenting Stress: Change Time 1-2

Child Characteristics	**Spearman's Correlations Parenting Stress**
Change Age	.166
Change ADOS	.175
Change CARS n = 43	.283
Change Mullen Visual Reception	.026
Change Motor	-.087
Change Expressive	-.207
Change Receptive	-.124
Change Vineland Daily Living n = 43	-.427**
Change Vineland Social n = 43	-.304*
Pile-Up Demands and External Resources	
Change Parent Age	.231
Number Children Time 2	-.017
Number ASD Children	-.007
Change Yearly Income	-.204
Change SSI	.002

*$p<.05$, **$p<.01$

Table 16
Time 1-2 Partial Correlations

Child Characteristics	**Total Parenting Stress**
Age	.234
ADOS Severity	.112
CARS total	.194
Mullen VR	.034
Mullen Fine Motor	.068
Mullen Expressive Language	-.027
Mullen Receptive Language	.006
Vineland Daily Living	-.336*
Vineland Social	-.143
Pile-Up Demands and External Resources	
Parent Age	.125
Yearly Income	-.204
SSI	.118

*p<.05, **p<.01

Table 17
Linear Regression Time 2 Total Parenting Stress: Time 1- Time 2

	ΔR^2	B (SE)	β
Step 1	0.40**		
Time 1Vineland Social Skills		-0.14 (0.31)	-0.07
Time 1Vineland Daily Living Skills		0.18 (0.22)	0.11
Time 1 Total Parenting Stress		0.57 (0.13)	0.60**
Step 2	0.07		
Time 1Vineland Social Skills		-0.03 (0.32)	-0.12
Time 1 Vineland Daily Living Skills		0.27 (0.22)	0.16
Time 1 Total Parenting Stress		0.67 (0.14)	0.71**
Time 2 Vineland Social Skills		0.12 (0.26)	0.08
Time 2 Daily Living Skills		-0.46 (0.23)	-0.33*

* $p \leq .05$. ** $p \leq .01$.
Note. The overall model was significant $F(5,37) = \pm 6.66, p < .001$

Table 18
Time 3 Pearson's and Spearman's Correlation Table

Child Characteristics	ρ Total Parenting Stress	ρ Difficult Child	ρ Parent-Child Dysfunctional Interaction	ρ Parent Distress
Age	.018	-.047	.089	-.016
ADOS	-.038	-.162	.134	.040
CARS	.285	.221	.276	.232
Nonverbal	-.272	-.176	-.396*	-.136
Verbal	-.384*	-.310†	-.387*	-.220
Daily Living Skills	-.505**	-.501**	-.359*	-.353*
Social	-.498**	-.528**	-.441**	-.248
Pile-Up Demands, External Resources and Perception				
Parent Age	-.098	-.130	-.077	-.084
Number Children	.045	.029	.017	.099
Number Children ASD	.055	.032	.140	.006
Yearly Income	-.243	-.297†	-.128	-.147
SSI	-.055	-.042	.090	-.133

† p<.06, *p<.05, **p<.01

Table 19
Time 2-3 Child Demographic Data

N= 21	Time 2	Time 3
Age (months)	M = 51.38, SD=5.61	M= 113.44, SD = 9.67
Gender		
Male	16 (76%)	16 (76%)
Female	5 (24%)	5 (24%)
Diagnosis		
Autism	17 (81%)	17 (81%)
PDD-NOS	4 (19%)	4 (19%)
Referral Source		
Pediatrician	5 (24%)	5 (24%)
Birth to Three	15 (71%)	15 (71%)
Parent	1 (5%)	1 (5%)

Table 20

Time 2-3 Parent Demographic Data

N = 21	Time 1	Time 2	t-test
Age (years)	M = 37.95 SD =6.48	M = 44.33 SD =6.17	N/A
Gender			N/A
Female	20 (95%)	20 (95%)	
Male	1 (5%)	1 (5%)	
Ethnicity			N/A
Caucasian	19 (75%)	19 (75%)	
Black/African American	1 (5%)	1 (5%)	
Asian	1 (5%)	1 (5%)	
Marital Status			N/A
Married/ Together	19 (90%)	18 (86%)	
Separated/Divorced	2 (10%)	2 (9%)	
Missing		1 (5%)	
Maternal Education			N/A
High School Diploma/GED	8 (38%)	8 (38%)	
Associate Degree/ Special Training	1 (5%)	1 (5%)	
College Degree	7 (33%)	7 (33%)	
Graduate/Professional Degree	5 (24%)	5 (24%)	
Yearly Income	n = 20 76,500 (26,611)	75,000 (27,338)	t(19) = .438, p = .666

Table 21

Time 2 – 3 Change in Parenting Stress Index- Short FormTime 2 – 3 Change in

n = 21	Time 2 Mean (SD)	Time 3 Mean (SD)	Wilcoxon t-test
Parenting Stress Total	89.29 (19.82)	91.62 (27.43)	z = -.575, p = .566
Difficult Child	35.10 (7.54)	36.19 (11.84)	z = -.296, p = .767
Parent-Child Dysfunctional Interaction	25.62 (7.54)	26.24 (9.06)	z = -.243, p = .808
Parental Distress	28.57 (8.01)	29.19 (9.48)	z = -.521, p = .602

Table 22

Spearman's Correlation Table: Child Characteristics and Parenting Stress: Change Time 2-3

Child Characteristics	**Spearman's Correlations Parenting Stress**
Change Age	-.025
Change ADOS	-.349
Change CARS	.208
Change Vineland Daily Living n = 19	-.354
Change Vineland Social n = 19	-.441
Pile-Up Demands and External Resources	
Change Parent Age	-.306
Number Children Time 2	-.259
Number ASD Children	.595**
Change Yearly Income	.053
Change SSI	-.173

Table 23
Time 2-3 Partial Correlations

Child Characteristics	**Total Parenting Stress**
Age	-.118
ADOS Severity	-.051
CARS total	.353
Vineland Daily Living	-.549*
Vineland Social	-.624**
Pile-Up Demands and External Resources	
Parent Age	-.106
Yearly Income	-.086
SSI	-.163
Number ASD Children	-.062

Table 24
Linear Regression Total Parenting Stress Time 2-Time 3

	ΔR^2	B (SE)	β
Step 1	0.26		
Time 2 Vineland Social Skills		-0.47 (0.50)	-0.21
Time 2 Total Parenting Stress		0.62 (0.29)	0.47*
Step 2	0.29**		
Time 2 Vineland Social Skills		0.08 (0.41)	0.03
Time 2 Total Parenting Stress		0.46 (0.24)	0.34
Time 3 Vineland Social Skills		-0.83 (0.27)	-0.60**

Note. The overall model was significant $F(3,15) = \pm 5.99$, $p = .007$
* $p \leq .05$. ** $p \leq .01$.

Figure 1

Double ABCX Model of Stress