EVALUATING THE PREDICTIVE ABILITY OF EARLY AUTISM RISK SCREENERS: A LONGITUDINAL FOLLOW UP STUDY OF DEVELOPMENTAL PROGRESS AND DIAGNOSTIC OUTCOMES

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SUMMARY

Autism Spectrum Disorder (ASD) is now considered one of the most common developmental disabilities (Newschaffer et al., 2007). Over the past 20+ years, researchers have worked towards identifying early behavioral or physiological predictors of ASD so that early treatment and intervention can be implemented. These efforts include the development of rapid, behavior-based screeners (e.g., Rapid-ABC by Ousley, Arriaga, Abowd, & Morrier, 2013) to supplement or replace the commonly used parent-report methods (e.g., Modified Checklist for Autism in Toddlers) and lengthy behavioral and interview assessments (Autism Diagnostic Observation Schedule; Autism Diagnostic Interview) that are considered the gold-standard for ASD screening and diagnosis. The present study explores how these different means of measuring early infant and toddler social communication and language behavior (i.e., parent-report via the M-CHAT vs. direct observation of behavior via the Rapid-ABC screener) collected at Time 1 correspond with later developmental progress and diagnostic outcomes as reported by parents in a semi-structured interview collected at Time 2. 56 parents of 57 children who previously participated in a study evaluating early infant ASD-risk behaviors when their children were 15-35 months of age participated in a follow-up phone interview about their child’s social communicative development and medical updates over the last 3-7 years. The results of the follow up interview with parents suggested there was fairly good correspondence with later autism diagnosis only for those children who showed Time 1 “at-risk” status from both parent-report and behavioral assessment. However, each individual form of assessment, considered on its own, did not have strong predictive ability in identifying
children who went on to have an autism diagnosis. Qualitative interviews with parents revealed that some of the Time 1 “at-risk” children demonstrated other kinds of social or communication concerns, yet still, the correspondences were not tight as some false positives and missed negatives were present. Ultimately, this study did not identify a clear leader among the evaluated tools used for identifying autism risk in infancy and toddlerhood. It does point to the importance of converging data from multiple sources (behavioral assessments as well as parent-report screeners) so that no child who presents some autism-related behaviors is overlooked given the literature demonstrating that early intervention is critical for this population and other developmental disorders. It is possible that with a larger sample, we may have found support for one early risk assessment tool over another. Future infant/toddler studies that include a longitudinal follow up will help address this gap in research on Autism Spectrum Disorder.
CHAPTER 1. INTRODUCTION

The term ‘autism’ has been used for over 100 years now, since Swiss psychiatrist Eugen Bleuler (1910) used it to describe some of the behavior and later thinking styles (1919) of individuals with schizophrenia (Kuhn, 2004). Years later, researchers and clinicians alike are still asking “What is autism?” or “What causes autism?” Characterized by deficits in social communication/interaction and restricted, repetitive behaviors and interests that often appear at birth or early in development, an ASD diagnosis can lead to lifelong problems with developing and maintaining relationships and can inhibit individuals from attaining functional independence. Autism is now considered one of the most common developmental disabilities as it has increased in prevalence over the past few decades (Bryson & Smith, 1998; Chakrabarti & Fombonne, 2001; Fombonne, 1999; 2002; 2009). Specifically, we have seen a rise from the early 4-6 in 10,000 rates first suggested in the 1960’s (Lotter, 1966), to 1 in 110 in 2006 (CDC, 2009) and 1 in 68 (1.47%) estimated in the U.S. in 2012 (Christensen et al, 2016). Today, the CDC reports 1 in 59 children are diagnosed with ASD (Baio et al., 2018). This increase in prevalence is likely due in part to an increase in knowledge and curiosity about the disorder and may have begun in the DSM-IV/IV-TR era. The DSM-III (APA, 1980) and DSM-III-R (APA, 1987) labeled the disorder as a unitary “infantile autism” and “autistic disorder” respectively. Infantile autism was restricted to only those who had early onset (before 30 months of age) following Leo Kanner’s early accounts (Verhoeff, 2013). “Autistic disorder” renaming dropped the <30-month age requirement but still grouped all individuals into a single diagnostic category. By having these strict, unitary categories and definitions, it is possible
that individuals may have been missed. In the DSM-IV/IV-TR, subtypes were included, widening the criteria for autism-like disorders which could have led to the marked increase in prevalence rates as more people could now be included who were less similar in the onset and severity of symptoms (Chakrabarti & Fombonne, 2001; Fombonne, 2009; Matson & Kozlowski, 2011; Wing, Gould, & Gillberg, 2011).

While ASD is continually diagnosed more frequently, we still do not fully understand its etiology. Research indicates a genetic component, as studies have shown a 20% recurrence risk in siblings of ASD children (Freitag, 2007; Ozonoff et al., 2011b) and rare chromosomal rearrangements or copy-number variants present in higher percentages of ASD individuals (~10-20%) compared to general population or unaffected siblings (only 1-2%) (Huquet, Ey, Bourgeron, 2013). However, there are currently no blood or lab tests that can screen for ASD, and researchers are looking for biomarkers through genetics and brain imaging testing. The research community has also yet to settle on a unified theory, with various theories of underlying causes such as Theory of Mind Deficit (Baron-Cohen, Leslie, & Frith, 1985; 1986), Executive Dysfunction (Ozonoff & Jensen, 1999; Ozonoff et al., 1991a), and Weak Central Coherence (Frith, 1989; Frith & Happé, 1994) and their alternate conceptualizations still being evaluated.

ASD is currently diagnosed on a “spectrum,” and variance exists in onset of symptoms, severity, and the degree of developmental change seen across the lifespan of individuals with autism. This has yielded questions about the diagnostic criteria and categorization, underlying theoretical causes, and best treatment/intervention practices (see Vaughn-Justus, 2018). Clinicians and researchers alike are still in pursuit of the earliest possible diagnostic age because much research has continually suggested that early,
intensive intervention is best (Estes et al., 2015; Helt et al., 2008; National Research Council, 2001; Zwaigenbaum et al., 2015). Early diagnosis offers the chance to identify precursors to prominent deficits seen in ASD and perhaps break or slow the cycle of atypical development. For example, early research such as Sigman et al. (1999) suggested that ASD children may fail to acquire language skills because of earlier limitations in symbolic and social precursors of language (e.g., gestures, joint attention). These lacking or limited language skills will then further intensify difficulties seen in symbolic and social realms. Intervening during the developmental windows for some of these precursors (e.g., joint attention) may prove beneficial in altering longitudinal developmental trajectories. Ongoing research has continued to demonstrate the impact of early intervention on improving cognitive, social, and communication skills in children with ASD (see Selemat, Renganathan, & Karim, 2018 for more in-depth review from 2013-2017). Through early intensive intervention, symptom severity may be reduced with the potential for individuals to move “off the spectrum” (Bradshaw, Koegel, & Koegel, 2017; Howlin, Magiati, & Charman, 2009; Lord et al., 2012a; McGovern & Sigman, 2005).

To that end, there have now been consistent research and policy efforts over the past 20+ years towards identifying ASD in children as young as age 2 (Charman, Taylor, Drew, Cockerill, Brown, & Baird, 2005; Chawarksa, Klin, Paul, Macari, & Volkmar, 2009; Kleinman et al., 2008; Lord, Risi, DiLavore, Shulman, Thurm, & Pickles, 2006; Stone et al., 1999; Wetherby, Brosnan-Maddock, Peace, & Newton, 2008; Zwaigenbaum et al., 2009). For example, abnormal social skills (e.g., language delays, failure to orient to name) have been seen as early as the first birthday in children later diagnosed with ASD (Chevallier, Kohls, Troiani, Brodkin, & Schultz, 2012; Baranek, 1999; Osterling &
Dawson, 1994; Osterling, Dawson, & Munson, 2002; Bolton, Golding, Emond, & Steer, 2012). Jones & Klin (2013) found that young infants who were later diagnosed with ASD showed decline in eye fixation from 2-6 months of age that compared to infants who were not later diagnosed. These fruitful efforts have included a number of prospective infant sibling studies (Bryson et al., 2007; Jones & Klin, 2013; Landa et al., 2012a; 2012b; Szatmari et al., 2016) that have helped to identify early behavioral and physiological manifestations of autism as early as 18-24 mos, compared to the previous diagnostic age typically falling around age 3 in the 80s-90s (Howlin & Moore, 1997; Siegel, Pliner, Eschler, & Elliot, 1988). Nevertheless, the mean age for diagnosing ASD is still 4-5 years today (Christensen et al., 2016; Wiggins, Baio, & Rice, 2006). Though delays may have been experienced and even acknowledged much earlier, by the time formal diagnosis is made (preschool age), children’s ability to pursue formal education, build relationships with peers and family, and overall quality of life may already be negatively impacted.

One might ask why, if research has made progress toward identifying early predictors, are we still unable to reliably catch ASD early out in the general population? This is largely because ASD is still idiopathic in nature today with symptomatology and severity differing widely across individuals with disorder (Caronna, Milunsky, & Tager-Flusberg, 2008). In theory, a developmental disorder diagnosis should provide insight into the general trajectory and possible intervention practices. However, with Autism Spectrum Disorder (ASD) it might be said that “no two individuals are alike.” We currently diagnose ASD as a spectrum disorder – individuals form a continuum that varies in symptom severity, onset, and level of required support (APA, 2013a). Presentations of ASD can differ widely from one child to the next making it difficult to identify early symptoms.
Also, current screening practices are heavily reliant on parent/pediatrician communication. Parents may have valid concerns, but pediatricians must ask about them and interpret them properly (i.e., lack of concerns ≠ typical development) (Dosreis, Weiner, Johnson, & Newschaffer, 2006; Glascoe, 2000; Glascoe & Dworkin, 1995; King & Glascoe, 2003). Retrospective studies have found that parents may have concerns as early as 15-18 months (Baghdadli, Picot, Pascal, Pry, & Aussillox, 2003; Chawarska et al. 2007; Herlihy, Knoch, Vibert, & Fein, 2015) but fail to mention to pediatricians until later or are met with reassuring “wait and see” responses from providers (Zuckerman, Lindly, & Sinche, 2015). Furthermore, deficits in social-communication as relevant for the child’s age (e.g., difficulty making friends, lack of interest in peers) may be difficult to evaluate until children enter formal school systems where they have a broader range of social interaction and additional sources of information (e.g., teachers, school professionals) (Wing et al., 2011). In sum, the variability in how autism presents behaviorally in the first two years of life combined with a lack of reliable tools for identifying children who may be showing subtle, early signs of autism are the likely causes behind the average diagnostic age hovering around 4-5 years.

1.1 Current Screening Practices

Before one can consider ways in which we could improve diagnostic approaches it is important to discuss what is common practice today for screening and diagnosis. Specifically, it is important to point out that early diagnosis is facilitated by early screening and that the tools used for each of these processes are different. Developmental screening is the process of casting a wide net to identify signs of ASD in the general population whereas more comprehensive diagnostic assessment is the process of determining whether
or not a child meets DSM criteria for ASD. Below I present a few options widely used as
diagnostic and screening instruments (see Gillberg, Nordin, & Ehlers, 1995; Klinger &
Renner, 2000 for broader reviews).

1.1.1 Parent-report Checklists

A lot of early cause for concern in ASD comes from parental observations of
abnormal communication behavior (Kozlowski, Matson, Horovitz, Worley, & Neal, 2011;
Pinto-Martin et al. 2008). Well-established and widely used parent-report screeners for
autism (e.g., Modified Checklist for Autism in Toddlers (M-CHAT), Robins, Fein, Barton,
& Green, 2001) are frequently utilized screening tools before more formal diagnostic
screeners or interviews are conducted. Screeners often describe behaviors that are
considered appropriate based on the infant’s age. Screener scoring involves calculating the
number of responses that indicate ASD risk (low, medium, high) which are then used to
make recommendations about future follow-ups or further investigation. Some screeners
(e.g., Communication and Symbolic Behavior Scales Developmental Profile Infant-
Toddler Checklist, Wetherby & Prizant, 2002) also provide composite scale scores that can
further compare an infant to percentile scores from infants his/her age. Pediatricians often
have parents complete these assessments at 18- and 24- month well-baby checkups even if
symptoms are not there. Screeners are evaluated based on the proportion of positive screens
(i.e., “at-risk” children) that go on to receive diagnosis (Positive Predictive Value or PPV).
For example, the M-CHAT has been assessed in large community samples as a level 1
screener and has shown PPV as high as .57-.65 (Chlebowski, Robins, Barton, & Fein, 2008;
Robins et al., 2014) though lower for younger children (e.g., 16-23 mos.) (Pandey et al.,
The social composite scores from the CSBS have also shown utility for detecting ASD by the end of the first year of life (Wetherby et al., 2008).

1.1.2 In-depth Interviews and Behavioral Observations

Children identified by parent-report screeners may then be evaluated through formal interviews or behavioral observation. Oftentimes this involves referral to an ASD specialist (e.g., child psychologist, speech-language pathologist, developmental pediatrician, neurologist, etc.). For interviews, the Autism Diagnostic Interview-Revised (ADI-R, Rutter, Le Couteur, & Lord, 2003) is commonly used. ADI-R is a semi-structured interview designed for parents or caregivers of individuals suspected for ASD. The interview takes 90-150 minutes to administer and score and covers topics such as family history, education, previous diagnoses, and medications in addition to the information collected on current and previous behavior. The ADI-R assessment covers three functional domains: 1) language/communication, 2) reciprocal social interaction, and 3) repetitive behaviors/interests. These are consistent with DSM-IV symptom criteria (i.e., social interaction, communication, stereotyped/restrictive/repetitive behavior) which was standard at the time the ADI-R was released. It is important to note that the large majority of interviews and screeners are targeted at the parent or caregiver. Self-report is not commonly used as part of an ASD assessment. Some individuals with autism have poor language skills and would make administering an interview very difficult. For these individuals, behavioral assessments are perhaps more telling. Baron-Cohen, Wheelwright, Skinner, Martin, and Clubley (2001) developed the Autism Spectrum Quotient (AQ) which was written in first-person and said to be appropriate for adults with normal intelligence. Bishop & Seltzer (2012) evaluated the use of AQ as compared to ADR-I data (from
mothers) and concluded that AQ was likely not useful across individuals. It may be good for some who have good insight into their impairments, but not for others who have limited insight into their difficulties or who are too young to respond appropriately. Instead, behavioral assessments are used as the primary approach to collect data from the actual individual who is suspected to be at risk for autism.

The Autism Diagnostic Observation Schedule, Second Edition (ADOS-2, Lord et al., 2012b) is considered the gold standard for autism diagnosis based on behavioral observation. ADOS-2 is considered appropriate from 12 months of age through adulthood and is split into five separate modules that each align with certain ages and ability levels. A given module takes 40-60 minutes to administer and assesses behavior through real-time interaction featuring objects and social presses designed to elicit behaviors such as eye contact, social smiling, and joint attention. These assessments often use checklists or ratings and establish “omnibus” scores that relate to cutoffs thought to indicate risk for ASD. The long-term stability of ASD diagnosis in children ≥24 months of age is considered well established (Charman et al., 2005; Kleinman et al., 2008; Lord et al., 2006; Turner & Stone, 2007) and emergent data suggests that diagnosis before age 24 is stable in significant proportions of children but ongoing research is needed in the context of early screening facilitating the earliest possible diagnosis (Gotham, Risi, Pickles, & Lord, 2007; Luyster et al., 2009).

To summarize, current screening practices often start with parent concerns before moving into the more in-depth follow-up assessments. Early parental cause for concerns is usually related to communication (De Giacomo & Fombonne, 1998; Kozlowski et al., 2011) with early abnormal social skills (e.g., language delays, failure to orient to name).
appearing by the first birthday in children later diagnosed with ASD (Baranek, 1999; Osterling & Dawson, 1994; Osterling et al., 2002; Bolton et al., 2012). These concerns may be voiced in a pediatrician’s office (i.e., baby checkup) but will likely be investigated through use of parent-report screeners that may then lead to more in-depth interview and behavioral observation procedures because social development is hard to evaluate in a clinical pediatric setting (Pinto-Martin et al., 2008). Additionally, administering these only to parents who express clear concerns would likely bias diagnosis in the same ways that self-report measures bias any psychological endeavor. Highly involved and concerned parents would get answers whereas children of less involved or concerned parents would be missed. The American Academy of Pediatrics (AAP) now recommends widespread autism screening at both 18- and 24-month well-baby visits (Johnson & Myers, 2007). However, pediatricians again do this through the use of parent-report screeners like the M-CHAT which require parents to have familiarity with child’s history and current behavior and are subject to biases. Further, pediatricians do not have time to thoroughly follow up parental voiced concerns and administer a 90-150-minute ADI-R interview or a 40-60-minute ADOS-2 module. Therefore, M-CHAT or other parent-screener flags typically yield recommendations for follow-up screening, which can be costly and rely on access to another clinician who can administer these more in-depth screeners. Administering the full protocol of current initial screeners and follow-up assessments to every child is a large undertaking that seems unlikely to gain clinical support. As a result, researchers have taken different approaches to explore possibilities for earlier diagnosis of ASD. This includes the creation of shorter, objective behavior screeners as well as looking primarily at infants considered genetically higher-risk for developing ASD.
1.2 New Screening Efforts

The Rapid-ABC or R-ABC task created by Dr. Opal Ousley & colleagues has answered the call for screeners that can facilitate earlier diagnosis through the development of a quick, interactive autism-specific screener for young infants and toddlers that could be utilized in pediatrician offices. In the Rapid-ABC, Rapid refers to the brief nature of the assessment (~4 min) and ABC refers to the protocol’s focus on eliciting social Attention, Back-and-forth interaction, and nonverbal Communication (Ousley, Arriaga, Abowd, & Morrier 2013). The screener features an adult examiner engaging in a semi-structured play interaction with the child that is designed to elicit a broad range of social behaviors. Activities include naturalistic play scenarios such as rolling a ball back-and-forth, tickling, or reading a book. Scoring includes looking at which behaviors are and are not elicited (“yes”/“no”) as well as the examiner’s subjective ratings of how difficult the child was to engage in a given activity. These engagement scores and non-present behaviors are considered potential ‘red-flags’ and are combined into a composite score that when compared with cut-offs identifies risk for ASD. In a validation study with 46 infants and toddlers (18 at-risk, 28 not at-risk for ASD based on an “all information available” judgment by an expert clinician), ages 15-24 months, Ousley et al. (2013) found the R-ABC to correlate with other common parent-report screening measures for ASD such as the M-CHAT \( r = .73, p < .001 \) and CSBS \( r = -.68, p < .001 \). They also found that the R-ABC cutoff scores distinguished between the children in the sample who were and were not considered at-risk for ASD diagnosis with high sensitivity and specificity. Ongoing research is needed to evaluate whether the R-ABC can be extended as a screening tool that can differentiate autism from other developmental disabilities as well as an evaluation of
whether this type of screener does a better job at identifying children who go onto be diagnosed with ASD than gold-standard parent-report screeners (i.e., are we adding anything novel by including the R-ABC?). The need for this type of research serves as a motivator for the present study. Specifically, in my Master’s thesis (Vaughn, 2017), I did an exploratory analysis investigating how the Rapid-ABC assessment classified a sample of infants as “At-Risk” for ASD compared to the risk classification outcomes based on well-known parent-report screeners that were also administered as part of this study (M-CHAT, CBCL, CSBS). The archival dataset from the original study included 237 sessions from 181 infants (56 had follow-ups 2-3 mos. after intake). Results revealed that parent-report data (from M-CHAT, CBCL, CSBS) flagged 44 of these infant sessions as “at-risk” for autism. 42 infant sessions were flagged as “at-risk” for ASD by the Rapid-ABC screener (using a cutoff score of 13 from Ousley et al., 2013). However, these two sources of risk information agreed for only 14 sessions. When considering only the parent-report screener (M-CHAT) that all infants’ parents completed (i.e., CBCL & CSBS were only given to parents of infants who were > or \( \leq \) 24 months respectively), this agreement dropped to only 9 infant sessions. However, this dataset was left incomplete as there was not currently a follow-up time point to assess true clinical diagnosis or later developmental progress beyond infancy. From this finding, I proposed the current investigation: to collect the follow-up data from the infants in the archival data set (turning the data set into a longitudinal study) and to directly compare these early sources of information (parent-report vs. behavioral observation) and how they related to later developmental outcomes.

In addition to the need for applied research directly comparing different sources of information about early delays as they relate to later outcomes, there is also a need for more
general population studies in ASD. Studies of concordance rates in twins and recurrence rates in younger siblings of children with ASD illustrate the genetic component of autism (Dawson, 2008; Grønberg, Schendel, & Parner, 2013, Ozonoff et al., 2011b; Zwaigenbaum et al., 2007). Specifically, younger siblings have a 1 in 5 chance of developing ASD, a statistic much higher than the 1 in 68 estimated prevalence rate in the general population (Ozonoff et al., 2011a; Sumi, Taniai, Miyachi, & Tanemura, 2006).

Since the symptomatology and onset is still not fully understood, a lot of studies capitalize on genetic underpinnings in order to zero in on “high-risk” infants (sometimes referred to as “baby sibs”). Using this genetic prevalence as a convenience sampling approach provides an opportunity to look at infant siblings of children diagnosed with ASD from first month of life. These high-risk groups also provide the opportunity to contrast the behavior of children who go on to develop autism from those who do not (i.e., prospective longitudinal studies). Many of the leaders in this field of research are involved with the Baby Siblings Research Consortium (BSRC) (e.g., Bryson, Charman, Klin, Landa, Ozonoff, Rogers, Tager-Flusberg, Zwaigenbaum) and are actively conducting these prospective studies in hopes of identifying the earliest indicators of autism. These efforts have been promising with differences being noticed as early as 6 months of age. For example, Chawarska, Macari, and Shic (2012) found noticeable deficits in regulation of attention when viewing social scenes in 6-month-old infants who are later diagnosed with ASD. Zwaigenbaum et al. (2005) found that atypicality in a large variety of early behaviors such as eye contact, orienting to name, visual tracking, disengagement of visual attention, imitation, social smiling, and receptive and expressive language skills could distinguish siblings who go on to develop ASD from both the high-risk siblings who do not go on to
develop ASD and low-risk (non-ASD sibling) controls. Also, some of the studies mentioned previously that have provided new information on the variance in developmental trajectories of those who go on to receive a later diagnosis (Bryson et al., 2007; Landa et al., 2012a,b) were prospective baby sibs studies.

Lastly, it is important to note that the majority of the research on screeners as accurate predictors of later diagnosis focus solely on true diagnostic outcome (i.e., clinical diagnosis of ASD or related disorders). While it is a regular practice to conduct validation studies investigating the accuracy (sensitivity/specificity) of both current and emergent screening practices, there is still much opportunity for applied studies that directly compare different sources of information collected at the same timepoint to one another. That is, many validation studies include blind administration of a given screener to individuals who have formal diagnoses that are revealed after data is collected. Using methods such as Receiver Operating Characteristic (ROC) area under the curve analyses, these studies investigate cutoff scores for accurate classifications. These cutoff scores are then used for widespread screening practices. Few studies investigate screener scores as they relate to diagnostic outcomes on a general population (not pre-selected with known diagnosis). Furthermore, children who rise above cut-off scores for ASD risk in early childhood may not have a later formal ASD diagnosis (i.e. false positive) but may in fact have a developmental profile that would be considered atypical. This study uses qualitative interviews with parents to determine whether early ASD risk may be associated with ASD-related behavioral patterns that may not meet cut-off standards.

1.3 Present Study
As illustrated above, one major push in recent ASD research is to learn more about early predictors of autism and how we may best capture these predictors. While much is left to be uncovered about the nature of autism, there are two arguments that most, if not all, researchers and clinicians would likely agree on: 1) diagnosing and treating as many individuals as early as possible is the goal, and 2) better understanding of the heterogeneity of this disorder (i.e., why no two people with ASD are alike) will inform these efforts towards optimal diagnosis and intervention practices. The present study builds off these ideas, advocating for an increase in studies that take an applied approach, gathering multiple sources of information (e.g., parent-report screeners, behavioral assessments) about early delays from general population samples and following these children longitudinally to see which sources of information (e.g., which specific predictors) should be used in conjunction to cast the most efficient net for capturing ASD.

**Focal Research Question:** Do early sources of information about of infant behaviors associated with Autism Spectrum Disorder risk predict later diagnostic outcomes?

Specifically, the aim of the present study was to explore which sources of information (screening instruments) for early infant and toddler risk for Autism Spectrum Disorder are the most predictive of not only formal ASD diagnosis but also more general ASD-related social communicative concerns (i.e., quantitative and qualitative outcomes) in childhood and adolescence. Rather than focusing on “what” we can see in infancy, I instead asked “how” we might collect the most useful information in infancy that relates to later developmental (including diagnostic) outcomes. This is the primary novel contribution from the present dissertation to the larger discussion on early ASD and
developmental delay identification. Though the greater number of information sources are considered ideal when evaluating ASD risk (Chawarska et al., 2007; Ousley et al., 2013), knowing which early sources provide the most predictive information could prove useful especially in situations where families may not have the resources to seek out an all-information-available type of assessment.

I approached this inquiry using a mixed-methods, longitudinal design. Specifically, I compared how information gathered from this a newer behavioral assessment (R-ABC) compares to parent-reported information from well-known screeners (M-CHAT, CSBS, CBCL) and how these different sources collected during infancy relate to ASD diagnostic outcomes as well as related social communicative challenges for children in later childhood. Through a brief (10-20 minute) phone interview (Time 2), I gained information from parents who previously participated in an institute IRB-approved study (Time 1) about their children's social and communicative development over the last 3-7 years. The infants who participated in the original study between 2011-2015 were now older (4-10 years, depending on the age when they entered the original study) and therefore more likely to have received an autism spectrum disorder diagnosis as research has shown that the average age of diagnosis lies around 4-5+ years (Wiggins et al., 2006). Through convenience sampling, the original study provided the opportunity to use a follow-up measure to create a longitudinal study with the data in which I gathered information about various sources of developmental progress (e.g., concerns within school system, education placement, general parent concerns) as well as medical updates (e.g., formal clinical diagnoses of any delays or disorders) as related to ASD. I outline next the specific hypotheses and justification for the present inquiry.
1.4 Hypotheses & Justification

1.4.1 Quantitative Inquiry

As mentioned previously, I looked into the disagreement of at-risk classification with two key sources of information that were both gathered during the previous study when the infants were 15-34 months: 1) the parent report screeners completed by caregivers and 2) the Rapid-ABC screener completed by the experimenter. Parent-report screener (M-CHAT, CSBS, CBCL) scores classified 44 infants as at-risk during a visit to the lab and the R-ABC scores classified 42 infants as at-risk. However, there was agreement amongst classification for only 14 infants (19.4%, 14/72). This was surprising as Ousley et al. (2013) reported that the Rapid-ABC found 84.7% agreement on risk-status classification with the M-CHAT. Though the agreement in the present sample is much smaller, I still anticipate that consensus (i.e., both sources say “at-risk”) would be most likely to predict later ASD diagnosis or related behavioral concerns in childhood. The individual screening tools have each been validated suggesting acceptable sensitivity and specificity for ASD and therefore it should be unlikely that agreement about ASD-risk from both sources of information is a “false positive”. From this premise, I still predict that parents of children who were considered At-Risk (AR) from both sources of screening information would be most likely to mention a formal diagnosis or express having substantial concerns about their child’s development during the follow-up interview compared to both those who were flagged on only one type (RABC behavioral assessment or parent-report) and those considered Typically Developing (TD) by both measures (i.e., ↑ number of failed screeners = ↑ risk). That is, I am hypothesizing that more sources of early risk classification yield greater potential for developmental delays:
Hypothesis 1: Children who have received at Time 2, a formal ASD diagnosis (or have substantial communication/social impairments that are deemed by parent as moderate or severe; and persistent or worsening) will be more likely at Time 1 to have failed both parent-report and the Rapid-ABC screener compared to children who failed only one type of screener and children who did not fail any initial screener. Children who failed only one type of screener at Time 1 (parent-report or R-ABC) will be more likely to have received an ASD diagnosis or demonstrated delays/impairments compared to children who did not fail any screeners at Time 1.

It is important to note that this hypothesis also accounts for the fact that some parents might not mention a formal ASD diagnosis made by a clinician during the follow-up interview but may discuss other developmental concerns (e.g., lack of friendships, lack of emotion or regulation, age inappropriate behavior) that should be noted (i.e., both qualitative and quantitative data should be evaluated). In this study, I consider both “strict” (formal diagnosis) and “lenient” (diagnosis or significant delays mentioned that could be related to ASD) outcome measures through the use of a semi-structured interview questionnaire. Through questions inquiring about variety of sources about concern (e.g., school, clinician, parent) and follow up probes about the “persistence”, “progression” and “severity” of any mentioned delays or deficits, I was able to create an expanded dependent measure.

Lastly, I also included a well-known parent-report screening measure as an additional screening measure. The Social Communication Questionnaire (SCQ) by Rutter,
Bailey, and Lord (2003) is a parent-report screener designed to screen for possible ASD, similar to parent-report questionnaires used in the original study that serve as Time 1 for the present inquiry. The SCQ is derived from one of the previously mentioned “gold-standard” assessments for ASD, the ADI-R (Berument, Rutter, Lord, Pickles, & Bailey, 1999) and has also been compared to the ADOS (Corsello et al., 2007). The screener has been widely scrutinized (see Chesnut, Wei, Barnard-Brak, & Richman, 2017 for metanalysis) but has demonstrated effectiveness in ASD vs. non-ASD prediction. The SCQ has two versions: Lifetime (used to support diagnosis) and Current (used to support evaluation of current difficulties), but the Lifetime version (used as part of present study) has been validated for children of four years or older (Le Couteur, Lord, & Rutter, 2003) and is more widely recommended (Marvin, Marvin, Lipkin, & Law, 2017; Wei, Chesnut, Barnard-Brak & Richman, 2015). Previous studies have also compared SCQ agreement on diagnosis with parent-report screeners such as the M-CHAT (Eaves, Wingert, & Ho, 2006).

Building off this research, I anticipate that initial risk status classification in infancy will predict higher scores on the objective SCQ measure in childhood. Particularly, I expect that group differences (at-risk at T1 vs. not at-risk at T1) will exist on the SCQ. That is, parents/caregivers of children who were at-risk at Time 1 would yield higher SCQ scores which indicate more challenges (i.e., a cutoff of £15 indicates possible ASD) than caregivers of children who were not considered at-risk at Time 1.

_Hypothesis 2:_ Children who were considered at risk by R-ABC and Parent Screeners at Time 1 will score higher on SCQ (i.e., more social/communicative challenges) at Time 2 than those who were not considered at risk by RABC and Parent Screeners at Time 1.
Taken together, these hypotheses add to the literature by investigating different sources of information in infancy (well-known parent-report measures vs. newer behavioral assessment) as well as different ways of quantifying outcome measures in childhood and adolescence. Hypothesis 1 seeks to capture not only formal diagnosis but also broader ASD-related developmental concerns. Hypothesis 2 serves as an additional check for possible ASD-diagnosis especially when formal diagnosis has not yet been made but parents are reporting general behavioral or developmental concerns (from self, clinician, or school).

This follow up study builds on an archival sample for ASD risk that was collected from the general population, not a genetically higher risk sub-group (“baby sibs”) or those with known ASD diagnosis. That being said, this approach has strong potential for broader ecological validity of risk-screeners for the population at-large.

1.4.2 Qualitative Inquiry

Another unique contribution of the present study is using a semi-structured interview questionnaire to gain a more thorough account of development. To this end, I pursued a small-scale qualitative analysis of my data in addition to Hypothesis 1-2. For this qualitative analysis, I developed a thematic coding system related to child education progress, social development, and general parental concerns based on known delays/deficits seen as characteristic of ASD. Specifically, I noted if parents expressed concern with their child’s development and the sources of concern (e.g., teachers, family, friends, physician). Thematic analyses go beyond a simple description of participants’ responses. The approach supports a discovery of patterns (e.g., prevalence of themes) and co-occurrences of themes between groups of interest. Phases of analysis include
Transcription; Initial Coding (data reduction/complication); Searching for Themes; Reviewing Themes; Defining and Naming Themes; and Producing the Report (see Braun & Clarke, 2006). While some qualitative studies do not begin with a priori research hypotheses, I proposed two hypotheses based on prior literature and hypotheses associated with the quantitative analyses proposed.

_Hypothesis 3:_ Caregivers of children who were considered at risk by R-ABC and Parent Screeners at Time 1 will show more response themes related to child’s social and communication challenges at Time 2 than those who were not considered at risk by R-ABC and Parent Screeners at Time 1.

_Hypothesis 4:_ T2 High SCQ scorers will also show greater response themes related to delays/social and communication challenges in caregiver interview.
CHAPTER 2. METHOD

This method for this study featured a follow-up interview with parents of children who participated in a previous study conducted in Dr. Agata Rozga’s Child Study Lab (CSL) at the Georgia Institute of Technology from 2011-2015. The Multimodal Dyadic Behavior (MMDB) dataset features 237 recorded sessions of audio, video, and physiological recordings of 181 children, ages 15-34 months old, who interact in a toy play assessment known as Rapid-ABC or R-ABC (Ousley et al., 2013). A subset, 56 children, came in for an additional, follow-up session 2-3 months after the initial visit. Intake (181) and follow-up (56) sessions together comprise the total number of infant sessions (237). Infants were given a unique participant ID and each de-identified session was classified as Typically Developing (TD) or At-Risk (AR) based on well-known, parent-report autism screeners (e.g., M-CHAT, CSBS, CBCL) filled out by the parent while in the lab. The MMDB team’s research goals are to work towards creating new computational methods of both measuring and analyzing behavioral data of children and adults during face-to-face social interaction (Rehg et al., 2013). The present study uses both quantitative and qualitative analysis techniques to assess how infants’ social and communicative behaviors relate to parent-reported child development outcomes in childhood and early adolescence. Specifically, archival data from both behavioral and parent-report screeners collected when the infants were 15-34 months old (i.e., MMDB dataset) was combined with information about parent-reported diagnostic outcomes (i.e., if child received a diagnosis of autism spectrum disorder or not) and developmental progression over the last 3-7 years collected as part of this follow-up study.
1.5 Participants

Convenience sampling from the MMDB participant pool was utilized for this study. All 181 families who previously participated in the original study from 2011-2015 were recruited via mailed and emailed letters to invite parents/caregivers to participate in the present follow-up study. The 181 children who had participated in the original study ranged in age from 15-35 months ($M = 22.3$, $SD = 4.71$) and 54% were male. Of the 181, 53 infants had participated in follow-up interviews ~3 months after the intake visit.

58 interviews were conducted with 56 parents\(^1\) as part of the present study. One interview was excluded due to the fact that we realized post-interview that the parent had been answering questions about a child not in the original study, resulting in a final sample size of 57 interviews from parents (55 mothers, 1 father) of children in the original study (30 boys, 27 girls). At time of follow-up interview, children of the participants ranged in age from 4-10 years ($M = 7.3$, $SD = 1.17$). Participants’ parents were highly educated with the majority holding at least a bachelor’s degree ($n = 26$) or higher (i.e., graduate school degree, $n = 25$). Family status was primarily “married” ($n = 52$) with only a few parents reporting separation ($n = 2$), divorced ($n = 2$) or widowed ($n = 1$). The majority of families were multi-child homes ($n = 49$) and reported household incomes of $75,000+ (n = 49)$. Fourteen families spoke multiple languages at home (e.g., French, Hebrew, Spanish, Mandarin, etc.), but English was the primary language at home for all but one family (Spanish). I checked the demographic characteristics of the populations of Time 1 (original

\(^1\) 56 parents completed 58 interviews. One parent had twins in the original Time 1 study and completed two, separate follow-up interviews at Time 2 (one per child). One other parent also completed two Time 2 interviews because we realized post-interview that this parent had discussed a sibling of the child who participated in Time 1 study rather than the child we were seeking follow-up data for. This parent later completed a second interview on the child who had participated in Time 1.
study) and Time 2 (present study) and found that they were very similar. Table 1 below summarizes all participant demographics.

Table 1 - Participant Demographic Characteristics

<table>
<thead>
<tr>
<th>Sample size (N)</th>
<th>57 children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Gender (% male)</td>
<td>53%</td>
</tr>
<tr>
<td>Child age at Time 2 (yr.) (SD; range)</td>
<td>7.26 (1.17; 4-10)</td>
</tr>
<tr>
<td>Parent-reported child ethnicity (%)</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>75.4</td>
</tr>
<tr>
<td>African-American</td>
<td>10.5</td>
</tr>
<tr>
<td>Asian</td>
<td>3.5</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>3.5</td>
</tr>
<tr>
<td>Mixed ethnic group</td>
<td>7</td>
</tr>
<tr>
<td>Language spoken at home (%)</td>
<td></td>
</tr>
<tr>
<td>English only</td>
<td>75.4</td>
</tr>
<tr>
<td>English plus additional language</td>
<td>24.6</td>
</tr>
<tr>
<td>Multi-child home (%)</td>
<td>86</td>
</tr>
<tr>
<td>Family Status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>91.2</td>
</tr>
<tr>
<td>Separated</td>
<td>3.5</td>
</tr>
<tr>
<td>Divorced</td>
<td>3.5</td>
</tr>
<tr>
<td>Widow/Widower</td>
<td>1.8</td>
</tr>
<tr>
<td>Maternal Highest Education</td>
<td></td>
</tr>
<tr>
<td>High school diploma/GED</td>
<td>-</td>
</tr>
<tr>
<td>Some college</td>
<td>10.5</td>
</tr>
<tr>
<td>Associate/Bachelor’s degree</td>
<td>43.9</td>
</tr>
<tr>
<td>Some graduate school</td>
<td>1.8</td>
</tr>
<tr>
<td>Graduate degree (Maters or above)</td>
<td>43.9</td>
</tr>
<tr>
<td>Paternal Highest Education</td>
<td></td>
</tr>
<tr>
<td>High school diploma/GED</td>
<td>5.4</td>
</tr>
<tr>
<td>Some college</td>
<td>10.7</td>
</tr>
<tr>
<td>Associates/Bachelor’s degree</td>
<td>35.7</td>
</tr>
<tr>
<td>Some graduate school</td>
<td>3.6</td>
</tr>
<tr>
<td>Graduate degree (Masters or above)</td>
<td>44.6</td>
</tr>
</tbody>
</table>
Table 1 (Continued)

Maternal Occupation
- Not employed outside home: 26.3%
- Employed part-time: 24.6%
- Employed full-time: 45.6%
- Employed full-time, multiple job: 3.5%

Paternal Occupation¹
- Not employed outside home: 1.8%
- Employed part-time: -
- Employed full-time: 96.4%
- Employed full-time, multiple job: 1.8%

Household Annual Income
- $25,000-$49,999: 3.5%
- $50,000-$74,999: 10.5%
- $75,000-$99,999: 14%
- $100,000-$124,999: 7%
- $125,000+: 64.9%

Note. SD = Standard Deviation. ¹n = 1 missing.

All interviews were conducted via a private Skype caller account that was linked to a private, OIT-maintained email address created solely for this study and were performed by the same interviewer (i.e., the author of this dissertation). All interviews were recorded using e-camm recording software for Skype. Each family was compensated for participating in the 30-minute follow-up interview with a $20 Target gift card.

1.5.1 Ethical Considerations

It is important to note that I did not know the Time 1 autism risk-status when conducting any interviews. In the original study, each participant had been given a unique identifier for data collection. For recruitment for the present follow-up study, the laboratory manager for the Child Study Lab created a randomized, master participant contact information list that did not include any of the original study identifiers. This list was
alphabetized by parent first name and included only child and parent/caregiver names and email/mailing address only. This list did not include any other data about the child (e.g., age, gender) to keep the study as blind and non-biased as possible. The original study participant IDs were revealed once all data collection was complete for this present study (see below procedure for more detail).

1.6 Materials

The materials outlined next first summarize the screening tools from the previous protocol that were used as archival data as ‘Time 1’ for the current study and then focus in greater detail on the materials that were created for ‘Time 2’ new data collection (i.e., the follow-up interview from the present study).

1.6.1 Time 1: Materials

In the original study, parents completed developmental screeners for autism spectrum disorder (i.e., M-CHAT, CSBS, CBCL). Their infants (ages 15-35 months) then interacted with an experimenter in a brief, autism-specific behavioral assessment (i.e., Rapid-ABC (R-ABC), Ousley et al., 2013). This interactive assessment was audio/video recorded and later annotated by trained coders using ELAN software. More in-depth descriptions of each screener and how it was used in the original study are provided below.

1.6.1.1 Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, Barton, & Green, 2001)

All parents completed the M-CHAT screener as part of the original study. The M-CHAT is a two stage, parent-report screener that is used to assess risk status for ASD in children ranging from 16 to 30 months of age. Parents respond “Yes” or “No” to a series of 23 questions about their child’s development. An example item is “Does your child look
at your face to check your reaction when faced with something unfamiliar?” Scoring involves calculating the number of responses that indicate ASD risk. Low risk (score 0-2), Medium risk (3-7), or High Risk (8-20) categories are then used to make recommendations about future follow-ups or surveillance of behavior.


Only parents of infants ages ≤ 24 mos. completed the CSBS screener as part of the original study. The CSBS-DP:ITC focuses on communication and social skills and is thought to be appropriate for identifying ASD risk in children ranging from 6- to 24-months of age. The screener is split into subsections (e.g., emotion and eye gaze, sounds, object use) and parents respond on a 3-point type scale for most questions (i.e., Not Yet, Sometimes, or Often). An example item is “When you look at and point to a toy across the room, does your child look at it?” Social, Speech, and Symbolic Composite scores are used to evaluate an infant in comparison to standard and percentile scores of other infants his/her age. Recommendations for follow-up checklist completion or developmental evaluation are then made based on how the child’s score compares to the criterion scores.

1.6.1.3 Child Behavior Checklist/1.5-5 (CBCL; Achenbach & Rescorla, 2000)

Only parents of infants ages >24 mos. completed the CBCL screener (as part of the original study. The CBCL is a screener designed to assess social, emotional, and behavioral problem behaviors. The tool is a part of the Achenbach System of Empirically Based Assessments (ASEBA) and multiple versions exist for children of different ages. For this study, the preschool (CBCL/1.5-5) version was used. Respondents are instructed to rate the child’s behavior on a 3-point scale (0 = Not True (as far as you know), 1 = Somewhat
or Sometimes True, or 2 = Very True or Often True) as it presently occurs or has occurred within the previous two months for 100 items. Certain items offer additional room for elaboration (e.g., “Fears certain animals, situations, or places (describe)”). The CBCL also features a Language Development Survey for children 18-35 months of age featuring questions about the child’s development and a list of 310 words in which respondents are instructed to circle each word that the child says spontaneously (rather than imitating or understanding).

1.6.1.4 Rapid-ABC Assessment (R-ABC; Ousley, Arriaga, Abowd, & Morrier, 2013)

All children in the original study participated in the Rapid-ABC assessment as part of their visit to the GT Child Study Lab. The Rapid-ABC or R-ABC task is an autism-specific behavioral assessment for young infants and toddlers in which an adult examiner engages in a semi-structured play interaction with the child that was designed to elicit a broad range of social behaviors which, if atypical, could be noted as potential ‘red-flags’ pointing towards possible ASD (Ousley et al., 2013). The interaction protocol consists of five distinct stages, in the following order:

1. Greeting – The experimenter greets the child by smiling and saying hello using the child’s name. The experimenter asks the child if he/she is ready to play then moves to retrieve a ball from below the table.

2. Ball play – Once the ball is visible over the table edge, the experimenter initiates a turn-taking type game of rolling the ball back-and-forth to the child. The experimenter rolls the ball to the child and requests the child to roll it back (if they do not do this on their own). The experimenter then puts the ball away (below the table) and retrieves a picture book.
3. Book reading – Once the book is visible over the table edge, the experimenter initiates a social reading activity in which she invites the child to look at the book with her. She reads the book to the child and asks the child “what do you see?” She also offers moments for the child to engage with the book or help turn the pages by asking, “what’s next?” Once finished with the book, the experimenter closes it and begins the hat activity.

4. Hat – The experimenter places the book on her head and pretends that it is a hat. She engages the child and asks, “Where is the book?” Once pointing out that the book is on her head like a hat (if the child does not do so him/herself) the experimenter closes the book and puts it away (below the table).

5. Tickle play – Lastly, the experimenter engages the child in a gentle tickling game. This game is social and similar to the back-and-forth ball activity in that the experimenter says, “I’m going to get/tickle you” and tickles the child (saying “tickle tickle tickle”) then retreats before repeating the activity.

As the examiner moves through the five activities, he/she is noting on a scoring sheet the presence or absence (based on a single occurrence) of seventeen target socio-communicative and participatory behaviors. For example, the experimenter scores whether or not the child initiated joint attention (e.g., looked at ball then to experimenter), smiled, turned book pages, pointed, etc. The examiner also rates the overall engagement of the child (i.e., how much effort was required to engage the child) during each stage of the protocol on a 3-point Likert type scale (0 = easily engaged, 3= significant effort required
to engage the child). Together, these yes/no behavior notations and social engagement scores are thought not only to provide ‘checks’ for key socio-communicative milestones expected to appear in the first years of life, but also to shed light on red flags (i.e., qualitative differences in behavior or diminished occurrence) for an ASD. Ousley and colleagues (2013) validation study found that the R-ABC discriminated between the children who were and were not at-risk for ASD diagnosis with good sensitivity/specificity using a cutoff score of as low as 13.

1.6.2 Time 2: Materials

In the present study, a follow-up phone interview with parents of children in the original study 3-7 years later is considered “Time 2”. Materials for this interview included a semi-structured interview questionnaire and an autism-specific screening instrument (Social Communication Questionnaire, SCQ; Rutter et al., 2003). More in-depth descriptions of the interview protocol and SCQ are provided below.

1.6.2.1 Interview Protocol

The protocol for this study was created to be a semi-structured interview dialog at the fundamental level (see Appendix A for questionnaire). The intended audience was parent/caregivers of children who were in the original study inquiring about the child’s progress over the last 3-7 years. Interview questions spanned the following topics: general (likes/dislikes, parent concerns about development), education placement and progress or concerns, social relationships (friendships), clinical diagnoses and formal treatments/therapies, and demographics (child gender and age, ethnicity, family socioeconomic status, family marital status, mother/father education level, number of children in household, language(s) spoken at home).
Though the interview spanned a lot of topics, child developmental progress was considered through an ASD lens when formulating questions to include. Specifically, we chose to include interview questions related to delays that would likely appear to some degree in children diagnosed with autism. For example, we included questions about social relationships, such as "Has <insert child name> developed any close friendships at school?" and "Does <insert child name> prefer playing in groups or alone?" Social reciprocity and communication are core deficits of ASD (APA, 2013a; Church, Alisanski, & Amanullah, 2000) and perhaps one of the most profound or defining (Bellini, 2004). Research has found that some children with autism can be excessively verbose when conversing with peers and many have difficulties using or understanding non-literal language including sarcasm and metaphors (Elder et al., 2006; Kerbal & Grunwell, 1998). Oftentimes these social deficits result in the failure to form friendships or diminished relationship quality (e.g., peer rejection, isolation, loneliness) in young children and adolescents with ASD compared to their TD peers (Bauminger & Kasari, 2000; Bauminger, Shulman, & Agam, 2003; Chamberlain, Kasari, & Rotheram-Fuller, 2007). These deficits may become even more prominent or impactful during adolescence and adulthood (Bagwell, Newcomb, & Bukowski, 2008). Specific treatment and intervention programs have even been developed (e.g., UCLA PEERS program by Laugeson & Frankel, 2010) that seek to improve social competence and friendship skills among ASD adolescents (Laugeson, Frankel, Gantman, Dillon, & Mogil, 2012).

When stepping back to evaluate the interview as a whole, we also felt it was possible that some parents would discuss ASD-relevant delays without mentioning a formal diagnosis. Therefore, the questionnaire was also designed with a goal in mind of
gathering rich data about broader developmental outcomes that might related to ASD rather than solely asking for any clinical outcomes (i.e., Yes/No ASD). By including a variety of open-ended questions, the protocol was designed to feel more conversational in nature (i.e., letting the parent share whatever they felt relevant or important) in hopes of illustrating a clearer, holistic picture of the child and interview. Follow-up questions for certain probes also allowed parents to elaborate further on their child’s progress. Using the previous example in which I would ask about friendships at school, I would then follow up and ask what kind of activities does he/she like to do when playing with friends? This provided an additional opportunity for parents to elaborate on general social concerns such as a failure to pursue or maintain friendships. Again, these questions keep ASD in mind, as research has found that children with developmental disorders such as autism engage less in symbolic play such as inventing imaginary objects or roles (see Jarrold, 2003 for review). Another example is if a parent answered “yes” to the question “Has <insert child name> receive any special supports while in school?” then I would probe further to elicit details by asking “What kind of things does he/she work on?”. This allowed parents to elaborate on things like Individualized Education Programs (IEP), special pull outs for 1:1 session(s) in speech/occupational therapy, tutoring, gifted classes, assigned parapro, etc. In sum, the Time 2 interview questionnaire was designed to elicit information not only about formal ASD diagnosis since the original study, but also to gain insight into ASD-like delays or other developmental delays that are described by parents but where no formal diagnosis has been made.
1.6.2.2 Social Communication Questionnaire (SCQ; Rutter, Bailey, and Lord, 2003)

For Time 2, we wanted to include an additional measure of ASD-risk as part of the interview protocol. Given the amount of time that had passed since the original study (3-7 years), the screeners previously used in Time 1 (i.e., M-CHAT, CBCL, CSBS) were no longer considered age appropriate at time of follow-up. I chose the Lifetime version of the Social Communication Questionnaire by Rutter and colleagues (2003). The SCQ is a brief instrument designed to evaluate social functioning and communication skills in relation to autism for children 4+ years of age (Appendix B). Parents respond “Yes” or “No” to a series of 40 questions about their child’s development. An example item is “Has she/he ever said the same thing over and over in exactly the same way or insisted that you say the same thing over and over again?” Scoring involves calculating the number of responses that indicate ASD risk (Appendix C). Scores of 15+ indicate possible Autism Spectrum Disorder and parents are then recommended to seek future follow-ups or a more comprehensive evaluation of their child’s behavior. This screener has been evaluated by multiple studies and shown cross cultural validity (e.g., Bölte, Holtmann, & Poutska, 2008; Chandler et al., 2007; Charman et al., 2008).

1.7 Procedures

The following sections detail the procedures for data collection and analysis phases of the current study. Figure 1 depicts a flowchart summarizing these processes.
### Figure 1 - Flowchart of Present Study Data Collection and Analysis Procedure

#### 1.7.1 Phone Interview Procedure

In the present study, a follow-up phone interview with parents of children in the original study 3-7 years later is considered “Time 2”. All interviews were administered in a single, private session lasting no more than thirty minutes. As mentioned previously (see section 2.1.1) I did not know the risk-status from Time 1 for any of the children of participants while collecting data for the follow-up (Time 2) study. At the time of the
follow-up interview, the participant was given a new unique identifier related to the follow-up study which was kept in a password protected, master list and only combined with original study’s master list once data collection was complete. For privacy purposes, I did not begin recording the phone calls until after verifying the parent name and child’s name and date of birth for purpose of creating this master list. Upon verifying this information, the master list file was saved and closed, and participants were read a briefing “welcome” script. I then read over the consent form and verified that participants were okay with starting the audio recording. Participants were also sent an electronic copy of the consent form via email for their personal records. Once audio recording began, I attained verbal consent and documented (time/date) on the interview sheet. A verbal “yes” signified consent to continue with the interview.

I then continued the interview by asking questions in the order found on the interview questionnaire (Appendix A). For all interviews, I made hand-written notes on a copy of the interview questionnaire as each interview proceeded. Upon completion of the full questionnaire, I then transitioned into the verbal administration of the Social Communication Questionnaire (SCQ) by Rutter et al. (2003; Appendix B). The completion of the SCQ concluded the study specific interview questions. For privacy, audio recordings were then stopped before parents were asked if they preferred to be compensated for their time with a physical (mailed) or electronic (e-mailed) $20 Target gift card and the appropriate compensation information was recorded. All participants were also provided with a copy of their SCQ responses that they may share with a pediatrician should they choose to do so. These copies were accompanied by a letter describing the results of the screener. If the parent’s responses led to a flagged concern (i.e., a SCQ score ≤15) the
letter contained reminder information explaining that this SCQ measure was not a
diagnosis and that the data was only being gathered for research purposes but encouraged
parents to share the results with their pediatrician or pursue follow-up comprehensive
assessments.

1.7.2 Risk Status Classification Procedure

Upon completion of Time 2 data collection, we revealed the Time 1 “risk status”
for the acquired sample using the data from the different sources of archival data collected
in Time 1. Specifically, scores from both parent-report screeners and the R-ABC
behavioral assessment were gathered to determine Time 1 risk status predictor variables
which were then used in conjunction with Time 2 interview data analysis. Children were
categorized by a parent-report risk as well as a Rapid-ABC risk (i.e., could be labeled as
“typically developing” (TD) or “at risk” (AR) by parent report only, Rapid-ABC only, or
both). For the purpose of capturing as much “risk” as possible, I made the decision to
collapse all Time 1 data and give the “at-risk” label to any child that failed that category of
screener (parent report or Rapid-ABC) at either initial or follow-up (if applicable) time
points from the original study. From this point forward, all original study data will be
considered in this way, discussing these sessions as “infants” and referring to the original
study as “Time 1”. Below I describe what it means to be “at-risk” for each of the sources
of information.

1.7.2.1 At-Risk Status Based on Parent Reported Information

For this study, parent reported information from the previous study includes the
responses on three, different parent-report screeners that assess child development. Each
of these screeners was completed by the parent (at Time 1) to assess child developmental
progress in areas such as social communication and language. The M-CHAT is designed as an ASD-specific screener whereas the CBCL and CSBS are broader developmental screeners. For the purposes of this study, caregiver responses to each of these screeners were scored to provide insight into whether or not the child in the original study was “at-risk” for autism-related developmental delays when he/she was 15-35 months old. That is, each child can be labeled as being “at-risk” or “typical developing”. “At-risk” was defined as a general risk group category encompassing any child for which any parent responses on any of the screeners flagged any sort of developmental delay. That is, a child who showed broad communication delays (e.g., failed M-CHAT) and a child who only had speech concerns (i.e., met speech concern only on CSBS or delayed speech based on CBCL) would all fall into this broad category. 44 infants (of 181) in the larger MMDB dataset had been flagged as at-risk based on parent-report. Of these infants, 15 had parents who participated in the Time 2 follow-up interview (present study). This “at-risk” categorization for those 15 infants can be broken down further into types of delay (social communication delay, speech only) as summarized below in Table 2.

Table 2 - Composition of "At-Risk" Delay Category (N=15) in Time 2 Sample

<table>
<thead>
<tr>
<th>Category</th>
<th>Definition</th>
<th>Screener Results</th>
<th>Subsample Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Communication Delay</td>
<td>Child has social communication delays</td>
<td>failed either M-CHAT or CSBS (or both)</td>
<td>n = 11</td>
</tr>
<tr>
<td>Speech Only</td>
<td>Child only has speech delay, no other developmental concerns</td>
<td>met for speech concern on CSBS or met &lt;20 percentile for word/phrase speech on CBCL</td>
<td>n = 4</td>
</tr>
</tbody>
</table>

Note. N = full sample of At-Risk infants based on all parent-report screener information collected at Time 1 (intake and follow-up visits combined). n = further breakdown of At-Risk infants into delay type.
1.7.2.2 At-Risk Status Based on Behavioral Assessment

For this study, behavioral assessment information from the previous study (i.e., Time 1) is gathered from the autism-specific behavioral assessment (i.e., Rapid-ABC, R-ABC) for young infants and toddlers in which an adult examiner engaged in a semi-structured play interaction with the child that was designed to elicit a broad range of social behaviors which, if atypical, could be noted as potential ‘red-flags’ pointing towards possible ASD (Ousley et al., 2013). The RABC has five different activities: 1) greeting, 2) back-and-forth ball play, 3) book-sharing, 4) symbolic play (i.e., using book as hat), and 5) tickling. As the examiner moved through the five activities, she noted on a scoring sheet the presence or absence (based on a single occurrence) of seventeen target socio-communicative and participatory behaviors. For example, the experimenter scored whether or not the child initiated joint attention (e.g., looked at ball then to her), smiled, turned book pages, pointed, etc. She also rated the overall engagement of the child (i.e., how much effort was required to engage the child) during each stage of the protocol on a 3-point Likert type scale (0 = easily engaged, 3= significant effort required to engage the child). Together, these yes/no behavior notations and social engagement scores are combined to designate if a child is or is not “at-risk” for ASD. Ousley et al. (2013) study propose the use of a cutoff score of 13 to classify “at-risk”.

1.8 Analysis

1.8.1 Quantitative Analysis

For quantitative analyses (testing Hyp. 1-2) Independent Variables (IV) were derived from data collected in Time 1 and the dependent measures were collected as part of the Time 2 parent/caregiver follow-up interview conducted 3-7 years later. Each child
was assigned a Time 1 “Risk Status” classification based on their parent report (i.e., combined M-CHAT, CBCL, CSBS screeners) and behavioral assessment (R-ABC) data. Children were categorized as:

- Typical Developing (TD\textsubscript{both}) by both Time 1 sources
- At-Risk (AR\textsubscript{one}) by only one Time 1 source (R-ABC or parent-report)
- At-Risk (AR\textsubscript{both}) by both Time 1 sources

The Dependent Variables (DV) of interest for this study were all chosen to investigate Time 2 typicality/atypicality as it relates to ASD. For Hypothesis 2, the DV of interest was SCQ score (evaluated as a continuous variable). For Hypothesis 1, I chose to consider both ‘strict’ and ‘lenient’ DV. ASD\textsubscript{strict} implies formal ASD diagnostic outcomes (Yes/No) as mentioned by parent in the Time 2 interview. ASD\textsubscript{lenient} considers both formal child diagnostic outcomes (i.e., ASD/non-ASD) as reported by parents during Time 2 interview but also information about school/clinicians/parent concerns related to social communication deficits seen in ASD also from the interview. As mentioned previously, we acknowledged that some parents might mention things that sound like ASD-related concerns but for various reasons may not have pursued formal diagnosis. Specifically, I wanted to screen for parent-mentioned social communicative delays or concerns (lacking formal diagnosis) as part of the “outcome” measure. In consideration of this ‘lenient’ DV, Hypothesis 1 was worded in terms of social communication deficits which is a hallmark feature of ASD. According to the DSM-5 criteria, these deficits or delays include verbal or nonverbal social skills, limited initiation of social interaction, minimal response or abnormal responses to social overtures from others, and decreased interest in social interactions (APA, 2013a). According to DSM-5 criteria, ASD is typically categorized
through severity ratings on a 3-level scale (1 = requiring support, 3 = requiring very substantial support) (see table found in Appendix D). Probes throughout the interview provided opportunity for parents to mention social-communicative delays or concerns that were not directly related to a formal diagnosis. Examples include:

- Does <insert child name> receive any special supports while in school? (Y/N)
  - If any supports are mentioned, probe for details of support:
  - What kinds of things does he/she work on?

- Is there any other aspect of your child’s medical or developmental history that you think may be important for us to know about? (i.e., do you have any concerns about his/her development?)

- Has anyone from <insert child name>’s school ever expressed concerns about his/her behavior or progress? (Y/N)

- Would you characterize this delay or behavioral issue as recent or persistent? Improving, worsening, or about the same? (check mentioned)
  - How severe would you say this delay is? (check one)
    - Mild, requiring none or little support
    - Moderate, requiring considerable support
    - Very severe, requiring very substantial support

1.8.1.1 Case Selection

After extracting all children with formal ASD diagnoses (n = 4) from the Time 2 sample, the research team then analyzed the remaining data from these above questions to identify any additional children whose parents mentioned communication or social concerns or impairments during the Time 2 interview. Each member of the team screened
the data independently, pulling out possible examples. From these, I then had two undergraduate research assistants individually rate the full sample set in terms of “severity”. Specifically, we wanted to consider concerns that parents described as persistent or worsening over time and moderate to severe in terms of how much they affected the child’s life (i.e., requiring substantial support). Research assistants initially came to agreement on all but one case (98%) in which I revisited the interview to make the final judgment. Of the full sample, 5 additional children were added to the “Time 2 ASD-related social communication atypicality” group. Justification for each of these five additions is summarized below (randomized and labeled as letters for privacy):

- Child A – mentioned an IEP that included work with social goals
- Child B – mentioned IEP for language/expressive difficulties and social skills
- Child C – mentioned outside of school therapy for social skills
- Child D – mentioned that the child had been evaluated for ASD but didn’t meet cutoffs
- Child E – mentioned that child had received ASD diagnosis at 18 months but later retracted but continues to attend social skills and play therapy

Together this formal diagnosis and additional ASD-related social communicative concerns or impairments were combined as the lenient outcome measure (ASD\textsubscript{lenient}). Hypothesis 1 was evaluated using Fisher’s Exact Tests to evaluate how the number of screeners failed at Time 1 predicted outcomes (ASD\textsubscript{strict} and ASD\textsubscript{lenient} evaluated separately) at Time 2. Lastly, I used SCQ score data as another way to evaluate outcomes related to ASD. Hypothesis 2 was evaluated using a Kruskal-Wallis H test and post-hoc t-tests testing for significant differences in the average parent-screener SCQ score at Time 2.
amongst children who at Time 1 were considered at-risk for ASD by neither, both, or only one source of information (parent-report or R-ABC). I chose the Kruskal-Wallis test in place of parametric one-way ANOVA after analysis revealed non-normal distribution of scores and unequal variance (i.e., Levene’s test was significant at \( p = .037 \)).

1.8.1.2 Exploratory Analysis: Discriminative Validity of Time 1 Screeners

Upon completion of analysis for Hypotheses 1-2, I decided to conduct exploratory analysis of the discriminative ability of the R-ABC and parent-report screener scores for correctly classifying the present sample based on Time 2 outcomes. For this analysis, I only evaluated ASD\textsubscript{strict} as the DV of interest. I felt the additional children who were included in the ASD\textsubscript{lenient} atypicality group due to parents mentioning various kinds of social communicative delays or ASD-related concerns for the previous analyses were more subjective. To this end, I chose to investigate the stricter classification outcome (i.e., only Yes/No formal diagnosis) for this analysis. As mentioned previously, the Time 1 original study included three, different parent-report screeners (i.e., M-CHAT, CBCL, CSBS). The M-CHAT was the only screener that all parents completed regardless of child age (i.e., CSBS only completed only if child was \( \leq 24 \) mos.; CBCL only if child was \( >24 \) mos.) Also, the M-CHAT, like the R-ABC, are designed as ASD-specific screeners whereas the CBCL and CSBS are broad developmental screeners. In efforts to evaluate a dataset without missing values and with the most comparable “at-risk” status, I also chose to compare only the M-CHAT parent report screener and the Rapid-ABC screener for this analysis. Binary logistic regression was used to evaluate the effects of M-CHAT score and R-ABC scores at Time 1 (as continuous variables) on the likelihood that children had parent-reported ASD diagnosis at Time 2. The ability of these two screeners to correctly
decide the dichotomous formal ASD/non-ASD outcome variable (ASD\textsubscript{strict} as reported by the parents in Time 2 interview) in this sample was also evaluated using area under the curve (AUC) scores from nonparametric Receiver Operating Characteristics (ROC) curve analyses. Results were interpreted based on AUC benchmarks suggested by Swets (1988): low (0.5-0.7), moderate (0.7-9), and high (>0.9) accuracy.

1.8.2 Qualitative Analysis

All recorded interviews were saved on a secure server under the de-identified participant ID number. All interviews had at least one second listener (undergraduate research assistant) who listened to the entire interview and transcribed key excerpts from individual responses to each question into Microsoft Excel spreadsheets. All transcribed responses were re-read multiple times before the data was combined and analyzed using any quantitative or qualitative methods.

For qualitative analysis I utilize thematic analysis based off recommendations from Braun and Clarke (2006). While some qualitative studies do not begin with a priori research hypotheses, I proposed preliminary hypotheses (Hyp. 3-4) about a possible “theme” that would exist in the data related to mentioned child social and communication challenges. This approach aligns with a theoretical or deductive (“top-down”) approach to thematic analysis (Boyatiz, 1998) in which the analysis is driven by theoretical interest in an area (Braun & Clarke, 2006). This anticipated theme informed the development of a coding scheme after studying the literature, reviewing the interview protocol and being immersed in the data at large. I devised a coding scheme based on common behaviors or problems mentioned in the literature to be associated with ASD. The scheme included categories related to challenges with verbal communication, nonverbal communication, social
engagement, and relationships. For each proposed category, I used the literature to create possible subcategories of the differing types of behaviors that could be mentioned. Segments from parent responses to selected interview questions were classified based on these categories. The five categories identified for the final coding scheme were: 1) no concerns, 2) verbal communication concerns, 3) nonverbal communication concerns, 4) social engagement concerns, and 5) relationship concerns (see Table 3).

**Table 3 - Coding Scheme for Hypotheses 3-4**

<table>
<thead>
<tr>
<th>Category</th>
<th>Sub-Category</th>
<th>Definition/Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>No concerns</td>
<td>n/a</td>
<td>Parent indicates no concerns or highlights only positive attributes of the child.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mutually exclusive with all other codes</td>
</tr>
<tr>
<td>Verbal Communication</td>
<td>Language errors</td>
<td>Parent mentions things related to the acquisition of age-appropriate language, or</td>
</tr>
<tr>
<td></td>
<td>Speech tempo/prosody</td>
<td>speech that atypical in some way</td>
</tr>
<tr>
<td></td>
<td>Pragmatics</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Repetitive/rigid</td>
<td></td>
</tr>
<tr>
<td></td>
<td>language</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Delayed language</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other: Specify</td>
<td></td>
</tr>
<tr>
<td>Nonverbal communication</td>
<td>Eye contact</td>
<td>Parent mentions trouble with the nonverbal aspects of conversation such as making</td>
</tr>
<tr>
<td></td>
<td>Facial expressions</td>
<td>eye contact, using facial expression or showing affect, or gesturing</td>
</tr>
<tr>
<td></td>
<td>Gestures</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other: Specify</td>
<td></td>
</tr>
<tr>
<td>Social Engagement</td>
<td>Nonresponsive</td>
<td>Parent mentions a failure or disinterest in holding conversation or participating</td>
</tr>
<tr>
<td></td>
<td>Disinterested</td>
<td>socially (e.g., games), inappropriate engagement behavior for child age, preferring</td>
</tr>
<tr>
<td></td>
<td>Age-inappropriate</td>
<td>solitude, or fixation on certain topics (e.g., reverting conversation to topics of</td>
</tr>
<tr>
<td></td>
<td>Fixation on topics</td>
<td>child’s interest)</td>
</tr>
<tr>
<td></td>
<td>Other: Specify</td>
<td></td>
</tr>
</tbody>
</table>
Table 3 (Continued)

<table>
<thead>
<tr>
<th>Relationships</th>
<th>Lack of Friendship</th>
<th>Parent mentions that the child has problems making or keeping friends, fails to pursue relationships with peers or family members</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Familial/sibling disinterest</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Failure to initiate</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other: Specify</td>
<td></td>
</tr>
</tbody>
</table>

1.8.2.1 Coding Scheme Related to Hypothesis 3-4

The above coding scheme was used as the classification system for codable segments of Time 2 interview data. For each participant, transcribed responses from questions 12 (school concerns), 13 (clinician/medical professional concerns), and 15 (other, general parent concerns) were evaluated and assigned to one or multiple categories of the coding scheme. The interviews were analyzed by three independent coders – myself and two undergraduate research assistants according to the finalized coding scheme. To evaluate agreement, we each individually coded an entire question (i.e., question 12) in separate password protected files. We then met and evaluated agreement (i.e., if all coders agreed that part(s) of the response from that participant fell into the same categories). Out of a total 57 participant responses coded using the finalized scheme, there were only disagreements related to two participant responses; both were instances where one coder placed a participant in a no significant concern category and the other did not. Coders reached an agreement of 96% (55/57) after completing the first question together. For the disagreements, I served as the deciding factor.

After agreement was met on the first question, each assistant worked on a separate question related to the overall coding scheme. For the assigned question, coders populated tallies into the columns related to the coding categories if a segment of a participant’s
response to the question fell in that category. Coders made notes about questions or concerns with responses that were brought to the next team meeting and resolved by consensus through discussion with the team. The team met weekly to discuss coding scheme, review notes, and resolve any issues that arose. Once all coding had been completed, I conducted a thorough review of all data, combining into a final dataset to be used for further analysis.

1.8.2.2 Exploratory Analysis: Inductive Thematic Analysis

Upon completion of analysis for Hypotheses 3-4, I decided to conduct an additional exploratory analysis for additional themes that may have existed in the dataset. While H3-4 utilized a deductive approach (i.e., driven by interest in the area), this exploratory analysis was more inductive (“bottom-up”) in nature (Patton, 1990) as hypotheses were not made a priori directly related to this inquiry. Inductive thematic analysis involves coding the data without trying to fit it into pre-existing coding frame (Braun & Clarke, 2006). Using a semantic approach, myself and the undergraduate coders first sought to gather additional themes in parent responses after having been immersed in the data at large. To do this, we revisited our notes we had written during initial coding and had open conversations during weekly lab meetings about other possible interesting themes or questions that we felt produced clear or unexpected divides in the data (i.e., strong response themes in one way or another). Though Time 1 risk status and Time 2 outcomes had been designated at this point, we still considered the transcribed responses to each question in the interview protocol as entire datasets, irrespective of those classifications.

From our conversations, we felt that there were potentially “themes” related to Question 11. Question 11 was part of the section related to education and social
relationships and asked “Does <insert child name> prefer playing in groups or alone?” This was interesting as one might expect a dichotomous (groups or alone) answer from all parents regarding this question. However, as I conducted the interviews and as the undergraduate assistants listened and transcribed them, we all agreed that there was something more to parent responses to this question. We felt that parents were not just providing a dichotomous answer and were perhaps interpreting this question in a different light. Braun and Clarke (2006) suggest that thematic analysis can utilize a contextualist method, “…acknowledging the ways individuals make meaning of their experience, and, in turn, the ways the broader social context impinges upon those meanings...” (p. 9). For Question 11, some parents’ answers seemed to have the connotation as if preference for “groups” was better than “alone”. Other parents seemed to consider preference for “alone” as a sign of healthy adjustment or being able to entertain oneself well. Other parents did not dichotomize at all, suggesting that their children were either indifferent or had equal preference for both types of play.

Given the scope and goals of the present dissertation, we decided that it was best to first consider the responses at face-value (semantic level) rather than trying to use a latent approach (Braun & Clarke, 2006) in which we would have defined features of each individual response that constituted positive or negative connotation. Therefore, our coding process included: revisiting all parents responses to this question and categorizing them within the three general themes that were derived from our basic understanding of the data. These themes were 1) preference for groups, 2) preference for alone, or 3) both/indifferent. For this analysis, codes were considered independent of one another. Upon coding all data, codes were then tagged with Time 1 Risk Status and Time 2 formal diagnostic outcomes.
so as to be analyzed through the lens of the rest of the paper. Specifically, I investigated if differences existed in Time 2 social play preference themes for parents of children who 1) were Time 1 At-Risk or not, and 2) had formal diagnosis at Time 2.
CHAPTER 3. RESULTS

The results discussed below are presented in two sections corresponding to the two types of inquiry. The first section includes the findings from the primary quantitative analyses regarding Time 1 Risk Status predicting Time 2 strict and lenient outcome measures. The second section then outlines the findings of the primary qualitative analyses regarding differences in response themes related to social communication concerns for parents whose children were or were not at risk for ASD at Time 1. Any post hoc or exploratory analyses are discussed within the appropriate section.

1.9 Quantitative Results

1.9.1 Hypothesis 1: Number of Screeners Failed Predicting Time 2 Outcome

The small sample size yielded expected cell counts that were less than 5 which led me to interpret Fisher’s Exact Test rather than Pearson Chi-Square for all analyses. When considering strict (i.e., ASD\textsubscript{strict}; formal diagnosis only) outcomes, results indicated a significant difference in outcomes mentioned at Time 2 with a prevalence of 66.7% (2/3) in the group considered at-risk by both Time 1 sources, compared to 5.3% (1/19) in the group considered at-risk by only one Time 1 screener, and 2.9% (1/35) in the group considered not at-risk (TD) by both Time 1 sources (p = .011). When considering lenient (i.e., ASD\textsubscript{lenient}; formal diagnosis or significant social communicative concerns mentioned) outcomes, results indicated a significant difference in outcomes mentioned at Time 2 with a prevalence of 100% (3/3) in the group considered at-risk by both Time 1 sources, compared to 15.8% (3/19) in the group considered at-risk by only one Time 1 screener, and
8.6% (3/35) in the group considered not at-risk (TD) by both Time 1 sources \( (p = .003) \).

These results are summarized in Table 4.

**Table 4 - Cross-tabulation Matrix for Time 2 Outcomes by Time 1 Risk Status**

<table>
<thead>
<tr>
<th>Time 1 Risk Status Classification</th>
<th>Time 2 Outcomes</th>
<th>ASD_{strict} Outcome</th>
<th>ASD_{lenient} Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>ASD ( (n = 4) )</td>
<td>No Diagnosis ( (n = 53) )</td>
</tr>
<tr>
<td>AR_{both} ( (n = 3) )</td>
<td>66.7%</td>
<td>33.3%</td>
<td>100%</td>
</tr>
<tr>
<td>AR_{one} ( (n = 19) )</td>
<td>5.3%</td>
<td>94.7%</td>
<td>15.8%</td>
</tr>
<tr>
<td>TD_{both} ( (n = 35) )</td>
<td>2.9%</td>
<td>97.1%</td>
<td>8.6%</td>
</tr>
</tbody>
</table>

*Note.* % are percentages of the possible subsample for that row (denoted by \( n \)). AR_{both} = At-Risk by both; child was considered at-risk for ASD by both parent-report and R-ABC screeners. AR_{one} = At-Risk by only one source; child was considered at-risk for ASD by either parent-report or R-ABC screener. TD_{both} = Typically Developing by both; child was not considered at-risk for ASD based either parent-report or R-ABC screeners. ASD_{strict} evaluates if parent mentions a formal ASD diagnosis \( (n=4) \) or not \( (n=53) \). ASD_{lenient} evaluates if parent mentions a formal ASD diagnosis or social communication concerns that were deemed significant by research team \( (n=9) \) or not \( (n=48) \).

We see differences in the prevalence of both strict and lenient ASD related reported outcomes at Time 2 across the three groups. These results support Hypothesis 1 showing that an increase in the number of ASD-related screeners failed in infancy suggests greater likelihood of diagnosis or social communicative concerns mentioned in childhood and adolescence.

1.9.1.1 Post-hoc Analyses
Upon completion of Hypothesis 1 analysis, I felt that it was still not clear whether one source of information (i.e., parent-report screeners or R-ABC) had a stronger relationship with Time 2 outcomes than the other. That is, the AR_{one} group needed further investigation. I then split the data by screener type (R-ABC fail/pass; Parent-report fail/pass) as related to the strict and lenient outcome variables and ran two separate cross-tabulation matrices and Fisher’s exact calculations. Odds ratios were calculated for all results. Results are presented below first for ASD_{strict} and then ASD_{lenient}.

3.1.1.1.1 ASD_{strict}: Formal Diagnosis Only

The difference in formal ASD outcomes at Time 2 with a prevalence of 20% (3/15) in the Time 1 Parent-screener At-Risk Group compared to 2.4% (1/42) in the Time 1 Parent-screener not At-Risk group was approaching significance ($p = .052$). In this sample, Time 1 Risk Status based on parent-report screeners did not have an effect on Time 2 reported parent-reported formal ASD outcome. Based on the odds ratio, the odds of parents mentioning that their child had been diagnosed with ASD were 10.25 times higher if the child had been flagged by parent-report screeners at Time 1 than if not-flagged by parent-report screeners at Time 1.

Fisher’s Exact test results indicated a non-significant difference in formal ASD outcomes at Time 2 with a prevalence of 20% (2/10) in the Time 1 R-ABC screener At-Risk Group compared to 4.3% (2/47) in the Time 1 R-ABC screener not At-Risk group ($p = .138$). In this sample, Time 1 Risk Status based on R-ABC screeners does not have an effect on Time 2 reported ASD outcome. Based on the odds ratio, the odds of parents mentioning that their child had been diagnosed with ASD were 5.63 times higher if the child had been flagged by R-ABC screener at Time 1 than if not-flagged by R-ABC
screener at Time 1. Combined cross-tabulation matrices for Parent-Report and R-ABC scores are shown in Table 5.

### Table 5 - Cross-tabulation Matrices for Time 1 Risk Status * Time 2 ASD\textsubscript{strict}

<table>
<thead>
<tr>
<th>Time 1 Parent-Report Risk Status</th>
<th>Time 2 Outcome</th>
<th>ASD (n = 4)</th>
<th>No diagnosis (n = 53)</th>
</tr>
</thead>
<tbody>
<tr>
<td>AR (n = 15)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TD (n = 42)</td>
<td></td>
<td>1</td>
<td>41</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>75%</td>
<td>22.6%</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>1</td>
<td>41</td>
</tr>
<tr>
<td></td>
<td>%</td>
<td>25%</td>
<td>77.4%</td>
</tr>
</tbody>
</table>

| Time 1 R-ABC Risk Status         |                |             |                       |
|----------------------------------|----------------|-------------|                       |
| AR (n = 10)                      |                | 2           | 8                     |
| TD (n = 47)                      |                | 2           | 45                    |
|                                  | n              | 2           | 8                     |
|                                  | %              | 50%         | 15.1%                 |
|                                  | n              | 2           | 45                    |
|                                  | %              | 50%         | 84.9%                 |

Note. N = 57. n = subsample of infants in that category. ASD = Autism Spectrum Disorder formal diagnosis mentioned. AR = At-Risk based on that screening tool. TD = Typically Developing or not at-risk for ASD based on that screening tool. % = percent within Time 2 outcome.

#### 3.1.1.1.2 ASD\textsubscript{lenient}: Formal Diagnosis or Substantial Concerns

Results indicated a significant difference in outcomes of formal ASD diagnosis or ASD-related concerns mentioned at Time 2 with a prevalence of 40% (6/15) in the Time 1 Parent-screener At-Risk Group compared to 7.1% (3/42) in the Time 1 Parent-screener not At-Risk group (p = .007). In this sample, Time 1 Risk Status based on parent-report screeners did have an effect on Time 2 reported parent-reported formal ASD outcome or ASD-related concerns mentioned. Based on the odds ratio, the odds of parents mentioning that their child had been diagnosed with ASD or that they had significant social communicative concerns about their child were 8.67 times higher if the child had been
flagged by parent-report screeners at Time 1 than if not-flagged by parent-report screeners at Time 1.

Fisher’s Exact test results indicated a non-significant difference in formal ASD diagnosis or ASD-related concerns mentioned at Time 2 with a prevalence of 30% (3/10) in the Time 1 R-ABC screener At-Risk Group compared to 12.8% (6/47) in the Time 1 R-ABC screener not At-Risk group ($p = .184$). In this sample, Time 1 Risk Status based on R-ABC screeners does not have an effect on Time 2 reported ASD outcome. Based on the odds ratio, the odds of parents mentioning that their child had been diagnosed with ASD or was having ASD-related concerns were 2.93 times higher if the child had been flagged by R-ABC screener at Time 1 than if not-flagged by R-ABC screener at Time 1. Combined cross-tabulation matrices for Parent-Report and R-ABC scores are shown in Table 6.

**Table 6 - Cross-tabulation Matrices for Time 1 Risk Status * Time 2 ASD$^{lenient}$**

<table>
<thead>
<tr>
<th>Time 1 Parent-Report Risk Status</th>
<th>Time 1 R-ABC Risk Status</th>
<th>Time 2 Outcome</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>ASD or concerned ($n = 9$)</td>
<td>$n$</td>
<td>%</td>
</tr>
<tr>
<td>AR ($n = 15$)</td>
<td></td>
<td>6</td>
<td>66.7%</td>
<td></td>
</tr>
<tr>
<td>TD ($n = 42$)</td>
<td></td>
<td>3</td>
<td>33.3%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>AR ($n = 10$)</td>
<td>3</td>
<td>33.3%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>TD ($n = 47$)</td>
<td>6</td>
<td>66.7%</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>9</td>
<td>18.8%</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>39</td>
<td>81.3%</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>7</td>
<td>14.6%</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>41</td>
<td>85.4%</td>
<td></td>
</tr>
</tbody>
</table>

*Note. N = 57. n = subsample of infants in that category. ASD = Autism Spectrum Disorder formal diagnosis mentioned. AR = At-Risk based on that screening tool. TD = Typically Developing or not at-risk for ASD based on that screening tool. % = percent within Time 2 outcome.*
1.9.2 **Hypothesis 2: Number of Screeners Failed Predicting SCQ Outcome**

A Kruskal-Wallis H test was run to determine if there were differences in SCQ score between the three groups with different Time 1 Risk status: “AR$_{both}$” ($n = 3$), “AR$_{one}$” ($n = 19$), and “TD$_{both}$” ($n = 35$) groups. Distributions of SCQ scores were not similar for all groups, as assessed by visual inspection of a boxplot. The distributions of SCQ scores were statistically significantly different between groups $\chi^2(2) = 6.878$, $p = .032$. Subsequently, pairwise comparisons were performed using Dunn’s (1964) procedure with a Bonferroni correction for multiple comparisons. Adjusted $p$-values are presented. This post hoc analysis revealed statistically significant differences in mean rank SCQ scores between the AR$_{both}$ (mean rank = 52.83) and AR$_{one}$ (mean rank = 26.21) ($p = .042$) and AR$_{both}$ and TD$_{both}$ (mean rank = 28.47) ($p = .028$) groups, but not between the AR$_{one}$ and TD$_{both}$ groups. I also found that only 2/4 children who went on to have formal ASD diagnoses mentioned at Time 2 received an SCQ score of 15+ which is the cutoff to indicate possible ASD. Possible explanations for this result are discussed later.

1.9.3 **Exploratory: Binary Logistic Regression and ROC Analysis**

A binomial logistic regression was performed to ascertain the effects of M-CHAT score and R-ABC score at Time 1 on the likelihood that children have parent-reported ASD diagnosis at Time 2. The logistic regression model was statistically significant, $\chi^2(2) = 6.961$, $p = .03$. The model explained 28.9% (Nagelkerke $R^2$) of the variance in ASD diagnosis and correctly classified 89.5 percent of the cases. M-CHAT score was the only statistically significant variable (as shown in Table 7). Increasing M-CHAT score was associated with an increased likelihood of parent-reported ASD diagnosis at Time 2.
Table 7 - Logistic Regression Predicting Likelihood of Time 2 ASD Diagnosis based on Time 1 M-CHAT and R-ABC screener scores

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>SE</th>
<th>Wald</th>
<th>df</th>
<th>p</th>
<th>Odds Ratio</th>
<th>95% CI for Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>M-CHAT</td>
<td>.39</td>
<td>.16</td>
<td>6.26</td>
<td>1</td>
<td>.012</td>
<td>1.48</td>
<td>1.09 - 2.00</td>
</tr>
<tr>
<td>R-ABC</td>
<td>.07</td>
<td>.11</td>
<td>.46</td>
<td>1</td>
<td>.498</td>
<td>1.08</td>
<td>.87 - 1.32</td>
</tr>
<tr>
<td>Constant</td>
<td>-4.10</td>
<td>1.26</td>
<td>10.64</td>
<td>1</td>
<td>.001</td>
<td>.02</td>
<td></td>
</tr>
</tbody>
</table>

For this sample, the area under the curve was .89 ($SE = .06, p < .001$) for the M-CHAT and .62 ($SE = .16, p = .44$) for the R-ABC respectively (Figure 2). This suggests that the M-CHAT was moderately valid in separating ASD from no ASD children in a similar manner as what was actually reported by the parents in the follow-up interviews. The R-ABC had low discriminative validity.

Figure 2 - Depiction of M-CHAT and R-ABC Receiver Operating Characteristics (ROC) Curves. Time 1 M-CHAT scores (red line) and R-ABC scores (green line) predicting dichotomous ‘strict’ risk-group outcome (diagnosed with ASD versus not diagnosed with ASD
The M-CHAT scoring involves calculating the number of responses that indicate ASD risk: low risk (score 0-2), medium risk (3-7), or high risk (8-20). Typically, scores of medium or higher risk are grounds for further screening or follow-up. In the full sample, 52/57 children (91.2%) had been considered “low” risk based on the M-CHAT at Time 1. 3/57 (5.3%) were considered “medium” and 2/57 (3.5%) were considered “high” risk. Of these five medium/high risks, two went on to receive ASD diagnoses (one was considered “medium risk” and the other “high risk”) and the other three went on to receive other, non-ASD diagnoses (i.e., genetic disorders, speech delay, sensory processing disorder, and dyslexia). An additional two children who went on to have ASD diagnosis mentioned at Time 2 were considered “low risk” at Time 1 based on the M-CHAT. In sum, this suggests that the M-CHAT screener “missed” two of the four later diagnosed ASD children and created “false positives” for three other children who went on to receive other, non-ASD diagnoses. For this sample, a cutoff score of as low as ~1 appears to yield sensitivity of .88 and specificity of .73. I also conducted a final, case-by-case exploratory investigation into the individual score profiles (M-CHAT and SCQ) for the four children who went on to have formal ASD diagnoses mentioned at Time 2. However, given the low incidence rate for this study, I have concerns with anonymity and will not include these findings as part of the present paper.

In Ousley and colleagues (2013) validation study, a score of 13 on the R-ABC yielded high specificity (.96) and sensitivity (.83) for correctly classifying TD and AR infants using to an “all-information available” approach. In this sample, the cutoff score of 13 only classified 9 children as At-Risk from Time 1 and of these only 1 went on to receive ASD diagnosis by Time 2. Of the remaining 8 who had been considered At-Risk for ASD,
2 went on to receive other, non-ASD diagnoses (i.e., genetic disorders, ADHD, and dyslexia), and 6 had no clinical diagnosis at Time 2. Using this cutoff suggests that the R-ABC screener alone “missed” two of the four later diagnosed ASD children and created “false positives” for eight other children. For this sample, there was not an R-ABC score that yielded very high sensitivity/specificity ratios. A cutoff score of ~8 yielded a sensitivity of .75 and specificity of .60. The full table of ROC coordinates for both the MCHAT and R-ABC can be found in Appendix E.

1.10 Qualitative Results

1.10.1 Hypothesis 3: Number of Screeners Predicting Response Themes

Upon investigation of the coding results for social communicative challenges reported by parents at Time 2, I found no significant trends in any of the categories for Time 1 AR_both, AR_one, or TD_both groups. The percent of the total sample (N = 57) that mentioned themes related to verbal communication, nonverbal communication, social engagement, and/or relationship concerns, or no concerns as part of questions 12, 13, and/or 15 are summarized below in Table 8. Table 8 also includes sample quotes from transcript segments that received that type of code. Given the low prevalence rate of each theme, all quotes use [he/she] in place of any parent-used gender pronouns to increase anonymity.
### Table 8 - Hypothesis 3 Qualitative Results Summary

<table>
<thead>
<tr>
<th>Coding Category</th>
<th>% mentioned (ratio)</th>
<th>Time 1 Classification</th>
<th>Sample quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verbal Communication</td>
<td>3.5% (2/57)</td>
<td>All TD &lt;i&gt;both&lt;/i&gt;</td>
<td>“...I have concerns about [his/her] speech... more articulation” [he/she] does this year we might pull [him/her] out and put [him/her] at the speech school if [he/she] is still really struggling...Right now [he/she] is on track but sometimes on track is not enough” [he/she] tends to be silly and the kids [his/her] age you know like to be silly but not as much as [him/her]”</td>
</tr>
<tr>
<td>Nonverbal communication</td>
<td>N/A</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Social Engageemnt</td>
<td>5.3% (3/57)</td>
<td>All TD &lt;i&gt;both&lt;/i&gt;</td>
<td>“I’m concerned still with [his/her] social interaction with kids. [he/she] tends to be silly and the kids [his/her] age you know like to be silly but not as much as [him/her]” [he/she] is doing really well”</td>
</tr>
<tr>
<td>Relationships</td>
<td>5.3% (3/57)</td>
<td>1 AR &lt;i&gt;one&lt;/i&gt;</td>
<td>“I will bring up with [him/her] that [he/she] is a bit too aggressive and will insult other kids... if I had a concern with [him/her] that would probably be it because you worry about [him/her] like relationally with others. Like your friends won’t like you if you call them an idiot all the time..” \no, I think the friendship is the only thing for me that I as a mother worry about”</td>
</tr>
<tr>
<td>No Concerns</td>
<td>47.4% (27.57)</td>
<td>1 AR &lt;i&gt;both&lt;/i&gt;</td>
<td>“no [he/she] is doing really well” \no [he/she] is generally a pretty just healthy happy kid... yeah [he/she] is thriving I would say”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9 AR &lt;i&gt;one&lt;/i&gt;</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>17 TD &lt;i&gt;both&lt;/i&gt;</td>
<td></td>
</tr>
</tbody>
</table>
The remaining 38.5% participants mentioned general developmental concerns (e.g., migraines, ear infections, weight/height, allergies) which caused them to not be classified in the “no concerns” category but instead noted that their mentioned concerns were not directly related to hypotheses that were not directly related to ASD or social communicative concerns. Taken together, these findings do not support Hypothesis 3. Caregivers of children who were considered at-risk by R-ABC and parent-report screeners at Time 1 do not show more response themes related to child’s social and communication challenges at Time 2 compared to those who were not considered at-risk at Time 1.

1.10.2 Hypothesis 4: SCQ scores Predicting Response Themes

When considering the SCQ scores from Time 2, I also found no significant trends social communicative challenges reported by parents at Time 2. I considered the range of SCQ scores for each coding category. The percent of total sample ($N = 57$) that mentioned each of these themes as part of the follow-up interview is again presented below alongside the range in SCQ scores for those participants.

- **Verbal Communication Concerns:** 3.5% (2/57; SCQ range: 4-5)
- **Nonverbal Communication Concerns:** N/A
- **Social Engagement Concerns:** 5.3% (3/57; SCQ range: 4-12)
- **Relationship Concerns:** 5.3% (3/57; SCQ range: 2-12)
- **No Concerns:** 47.4% (27/57; SCQ range: 0-10)

As stated previously, the remaining 38.5% participants mentioned general developmental concerns (e.g., migraines, ear infections, weight/height, allergies) which caused them to not be classified in the “no concerns” category but instead noted that their mentioned concerns were not directly related to hypotheses that were not directly related
to ASD or social communicative concerns. For these other “general, non-ASD concerns” the SCQ scores ranged from 0-29. This category was the only category in which our “highest” SCQ scorers appeared. Taken together, these findings do not support Hypothesis 4. Caregivers of children who produced “high” SCQ scores do not show more response themes related to child’s social and communication challenges at Time 2 compared to those who produced “low” or “moderate” SCQ scores. Contrary to expectation, the “high” SCQ scorers only mentioned concerns related to other general development issues that did not fall in the social communicative coding scheme used as part of this analysis.

1.10.3 Exploratory: Inductive Thematic Analysis

As part of an exploratory qualitative analysis, we conducted an additional inductive thematic looking for other possible themes in the data. From this analysis, we decided that play preferences would likely yield differences in response themes across this sample. We then coded whether responses to Question 11 of the interview questionnaire yielded indicated the child’s strong preferences for group or alone play or indifference/enjoys both types equally. I then investigated if differences existed in Time 2 social play preference themes for parents of children who 1) were Time 1 At-Risk or not, and 2) had formal diagnosis or significant ASD-related concerns at Time 2. I note that both of these inquiries involve the same sample and are simply different ways of splitting the dataset to evaluate themes. Descriptive results from each of inquiries are discussed below.

Table 9 depicts the prevalence of these response categories amongst the three T1 risk categorization groups. Results suggest no significant prevalence of any parent-reported play preference across Time 1 ARboth, ARone, or TDboth groups (i.e., no preference appeared
in one category but not the others). One notable finding is that all infants who were considered at-risk by both types of screeners at Time 1 (ARboth; \( n = 3 \)) were reported to prefer group play by parents in Time 2. However, the majority of parents of children from the other Time 1 categories (ARone and TDboth) also gave response themes indicating preferred group play.

**Table 9 - Time 2 Play Preference Themes Split by Time 1 Risk Categorization**

<table>
<thead>
<tr>
<th>Play Preference</th>
<th>Time 1 Risk Classification</th>
<th>Alone ((n = 6))</th>
<th>Groups ((n = 41))</th>
<th>Indifferent ((n = 10))</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ARboth ((n = 3))</td>
<td>0 (n/a)</td>
<td>3 (100%)</td>
<td>0 (n/a)</td>
</tr>
<tr>
<td></td>
<td>ARone ((n = 19))</td>
<td>3 (15.8%)</td>
<td>13 (68.4%)</td>
<td>3 (15.8%)</td>
</tr>
<tr>
<td></td>
<td>TDboth ((n = 35))</td>
<td>3 (8.6%)</td>
<td>25 (71.4%)</td>
<td>7 (20%)</td>
</tr>
</tbody>
</table>

*Note. N = 57. \( n \) = subsample. \% = percent of children in that T1 risk category that parents reported themes related play preference category during T2 interview.*

Table 10 depicts the prevalence of these response categories amongst the two Time 2 ASD outcome groups. Results suggest no significant prevalence of any parent-reported play preference across Time 2 ASD or no diagnosis groups (i.e., no preference appeared in one category but not the others). Parents of children both with and without ASD diagnoses at Time 2 mentioned that children preferred to play alone, in groups, or were indifferent.
### Table 10 - Time 2 Play Preference Themes Split by Time 2 Diagnostic Outcome

<table>
<thead>
<tr>
<th>Play Preference</th>
<th>Alone ($n = 6$)</th>
<th>Groups ($n = 41$)</th>
<th>Indifferent ($n = 10$)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$n$ (%)</td>
<td>$n$ (%)</td>
<td>$n$ (%)</td>
</tr>
<tr>
<td><strong>Time 2</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ASD ($n = 4$)</td>
<td>1 (25%)</td>
<td>2 (50%)</td>
<td>1 (25%)</td>
</tr>
<tr>
<td>No diagnosis ($n = 53$)</td>
<td>5 (9.4%)</td>
<td>39 (73.6%)</td>
<td>9 (17%)</td>
</tr>
</tbody>
</table>

*Note.* $N = 57$. $n =$ subsample. % = percent of children in that T2 formal diagnostic (ASD$_{strict}$) category that parents reported themes related play preference category during T2 interview.
CHAPTER 4. DISCUSSION

The present study goals were to contribute not only to research on autism but to the broader developmental psychology literature by investigating sources of information collected about child development in infancy and how those early sources do or do not relate to later developmental progress and diagnoses (as reported by a parent/caregiver) in later childhood. I tested 4 hypotheses in a mixed-methods approach about how two different sources of screening information (parent-report, behavioral assessment) at infancy (15-35 mos.) related to later parent-reported autism diagnosis or significant concerns about social communication development. The small sample size ($N = 57$) leads me to interpret all results with caution, however, I discuss the findings here.

1.11 Parent-Report vs. R-ABC Predicting Diagnosis

Of the 15 children that parent-report screeners flagged during Time 1 as being At-Risk for ASD, 3 (20%) went on to have a formal ASD diagnosis mentioned at Time 2 and 12 (80%) did not. Of the 42 children that parent-report screeners considered Typical Developing (i.e., not At-Risk for ASD) during Time 1, 1 (2.4%) went on to have formal ASD diagnosis mentioned at Time 2 and 41 (97.6%) did not. When expanding to consider a more lenient DV that included parent concerns deemed significant and ASD-related by the research team, 6/15 (40%) who were flagged by parent report went on to have a formal ASD diagnosis or ASD-related concerns mentioned at Time 2 and 9 (60%) did not. 3/42 of those who were considered TD by parent-report at Time 1 (7.1%) went on to have formal ASD diagnosis or ASD-related concerns mentioned at Time 2 and 39 (92.9%) did not. For parent-report data, this suggests commendable “accurate positive” and “accurate negative”
rates for true diagnosis as well as predicting later remaining social communicative concerns. However, there were notable “false positive” rates and, most importantly, still some “missed” children as evidenced by the “false negative” rates. Research has shown that early social communicative behaviors like eye contact and joint attention typically emerge between 2-18 months (Butterworth & Jarrett, 1991; Scaife & Bruner, 1975) and that these early behaviors then support language development and more complex social understanding at 18-24 months (Tomasello, 1995). These early behaviors are evaluated as “flags” in the early screening tools used in the present study as well as inform the creation of milestone checklists (such as CDC, 2016). It is possible that the false positive rate is explained in part by the increased media attention that ASD has gotten in recent years as well as the overall ‘milestone’ approach that many parents follow, leading to flagged concerns in the 15-35 month age window that may have resolved within a few months of the original study’s data collection. Ideally, future studies would have more frequent and consistent follow-ups in infancy to evaluate the stability of parent-report risk status. However, to look at this within the present sample, one could conduct a further investigation into the infants who had both Time 1 intake and follow-up visits (~3 months apart) to see if any children transitioned from “at-risk” to “typically developing” within that 3-month period. It is possible some children, especially those who came at 15-24 mos. (i.e., “critical periods”) could have been flagged during intake as at-risk and then lost risk status at follow up.

The post-hoc investigation directly comparing the two sources of Time 1 risk information was conducted to see if one screener was more predictive than the other. That is, of those who failed both screeners and those who failed only one or the other, would
one screener have been sufficient. Ideally, the R-ABC instrument could further tease apart these “false” rates (i.e., catch the few “misses” and lower the rate of “false positives”) resulting from parent-report screeners that are currently recommended as initial steps in the widespread ASD screening protocols. However, the present study found that the R-ABC did not add significant discriminative information. Of the 10 children that the R-ABC screener flagged during Time 1 as being At-Risk for ASD, only 2 (20%) went on to have a formal ASD diagnosis mentioned at Time 2 and 8 (80%) did not. Of the 47 children that R-ABC screeners considered Typical Developing (i.e., not At-Risk for ASD) during Time 1, 2 (4.3%) went on to have formal ASD diagnosis mentioned at Time 2 and 45 (95.7%) did not. When expanding to consider a more lenient DV that included parent concerns deemed significant and ASD-related by the research team, 3/10 (30%) who were flagged by the R-ABC went on to have a formal ASD diagnosis or ASD-related concerns mentioned at Time 2 and 7/10 (70%) did not. 6/47 (12.8%) of those who were considered TD by R-ABC at Time 1 went on to have formal ASD diagnosis or ASD-related concerns mentioned at Time 2 and 41/47 (87.2%) did not. This brief, behavioral assessment appears to yield a similar “accurate positive” rate for true diagnosis (20%, 2/10) as parent-report data (20%; 3/15). However, when considering how many children were flagged by the R-ABC and the cross-over with parent-report flags, we find that the two who flagged by R-ABC and went on to have diagnosis would also have been captured by parent-report alone in addition to a third child that only parent-report had captured. A similar pattern emerges when considering the more lenient social concern outcome measure.

The exploratory ROC analysis revealed that for this sample a single parent-report screener M-CHAT) appeared to be better as the “one source” of information than R-ABC
when correctly classifying T2 parent reported outcomes (strict or lenient) with good specificity/sensitivity. Findings from the exploratory investigation of the parent-report M-CHAT curve compared to the R-ABC curve were that the M-CHAT had 2 children that were ‘low risk’ at Time 1 and went on to be formally diagnosed in T2, and 2 other children (1 med, 1 high) were also diagnosed in T2. For the M-CHAT “any risk” might be worth investigating (going lower in terms of referral for later follow-up). The R-ABC curve revealed that the cutoff score of 13 suggested by Ousley et al. (2013) did not correctly capture T2 outcomes. These findings are important when considering if the widespread implementation of an assessment like the Rapid-ABC in well-baby checkups would be capturing something unique (i.e., additional children that were being otherwise missed by parents). From the present study, it appears that the R-ABC did not capture “true risk” in a way that differed from the parents alone. One possible explanation is that the R-ABC assessment lacks external validity. Though R-ABC assessment was administered in a lab designed to look like a play room and with substantial warm-up play time (~30 minutes) in hopes of familiarizing the children with the experimenter and setting, it is still possible that the behaviors captured were not typical of the infants in the present sample. Disinterest or a “bad day” for an infant could have yielded inaccurate data within the present sample and might warrant a further investigation into the annotated videos from Time 1.

It is also possible that the R-ABC and/or parent-report “false positives” were mostly children who went on to receive other non-ASD diagnoses, which could be investigated by looking at the non-ASD clinical diagnosis data gathered by the present study’s follow-up interview. As part of the initial Ousley et al. (2013) study, the authors pointed out that future research was needed to be conducted to determine if R-ABC could discriminate
ASD from other developmental disorders. Autism has a variety of behavioral, cognitive, genetic, and medical comorbidities (e.g., anxiety, intellectual disability, ADHD, seizures) that make the development of biomarkers especially challenging (Hewitson, 2013; Johnson, Gliga, Jones, & Charman, 2015). This further illuminates the need for continued investigation of not only the R-ABC but any existing or emergent screening instruments for the ability to discriminate ASD from other developmental disorders. It is particularly challenging to gather evidence of validity on general population samples without longitudinal follow ups on large numbers of children. Some have started to investigate discrimination amongst other disorders (e.g., Schwenck & Freitag, 2014). However, many of the screeners are validated using samples that have known diagnoses vs. a control group or zeroing in on high-risk infant siblings and following those children longitudinally. This approach may be focusing more on sensitivity rather than specificity. However, it is important that we place equal emphasis on specificity because the treatment and interventions currently offered are not as widespread or effective as those seen for other disorders (see Vaughn-Justus, 2018). In sum, the ultimate goal is to correctly capture ASD risk amongst the general population so that our resources can be appropriately channeled to those needing intervention, and therefore I advocate for continued pursuit of such longitudinal studies. These studies will help inform the creation of consistent, highly sensitive and specific screening protocols that could be implemented on a larger scale.

Another small but very important finding worthy of discussion is that one child of the four who went on to receive a formal diagnosis at Time 2 was “missed” by both parent-report and R-ABC assessments at Time 1 (i.e., false negative). While this was contrary to expectations, this finding is perhaps the most congruent with the current state of the science
with ASD: diagnosing on a spectrum (see Appendix D) and investigating the possibility of multiple, different symptom emergence profiles and developmental trajectories (e.g., Landa, Holman, & Garrett-Mayer, 2007; Landa, Gross, Stuart, & Bauman, 2012a; Landa, Gross, Stuart, & Faherty, 2012b). Specifically, Landa et al. (2012b) suggest that the early differences in social and communicative symptoms (e.g., lower expressive language, diminished prosocial behavior) that can differentiate early (≤14 months) onset ASD, late (>14 months) onset ASD, and TD start to diminish as early as 24-36 months. Landa et al. (2012a) also suggest that there is not one clear trajectory that solely predicts ASD outcome and most infants will look as if they are developing normally (40%) whether they go on to be diagnosed with ASD or not. It is possible that the “missed” child in the present sample had either not developed symptoms yet (i.e., late onset) or came in at an age when early symptoms had already diminished or improved to a point where they were not flagged. Further investigation into this child as a single case would be needed to make strong claims in either direction. However, for the purposes of anonymity this will not be included as part of this published work. Continued research into these “missed” cases will again contribute towards the refining of existing screeners and creation of new assessments to yield the best possible screening protocol for widespread implementation.

1.12 Response Themes

Results of the qualitative analyses from the present study did not reveal significant themes in parent responses related to concerns about child development at Time 2. Specifically, parents of children who were considered at-risk during Time 1 were not more likely to report significant social communicative concerns at Time 2 than parents of children who were not considered at-risk for ASD in infancy. In fact, results revealed that
parents of those who were considered typically developing by all screening assessments in infancy voiced concerns about social communication related behaviors during the follow up interview. It is possible that parents of children who were at-risk at Time 1 for ASD did not mention significant concerns at follow-up because the original study had alerted parents to possible concerns and these children had since received appropriate treatments or interventions. These interventions may have resolved the issues entirely or may still be ongoing and therefore the parents did not feel that these issues were significant enough to mention as part of the interview (i.e., they are being managed or addressed). None of the four parents of children who had formal ASD diagnosis at Time 2 mentioned any remaining significant social communicative concerns for coding based on the proposed scheme. Again, these parents could have assumed that ASD-related concerns were implied by diagnosis or were being managed by therapies/interventions and therefore did not state them explicitly in the interview yielding lack of response themes.

The exploratory analysis also did not reveal significant themes in preference for play (alone, in groups, or indifferent) across either early risk status or the dichotomous diagnostic outcome. This suggests that children vary in play preference irrespective of these categorizations. This finding is important as early research has suggested that tendency to avoid social games or interaction yields diminished friendships and can impact individuals with autism well into adolescence and adulthood (Bagwell et al., 1998; Bauminger & Kasari, 2000; Bauminger et al., 2003; Chamberlain et al., 2007). Taken together, the lack of “themes” or quantitative patterns in the present study adds to the literature supporting the diversity of the autism profile - a true spectrum. As discussed

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previously, the variance in symptom profiles makes it challenging to predict true risk as well as diagnosis that distinguishes autism from other developmental concerns.

By using a semi-structured interview with qualitative analysis in mind, parents were allowed to interpret questions how they wished and give as much or as little information in response to each question as they desired. As presented above, this could have produced lack of support for Hypothesis 3. Also, the exploratory inductive analysis conducted as part of the present study suggests the potential for parents to interpret a question about play preference in a positive or negative light. Some parents responded as if a certain play preference was superior to the other (e.g., group was good, alone would be bad) whereas others responded as if all preferences were equal (e.g., alone could be a sign of a child who is able to self-regulate). While not aligned with the scope of the present study, a deeper dive into the latent features of parent responses that indicate possible positive/negative connotation might prove fruitful in the future. In sum, I feel that the present study illustrates the potential for qualitative assessments to shed light on ASD vs. neurotypical outcomes while emphasizing the importance of considering alternate question interpretations (in respect to area of interest) when designing these assessments.

1.13 Limitations and Future Directions

As with all research, the present study is not without limitations. Though some limitations were discussed above in respect to the specific results of the present study, others are summarized here. The primary limitation of the present study was that I had a smaller sample size ($N = 57$) and was unable to make contact with all families from the original study ($N = 181$) in spite of my best efforts. Given the amount of time that passed since the original study (3-7 years), many factors (e.g., family relocation, disinterest in
follow-up) likely resulted in lower participation. For this study, recruitment letters were sent out via mail and/or e-mail when applicable. For the original sample (N=181), retention rate (i.e., participation in the present, follow-up study) is only 31.5% (57/181). There were 8 parents/caregivers that responded to the initial recruitment letter but then failed to schedule an appointment for the interview, as well as 10 additional individuals that were not contactable (i.e., returned mail and/or failed emails). When investigating base rate of attrition, I also found that parents of children who had failed the parent-report screeners (N = 44) during the original study were underrepresented in the present study (65% attrition). In the original study, parents of children who failed the parent-report screeners were given a letter recommending a follow-up with pediatrician or other professional. It is possible that such letters deterred parents from participating in future studies with the lab. Future longitudinal studies would benefit from a larger sample size and consistent follow-up time points. Also, the method of follow-up study is phone interview with the parents/caregivers as respondents. This method was chosen as researchers such as Pascal and Bertram (2009) have suggested that survey and interview of young children are not usually appropriate or effective. However, similar to self-report biases, there can be tendencies for parents to discuss their children in a way that is socially desirable or not disclose certain information at all (out of discomfort, fear of confidentiality, embarrassment) during interviews. In the present study, I consider “at-risk” from Time 1 to include results from both ASD-specific screeners (M-CHAT) as well as more broad developmental screeners (CSBS, CBCL). Also, I discuss outcomes from the data as if Time 2 interview mentioning of ASD or significant ASD-related concerns are “gold-standard”, however there is potential for under-reporting of diagnosis. ASD-specific screeners such as the M-CHAT have shown Positive
Predictive Values (PPV) as high as .57-.65 (Chlebowski, Robins, Barton, & Fein, 2008; Robins et al., 2014). In the present sample, 5 children scored medium/high risk on the M-CHAT at Time 1, which means the expected value of diagnoses at Time 2 for the present study would be 2.85-3.25 children. Two of these five children went on to have formal diagnosis mentioned at Time 2, indicating underdiagnosis (PPV = 0.4). It is also possible that getting the “at-risk” screening result letter at Time 1 caused a reactive effect in which parents sought out early intervention or treatment that may have resolved concerns. Future studies could include in-person visits as well as explore the inclusion of response tendency scales.

As mentioned in the previous section, I also found that the level of detail or types of responses provided by parents in response to a given question varied considerably. Another example of this is the opening interview question which asked, “First I’d like to get a general sense of <insert child’s name>, what is he/she generally like?” Some parents responded with brief answers, using generic terms like “good kid” or descriptors such as “social”, “funny”, “shy”. Other parents responded to this question with more detail about what their child likes doing and provided examples or short stories to support such as “she loves being the center of attention”. The interview questionnaire for this study (Appendix A) was purposefully designed to include a balance of these general questions alongside the questions about potential developmental concerns or formal diagnoses. This balance was created so that the interview did not have an inherently negative feel (i.e., not perseverating on diagnoses or delays) for participants. However, it is possible that the questions used were still leading (i.e., worded in a way that parents felt compelled to give some sort of answer rather than choosing not to respond). It is possible that this variability in
interpretation of a certain question or level of detail provided could have resulted in a dataset that is not fully complete or accurate for each child. Also, since this interview was conducted over the phone, all questions had to be asked by the present author rather than read by the respondents. This included the administration of the Social Communication Questionnaire (Rutter et al., 2003) screener. I read both the instructions and each probe to the interviewee and recorded yes/no responses. However, I noticed some hesitation or indecisiveness for certain questions in the SCQ (e.g., parents asking “do you mean has he/she ever done this even just once or is this typical/regular behavior). While I made efforts to stick to the administration instructions/clarifications as consistently as possible, I noted in my memos that perhaps sending the SCQ via email or other method, so parents could read/interpret the questions and respond in a more definite way either on paper or electronically may have produced different results. In the future, a longitudinal study which includes an in-person observation with a licensed clinician would improve upon the present study’s methods by providing an addition objective follow-up measure and adding contact with the child at follow-up.

1.14 Conclusion

For this study, the goal was to evaluate the predictive abilities of a behavioral assessment (R-ABC) and parent self-report screeners (name them) for autism risk on eventual diagnosis of autism or other developmental challenges at a later point in time. I was able to draw from an archival data set of measures (Time 1) and conduct follow up interviews and questionnaire (SCQ) with parents of children in the original study (Time 2). In spite of the fairly small sample size, the results suggested there was notable correspondence with later autism diagnosis only for the children who were considered “at-
risk” in infancy (Time 1) by both parent-report and behavioral assessment screening tools. When the early sources of information were not in agreement (i.e., children were considered “at-risk” by only one or the other) there was not strong predictive ability in identifying those who went on to have an autism diagnosis. If a child had failed only one type of screener, parent-report was trending (though not significant) towards being the most predictive. Further, the qualitative interviews with parents revealed that though some “at-risk” children demonstrated other kinds of social or communication concerns, these concerns varied considerably and were also seen amongst the not at-risk group.

While the present study did not support a clear frontrunner amongst the tools being used to identify autism risk in infancy and toddlerhood, it does restate the importance of gathering information from multiple sources (i.e., both parent and early behavioral assessments) and investigating agreement amongst these sources. The question still remains if parents have more accurate insight into daily behavior that might be indicative of ASD risk (i.e., greater understanding of what is child’s “normal behavior” vs. what might be a one-off instance during behavioral assessment with an unfamiliar personsetting) compared to what may captured in a short, behavioral assessment that could be implemented as part of regular infant checkups. It is possible that with a larger sample, we may have found support for assessment over another and future infant/toddler studies that include longitudinal follow ups with general population samples will help address this gap in Autism Spectrum Disorder literature. At this stage, I would recommend that these different sources of information for early infant/toddler risk assessment be considered only as part of a comprehensive surveillance program to identify children in need of further assessment but not yet to ‘screen out’ autism. Future steps towards further teasing apart the
true predictive ability of these different sources of early information will hopefully yield a practical, affordable screening protocol that should then be administered to all children. While widespread screening will undoubtedly have continued impact on national prevalence rates (i.e., likely increase), it will most importantly continue to decrease the likelihood that children who present early autism-related behaviors are being overlooked, missing the window for early intervention that has been shown to be critical for not only this population but also other developmental disorders.
APPENDIX A. TIME 2 INTERVIEW QUESTIONNAIRE

Section 1: Consent
*Note: Only complete this section for initial interview, not if transcribing*
Verbal consent attained at (date; time EST) _____________________
Relationship to child of caregiver being interviewed (circle one):

- mother
- father
- other

Section 2. General Questions
1. First I’d like to get a general sense of <insert child’s name>, what is he/she generally like?
2. What does he/she like to do? When is he/she at her best?
3. What are the things he/she doesn’t enjoy?

Section 3. Education & Social Relationships
4. At what age did <insert child name> begin school? (Age): _______
5. What type of school did he/she start? (circle mentioned)
   - Public Pre-School or Kindergarten
   - Private Pre-School or Kindergarten
   - Montessori
   - Homeschool
   - Special education school
   - HeadStart
   - Other, please specify: ______________
6. What type of school does he/she currently attend? ______________
7. Does <insert child name> receive any special supports while in school? (circle) Yes   No
   *If yes, probe further to get details. Some options include: Individualized Education Program (IEP); general classroom for part of day, special education for rest the day; mostly general classroom but pulled out for 1:1 sessions (speech, OT); general classroom but with parapro assigned to the child).*
   *If any supports are mentioned, probe for details of support:*
   What kinds of things does he/she work on?
8. What are some things that <insert child name> is really good at in school? What subjects does she/he excel at?
9. Has <insert child name> remained on-track in school (i.e., has he/she ever been held back for any reason or repeated a grade)? Yes   No
   *If No:*
   Grade/reason:
10. Has <insert child name> developed any close friendships at school?  Yes  No
How many friends does your child have? ___________
If none, Does he/she express interest in having friends? Has he/she ever had friends?

If any friends mentioned: What kinds of things do they do together?

11. Does <insert child name> prefer playing in groups or alone?
What does he/she like to do when playing?

12. Has anyone from <insert child name>'s school ever expressed concerns about his/her behavior or progress?  Yes  No
If yes: Whom/Reason:
Would you characterize this delay or behavioral issue as recent or persistent?
Improving, worsening, or about the same? (check mentioned)
__ recent (within last year)  __ improving
__ persistent  __ worsening
__ about the same

How severe would you say this delay is? (check one)
__Mild, requiring none or little support
__Moderate, requiring considerable support
__Very severe, requiring very substantial support

Section 4. Clinical Diagnosis or Formal Treatments
13. Has anyone else, outside of your child's school, ever expressed concerns about your child's development, such as a pediatrician or other professional? (circle)  Yes  No
If yes, Has your child ever been diagnosed with delays or other conditions?
(circle) Yes  No

For any mentioned ask age or date of diagnosis & by whom they were diagnosed then ask the scaled questions below:
Autism Spectrum Disorder:
Age or date of diagnosis: _______  By whom: ______________

PDD-NOS:
Age or date of diagnosis: _______  By whom: ______________
Asperger Syndrome:
Age or date of diagnosis: _______
By whom: ______________________

Global Developmental Delay:
Age or date of diagnosis: _______
By whom: ______________________

Speech Delay:
Age or date of diagnosis: _______
By whom: ______________________

Other: ___________________________
Age or date of diagnosis: _______
By whom: ______________________

Would you characterize this delay or behavioral issue as recent or persistent? Improving, worsening, or about the same? (check mentioned)
__ recent (within last year) __ improving
__ persistent __ worsening
__ about the same

How severe would you say this delay is? (check one)
__ Mild, requiring none or little support
__ Moderate, requiring considerable support
__ Very severe, requiring very substantial support

14. Has your child ever received any kind of therapy or treatment? (circle) Yes No
If yes,
What are they?
For any mentioned ask when started, what for, and for how long:

Type: ___________________________ Notes:
Age started: _______
Age finished: _______

15. Is there any other aspect of your child’s medical or developmental history that you think may be important for us to know about? (i.e., do you have any concerns about his/her development?)

Section 5: Demographics
Please answer the following questions about the child who participated in the previous study:
16. Child’s age (years): _______

17. Child’s gender: (circle one)  male  female

18. Ethnicity of child?: (you may select more than one answer)
   1. African-American
   2. Asian
   3. Pacific Islander/Native Hawaiian
   4. Caucasian
   5. American Indian/Native Alaskan
   6. Hispanic or Latino/Latina
   7. Other, please specify:______________

19. If multiple ethnicity/if more than one above were circled: how do you view your child’s primary ethnic identification? ____

Please answer the following questions about your family:

20. Family Status:
   1. Married
   2. Separated
   3. Divorced
   4. Single Parent
   5. Living with a partner without marriage
   6. Widow/Widower
   7. Divorced and remarried
   8. Widow/Widower and remarried
   9. Other, please specify

21. Mother’s Education: (circle one)
   1. Less than 8th grade
   2. Some high school
   3. High school diploma/ GED
   4. Some college
   5. College degree (A.A., B.A., B.S.)
   6. Some graduate school
   7. Graduate school degree (Master’s or above)
   8. Other, please specify

22. Mother’s Occupation
Current employment status: (circle one)
   1. not employed outside the home
   2. employed part-time
   3. employed full-time
   4. employed full-time and have a second job

23. Father’s Education: (circle one)
   1. Less than 8th grade
   2. Some high school
   3. High school diploma/ GED
   4. Some college
   5. College degree (A.A., B.A., B.S.)
   6. Some graduate school
   7. Graduate school degree (Master’s or above)
   8. Other, please specify

24. Father’s Occupation
Current employment status: (circle one)
   1. unemployed
   2. employed part-time
   3. employed full-time
4. employed full-time and have a second job

25. Family Annual Income (circle one)
1. under $25,000
2. $25,000-$49,999
3. $50,000-$74,999
4. $75,000-$99,999
5. $100,000-$124,999
6. $125,000 and above

26. Are there other children living in the household?:
   If yes,
   Age: ___/___/____  Gender: (circle one)  male  female
   Age: ___/___/____  Gender: (circle one)  male  female
   Age: ___/___/____  Gender: (circle one)  male  female

27. What language(s) are spoken in the household?____________________________________________

28. What is the primary language spoken in the household? - _____________________________
APPENDIX B. SOCIAL COMMUNICATION QUESTIONNAIRE

(RUTTER, BAILEY, & LORD, 2003)

**Lifetime Form**

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**SCQ**
Social Communication Questionnaire
Michael Rutter, MD, FRS, Anthony Bailey, MD, Sibel Kazak Berument, PhD, Catherine Lord, PhD, and Andrew Pickles, PhD

<table>
<thead>
<tr>
<th>Name of Subject</th>
<th>Gender</th>
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<tbody>
<tr>
<td></td>
<td>☐Male  ☐Female</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Date of Interview</th>
<th>Date of Birth</th>
<th>Chronological Age</th>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Name of Respondent</th>
<th>Relation to Subject</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Clinician Name</th>
<th>School/Clinic</th>
</tr>
</thead>
</table>

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**Directions**

Thank you for taking the time to complete this questionnaire. Please answer each question by circling yes or no. A few questions ask about several related types of behavior; please circle yes if any of these behaviors have ever been present. Although you may be uncertain about whether some behaviors were ever present or not, please answer yes or no to every question on the basis of what you think.

1. Is she/he now able to talk using short phrases or sentences? If no, skip to question 8.
   - Yes
   - No

2. Can you have a to and fro “conversation” with her/him that involves taking turns or building on what you have said?
   - Yes
   - No

3. Has she/he ever used odd phrases or said the same thing over and over in almost exactly the same way (either phrases that she/he has heard other people use or ones that she/he has made up)?
   - Yes
   - No

4. Has she/he ever used socially inappropriate questions or statements? For example, has she/he ever regularly asked personal questions or made personal comments at awkward times?
   - Yes
   - No

5. Has she/he ever got her/his pronouns mixed up (e.g., saying you or she/he for I)?
   - Yes
   - No

6. Has she/he ever used words that she/he seemed to have invented or made up her/himself; put things in odd, indirect ways; or used metaphorical ways of saying things (e.g., saying hot rain for steam)?
   - Yes
   - No

7. Has she/he ever said the same thing over and over in exactly the same way or insisted that you say the same thing over and over again?
   - Yes
   - No

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Copyright © 2003, 2017 by Western Psychological Services. Permission is granted to qualified individual users of the WPS Online Evaluation System to reproduce this form for the sole purpose of collecting a client’s SCQ responses. No other use—including and not limited to adaptation and/or translation—may be made without the prior written permission of WPS (rights@wpspublish.com). All rights reserved. 9 8 7 6 5 4 3 2 1
8. Has she/he ever had things that she/he seemed to have to do in a very particular way or order or rituals that she/he insisted that you go through? | Yes | No |
9. Has her/his facial expression usually seemed appropriate to the particular situation, as far as you could tell? | Yes | No |
10. Has she/he ever used your hand like a tool or as if it were part of her/his own body (e.g., pointing with your finger, putting your hand on a doorknob to get you to open the door)? | Yes | No |
11. Has she/he ever had any interests that preoccupy her/him and might seem odd to other people (e.g., traffic lights, drainpipes, or timetables)? | Yes | No |
12. Has she/he ever seemed to be more interested in parts of a toy or an object (e.g., spinning the wheels of a car), rather than using the object as it was intended? | Yes | No |
13. Has she/he ever had any special interests that were unusual in their intensity but otherwise appropriate for her/his age and peer group (e.g., trains, dinosaurs)? | Yes | No |
14. Has she/he ever seemed to be unusually interested in the sight, feel, sound, taste, or smell of things or people? | Yes | No |
15. Has she/he ever had any mannerisms or odd ways of moving her/his hands or fingers, such as flapping or moving her/his fingers in front of her/his eyes? | Yes | No |
16. Has she/he ever had any complicated movements of her/his whole body, such as spinning or repeatedly bouncing up and down? | Yes | No |
17. Has she/he ever injured her/himself deliberately, such as by biting her/his arm or banging her/his head? | Yes | No |
18. Has she/he ever had any objects (other than a soft toy or comfort blanket) that she/he had to carry around? | Yes | No |
19. Does she/he have any particular friends or a best friend? | Yes | No |

For the following behaviors, please focus on the time period between the child’s fourth and fifth birthdays. You may find it easier to remember how things were at that time by focusing on key events, such as starting school, moving house, Christmastime, or other specific events that are particularly memorable for you as a family. If your child is not yet 4 years old, please consider her or his behavior in the past 12 months.

20. When she/he was 4 to 5, did she/he ever talk with you just to be friendly (rather than to get something)? | Yes | No |
21. When she/he was 4 to 5, did she/he ever spontaneously copy you (or other people) or what you were doing (such as vacuuming, gardening, or mending things)? | Yes | No |
22. When she/he was 4 to 5, did she/he ever spontaneously point at things around her/him just to show you things (not because she/he wanted them)? | Yes | No |
23. When she/he was 4 to 5, did she/he ever use gestures, other than pointing or pulling your hand, to let you know what she/he wanted? | Yes | No |
24. When she/he was 4 to 5, did she/he nod her/his head to mean yes? | Yes | No |
25. When she/he was 4 to 5, did she/he shake her/his head to mean no? | Yes | No |
26. When she/he was 4 to 5, did she/he usually look at you directly in the face when doing things with you or talking with you? | Yes | No |
27. When she/he was 4 to 5, did she/he smile back if someone smiled at her/him? | Yes | No |
28. When she/he was 4 to 5, did she/he ever show you things that interested her/him to engage your attention? | Yes | No |
29. When she/he was 4 to 5, did she/he ever offer to share things other than food with you? | Yes | No |

Continued on next page
<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>30. When she/he was 4 to 5, did she/he ever seem to want you to join in her/his enjoyment of something?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>31. When she/he was 4 to 5, did she/he ever try to comfort you if you were sad or hurt?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>32. When she/he was 4 to 5, when she/he wanted something or wanted help, did she/he look at you and use gestures with sounds or words to get your attention?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>33. When she/he was 4 to 5, did she/he show a normal range of facial expressions?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>34. When she/he was 4 to 5, did she/he ever spontaneously join in and try to copy the actions in social games, such as <em>The Mulberry Bush</em> or <em>London Bridge Is Falling Down</em>?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>35. When she/he was 4 to 5, did she/he play any pretend or make-believe games?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>36. When she/he was 4 to 5, did she/he seem interested in other children of approximately the same age whom she/he did not know?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>37. When she/he was 4 to 5, did she/he respond positively when another child approached her/him?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>38. When she/he was 4 to 5, if you came into a room and started talking to her/him without calling her/his name, did she/he usually look up and pay attention to you?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>39. When she/he was 4 to 5, did she/he ever play imaginative games with another child in such a way that you could tell that they each understood what the other was pretending?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>40. When she/he was 4 to 5, did she/he play cooperatively in games that required joining in with a group of other children, such as hide-and-seek or ball games?</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
### SCQ TOTAL SCORE: 25

Total scores of 15 or greater on the Lifetime form indicate a possible autism spectrum disorder (ASD) and, therefore, the need for a comprehensive evaluation.

<table>
<thead>
<tr>
<th>Item</th>
<th>Score</th>
</tr>
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<tbody>
<tr>
<td>1.</td>
<td>Yes</td>
</tr>
<tr>
<td>2.</td>
<td>N (1)</td>
</tr>
<tr>
<td>3.</td>
<td>Y (1)</td>
</tr>
<tr>
<td>4.</td>
<td>Y (1)</td>
</tr>
<tr>
<td>5.</td>
<td>N (0)</td>
</tr>
<tr>
<td>6.</td>
<td>Y (1)</td>
</tr>
<tr>
<td>7.</td>
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#### SUMMARY OF TEST DATA ENTRY

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**Response Key:**

- **Y** = Yes
- **N** = No
- **-** = Missing (not answered)
- **n/a** = Not Applicable

**Missing required responses:** 0

If Item 1 was marked **Yes**: The Total Score was calculated from Items 2-40
If Item 1 was marked **No**: The Total Score was calculated from Items 8-40
# APPENDIX D. DSM-5 DIAGNOSTIC CRITERIA SEVERITY RATINGS FOR AUTISM SPECTRUM DISORDER (APA, 2013A)

<table>
<thead>
<tr>
<th>Severity Level</th>
<th>Level 3: “Requiring very substantial support”</th>
<th>Level 2: “Requiring substantial support”</th>
<th>Level 1: “Requiring support”</th>
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<tbody>
<tr>
<td><strong>Social communication</strong></td>
<td>severe deficits in verbal and nonverbal social communication skills; very limited initiation of social interactions; minimal response to social overtures from others</td>
<td>marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiations of social interactions reduced or abnormal responses to social overtures from others</td>
<td>without supports, social communication deficits cause noticeable impairment; difficulty initiating social interactions; atypical or unsuccessful response to social overtures of others; may have decreased interest in social interactions</td>
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<tr>
<td><strong>Restricted, repetitive behaviors</strong></td>
<td>inflexibility of behavior; extreme difficulty coping with change or other restricted/repetitive behaviors markedly interfere with functioning in all spheres; great distress/difficulty changing focus or action</td>
<td>inflexibility of behavior; difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts; distress/difficulty</td>
<td>inflexibility of behavior causes significant interference with functioning in one or more contexts; difficulty switching between activities; problems of organization and planning hamper independence</td>
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<td>Example</td>
<td>changing focus or action</td>
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<td></td>
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<tr>
<td>------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------</td>
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<tr>
<td>A person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches</td>
<td>A person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication</td>
<td></td>
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<tr>
<td>A person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication</td>
<td>A person who is able to speak in full sentences and engages in conversation with others, and whose attempts to make friends are odd and typically unsuccessful.</td>
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## Coordinates of the ROC Curve

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REFERENCES


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Schwenck, C., & Freitag, C. M. (2014). Differentiation between attention-deficit/hyperactivity disorder and autism spectrum disorder by the social communication questionnaire. *ADHD Attention Deficit and Hyperactivity Disorders, 6*(3), 221-229.


