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Quantitative Measurement of Reciprocal Social Behavior among Toddlers Aged 18 to 24

Months

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A Clinical Scholarship proposal submitted to The Graduate School at the University of Missouri—St. Louis in partial fulfillment of the requirement for the degree Doctor in Nursing Practice May 2014

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Abstract

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that starts in early childhood. It is characterized by impairments in reciprocal social behavior, impaired language, and stereotypic behavior/restricted interests (Pine, Luby, Abbacchi, & Constantino, 2006). One in 68 children is affected by ASD (Centers for Disease Control and Prevention, 2014). The prevalence of ASD is rapidly increasing. New estimates show a 23% increase in the number of cases since 2009 and a 78% increase in case numbers since 2007 (CDC, 2013). The purposes of this project were to: (a) establish normative parameters of reciprocal social behaviors, among toddlers aged 18 to 24 months, (b) assess the validity and reliability of the quantitative instrument, the Video-Referenced Rating of Reciprocal Social Behavior (vrRSB) to quantitatively measure changes in reciprocal social behavior, among toddlers aged 18 to 24 months and (c) to assess for changes in reciprocal social behaviors in toddlers aged 18 to 24 months. Identification of these behavioral parameters, serves as a foundation for measuring incremental changes in reciprocal social behavior, imperative for clinical diagnosis and management of ASD. This project used existing data from a longitudinal study, from within a greater longitudinal study conducted through a private university in St. Louis. The utilization of the vrRSB allowed researchers to quantitatively measure incremental changes in reciprocal social behavior over time. The normative values of reciprocal social behaviors of 64 toddlers at 18 and 24 months total vrRSB scores were examined. Higher scores on the vrRSB are indicative of more social impairment. Significant improvement in reciprocal social behavior between 18 and 24 months based on a mean of 23.2 at 24 months and 27.4 at 18 months indicated an improvement in social behavior

within a 6 month range. The vrRSB effectively captured quantitative incremental changes in reciprocal social behavior among toddlers aged 18 to 24 months. These results indicated that the vrRSB is a valid and reliable instrument. The utilization of this measurement instrument is significant for pediatric clinicians involved in screening, diagnosing and managing ASD.

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Introduction

Purpose Statement

The purposes of this project were to (a) establish normative parameters of reciprocal social behaviors among toddlers aged 18 to 24 months, (b) validate the ability of the Video-Referenced Rating of Reciprocal Social Behavior (vrRSB) to quantitatively measure changes in reciprocal social behavior, among toddlers aged 18 to 24 months and to (c) assess for changes in reciprocal social behavior between toddlers aged 18 to 24 months. Identification of these normative parameters, functions as the foundation for measuring incremental changes in reciprocal social behavior, imperative for clinical diagnosis and management of ASD. The data collected from this study function as a baseline allowing clinicians to quantitatively monitor incremental changes in reciprocal social behaviors, with this knowledge, pediatricians and pediatric nurse practitioners (PNPs) are better able to evaluate impaired reciprocal social behaviors, diagnose toddlers presenting with ASD; and recommend interventions and management options to toddlers and their family.

Rationale for the Project

Autism spectrum disorder is a neurodevelopmental disorder that starts in early childhood. It is characterized by impairments in reciprocal social behavior, impaired language, and stereotypic behavior/restricted interests (Pine, Luby, Abbacchi, & Constantino, 2006). One in 68 children is affected by ASD (Centers for Disease Control and Prevention [CDC], 2014). The prevalence of ASD is rapidly increasing. New estimates show a 23% increase in the number of cases since 2009 and a 78% increase in case numbers since 2007 (CDC, 2013).

This study focused on establishment of normative parameters related to the domain of reciprocal social behavior, an essential component of relational interactions. Constantino et al. (2003) indicate that reciprocal social behavior involves an understanding of interpersonal emotions and a desire to engage socially with others. Social behavior is defined as joint attention with gaze shifts between an object to another person and back to the object of interest, as well as, includes responses to others requests to look at an object and initiation of sharing interest in an object (Landa, Holman and Garrett-Mayer, 2007). It is important to note that reciprocal social behavioral impairments, commonly seen in ASD, are on a continuum and are not discrete entities (Constantino & Todd, 2003). Constantino (2011) also indicates that the distribution of ASD symptomatology is continuous among the population and it becomes subjective where the clinical versus non-clinical threshold exists among symptom domains.

This study analyzed and interpreted data from the longitudinal study *Early Quantitative Characterization of Reciprocal Social Behavior* in a large metropolitan city in the Midwest (Constantino, 2013). This project evaluated and analyzed existing data on a normative sample of toddlers aged 18 and 24 months, not diagnosed with ASD, but during a developmental time when symptomatology emerged and became appreciable for ASD. The American Academy of Pediatrics (2008) recommends universal screening for ASD among toddlers aged 18 and 24 months at the well child checkup, because this is an important time to initiate early interventions if the toddler is diagnosed with ASD.

To better evaluate impaired reciprocal social behaviors, normative quantitative analyses of reciprocal social behaviors, must be collected. The vrRSB instrument is a novel quantitative instrument developed to measure reciprocal social behavior, among toddlers aged 18 to 24 months. Because ASD significantly impacts families causing emotional stress and a strain on the families' financial resources, it is important to be able to have a reliable measure that can detect the progression of reciprocal social behaviors. The aim of this project was to validate the ability of the Video-Referenced Rating of Reciprocal Social Behavior (vrRSB) to quantitatively measure changes in reciprocal social behavior, among toddlers aged 18 to 24 months. The results provided valuable insight, including the ability to identify impaired reciprocal social behavior at an early age, lending to an eventual ASD diagnosis. The vrRSB also provides clinicians the capability to manage impairments through measuring efficacy of interventions, as the vrRSB can monitor incremental changes in reciprocal social behavior. This ultimately improves patient outcomes, as practice can then be guided on evidenced-based results.

Relevance to Clinical Practice

This study explored an optimal way clinicians can measure changes in reciprocal social behavioral maturation among 18 to 24 month old toddlers. This time frame is significant, because this is when characteristics of ASD emerge, become appreciable, and recognizable to clinicians. This is often the time period, when many interventions for ASD are initiated. Due to the importance of this time period, The American Academy of Pediatrics (2008) recommends universal ASD screenings at the coinciding well child exams. Pediatricians and PNPs are responsible for screening, diagnosing and managing patients with ASD. As healthcare policy evolves and emphasizes the medical home model, ASD management in primary care will be essential. Hyman and Johnson (2012) indicate that the medical home model provides coordinated, comprehensive and continuous care for ASD children. Having the ability to screen, diagnose and manage

ASD within the medical home, allows clinicians to take advantage of frequent continuous contact with children and an established family rapport (Honigfeld, Chandhok, & Spiegelman, 2012). With a rapid instrument that allows for quantitative measurement, clinicians are more optimally able to diagnose and manage their patients. With an instrument that monitors incremental changes in reciprocal social behavior, confident early diagnosis of ASD can occur, as well as, effective and appropriate recommendations for intervention.

Epidemiology

The CDC reports that one in 68 children have ASD (CDC, 2014). The prevalence of ASD is rapidly rising; it remains unclear if this rise is due to a true increase in prevalence, increased awareness or possible differences in study methodology (American Psychiatric Association, 2013). This rise in prevalence has established ASD as a public health concern requiring intense monitoring and surveillance (Baio, 2012). To assist in this surveillance, the ASD and Developmental Disabilities Monitoring Network (ADDM), funded by the CDC, was developed with a primary objective of identifying the prevalence among various populations in the United States (U.S.).

Initiatives

Due to the increasing prevalence of ASD, public health interventions are addressing the needs of children and families affected. In order to better understand how to target early interventions, allocate ASD resources and optimize life for those affected; the ability to quantify reciprocal social behaviors in 18 to 24 month old toddlers was essential. Healthy People 2020 (U.S. Department of Health and Human Services, 2013) targets ASD as a priority within the Hearing Sensory and Communication Disorder Objective, with a goal of reducing the prevalence of these disorders. The Institute of Medicine (IOM) has created a committee whose primary purpose is to obtain knowledge related to childhood health and development and to then apply this to fostering the academic advancement of ASD (Institute of Medicine [IOM], 2013). Bright Futures has established guidelines stating that universal screening must be performed at all 18 and 24 month well child check-ups to assess for ASD (The American Academy of Pediatrics, 2008). ASD has become a major public health priority and as the prevalence continues to escalate, it will remain essential to address the needs of children affected (Dawson, 2010).

Review of the Literature

This section includes a comprehensive review of the literature related to ASD and quantitative measurement of reciprocal social behavior. Currently many formal screening and/or diagnostic instruments exist for identification of ASD, but no instrument is available that can rapidly quantitatively measure incremental changes in reciprocal social behavior in this young toddler group. This review also includes a comprehensive review of the literature related to ASD and quantitative measurement of reciprocal social behavior. Key words for this review of literature include autism spectrum disorder (ASD), 18 to 24 month toddler, early interventions, quantitative, measurement and reciprocal social behavior. Databases searched include CINAHL, PubMed, Medline, Mental Measurement Yearbook, HaPI and PsychInfo.

Autism Spectrum Disorder

Autism spectrum disorder is a neurodevelopmental disorder characterized by impairment in three domains; reciprocal social behavior, impaired communication, and stereotypic behavior/restricted interests (Pine, Luby, Abbacchi, & Constantino, 2006). Symptoms are typically apparent before 30 months (Pine et. al. 2006). ASD is "highly heritable with the recurrence rates among families to be approximately 5% to 6%" (Johnson & Myers, 2008, p. 44). The CDC 2013 report that if parents of a child with ASD have additional children, there is a 2% to 18% chance other children will be affected, and if one identical twin child has ASD, there is a 36% to 95% chance that the second twin will have ASD. Additionally, ASD is diagnosed five times more often in males than females (CDC, 2014).

Historically, Leo Kanner first described ASD as aloof children in 1943; in 1944 Hans Asperger described similar children, but noted these children had higher verbal and cognitive skills (Johnson & Myers, 2007). Guidelines in the newest *Diagnostic and Statistical Manual of Mental Disorders Fifth Edition* have been recently modified to indicate that individuals previously given a diagnosis of autistic disorder, Asperger's disorder or pervasive developmental disorder will now all inclusively be classified as ASD (American Psychiatric Association, 2013).

Etiology. A variety of nonspecific risk factors have been implicated in ASD, such as advancing parental age, low birth weight, fetal exposure to the medication valproate during pregnancy, as well as genetic association (American Psychiatric Association, 2013). A minority of cases of ASD are associated with a syndrome, such as Fragile X syndrome, Rett syndrome, or tuberous sclerosis (Johnson & Myers, 2007). Most cases of ASD are the result of genetics; although their genetic expression may be influenced by environmental factors, during intrauterine life, or early childhood (Johnson & Myers, 2007).

Autism spectrum disorder aggregates in families, with family members also displaying traits of ASD at a subclinical threshold (Constantino & Todd, 2003). The recurrence rate in families with one child with ASD appears to be 10%, indicating the tendency for repetitive familial distribution (Constantino et al., 2006).

Screening and diagnosis. Current practice guidelines for primary care pediatricians and PNPs include screening for ASD. The American Academy of Pediatrics (2008) has established guidelines for universal ASD screenings for children aged 18 and 24 months during well-child visits. If there is a family history of ASD, screenings may be done prior to 18 months (Johnson & Myers, 2008). Most children who screen positive during the ASD screenings will have some type of delay or impairment that will require intervention and attention, regardless if the child ultimately meets diagnostic criteria for ASD (Johnson & Myers, 2008). Due to the significant information a positive screening instrument can yield, the American Academy of Pediatrics is recommending formal instrument usage. If a child screens positive for ASD, a referral to a specialist (pediatric neurologist or pediatric psychiatrist) who can perform a comprehensive evaluation to confirm the diagnoses of ASD is warranted (Johnson & Myers, 2008). A widely used screener in pediatric primary care is the Modified Checklist for Autism in Toddlers (M-CHAT) (see Appendix B), an instrument designed to screen for ASD and related disorders, at the 18 month well-child checkup; it is a brief instrument that utilizes parental report and does not rely on clinician observation (Robins, Fein, Barton, & Green, 2001).

Currently available ASD screening instruments continue to have barriers for use in practice. Barriers to developmental screening in practice include difficulty finding time to administer the screening instruments, confidence in instrument usage and inadequate reimbursement for conducting formalized screenings (Honigfeld & McKay, 2006). Pinto-Martin et al. (2005) described additional barriers to ASD screening to include lack of provider training on childhood development, fear of identifying a positive screen, and having to give the news of a positive ASD screening result to the family. In general, primary care providers report competency for care of ASD children to be lower when compared to other chronic medical conditions (Golnik, Ireland, & Wagman Borowsky, 2008).

Autism spectrum disorder has impairments in three core clinical areas. These deficits include impaired reciprocal social behavior, impaired communication, and repetitive interests/behaviors (Constantino & Todd, 2003). Diagnostic criteria presented in the *Diagnostic and Statistical Manual of Mental Disorders Fifth Edition* specifies that (a) ASD has the previously stated core clinical impairments, (b) symptoms must present in the early childhood years, (c) symptoms are significant enough to cause impairment in social or occupational functioning, and (d) symptoms are not better described by an intellectual disability (American Psychiatric Association, 2013). Steiner et al. (2012) states that ASD diagnosis can be made by an expert clinician; a provider who holds professional credentials for diagnosing ASD, is knowledgeable of childhood development, and specifically ASD (Mossman Steiner, Goldsmith, Snow, & Chawarska, 2012). This study will specifically focus on quantitative measurement of the reciprocal social behavior, clinicians may be able to more effectively diagnose, manage and improve outcomes.

Interventions. Interventions initiated at an early age, while the brain is still placid and developing, are currently the standard of care for yielding optimal outcomes for children with ASD. Early intervention of ASD includes educational plans, speech and occupational therapy, behavioral modification, and medication for associated symptoms (Myers & Plauche Johnson, 2007). The pediatric clinician's objectives are to maximize independence and minimize core clinical features, thus achieving optimal outcomes for these patients (Myers & Plauche Johnson, 2007).

Education intervention. The Individuals with Disabilities Education Act (IDEA) has made early interventions accessible for infants and toddlers, through specifically identifying ASD as a disability (Crane & Winsler, 2008). The Individuals with Disabilities Education Act further encompasses the Individualized Family Service Plan (IFSP) for infants and toddlers, which include comprehensive access to therapy including speech and occupational therapy, as well as, educational resources (Crane & Winsler, 2008). Educational intervention includes academic learning, as well as, socialization and learning adaptive skills (Myers & Plauche Johnson, 2007).

Speech. Children with ASD have deficits in language and communication, thus assistance from a therapist specializing in speech and language is often helpful for teaching the child tools to promote communication (Myers & Plauche Johnson, 2007). A speech therapist is often used to evaluate language ability, differentiate between expressive and/or receptive delays and to facilitate language progression (Johnson & Myers, 2007).

Occupational therapy. Occupational therapists are often utilized for children with ASD to improve daily self-care skills, improve fine motor skills and to modify

classroom routines to improve attention and organization of the child (Myers & Plauche Johnson, 2007). Sensory issues are more common in children with ASD, such as oral defensiveness and motor clumsiness (Johnson & Myers, 2007).

Behavioral intervention. A variety of behavior modification approaches are implemented with ASD. The commonalities between the different approaches include structured learning sessions, small student/instructor ratios, socialization skills, generalization to other environments, cognitive skills and reduction of maladaptive behaviors (Myers & Plauche Johnson, 2007).

A study by Dawson, Rogers, Munson, Smith, and Winter (2010) indicated that a behavioral intervention program for toddlers diagnosed with ASD initiated at 12 months, showed significant improvements in symptoms. A prospective study of toddlers aged 18 to 30 months reported children who were assigned to the Early Start Denver Model group, a specific type of ASD therapy, showed greater improvement and were more likely to develop into a milder diagnosis, than their counterparts who participated in community interventions and continued to show decline and delay (Dawson et al., 2010). Additionally in a study by Pellicano (2012), it was demonstrated that children participating in early intervention programs had the greatest advances in social development.

In managing ASD patients, clinicians should be aware that there are associated co-morbid disorders that develop due to maladaptive functioning and behavior; these may manifest as conduct problems, hyperactivity, emotional difficulties and difficulties interacting with peers (Skuse et al., 2009). Skuse et al. also depicted in a study among the general population that reciprocal social impairments, are prognostic risk factors for impairments within the behavioral domain, indicating the direct relationship between the two domains. Constantino (2011) indicates that ASD largely shares genetic variance with attention deficit hyperactivity disorder, developmental coordination disorder, tic disorders, as well as learning disorders. Although early management of children with ASD is recommended, a study by Darrou et al. (2010), found that the timing of the manifestation of ASD symptomatology, had the most significant role in predicting a prognosis of developmental outcome, not the specific interventions utilized.

Medication treatment. A therapeutic trial of medication management for a targeted behavior or symptom may be considered after behavioral interventions have been instituted (Myers & Plauche Johnson, 2007). Evidenced-based research reports potential effectiveness with the use of Risperidone; indicated for ASD clinical symptoms (Jesner, Aref-adib, & Coren). Risperidone is the first Federal Drug Administration approved medication for ASD (Johnson & Myers, 2008). Other medications may be recommended, based on the core symptoms needing to be addressed.

Quantitative Measurement of Reciprocal Social Behavior

For improved evaluation and management of ASD, quantitative measurement of reciprocal social behavior, a core clinical feature of ASD, is imperative. A quantitative assessment of reciprocal social behavior captures severity and is able to be utilized in a multitude of diverse settings in which children have access to care (Constantino et al., 2007). Incremental measurement of social behaviors allows for normative variances in age and gender to be represented, and will allow for differences in severity of symptomatology to be captured (Hudziak, Achenbach, Althoff, & Pine, 2007). Constantino (2011) indicated that being able to measure severity and a range of

symptomatology, allows for monitoring of outcomes and evaluates effectiveness of interventions. Constantino et al. (2009) indicated that reciprocal social impairments, as well as clinical symptoms from other domains, are constantly changing in severity, and can be measured using a quantitative instrument, such as the Social Responsiveness Scale (SRS). Instruments that measure quantitatively can capture symptomatology that may otherwise be lost or outside the arbitrary cutoff with a categorical instrument (Duvall et al., 2007). Cunningham (2012) reviewed the quantitative measurement instruments that currently exist for measuring autistic symptomatology; the current instruments lack applicability to toddlers aged 18 to 24 months and they lack the ability to be used in widespread general practice without intensive clinician training on administration and scoring the instruments.

In a twin study by Constantino and Todd (2003), the continuous distribution of social traits was explored among children aged 7 to 15 years, and found a subjective threshold for behavior symptom severity among autistic children and typically developing children. The study by Constantino and Todd (2003) also reported that characteristics of social behavior difficulties were widespread among the general population. Through the usage of a quantitative measurement, severity of reciprocal social behavioral impairment can be captured. Cunningham (2012) indicated that when assessing for reciprocal social behavior, measuring incremental changes in severity is essential, rather than broadly looking for absolute presence or complete resolution of symptoms.

Instruments that are currently available for the toddlers aged18 to 24 months, are not sufficient to capture a range of reciprocal social behavioral symptomatology, they are designed to be categorical in nature and provide only a definitive presence or absence of symptomatology and not necessarily measurement of subtle changes in symptoms over time; other limitations include requiring intensive administration and are not practical for widespread usage (Cunningham, 2012). Following are examples of the instruments:

The Autism Diagnostic Observation Scale (ADOS) is an instrument which includes a toddler version that involves an intensive observation period to measure social behaviors (Cunningham, 2012). Its limitation is the training required for administration, therefore it is not practical for widespread public use; and it is also only designed to assess categorical presence of ASD symptoms, not to measure incremental social behavioral changes over time (Cunningham, 2012).

The Autism Diagnostic Interview Revised (ADI-R) is an additional available instrument; it requires a lengthy parent interview (Cunningham, 2012). The instrument is appropriate for children over 20 months; although it has limited use in measuring severity and incremental changes in social behaviors over time (Cunningham, 2012). This hinders its ability to monitor progression in social behaviors, as well as, before and after effects of treatment (Cunningham, 2012).

The Vineland Adaptive Behavior Scale (VABS) is another instrument that measures social behaviors and can be applied directly to this toddler age group, and is sensitive to behavioral changes over time; but is not sensitive to subtle incremental social behavioral changes, limiting its use (Cunningham, 2012). Finally, The Early Social Communication Scales (ESCS) is available to measure social communication among the toddler age group, but it is limited in its usefulness, due to the inconsistency and its lack of standardization (Cunningham, 2012). Reciprocal social behavioral severity and progression over time are significant factors for practicing clinicians. There was no instrument available for clinicians that quickly measured quantitative incremental change in reciprocal social behavior among toddlers aged 18 to 24 months. This review of the literature highlights ASD, its symptoms, etiology, treatment, screening instruments, and quantitative measurement of reciprocal social behavior in children. Findings of this review of the literature highlight the importance of validating the ability of the Video-Referenced Rating of Reciprocal Social Behavior (vrRSB) (see Appendix A) to quantitatively measure changes in reciprocal social behavior, among toddlers aged 18 to 24 months.

Methodology

Project Design

This normative data analysis study was designed to identify the normative parameters of reciprocal social behavior, among toddlers without existing diagnosis, and to validate the usage of the Video-Referenced Rating of Reciprocal Social Behavior (vrRSB) that quantitatively measures changes in reciprocal social behavior, among toddlers aged 18 to 24 months. With the identification of these normative parameters, they may be applied in the future, to ASD toddlers or toddlers with diagnosed impaired reciprocal social behaviors. O'Connor (1990) defines normative data as data that describe what is considered typical within a specific population at a referenced point in time. This was a brief longitudinal research project, from within a greater longitudinal study *Early Quantitative Characterization of Reciprocal Social Behavior* (Constantino, 2013). The fundamental steps of data organization, allowed for further multivariate and longitudinal analysis. Through quantitative analysis of two points of data, normative values were

established. Data were collected from parents via questionnaire completion of the vrRSB and completion of the Modified Checklist for Autism in Toddlers (M-CHAT). This yielded the targeted information related to the research questions, serving as the foundation for measuring incremental changes in reciprocal social behavior.

Research Questions

This project answered the following research questions:

- What are the normative descriptive statistics of the vrRSB of toddlers aged 18 to 24 months, including the mean, standard deviation and range? Norms were computed for total sample, as well as, males and females separately.
- 2. Was the vrRSB a valid and reliable instrument for measurement of reciprocal social behaviors in toddlers aged 18 to 24 months?
- 3. Did the vrRSB effectively measure incremental changes in reciprocal social behavior among toddlers between 18 and 24 months?

Setting and Sample

Existing data that were de- identified were used from the longitudinal study *Early Quantitative Characterization of Reciprocal Social Behavior* (Constantino, 2013). Data were derived from the parents of twins at 18 months or time point one; and 24 months or time point two, via the specified mailed instrument questionnaires. Parents were allowed to complete the mailed instruments in the privacy of their own home environments.

Project Participants

The study included 168 total toddler participants, who were longitudinally followed. (Four enrolled individuals from the study were omitted, because they only submitted data at the 24 month time point, and did not complete the initial vrRSB

questionnaire at 18 months). From those participants who completed both time points, data was obtained for analysis. In order to control for inflation effects (ie. genetic and environmentally identical exposures), a random sample of each twin pair was selected by flipping a coin; resulting with a total (N=84) for analysis. The coin flip randomly selected one twin from each pair to be involved in the study. This yielded a large quantity of data which was essential in order to establish generalizable results. This study only examined data from two points in time, 18 month and 24 month time points. Participants comprised a normative sample, recruited from the Missouri Family Registry. Participants completed an informed consent and mailed consent forms back to the private university research team, prior to initiation of the study.

Protection of Human Subjects

Permission to initiate the project was obtained from the primary investigator of the longitudinal study *Early Quantitative Characterization of Reciprocal Social Behavior* (Constantino, 2013). Permission to undertake the study was also obtained from the institutional review boards (IRBs) from the University of Missouri - St. Louis and Washington University School of Medicine in St. Louis. There was no violation to human rights during this study.

Instrumentation for Data Collection

Video-Referenced Rating of Reciprocal Social Behavior (vrRSB). The vrRSB (see Appendix A) was designed for children under the age of 36 months and targets children aged 18 months (Cunningham, 2012). The vrRSB is an adapted version of the Social Responsiveness Scale (SRS). The SRS is useful for quantitatively identifying milder cases of ASD, and for evaluating and measuring effectiveness of interventions

(Pine, Luby, Abbacchi, & Constantino, 2006). The SRS primarily focuses on impaired reciprocal social behaviors, but with acknowledgement into the domains of repetitive behaviors and language delay and has an internal consistency measured with Cronbach's alpha of 0.97 (Constantino, Przybeck, Friesen, & Todd, 2000). The SRS has a test-retest reliability of 0.88 and a correlation coefficient of 0.75-0.91(Constantino et al., 2003). The SRS can assess and distinguish severity and is therefore useful in measuring subtle progression in impaired reciprocal social behaviors (Wilson & Starling, 2011).

In the vrRSB, parents watched a three minute video of a typically developing prototype toddler who was a socially unimpaired toddler; scored their child, based on comparison to the prototype child; and answered additional questions about the social behaviors of their toddler (Cunningham, 2012). The vrRSB consists of a total of 51 questions. The questions on the vrRSB include 13 from watching the video and an additional 38 questions which have been adapted from the SRS. This is the initial usage of this instrument and no previous studies utilize a comparable instrument. The instrument is scored, based on a Likert scale (not true, sometimes, often, always true) format, with three questions for a written response at the end. There are 25 questions which are scored in reverse, based on the information they elicit. With this test, a higher score is indicative of more impairment.

Although this is the first video modeling instrument of this type, Hane et al., (2010) used an internet based parental report of child symptomatology of ASD using the Interactive ASD Network, with access to a large-scale population and found a 95% confidence with diagnostic results, demonstrating the reliability of parents as historians.

Modified Checklist for Autism in Toddlers (M-CHAT). The M-CHAT (see Appendix B) is an instrument designed to categorically screen for ASD and related disorders, at the 18 month well-child checkup. It is widely utilized in primary pediatric care settings. It is a brief instrument that utilizes parental report and does not rely on clinician observation (Robins, Fein, Barton, & Green, 2001). Internal reliability is found to be adequate on the M-CHAT, the sensitivity is 0.87 and specificity is 0.99, positive predictive power of 0.80, and negative predictive power of 0.99 (Robins, Fein, Barton, & Green, 2001).

Data Analysis

From the parental interviews and instrument responses, the data collected included: demographic data (including age, race and gender), and parental assessments via the vrRSB and the M-CHAT. Data obtained related to this study were used for the: (a) establishment of normative parameters of reciprocal social behaviors among male and female toddlers aged18 to 24 months male (b) establishing validity and reliability of the Video-Referenced Rating of Reciprocal Social Behavior (vrRSB) as an effective instrument for measuring reciprocal social behavior and (c) obtaining incremental change measurements between 18 and 24 months of age. It is the data from the vrRSB that allowed the quantitative statistical analysis to occur. The vrRSB was a novel instrument; and in a pilot study, had shown promising results in establishing the distribution of reciprocal social behavioral data among toddlers aged18 to 21 months (Constantino, 2013).

To complete this quantitative statistical analysis, the following calculations were completed:

- To establish normative parameters of reciprocal social behaviors at 18 and 24 months of age, the mean, standard deviation and range of the vrRSB data were computed for the total population, as well as for each gender individually at both 18 and 24 month age points.
- To establish validity and reliability of the vrRSB; internal consistency of the vrRSB was assessed by Cronbach's alpha at both the 18 and 24 month ages. Test-retest reliability was computed of the vrRSB at 18 and again at 24 months of age. A correlation of the vrRSB to the M-CHAT was also completed to examine external validity.
- 3. A repeated measures t-test at 18 and 24 months of age were calculated to establish incremental changes between 18 and 24 months of age.

There currently existed no effective way to measure incremental changes occurring in reciprocal social behavior among the 18 to 24 month old population. This study aimed to identify normative values and validate the vrRSB as an effective quantitative measurement instrument for reciprocal social behavior among 18 to 24 month old toddlers. Through validation of the vrRSB in this age group, clinicians are better able to diagnosis and manage impairments in reciprocal social behavior.

Results

Twin participants came from the Missouri Family Register, and were a normative sample, selected from within that database. The demographic data of this population that was captured for this study were obtained from the SDS form (Appendix C-D) and were representative of the general population. The project sample consisted of 168 toddler participants, 91 (54.2%) males and 77 (45.8%) females. The majority of toddlers were

Caucasian 130 (77.4%), 20 (11.9%) were African American, 8 (4.8%) were of mixed race, 6 (3.6%) were bi-racial, and 4 (2.4%) were Asian.

After random sampling of one toddler from each twin pair, this sample (N = 84) used for data analyses, consisted of: 45 (53.6%) males and 39 (46.6%) females. The majority of toddlers were Caucasian 65 (77.4%), 10 (11.9%) were African American, 4 (4.8%) were of mixed race, 3 (3.6%) were bi-racial, and 2 (2.4%) were Asian.

Toddlers (N = 84) at the first time point, (18 months) had a mean age of 19.1 months (range 17.4 to 22.6 months, SD = 1.13). Due to attrition, the study lost 20 participants at the second point (24 months) resulting in 64 toddlers. The mean age at the second time point was of 24.1 months (range 23.23 to 24.87 months, SD = .34). Thus there were 64 toddlers with data at both the 18 and 24 month assessment time points. Variable filters were established during the data analysis to account for this exclusion.

Normative Parameters of Reciprocal Social Behaviors

The normative values of reciprocal social behaviors in 64 toddlers at 18 and 24 months based on total vrRSB scores were examined. Higher scores on the vrRSB are indicative of more social impairment. To obtain normative values of reciprocal social behaviors for toddlers at 18 and 24 months, total vrRSB scores were examined. Since this was a quantitative study, analysis included the mean, standard deviation and range of the data. Descriptive analysis of the vrRSB at18 and 24 months indicated a mean of 27.4 at 18 months and 23.2 at 24 months. Normative values of reciprocal social behaviors were computed for the total sample, as well as, males and females separately at each time point (see Table 1).

Figure 1 presents a bar graph representation of the frequency and distribution of

the vrRSB scores of the total population of males and females at 18 months. Descriptive

statistics of the total population at 18 month time point were M = 27.4, SD = 9.9,

Minimum = 9.0, Maximum = 52.0 (see Table 1).

Table 1

VrRSB Scores							
Variable	N	Minimum	Maximum	М	SD		
Age in Months							
18 months	84	9.00	52.00	27.44	9.88		
24 months	64	4.00	50.00	23.16	8.48		
Gender by Age							
Male 18 months	45	11.00	52.00	29.60	9.79		
Male 24 months	36	4.00	50.00	24.89	8.84		
Female 18 months	39	9.00	52.00	24.95	9.49		
Female 24 months	28	7.00	41.00	20.93	7.58		

VrRSB Scores by Age, Gender and Time Points

Figure 1. VrRSB Total Scores of Total Population at 18 Months



Figure 2 presents a bar graph representation of the frequency and distribution of the vrRSB scores of males at 18 months. Descriptive statistics of males at the 18 month time point were M = 29.6, SD = 9.8, Minimum = 11.0, Maximum = 52.0 (see Table 1).



Figure 2. VrRSB Total Scores of Males at 18 Months

Figure 3 presents a bar graph representation of the frequency and distribution of the vrRSB scores of females at 18 months. The descriptive statistics for females at the 18 month time point were M = 24.9, SD = 9.5, Minimum = 9.0, Maximum = 52.0 (see Table 1).

Figure 4 presents a bar graph representation of the frequency and distribution of the vrRSB scores of the total population of males and females at 24 months. The descriptive statistics of the total population at the 24 month time point were M = 23.2, SD = 8.5, Minimum = 4.0, Maximum = 50.0 (see Table 1).



Figure 3.VrRSB Total Scores of Females at 18 Months

Figure 4. VrRSB Total Scores of Total Population at 24 Months



Figure 5 presents a bar graph representation of the frequency and distribution of the vrRSB scores of males at 24 months. Descriptive statistics for Males at the 24 month time point, M = 24.9, SD = 8.8, Minimum = 4.0, Maximum = 50.0 (see Table1).

Figure 6 presents a bar graph representation of the frequency and distribution of the vrRSB scores of females at 24 months. Descriptive statistics for females at the 24 month time point included, M = 20.9, SD = 7.6, Minimum = 7.0, Maximum = 41.0 (see Table 1).

Figure 5. VrRSB Total Scores of Males at 24 Months





Figure 6. VrRSB Total Scores of Females at 24Months

Internal Consistency of VrRSB

The vrRSB was found to have a high internal consistency, as evidenced by a high measure of reliability with Cronbach's alpha of .86 at time point one (18 months), of the 48 quantitative variables. Cronbach's alpha at time point two (24 months) was high at .82, also indicative of a high reliability. Field (2009) stated these values for Cronbach's alpha are considered good.

Test-Retest Reliability of VrRSB

Correlation of total vrRSB scores at 18 months with total scores at 24 months was 0.786 (p < .001) which was statistically significant and yields a high positive correlation. This finding indicated high test-retest reliability and inter-individual variation was preserved over time.

External Validity of VrRSB

VrRSB correlations with M-CHAT were used to measure external validity. Concurrent validity was strong for the vrRSB at 24 months to the standard M-CHAT collected at 24-months. The total vrRSB scores at 18 months compared to the total M-CHAT score was .414, p < .001 and was also statistically significant, yielding a moderate correlation. Finally, the total vrRSB score at 24 months compared to the total M-CHAT score was .410, p < .001 which is statistically significant. All results are evidence of strong to moderate positive relationships. The test-retest reliability of the vrRSB was very high. A correlation of the vrRSB to the M-CHAT was also completed to examine external validity.

Ability of VrRSB to Measure Incremental Change

Through repeated measures T-test, data depicted statistically significant improvement in reciprocal social behavior between 18 and 24 months t(63) = 5.78; p < .001(two tailed). This finding demonstrates significant improvement in reciprocal social behavior between 18 (M = 27.61; SD = 9.91) and 24 months (M = 23.16; SD = 8.48), indicating an improvement in social behavior within a 6 month range. These findings suggest that this normative sample of toddlers' social behavior improves between 18 and 24 months of age as measured by the VrRSB, indicative of maturation.

Discussion of the Results

The novel instrument, the vrRSB, does not have prior studies for comparing results. When comparing the vrRSB to the instrument that it was adapted from, the SRS, the vrRSB was found to have a Cronbach's alpha of .86 at time point one (18 months), and at time point two (24 months) it was also considered highly reliable at .82. The SRS,

has a Cronbach's alpha of 0.97 (Constantino, Przybeck, Friesen, & Todd, 2000). The vrRSB has a test-retest reliability of .786 compared to its model the SRS, which has a test-retest reliability of .88 (Constantino et al., 2003). The results proved that this novel instrument yields reliable quantitative data for this young toddler population.

Findings suggest that the vrRSB is a good, valid, and reliable measure, as evidenced

by the internal consistency and reliability assessment. The vrRSB proved to be a consistent measure across time, as demonstrated from observing incremental change from the 18 month to 24 month correlation. The vrRSB was valid when compared to the standardly recommended M-CHAT, which measured similar variables. The correlation of the vrRSB to the M-CHAT was modest, demonstrating that the vrRSB captures unique information; this may also indicate that the sample size was too small. The vrRSB also proved to be a good measure, because it preserved inter-individual differences over the course of time, as evidenced by a high positive correlation.

These findings suggest that this normative sample of toddler's social behavior improved between 18 and 24 months of age, reflective of normative maturation over 6 months, and evidenced by total scores on the vrRSB. This is a statistically significant improvement. Due to the significance of this time period, 18 to 24 months; and the initiation of many interventions for ASD during this period, it is important to note that many symptoms of reciprocal social behavior impairment are naturally improving. This is significant for clinicians and therapists to recognize, as they allocate and recommend therapy services.

This data as described was significant to impact current practitioners practice and management. By utilizing the vrRSB in widespread daily practice, practitioners will have

an effective instrument, with quantitative capabilities, which is easy to use and appropriate for this young 18 to 24 month population. This instrument allows for early identification of reciprocal social impairments and will also allow for evaluation of incremental changes in scores, due to implementation of interventions.

Limitations

The sources of potential bias for this study were from representativeness of the socioeconomic and demographic information obtained. The study was largely comprised of Caucasians (77%) and was limited to the Missouri region. Another limitation to the study was the small sample size. A major limitation to this study was the high rate of attrition, common to any longitudinal study. There were 20 participants lost before the 24 month data collection time point. One should also consider the bias of those participants who voluntarily chose to involve themselves with this study. The main limitation of this study was that there are no previous studies to compare results.

Future Research

As stated, there are no previous studies for comparison. Future research should involve replicating this study. Future research should also involve applying this data to a population previously diagnosed with ASD or reciprocal social behavior impairment, to identify if the results are comparable to this normative sample population. This provides an opportunity to compare and contrast results from this study. Additional research in the future should include a larger sample size, as well. Future research may also involve repeating an M-CHAT data collection at 24 months, in addition to the 18 month time point, for a more thorough correlational comparison. Finally, future research should also further compare and correlate individual twin differences, as we know that twin studies yield significant insight into Autism Spectrum Disorder.

The Stakeholders

The stakeholders for this project ensured that the project was completed and the results were disseminated, they included those whom were most impacted by the results of this study.

Professional Stakeholders. Pediatric medical providers, including neurologists, psychiatrists, pediatricians and PNPs were impacted by this study, since they are screening, diagnosing and managing referrals to therapies as well as recommending evidenced-based treatments. This study, by validating the measurement capabilities of the vrRSB, allows clinicians to identify the subtle emergence or resolution of impairment in reciprocal social behaviors. By assessing subtle symptom changes, effects of treatments and interventions can also be monitored and their effect on symptomatology measured.

Occupational therapists, speech therapists and behavioral therapists were greatly impacted, because their patient volumes are influenced by the ability to evaluate the usefulness of their interventions. The ability to evaluate interventions will help select the most effective and safest interventions to be pursued. Therapy outcomes will then further be influenced by reimbursement policies for their services, again based on whether their services are yielding desirable and effective outcomes.

Organizations that were stakeholders for this project include The American Academy of Pediatrics (AAP) and ASD Speaks (AS). These are national organizations that promote evidenced-based research for pediatrics and ASD, respectively. The AAP
sets guidelines for pediatricians to follow regarding ASD screenings and management. AS establishes grants for research and helps to promote ASD awareness. Both of these organizations will share an interest in the findings from this study.

As mentioned previously, policy makers and insurance companies will be stakeholders in this project, because they allocate funding for interventions to treat and manage ASD. After this project, interventions are able to be measured and evaluated to determine effectiveness, which is important to those responsible for allocation of funding.

Stakeholders Personally Affected. This study directly benefitted patients and families affected by ASD, because the results of the study yielded a better ability to quantitatively monitor their symptom progression. By monitoring symptomatology, patients and families are able to make more informed choices regarding effective providers and interventions to help manage their symptoms. This allows families to pursue those interventions that are most effective, and thus achieve the most optimal therapeutic outcomes.

Key Stakeholders. Dr. John Constantino, a pediatric psychiatrist and researcher from a private university in St. Louis, was a key stakeholder in this study. He also participated in this project as an expert consultant. This project benefitted him by establishing an inter-professional relationship. He increased the credibility of this project significantly. This project helped to support his primary research, related to ASD.

Operational Stakeholders. The research team at Washington University in St. Louis, Missouri which facilitates Dr. Constantino's research was included as stakeholders for this project. Also of significance for this project, included the statistician at the University of Missouri St. Louis (UMSL) to help with data analysis. Finally, the UMSL and Washington University IRB departments were stakeholders based on their approval and acceptance of this project.

Plan for Stakeholder Involvement. Dissemination of the results of this project will encourage engagement of the stakeholders. Through a participatory approach, the stakeholders supported this project, because they want to implement effective measurement options, as identified by this study.

Anticipated Project Barriers

A potential barrier of this project was with regard to stakeholders. Dr. Constantino, his team, and the DNP committee who inhabit different cultures, potentially influenced the direction of this project. Thorough communication related to translation of information was essential for making sure everyone understood what was happening and was satisfied with the progress of the project. Effective communication between Dr. Constantino, the research team and the DNP committee was vital.

Ethical Concerns

There were no ethical concerns related to this study. There was no harm or violation of human rights to these study participants. Parents merely provided a report of their children's reciprocal social behavioral status.

Project Approvals

This project received approvals from the UMSL graduate school, Washington University School of Medicine IRB department and UMSL IRB department. The project was granted exempt status from both IRB departments. HIPPA compliance was strictly observed. Data was coded to protect anonymity and data was securely locked and protected.

Project Timeline

Data collection completed in December 2013. Once the data collection was completed, stratification and analysis of data began in January 2014. A conclusion and discussion of data results is expected to be completed in April of 2014. The project was completed once the clinical scholarly project was formally defended in May 2014.

Outcomes

Primary care providers needed to change current practices and be able to quantitatively evaluate reciprocal social behaviors among their 18 to 24 month old patients; this was on target with current guidelines recommending universal ASD screening at 18 and 24 month visits. To improve diagnosis and intervention, a better measurement instrument to quantify reciprocal social behavior was needed, as well as, establishment of normative parameters of reciprocal social behavior among 18 to 24 month olds.

Evaluation of Outcomes

The specific measurable outcomes of this project were the data provided from completion of the vrRSB which were compared to data obtained from the M-CHAT by the children's parents. The data were related to the reciprocal social behavioral domain of the children's development. The data were then compiled to yield the results for statistical analysis. Evaluation questions to ascertain study effectiveness included: What were the normative descriptive statistics of reciprocal social behavior among 18 to 24 month olds, including the mean, standard deviation and range? Norms were computed for total sample, as well as, males and females separately. Did the vrRSB effectively quantitatively measure change in reciprocal social behavior, among 18 to 24 month olds? Was this new information significant enough to impact practitioners' current clinical practice? And finally, how does this new information influence intervention practices for ASD management?

Application for Practice

The outcome of this project has sustained a new validated measurement instrument, which can be utilized in widespread pediatric settings where children have access to developmental care. Utilization by all pediatric providers— especially pediatricians, pediatric nurse practitioners, psychiatrists and neurologists who diagnose and manage children with regard to reciprocal social behavioral impairments, will benefit from this instrument. The vrRSB can help providers identify which toddlers are outside of the normative parameters and may be in need of intervention for reciprocal social behavior impairments. Therapists, including occupational, speech/language and behavioral, will also benefit from utilization of the vrRSB to help identify the effectiveness of their interventions on symptomatology and characteristics of reciprocal social development. Finally, parents will benefit from the results of this vrRSB study, as they select interventions for their child, to help achieve optimal social outcomes. This measure is a rapid instrument, which can be used in diverse settings, allowing for widespread usage.

The vrRSB can be utilized as a powerful instrument, encouraging earlier detection and evaluation of reciprocal social behavioral impairments. The vrRSB is a novel instrument, but would provide great benefit to pediatric clinicians and providers, in an area that requires immense attention. The valuable information that the vrRSB provides to clinicians is accessible and will improve practitioners' management of pediatric reciprocal social behavioral development. The vrRSB will allow clinicians to recognize subtle impairments, outside of the normative parameters, at a younger age. This is valuable for early initiation of intervention.

To disseminate the study results, information will be submitted for publication to various journals, including Pediatrics and The Journal of Pediatric Health Care. Submission for publication through a variety of journals will occur, to target all stakeholders. When presenting this information to the clinicians or various audiences, the purpose of the study will continuously be revisited and adapted. The audiences will have various levels of preexisting knowledge on this subject, so language and terminology will be modified to accommodate various audiences. The usage of the AAP and AS to help promote awareness and education related to these results will be imperative.

DNP Influence on PNP Practice

The role of the DNP in clinical PNP practice has become an established priority of the American Association of Colleges of Nursing. They have created a position statement, The Essentials of Doctoral Education for Advanced Nursing Practice (2006) which outlines the necessary elements for preparing a DNP for clinical practice. The DNP has prepared me for a more specialized role as a PNP, with a deeper appreciation and understanding for symptom recognition, diagnosis and clinical management of toddlers with ASD. With the DNP, I have developed the ability to translate ongoing research and integrate it into my daily practice, ultimately improving my ASD management and my patient outcomes. By directly bringing research to the clinic, it may help to improve a vast number of ASD patients from a more global perspective. As a DNP, new plans of practice for my patients can be implemented and outcomes evaluated. I will access and utilize best practice techniques, as defined through evidenced-based research, with the intent of providing the highest quality and most effective care for my patients. Through the leadership skills I have developed, I will be able to collaborate among multiple disciplines, to achieve the best care for my patients. The DNP has given me the essential instruments to provide optimal care for my patients and to deliver my expertise in the most influential manner.

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Video-Referenced Rating of Reciprocal Social Behavior Please fill in today's date: __/ __/

This form filled out by: Mother Father Day Care Provider Other _____ (< Please circle one)

Name:_

STOP

VISIT: <u>https://cme-online.wustl.edu/psychiatry/site1.aspx</u> to watch the video. PASSWORD: lcampbell

Instructions for Section I:

You are about to view a brief video segment that shows the social behaviors of a child who has not yet begun to talk (other than a few simple words). Then you will complete a series of questions, some of which ask you to compare your child's behavior to the child in the video.

	In comparison to the child in the video.	Not at all	Some- what but less than child in video	About the same as child in video	More than child in video
1)	Is your child able to express feelings by changes in facial expression?(For example: smiling in response to something that makes him or her happy or frowning in response to something that makes him or her sad)				
2)	Is it typical for your child to be "on the same wavelength" with you?				
3)	Is your child able to pretend (engage in make-believe play)?				
4)	Does your child have a sense of humor?				
5)	Does your child try to involve others in play?				
6)	Does your child respond positively to adults who are trying to hold his/her attention?				
7)	Does your child look at you (making eye contact) when you are playing together?				
8)	When you approach your child to play with him or her, does he/she seem happy to include you or glad that you are involved?				
9)	Does your child seem interested in whether you are paying attention to what he or she is doing?				

PLEASE CONTINUE ON TO THE BACK OF THIS PAGE \longrightarrow

	<u>In comparison to the child in the video.</u>	Not at all	Some- what but less than child in video	About the same as child in video	More than child in video
10)	Is your child able to let you know what he or she DOESN'T want?				
11)	Is your child able to let you know what he or she DOES want?				
12)	Does your child cooperate with an adult's request for help (e.g., clean-up, picking up toys)?				
13)	Does your child <u>understand</u> simple verbal requests?				



Please answer the following:

- 1. Were you able to view the video?_
- 2. Were you able to hear the sound of the video?_____

*** IF YOU ANSWERED NO FOR EITHER OF THESE QUESTIONS PLEASE CONTACT US IMMEDIATELY TO LET US KNOW***

Laura Campbell : 314-362-5706 Erika Mortenson: 314-362-5988

***IF YOU ANSWERED YES FOR THE ABOVE QUESTIONS: PLEASE CONTINUE ON TO THE NEXT PAGE \rightarrow

Instructions for Section II and Appendix Items :

For each question, please check the box that best describes your child's behavior <u>over the last</u>. <u>Month</u>. Note that the headings for the answers are different from Section I:

	over the last month	Not TRUE	Sometimes TRUE	Often TRUE	Almost Always TRUE
14)	Reacts to changes in other's tone of voice and facial expressions				
15)	Avoids eye contact or has unusual eye contact				
16)	Seems obsessed with certain sensory interests (e.g., mouthing or spinning objects for prolonged periods of time)				
17)	Is able to imitate others' actions				
18)	Has more difficulty than other children his/her age with changes in his/her routine				
19)	Avoids starting social interactions with peers or adults				
20)	Seems odd or weird				
21)	Avoids people who try to be emotionally close to him/her				
22)	Has an unusually narrow range of things that he/she is interested in				
23)	Behaves in ways which seem strange or bizarre				
24)	Seems uncoordinated for his/her age				
25)	Wanders aimlessly from one activity to another				
26)	Seems overly sensitive to sounds, textures, or smells				
27)	Focuses his/her attention on the same thing that others are looking at or listening to				
28)	Has overly serious facial expressions				
29)	Has repetitive, odd behaviors such as hand flapping or rocking				
30)	Seems to interact with people as if they are objects				
31)	Concentrates too much on parts of toys rather than using the whole toy for its intended purpose				
32)	Is emotionally distant, doesn't show his/her feelings				

CONTINUED ON THE BACK OF THIS PAGE ightarrow

4

	over the last month	Not TRUE	Sometimes TRUE	Often TRUE	Almost Always TRUE
33)	Stares or gazes off into space				
34)	When seeing a spinning object (e.g. a fan or mobile), may stare at it for more than five minutes				
35)	Is interested in what people around him/her are doing				
36)	Shows unusual responses to being held / cuddled				
37)	Is capable of expressing joy by smiling or facial gestures				
38)	When offered a stuffed animal, will try to interact or pretend with it (hug it, pet it, or feed it)				
39)	Responds to his/her name being called				
40)	Seems to prefer to be by himself/herself				
41)	Has strange ways of playing with toys				
42)	Indicates, by pointing, when he/she wants something or is interested in something				
43)	Has unusual sleep patterns/ wakes up repeatedly in middle of night				
44)	Can assemble a puzzle with 8 or more inter-locking pieces				
45)	Seems eager to explore new play materials				
46)	Seems inquisitive or fascinated by complicated toys or materials				
47)	Is content to play with the same toy for hours				
48)	Able to perform simple construction tasks, such as placing four different shapes into the correct place in an inset (wooden) puzzle				
49)	Please estimate approx. total # of words your child uses	TO COMM	UNICATE wit	h you/an	yone:
50)	In the space provided, please write the most sophisticate past 2 months—if he/she ONLY speaks in phrases, pleas your child has spoken in the past 2 months:	d sentence se write the	e your child ha most sophist	as spoke licated pl	n in the hrase

Appendix Items:

		Not TRUE	Sometimes TRUE	Often TRUE	Almost Always TRUE
1)	Tends to withdraw or isolate him/her self when you attempt to play with him/her?				

MCHAT / ESAT QUESTIONNAIRE

(M-CHAT; Robins, Fein, & Barton, 1999 - University of Connecticut Department of Psychology) (ESAT; Jan K. Buitelaar, Dept Cognitive Neuroscience, Radboud University Nijmegen Med Center)

Please fill out the following about how each twin **usually** is, marking an 'X' for either YES or NO. Please try to answer every question. If the behavior is rare (e.g., you've seen it once or twice), please answer as if the child does not do it.

		Twin 1		Twin 1		Twin 2		
		YES	NO		YES	NO		
1	Does your child enjoy being swung, bounced on your knee, etc?							
2	Does your child take an interest in other children?							
3	Does your child like climbing on things, such as upstairs?							
4	Does your child enjoy playing peek-a-boo/hide-and-seek?							
5	Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend other things?							
6	Does your child ever use his/her index finger to point, to ask for something?							
7	Does your child ever use his/her index finger to point, to indicate interest in something?							
8	Can your child play properly with small toys (e.g. cars or bricks) without just mouthing, fiddling, or dropping them?							
9	Does your child ever bring objects over to you (parent) to show you something?							
10	Does your child look you in the eye for more than a second or two?							
11	Does your child ever seem oversensitive to noise? (e.g., plugging ears).							
12	Does your child smile in response to your face or your smile?							
13	Does your child imitate you? (e.g., you make a face-will your child imitate it?)							
14	Does your child respond to his/her name when you call?							
15	If you point at a toy across the room, does your child look at it?							

		Twi	in 1	Tw	in 2
		YES	NO	YES	NO
16	Does your child walk?				
17	Does your child look at things you are looking at?				
18	Does your child make unusual finger movements near his/her face?				
19	Does your child try to attract your attention to his/her own activity?				
20	Have you ever wondered if your child is deaf?				
21	Does your child understand what people say?				
22	Does your child sometimes stare at nothing or wander with no response?				
23	Does your child look at your face to check your reaction when faced with something unfamiliar?				

M-CHAT: © 1999 Diana Robins, Deborah Fein, & Marianne Barton

MCHAT / ESAT QUESTIONNAIRE

		Twin 1		Tw	in 2
		YES	NO	YES	NO
24	Is your child interested in different sorts of objects and not for instance mainly in cars or buttons?				
25	When your child expresses his/her feelings, for instance by crying or smiling, is that mostly on expected and appropriate moments?				
26	Does your child react in a normal way to sensory stimulation, such as coldness, warmth, light, sound, pain or tickling?				
27	Can you easily tell from the face of the child how he/she feels?				
28	When your child has been left home alone for some time, does he/she try to attract your attention, for instance by crying or calling?				
29	Is the behavior of your child free from stereotyped repetitive movements like banging his/her head or rocking his/her body?				
30	Does your child, on his/her own accord, ever bring objects over to you or show you something?				
31	Does your child like being cuddled?				
32	Does your child react when spoken to, for instance by looking, listening, smiling, speaking or babbling?				

Appendix C. FAMILY ID:		Lig TWIN NAME:	ht-Pearlman, Re	ebecca, 2014, l	JMSL, 57	
RESPONDANT ID:		DATE:	STAFF REPORTING:			
		SDS INTAKE CHART				
Parent Infor	mation	Legal First, Middle, and Last name at birth? If already provided: Mark "X" (NDAR)	GENDER	BIRTH DATE	CITY OF BIRTH (NDAR)	
(Mother) FULL NAME:			F			
AK Native Asian AA/Black Cauc	Spanic Unknown Native HI / Pac. Islander Mixed Race	Black +1 Unk				
STREET ADDRESS (CITY, STATE,ZIP)						
Но	ome:		CIR	CLE BEST II	ME TO CALL:	
PHONE W	ork:			NOON	Pivi Evening	
E-MAIL ADDRESS / INTERNET ACCESS						

Appendix C. FAMILY ID:	Light-Pearlman, Rebecca, 2014, UMSL, 58 TWIN NAME:			IMSL, 58
RESPONDANT ID:	DATE:	STA	AFF REPORTIN	NG:
Parent Information	Legal First, Middle, and Last name at birth? If already provided: Mark "X" (NDAR)	GENDER	BIRTH DATE	CITY OF BIRTH (NDAR)
(Father) FULL NAME:		м		
ETHNICITY: Hispanic Non- HIspanic Unknown RACE: Amer. Indian/ Asian Native HI / AK Native Air Pac. Islander AA/ Black Cauc Mixed Race	Black + 1 Unk			

STREET ADDRESS (CITY, STATE,ZIP)	Same as MOM				
	Home:Same as MOM		CIRCLE BES	Τ ΤΙΜΕ Τ	O CALL:
	Cell:	AM	Noon	PM	Evening
PHONE	Work:				
E-MAIL ADDRESS / INTERNET ACCESS					

DATE:

STAFF REPORTING:

EMERGENCY C	ONTACTS
NAME: PHONE:	-
NAME:	
PHONE: RELATION TO TWINS:	-
NAME: PHONE:	-
NAME:	
RELATION TO TWINS:	

Appendix	C.
FAMILY	ID:

DATE:

STAFF REPORTING:

TWIN INFORMATION

Twin Information	Legal First, Middle, and Last name at birth? If already provided: Mark "X" (NDAR)	GENDER	BIRTH DATE	CITY OF BIRTH (NDAR)
(Twin 1) FULL NAME:				
(Twin 2) FULL NAME:				
ENROLLED SIBLING (IF APPLICABLE) FULL NAME:				

Do the twins live in the same	CIRCI	E ONE
household?	YES	NO

** <u>Starting here</u> staff will need to fill out two separate forms : one for TWIN 1 and one for TWIN unless parents endorse that the twins spend equal amount of time with each family member/ caregiver – If both twins have the same amount of exposure to each family member / caregiver mark an 'X' in the box next to "Twin 2 has the same exposure**

Mark any differences in language exposure if applicable

DATE:

STAFF REPORTING:

	Since the birt	h of the twins:	
Parent Information	How many months and week do the following household a	MAJOR CAREGIVER FOR THIS TWIN?	
	# OF MONTHS IN		
	HOUSE HOUSE		
BIO MOTHER			
BIO FATHER			

HOW MANY OF THIS TWIN'S WAKING HOURS DO THEY SPEND WITH EACH

Type of Household:

	Period of time	:	Period of time	:	Period of time	e:
Maternal						
Paternal						
	Hours	Hours	Hours	Hours	Hours	Hours
Other	(MOM)	(DAD)	(MOM)	(DAD)	(MOM)	(DAD)
Monday						
Tuesday						
Wednesday						
Thursday						
Friday						
Saturday						
Sunday						

DATE:

STAFF REPORTING:

If there was any change in household since twins were born

Type of Housebold:						
nousenoia.	Period of time	•	Period of time	•	Period of time	<u>.</u>
Maternal		•				
Paternal						
	Hours	Hours	Hours	Hours	Hours	Hours
Other	(MOM)	(DAD)	(MOM)	(DAD)	(MOM)	(DAD)
Monday						
Tuesday						
Wednesday						
Thursday						
Friday						
Saturday						
Sunday						
Type of			·			
Household:			1		1	
	Period of time	:	Period of time	:	Period of time	2:
Maternal						
Paternal						
	Hours	Hours	Hours	Hours	Hours	Hours
Other	(MOM)	(DAD)	(MOM)	(DAD)	(MOM)	(DAD)
Monday						
Tuesday						
Wednesday						
Thursday						
Friday						
Saturday						
Sunday						

Appendix C. FAMILY ID:		TWI	N NAME:	Light-Pearlma	an, Rebecca, 2014,	UMSL, 63
RESPONDANT ID:		I	DATE:		STAFF REPORT	ING:
Type of Household:						
Maternal	Period of time	:	Period of time	:	Period of time	2:
Paternal						
	Hours	Hours	Hours	Hours	Hours	Hours
Other	(MOM)	(DAD)	(MOM)	(DAD)	(MOM)	(DAD)
Monday						
Tuesday						
Wednesday						
Thursday						
Friday						
Saturday						
Sunday						

DATE:

STAFF REPORTING:

Do you or the father/mother speak any language									
other than English with/to this twin? Are there									
any other lar	nguages being sp	oken in the house							
that this twi	n might hear the	following people							
speak? (ie. s	peaking another	language on the							
	phone)								
% of English	% of Spanish % of Other								

DATE:

STAFF REPORTING:

Sibling Information	Since the birth How many mo many days of the following peo same househo	n of the twins: onths and how he week do the ple live in the ld as this twin?	HOW MANY TWIN'S WAKI DO THEY SPE EACH SIB	OF THIS NG HOURS ND WITH	Do the follov than English languages be might hear the ano	ving people speak with/to this twin? ing spoken in the e following people ther language on t	any language other Are there any other house that this twin speak? (ie. speaking the phone)
	# OF MONTHS IN HOUSE	# OF DAYS A WEEK IN HOUSE	WEEKDAYS	WEEKENDS	% of English	% of Spanish	% of Other
(Full Sibling1) FULL NAME:							
Gender: Age:							
(Full Sibling2) FULL NAME:							
Gender: Age:							
(Full Sibling3) FULL NAME:							
Gender: Age::							
(Full Sibling4) FULL NAME:							
Gender: Age:							
(Full Sibling5) FULL NAME:							
Gender: Age:							

DATE:

STAFF REPORTING:

ADDITIONAL HOUSEHOLD MEMBERS

Are there any additional people living in the household with this twin? (this will include half siblings, step parents, and	Since the birth How many mo many days of the following the same hou tw	n of the twins: onths and how f the week do people live in sehold as this in?	IS THIS PERSON A MAJOR	HOW MAN TWIN'S WA DO THEY S EA	NY OF THIS KING HOURS PEND WITH .CH	Do the follow other than E there any oth the house th Someone spea	ing people speal inglish with/to ther languages be hat the twins mi aking another la phone)	k any language his twin? Are ing spoken in ght hear (ie. nguage on the
any other person living in the house)	# OF MONTHS IN HOUSE	# OF DAYS A WEEK IN HOUSE	CAREGIVER FOR THE TWIN?	WEEKDAYS	WEEKENDS	% of English	% of Spanish	% of Other
FULL NAME:								
Relationship to twin:								
Gender: Age:								
FULL NAME:								
Relationship to twin:								
Gender: Age:								
FULL NAME:								
Relationship to twin:								
Gender: Age:								
FULL NAME:								
Relationship to twin:								
Gender: Age:								
FULL NAME:								
Relationship to twin:								
Gender: Age:								

DATE:

STAFF REPORTING:

ADDITIONAL CAREGIVERS

Are there any Additional Caregivers for this Twin? Including babysitters, daycare, staying at grandmas house	IS THIS PERSON A	HOW MAN TWIN'S WAI DO THEY S EACH CAREG	IY OF THIS KING HOURS PEND WITH IVER LISTED?	Do the followi than English w languages beir might hear (ie.)	ng people speak ar ith/to this twin? Ar ng spoken in the ho Someone speaking on the phone)	ay language other re there any other use that this twin another language
	MAJOR CAREGIVER FOR THIS TWIN?	WEEKDAYS	WEEKENDS	% of English	% of Spanish	% of Other
NAME:						
Relation to Twin:						
NAME:						
Relation to Twin:						
NAME:						
Relation to Twin:						
NAME:						
Relation to Twin:						
NAME:						
Relation to Twin:						

Applies to Twin 2(Name:_____)

STAFF: If caregiver endorses Day care: list as "Day care": Mark Relation to twin as N/A STAFF:

Have caregiver indicate if the twin is at day care AM/PM/both, Weekdays/Weekends/both

DATE:

STAFF REPORTING:

ADDITIONAL QUESTIONS REGARDING EACH TWIN

IF THIS TWIN WAKES UP IN THE MIDDLE OF THE NIGHT, WHO IS THERE FOR THEM? (list all ppl that are reported)

Applies to Twin 2(Name:_____)

ON AVERAGE, HOW MANY HOURS A DAY IS THIS TWIN EXPOSED TO LANGUAGE THROUGH THE FOLLOWING SOURCES?			
ENGLISH	SPANISH	OTHER	
DAYCARE: PLAY GROUP/FRIENDS TELEVISION RADIO	DAYCARE: PLAY GROUP/FRIENDS TELEVISION RADIO	DAYCARE: PLAY GROUP/FRIENDS TELEVISION RADIO	

TWIN NAME:

RESPONDANT ID:

DATE:

STAFF REPORTING:

24M_ERSB INTAKE CHART UPDATE

STAFF to READ: We wanted to take a few minutes to update any changes that might have occurred to any of the information you provided the study during our initial interview with you a few months ago.

Specifically, have there been any changes to any of the following:

	Biological Mother of the Twins				
STREET ADDRESS (CITY, STATE,ZIP)	Same ADDRESS as provided during the 18M ERSB Intake Form				
(Maning Address)	D <u>NEW</u> MAILING ADDRESS BELOW:				
PHONE	Same PHONE NUMBERS as provided during the 18M ERSB Intake Form				
	□ <u>NEW</u> HOME; CELL; OR WORK NUMBERS BELOW:				
	Home: ()		CIRCLE BEST	TIME TO	CALL:
	Cell: ()	AM	Noon	PM	Evening
	Work: ()				
	Same EMAIL address as provided during the 18M ERSB Intake Form				
E-MAIL ADDRESS / INTERNET ACCESS	□ <u>NEW</u> EMAIL ADDRESS BELOW:				

DATE:

STAFF REPORTING:

	Biological Father of the Twins				
STREET ADDRESS (CITY, STATE,ZIP) (Mailing Address)	 Same ADDRESS as MOM/provided during the 18M ERSB Intake Form <u>NEW MAILING ADDRESS BELOW:</u> 				
PHONE	 Same PHONE NUMBERS as provided during the 18M ERSB Intake Form NEW HOME; CELL; OR WORK NUMBERS BELOW: Home: () same as MOM Cell: () Work: () 	AM	CIRCLE BES Noon	T TIME TO PM	CALL: Evening
E-MAIL ADDRESS / INTERNET ACCESS	 Same EMAIL address as provided during the 18M ERSB Intake Form <u>NEW EMAIL ADDRESS BELOW:</u> 				

DATE:

STAFF REPORTING:

EMERGENCY CONTACTS: "Are there any NEW emergency comprovide to the study?" (Names and phone numbers of relative contact in case we can't get a hold of you for any reason?").	ntacts that you would like to es or close friends that we can
NAME:	_
PHONE:	
RELATION TO TWINS:	
NAME:	_
PHONE:	
RELATION TO TWINS:	
NAME:	_
PHONE:	
RELATION TO TWINS:	-

READ: Now, I'd like to take a few minutes to update any changes that might have occurred in the amount of time that each twin spends with each biological parent, sibling, other household members, and additional caregivers. In addition, I will also be asking about any changes that might have taken place with the twins' exposure to various languages (both inside and outside the home).

Do the twins live in the same household?	CIRCLE ONE			
	YES	NO		

** Starting here staff will need to fill out two separate forms: one for TWIN 1 and one for TWIN2 unless parents endorse that the twins spend equal amount of time with each family member/ caregiver – If both twins have the same amount of exposure to each family member / caregiver mark an 'X' in the box next to "Twin 2 has the same exposure**

Mark any differences in language exposure if applicable
DATE:

STAFF REPORTING:

How many of this twin's AVERAGE WAKING HOURS do they spend with each;

BIOLOGICAL MOTHER AND BIOLOGICAL FATHER on an average week day and weekend day? Type of MATERNAL AND PATERNAL HOUSEHOLD

Household

		Period of time (in months):		Period of time (in months):		Period of time (in months):	
		AVERAGE	AVERAGE	AVERAGE	AVERAGE	AVERAGE	AVERAGE
		HOURS (BIO MOM)	HOURS (BIO DAD)	HOURS (BIO MOM)	HOURS (BIO DAD)	HOURS (BIO MOM)	HOURS (BIO DAD)
	Monday						
AYS	Tuesday						
EEKD	Wednesday						
3	Thursday						
	Friday						
ENDS	Saturday						
WEEK	Sunday						

Appendix D.	
FAMILY ID:	

DATE:

STAFF REPORTING:

	INDICATE BY MARKING "YES" OR "NO"	Do you or the fathe this twin? Are there twin might hear the	er/mother speak any la e any other languages e following people spe on the pho	anguage other than English with/to being spoken in the house that this ak? (ie. speaking another language one)
	IS THIS PERSON A MAJOR CAREGIVER FOR THE TWIN? (Both can be marked YES)	% of English	% of Spanish	% of Other
BIO MOTHER				
BIO FATHER				

TWIN NAME:

RESPONDANT ID:

DATE:

STAFF REPORTING:

STAFF: Complete the below tables for any of the following:

If there is a disruption in the presence of a caregiver

If there was any change in household composition since twins were born

Type of Household (CIRCLE ONE):

Maternal	Period of time:	Period of time:	Period of time:
Paternal			
Other (specify Relation to Twin)	Caregiver:	Caregiver:	Caregiver:
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

Type of Household (CIRCLE ONE):

Maternal	Period of time:	Period of time:	Period of time:
Paternal			
Other (specify Relation to Twin)	Caregiver:	Caregiver:	Caregiver:
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

DATE:

STAFF REPORTING:

SIBLING INFORMATION [KNOWN AND <u>NEW</u>] - Part 1

			INDICATE BY	Do the following	people speak any l	anguage other than	
			MARKING	English with/to th	English with/to this twin? Are there any other languages		
				being spoken in the house that this twin might hear the			
KNOWN Sibling			TES OK NO	following people	speak? (ie. speakir	ig another language	
Information					on the phone,		
Information			IS THIS PERSON A	% of English	% of Spanish	% of Other	
	OFNIDED	105	MAJOR CARGIVER				
	GENDER	AGE	OF THIS TWIN?				
(Full Sibling 1)							
FULL NAME:							
(Full Sibling 2)							
FULL NAME:							
(Full Sibling 3)							
FULL NAME:							
(Full Sibling 4)							
FULL NAME:							
NEW_SIBLIN	G INFORM	ATION (SII	NCE LAST ERSB INT	AKE CHART WA	S COMPLETED)		
(NEW ELILL Sibling - 5)							
FUIL NAME:							
(NEW FULL Sibling – 6)							
FULL NAME:							

DATE:

STAFF REPORTING:

SIBLING INFORMATION – Part 2

How many of this twin's AVERAGE WAKING HOURS do they spend with each;

SIBLING (KNOWN AND <u>NEW</u>) on week days and weekends?

Staff should record what household these siblings are living in with the twin

	Period of					
	time:	time:	time:	time:	time:	time:
	SIBLING	SIBLING	SIBLING	SIBLING	SIBLING	SIBLING
	#	#	#	#	#	#
Monday						
Tuesday						
Tuesday						
Wednesday						
Thursday						
Friday						
Thouy						
Saturday						
Sunday						

DATE:

STAFF REPORTING:

ADDITIONAL HOUSEHOLD MEMBERS – Part 1

Are there any additional people living in the household with this twin? (this will include half			INDICATE BY MARKING "YES" OR "NO"	Do the follow other than En any other lang that the tw speaking ar	Do the following people speak any language other than English with/to this twin? Are there any other languages being spoken in the house that the twins might hear (ie. Someone speaking another language on the phone)		
siblings, step parents, and any other person living in the house)?	Gender	Age	IS THIS PERSON A MAJOR CARGIVER OF THIS TWIN?	% of English	% of Spanish	% of Other	
FULL NAME:							
Relationship to twin:							
FULL NAME:							
Relationship to twin:							
FULL NAME:							
Relationship to twin:							
FULL NAME:							
Relationship to twin:							

DATE:

STAFF REPORTING:

ADDITIONAL HOUSEHOLD MEMBERS – Part 2

	Hausahald	Household	Household	Household
	Housenoid	Housenoid	Housenoid	Housenoid
	member:	member:	member:	member:
	Period of time	Period of time	Period of time	Period of time
	r choù or time.	r choù or time.	r choù or time.	renou or time.
				AVERAGE HOURS
	AVERAGE HOURS	AVERAGE HOURS	AVERAGE HOURS	
Monday				
Tuesday				
•				
Wednesday				
i canceaa,				
Thursday				
mursuay				
Entral and				
Friday				
Saturday				
Sunday				

TWIN NAME:

RESPONDANT ID:

DATE:

STAFF REPORTING:

ADDITIONAL CAREGIVERS – Part 1

Are there any Additional Caregivers for this Twin? Including babysitters, daycare, staying at grandmas	INDICATE BY MARKING "YES" OR "NO"	Do the following people speak any language other than English with/to this twin? Are there any other languages being spoken in the house that this twin might hear (ie. Someone speaking another language on the phone)			
house?	IS THIS PERSON A MAJOR CAREGIVER FOR THIS TWIN?	% of English	% of Spanish	% of Other	
NAME:					
Relation to Twin:					
NAME:					
Relation to Twin:					
NAME:					
Relation to Twin:					
NAME:					
Relation to Twin:					

Applies to Twin 2 (Name:_____)

STAFF: If caregiver endorses Day care: list as "Day care": Mark Relation to twin as N/A

STAFF: Have caregiver indicate if the twin is at day care AM/PM/both, Weekdays/Weekends/both

DATE:

STAFF REPORTING:

ADDITIONAL CAREGIVERS – Part 2

	Caregiver:	Caregiver:	Caregiver:
	Period of time:	Period of time:	Period of time:
	AVENAUL HOUNS	AVENAUL HOUNS	AVENAGE HOURS
Monday			
Tuesday			
Wednesday			
Thursday			
,			
Friday			
,			
Saturday			
Jaculuay			
Sunday			

DATE:

STAFF REPORTING:

ADDITIONAL QUESTIONS REGARDING EACH TWIN

IF THIS TWIN WAKES UP IN THE MIDDLE OF THE NIGHT, WHO IS THERE FOR THEM? (list all people that are reported)

Applies to Twin 2 (Name:)
•••••••••••••••••••••••••••••••••••••••

ON AVERAGE, HOW MANY <u>HOURS A DAY</u> IS THIS TWIN EXPOSED TO LANGUAGE THROUGH THE FOLLOWING SOURCES?			
ENGLISH	SPANISH	OTHER	
DAYCARE: PLAY GROUP/FRIENDS TELEVISION RADIO	DAYCARE: PLAY GROUP/FRIENDS TELEVISION RADIO	DAYCARE: PLAY GROUP/FRIENDS TELEVISION RADIO	