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**Publication Date**

2021

Peer reviewed|Thesis/dissertation

UNIVERSITY OF CALIFORNIA

Los Angeles

Longitudinal Outcomes of Toddlers at High-Risk for Autism Spectrum Disorder:  
Diagnosis, Developmental Trajectories, and Parental Wellbeing

A dissertation submitted in partial satisfaction of the requirements for the degree  
Doctor of Philosophy in Special Education

by

Cristiana Michele Vattuone

2021

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## ABSTRACT OF THE DISSERTATION

Longitudinal Outcomes of Toddlers at High-Risk for Autism Spectrum Disorder:  
Diagnosis, Developmental Trajectories, and Parental Wellbeing

by

Cristiana Michele Vattuone

University of California, Los Angeles 2021

Doctor of Philosophy in Special Education

Professor Connie L. Kasari, Chair

Autism Spectrum Disorder (ASD) is one of the most common neurodevelopmental disorders with recent surveillance efforts estimating that 1 in 44 children are affected (CDC, 2021). Autism symptoms manifest early in life at different rates through infancy and toddlerhood, with diagnosis reliably available by 3 years of age. Our increased ability to identify and diagnose children with ASD has resulted in a strong research base of highly effective evidence-based practices for the early treatment of ASD symptoms.

Despite these advancements, parents of children with ASD continue to report elevated levels of parenting stress. Elevated stress in parents of children with ASD is well indicated in the literature and has been associated with mental health outcomes related to anxiety, depression, and lowered self-efficacy. The unique complexities associated with raising a child with ASD put parents at greater risk, warranting a closer examination into the characteristics associated with stress and potentially sensitive periods of stress throughout development as it relates to raising a child at high-risk.

Advancement in evidence-based treatment practices for children with ASD supports optimal outcomes for children at high risk, however, relatively less is understood regarding the long-term outcomes of infants at high-risk into middle childhood. Thus, the current study aimed to examine long-term outcomes of toddlers at-risk for ASD and their caregivers over a five-year follow up period from initial diagnosis to middle childhood. The study follows from an earlier treatment trial on promoting development in young children with communication delays (Kasari, Siller, Huynh, Shih, & Swanson, 2014). High-risk toddlers aged 15 to 30 months demonstrated communication delay, exhibited early signs and symptoms consistent with ASD, and screened positive on autism risk measures. Toddlers and their caregivers were followed across a 12-month period from baseline to 36-months at the time of initial diagnostic evaluation (Phase 1), and over a five-year follow period up when participants were in middle childhood (mean=8.03 years) (Phase 2).

*Methods:* The goal of the study was to prospectively examine longitudinal outcomes in infants at high-risk for ASD and their caregivers. The first aim was to examine cognitive, behavioral and clinical outcomes in toddlers at high-risk for ASD over time, including: developmental patterns of cognitive growth using DQ measured across five timepoints, stability of autism diagnostic status (autism, autism spectrum, non-spectrum) as indicated on ADOS algorithm scores, and stability of autism severity as indicated on standardized ADOS Comparison Severity Scores.

The second aim of the study was to examine parental stress and wellbeing as it relates to child and parent characteristics across potentially sensitive developmental stages, including identification and diagnosis (Phase 1) and entry into the early school years

(Phase 2). Lastly, the third aim of the study was to examine perceived social support and positive perceptions of parenting as a protective factor to mitigating parenting stress associated to raising a child at high-risk for autism.

*Results:* The analyses yielded three main findings. First, early identification, diagnosis and treatment seem critical for optimal outcomes for toddlers at high-risk for autism as the entire sample of high-risk infants showed significant improvement in cognitive gains from baseline to the five-year follow up with more early intervention hours associated with significantly greater improvement in cognitive gains over time. Three distinct growth patterns emerged in toddlers at high-risk for ASD: (1) inclining; (2) stable; and (3) slowing- plateauing. Further, membership in these groups was significantly associated with autism diagnostic status with a clear increasing trend in DQ over time for both non-spectrum and autism spectrum groups, with the autism group demonstrating a much slower trend over time with initially inclining then slight slowing-plateauing trend in DQ over time.

The second finding is that participants in the sample demonstrated stable diagnostic status over time as indicated on ADOS algorithm scores (autism, autism spectrum, non-spectrum) and stable autism severity over time as indicated on standardized ADOS CSS, with small groups demonstrating increasing or decreasing severity over time.

Lastly, parents of children with ASD experienced elevated levels of parenting stress across time attributed to child characteristics of dysregulation in infancy and toddlerhood (Phase 1), and dysregulation and problem behavior in middle childhood (Phase 2). Despite persistently high levels of parenting stress, positive perceptions of parenting and perceived support from a significant other were protective factors in mitigating parenting stress associated with raising a child at high-risk.

The dissertation of Cristiana Michele Vattuone is approved.

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## Dedication

This work is dedicated to my sister, Jennifer, whose grace, exquisite wit, and devotion to early childhood education inspires the deeply meaningful work I do today. You are my greatest teacher and profoundly missed.



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## ACKNOWLEDGEMENTS

I wish to thank the children and families that participated in this study. You graciously welcomed me into your homes and shared your stories of strength and resilience. A truly courageous act of love that I am honored to have been a part of. Thank you for your commitment to research, and for the invaluable lessons that you imparted.

My deepest appreciation to my distinguished committee chair, Connie Kasari and esteemed mentors Lois Weinberg and Elisheva Gross. Your dedication and scientific contribution have improved the lives of countless individuals, and your creativity in teaching and in life is deeply inspiring. I am grateful for your wisdom, support, and collaboration, and incredibly blessed to continue my life's work with integrity as result of your excellence and leadership. My sincere thanks to Wendy Shih, Amy Gershon, and my esteemed committee members whose consultation and optimism of this project was a tremendous support.

My sincere thanks to my early mentors Aubyn Stahmer, Annette Estes, and Paul Coyne, whose wisdom and knowledge were instrumental in paving my path forward in research. My sincere gratitude to Jennifer Phillips and Antonio Hardan, it is a great privilege to continue this next chapter with your guidance and expertise. To Robert Makus, whose encouragement and excellence in teaching sparked a deep love and lifetime pursuit of knowledge.

My deepest gratitude to April, Aulii, Jenny, and Kate, for adding richness to my life with your beauty, laughter, and light. Your friendship is gold, a treasure I will forever hold close to my heart.

To my parents, Richard and Michele, your life is a testament to the success brought by hard work and authenticity. You taught me to live with curiosity and encouraged me to grow through discovery. I am immensely grateful for these values and thank you for providing the strong foundation from which I thrive today. To my brother, Ricky, for your inspiring compassion, optimism and humor that shines brightly in all of us, and in all that you do in service of others. To my amazing grandparents, for their unconditional love, joy, and appreciation of life.

Lastly, to my partner in life Derek Papa. Enrolling in Italian class was the best decision I ever made. You are my true north, offering your absolute love and support from day one. We created the life imagined and the result is extraordinary. Thank you for being my greatest champion, I am eternally grateful to share this life with you.

To my children, Julian, Francesca and Roman, without whom this study would have been completed years earlier. You are my greatest joy, and my most brilliant achievement. It is truly an honor and delight to be your mamma.

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Longitudinal Outcomes of Toddlers at High-Risk for Autism Spectrum Disorder:  
Diagnosis, Developmental Trajectories, and Parental Wellbeing

**CHAPTER I**  
**INTRODUCTION**

Autism Spectrum Disorder (ASD) is a pervasive neurodevelopmental disorder characterized by impairment in social communication, and repetitive interests and behaviors (American Psychiatric Association, 2013). Approximately 1 in 44 children are diagnosed with ASD annually in the United States (CDC, 2021). With increased prevalence ASD is now considered a significant public health concern. Our increased ability to identify and diagnose children with ASD has resulted in a strong research base of highly effective evidence-based practices for the early treatment of ASD symptoms. Consequently, early targeted interventions aimed to modify atypical developmental trajectories when they first emerge is considered critical for best prognosis. Despite these advancements, relatively little is known concerning the long-term outcomes of young children at high-risk for ASD and their families. A closer examination into the long-term outcomes of young children who display signs and symptoms consistent with ASD is warranted.

Elevated stress in parents of children with ASD is well indicated in the literature (Hayes et. al., 2013; Estes et. al., 2009, Davis & Carter, 2008). The unique complexities associated with raising a child with ASD put parents at greater risk warranting a closer examination into the characteristics that contribute to stress across potentially sensitive periods of development, including identification and diagnosis, and entry into the early school years. Chronic stress has been associated with psychological outcomes such as anxiety, depression, diminished self-efficacy, and may negatively influence treatment gains and behavioral management for the child, particularly with parent-mediated interventions.

## **Significance and Statement of the Problem**

Early identification, diagnosis, and intervention is critical for children at high-risk for ASD, however less is understood regarding the long-term outcomes of very young children at-risk across early development. Research on high-risk infants and toddlers initially included retrospective studies analyzing home videotapes from the child's first years, rather than prospective analyses of the signs and symptoms of ASD as they first emerge in early development. Prospective studies are imperative in broadening our understanding of the early signs of ASD as they manifest throughout infancy and toddlerhood.

Despite advancement in the quality and delivery of early intervention treatment practices, caregivers of children with ASD continue to demonstrate elevated levels of parenting stress. Research supports that parent-mediated treatments show great promise in reducing ASD symptoms and promote overall family wellbeing. However, efficacy of parent-mediated practices may be impacted due to elevated stress. Chronic stress has been associated with adverse outcomes for the parent and may influence treatment integrity for the child. A closer examination of parenting stress over time as it relates to raising a child at high-risk for ASD is warranted.

The goal of this prospective study is to examine the long-term outcomes of toddlers at high-risk for ASD and their caregivers. Such knowledge will expand the literature on prospective studies of children with ASD and contribute to our understanding of children at high-risk as they develop across early childhood. A closer examination into parental wellbeing and stress as it relates to parent and child characteristics across developmental stages, including diagnosis and entry into the early school years presents both research and clinical implications.

## CHAPTER II

### Review of the Literature

#### *Autism Spectrum Disorders*

Autism Spectrum Disorder (ASD) is a pervasive neurodevelopmental disorder characterized by social communication deficits, and the presence of restrictive and repetitive patterns of interests and behaviors (American Psychiatric Association, 2013). Once considered a low prevalence disorder, ASD is currently one of the most common developmental disabilities with an estimated prevalence of 1 in 44 children, approximately 2% of children in the United States (Centers for Disease Control and Prevention, 2021). First described in the 1940's by renowned physician Leo Kanner, ASD was observed as a childhood disorder consisting of unusual patterns of behavior in social, communication, cognition, and motor development (Kanner, 1943). These initial observations gave rise to decades long research focused on delineating the behavioral manifestations of ASD symptoms across development.

Through systematic studies, ASD is presently understood as a neurodevelopmental disorder that manifests in the first years of life and continues to affect development throughout the lifespan. Symptom presentation is highly variable and influenced by individual characteristics such as age, intellectual functioning, language, adaptive ability, and medical or genetic conditions (American Psychiatric Association, 2013). Although heterogeneity in ASD is well-accepted, the core features can be categorized into two domains including social communication, and repetitive interests and behaviors. Social communication symptoms may present as difficulty in joint attention, communication, social-emotional reciprocity, initiating or responding to social interactions, imitation and play, and the ability to understand and maintain relationships with others (American Psychiatric Association, 2013).

Restrictive, repetitive patterns of interests and behaviors may manifest as insistence on sameness, repetitive speech or motor movements, intense circumscribed interests, inflexibility with routines, and hyper-or hypo- orientation to sound (American Psychiatric Association, 2013).

Following advancement in the early behavioral expression of ASD, science expanded into the neurobiological underpinnings in the second half of the 20<sup>th</sup> century with the first twin studies (Folstein & Rutter, 1977). Researchers discovered an elevated prevalence of ASD among identical twins, attributing a genetic variation to differences in brain development (Folstein & Rutter, 1977). This new wave of neurobiological research shifted perceptions of ASD as a primarily developmental disorder and expanded into both familial and genetic contributions to ASD. Genetic studies have advanced over the last two decades to include infants at high familial risk of ASD. Research supports that infant siblings, the younger brother or sister of a child diagnosed with ASD, are at increased risk for developing ASD outcome or subclinical characteristics of ASD. While our understanding of the genetic and environmental contributions of ASD continue to advance with neuroscience and genetic biomarkers, we primarily rely on the behavioral core features of ASD in early treatment.

#### *Early Detection and Diagnosis of ASD*

Presentation of early autism symptoms is highly variable, yet there are unifying characteristics among children with ASD that include difficulties with social relatedness, communication, and patterns of stereotyped and repetitive interests and behaviors. ASD includes a wide range of symptoms, skills, and levels of impairment that emerge differently across early development. While the exact cause of ASD is unknown, genetic and environmental factors and the interplay between them play an important role (Hallmayer, Cleveland, Torres, Phillips, & Cohen, 2011; Dawson, 2008).

Diagnosis of ASD has become more reliable and precise with the availability of standardized measures (Lord, 2012; Luyster et al., 2009; Lord, 2000). Diagnostic criteria are determined utilizing both standardized and observational measures with the following framework: Diagnostic and Statistical Manual of the American Psychiatry Association (DSM-5), algorithm scores from the Autism Diagnostic Observation Schedule (ADOS) (Lord, 2012), medical history records, and parent interview on the Autism Diagnostic Interview-Revised (ADI-R) (Rutter, Couteur & Lord, 2003).

The ADOS is a standardized, semi-structured assessment and is widely considered the ‘gold standard’ diagnostic instrument in clinical and research protocols (Lord, 2012; Luyster et al., 2009). The ADOS is designed to create a social world in which to evaluate social interaction, communication, and play skills through structured *presses* in a naturalistic exchange between the examiner and examinee (Lord, 2012).

Early identification of ASD has become a concentrated area of research for young children at high-risk. With the growing understanding of ASD symptoms in the first two years of life, diagnostic standards have changed to address the need for specialized instruments for very young infants and toddlers (Luyster et al., 2009). The ADOS modified its original diagnostic instrument to include the Toddler Module (ADOS-T), maintaining a similar structure of the original ADOS but making it more appropriate for use with very young children (Luyster et al., 2009). The ADOS-T is administered by clinicians with specialized expertise and experience in the diagnosis of autism spectrum disorders (Luyster et al., 2009).

Identification of children at risk for autism has also improved as a result of early detection and screening measures. Several standardized observational measures have been utilized to identify very young children at high-risk. The most widely used measures include:

The Modified Checklist for Autism in Toddlers (M-CHAT) (Robins, Fein, Barton & Green, 2001), Screening Tool for Autism in Two-Year-Olds (STAT) (Stone, Coonrod, Turner, & Pozdol, 2004), the Communication and Symbolic Behavior Scales- Developmental Profile (CSBS-DP; Wetherby & Prizant, 2001), and the Autism Observational Scale for Infants (AOSI; Bryson, Zwaigenbaum, McDermott, Rombough & Brian, 2008). Screening tools are used as direct observational instruments to screen for, detect and monitor early autism symptoms in very young children. Trained clinicians who are familiar with early signs and symptoms associated with autism spectrum disorders perform the administration.

Early identification measures are used as screening tools to detect early signs and symptoms of ASD, and each serve a unique purpose. The M-CHAT is one of the first measures designed to identify young children at-risk for ASD (Robins et al., 2001). Unlike other screening measures, the M-CHAT relies solely on parent report. Six of the items on the measure are considered ‘critical’ for the detection of early risk of ASD. The M-CHAT is used for children ages 14 to 24 months.

The ASOI is a tool that provides one of the earliest ways to detect ASD symptoms in children ages 6-18 months (Bryson et al., 2008). The STAT is primarily used as a screening tool in clinics for children between 24 and 35 months of age. The CSBS is used to identify children on the spectrum, as well as those with other non-spectrum conditions (Wetherby, 2001). In addition, the CSBS provides “red flag” items which identify children at early risk for ASD. The CSBS is used with children between 12 and 24 months of age.

### *Early Identification and Diagnosis of ASD*

Early identification measures are invaluable for detecting very young children at high-risk of ASD. Nonetheless, a standardized way of diagnosing very young children remains

problematic (Luyster et al., 2009). Stability of ASD diagnosis for infants and toddlers is an important consideration given the impact on the family and resources. Over the last two decades studies have shown a high degree of stability of autism diagnosis in children ages three years and older (Ozonoff et al., 2015; Charman, Taylor, Drew Cockerill, Brown & Baird, 2005). However, given the increasing prevalence and advancement in identification of children at-high risk, reliable diagnosis before the age of three is still a concern (Ozonoff et al, 2015).

In recent years several studies have shown stability of autism diagnosis as early as 24 months of age (Lord, Luyster, Guthrie, & Pickles, 2012), with high stability of diagnosis over time (Rondeau et al., 2012). In a recent study Ozonoff and colleagues examined the stability of ASD diagnosis in a cohort of children with clinical familial risk, more specifically infant siblings of children with ASD (Ozonoff et al., 2015). Findings showed that diagnosis at 18 and 24 months was highly predictive of diagnosis at 3 years of age (Ozonoff et al., 2015). These findings were also consistent with studies of children with ASD found in community-ascertained samples (Guthrie, 2013).

With prevalence increasing each year ASD is now considered a significant public health concern (Zwaigenbaum, Bryson, Lord, Rogers & Carter, 2009). The American Academy of Pediatrics recommends developmental surveillance at well-baby visits for all children at 9- 18- and 24-months of age (Academy of Pediatrics, 2006). Parents generally express first concerns to their pediatrician, with the most common concern being delay with speech and communication (Rogers, 2009). The expectation of developmental surveillance is to detect early signs of ASD in order to implement intervention services during a sensitive period of development.

Given the high prevalence of autism and improved prognosis associated with early intervention, there has been a concentrated research effort focused on the early indicators of



ASD (Ozonoff et al., 2015). While current research on early biomarkers of ASD remains inconclusive, a growing research base has informed early behavioral signs in very young infants and toddlers later diagnosed with ASD (Rogers, 2009).

Studies on early indicators suggest that parents report first concerns by the second year, and one-third of parents report concerns within the first year (Ozonoff, Young, Steinfield, Hill & Cook, 2009; Baird, Charman, Pickles, Chandler, Loucas, 2008; Zwaigenbaum et al., 2009). Among the most common concerns are language delays, lack of responsiveness to the child's name being called, and differences in social communication and play (Zwaigenbaum et al., 2009; Frith & Soares, 1993). Dahlgren and colleagues report that children appeared isolated, played differently from other children, and did not seek out help from an adult (Dahlgren & Gillberg, 1989).

In 15-40% of children parents report a regression, or a marked loss of language or acquired skills by the second year (Chakrabarti & Fombonne, 2001; Ozonoff, et al., 2009). However, recent findings suggest that a high percentage of children with ASD show a slow onset of symptoms, and perhaps the percentage of children experiencing loss of skills is lower than previously believed (Rogers, 2009).

#### *Retrospective and Prospective Studies of Infants at High-Risk*

Home videotapes have been used to retrospectively analyze early autism indicators in young children later diagnosed. In a study conducted by Osterling and Dawson home videotapes of children's first birthday parties were analyzed for early autism symptoms (Osterling & Dawson, 1994). When compared to typically developing one-year-olds, children with ASD exhibited significantly less social behaviors, such as pointing, showing objects, and responding to social cues (Osterling et al., 1994). This pioneering study was one

of the first to examine home videotapes for early ASD indicators that anchored the time frame of child's first birthday party. Other studies detected early signs of regression (Werner & Dawson, 2005), and less pointing (Baranek, 1999), vocalizations (Osterling et al., 1994), eye-gaze (Adrien et al., 1993; Osterling et al., 1994) and response to name (Baranek, 1999; Osterling et al., 1994) compared to neurotypically developing children. While these retrospective studies informed early developmental indicators of ASD, parental bias, difficulties in recall, and lack of comparison groups were design limitations.

Prospective studies have significantly advanced our understanding of the emerging signs of ASD by examining high-risk children from community settings, as well as infant siblings of children with ASD who are at 19% increased genetic risk (Messinger, Young, Ozonoff, Dobkins, & Carter, 2013; Ozonoff, Young, Carter, Messinger, & Yirmiya, 2011; Newschaffer, Croen, Fallin, Hertz-Picciotto, & Nguyen, 2012; Zwaigenbaum et al., 2009). The promise of prospective studies is to allow for observation of developmental trajectories longitudinally (Zwaigenbaum, Thurm, Stone, Baranek, & Bryson, 2007). Sibling studies have examined symptoms in infants as young as six months and observe development over the course of three years, at which point ASD diagnosis can be confirmed.

The literature on high-risk infants suggests that there are no reliable behavioral markers established at 6 months of age, however by 12-months of age autism symptoms in the areas of communication and social engagement could be distinguished from typically developing infants (Zwaigenbaum et al., 2007; Ozonoff et al., 2011; Rogers, 2009). Furthermore, results showed that high-risk infants demonstrate a range of risk factors across several areas of development over time (cognitive, motor, sensory, social) not just impairment in one specific

domain (Newschaffer et al., 2012; Rogers, Estes, Lord, Vismara, & Winter, 2012; Rogers, 2009).

Development in young children vastly changes in the first years of life, with some children at-risk showing improvement, and others a consistent developmental trajectory that leads to later diagnosis of autism. Longitudinal research on early signs of ASD have informed our understanding that children who are later diagnosed do show signs in the core features of autism at very young ages (Lord et al., 2012; Rogers et al., 2012). Despite these advances, relatively little is understood about the long-term trajectories of young children at high-risk for autism and their families.

### **Early Intervention Treatment for Autism Spectrum Disorder**

#### *The Lovaas Method*

Growing prevalence and increased public awareness placed a considerable amount of pressure from families and policy makers to develop effective interventions and services for children with autism. This resulted in the development of efficacious evidence-based treatment practices utilizing behavioral, developmental, and cognitive approaches. Early intervention is deemed critical in the treatment of ASD to promote optimal outcomes for children and families, and research further supports improved outcomes the earlier treatment begins in a child's life (National Research Council, 2001).

Early intervention for the treatment of ASD is now standard practice, however it is a scientifically complex topic from the historical context. The first behavioral study for children with ASD was introduced by UCLA clinical psychologist, Ivar Lovaas (Lovaas, 1987). Utilizing the methods of learning and applied behavioral analysis, Lovaas' study involved an intensive treatment for young children with ASD between the ages of two and four years (Lovaas, 1987).

The method was designed to target skills in language and communication, imitation, requesting, social engagement, and behavioral management. The intensive program provided 40-hours per week of treatment over several years with the end goal of mainstreaming children into preschool settings with neurotypical peers. At the conclusion of the study, Lovaas reported a ‘recovery’ of 50% of the participants indicating significant improvement in intellectual functioning as a result of treatment that was maintained through the first grade. Results of this study were a significant contribution in support of early behavioral intervention for the treatment of ASD and provided a new framework of autism as a disorder marked by great plasticity, a paradigm shift from earlier perceptions that individuals with ASD were not likely to respond to treatment. Lovaas’ research had far-reaching effects on public service agencies providing intervention for individuals with disabilities, as well as families who hoped to have similar outcomes for their child.

While Lovaas’ method proved efficacious for this group of individuals, the findings were highly debated regarding the empirical and scientific validity of the study, as well as the feasibility of providing intensive early intervention at the same level of dose and duration (Schopler, Short & Mesibov, 1989). This ultimately influenced a wave of scientifically rigorous research into the development of early intervention practices for the treatment of ASD. Over several decades the methods originally introduced by Lovaas resulted in what we presently know as Applied Behavioral Analysis (ABA), the most widely used early category of intervention for young children with ASD (Cooper, Heron & Heward, 2007). The methods of ABA aim to bring about positive behavioral change through reinforcement strategies, prompting, and structured learning opportunities within one-to-one teaching sessions across home, school, and community

settings. ABA targets skills in communication, social interaction, and imitation by breaking down large concepts into smaller discernable parts.

While the methods of ABA were found to be highly effective for early intervention treatment, researchers expanded upon behavioral analytic principles to incorporate more naturalistic practices. Students of Lovaas, Robert Koegel and Laura Schreibman, developed Pivotal Response Training (PRT) as an answer to concerns of child motivation, generalizability, and the highly structured nature of the original Lovaas method (Koegel, Schreibman, Goode Harrower & Carter, 1989). PRT differentiated from Lovaas and other forms of ABA by creating naturalistic learning opportunities to promote social communication by incorporating functional and varied stimuli, providing natural and imbedded forms of reinforcement, and creating naturalistic teaching opportunities by following the child's lead. PRT demonstrated great promise in promoting early social language, and generalization of acquired skills across contexts and settings. Subsequently, PRT became an increasingly widespread early intervention for children with ASD as one of the first to incorporate naturalistic and developmental practice in treatment (Schreibman et. al., 2015).

#### *Naturalistic Developmental Behavioral Interventions (NDBI)*

The increasing demand from families and policy makers to provide efficacious, evidence-based treatments for individuals with ASD converged into promising research studies and consequently new successful treatment approaches. To create parsimony around the number of newly emerging treatments, experts in the field of ASD came together to create a new category of treatment referred to as Naturalistic Developmental Behavioral Interventions (NDBI; Schreibman et. al., 2015). Delineation of the empirical and theoretical basis of NDBI was satisfied by grouping together high-quality early treatment practices with common features,

including scientifically rigorous, empirically based approaches with the goal of teaching developmentally appropriate skills for children with ASD (Schreibman et. al., 2015).

The classification of NDBI includes some of the following treatment approaches: Early Start Denver Model (ESDM; Dawson et al., 2010), Enhanced Milieu Teaching (EML; Kasier & Hester, 1994), Joint Attention and Symbolic Play Engagement and Regulation (JASPER; Kasari et al., 2006), and Pivotal Response Training (PRT; Koegel et al., 1989). The common treatment features of NDBI include naturalistic, individualized behavioral strategies focusing on developmentally appropriate skills in the areas of social communication, play, and joint engagement. The classification of NDBI helped to unify high-quality treatments in the field and assist in the decision-making process for families navigating treatment for their child, as well as providers servicing young children with ASD and their families.

#### *Parent-Mediated Early Interventions*

The increased utilization and popularity of NDBI for young children with ASD continued to show improvements in child outcomes, especially those treatments utilizing parent-mediated components (Kasari, Gulsrud, Paparella, Hellemann, & Berry, 2015; Hellemann, Shire, & Kasari, 2016). Parents of children with ASD began to receive training in the implementation of treatment strategies with their child to increase engagement and responsivity. Researchers found the parent-mediated model highly effective in augmenting treatment gains, generalization of skills, and maintenance of treatment over time (Kasari, Gulsrud, Wong, Kwon & Locke, 2010; Rogers et.al., 2012). Further, researchers found that parents reached fidelity of treatment strategies with their child over time, indicating that parents are instrumental agents of change in their child's treatment goals (Gulsrud et al., 2015).

## **Cognitive Trajectories in Infants at High-Risk for ASD**

Early intervention for children with ASD has been associated with optimal outcomes and improved cognitive gains over time, however longitudinal studies of high-risk infants are relatively lacking. The literature base that includes prospective studies of children at-risk have compared high-risk and low-risk infants to examine differences in development in the first two years of life, with follow-up at 3 years when diagnostic tools are reliable (Messinger et al., 2013; Landa & Mayer, 2006). While findings are somewhat mixed, studies consistently show that siblings of children with ASD are at 19 percent increased risk for both manifesting subclinical characteristics of ASD in the first 6-12 months, and an outcome of ASD by 3 years. These studies also distinguish social communication differences between high-risk and low-risk infants within the first two years (Landa & Mayer, 2006). Manifestation of ASD symptoms in high-risk siblings is referred to as broader autism phenotype (Ben-Yizhak, 2011; Messinger et al., 2013), with subclinical characteristics noted in social-communication and behavioral styles during the first two years (Messinger et al., 2013).

Longitudinal studies of infants at high-risk have examined young infants and toddlers through their third birthday at which point ASD diagnosis is more stable (Kasari et al., 2014; Brian, Roncadin, Duku, Brysonb & Smith, 2014; Landa, Gross, Stuart, & Bauman, 2013). Relatively few studies have considered developmental trajectories beyond the third year (Landa & Kalb, 2012). Methodological and procedural differences in sample size, age of participants at entry, exposure to intervention, and time to follow-up make results difficult to generalize. However, due to the significant increase in prevalence rates of children being diagnosed, a closer examination of high-risk populations across development is warranted.

Brian and colleagues examined developmental trajectories in a group of high-risk infants at 6-, 12-, 24 months, and 3 years (Brian, Roncadin, Duku, Bryson, & Smith, 2014). This large-scale study compared cognitive outcomes of high-risk and low-risk infants, and what emerged were three distinct developmental categories: (1) inclining; (2) stable (average); and (3) declining. For the high-risk infant group approximately 50% were in the stable trajectory, 17% inclining, and 33% declining, compared to approximately 92% of low-risk controls who were in the inclining or stable trajectories (Brian et. al, 2014). Developmental trajectories across the first 24 months predicted out to diagnosis at 3 years, with 84% of ASD cases in the stable trajectory or the declining trajectory. The authors distinguish declining as being related to developmental slowing, rather than a regression or marked loss of skills as demonstrated by some children with ASD. Of the 307 high-risk infants that were assessed at 3 years, approximately 25% were diagnosed with ASD. Findings suggest that high-risk infants in this sample demonstrated an atypical trajectory when compared to low-risk controls.

Landa and colleagues conducted one of the few longitudinal studies following children at high-risk for ASD from toddlerhood into the early school years (Landa & Kalb, 2012). Participants were 27-months on average upon entry to the study and received 10 hours per week of early intervention (combination Discreet Trial Training, Pivotal Response Training, and TEACCH). IQ, autism severity, and adaptive ability were examined at four time points: entry, exit, 6-month follow-up, and 4-year follow-up. Three main findings were achieved from entry to exit of treatment: significant gains in IQ, communication domain scores improved, and autism severity decreased. 6-months post intervention IQ and communication domain scores stabilized, while ASD severity significantly increased. Between the 6-month and the long-term follow-up IQ and communication domain scores significantly increased, however with that ASD severity



increased back to pre-intervention levels. The overall trajectory demonstrated significant gains in IQ and communication, with ASD severity remaining stable.

These findings suggest increases in cognitive gains were observed, and ASD severity decreased during intervention and then significantly increased upon exiting intervention. It is unclear if IQ gains were an effect of intervention or maturation, particularly without a control group. At follow-up participants were on average 6-years of age and were entering into school settings. This coincided with the second developmental surge, which could potentially be attributed to full-time educational services. Nonetheless, ASD symptom severity remained stable.

Participants in the current study followed from a previous study on promoting development in toddlers with communication delays (Kasari et. al., 2014). The study provided a short-term, low-dose intervention on synchronized play between parents and their high-risk toddlers (Kasari et. al., 2014). Results demonstrate gains in cognition and language for all high-risk toddlers in the study. Participants were on average 22 months of age. While cognitive gains were observed at follow-up, participants continued to show delays warranting a longitudinal examination of patterns of cognitive growth over time.

Research supports the use of NDBI and parent-mediated approaches to improve the core symptoms of ASD over time and empowers parents to be agents of change in their child's treatment gains over time. However, despite this advancement parents of children with ASD continue to demonstrate elevated levels of parenting stress.

## **Parental Stress and Autism Spectrum Disorder**

### **Parenting Stress and Children with Developmental Disabilities**

Stress has long played an integral role in parenting processes related to raising a child with developmental disabilities (DD). Indeed, parenting stress is a family-level attribute well implicated in the research as one of the most significant factors of familial risk (Baker et al., 2003). Parenting a toddler or child can be challenging, however parents of children with developmental disabilities are at increased risk of experiencing elevated levels of stress when compared to parents of neurotypical children (Baker et al., 2003; Crnic & Greenberg, 1990).

Research supports that overall stress in parents of children with DD are higher across developmental periods with stress being attributed to adjustment to diagnosis, making decisions about interventions and related services, school placements, and navigating complex educational systems for their child (DuPaul et al., 2009). Further, stressors associated with level of daily caregiving demands, behavioral or medical stressors related to the child's condition, and perceived impact on the family system are further implicated (Baker et al., 2003; Crnic, Arbona, Baker & Blacher, 2009; Donenberg & Baker, 1993; Crnic & Greenberg, 1990). While all parents report elevated levels of stress related to daily caregiving demands, parents of children with DD experience greater levels of stress related to impact on the family system and financial resources.

Trajectories of stress vary across development for parents of children with developmental disabilities, with some research supporting elevated child related stress from infancy through adolescence (Baker et al., 2003) with peak stress in the preschool transition period, and potentially increasing stress over time due to varying child problem behavior (Neece, Green & Baker, 2012; Crnic et al., 2009).

## **Parenting Stress and Children with Autism Spectrum Disorder**

Among parents of children with disabilities, those raising a child with autism spectrum disorders consistently report the most elevated levels of stress (Estes et al., 2009; Blacher & McIntyre, 2006; Eisenhower, Baker & Blacher, 2005). Research suggests that parenting a child with or without a disability can be stressful, however parents of children with ASD are particularly vulnerable (Rogers, Estes, Lord, Vismara, & Winter, 2012; Estes, Munson, Dawson, Koehler, & Zhou, 2009; Davis & Carter, 2008; Baker-Ericzen et al., 2005; Bebko, Konstantareas & Springer, 1987). Research indicates that parent and child factors may contribute to elevated stress, as well as parent resources such as adaptive processes, social support, and coping strategies. Research on parenting stress is largely focused on parents of young children, with relatively less consideration of perceived stress across developmental stages.

### *Parenting Stress Associated with Young Children with ASD*

Research on parenting stress and ASD has largely focused on mothers of young children, adolescents, or young adults with little consideration of the trajectory of stress across developmental stages (Azad, Blacher & Marcoulides, 2013). Research on parenting stress and young children with ASD suggests that higher stress levels of perceived stress are associated with adjustment to diagnosis and navigating the number of interventions and alternative treatments available to young children with ASD (Davis et. al, 2008; Guralnick, 2000). Furthermore, child characteristics such as varying intellectual profiles, challenging behavior, and difficulties with communication may also play a significant role (Baker-Ericzen et al., 2005; Fisman & Wolf, 1991; Bristol, 1987).

Research suggests that parents of young children with ASD exhibit elevated levels of parenting stress during the identification and diagnostic period, leading up to coordination of

care and navigating supports and services. In a study conducted by Davis and Carter (2008), parents of young children with ASD reported that lower Social Relatedness and higher Dysregulation on the ITSEA was associated with elevated levels of parenting stress (Davis & Carter, 2008). Findings suggest that mothers were especially stressed with regards to their child's difficulty with self-regulation including eating, sleeping and emotion regulation. Cognitive functioning, language, and autism symptom severity were not significantly predictive of parenting stress.

### *Parenting Stress Related to Middle Childhood*

Autism Spectrum Disorder is a pervasive neurodevelopmental disorder that impacts an individual throughout their lifetime. As such, parents of children with ASD take on caretaking roles that continuously evolve throughout their child's development and into adulthood. Caretaking demands include coordination of services from early intervention, social skills for school age children, and vocational support in adulthood (Osborne et al., 2008; Ganz, 2007). Research suggests that parents of children with ASD experience unique peaks of stress during pivotal transitional periods, including identification and diagnosis, preschool, elementary school, and middle school. Caretaking demands related to transitional periods requires additional parental resources, and management of the associated outcomes for their child (Tehee, Honan, & Hevey, 2009). Together this creates unique sources of elevated stress for parents of children with ASD (Schieve et al., 2007; Tehee et al., 2009).

The literature on parenting stress in school age children has demonstrated an association between elevated parenting stress and autism symptom severity, cognitive ability (Bebko et al., 1987), and restricted and repetitive behavior (Bishop et al., 2007) all with mixed results. However, studies have consistently shown a strong association between externalizing problem

behavior contributing to overall parenting stress in school age children with ASD (Estes et al., 2009, 2013; Hastings, 2003). More specifically, externalizing behaviors of conduct problems and disruptive behavior are strongly associated with elevated parenting stress, whereas internalizing behavior was not (Zaidman-Zait et al., 2017; Davis & Carter, 2008; Osborne & Reed, 2009; Hastings et al., 2005).

### **Outcomes of Stress for Parents of Children with ASD**

Parents of children with ASD are at increased risk of experiencing elevated levels of parenting stress, which has been associated with adverse psychological outcomes such as anxiety, depression, and lowered self-efficacy (Carpenter & Steffen, 2004). The unique complexities associated with raising a child with ASD put parents at greater risk than parents of neurotypically developing children, and children with Fragile X, Down Syndrome, and other developmental disabilities (Blacher & McIntyre, 2006). Further, chronic stress impacts coping strategies, self-efficacy, and synchrony within the family system (Weiss et al., 2013).

Parenting stress is well indicated in the literature, with results emerging regardless of ethnicity, geographical location, or child intellectual functioning (Koegel et al., 1992). Given the pervasive nature of stress that parents of children with ASD are experiencing, and the associated outcomes implicated in chronic stress over time a closer examination of the processes by which families experience stress is warranted. Furthermore, longitudinal studies allow for multidimensional accounts of parental wellbeing across developmental stages and can illuminate the ways to best intervene to support family adjustment and resiliency over time.

## **Family Processes: Resiliency, Positive Parenting Perceptions, and Social Support**

The literature on parenting stress and ASD has largely focused on the impact of raising a child with disabilities, and the psychological distress that parents experience due to associated caregiving demands (Ellingsen, Baker, Blacher & Crnic, 2014; Blacher & Baker, 2009). However, over the last decade the construct of resiliency and positive impact has become increasingly robust in family research (Ellingsen, et al., 2014; Vanderbilt-Adriance, Shaw, Brennan, Dishion & Gardner, 2015).

Resiliency refers to the ability to sustain mental health despite experiencing high levels of stress, and the ability to remain mentally flexible in order to overcome the stressful event and the associated vulnerabilities that may follow (Luthar, Cicchetti & Becker, 2000; McCubbin & McCubbin). Resiliency also includes coping strategies that one employs to effectively manage stress over time to mitigate lasting negative impact, which consequently can also result in positive outcomes (Ellingsen et al., 2014). Parents who report higher levels of resiliency have demonstrated reductions in anxiety and depressive symptoms, and improved self-efficacy over time (Kent et al., 2011). Protective factors associated with parenting stress and children with disabilities includes resiliency for stress adaptation and the level of family support and resources available (Weiss & MacMullin, 2014). Further, positive perceptions of parenting, perceived optimism, social support, and marriage satisfaction have all been associated with building resiliency and better adaptation over time (Vanderbilt-Adriance et al., 2015; Ellingsen et al., 2014). These associated protective factors have been shown to build stress adaptation to support positive outcomes despite adverse circumstances of parenting stress, and to improve emotional and mental health outcomes over time (Agaibi & Wilson, 2005).

Working from a resiliency model of positive impact rather than a deficit model of negative impact shifts perceptions of the family strengths and opportunities from which to build from when considering intervention strategies for parents raising children at high-risk (Hodgetts, McConnell, Zwaigenbaum, & Nicholas, 2016). The construct of resiliency and family processes is a relatively new one in ASD research. Ellingsen and colleagues examined resilient parenting of children at developmental risk across middle childhood (5-8 years of age) indicating that positive perceptions of parenting decreased as the level of risk increased (e.g.- diagnosis, low family income) (Ellingsen et al., 2014). However, their findings further support that perceived optimism was a protective factor in mitigating parenting stress despite the level of developmental risk their child was experiencing. Similarly, Blacher and colleagues examined parental wellbeing in parents of children with developmental delay (Blacher et al., 2006). Findings support that parental wellbeing was strongly associated with child problem behavior demonstrating that higher externalizing behavior was associated with elevated parenting stress, and perceived optimism moderated the effect of child problem behavior and parental stress.

While resiliency and positive impact are relatively new constructs in family processes of ASD, it provides a framework in which to examine parental wellbeing in children at high-risk. While parents of children with ASD are at increased risk for elevated stress, positive perceptions about parenting their child and perceived social support may act as protective factors in mitigating parenting stress and promote resiliency within the family system. Family-centered care is integral for improved parent and child outcomes and understanding how to best support families of children at high-risk.

## Theoretical Model

The rationale of the proposed study is based on a Family Resiliency Model (McCubbin et al., 1989). Resiliency is the ability for the family unit to respond to and adapt over time to otherwise unexpected or unplanned events that cause stress to the system. This developmental model is used to explore stress in families as some family systems adapt, and even grow and thrive in the face of hardship, while other family systems deteriorate under similar circumstances (McCubbin et al., 1989). The process by which families grow to cope with stressors over time provides protection for individual family members and the family system as a whole.

Family Resiliency Model was utilized to explore family processes of parents of children at high-risk for ASD, and the way in which families adapt to potentially stressful changes to the family system. As stressors begin cumulating within the family system, such as adjustment to a new diagnosis, the decision to uptake services, dynamic changes among siblings, the family system is required to adapt and adjust to increasing demands. Moving towards the positive impact model of raising a child with ASD, the family resiliency model was utilized to explore the positive ways in which families demonstrate resiliency despite stressful circumstances.

Sameroff's Transactional Model was used as the theoretical underpinning of this study to explore the bi-directionality of parenting stress of raising a child at high-risk for ASD (Sameroff, 1983). The transactional model emphasizes the bi-directional relationship between a parent and a child, as child characteristics are believed to influence the parent, and parent perceptions, beliefs and attitudes are believed to influence the child. This bi-directional relationship, and the interchanges that occur throughout development are believed



to influence child outcomes over time. Given the literature on the relationship between parenting stress and child problem behavior, the transactional model will be utilized to explore this relationship and how it changes over developmental stages.

### **Summary of the Literature**

Despite advancement in early identification, diagnosis, and treatment of infants at high-risk for ASD, developmental trajectories of children over time from initial diagnosis into middle childhood is relatively less understood. Given increased prevalence of ASD and the importance of early intervention for best prognosis, longitudinal studies of children at risk across developmental stages is warranted.

The current study aimed to examine developmental trajectories of children at high-risk for ASD including overall cognitive growth over time, and cognitive growth patterns including inclining, stable, and declining patterns. The second aim was to examine stability of diagnostic status and stability of autism severity over time. Lastly, the third aim of the study was to examine parental stress and wellbeing as it relates to child and parent characteristics across potentially sensitive developmental stages, including identification and diagnosis and entry into the early school years. Parental wellbeing has historically been examined at one time point, and primarily focused on the negative impact of raising a child with ASD. Examination of parenting stress over time is warranted, as well as the protective aspects that mitigate parenting stress as a result of raising a child at high-risk for ASD. While parenting stress and ASD is well indicated in the literature, relatively less is understood regarding the processes by which families adjust and cope. Therefore, positive parenting perceptions and social support will be examined as a protective factor in mitigating parenting stress over time.

## **Hypotheses**

### **Child Outcomes**

Hypothesis 1: Toddlers at high-risk for ASD are expected to demonstrate significant cognitive gains over time as demonstrated on developmental quotient scores on the Mullen Scales of Early Learning and the Differential Ability Scale measured across five different timepoints from baseline through the five-year follow up study. Developmental patterns of growth are expected to emerge across time demonstrating: (1) inclining; (2) stable; and (3) slowing-declining patterns of growth across time.

Hypothesis II: Toddlers at high risk for ASD are expected to demonstrate stable diagnostic status (autism, autism spectrum, non-spectrum) from time of the initial diagnostic evaluation at 3-years of age to the five-year follow up when children were on average 8-years of age as measured by the Autism Diagnostic Observation Schedule (ADOS). Autism severity is also expected to remain stable across time and modules as measured by standardized ADOS Comparison Severity Score (CSS).

### **Parent Outcomes**

Hypothesis III: Parents of children at high-risk for ASD are expected to exhibit overall elevated levels of stress over time, with parenting stress attributed to child characteristics. Despite high levels of stress, positive perceptions of parenting and perceived social support are expected to be a protective factor to mitigating parenting stress over time.

## CHAPTER III.

### METHOD

#### Study Design

##### **The Parent Study: Identification and Diagnosis**

This study follows from an earlier randomized controlled treatment trial focused on promoting development in toddlers at high-risk for ASD based on the parent synchrony program *Focused Playtime Intervention, FPI* (Kasari, Siller, Huynh, Shih, & Swanson, 2014). Children in the parent study were between the ages of 15 and 30 months at entry with an average age of 22 months. This multi-site study recruited participants from the greater Los Angeles and New York metropolitan areas, with families being referred by pediatricians, local and community agencies, and autism evaluation clinics. High-risk toddlers demonstrated a communication delay and exhibited early signs and symptoms consistent with ASD based on early risk measures (Phase 1).

After being referred to the study, parents completed autism screening measures including the Modified Checklist for Autism in Toddlers (M-CHAT). If the child was identified at-risk based on parent responses a structured phone screen interview was scheduled (M-CHAT-FU). Exclusion criteria included children with a known medical condition that might contribute to intellectual disability, a severe visual, hearing or motor impairment, or those with a fragile health condition.

Families that met criteria on ASD risk measures were invited to participate in the study and informed consent was obtained. The original sample included 66 children (UCLA Site 1: n=40; Hunter College Site 2: n=22) and their families with random assignment generated by a centralized computer program, thus maintaining blindness by site and researchers. Participants were assigned to the treatment group (n=32) or the active control group (n=34) whereby the

experimental group received a parent-mediated intervention focused on parental responsiveness once a week for 12-weeks, and the active control group received parent education and behavioral support over a 12-week period. Primary outcome measures of the experimental treatment, as well as child and parent measures and questionnaires were evaluated over a 12-month period at baseline and end of the 3-month treatment, and 6-and 12-months post-study entry. ASD diagnosis was evaluated at 36-months of age by a licensed psychologist with expertise in the diagnosis and treatment of autism spectrum disorders.

### **The Current Study: Five-Year Follow Up**

The present study was a prospective, longitudinal five-year follow-up of children at high-risk for ASD and their caregivers who participated in the parent study (Phase 1). The aim of the current study was to examine developmental trajectories over time, including intellectual functioning, cognitive growth patterns, stability of ASD diagnostic status, ASD severity, early intervention services received, school placement, and clinical child characteristics. Further, parental wellbeing and child and parent characteristics attributing to parenting stress over time were also evaluated. Children were between the ages of 15 and 30 months at baseline with an average age of 22-months, 36-months at the initial diagnostic evaluation for ASD, and a mean age of 8.03 years in the current study (Phase 2). Parents of children who met criteria for the parent study and agreed to participate in future research were contacted. Eligibility for the study was determined based on prior participation in Phase 1, recruiting solely from the University of California, Los Angeles (UCLA) cohort of families who continued to reside in the greater Los Angeles area. Due to difficulties of bicoastal study sites and study attrition from Phase 1 to the five-year follow-up approximately half of the original Site 1 sample participated in the current study (n=18).

## **Study Procedure**

### *Screening Measures*

All procedures for this study were approved by The Institutional Review Board at the University of California, Los Angeles. Parents were contacted by telephone and completed a phone screen interview to determine eligibility and interest in participating in the study. Once the family expressed interest in participating, an in-home assessment session was scheduled. The consent process was explained at the first meeting, with questions and concerns discussed at that time.

### *Home Visit*

The home visit consisted of diagnostic and cognitive child measures, as well as parent measures and questionnaires. The child battery included cognitive and behavioral testing on the Differential Ability Scales (DAS) and a play-based autism diagnostic assessment (ADOS). The parent completed questionnaires regarding their child's development, and measures on perceived stress, family wellbeing, and social support. After questionnaires were completed, the researcher conducted an interview with the caregiver regarding family wellbeing and social support.

## **Autism Risk Screening Measures**

### *Modified Checklist for Autism in Toddlers-Revised*

The Modified Checklist for Autism in Toddlers (M-CHAT) (Robins, Fein, & Barton, 1999) is a screening measure designed to identify young children at-risk for autism spectrum disorder. It is an expanded version of the original Checklist for Autism in Toddlers (CHAT) (Baron-Cohen, Allen, & Gillberg, 1992) and relies solely on parent report. The M-CHAT was first used as a screening measure in pediatric offices and early intervention sites for children ages 18-24 months. In a follow-up study (Dumont-Mathieu & Robins, 2005) the M-CHAT was used for

children as young as 14-months showing similar sensitivity to the original sample. The M-CHAT consists of 23 ‘yes or no’ items (e.g.- does your child bring objects to show you; does your child imitate you) that address the current skills and behaviors of the child. Six of the items are considered ‘critical’ for the identification of risk for autism spectrum disorder. A child is identified at-risk if the parent responds positive to any 3 items, or 2 of the 6 items that are considered critical for the screening and identification of ASD. The critical items include: item 2 (interest in other children), item 7 (pointing to reference something), item 9 (bringing objects to show the parent), item 13 (imitating), item 14 (responding to name), and item 15 (following gaze). If scores on the M-CHAT indicated that a participant was at-risk, parents were asked to do a follow up telephone interview.

#### *Modified Checklist for Autism in Toddlers- Telephone Interview Follow-Up*

The M-CHAT-Follow-Up (Robins & Dumont-Mathieu, 2006) is a structured telephone interview designed to clarify items failed on the M-CHAT. This allows parents the opportunity to expand on their answers and to offer more detailed information about the child. The follow-up interview is used to control for false-positive identification of children at-risk for autism spectrum disorder by having the parent explain in further detail their answers from the M-CHAT.

### **Child Assessments**

#### *Mullen Scales of Early Learning (MSEL)*

The MSEL is a standardized developmental assessment for children ages birth to 5 years of age that yields age-equivalent scores across four cognitive subscales: Receptive Language, Expressive Language, Fine Motor and Visual Reception. Developmental quotients (DQ) were calculated by dividing the subscale age-equivalent score by the child’s chronological age and multiplying by 100 thus avoiding potential floor and ceiling effects while maintaining a reliable

and valid IQ metric, as recommended in the literature. Verbal DQ (Receptive and Expressive Language), Nonverbal DQ (Fine Motor and Visual Reception), and Developmental Quotient composite scores were used at four different timepoints including baseline (T1), exit from treatment (T2), and 6- and 9-months post entry (T3 and T4).

#### *Differential Abilities Scale (DAS)*

The DAS (Elliott, 1990) is a standardized cognitive assessment of verbal and nonverbal ability, reasoning, and spatial ability. The DAS maintains high reliability and consistency when compared with the MSEL as demonstrated in the literature. The DAS produces subscale composite scores, and an overall developmental composite score. This study utilized the verbal, nonverbal, and developmental composite for analyses utilizing the DAS at the five-year follow up (T5).

#### *Autism Diagnostic Observation Schedule (ADOS)*

ADOS (Lord, Rutter, DiLavore, & Risi, 2012) is a standardized behavioral assessment for diagnosing autism spectrum disorder. This observational measure is used to assess ASD characteristics across communication, social interaction, play and behavior. Five different modules can be used to assess young toddlers through adulthood with varying levels of language fluency and ability. The ADOS, combined with the DSM-5, medical records, and a thorough parent interview are used in combination as the ‘gold standard’ for diagnosis of autism spectrum disorder. To statistically analyze ADOS scores across time and modules, total domain scores were converted to standardized ADOS Calibrated Severity Scores (CSS). The score reflects the overall symptom presentation of ASD behavioral characteristics across the social communication, and repetitive behavior domains (Gotham, Pickles, & Lord, 2009). Standardized Comparison Severity Scores (CSS) range from 1 to 10 and are descriptively classified into three

levels of ASD symptom severity: (1) non-spectrum (no to minimal evidence); (2) autism spectrum (low to moderate evidence), and (3) autism (moderate to high evidence). The ADOS was administered by expert clinicians with expertise in the assessment of individuals with ASD. Clinicians had no prior knowledge of diagnostic status or prior experience with the child and family.

### **Parent Measures**

#### *Parenting Stress Index (PSI)*

The Parenting Stress Index (PSI) (Abidin, 1995) is a 120-item measure to evaluate parent and child characteristics that contribute to parenting stress. Parenting stress as reported on the PSI was collected across five time points, including: baseline (T1), exit from treatment (T2), and 6- and 9-months post entry (T3 and T4) and for the current study five-year follow up (T5). The PSI is a self-report questionnaire that identifies potential areas of stress within the bi-directional, parent-child relationship. The parent and child domain measures stress as it relates to parent, child, and life-situational events. Items are scored on a five-point Likert-scale ranging from *strongly agree to strongly disagree*. Percentile scores as indexed on the PSI fall into the following ranges: normal stress in the 15%-74% percentile range, elevated stress in the 75%-85% percentile range, and above 85% in the clinically significant range. Consistent with the literature on parenting stress and ASD, the proposed study will utilize percentile scores to identify elevated levels of parenting stress (Baker-Erikzen et al., 2005), total raw scores in the parent domain and the child domain, and total stress composite scores in the analyses.



### *Family Impact Questionnaire, Revised (FIQ-R)*

The Family Impact Questionnaire, Revised (Donenberg & Baker, 1993) is a 50-item measure to assess the impact of chronic childhood disability on the family system. The parent report measure rates each item on a 4-point Likert-scale ranging from *not at all* to *very much*. The FIQ is composed of six scales: (1) Positive Feelings About Parenting, (2) Negative Feelings About Parenting, (3) Social Relationships, (4) Financial Impact, (5) Impact on Marriage, and (6) Impact on Siblings. Items focus on behavioral, social, and emotional impact for each scale, and together creates the Negative Composite Score. The FIQ has high test-retest reliability in normative samples and validity is highly correlated with the PSI. Scores from all six scales were used as dependent variables in this study.

### *Infant and Toddler Social and Emotional Assessment (ITSEA)*

The Infant Toddler Social Emotional Assessment (ITSEA; Carter & Briggs-Gowan, 2006) is a measure to assess social and emotional behavior and competencies of young children ages 12 to 36 months. Caregivers rate items based on a three-point scale with 0= not true or rarely; 1= somewhat true or sometimes; and 2= very true or often. ITSEA includes four domains Externalizing (Activity/ Impulsivity, Aggression/ Deviance, Peer Aggression), Internalizing (Depression/ Withdrawal, General Anxiety, Separation Distress, and Inhibition to Novelty), Dysregulation (Sleep, Negative Emotionality, Eating, Sensory Sensitivity), and Competence (Compliance, Attention, Imitation/ Play, Mastery Motivation, Empathy, and Prosocial Peer Relations), as well as item cluster scores Atypical, Maladaptive, and Social Relatedness. The ITSEA has strong psychometric properties and is highly correlated with the PSI and CBCL. The ITSEA main domain scales were used in the analyses as a predictor of parenting stress, and the ITSEA Atypical domain was used as a predictor of future ASD diagnosis.

### *Child Behavior Checklist (CBCL)*

The Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2000) is an internationally recognized measure to assess competencies and problems of children and adolescents.

Caregivers rate items based on behavior observed in their child over a two-month period. The three-point response scale includes: 0= not true; 1= somewhat or sometimes true; 2= very true or often. CBCL raw scores are converted into T-scores with a mean of 50 and standard deviation of 10. T-scores between 60 and 69 are considered of borderline significance, and T-scores 70 and above are considered clinically significant. For the purposes of this study the Internalizing and Externalizing Composite T-scores were used, as well as the Dysregulation Profile that is computed from T-scores from the Anxious/Depressed, Attention, and Aggressive subdomains.

### *Multidimensional Scale of Perceived Social Support (MSPSS)*

Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley, 1988) is a 12-item questionnaire designed to assess perceived social support across three main domains, including: family, friends, and significant other. Respondents rate items based on a 7-point Likert-scale with responses ranging from *strongly disagree* to *very strongly agree*. Sample questions include, *there is a special person who is around when I am in need; my family really tries to help me; and I have friends with whom I can share my joys and sorrows*. MSPSS has been widely used for research purposes with high levels of perceived support being associated with lower levels of stress and depression. Mean scale scores include three ranges from low support= 1 to 2.9; moderate support= 3 to 5; and high support= 5.1 to 7. Main domain scale scores and total perceived support scores were used to determine which form of support was perceived as most useful to the parent, and to examine the association of perceived support on parenting stress.

## **CHAPTER IV.**

### **RESULTS**

#### **Introduction**

Discussion of results are divided into the following sections: (a) description of the sample, (b) demographic characteristics of the parent sample, (c) demographic characteristics of the child sample, and (d) individual sections for each study hypotheses. Descriptive statistics are depicted in Tables 1 and 2 for parent and child demographics.

#### *Description of the Sample*

Phase 1 of the study included a total of 66 participants across two sites (University of California, Los Angeles= Site 1 (n=40); Hunter College= Site 2; n=22). Given the timing of the study and the difficulty navigating two bicoastal sites, only participants at Site 1 were available for testing. Although the goal was to assess all of the participants at Site 1, approximately 45% of families (n=18) were retained for the current study accounting for study attrition and willingness to participate from Phase 1 to the five-year follow-up.

#### *Parent Demographic Characteristics*

Demographic data were collected from each family at the baseline and follow up visits including parent gender, marital status, maternal age at the birth of their child, maternal education, family income, and race/ethnicity. In the sample, parents were mostly female (84%), married (83%), and highly- educated (83%). 56% Caucasian, 44% mixed race/ ethnicity, and on average 33-years old at the birth of their child. Characteristics of the parents are presented in Table 1.

Table 1

## Parent demographic characteristics

	Participants (n=18)	Percentage (Frequency)
<i>1. Parent Characteristics</i>		
Gender(%)		
Female	94	(17)
Male	6	(1)
Marital Status(%)		
Married	83	(15)
Divorced	17	(3)
Maternal Education(%)		
Some College	17	(3)
College/Professional School	44	(8)
Graduate School	39	(7)
Income(%)		
Below 50,000	16	(3)
50,001-95,000	28	(5)
95,001-above	56	(10)
Ethnicity(%)		
White	56	(10)
Asian	17	(3)
Other/Mixed	33	(6)

*Child Demographic Characteristics*

Demographic data were collected from child participants at baseline (Phase 1) and for the current study (Phase 2). Demographic variables include gender, age, race/ethnicity, diagnostic status, younger sibling of a child with ASD, weekly hours of ABA services received through their fourth year, and school services including classroom placement and affiliated services.

Child characteristics are presented in Table 2.

Children in the sample had a mean chronological age of 97.44 months( $SD=10.82$ ), a mean mental age of 95.00( $SD=35.59$ ), and an average quotient of 90.33( $SD=29.74$ ). Subjects were 56% Caucasian, 44% mixed race/ ethnicity, and predominantly male (72%) which is consistent with the elevated rates of males with ASD found in the general population.

Most of the children in the study met criteria for an autism spectrum disorder (72%), more specifically 44% met criteria for autism, 28% met criteria for autism spectrum, and 28% did not meet criteria for an autism spectrum disorder (non-spectrum). Three participants were the younger sibling of a child with ASD (17%).

Participants in this sample (89%) received weekly ABA early intervention services through their fourth year with service hours ranging from 4 to 25 hours per week, with total ABA service hours received ranging from 528 to 3936 hours. Most participants also received various associated services of occupational therapy, physical therapy, and speech therapy. Given the dose and duration of early intervention ABA services for participants in this study total ABA hours were used for analyses.

Participants were predominantly enrolled in General Education mainstream classrooms (67%). 28% of those participants were children with ASD and have a 1:1 Aide between 20-100% of the school day. 33% of participants with ASD were enrolled in Special Education Day classrooms, and 22% of participants with ASD had a school Behavioral Intervention Plan (BIP). 33% of participants on the autism spectrum were also reported as having comorbid clinical symptoms of Attention Deficit/ Hyperactivity Disorder. Child characteristics are presented in Table 2.

Table 2

Child demographic characteristics five-year follow-up

	<u>Participants (n=18)</u>	<u>Percentage (Frequency)</u>
<i>1. Child Characteristics</i>		
Gender(%)		
Female		28 (5)
Male		72 (13)
Ethnicity(%)		
White		56 (10)
Asian		17 (3)
Mixed/Other		33 (6)
Diagnostic Status(%)		
Autism		44 (8)
Autism Spectrum		28 (5)
Non-spectrum		28 (5)
Infant Sibling(%)		17 (3)
Weekly ABA Hours(%)		
0- 9		33 (6)
10- 14		28 (5)
15- 25		39 (7)
School Placement and Associated Services(%)		
General Education		39 (7)
General Ed. w/ 1:1 Aide		28 (5)
Special Day Class		33 (6)
Behavioral Plan		22 (4)
Comorbid ASD(%)		
Attention Deficit/ Hyperactivity Disorder		33 (6)
		Mean(SD)
ADOS Comparison Severity Score		
Phase 1		5.11 (2.58)
Phase 2		5.00 (2.52)
Chronological Age (months)		97.44 (10.82)
Mental Age (months)		95.00 (35.59)
Developmental Quotient		90.33 (29.74)

## Analyses of Study Hypotheses

### Child Outcomes

#### **Hypothesis I: Developmental Trajectories in Infants at High-Risk for ASD**

Hypothesis I stated that cognitive gains were expected for all participants in the study, and that different patterns of growth would emerge for infants at high-risk for ASD within three distinct categories: (1) inclining, (2) stable, and (3) declining as measured across five different timepoints on the Mullen Scales of Early Learning (MSEL) administered in Phase 1 (T1-T4) and the Differential Abilities Scale (DAS) at the five-year follow up administered in Phase 2 (T5). As indicated in the literature, the MSEL and DAS have high convergent validity when assessing children with ASD across ages and timepoints (Bishop, Guthrie, Coffing & Lord, 2011).

Results indicate that all participants in the study made significant improvement in DQ over time with three distinct developmental patterns emerging: (1) inclining, (2) stable, and (3) slowing-plateauing. There was a clear increasing trend in DQ with 67% of participants presenting in the inclining and stable groups, and 33% of the participants demonstrating a slowing and plateauing trend over time. More specifically, 17% of children presented in the inclining group (n=3) with an average DQ of 128(SD=9.23) two standard deviations above the mean; 50% of children presented in the stable group (n=8) with an average DQ of 101.56(SD=9.65) presenting an overall average trajectory over time; and 33% of children presented in the plateauing group (n=6) with an average DQ of 54.5(SD=13.75) two standard deviations below the mean. Averages of cognitive assessment outcomes across three timepoints are presented in Table 3.

Table 3

Child cognitive DQ outcomes on the MSEL and DAS across timepoints

		<u>Baseline MSEL assessment</u>	<u>12-month MSEL follow-up</u>	<u>DAS Five-year follow-up</u>
	<i>n</i>	Mean (SD) [range]		
Nonverbal DQ	18	80.11 (17.53) [50-113]	96.58 (23.20) [54-138]	93.44 (27.82) [36-135]
Verbal DQ	18	50.39 (23.31) [24-112]	84.39 (32.38) [28-134]	86.11 (32.23) [31-130]
DQ Composite	18	65.24 (16.88) [38-95.6]	90.56 (26.86) [41-139]	90.33 (29.73) [38-139]

\*Mean ages at baseline 20.38 months (3.04), 12-month follow-up 34.0 (3.5), Five-year follow-up 97.44 (10.8)

Membership in these groups (inclining, stable, plateauing) was significantly associated with autism diagnostic status (autism, autism spectrum, and non-spectrum). Repeated measures ANOVA were utilized to examine diagnostic status predicting to outcomes in DQ across time. Results demonstrate significant overall change in DQ across time for all three diagnostic groups ( $p < 0.01$ ), demonstrating a clear increasing trend in DQ over time for both non-spectrum and autism spectrum groups, with the autism group demonstrating a much slower trend over time with initially inclining then slight declining-plateauing trend in DQ over time.

ANOVA demonstrated that changes in DQ across time significantly differed by ASD diagnostic status (autism, autism spectrum, non-spectrum) ( $p=0.001$ ). More precisely, non-spectrum participants presented inclining and stable trajectories, autism spectrum group presented with stable trajectories, and participants in the autism group presented with slowing-plateauing trajectories over time.

ANOVA was utilized to determine at which timepoint DQ differentiated by diagnostic status group across time (non-spectrum, autism spectrum, autism). Results demonstrate that by T3 (average age 28- months) differences in DQ were beginning to emerge, and by T4 (average age 36-months) significant group differences were observed among the diagnostic status groups



( $p=.047$ ), and significant differences were maintained through the five-year follow up ( $p=.047$ ). Results of child cognitive trajectories over time are presented in Figure 1.

### *Predictors of Cognitive Growth Over Time: Outcome of Early Intervention Services*

To examine the effect of early intervention services on cognitive gains over time total number of ABA early intervention service hours received through the child's fourth year of age was calculated for each participant. Correlational analyses were utilized to examine whether total number of ABA hours received prior to age five predicted to long-term cognitive gains at follow-up for all participants (autism, autism spectrum, non-spectrum). There was positive correlation ( $r=0.23$ ,  $p=.268$ ) between total number of ABA hours received and DQ over time, indicating that participants receiving more ABA hours made greater improvement in cognitive gains (T1 to T5).

One-way mixed analysis of variance (ANOVA) was utilized to examine the effect of total ABA hours on cognitive outcomes for all ASD diagnostic status group (autism and autism spectrum) with total ABA hours received predicting to changes in DQ over time (T1 to T5). ANOVA demonstrated a significant effect indicating that participants who received 15 or more hours of early intervention services per week demonstrated significantly greater improvement in DQ compared to participants that received less than 15 hours of early intervention services per week ( $p<0.001$ ).

### **Hypothesis II: ASD Diagnosis, Symptom Severity, and Predictors to ASD Diagnosis**

#### *Stability of ASD Diagnosis*

Hypothesis II stated that ASD diagnosis would remain stable from time of initial diagnosis at 3-years of age (T4) to the five-year follow up when children were on average 8-years of age (T5) as measured by the Autism Diagnostic Observation Schedule (ADOS).

Descriptive statistics indicate that at the time of their initial diagnostic evaluation 89% of infants at high-risk for ASD were administered an ADOS Module 1 denoting language level ranging from no use of speech to single words, and 11% of participants received an ADOS Module 2 administration denoting a language level ranging from single word use to simple phrases. ADOS algorithm scores from Phase 1 initial diagnostic evaluation demonstrate that 72% of participants met criteria for an autism spectrum disorder (n=13). More specifically, 55% of participants met criteria for autism (n= 10), 16% of participants met criteria for autism spectrum (n=3), and 27% of participants did not meet criteria for ASD (non-spectrum; n= 5).

Analyses of diagnostic status for the current study as evidenced by the ADOS algorithm scores demonstrate that 72% of participants received an ADOS Module 3 administration denoting a language level of fluent speech, 22% of participants received an ADOS Module 2 administration denoting language level from single word use to simple phrases, and 6% of participants received an ADOS Module 1 administration denoting no use of speech or use of single words. ADOS algorithm scores at the five-year follow up yielded similar results with 72% of participants again meeting criteria for an autism spectrum disorder (n=13). Diagnostic differences at T5 include 44% of participants meeting criteria of autism (n=8), 27% meeting criteria for autism spectrum (n=5), and 27% meeting criteria for non-spectrum (n=5) based on ADOS algorithm scores.

Descriptive analyses demonstrate that overall ASD diagnosis remained stable with 83% of participants (n=15) maintaining the same diagnostic category (autism, autism spectrum, non-spectrum), and 17% of participants changing diagnostic status from autism (T4) to autism spectrum (T5). While diagnostic status changed among these three subjects as measured by the ADOS, participants remained on the spectrum and change in status indicated decreases in autism

symptom severity from T4 to T5. Spearman rank order correlation was utilized to determine the relationship between T4 and T5 ASD diagnostic status. Results demonstrate a strong, positive correlation between diagnosis at T4 and T5 and was statistically significant ( $p < .001$ ).

#### *Stability of ASD Symptom Severity*

Further, it was hypothesized that ASD severity would remain stable across time and modules as measured by standardized ADOS Comparison Severity Scores (CSS). Descriptive statistics demonstrate that 44% of participants remained stable presenting with same ASD CSS across time, 27% of participants demonstrated an increase in symptom severity across time; and 27% of participants showed a decrease in symptom severity across time as indicated on standardized ADOS CSS. Paired t-tests were utilized to compare symptom severity scores across time from T4 to T5 yielding no significant differences in change ( $p = 0.6852$ ). ADOS diagnostic status and ADOS CSS across time are presented in Table 4.

Utilizing a metric in the literature to compare ADOS CSS across time (Waizbard-Bartov et al., 2021) scores were categorized into three groups: (1) stable severity (CSS changed by 1 point or less); (2) decreased severity (CSS changed by 2 or more points); and (3) increased symptom severity (CSS changed by 2 or more points). Results indicate that 83% of participants in this sample presented in the stable severity category, 12% presented in the decreasing category, and 5% presented in the increasing severity category. Participant autism diagnostic status and ADOS CSS are presented in Table 4.

Table 4

ADOS Diagnostic status and ADOS Comparison Severity Score across time

Participants <i>n=18</i>	<u>Percentage (Frequency)</u>		<u>Mean (SD)</u>	
	<u>Phase 1</u>	<u>Phase 2</u>	<u>Phase 1</u>	<u>Phase 2</u>
	Autism Diagnostic Status		ADOS Comparison Severity Score	
Autism	56 (10)	44 (8)	6.90 (1.60)	7.13 (1.46)
Autism spectrum	17 (3)	28 (5)	4.67 (0.58)	4.80 (0.45)
Non-spectrum	28 (5)	28 (5)	1.80 (0.84)	1.80 (1.10)

### *Predicting to ASD Diagnosis*

It was hypothesized that baseline ITSEA Atypical item cluster scores would predict to ASD diagnosis at (T4) when children received their initial diagnostic evaluation for ASD. As a highly valid measure of ASD symptomology, the ITSEA Atypical item cluster was analyzed to test the predictive value of ASD risk at entry (T1) predicting to ASD diagnosis at (T4). One-way ANOVA indicated that ITSEA Atypical scores significantly differed by diagnostic status demonstrating that ITSEA Atypical score was a significant predictor of future ASD diagnosis ( $p=.007$ ) where children with autism ( $m=0.83$ ,  $sd=0.13$ ) had the highest Atypical score followed by autism spectrum group ( $m=0.72$ ,  $sd=0.28$ ), and non-spectrum group ( $m=0.42$ ,  $sd=0.06$ ).

### **Parent Outcomes**

#### **Hypothesis III: Predictors of Parenting Stress Related to Child Characteristics Over Time**

##### *Outcomes of PSI Total Stress, Parent Domain, and Child Domain*

Hypothesis III stated that parents are expected to exhibit overall elevated levels of stress over time, with parenting stress being attributed to child characteristics as measured by the

Parenting Stress Index (PSI). Stress profiles on the PSI focus on three major domains of stress: parent characteristics, child characteristics, and situational life stressors. Percentile scores as indexed on the PSI fall into the following ranges: normal stress in the 15%-74% percentile range, elevated stress in the 75%-85% percentile range, and above 85% in the clinically significant range.

The PSI total stress score is designed to provide an indication of the overall level of stress that a parent is experiencing. Across time 67% of parents reported total stress within the normal range, and 33% of parents reported total stress in the elevated range. While parents did not report having experienced elevated levels of stress over time, on average parenting stress was reported in the high-normal range.

The PSI Parent domain score is designed to provide an indication of stressors related to parenting including feelings of depression, sense of competence in the parenting role, and perceived parental attachment. Across all timepoints 88% of parents reported overall parenting stress related to parent characteristics in the normal range, and 11% of parents reported overall stress related to parent characteristics in the elevated range.

The PSI Child Domain score is designed to provide an indication of stressors experienced by parents as it relates to child temperamental characteristics including adaptability, demandingness, mood, and distractibility. Across all timepoints 78% of parents reported overall parenting stress attributed to child characteristics in the clinical range, and 22% of parents reported parenting stress attributed to child characteristics in the high-normal range as indexed by the PSI. PSI scores and standard deviations over time are presented in Table 5.

Table 5

Parenting stress mean scores across time as measured on the Parenting Stress Index (PSI)

	Mean (SD)				
	T1	T2	T3	T4	T5
PSI total score raw	250.71 (33.30)	252.31(28.11)	259.71(36.30).	257.05(31.13)	255.77 (41.36)
PSI total score%	69.94(19.76)	72.5 (19.19)	73.55 (20.99).	72.44 (20.15)	73.50 (29.59)
PSI parent domain raw	123.54 (25.47)	128.47 (19.80)	131.42 (15.15)	128.05 (21.77)	133.08 (18.91)
PSI parent domain%	49.33 (26.45)	53.83 (24.05)	55.5 (27.50)	46.67 (25.86)	63.56 (24.33)
PSI child domain raw	127.17 (19.38)	123.88 (15.09)	128.27 (19.50)	128.94 (18.47)	122.72 (26.88)
PSI child domain%	<b>85.61 (14.95)*</b>	<b>84.77* (18.20)</b>	<b>84.67* (20.47)</b>	<b>84.94* (21.93)</b>	74.44 (32.29)

*Note:* Elevated levels of stress as indexed by PSI percentile scores 75% – 90%\*

To examine parenting stress attributed to parent characteristics and child characteristics across time, a composite score was utilized by calculating the difference between total child-related percentile scores and total parent-related percentile scores with a *positive* score reflecting stress attributed to child characteristics, a score of *zero* reflecting stress being equally attributed to child and parent characteristics, and a *negative* score reflecting stress attributed to parent characteristics. 89% of parents reported stress attributed to child characteristics as indexed on the PSI, and 12% of parents reported stress as being equally attributed to both parent and child characteristics over time. Mixed linear models were utilized with results indicating that on average parents reported significantly more stress attributed to child characteristics over time ( $p < .001$ ). Parenting stress related to parent characteristics shows a slight increasing trend from T4 to T5 ( $p = .039$ ), and parenting stress attributed to child characteristics shows a slight decreasing trend from T4 to T5 ( $p = .028$ ). Mother's level of education was a significant predictor of child related stress indicating that higher level of maternal education was associated with

decreases in child related parenting stress ( $p=.033$ ). Maternal age and income were not significant predictors of parenting stress.

*Parenting Stress in Infancy and Toddlerhood: Identification and Diagnosis*

Hypothesis IV stated that elevated levels of parenting stress would be attributed to child characteristics as measured by the PSI, ITSEA, and CBCL. First, to examine parenting stress in Phase 1: identification and diagnosis (T1 to T4), linear regression models were used to analyze child characteristics as measured by the ITSEA and parenting stress as indexed on the PSI.

Linear regression models were utilized to examine the four main scales that comprise the ITSEA including Externalizing, Internalizing, Dysregulation and Competence on total parenting stress as measured on the PSI. Results indicate that of the four main ITSEA scales Dysregulation was a significant predictor of total parenting stress ( $r=.80$ ,  $p<.001$ ) demonstrating that increase in child dysregulation is associated with higher parenting stress. ITSEA item cluster subdomains Maladaptive, Atypical, Social Relatedness and Dysregulation were also analyzed. Linear regression models demonstrated that ITSEA Dysregulation was again the only significant predictor.

Next, to further delineate child characteristics predicting to parenting stress in Phase 1 (T4), regression models were used to analyze child intellectual functioning, ASD symptom severity, ITSEA Social Relatedness, and ITSEA Dysregulation. Linear regression models demonstrated that ITSEA Dysregulation was the only significant predictor of overall parenting stress ( $p<.001$ ).

### *Parenting Stress and School Age Children*

Predictors of parenting stress at the five-year follow up when children were on average 8-years of age were examined utilizing child characteristics from the CBCL predicting to total parenting stress on the PSI. Linear regression models were employed to examine the three main scales on the CBCL including Internalizing, Externalizing, and Total Problem Behavior on total parenting stress percentile scores on the PSI. Results indicate that Externalizing behavior significantly predicted to overall parenting stress ( $r=.882$ ,  $p=.022$ ) demonstrating that increased externalizing behavior is associated with increases in parenting stress. To further examine child characteristics predicting to parenting stress the CBCL Dysregulation Profile was analyzed. Results indicate that CBCL Dysregulation (Anxious/ Depressed, Attention, Aggressive) significantly predicted to overall parenting stress ( $r=.664$ ,  $p=.003$ ).

Next, to further examine child characteristics as a predictor to total parenting stress regression models were used to analyze child intellectual functioning, ASD symptom severity, and Dysregulation Profile as a predictor to parenting stress on the PSI. Results demonstrate that Dysregulation was the only significant predictor to overall parenting stress ( $r=.664$ ,  $p=.003$ ).

Lastly, correlational analyses were used to examine parent perceptions of child Externalizing and Internalizing behavior as measured on the CBCL and their association with parent perceptions of family impact on the FIQ. Results indicate a strong predictive relationship between externalizing behavior on the CBCL on parenting stress indicating that higher Externalizing behavior was significantly associated with more negative feelings towards parenting ( $r=.704$ ;  $p=.001$ ), and perceived greater impact on family social relationships ( $r=.746$ ;  $p<.001$ ), financial burden ( $r=.572$ ;  $p=.013$ ), marriage ( $r=.645$ ;  $p=.004$ ), and overall negative



feelings towards parenting ( $r=.830$ ;  $p<.001$ ). Correlation matrix of child externalizing behavior and the association with family impact are presented in Table 6.

Table 6  
Correlation matrix of externalizing behavior and perceived family impact

	1	2	3	4	5	6	7
1. Externalizing problems	1.00	<b>.830*</b> ( $p<.001$ )	<b>.704*</b> ( $p=.001$ )	<b>-.695*</b> ( $p=.001$ )	<b>.645*</b> ( $p=.004$ )	<b>.746*</b> ( $p<.001$ )	<b>.572</b> ( $p=.013$ )
2. Negative composite		1.00	<b>.809*</b> ( $p<.001$ )	<b>-.645*</b> ( $p=.004$ )	<b>.669*</b> ( $p=.002$ )	<b>.924*</b> ( $p<.001$ )	<b>.731*</b> ( $p<.001$ )
3. Negative feelings about parenting			1.00	<b>-.645*</b> ( $p=.004$ )	.414 ( $p=.088$ )	<b>.522</b> ( $p=.026$ )	.378 ( $p=.122$ )
4. Positive feelings about parenting				1.00	<b>-.513</b> ( $p=.029$ )	<b>-.515</b> ( $p=.029$ )	-.417 ( $p=.087$ )
5. Impact on marriage					1.00	<b>.701*</b> ( $p=.001$ )	<b>.609</b> ( $p=.007$ )
6. Impact on social Relationships						1.00	<b>.814*</b> ( $p<.001$ )
7. Financial impact							1.00

Note: Correlations that are significant at the .05 level are bolded and correlations at the .01 level are bolded with \*

### Positive Perceptions of Parenting and Perceived Social Support

Despite persistently high levels of parenting stress, positive perceptions of parenting as measured on the FIQ and perceived social support as measured on the MPSS were examined as protective factors to parenting stress. Correlational analyses were used to examine positive perceptions towards parenting as measured on the FIQ predicting to lower parenting stress as measured on the PSI. Results demonstrate a strong, negative relationship between positive parenting perceptions and parenting stress indicating higher perceptions towards positive parenting was significantly predictive of lower parenting stress ( $r=-.559$ ,  $p=.011$ ).

Next, to examine perceived social support predicting to parenting stress, correlational analyses were used for perceived sources of support (family, friends, significant other) on the MPSS predicting to total parenting stress on the PSI. Results demonstrate a significant relationship between MPSS Significant Other and parenting stress, indicating that greater perceived support from a significant other was associated with lower levels of parenting stress ( $r=-.634, p=.005$ ).

## **CHAPTER V.**

### **DISCUSSION**

#### **Summary of the Study and Main Findings**

Prospective studies of children at high-risk for ASD and their caregivers are vital to our understanding of early developmental patterns and symptoms of ASD as they first emerge in children at high-risk. These studies can illuminate the unique experiences and challenges of caregivers raising a child at high-risk across developmental stages. Thus, the goal of the study was to prospectively examine longitudinal outcomes of infants at high-risk for ASD and their caregivers. The study yielded three main findings.

The first was that early identification, diagnosis and treatment seem critical for optimal outcomes for toddlers at high-risk for ASD as the entire sample of children demonstrated significant improvement in cognitive gains that maintained over the five-year follow up with more early intervention hours received being associated with significantly greater improvement in cognitive gains over time.

Three distinct growth patterns emerged in toddlers at high-risk for ASD: (1) inclining; (2) stable; and (3) slowing-plateauing. Further, membership in these groups was significantly associated with ASD diagnostic status with clear increasing trend in DQ over time for both non-spectrum and autism spectrum groups, with the autism group demonstrating a much slower trend over time with initially inclining then slight slowing-plateauing trend in DQ over time.

Second, toddlers at high risk for ASD in the sample demonstrated stable diagnostic status over time (autism, autism spectrum, non-spectrum), and stable autism severity over time, with small groups demonstrating increasing or decreasing severity over time.

Lastly, parents of children with ASD experienced elevated levels of parenting stress across time attributed to child characteristics of dysregulation in infancy and toddlerhood and dysregulation and problem behavior in middle childhood. Despite persistently high levels of parenting stress, positive perceptions of parenting and perceived support from a significant other were protective factors in mitigating parenting stress associated with raising a child at high-risk.

## **Interpretation and Implications of Results**

### **Early Identification, Diagnosis and Treatment for Infants at High-Risk for ASD**

This prospective, longitudinal study of infants at high-risk for ASD followed children from early diagnosis through middle childhood. While an increasing number of studies have followed infants at high-risk through the first three years of life at which time ASD diagnosis is reliable, relatively few have followed children from initial diagnosis into middle childhood. Children were evaluated from the time parents expressed first concerns, through screening and identification, initial diagnostic evaluation, and into school age.

### *Developmental Trajectories in Infants at High-Risk for Autism*

The first aim of the study examined developmental patterns in infants at high-risk for ASD at five different timepoints across early toddlerhood (average age 22 months), three-years of age at the time of diagnostic evaluation, and over a five-year follow up period (average age 8.03 years). Overall, significant cognitive gains were observed for the entire sample of children from baseline to the five-year follow-up. Participants receiving 15 or more hours of ABA early intervention per week made the most significant gains over time.

The most robust pattern of growth occurred over the 12-month period from T1 to T4, where children had average gains of approximately 25 standard points in their DQ, 16-month gains in their mental ages, and 16-month gains in their language ages over the year. Between the initial study and the five-year follow-up DQ remained stable (T4 to T5) with an average DQ 90.56 (SD=26.86) obtained at T4 and an average DQ of 90.33 (SD=29.74) obtained at T5. While some participants demonstrated cognitive gains and others showed cognitive slowing and plateauing, on average participants demonstrated mostly stable trajectories across the five-year developmental period.

These findings add to an existing body of evidence supporting as that toddlers at high-risk continue to make significant cognitive gains over time and the effectiveness of early intervention on cognitive gains over time as demonstrated in this sample. There is strong research to support that early intervention promotes better outcomes over time, with earlier initiation of services the better (Dawson & Osterling, 1997; Harris & Handleman, 2000; Luiselli, Cannon, Ellis & Sisson, 2000; Scheffer, Didden, Korzilius, & Sturme, 2011). Findings from this study demonstrate that infants receiving 15 or more early intervention service hours per week made significantly greater improvement in cognitive gains over time. Children in the

present study began early intervention services during the first two years of life before a formal diagnosis was available. As the ability to identify children at high-risk for ASD continues to improve, further research on the efficacy of evidence-based practices for infants and toddlers is more critical. Early intervention is generally designed for preschool-age children who have different developmental needs and learning styles than children 0-3 years. Therefore, research into intervention practices accounting for the unique developmental characteristics of young infants and toddlers at high-risk for ASD is warranted.

Findings from this study are consistent with Landa and colleagues who also examined cognitive trajectories in infants at high-risk from toddlerhood (mean age 27-months) into the school years when children were approximately 6 years of age (Landa & Kalb, 2012). Children received 10 hours per week of early intervention with results demonstrating that infants at high-risk made significant cognitive gains between the 12-month study period, and then again in the three-year follow up period (3 to 6 years). ASD severity initially decreased during treatment, then returned to pre-treatment levels at follow-up indicating stable ASD severity over time.

Similarly, findings from Clark and colleagues found that infants at high-risk followed from toddlerhood into middle childhood made significant cognitive gains over time with a reduction of 64% to 8% of children with intellectual disabilities at follow up (Clark, Barbaro & Dissanayake, 2017). Utilizing this metric, 67% of participants in the current study demonstrated intellectual disability at entry and 28% at follow up with most participants demonstrating cognitive gains into the average and high average ranges. Lastly, Lord and colleagues followed infants at high-risk from 24 months into young adulthood with participants demonstrating marked improvement over time and two-thirds of the group continuing to show improvement from middle childhood into adulthood over time (Lord, Bishop, Anderson, 2015).

Three distinct patterns of growth emerged in infants at high-risk over time in this sample: (1) inclining; (2) stable; and (3) slowing-plateauing with membership in these three categories associated with ASD diagnostic status (autism, autism spectrum, and non-spectrum). There is a clear increasing trend in DQ over time for both non-spectrum and autism spectrum groups, with the autism group demonstrating a much slower trend over time with initially inclining then slight slowing and plateauing trend in DQ over time. These findings are consistent with studies of infants at risk as previously discussed, with all participants showing marked improvement over time, with approximately one third of the high-risk infants demonstrating a much slower-plateauing growth pattern over time. Brian and colleagues found similar results showing significant gains for infants at high-risk over time with either inclining, stable, or declining-slowing trajectories (Brian et al., 2014).

One possible interpretation for the slowing-plateauing trend for the autism group in this sample could be explained by the degree of intellectual disability and the challenge in disentangling ASD from IQ. The relationship between IQ and symptom severity is high in the autism sample ( $n=5$ ) indicating cognitive scores in the intellectually disabled range ( $IQ < 70$ ). It is difficult to derive standard scores for children with ASD given the associated behavioral and motivational characteristics inherent when testing this population (Bishop, Guthrie, Coffing & Lord, 2011). While psychological assessment is an important component in the overall evaluation in young children with ASD, performance may be hindered by behavioral, attentional and motivational factors. Akshoomoff examined the use of the Mullen for assessment of children with ASD, with findings suggesting that when compared with age-matched neurotypical controls children with ASD were less engaged with the testing and exhibited proportionately more off-task behavior (Akshoomoff, 2006). Additionally, as children become school age cognitive testing

increases in social and language demands which becomes increasingly more difficult for children with ASD. Thus, it may be difficult to capture the true ability of children with ASD on measures of cognitive ability especially when associated symptoms of ASD hamper or even nullify testing results.

Lastly, findings from this study demonstrate stabilized cognitive trajectories from three to eight years of age (T4 to T5), with mixed findings in the literature regarding developmental stages of growth for children with ASD. In a recent longitudinal study of cognitive trajectories in children with ASD, Simonoff and colleagues found that children with ASD made significant cognitive gains or experienced a ‘cognitive spurt’ between 12 to 19 years (mean of 7.48 points) (Simonoff, Kent, Stringer & Lord, 2020). While children in this study demonstrated mostly stable cognitive gains across the five-year follow up from 3 to 8 years, findings from Simonoff and colleagues suggest that cognitive growth patterns may emerge at different stages in development continuing into adolescence for children with ASD. Further, developmental trajectories are vastly different for children with ASD due to the variation in cognitive and language skills, with some individuals making marked gains and others demonstrating a slow but inclining trend over time. Development in the first few years of life for infants at high-risk for ASD is often marked by large discrepancies in cognition and uneven developmental profiles that may persist through childhood (Fombonne, 2005; Joseph et al., 2002). Therefore, it is important to account for ASD severity discrepancies in nonverbal, verbal, and adaptive abilities, and gather additional measures of cognitive ability when evaluating true developmental gains for children with ASD.

### *Stability of ASD Diagnosis and ADOS CSS over time*

For the participants in this study ASD diagnostic status (autism, autism spectrum, non-spectrum) remained stable from initial diagnosis at 36- months to the five-year follow up when children were on average 8 years of age (T4 and T5). Further, ASD severity as indicated on ADOS CSS remained stable for 83% of participants, with small groups demonstrating decreasing or increasing severity over time. Consistent with previous findings examining ADOS CSS over time, Gotham and colleagues found similar results with over 80% of participants demonstrating stable severity over time, with small groups decreasing or increasing over time (Gatham et al., 2012). Moreover, for participants in this study autism symptom severity at age 3 was strongly predictive of severity level five years later (mean age 8.03).

ADOS CSS was designed for greater understanding of the manifestation of core symptoms of ASD over time regardless of language level or intellectual functioning. For the purposes of this study, ADOS CSS was useful and necessary when comparing severity across participant ages, language levels, and ADOS modules over a five-year age period. While ADOS CSS remained stable over time, interpretation of symptom severity must be considered. The ADOS is an observational assessment designed to capture social communication as it develops across language and modules. As such, abilities and symptoms are not perfectly captured within the ADOS CSS alone. While severity remained stable over time, the type of symptom may have altered. ADOS domain scores can be used for best measurement of improvements in core symptoms and to best capture the variation of ASD dimensions

This study adds to the existing literature on the reliability and stability of ASD diagnosis over time. Results indicate that toddlers at high-risk for ASD showed early signs in core symptoms of ASD at very young ages. Children were between 15 and 30 months when they



entered the study, and 3 years of age at their initial diagnostic evaluation. 72% of children in this sample met criteria for ASD with diagnostic status and ASD severity scores remaining stable over time, with small groups showing decreases or increases in severity.

Additionally, this study adds to the literature on the research use of the ITSEA measure for young toddlers at high risk as baseline Atypical scores predicted to later ASD diagnosis in this sample. These findings seem to demonstrate the sensitivity of the ITSEA measure for use with very young children at high-risk and highlight that the toddlers in this study were already demonstrating signs and symptoms consistent with ASD as early as 15 months of age.

Considering the pervasive and stable nature of ASD diagnosis and severity from early toddlerhood over time, repeated screening and detection is critical for toddlers at high-risk for ASD. As demonstrated in the current study, signs and symptoms of autism emerged in the first years of life and persisted into middle childhood. These findings illuminate the importance of continued surveillance of children at high-risk

## **Parenting Stress and Autism Spectrum Disorder**

### *Parenting Stress in Early Infancy and Toddlerhood*

Parenting stress is a family-level attribute well implicated in the research as one of the most significant factors of familial risk. Parents of children with autism spectrum disorder are the most vulnerable given the complexities associated with raising a child with ASD. While a strong research base supports parenting stress and ASD in the literature, relatively less is understood regarding experiences of stress over time and the potentially sensitive periods of stress including early identification and diagnosis and entry into the school years.

Results of this study add to a large body of research that indicate high levels of parenting stress among parents of children with ASD. An examination of parenting stress over time demonstrates that parents of children with ASD reported clinical levels of stress related to child characteristics, with the most significant predictor of stress attributed to dysregulation in infancy and toddlerhood, and externalizing behavior and dysregulation in middle childhood.

Parents of very young children with ASD were especially affected by child dysregulation associated with eating, sleeping, and emotion regulation. These findings are not surprising given the caregiving demands associated with raising a child at high risk, and the critically sensitive period during diagnosis and the decision to initiate early intervention services.

This study extends prior work by demonstrating that parents of children with ASD are experiencing elevated levels of stress when children are quite young due to child dysregulation. While not part of the diagnostic criteria for ASD, sleep, eating and emotional regulation all contribute to common clinical features of children with ASD (Schreck, Williams & Smith, 2004; Hoffman, Sweeney, Lopez-Wagner & Hodge, 2008; Gulsrud, Jahromi & Kasari, 2009). Parents of children with ASD report more frequent and more severe sleep problems, selective eating problems, and experience higher levels of emotional dysregulation when compared with neurotypical peers. The unique caretaking demands of parents of children with ASD require considerable resources and creates additional stress in the family system when children are experiencing dysregulated, restricted sleep and eating patterns, and heightened verbal or physical displays of negative emotion. Gulsrud and colleagues found that children with ASD are demonstrate more negative emotional expression and more frequent episodes of distress when compared with neurotypical children, with greater child dysregulation associated with higher parental stress. Results from a brief, 8-week parent mediated engagement program found

improvement in engagement and emotion regulation supporting the vital role that parents play in the development of emotional understanding for their child with ASD. Early intervention practices that target and therefore support parent-mediated co-regulation are necessary to address the specific sources of stress that parents of young children with ASD experience associated with dysregulation.

### *Parenting Stress in Middle Childhood*

Previous findings support higher levels of parenting stress associated with increased behavior problems; thus results extend these outcomes for children with ASD in middle childhood. Significant sources of parenting stress experienced by children with ASD in middle childhood include externalizing behavior and dysregulation. Studies consistently report a strong association between externalizing problem behavior contributing to overall parenting stress in school age children with ASD (Estes et al., 2009, 2013; Hastings, 2003), with externalizing behaviors of conduct problems and disruptive behavior being particularly stressful (Zaidman-Zait et al., 2017; Davis & Carter, 2008; Osborne & Reed, 2009; Hastings et al., 2005). As children with ASD progress through the early school years, social demands increase which create unique sources of stress for parents and the associated outcomes for their child (Schieve et al., 2007; Tehee et al., 2009). Further, externalizing behavior impacts the family system with higher negative emotionality associated with more negative feelings towards parenting, and perceived greater impact on family social relationships, financial burden, and marriage. Intervention targeting emotion regulation would be beneficial, further improved by parent-mediated co-regulation practices to best support parents and children with ASD in middle childhood.

Overall, these results contribute to a robust literature base on parenting stress and autism spectrum disorders and extend these outcomes to experiences of stress in parents of very young children with ASD and parents of children in middle childhood. Parenting stress was not associated with autism severity, disability, intellectual functioning, or adaptive ability in either phase of the study. However, child dysregulation was a unique source of stress for parents across age ranges highlighting the importance of targeted interventions for children and their caregivers to support coping, adaptive strategies, and co-regulation of emotion to best support individual family members and the family system as a whole.

### **Positive Perceptions Towards Parenting and Social Support**

Parents of children at high-risk for ASD reported elevated levels of stress, with perceived positive parenting toward their child and social support from a significant other acting as protective factors in mitigating parenting stress over time. Parents that reported more positive thoughts toward parenting their child experienced significantly lower levels of parenting stress. Additionally, perceived support from a significant other acted as a protective factor for parents who reported higher levels of support from a significant other experiencing significantly less parenting stress.

Despite persistently high levels of child related stress, parents continued to report overall positive thoughts towards parenting their child. Further, parents reported overall parent-related stress in the normal range, that is stress related to the parenting role including feelings of depression, sense of competence as a parent, and perceived parental attachment, suggesting that despite experiencing persistently high levels of stress and concern for their child, parents also report feeling competent in their parenting role towards their child.

These findings suggest that families provide important strengths, drawing upon social support and coping strategies as protective factors in mitigating overall stress associated with raising a child with ASD. Family-centered care is integral for improved family adjustment and child outcomes over time, with positive perceptions of parenting, social support, and marriage satisfaction associated with building resiliency and better adaptation over time. Protective factors have been shown to build stress adaptation to support positive outcomes despite adverse circumstances of parenting stress, and to improve emotional and mental health outcomes over time.

### **LIMITATIONS**

The present study lends valuable insight into the long-term outcomes of infants at high-risk for ASD and their families noting several limitations. The first limitation is the small sample size, which presents a challenge when considering the representation of this sample in the general population and the generalizability of the findings. While community-based sample and “gold standard” ASD diagnoses are a relative strength of the study, control group and increased sample size would strengthen the power of the results. Another limitation is the relatively highly educated, middle-income sample which limits generalization to the broader population of infants at risk for autism. The third limitation is that one father participated in this study. Fathers are disproportionately represented in studies of ASD and parenting stress, and research suggests that caregivers may report differently on perceptions of parenting stress and perceptions of their child. In order to gain a deeper appreciation and holistic understanding of the family system father report is essential. Lastly, parent data was predominantly collected using parent-report measures. Self-report data may be subject to bias, exaggeration, or misinterpretation of questions. While repeated measures over time limits this effect, it is important to incorporate

more objective measures of parenting experiences and stress, such as cortisol indexing of stress, dual responders of both parents reporting, and behavioral measures.

### **IMPLICATIONS FOR RESEARCH**

The increased prevalence rates of children with ASD highlight the importance of early detection and identification, placing a considerable focus on high-risk populations including siblings and young infants and toddlers who demonstrate early signs and symptoms consistent with ASD. Identification of children at high-risk for ASD is increasingly more common, with children being screened and identified as early as the first year of life. To improve upon our understanding of the early indicators of ASD, prospective longitudinal studies are warranted to investigate developmental trajectories of children at high-risk as they first emerge.

Indeed, findings from the study support the benefit of early screening, diagnosis, and treatment for infants at high-risk for ASD. Children were identified between the ages of 15 and 30 months and showed significant delays across multiple domains of development. Over the 12-month study period (Phase 1) children demonstrated significant gains in cognitive and language growth over time that maintained through the five-year follow-up, with children receiving 15 or more hours of early intervention per week making the most improvement in cognitive gains over time. These findings are consistent with the literature which support that early signs and symptoms of ASD are emergent in early development at varying rates through infancy and toddlerhood. This study further demonstrates the high specificity and validity of early ASD risk measures, including the ITSEA which this study utilized to predict to later ASD diagnosis. Results of this study add to the existing literature on the use of ITSEA for identifying children at high-risk for ASD as baseline scores on the atypical domain significantly predicted to later ASD diagnosis.

Development vastly changes in the first few years of life, highlighting the importance of repeated developmental screenings and consistent following of children at high-risk. As increased attention is given toward early intervention for children with ASD, many families receive services even before a diagnosis is formally given. 88% of participants in this study initiated early intervention services in the first two years of life with those children receiving 15 or more hours demonstrating significantly greater improvement in cognitive gains over time. These findings add to the robust literature on early identification, diagnosis, and intervention for optimal outcomes in children at high-risk for ASD. Participants in this sample demonstrated stable diagnostic status and ASD severity, with small groups showing decreasing or increasing severity over time. This supports the pervasive nature of ASD as symptoms continue to persist across development, highlighting the importance of early screening and detection for toddlers at high risk. Further, while children in this sample made significant cognitive gains related to early intervention hours, ASD severity was stable across middle childhood. Treatment approaches that target the foundations of social communication and emotion regulation as core features of ASD would be largely beneficial.

### **IMPLICATIONS FOR PRACTICE**

Longitudinal research on developmental trajectories of infants at high-risk for ASD and their caregivers has useful implications for clinical practice. Research supports the use of parent-mediated intervention strategies for children with ASD, especially when providing early intervention for the youngest infants and toddlers at high-risk. Further, research supports that not only is parent participation vital for improved child outcomes the quality of parent participation is also a significant factor. Clinicians working with parents of children with ASD should

implement parent-mediated strategies to maintain treatment integrity over time, and to promote caregiver confidence, engagement, and responsiveness with their child.

While the association of parenting stress and ASD is well indicated in the literature, the mechanisms at play in these family systems continues to emerge across developmental stages. This study illuminates that sources of stress for parents of children with ASD change over time as a function of child characteristics over time. Parents experienced elevated stress when their child was quite young, suggesting that the period of identification and diagnosis is a critical one. Furthermore, unique sources of stress for parents of young infants and toddlers attributed to child dysregulation, more specifically sleep, eating and emotion regulation. Intervention strategies focusing on family adjustment to diagnosis, support in navigating early intervention services, and coping strategies over time may be beneficial to building upon strengths in the family system and resiliency over time. Furthermore, behavioral support and co-regulation strategies are necessary in parent-mediated intervention practices to address the unique source of stress in parents of very young children at high-risk that are dysregulated.

As developmental needs shift, likewise parental concerns shift to meet the changing social demands of children with ASD in middle childhood. Results indicate that sources of stress in middle childhood are uniquely related to externalizing behavior and emotion regulation related to anxiety, attentional issues, and aggression. Further, higher externalizing behavior significantly impacted the family system as a whole. This illuminates the importance of intervention focused on behavioral regulation of externalizing behavior, and further supports child dysregulation as a significant source of stress across developmental stages as parents reported in early toddlerhood and middle childhood. Early intervention and implementation of co-regulation and emotion regulation strategies to support parents and children with ASD may be largely beneficial.



Lastly, it is vital to implement family-centered systems of care to build upon the unique strengths and coping strategies within the family system as the foundation for family resiliency over time.

## **CONCLUSION**

In conclusion, the study adds to a robust body of research on the importance of early screening, diagnosis and treatment for toddlers at high-risk for ASD. The increased prevalence of children being diagnosed highlight the importance of continued early surveillance and identification, maintaining a considerable focus on high-risk populations including siblings and young infants and toddlers who demonstrate early signs and symptoms consistent with ASD. Prospective, longitudinal studies illuminate and improve upon our understanding of the early manifestations of ASD symptoms and developmental trajectories in children at high-risk across time. The results provide promising future directions in support of early autism screening of high-risk toddlers and the importance of initiating early intervention services when symptoms first emerge. The study further supports the stability of ASD diagnosis and severity over time implicating targeted interventions for the treatment of core symptoms of ASD. The study further supports the literature on parenting stress and ASD, illuminating the unique sources of stress that parents may experience across developmental stages, including dysregulation in early childhood and externalizing behavior and dysregulation in middle childhood offering future directions for intervention that support caregiver co-regulation of emotion and coping strategies to strengthen family resiliency over time.

Figure 1

Child cognitive trajectories across time by diagnostic group

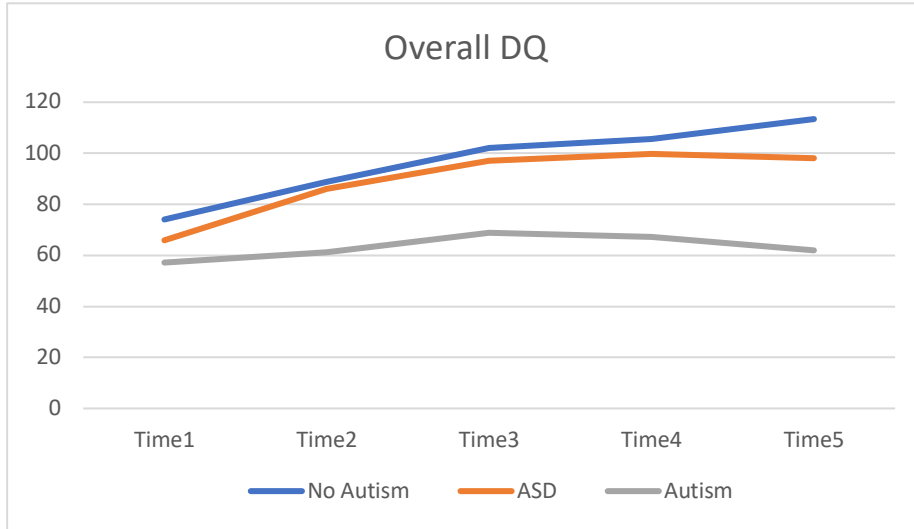


Figure 2

Child nonverbal trajectories across time by diagnostic group

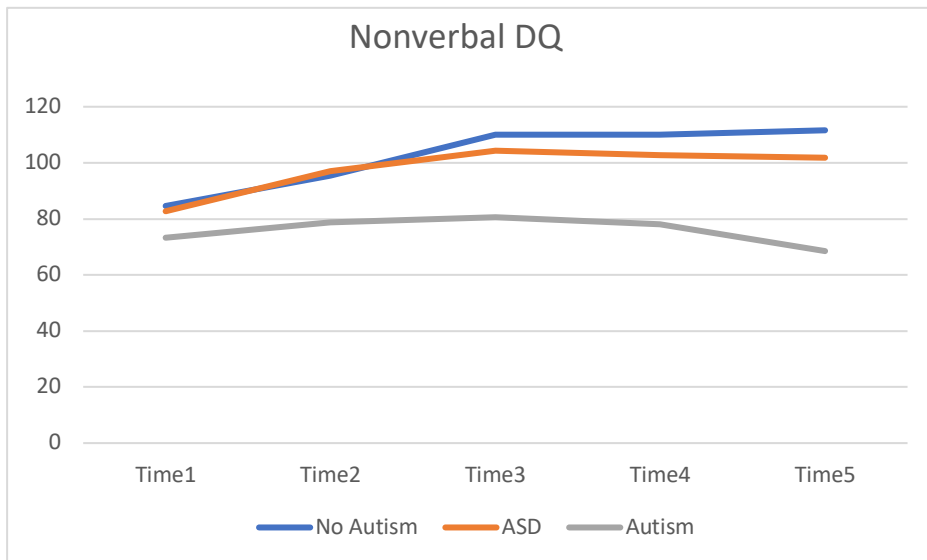


Figure 3

Child verbal trajectories across time by diagnostic group

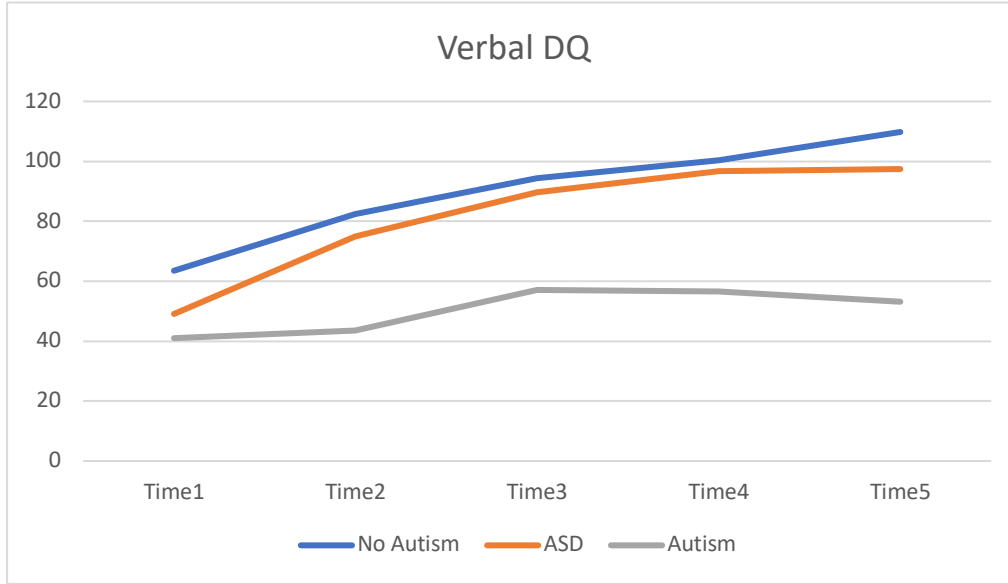


Figure 4

Child expressive language growth by diagnostic group

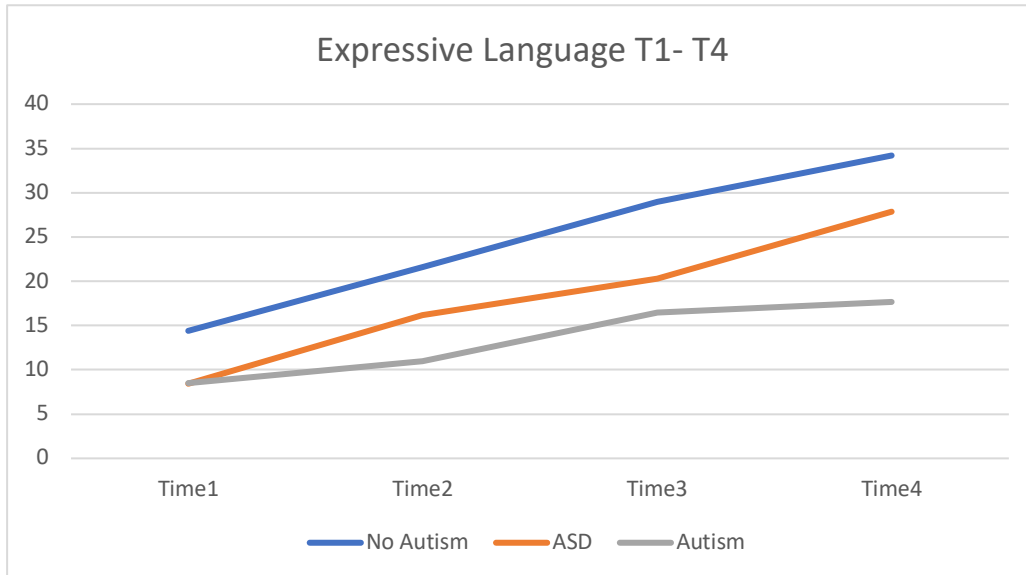


Figure 5

ADOS Comparison Severity Score by diagnostic status at Phase 1

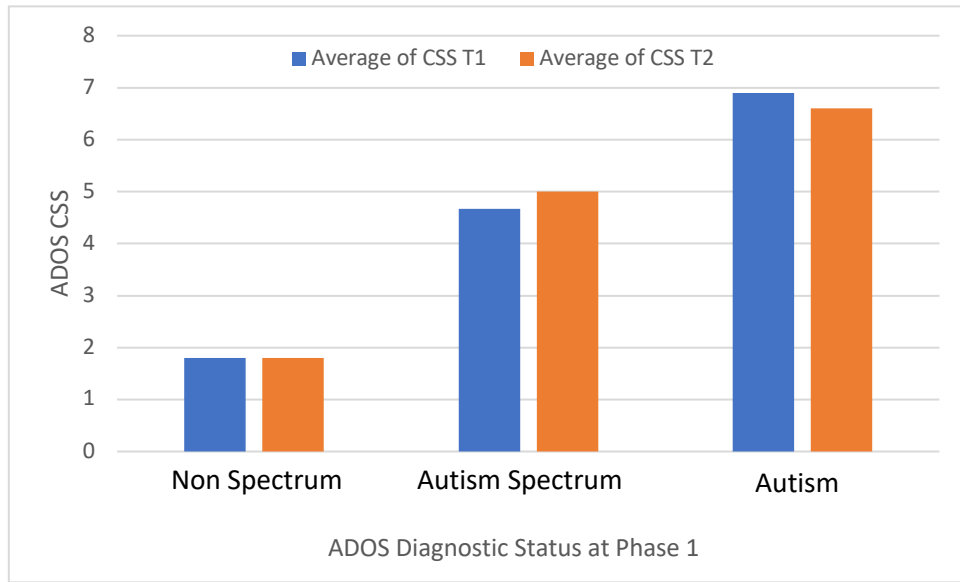
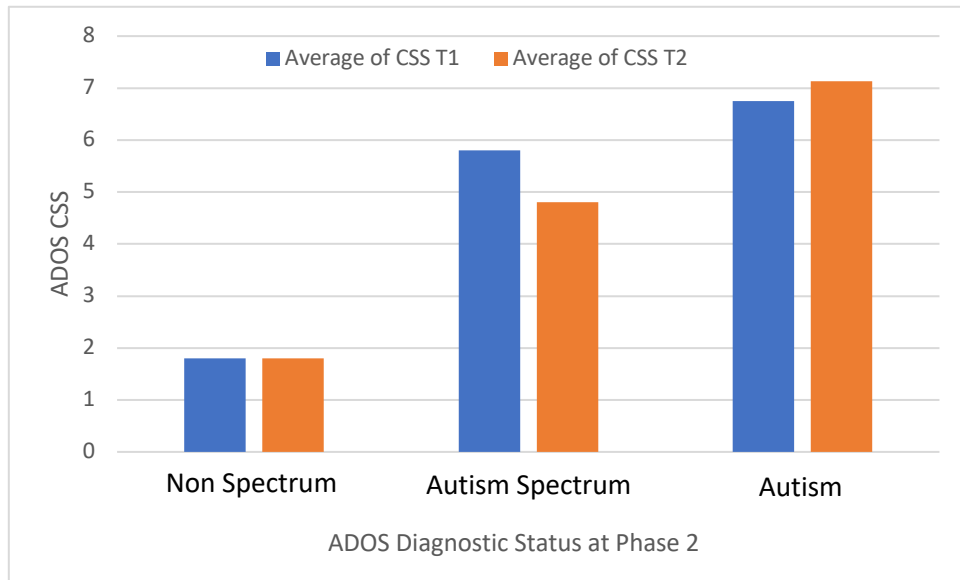


Figure 6

ADOS Comparison Severity Score by diagnostic status at Phase 2



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