SOCIAL COMMUNICATION PROFILES OF TODDLERS WITH AND WITHOUT AUTISM SPECTRUM DISORDER FROM THREE RACIAL/ETHNIC GROUPS

By

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A Dissertation submitted to the School of Communication Science and Disorders in partial fulfillment of the requirements for the degree of Doctor of Philosophy

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In loving memory of my father, Keith “Tracy” Tracy.
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ABSTRACT

Racial and ethnic diversity is growing rapidly in the United States (US), leading to heightened concerns about racial/ethnic disparities in the provision of services for young toddlers with autism spectrum disorder (ASD). This investigation of the FIRST WORDS® Project studied a sample of 364 toddlers between the ages of 18 and 36 months who had a diagnosis of ASD confirmed ($n = 195$) or ruled out ($n = 169$) from three racial/ethnic categories: non-Hispanic White ($n = 226$), non-Hispanic Black ($n = 74$), and Hispanic White ($n = 64$). Differences across the groups were examined using scores from an observational measure of social communication, the Communication and Symbolic Behavior Scales (CSBS; Wetherby & Prizant, 2002) Behavior Sample, and a parent-report measure of autism red flags, the Early Screening for Autism and Communication Disorders (ESAC; Wetherby, Woods, & Lord, 2007). After controlling for maternal education, findings revealed that, compared to children without ASD, children with ASD scored lower on the CSBS, indicating poorer social communication and scored higher on the ESAC, indicating more red flags of ASD. Racial/ethnic groups did not differ on six of the seven clusters of the CSBS, but Non-Hispanic White toddlers were observed to score significantly higher than non-Hispanic Black and Hispanic White toddlers on the understanding cluster. There were no significant interactions between diagnostic classification and race/ethnicity on either the CSBS or ESAC. These findings indicate good agreement between observed social communication and parent report of autism red flags in a diverse sample of toddlers. Results from this study suggest that the CSBS and ESAC could be instrumental in identifying young toddlers with ASD from these racial/ethnic categories and may contribute to improving early detection and access to early intervention for toddlers with ASD.
CHAPTER ONE

INTRODUCTION

The criteria of the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; American Psychiatric Association [APA], 2013) include persistent deficits in social communication and social interactions as one of two domains required for a diagnosis of autism spectrum disorder (ASD). Research shows that these deficits can be observed as early as the second year of life (Chawarska, Klin, Paul, & Volkmar, 2007; Colgan et al., 2006; Lord et al., 2006; Shumway & Wetherby, 2009; Wetherby et al., 2004; Wetherby, Watt, Morgan, & Shumway, 2007). Early identification and enrollment in intensive intervention, preferably before the age of 3 years, is recommended for optimum treatment outcomes for children with ASD (National Research Council, 2001; Wetherby et al., 2004), but Mandell and colleagues (2002) found that Black children were not diagnosed until 7.9 years on average, 1.6 years later than the average age of diagnosis for White children. Based on parent report, Kogan et al. (2009) reported that Black children had a 57% lower chance of having a diagnosis of ASD compared to White children. Other studies have demonstrated that non-Hispanic students with ASD are approximately two times more likely to be diagnosed with ASD than their Hispanic peers (Liptek et al., 2008; Palmer, Walker, Mandell, Bayles, & Miller, 2010; Travers, Tincani, & Krezmien, 2011). This health disparity is more significant in light of the growth of the Hispanic population in the United States (US), which increased by 43 percent from 2000 to 2010—four times the national growth rate (U.S. Census Bureau, 2010). Data from the National Survey of Children’s Health revealed that most of the research emerging on social communication in toddlers with and without ASD has used relatively homogenous samples of primarily non-Hispanic White children.
(Liptak et al., 2008), and only one study to date has explored potential differences in early symptom presentation among minority and non-minority toddlers with ASD (Tek & Landa, 2012).

The need is increasing in our country for examination of the impact of racial, ethnic, and cultural diversity on social and communication development. The resources available to the family of a young child can be social, economic, and/or cultural and, in the US, isolating these factors is often difficult because of their interrelatedness. The U.S. Census Bureau (2010) reported that 25.9% of children under the age of 5 years live in poverty, indicating a lack of economic resources. Maternal education, commonly used as a metric for socioeconomic status (SES), can be directly linked to poverty level, as 47% of adult females in the US with 12 or fewer years of education live in poverty (U.S. Census Bureau, 2010). As Lindsey (2009) illustrated, a discrepancy is apparent among the SES of children of different racial/ethnic backgrounds, indicating a relationship between SES and sociocultural factors. Forty-five percent of Black children and 38% of Hispanic children live in poverty, compared to only 15% of non-Hispanic White children who live in poverty (U.S. Census Bureau, 2010). Tileston and Darling (2008) suggested that children living in poverty must be considered in the context of their culture; the differences in the language learning environments of children from differing SES levels therefore cannot be considered without consideration of the impacts of their family and community’s culture. Culture can be defined as a set of norms, roles, beliefs, and values that is learned and shared socially, while ethnicity—a shared nationality, culture, or language—is a means of transmitting culture (Betancourt & Lopez, 1993).

A disparity is evident in the services and diagnoses received by children from diverse racial/ethnic groups and low SES. In a study of racial differences in enrollment into early
intervention services, eligible Black children were close to five times less likely to receive services than White children, especially Black children with developmental delay without an accompanying medical condition (Feinberg, Silverstein, Donahue, & Bliss, 2011). Mandell et al. (2009) examined disparities in ASD diagnosis among racial/ethnic minorities across 14 states by using data from a sample of 2,568 8-year-old children with ASD collected as part of a multisite screening network. The children were identified through review of their records for characteristics of ASD rather through reported diagnosis, so the authors were able to find children who had not previously been diagnosed with ASD. The results indicated that children from all non-White minority groups were less likely than White children to have a diagnosis of ASD in their records. These disparities exist even at the level of screening for ASD. Pediatricians with caseloads consisting of more than 30% Medicaid-insured patients were significantly less likely to screen for ASD than pediatricians with only 10-30% of their patients insured through Medicaid (Arunyanart et al., 2012). Because a delay in or absence of a diagnosis of ASD could prevent these children from receiving intervention services, more research is critically needed that will help to identify ASD at an early age across racial/ethnic groups and across levels of SES.

**Relation Between Social Communication and Maternal Education**

Cultural learning theory proposes that children develop cognitive, social, and communication skills not only through biological and experiential learning, but also through the symbols, social interactions, and culture of their unique social world (Tomasello, 2000). Research has established that the social, emotional, and cultural resources available to families of toddlers can have an impact on preverbal communication abilities. One particular factor that has been shown to impact early communication is level of maternal education. Of the variables used
to measure SES, maternal education has been shown to have the strongest relationship with developmental outcomes (Noble, Norman, & Farah, 2005). It is also easy to obtain, potentially less biased than other measures of SES (Hurtado, Marchman, & Fernald, 2007), and can be measured on a continuous scale.

In their pioneering work, Hart and Risley (1995) completed a longitudinal study of 42 families with typically developing (TD) young children. They observed hour-long language samples of parent-child interactions once per month for 2.5 years. These authors found a strong relationship between SES and language development over time. This relationship has been illustrated in other studies as well (Dollaghan et al., 1999; Hoff, 2003; Qi, Kaiser, Marley, & Milan, 2012). The gap in language level between toddlers and preschoolers widens as these children enter school (Hart & Risley, 1995), so looking at communication even before this linguistic stage is crucial. Because of this language gap, researchers have begun to look at differences in preverbal communication across resource levels.

Given this relationship between preverbal communication and later language abilities and the established impact of low SES level on language abilities in the second and third years of life, this effect of SES level can be hypothesized to be observable even in preverbal communication. Rowe and Goldin-Meadow (2009) found this to be the case in their sample of 50 children from differing SES levels. They found that the effect of SES on vocabulary at 54 months of age was mediated by child gesture use at 14 months. Examining comprehension abilities in Spanish-speaking toddlers between the ages of 15 and 37 months, Hurtado, Marchman, and Fernald (2007) observed a relationship between maternal education and spoken word recognition using an eye-tracking task. They found that children whose mothers had fewer
years of education were slower and less accurate when presented with a spoken word and two picture choices.

Not all studies have found a relationship between resource level and rates of preverbal communication. In a study of 64 children ages 10 and 12 months from low- and middle-SES Spanish-speaking homes in Mexico, Jackson-Maldonado and Acosta (2006) observed no significant differences between groups in parental report of vocabulary comprehension, production, or gesture use. In direct observations, children from low-SES families used more gestures than children from middle-SES families, but the researchers did not measure spoken words during direct observation. In a population study of 1,911 Australian children at 8 and 12 months of age, Reilly et al. (2006) found that maternal education did not significantly predict scores of preverbal communication as measured by the Infant Toddler Checklist of the Communication and Symbolic Behavior Scales (CSBS; Wetherby & Prizant, 2002).

It is especially important to study preverbal communication, as it has been found to predict later language outcomes. For example, Rowe, Özçaliskan, and Goldin-Meadow (2008) found that children’s gesture use at 14 months significantly predicted vocabulary size at 42 months. In a study of 160 children assessed in the second and third years of life, Watt, Wetherby, and Shumway (2006) found that early communication, including joint attention, gestures, vocalizations, and comprehension abilities measured during the CSBS Behavior Sample (Wetherby & Prizant, 2002), significantly predicted later receptive and expressive language skills. Laakso and colleagues (1999) found similar results using both parent report of gestures and observational measures of joint attention.
Social Communication across Cultural, Racial, and Ethnic Groups

Culture, race, and ethnicity may play a role in preverbal communication development in addition to maternal education. In a study of 6 children between the ages of 10 and 24 months from American and Italian middle- to upper-income families, Italian children demonstrated a larger repertoire of representational gestures, whereas American children used primarily deictic gestures (Iverson, Capirci, Volterra, & Goldin-Meadow, 2008). These results have not been replicated in low-income families or with children with communication delays including ASD.

Tamis-LeMonda and colleagues (2012) observed gesture use and vocalizations in a sample of 226 mother-child dyads at the ages of 14 and 24 months from three cultural groups: Mexican, Dominican, and African American. At both time points, Dominican children were observed to vocalize more than children from the other groups. Using the McArthur Communication Development Inventory (Fenson et al., 2004), mothers of Mexican and Dominican children reported larger gesture repertoires than mothers of African American infants. Mexican children used more gestures than the other groups during a book sharing task but fewer gestures during a task involving putting beads onto a string.

In order to examine potential racial differences on a measure of early communication, Roberts, Medley, Swartzfager, and Neebe (1997) assessed 90 TD African American children at 12 months of age using the CSBS Research Edition (Wetherby & Prizant, 1990), and compared their performance to the original standardization group. The study showed generally similar language profiles, indicating a lack of racial differences in social communication abilities as measured by the CSBS.

One proposed impact of race, ethnicity, or culture on the assessment of communication abilities is a decrease in performance secondary to unfamiliarity with the tasks asked of the
children during testing. Hammer, Farkas, and Maczuga (2010) found differences across ethnicity in the amount of literacy-related experiences in the home, with Hispanic parents reporting fewer literacy activities than non-Hispanic parents. This lack of exposure to early literacy activities could have an effect on performance during standardized assessments. Peña, Quinn, and Iglesias (1992) proposed that parents might not ask their children to label or identify objects at equal rates across languages or cultures. They found that children enrolled in Head Start from primarily African American and Puerto Rican families had more difficulty with a labeling task than a description task. The children’s performance on the assessment increased when a dynamic assessment strategy was implemented, in which a teaching component was added to the assessment protocol. Similarly, Anderson (1996) found that typically developing Spanish-speaking preschoolers performed higher on a task in which they interacted with a set of objects and an examiner using naturalistic prompts and role-playing compared to their performance on a structured task in which they were presented with pictures and asked direct questions.

Multiple factors beyond SES and race/ethnicity also affect communication development, including learning English as a second language. Hammer and colleagues (2012) observed that six factors accounted for 61% of the variance in vocabulary scores of bilingual Spanish-speaking preschoolers including age, length of time in US, children’s language spoken to their father, children’s language spoken to their teacher, maternal education, and maternal English language proficiency. While SES has been to shown to have more of an impact on social communication development than culture (Whiteside-Mansell, Bradley, & McKelvey, 2009), other studies have found cultural differences in preverbal communication (Iverson, Capirci, Volterra, & Goldin-
Meadow, 2008). Given the heterogeneity in families in the US, further exploration into this relationship between cultural, racial, and ethnic differences and SES is warranted.

**Social Communication Profiles of Children with ASD**

An abundance of research has indicated that preverbal communication abilities in toddlers with ASD are significantly lower than children with TD or developmental delays (DD). Several studies have shown significantly lower rates of communication in toddlers with ASD compared to children with DD or TD (Wetherby, Watt, Morgan, & Shumway, 2007; Shumway & Wetherby, 2009). Charman and colleagues (2005) found that the rate of communicative acts at 2 years of age better predicted outcomes at age 7 than formal measures of language or nonverbal IQ. Werner and Dawson (2005) observed lower rates of complex babbling in children with ASD than children with TD. This study did not include children with DD, and other studies have suggested that reduced vocalizations may be associated with DD and not ASD specifically (Wetherby et al., 2007).

Gestures serve many functions in typical communication development and have been shown to predict later expressive vocabulary (Rowe et al., 2008). A communicative gesture can be defined as a nonverbal action directed toward another individual to serve a communicative function (Shumway & Wetherby, 2009). Young children use two main types of gestures, deictic and representational (Iverson et al., 2008; Rowe et al., 2008; Shumway & Wetherby, 2009). Pointing, showing, and reaching are characterized as deictic gestures, which are used to direct attention or establish reference. Representational gestures are used to establish reference but also carry semantic content. Examples of representational gestures include shaking the head yes or no, clapping, using hands to indicate size, or using gestures or signs that depict an object or action (e.g., pretending to drink from a cup).
Several studies have demonstrated impaired gesture use in toddlers with ASD. Colgan et al. (2006) found that children ages 9–12 months who were later diagnosed with ASD displayed less variety in the types of social gestures they used than age-matched children with TD. Groups did not differ with respect to quantity or initiation of gestures. In a study comparing children with ASD between the ages of 18 and 24 months to children with both TD and other DD, Shumway and Wetherby (2009) found reduced use of deictic gestures to be a core deficit for the children diagnosed with ASD. The groups did not differ with respect to representational gestures. The authors also found that the children with ASD used a higher proportion of contact-without-object gestures, defined as gestures used for the purpose of directing communication but without a fixed semantic contact, for example touching an adult to communicate.

Social Communication and Autism Symptoms across Race/Ethnicity

Children from diverse backgrounds within the US have been underrepresented in ASD research as much of the available ASD research has used samples of children from populations with middle to upper SES and primarily non-Hispanic White participants. Recently, Tek and Landa (2012) completed a study examining differences in autism symptomatology between non-minority and minority toddlers with ASD. Their participants included 65 White toddlers and 19 minority toddlers (African American, Asian, or Hispanic) between the ages of 16 and 38 months. Raw scores were used from the CSBS Caregiver Questionnaire (Wetherby & Prizant, 2002), a parent-report tool that measures language and social development. In addition, T scores for the Mullen Scales of Early Learning (MSEL; Mullen, 1995) were calculated for visual reception, fine motor, gross motor, receptive language, and expressive language. The results indicated that minority toddlers with ASD scored significantly lower than White children on several language and communication measures. Specifically, the minority toddlers scored lower on the CSBS
Caregiver Questionnaire measures of words and understanding of words and the MSEL receptive language and gross motor scales. It should be noted that this study did not include children with parents who had less than a high school education, and the majority of the sample consisted of upper-middle class families. Also, the individual race/ethnicity of the minority children were not considered separately. Finally, this study was limited by the lack of comparison groups of children without ASD. Further research examining the characteristics of toddlers with ASD from diverse and low-resource backgrounds is essential to ensure that these children have equal opportunities for early intervention.

Scarpa and colleagues (2013) recently looked at the relationship between race/ethnicity and parent report of autism red flags based on the Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al., 2001). Participants included 447 children from a rural, low SES community whose caregivers completed an M-CHAT at 18 or 24 months. They observed significant group differences for level of maternal education and total M-CHAT score, such that children whose mothers had less than 12 years of education failed the most M-CHAT items. In contrast, no significant group difference for minority status (with minority defined as Black, Hispanic, Asian, Mixed race, and Native American) on total M-CHAT scores was observed. Follow-up testing was not completed for participants of this study, so information regarding the diagnostic classification of participants is not available, and thus conclusions regarding the utility of the M-CHAT as an ASD screener for this sample could not be drawn.

Other studies have examined potential racial/ethnic differences in the presentation of ASD symptoms in older children. In their study of children ages 5 to 9 years, Sell et al. (2012) found no differences between these samples of Black and White children with ASD on measures of social communication. It was noted that these White children with ASD displayed more
restricted and repetitive behaviors than the Black children with ASD. Another study comparing White and Black children (ages 3 to 21 years) reported that Black participants said their first words and started using phrase speech significantly later than White participants, according to parent report (Cuccaro et al., 2007). There were no racial differences on any of the core symptoms of ASD. Chaidez, Hansen, and Hertz-Picciotto (2012) explored differences in developmental abilities and autism symptomatology in a large sample of Hispanic children \( n = 352 \) compared to non-Hispanic children \( n = 709 \). All participants were between the ages of 24 and 60 months and had received diagnoses of ASD, DD, or TD confirmed with the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 2002) and the Autism Diagnostic Interview-Revised (Rutter, Le Couteur, & Lord, 2003). Results indicated generally similar profiles of nonverbal cognitive and adaptive functions, and autism symptoms for Hispanic and non-Hispanic participants with ASD. Significant differences in performance on the MSEL receptive and expressive language subscales were observed, with Hispanic children with ASD and TD scoring lower than non-Hispanic children with ASD and TD, respectively.

The purpose of the current study was to examine social communication profiles of toddlers with ASD compared to toddlers with TD or other DD in which ASD has been ruled out (non-ASD) from three racial/ethnic groups within the US: non-Hispanic White, non-Hispanic Black, and Hispanic White, across a wide range of maternal education levels.

This study aimed to answer the following specific research questions about this sample of toddlers: 1) Are there group differences across diagnostic classification (ASD or non-ASD) and racial/ethnic categories (non-Hispanic White, non-Hispanic Black, Hispanic White) on measures of demographics including maternal education; 2) Are there group differences across diagnostic classification and racial/ethnic categories on social communication skills using the CSBS
Behavior Sample; 3) Are there group differences across diagnostic classification and racial/ethnic categories on red flags of ASD based on parent report using the Early Screening for Autism and Communication Disorders (ESAC; Wetherby, Woods, & Lord, 2007); and 4) What are the relationships among age, maternal education, social communication skills, and parent report of red flags of ASD?
CHAPTER TWO

METHOD

Participants

The current study included 364 toddlers between the ages of 18 and 36 months from three racial/ethnic groups: non-Hispanic White, non-Hispanic Black, and Hispanic White. Racial/ethnic group membership was determined based on parent report. Children of mixed racial background (e.g., Black father and White mother) were excluded. Additionally, only participants with maternal education reported were included in this study; however, only three participants were excluded for not meeting this criterion. The majority of the children and their families were recruited as part of the FIRST WORDS® Project, a prospective longitudinal study of children recruited through a general population screening in northern Florida. Additional Hispanic White families were recruited as part of a study examining early signs of ASD from diverse cultures. This study identified 30 Spanish-speaking toddlers in southern Florida, recruited through referrals to Early Steps, Florida’s early intervention program, as well as from community recruitment through healthcare providers, child care centers, and word of mouth. The process for recruiting children in southern Florida is further described in Grinker et al. (2012).

Each racial/ethnic group was divided further into groups of children with ASD and children without ASD, for a total of six groups: White ASD (n = 120), White non-ASD (n = 106), Black ASD (n = 35), Black non-ASD (n = 39), Hispanic ASD (n = 40), and Hispanic non-ASD (n = 24). Children in each of the ASD groups received a best-estimate diagnosis of ASD based on results from the ESAC, the ADOS, and clinical judgment incorporating standardized
Table 1
Summary of Participant Demographics

<table>
<thead>
<tr>
<th>Demographic</th>
<th>ASD (n = 195)</th>
<th>Non-ASD (n = 169)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Non-Hispanic White (n = 120)</td>
<td>Non-Hispanic Black (n = 35)</td>
</tr>
<tr>
<td>Child’s age at BS (M, SD)</td>
<td>21.07 (1.99)</td>
<td>20.69 (1.64)</td>
</tr>
<tr>
<td>Males (n, %)</td>
<td>100 (83.33)</td>
<td>31 (88.57)</td>
</tr>
<tr>
<td>First born (n, %)</td>
<td>57 (47.50)</td>
<td>14 (40.00)</td>
</tr>
<tr>
<td></td>
<td>n = 109</td>
<td>n = 29</td>
</tr>
<tr>
<td>Child’s age at ESAC (M, SD)</td>
<td>21.81 (4.51)</td>
<td>21.16 (5.58)</td>
</tr>
<tr>
<td>Parent’s education in years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother (M, SD)</td>
<td>15.03 (2.59)</td>
<td>14.57 (2.13)</td>
</tr>
<tr>
<td></td>
<td>n = 118</td>
<td>n = 30</td>
</tr>
<tr>
<td>Father (M, SD)</td>
<td>14.58 (2.91)</td>
<td>14.60 (2.50)</td>
</tr>
<tr>
<td>Parent’s age at child’s birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother (M, SD)</td>
<td>31.04 (5.99)</td>
<td>29.94 (6.55)</td>
</tr>
<tr>
<td></td>
<td>n = 118</td>
<td>n = 31</td>
</tr>
<tr>
<td>Father (M, SD)</td>
<td>34.22 (6.66)</td>
<td>32.38 (6.64)</td>
</tr>
<tr>
<td>Non-ASD (n = 169)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Non-Hispanic White (n = 106)</td>
<td>Non-Hispanic Black (n = 39)</td>
</tr>
<tr>
<td>Child’s age at BS (M, SD)</td>
<td>20.23 (1.77)</td>
<td>21.00 (3.10)</td>
</tr>
<tr>
<td>Males (n, %)</td>
<td>68 (64.15)</td>
<td>25 (64.10)</td>
</tr>
<tr>
<td>First born (n, %)</td>
<td>37 (34.91)</td>
<td>17 (43.59)</td>
</tr>
<tr>
<td></td>
<td>n = 101</td>
<td>n = 28</td>
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<tr>
<td>Child’s age at ESAC (M, SD)</td>
<td>21.89 (4.86)</td>
<td>22.93 (5.41)</td>
</tr>
<tr>
<td>Parent’s education in years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother (M, SD)</td>
<td>15.55 (2.80)</td>
<td>14.05 (2.10)</td>
</tr>
<tr>
<td></td>
<td>n = 105</td>
<td>n = 36</td>
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<tr>
<td>Father (M, SD)</td>
<td>15.43 (2.90)</td>
<td>13.36 (2.86)</td>
</tr>
<tr>
<td>Parent’s age at child’s birth</td>
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<tr>
<td>Mother (M, SD)</td>
<td>31.61 (5.00)</td>
<td>28.95 (6.96)</td>
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<td>n = 104</td>
<td>n = 37</td>
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<td>Father (M, SD)</td>
<td>33.65 (5.91)</td>
<td>31.45 (8.56)</td>
</tr>
</tbody>
</table>
measures as well as structured and naturalistic observations using the criteria outlined in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV; APA, 2000). An additional group of children was sampled from each racial/ethnic group to serve as a non-ASD comparison group. The non-ASD groups included children with TD as well as children with DD in which ASD has been ruled out. Children assigned to the non-ASD group received a best estimate clinical diagnosis of non-ASD in addition to a classification of nonspectrum on the ADOS. Participant demographic characteristics are summarized in Table 1.

**Procedure**

**Measures**

*CSBS Behavior Sample.* The CSBS Behavior Sample is a clinical evaluation of social communication in which children interact with a clinician and a caregiver. The Behavior Sample was standardized for children between the ages of 12 and 24 months and was administered in approximately 20 to 30 minutes. A standard set of systematic procedures was used to encourage spontaneous social and communicative behaviors. Children were seated at a table between their caregiver and a clinician and the clinician presented a series of 12 communication opportunities. They were first presented with a series of temptations using a wind-up toy, balloon, bubbles, jar with food, bag of toys, and books. Then they were presented with a feeding and cooking play set and stuffed animal to encourage pretend play and blocks to encourage constructive play. The Behavior Sample also included probes of following joint attention and comprehension of person name, body part, and object name. The Behavior Sample was video recorded and scored using standard procedures of the CSBS by trained examiners blind to child diagnosis, resulting in seven cluster scores and three composite scores. Interobserver agreement for the CSBS clusters and composites was calculated using intraclass correlation coefficients, each rater reached and
maintained a minimum of .80 using randomly selected samples for at least 10% of the FIRST WORDS® Project archival data.

The seven cluster scores include emotion and eye gaze, communication, gestures, sounds, words, understanding, and object use. The social composite score is a sum of the emotion and eye gaze, communication, and gesture clusters. The speech composite is a sum of the sounds and words clusters. The symbolic composite is a sum of the understanding and object use clusters. The standardization of this measure demonstrated good internal consistency and test-retest stability based on norming of a national sample (Wetherby & Prizant, 2002) and the Behavior Sample has been demonstrated to have good predictive validity with language outcomes at 2 and 3 years of age (Wetherby et al., 2002). Because the Behavior Sample scores were only standardized up to 24 months, raw cluster, composite, and total scores were used for this study.

The Behavior Sample was administered in a clinic setting for the participants in northern Florida, and in a home or library setting in southern Florida. Trained clinicians administered this assessment in English or in Spanish. For the southern Florida site, the clinician was a native Spanish-speaker and administered all assessments in Spanish. For families in northern Florida who indicated that Spanish was their primary language, efforts were made to accommodate based on the family’s use of English and their preference by offering a Spanish-speaking clinician if available, or an interpreter, or having the family bring a family member or other professional who worked with the family (e.g., social worker) to provide translation into Spanish. The verbal instructions to the Behavior Sample are minimal as the opportunities are set up nonverbally, with the exception of the probes for comprehension. For assessments conducted
in English, parents were invited to provide familiar words in their native language for the understanding probes after the clinician attempted them in English.

**ESAC.** The ESAC is a parent-report screening tool developed to detect the absence of or delay in typical skills and presence of unusual behaviors associated with ASD using the DSM-IV framework (APA, 2000). It has been designed for use with children ages 12 to 36 months and has been translated into Spanish. See Grinker et al. (2012) for a description of the translation process for this tool, which included focus groups of clinicians and parents who reviewed the translation and cultural appropriateness of the ESAC items. Preliminary field-testing indicated sensitivity from .84 to .86 and specificity from .83 to .85 for a total of 47 items (Wetherby et al., 2009). Follow-up analyses narrowed the number of items down from 47 to the best 30 items for differentiating children with and without ASD, based on ROC curve analyses (Wetherby et al., in preparation). The top 30 items were selected on the basis of their psychometric properties as well as clinical utility. For these top 30 items, good sensitivity (.88), good specificity (.81), and excellent AUC (.92) were found using a cutoff score of 18.

**ADOS.** The ADOS is a standardized assessment of the features of ASD, including social communication and play or use of materials. The ADOS used a semi-structured interaction between a child and clinician to create opportunities for observing signs of ASD and yielded scores in the domains of social affect, restricted and repetitive behavior and an overall score (Gotham, Risi, Pickles, & Lord, 2007). Participants received Module 1, 2, 3 or the Toddler Module (Luyster et al., 2009) based on age and expressive language level. Diagnostic classifications of non-spectrum, and autism were based upon the overall total score. Trained clinicians administered and scored the ADOS for participants in northern Florida in a clinical setting. For the participants from southern Florida, the ADOS was administered by trained
clinicians in a clinical or community setting (e.g., library or child care center) and scored by the first author, who has achieved research reliability on the ADOS, which is defined as three consecutive administrations scored at or above 80% agreement at the item and protocol levels. ADOS scores were used to assist in making a best estimate diagnosis of ASD or nonspectrum.
CHAPTER THREE

RESULTS

Group Differences on Demographic Measures

Preliminary analyses were completed to determine between-group differences on measures of participant demographics, including child age at the time of the Behavior Sample and ESAC, parental age at child’s birth, and parental years of education. Descriptive statistics for these demographic measures are provided in Table 1 (in Method section). The results of the between-group analyses are presented in Tables 2 and 3. Effect sizes are reported using Hedge’s $g$, which is calculated by dividing the means of two groups by the pooled standard deviation of the entire sample, with the assumption that the pooled standard deviation mirrors the variance of the population (Olejnik & Algina, 2000). While both Cohen’s $d$ and Hedge’s $g$ pool variance with the assumption of equal population variance, Hedge’s $g$ uses $n−1$ rather than $n$ for each sample. This provides a better estimate, especially with small sample sizes (Grissom & Kim, 2005). Interpretations of the common index for Hedge’s $g$ were used with values between .20 and .49 considered to indicate a small effect size, between .50 and .79 a medium effect, and ≥.80 a large effect (Cohen, 1988).

Maternal education is often reported in the literature as an indicator of SES because it has been shown to predict child outcomes (Christian, Morrison, & Bryant, 1998; Hoff, 2003), and therefore was examined. Because there were large significant correlations between maternal and paternal education, $r = .756$, $p < .001$ and maternal and paternal age at child’s birth, $r = .707$, $p < .001$, subsequent analyses use only maternal variables. Within racial/ethnic categories, differences in maternal education were only found between the ASD and non-ASD groups for
the Hispanic White toddlers, $F(1, 62) = 5.75, p = .019, g = .613$. Maternal education was significantly higher for Hispanic White toddlers with ASD ($M = 13.45, SD = 3.93$) than for Hispanic White toddlers without ASD ($M = 10.54, SD = 5.76$). Across racial/ethnic categories, there were significant differences in the years of maternal education only for toddlers without ASD. Mothers of Non-Hispanic White toddlers without ASD had significantly higher levels of education ($M = 15.55, SD = 2.80$) than non-Hispanic Black toddlers ($M = 14.05, SD = 2.10$), $p = .002, g = .567$, and Hispanic White toddlers ($M = 10.54, SD = 5.76$), $p = .001, g = 1.415$. The difference in maternal education between non-Hispanic Black and Hispanic White toddlers was also observed to be significant, $p = .023, g = .888$.

Non-Hispanic White children with ASD were observed to be significantly older at the time of the Behavior Sample than Non-Hispanic White children without ASD, $F(1, 224) = 11.13, p = .001, g = .443$. Differences in age at the time of the Behavior Sample were also observed across race and ethnicity for children with ASD, $F(2, 192) = 24.83, p < .001$ and for children without ASD, $F(2, 166) = 18.90, p < .001$; for both diagnostic classifications Hispanic White children were observed to be significantly older than children from the other racial/ethnic groups.
Table 2
Group Comparisons of Participant Demographics across Diagnostic Classification

<table>
<thead>
<tr>
<th>Demographic</th>
<th>( F ) value</th>
<th>( p^a )</th>
<th>( g^b )</th>
<th>( p^a )</th>
<th>( g^b )</th>
<th>( p^a )</th>
<th>( g^b )</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD (( n = 195 ))</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Non-Hispanic to non-Hispanic</td>
<td></td>
<td></td>
<td>Non-Hispanic to Hispanic</td>
<td></td>
<td></td>
<td>Non-Hispanic to Hispanic</td>
</tr>
<tr>
<td></td>
<td>White</td>
<td>Black</td>
<td>White</td>
<td>Black</td>
<td>White</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age at BS</td>
<td>24.83**</td>
<td>.582</td>
<td>.197</td>
<td>.001</td>
<td>-1.127</td>
<td>&lt;.001</td>
<td>-1.491</td>
</tr>
<tr>
<td>Age at ESAC</td>
<td>6.82**</td>
<td>.919</td>
<td>.136</td>
<td>.013</td>
<td>-.643</td>
<td>.028</td>
<td>-.372</td>
</tr>
<tr>
<td>Parent’s education in years</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>4.68*</td>
<td>.634</td>
<td>.183</td>
<td>.061</td>
<td>.528</td>
<td>.324</td>
<td>.344</td>
</tr>
<tr>
<td>Father</td>
<td>5.06*</td>
<td>1.000</td>
<td>-.007</td>
<td>.052</td>
<td>.559</td>
<td>.087</td>
<td>.512</td>
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<tr>
<td>Parent’s age at child’s birth</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>1.19</td>
<td>.755</td>
<td>.179</td>
<td>.356</td>
<td>.261</td>
<td>.985</td>
<td>.073</td>
</tr>
<tr>
<td>Father</td>
<td>2.74</td>
<td>.441</td>
<td>.275</td>
<td>.044</td>
<td>.391</td>
<td>.958</td>
<td>.108</td>
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<tr>
<td>Non-ASD (( n = 169 ))</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Non-Hispanic to non-Hispanic</td>
<td></td>
<td></td>
<td>Non-Hispanic to Hispanic</td>
<td></td>
<td></td>
<td>Non-Hispanic to Hispanic</td>
</tr>
<tr>
<td></td>
<td>White</td>
<td>Black</td>
<td>White</td>
<td>Black</td>
<td>White</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age at BS</td>
<td>18.89**</td>
<td>.377</td>
<td>-.347</td>
<td>.001</td>
<td>-1.491</td>
<td>.020</td>
<td>-.779</td>
</tr>
<tr>
<td>Age at ESAC</td>
<td>1.42</td>
<td>.731</td>
<td>-.207</td>
<td>.344</td>
<td>-.372</td>
<td>.931</td>
<td>-.148</td>
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<tr>
<td>Parent’s education in years</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>23.66**</td>
<td>.002</td>
<td>.567</td>
<td>.001</td>
<td>1.415</td>
<td>.023</td>
<td>.888</td>
</tr>
<tr>
<td>Father</td>
<td>23.19**</td>
<td>.001</td>
<td>.712</td>
<td>.001</td>
<td>1.495</td>
<td>.069</td>
<td>.766</td>
</tr>
<tr>
<td>Parent’s age at child’s birth</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>4.76*</td>
<td>.096</td>
<td>.473</td>
<td>.071</td>
<td>.559</td>
<td>.999</td>
<td>.031</td>
</tr>
<tr>
<td>Father</td>
<td>2.72</td>
<td>.396</td>
<td>.327</td>
<td>.232</td>
<td>.496</td>
<td>.962</td>
<td>.111</td>
</tr>
</tbody>
</table>

* = significant at \( p = .05 \), ** = significant at \( p = .001 \), \(^a\) = based on post-hoc Dunnett T3 comparisons,
\(^b\) Effect size based on Hedge’s \( g \geq .20 \) is small, \(.50 \) is medium, and \(.80 \) is large.
# Table 3
Group Comparisons of Participant Demographics across Race and Ethnicity

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Non-Hispanic White ($n = 226$)</th>
<th>Non-Hispanic Black ($n = 74$)</th>
<th>Hispanic White ($n = 64$)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$F$ value</td>
<td>$p$</td>
<td>$g^a$</td>
</tr>
<tr>
<td>Child’s age at BS</td>
<td>11.13**</td>
<td>.001</td>
<td>.443</td>
</tr>
<tr>
<td>Child’s age at ESAC</td>
<td>0.02</td>
<td>.892</td>
<td>-.017</td>
</tr>
<tr>
<td>Parent’s education in years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>2.07</td>
<td>.152</td>
<td>-.192</td>
</tr>
<tr>
<td>Father</td>
<td>4.69*</td>
<td>.031</td>
<td>-.291</td>
</tr>
<tr>
<td>Parent’s age at child’s birth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>0.58</td>
<td>.446</td>
<td>-.102</td>
</tr>
<tr>
<td>Father</td>
<td>0.45</td>
<td>.503</td>
<td>.090</td>
</tr>
</tbody>
</table>

* = significant at $p = .05$, ** = significant at $p = .001$

$^a$Effect size based on Hedge’s $g \geq .20$ is small, $.50$ is medium, and $.80$ is large
Group Differences on Measure of Social Communication

CSBS Total Scores

A series of analyses were completed to examine group differences on the CSBS Behavior Sample. First, a $2 \times 3$ between-subjects analysis of variance was used to observe potential group differences on the Behavior Sample total score. Independent variables (IVs) were diagnostic classification (ASD and non-ASD) and race/ethnicity (non-Hispanic White, non-Hispanic Black, and Hispanic White). There were no missing data or outliers and there was a normal distribution of total scores (skewness = .008, kurtosis = -.694). Using IMB SPSS GLM, a significant group difference was observed between total scores of children with ASD ($M = 57.65, SD = 27.37$) and children without ASD ($M = 88.15, SD = 26.69$), $F(1, 358) = 74.17, p < .001$. No significant differences were observed among race/ethnicity, $F(2, 358) = 2.44, p = .088$, or the interaction between diagnostic classification and race/ethnicity, $F(2, 361) = .931, p = .395$.

CSBS Composite Scores

Next, a $2 \times 3$ between-subjects multivariate analysis of variance was conducted using the same IVs but this time using the three Behavior Sample composite scores (social, speech, and symbolic) as dependent variables (DVs). The social (skewness = -.407, kurtosis = -.614), speech (skewness = .688, kurtosis = .054) and symbolic (skewness = .212, kurtosis = -.906) composites all had a normal distribution, and no missing values. There were no univariate or multivariate within-cell outliers at $\alpha = .001$. Using Wilk’s criterion, significant group differences were observed for diagnostic classification, $F(3, 356) = 32.76, p < .001$, and race/ethnicity, $F(6, 712) = 2.63, p = .016$, but not for the interaction between diagnostic classification and race/ethnicity, $F(6, 712) = .61, p = .724$. Further tests of between-subjects effects revealed a main effect of race/ethnicity for the symbolic composite, $F(2, 358) = 4.47, p = .012$, but not for social $F(2, 358)$.
Post-hoc tests using a Bonferroni correction to reduce the chance of Type I error revealed an observed significant difference between the symbolic scores of non-Hispanic White children and Hispanic White children, \( p = .006 \), but not between non-Hispanic White and non-Hispanic Black children, \( p = .291 \), or between non-Hispanic Black and Hispanic White children, \( p = .595 \).

Because significant group differences in maternal education and the child’s age at the Behavior Sample were observed across race/ethnicity, these comparisons were reanalyzed using a 2 × 3 between-subjects multivariate analysis of covariance with adjustment made for two covariates: child’s age at the time of the Behavior Sample and years of maternal education. The observed group difference between children with and without ASD continued to be significant with the addition of the covariates, \( F(3, 354) = 33.99, p < .001 \), and the interaction of diagnostic classification and race/ethnicity continued to be observed to be nonsignificant, \( F(6, 708) = .47, p = .828 \). In contrast to the previous analysis, no significant group differences were observed for race/ethnicity, \( F(6, 708) = 1.99, p = .065 \).

**CSBS Cluster Scores**

To examine group differences in social communication profiles, a 2 × 3 between-subjects multivariate analysis of variance was performed on the seven clusters of the CSBS Behavior Sample: emotion and eye gaze, communication, gestures, sounds, words, understanding, and object use. IVs were diagnostic classification and race/ethnicity.

IBM SPSS GLM was used for the analyses, with group means given equal weight regardless of sample size. Because it’s sensitivity to outliers is one of the more serious limitations of MANOVA (Tabachnick & Fidell, 2013), multivariate outliers were assessed using Mahalanobis distances. With seven DVs and a criterion \( \alpha = .001 \), the critical \( \chi^2 = 24.32 \). Five
outliers were found in the data at this level. Further investigation revealed that these cases had high values on the words cluster and this cluster was leptokurtic (kurtosis = 4.12, skewness = 1.76). Analyses were run with and without these five outliers included, and the exclusion of the outlying cases did not have an effect on the interpretation of the analyses. Because of this lack of effect, and because the outliers accounted for only .01% of the sample, the outliers were kept in the sample for all subsequent analyses. Measures of normality were calculated for each of the CSBS Behavior Sample cluster scores to assess skewness and kurtosis and, with the exception of words, skewness for all variables fell between -.57 and .59 and kurtosis fell between -1.06 and -.09. Following conventions of skewness and kurtosis values between -2 and 2 being considered acceptable, these cluster scores all meet criteria for normality.

Table 4 provides the group means for raw cluster scores on the Behavior Sample. Using Wilk’s criterion, significant group differences among the combined DVs were observed for both diagnostic classification, $F(7, 352) = 16.50, p < .001$, and race/ethnicity, $F(14, 704) = 2.61, p = .001$, but not for their interaction, $F(14, 704) = 1.06, p = .389$. Univariate analyses of individual DVs were used to investigate the impact of each main effect on each of the seven cluster scores. Diagnostic classification yielded observed significant differences for all of the cluster scores. The only cluster score to differ by race/ethnicity was understanding, $F(2, 358) = 9.68, p < .001$. Post-hoc tests using Bonferroni correction to reduce the chance of Type I error revealed significant differences in understanding between non-Hispanic White children and non-Hispanic Black children, $p = .009$, between non-Hispanic White children and Hispanic White children, $p < .001$, but not between non-Hispanic Black children and Hispanic White children, $p = .783$. 

25
Table 4
Descriptive Statistics of CSBS Behavior Sample Cluster Raw Scores ($N = 364$)

<table>
<thead>
<tr>
<th>Behavior Sample Cluster</th>
<th>ASD ($n = 195$)</th>
<th>Non-ASD ($n = 169$)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>non-Hispanic White</td>
<td>non-Hispanic Black</td>
</tr>
<tr>
<td></td>
<td>$n = 120$</td>
<td>$n = 35$</td>
</tr>
<tr>
<td>Emotion and eye gaze</td>
<td>9.33 (4.49)</td>
<td>9.14 (4.01)</td>
</tr>
<tr>
<td>Communication</td>
<td>12.49 (4.83)</td>
<td>11.37 (3.69)</td>
</tr>
<tr>
<td>Gestures</td>
<td>8.66 (4.72)</td>
<td>7.86 (3.59)</td>
</tr>
<tr>
<td>Sounds</td>
<td>7.01 (6.49)</td>
<td>6.49 (5.23)</td>
</tr>
<tr>
<td>Words</td>
<td>2.80 (5.16)</td>
<td>1.43 (2.19)</td>
</tr>
<tr>
<td>Understanding</td>
<td>6.55 (7.71)</td>
<td>3.26 (4.51)</td>
</tr>
<tr>
<td>Object use</td>
<td>13.65 (5.42)</td>
<td>14.15 (4.20)</td>
</tr>
<tr>
<td></td>
<td>Non-Hispanic White</td>
<td>non-Hispanic Black</td>
</tr>
<tr>
<td></td>
<td>$n = 106$</td>
<td>$n = 39$</td>
</tr>
<tr>
<td>Emotion and eye gaze</td>
<td>14.25 (3.06)</td>
<td>12.69 (3.50)</td>
</tr>
<tr>
<td>Communication</td>
<td>17.00 (3.08)</td>
<td>16.18 (3.47)</td>
</tr>
<tr>
<td>Gestures</td>
<td>13.80 (4.07)</td>
<td>12.44 (4.17)</td>
</tr>
<tr>
<td>Sounds</td>
<td>11.45 (6.87)</td>
<td>10.64 (5.97)</td>
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<tr>
<td>Words</td>
<td>5.72 (7.02)</td>
<td>4.92 (6.10)</td>
</tr>
<tr>
<td>Understanding</td>
<td>13.61 (7.65)</td>
<td>10.31 (8.25)</td>
</tr>
<tr>
<td>Object use</td>
<td>15.58 (4.80)</td>
<td>16.08 (4.94)</td>
</tr>
</tbody>
</table>

To account for significant group differences in maternal education and child’s age at the time of the Behavior Sample observed across race/ethnicity, a $2 \times 3$ between-subjects multivariate analysis of covariance controlling for child’s age at the Behavior Sample and years of maternal education was used to reanalyze this data. IVs (diagnostic classification and race/ethnicity) and DVs (seven Behavior Sample cluster scores) remained the same. IBM SPSS GLM was again used for this analysis.
With the use of Wilk’s criterion, the combined DVs were observed significantly differ across the covariates of Behavior Sample age, $F(7, 350) = 6.57, p < .001$, and maternal education, $F(7, 350) = 4.83, p < .001$, diagnostic classification, $F(7, 350) = 17.39, p < .001$, and race/ethnicity, $F(14, 700) = 2.08, p = .011$, but not the interaction between diagnostic classification and race/ethnicity, $F(14, 700) = 1.02, p = .436$.

The effects of diagnostic classification and race/ethnicity on the DVs after adjustment for covariates were investigated in univariate analyses. Results of these analyses are reported in Tables 5 through 7 and illustrated in Figures 1 and 2. Small to medium effects were observed for differences in race/ethnicity for all comparisons except for the difference between non-Hispanic Black and Hispanic White children without ASD ($g = .024$). Based on these follow up analyses, significant differences continue to be observed for all clusters between children with and without ASD.
Table 5
Descriptive Statistics of CSBS Behavior Sample Cluster Raw Scores Using Estimated Means Controlling for Maternal Education and Behavior Sample Age (N = 364)

<table>
<thead>
<tr>
<th>Behavior Sample Cluster</th>
<th>ASD (n = 195)</th>
<th>Non-ASD (n = 169)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 120</td>
<td>n = 35</td>
</tr>
<tr>
<td>Emotion and eye gaze</td>
<td>9.37 (4.49)</td>
<td>9.20 (4.01)</td>
</tr>
<tr>
<td>Communication</td>
<td>12.43 (4.83)</td>
<td>11.45 (3.69)</td>
</tr>
<tr>
<td>Gestures</td>
<td>8.51 (4.72)</td>
<td>7.92 (3.59)</td>
</tr>
<tr>
<td>Sounds</td>
<td>6.88 (6.49)</td>
<td>6.86 (5.23)</td>
</tr>
<tr>
<td>Words</td>
<td>2.78 (5.16)</td>
<td>1.77 (2.19)</td>
</tr>
<tr>
<td>Understanding</td>
<td>6.51 (7.71)</td>
<td>3.52 (4.51)</td>
</tr>
<tr>
<td>Object use</td>
<td>11.91 (5.42)</td>
<td>12.09 (4.20)</td>
</tr>
</tbody>
</table>

|                         | n = 106       | n = 39            | n = 24     | n = 106 | n = 39 | n = 24 | Hedge’s g<sup>a</sup><br>nW-nB | nW-HW | nB-HW |
| Emotion and eye gaze    | 14.37 (3.06)  | 12.71 (3.50)      | 14.06 (2.58)| .519    | .103   | -.419 |
| Communication           | 17.02 (3.08)  | 16.28 (3.47)      | 15.89 (4.23)| .232    | .338   | .102  |
| Gestures                | 13.72 (4.07)  | 12.56 (4.17)      | 13.08 (5.12)| .282    | .149   | -.113 |
| Sounds                  | 11.63 (6.87)  | 11.08 (5.97)      | 10.64 (5.62)| .082    | .148   | .074  |
| Words                   | 5.96 (7.02)   | 5.28 (6.10)       | 5.37 (4.75)| .100    | .088   | -.015 |
| Understanding           | 13.63 (7.65)  | 10.68 (8.25)      | 10.48 (7.61)| .376    | .410   | .024  |
| Object use              | 15.60 (4.80)  | 16.20 (4.94)      | 14.93 (4.85)| -.123   | .139   | .255  |

<sup>a</sup>Effect size based on Hedge’s g ≥ .20 is small, .50 is medium, and .80 is large.
Table 6
Pearson Partial Correlations of CSBS Behavior Sample Cluster Raw Scores Controlling for Maternal Education and Behavior Sample Age (N = 364)

<table>
<thead>
<tr>
<th>Behavior Sample Cluster</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Emotion and eye gaze</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Communication</td>
<td>.675**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Gestures</td>
<td>.622**</td>
<td>.773**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Sounds</td>
<td>.470**</td>
<td>.650**</td>
<td>.629**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Words</td>
<td>.436**</td>
<td>.566**</td>
<td>.559**</td>
<td>.753**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Understanding</td>
<td>.546**</td>
<td>.563**</td>
<td>.564**</td>
<td>.431**</td>
<td>.504**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Object use</td>
<td>.554**</td>
<td>.608**</td>
<td>.611**</td>
<td>.525**</td>
<td>.486**</td>
<td>.562**</td>
<td></td>
</tr>
</tbody>
</table>

** = significant at p = .001

Table 7
Group Comparisons of CSBS Behavior Sample Cluster Raw Scores Using Estimated Means Controlling for Maternal Education and Behavior Sample Age (N = 364)

<table>
<thead>
<tr>
<th>Behavior Sample Cluster</th>
<th>Non-Hispanic to non-Hispanic White</th>
<th>Non-Hispanic to Hispanic White</th>
<th>Non-Hispanic to Hispanic Black</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>F value</td>
<td>p&lt;sup&gt;a&lt;/sup&gt;</td>
<td>g&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Emotion and eye gaze</td>
<td>1.58</td>
<td>.077</td>
<td>.242</td>
</tr>
<tr>
<td>Communication</td>
<td>1.36</td>
<td>.110</td>
<td>.222</td>
</tr>
<tr>
<td>Gestures</td>
<td>1.25</td>
<td>.121</td>
<td>.204</td>
</tr>
<tr>
<td>Sounds</td>
<td>0.10</td>
<td>.705</td>
<td>.044</td>
</tr>
<tr>
<td>Words</td>
<td>1.27</td>
<td>.146</td>
<td>.149</td>
</tr>
<tr>
<td>Understanding</td>
<td>7.69**</td>
<td>.002</td>
<td>.401</td>
</tr>
<tr>
<td>Object use</td>
<td>0.30</td>
<td>.559</td>
<td>-.078</td>
</tr>
</tbody>
</table>

* = significant at p = .05, ** = significant at p = .001, * = based on post-hoc Bonferroni comparisons.
<sup>a</sup>Effect size based on Hedge’s g ≥ .20 is small, .50 is medium, and .80 is large.
Figure 1
Mean CSBS Behavior Sample Cluster Raw Scores for Children with ASD Using Estimated Means Controlling for Maternal Education and Behavior Sample Age
Figure 2
Mean CSBS Behavior Sample Cluster Raw Scores for Children without ASD Using Estimated Means Controlling for Maternal Education and Behavior Sample Age
Group Differences on Measure of Autism Red flags

A 2 (diagnostic classification) × 3 (race/ethnicity) between-subjects analysis of variance was conducted to detect group differences in parent report of autism red flags based on the ESAC. There were 37 children (16 non-Hispanic White, 15 non-Hispanic Black, 4 Hispanic White) whose caregiver did not complete an ESAC of the total sample of 364 children, therefore for this analysis \( n = 327 \). Skewness (.367) and kurtosis (-.668) values for the ESAC indicate a normal distribution. No outliers were detected at \( \alpha = .001 \). IBM SPSS UNIANOVA was used to calculate main effects and post hoc contrasts using a Bonferroni correction to reduce chances for Type 1 error. As expected, a significant group difference was observed on the total score of the ESAC for children with ASD compared to children without ASD, \( F(1, 321) = 64.31, p < .001 \). Additionally there was a significant main effect observed for race/ethnicity, \( F(2, 321) = 7.67, p = .001 \). No significant group differences were observed for the interaction between diagnostic classification of ASD or non-ASD and race/ethnicity, \( F(2, 321) = 1.88, p = .155 \). Post hoc contrasts revealed significant differences between non-Hispanic White children and non-Hispanic Black children, \( p = .026 \), and between non-Hispanic White children and Hispanic White children, \( p < .001 \), but not between non-Hispanic Black children and Hispanic White children, \( p = .601 \).

To determine if this group difference among children from different race/ethnicity remains significant when controlling for maternal education and ESAC age, a 2 × 3 between-subjects analysis of covariance was performed on the ESAC score. IBM SPSS UNIANOVA was used again with the same IVs, diagnostic classification and race/ethnicity, and maternal education and ESAC ages were added as covariates. The observed group difference between ASD (Estimated Marginal \( M = 29.67, SD = 11.76 \)) and non-ASD (Estimated Marginal \( M = 32 \).
16.63, \( SD = 10.77 \) participants remained, \( F(1, 319) = 79.16, p < .001 \), with a large effect size, Hedge’s \( g = 1.15 \). When controlling for differences in maternal education and ESAC age, the main effect of race/ethnicity is only observed to be marginally significant, \( F(2, 319) = 2.95, p = .054 \). Estimated marginal means and standard deviations as well as effect sizes for each racial/ethnic category are reported in Table 8. Although the omnibus test was observed to be only marginally significant, there are medium effect sizes for the differences between scores on the ESAC in the non-ASD group for non-Hispanic White children compared to non-Hispanic Black children, \( g = -.668 \), and for non-Hispanic Black children compared to Hispanic White children, \( g = .485 \). The ESAC scores of the non-ASD non-Hispanic Black participants were significantly higher than the scores of the other two non-ASD groups. As expected, the observed interaction between diagnostic classification and race/ethnicity continued to be nonsignificant, \( F(2, 319) = 1.68, p = .189 \).

**Table 8**
Descriptive Statistics of ESAC Scores Using Estimated Means Controlling for Maternal Education and ESAC Age

<table>
<thead>
<tr>
<th></th>
<th>ASD (( n = 176 ))</th>
<th>Non-ASD (( n = 151 ))</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>non-Hispanic White</td>
<td>non-Hispanic Black</td>
</tr>
<tr>
<td></td>
<td>( n = 109 )</td>
<td>( n = 28 )</td>
</tr>
<tr>
<td>ESAC ( M (SD) )</td>
<td>28.37 (12.05)</td>
<td>29.58 (10.65)</td>
</tr>
<tr>
<td>Hedge’s ( g^a )</td>
<td>-.102</td>
<td>-.225</td>
</tr>
<tr>
<td></td>
<td>nW-nB</td>
<td>nW-HW</td>
</tr>
<tr>
<td>ESAC ( M (SD) )</td>
<td>14.11 (9.95)</td>
<td>20.57 (8.27)</td>
</tr>
<tr>
<td>Hedge’s ( g^a )</td>
<td>-.668</td>
<td>-.102</td>
</tr>
</tbody>
</table>

\( ^a \) Effect size based on Hedge’s \( g \geq .20 \) is small, \(.50 \) is medium, and \(.80 \) is large.
Relationships among Maternal Education, Age, and Measures

Pearson product moment correlations were used to observe the relationships among age at the time of the Behavior Sample, cluster scores on the Behavior Sample, ESAC age, ESAC score, and maternal education level (See Table 9). Small, significant correlations were observed between Behavior Sample age and the clusters of sound, \( r = .137, p = .009 \) and words, \( r = .196, p < .001 \). Small significant correlations were observed between maternal education and gesture, \( r = .103, p = .049 \) sounds, \( r = .143, p = .006 \) words, \( r = .133, p = .011 \) understanding, \( r = .174, p = .001 \) and ESAC scores \( r = -.244, p < .001 \).

Table 9
Pearson Product Moment Correlations

<table>
<thead>
<tr>
<th>Score</th>
<th>Age in months</th>
<th>Maternal Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavior Sample Cluster</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotion and Eye Gaze</td>
<td>-.012</td>
<td>-.040</td>
</tr>
<tr>
<td>Communication</td>
<td>.006</td>
<td>.056</td>
</tr>
<tr>
<td>Gestures</td>
<td>-.044</td>
<td>.103*</td>
</tr>
<tr>
<td>Sounds</td>
<td>.137**</td>
<td>.143**</td>
</tr>
<tr>
<td>Words</td>
<td>.196**</td>
<td>.133*</td>
</tr>
<tr>
<td>Understanding</td>
<td>-.031</td>
<td>.174**</td>
</tr>
<tr>
<td>Object Use</td>
<td>.000</td>
<td>.064</td>
</tr>
<tr>
<td>ESAC Score</td>
<td>.085</td>
<td>-.244**</td>
</tr>
</tbody>
</table>

Using Pearson partial correlations controlling for Behavior Sample age, ESAC age, and maternal education, a large, negative significant correlation was observed between ESAC scores and total Behavior Sample scores, \( r = -.567, p < .001 \). Medium to large negative significant
correlations were also observed for ESAC scores and Behavior Sample social, \( r = -.526, p < .001 \), speech, \( r = -.385, p < .001 \), and symbolic, \( r = -.567, p < .001 \), composites. Additional Pearson product moment correlations revealed small to medium negative correlations between maternal education and ESAC age, \( r = -.217, p < .001 \), and Behavior Sample age, \( r = -.324, p < .001 \).
CHAPTER FOUR

DISCUSSION

Summary of Findings

This study examined the effects of race and ethnicity on early observed social communication and reported autism red flags in young toddlers with and without ASD. The results of this study suggest that the patterns of social communication deficits and autism red flags seen in children with ASD are consistent across race and ethnicity. No significant interaction effects for diagnostic classification and race/ethnicity were observed for the clusters of the CSBS Behavior Sample or for parent report of autism red flags using the ESAC. There were significant group differences between toddlers with and without ASD on both the observed measure of social communication and parent-report measure of autism red flags. Specifically, children with ASD scored significantly lower on all seven cluster scores of the Behavior Sample and parents of children with ASD reported significantly higher levels of autism red flags.

Significant differences in maternal education level were observed across race/ethnicity for children without ASD. For the non-ASD groups, non-Hispanic White mothers had significantly more years of education than mothers in both other groups, and non-Hispanic Black mothers had significantly more years of education than Hispanic White mothers. This observed difference represents a bias in our sample of children without ASD, yet reflects the racial/ethnic educational disparity in the US. According to the U.S. Census (2010), 30.3% of non-Hispanic White adults have graduated from college compared to only 19.8% of non-Hispanic Black and 13.9% of Hispanic White adults. In contrast, no significant differences in maternal education
were observed for toddlers with ASD, which could indicate an underrepresentation of non-Hispanic Black and Hispanic White participants with less education in the ASD sample.

Differences related to race/ethnicity were only observed in one cluster of the CSBS Behavior Sample: understanding. This cluster measures a child’s response to instructions to identify common objects (i.e., bowl, cup, spoon, bottle), familiar people, and body parts (e.g., nose, eyes, mouth). Non-Hispanic White children were observed to score significantly higher on this cluster than non-Hispanic Black children and Hispanic White children. This pattern of performance on the Behavior Sample was the same for both children with and without ASD, even when controlling for differences in age and maternal education. The difference in understanding could reflect group differences in cognitive functioning, given previous findings that observed a strong correlation between the understanding cluster of the Behavior Sample and nonverbal developmental level (Wetherby, Watt, Shumway, & Morgan, 2007). Alternatively, this difference could reflect a cultural difference in responding to requests to point to or show objects or body parts (Anderson, 1996; Hurtado, Marchman, & Fernald, 2007; Peña, Quinn, & Iglesias, 1992). The finding that both non-Hispanic Black and Hispanic White children performed lower on this understanding cluster suggests that this difference is not likely due to a language difference, as might be expected in the Hispanic White participants, but may reflect a broader cultural difference, such as limited experience with the nature of the task.

Significant group differences in parent report of autism red flags measured by the ESAC were found for diagnostic classification and also for race/ethnicity. However, the relationship between race/ethnicity and ESAC scores was observed to be only marginally significant when controlling for age and maternal education. A small, significant negative correlation was observed between maternal education and ESAC scores and a medium, negative significant
correlation was observed between maternal education and ESAC age. These results suggest that children whose mothers had fewer years of education reported more autism red flags, which may reflect that these children do not get referred until the red flags are more obvious and may contribute to later diagnosis.

A large, negative correlation was observed between the CSBS and the ESAC. In other words, children with lower social communication scores based on observation during the CSBS had higher parent report of autism red flags and vice versa. These findings indicate good agreement between the observed and parent report measures. Taken together, the results of this study suggest that the use of the CSBS Behavior Sample and ESAC could be instrumental in finding young toddlers with ASD across race/ethnicity.

**Strengths of Current Study**

Strengths of the current study include a relatively large sample of young toddlers from three racial/ethnic groups with ASD confirmed or ruled out. The sample size was sufficient to allow for separation into six groups, with analysis of group differences based on diagnostic classification, racial/ethnic categories, and level of maternal education. The sample for this study included children from multiple counties in both northern and southern regions of the state of Florida and was more diverse than most studies comparing toddlers with and without ASD. Because the racial/ethnic groups differed in Behavior Sample age and maternal education, we controlled for these variables in subsequent analyses. For Hispanic White participants recruited in south Florida, all assessments were administered in the families’ primary language, which was Spanish. In the north Florida assessments, bilingual clinicians or interpreters were available for Spanish-speaking families if requested.
An additional strength of the current study was the measures used. Both a standardized observational measure and a parent report measure were used to assess social communication and autism red flags. Rather than looking only at developmental level and language abilities, the CSBS Behavior Sample allowed us to examine potential differences across six domains of social communication, one of the two core domains of ASD in the recently released DSM-5 criteria (APA, 2013). The Behavior Sample is also an interactive measure that incorporates social communication among the child and both an examiner and parent and provides naturalistic communication temptations rather than direct questioning. These are characteristics of assessments that have been found to be beneficial for Spanish-speaking children (Anderson, 1996; Peña, Quinn, & Iglesias, 1992) and may also benefit children from other cultural groups who may have limited experience with testing situations. The ESAC included questions that covered both core domains in the DSM-5 criteria for ASD.

Finally, red flags for ASD were detected at a very young age in this study, as all of the toddlers in this study were screened between 18 and 36 months of age. In their 2002 study, Mandell and colleagues found that the average age of diagnosis for Black children was 7.9 years, while our non-Hispanic Black participants were screened at an average age of 20.7 months. Despite the Hispanic White children being screened at a significantly older age than non-Hispanic White and non-Hispanic Black participants, their mean age of screening was only 24.9 months.

**Limitations of Current Study**

This study has several limitations. First of all, while the ESAC has been translated into Spanish, it has not been field-tested with a Hispanic population. Secondly, the ESAC, which relies on parent report of autism red flags, was the only measure of autism red flags used.
Potential differences in autism symptomatology in young toddlers should also be examined using measures from systematic observation, such as through administration of the ADOS. Additionally, the CSBS Behavior Sample is only normed up to 24 months of age, so raw scores rather than standard scores were used for all analyses. Children older than 24 months of age, especially in the non-ASD group, may have hit a ceiling of performance on some of the clusters of the Behavior Sample. There may be a ceiling effect evident by higher scores and slightly smaller standard deviations for the emotion and eye gaze, communication, and object use clusters in the non-ASD groups. Furthermore, in the north Florida assessments, although bilingual clinicians or interpreters were available for Spanish-speaking families if requested, families may have been reluctant to ask for or indicate the need for an interpreter.

Another important limitation of this study is the division of groups by reported race and ethnicity. Although separating groups by race and ethnicity mirrors Census categories and other classification systems, racial or ethnic membership does not equate with culture (Betancourt & Lopez, 1993). In order to fully examine the effects of a family’s culture on a child’s social communication development, further information is needed regarding the family’s level of acculturation with the mainstream culture, language or dialect use at home, and the family’s self-identified beliefs and values. Future studies need to examine these variables in relationship to the CSBS Behavior Sample to determine the relationships between cultural factors and social communication development.

**Clinical Implications**

Because the diversity of the US population is increasing, the need for communication assessments that are culturally sensitive and account for potential cultural, racial, or ethnic differences is also increasing. Reducing health disparities across SES and racial/ethnic
categories is a national priority. The U.S. Department of Health and Human Services (2011) has created an action plan to reduce the effects of racial and ethnic disparities in health care, and have included early childhood development as one of its priorities. It is crucial for clinicians to be able to differentiate cultural differences from communication disorders, including ASD. This study did not find an interaction between diagnostic classification and race/ethnicity. For example, racial/ethnic differences in understanding were noted in both children with and without ASD and no other significant differences were found. These results support the use of the CSBS Behavior Sample across racial/ethnic groups, given the similarities in performance across six of the seven cluster scores. The strong relationship between the CSBS and the ESAC supports the clinical utility of both of these measures with diverse families.

The results of the current study are consistent with Tek and Landa’s (2012) findings that minority toddlers with ASD were observed to perform lower on a behavioral measure of receptive language. While Roberts and colleagues (1997) did not observe differences in African American children’s performance on the CSBS Behavior Sample cluster scores compared to the standardization sample, the current study did find differences in both ASD and non-ASD groups for the understanding cluster. However, the lack of significant differences across race/ethnicity for the other six cluster scores supports the findings of this earlier study and suggests that the CSBS Behavior Sample can be useful for detecting social communication delays in a diverse sample. The current sample of participants was older than the sample recruited for their study and their sample consisted of only typically developing children.

The finding that children in the non-Hispanic Black and Hispanic White groups were observed to perform lower on the understanding cluster of the CSBS than non-Hispanic White toddlers has important potential clinical implications. Watt, Wetherby, and Shumway (2006)
found that the understanding cluster of the Behavior Sample, which is a measure of comprehension of spoken words, measured in the second year of life significantly predicted measures of both receptive and expressive language concurrently and a year later. While lower scores on understanding may reflect cultural differences or limited experience with listening tasks, an early delay in this area could have consequences for later language and literacy development, as seen in previous research (Hart & Risley, 1995; Hoff, 2003; Qi, Kaiser, Marley, & Milan, 2012). While there is an ongoing debate among researchers on the distinctions between communication deficits due to a disorder or differences due to culture, Hoff (2013) has proposed that the criterion for interpretation of a difference in performance as a deficit be pragmatic in nature, such that any differences which may lead to negative effects on future success be considered deficits and thus targets for intervention. This perspective underscores the importance of early detection of ASD and other communication disorders. Social communication assessment using systematic observation with naturalistic procedures may be instrumental in improving detection of these early differences thus leading to earlier access to intervention.

**Future Directions**

Further research is needed in this area of study in order to improve early detection of communication disorders including ASD across an increasingly diverse population of young children. As ASD is detected at younger ages and research continues to improve diagnostic accuracy, we need to ensure that all toddlers, regardless of culture, race, or ethnicity, have equal access to early diagnosis and early intervention. Future research directions should include examining the barriers to detection of ASD across culture/race/ethnicity and investigating strategies to improve screening in diverse populations. Additional research is also needed to
further investigate racial/ethnic differences in the early development of comprehension skills. Whether this observed difference is due to the task of being asked to give, point to, or show the examiner an object, body part, or person, or to an actual lack of understanding of the words needs to be further explored. Additionally, the relationship between maternal language use and exposure to vocabulary needs to be examined in relation to this difference. While this study revealed only marginal differences in autism red flags across race/ethnicity based on a parent report measure, further investigation of potential differences in autism symptoms across race/ethnicity is needed, including research on observed symptoms in addition to parent report measures. Additionally, early intervention research is needed in order to determine culturally appropriate strategies for maximizing outcomes in children from diverse cultures.

Conclusions

The current study adds to an emerging body of research examining differences across race/ethnicity in young toddlers with and without ASD. Social communication and red flags of ASD were studied in a large, sample of toddlers with ASD. A strong relationship was found between observed and parent report measures and these measures were able to identify children from diverse backgrounds at a young age. Results of this study indicate that on most measures there were not differences across race/ethnicity. Specifically, there was not an interaction between diagnostic classification and race/ethnicity. However, non-Hispanic Black and Hispanic White children were observed to perform lower than non-Hispanic White children on measures of understanding, even when controlling for age and maternal education. Racial/ethnic differences in parent report of autism red flags were only marginally significant, but further research is needed to determine potential differences in the presentation of early red flags for ASD across race/ethnicity. As clinicians are seeing a more diverse sample of children, they need
to consider potential differences that may reflect cultural diversity. Findings from this study contribute to the understanding of social communication and autism red flags of young toddlers from diverse racial/ethnic backgrounds. Using the CSBS Behavior Sample and the ESAC, differences between children with and without ASD were evident at a very young age across race/ethnicity, indicating that these tools may be fruitful to identify ASD earlier in diverse populations. Given the growing diversity in the US, racial/ethnic disparities in the provision of services for young toddlers with ASD will be an increasing public health challenge. This improved knowledge about the social communication profile of ASD and early autism red flags will aid in improved early detection and access to earlier intervention for ASD, which may reduce health disparities.
APPENDIX A

HUMAN SUBJECTS APPROVAL

Office of the Vice President For Research
Human Subjects Committee
Tallahassee, Florida 32306-2742

APPROVAL MEMORANDUM

Date: 04/24/2013
To: Sherr Stromich
Address: [Redacted]
Dept.: COMMUNICATION DISORDERS
From: Thomas L. Jacobson, Chair
Re: Use of Human Subjects in Research
Social communication profiles of soldiers with and without autism spectrum disorder from three racial/ethnic groups

The application that you submitted to this office in regard to the use of human subjects in the research proposal referenced above has been reviewed by the Human Subjects Committee at its meeting on 04/10/2013.

Your project was approved by the Committee.

The Human Subjects Committee has not evaluated your proposal for scientific merit, except to weigh the risk to the human participants and the aspects of the proposal related to potential risk and benefit. This approval does not replace any departmental or other approvals which may be required.

If you submitted a proposed consent form with your application, the approved stamped consent form is attached to this approval notice. Only the stamped version of the consent form may be used in recruiting research subjects.

If the project has not been completed by 04/09/2014, you must request a renewal of approval for continuation of the project. As a courtesy, a renewal notice will be sent to you prior to your expiration date, however, it is your responsibility as the Principal Investigator to timely request renewal of your approval from the Committee.

You are advised that any change in protocol for this project must be reviewed and approved by the Committee prior to implementation of the proposed change in the protocol. A protocol change/amendment form is required to be submitted for approval by the Committee. In addition, federal regulations require that the Principal Investigator promptly report, in writing, any unanticipated problems or adverse events involving risks to research subjects or others.

By copy of this memorandum, the chairman of your department and/or your major professor is reminded that he/she is responsible for being informed concerning research projects involving human subjects in the department, and should review protocols as often as needed to assure that the project is being conducted in compliance with our institution and with DHEHS regulations.

This institution has an Assurance on file with the Office for Human Research Protection. The Assurance Number is IRB00000446.

Cc: Amy Wetherby, [Redacted], Advisor
HSC No. 2013.10179

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APPENDIX B

PARENT PERMISSION FORM

The FIRST WORDS® Project is a federally-funded research study of early communication development in young children. We are interested in studying both children with typical development and children whose families have concerns about their child’s development. The Early Screening for Autism and Communication Disorders (ESAC) is used as the first step in screening for autism and communication delays to decide if a communication evaluation is needed. Communication skills include looking and smiling at people, using gestures, sounds or words, understanding others, and playing. When a child has difficulties with these skills, they may have autism spectrum disorder. The American Academy of Pediatrics recommends that all children be screened for autism at 18 months of age. For some children the problems can be very mild, and for others they can be more noticeable. We want to be able to find these problems early so that we can help parents when their children are still very young.

The FIRST WORDS Project will send you a report to tell you how your child did on the ESAC. If your child is not developing as expected for his/her age based on the information that you provide on the ESAC, we will ask you to bring your child for a communication evaluation at no charge. However, you are under no obligation to provide any further information or have your child evaluated. We are also asking you to complete the attached Child and Family Information Form so that we can contact you if an evaluation is needed and so we have background information about you and your child for our research. In order to estimate the percentage of young children with autism spectrum and communication disorders born in the panhandle of Florida, we will be gathering information from your child’s birth certificate records obtained from the Florida Department of Health.

The information you provide may help your child access early intervention services and will help us identify other children with autism and communication problems earlier. Please be assured that the names of all children and families participating in the FIRST WORDS Project will be kept strictly confidential to the extent allowed by law.

By signing this permission form you are indicating that you have read this form and agree to have the information that you provide about your child and family included in this research project. If you have any questions about this study, please don’t hesitate to call the FIRST WORDS Project at [Contact Information]. If you have any questions about your participation in this research, you can also contact the Chair of the FSU Human Subjects Committee, Institutional Review Board at [Contact Information].

I, ________________________________, as legal guardian of ________________________________, have read this form and give my permission for my child to be included in this research study.

________________________________________________________________________________________

Signature of Parent or Legal Guardian

Today’s Date: ______/_______/_______

Month Day Year

[Contact Information]

Tallahassee, Florida 32303

Fax [Contact Information]

FSU Human Subjects Committee Approved on 9/14/2012. Void after 9/11/2013. HSC # 2012.8878
APPENDIX C

AGREEMENTS TO PARTICIPATE IN A CLINICAL RESEARCH STUDY

FLORIDA STATE UNIVERSITY

The College of Medicine

FIRST WORDS® Project
Providing Early Identification & Referral for Families of Infants & Toddlers with Communication Delays

AGREEMENT TO PARTICIPATE IN A CLINICAL RESEARCH STUDY

Project Title: FIRST WORDS Project: Early Identification of Speech, Language, Communication, and Autism Spectrum Disorders

Principal Investigator: Amy M. Wetherby, Ph.D., CCC-SLP

Your child is being asked to participate in a research project as described in this form below. All such research projects carried out at the University are governed by the rules of both the federal government and Florida State University. These rules require that you give your signed agreement for your child to participate in this project.

The research staff who will evaluate your child will explain to you, in detail, the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask any questions you have to help you understand the project. A basic explanation of the project is written below. Please read this explanation and discuss with the research staff any questions you might have.

If you then decide that your child may participate in the project, please sign this form in the presence of the person who explained the project to you. You will be given a copy of this form to keep.

1. Nature and Purpose of the Project: The purpose of this study is to determine if communication disorders can be identified in very young children who demonstrate delays in early communication development. Being late in talking is often the first symptom evident to parents and professionals of children with communication disorders. Because children usually begin acquiring words between 12 and 18 months of age, a child may not be referred for a language delay until at best 20 to 24 months, but more typically, after 30 months. This longitudinal study of communication development in infants and toddlers will provide information on the predictive value of our checklist and early measures of social communication and play development in relation to performance on follow-up evaluations. We hope that this research project will help to develop better tools to guide referrals of children at risk for speech, language, communication, autism spectrum, and other developmental disorders at earlier ages. Early identification may lead to earlier treatment and support for children and families, which would have a positive effect on a children’s development.

2. Explanation of Procedures: You and your child will be asked to participate in a number of procedures as part of this project. We will be giving you a questionnaire to complete to provide information about how your child communicates and plays with objects. Your child will participate in an evaluation lasting approximately 30-40 minutes. Activities during the session include standard assessment procedures for young children to measure eye gaze, gestures, sounds, words, understanding, and play. This involves the presentation of toys and interesting materials to encourage our child to communicate and simple instructions. We will ask your permission to videotape the evaluation session to help us score behavior accurately. We will give you a summary of the results of this evaluation. If your child shows any red flags of autism spectrum disorders, we will invite you for a diagnostic evaluation to identify or rule-out autism spectrum. We may ask you to return to for a follow-up evaluation in 3 to 6 months in order to follow the

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development of your child. However, the diagnostic evaluation for autism and the follow-up visit are optional, and you can decide to refuse at a later time. We will save the videotape of this evaluation session so we can continue to study precise measures of social communication and play of your child over the course of this longitudinal project. Because this study is exploratory in nature, research staff may review your child’s videotape at a later time to rate more precise measures of social communication and play. Your child’s scores on questionnaires and ratings of the videotape will become part of the FIRST WORDS Project database and may be used to study early indicators of typical development and communication delays.

3. **Discomforts and Risks:** All of the procedures to be used are commonly used with young children one to two years of age. Therefore, they do not involve activities that would cause discomfort to your child or put your child at any risk. However, if your child should become upset for any reason, the evaluation will be stopped, and rescheduled with your permission.

4. **Benefits:** You and your child may benefit from involvement in this project in a number of ways. First, we will provide you with information about your child’s social communication and play development. Second, the results of this study will provide information for professionals regarding patterns of early communication development, which will help with the early identification of communication delays in children. This information should lead to earlier and more appropriate services to young children and their families.

5. **Confidentiality:** All records relating to this project will be handled and safeguarded according to standard clinical policy for all patient records and will remain confidential to the extent allowed by law. Any research reports will carry no identifying information of individual children or families.

6. **Refusal/Withdrawal:** At any time during your participation in this study, you will have the opportunity to refuse to participate in any procedures or withdraw from the study at any time without prejudice or effect on you and your child. If you would like to remove your child’s records from the research database at any time in the future, call the project at [phone number] to let us know.

7. **Risks:** We do not expect any unusual risks as a direct result of participation in this project, since all testing procedures are part of standard routine clinical test batteries.

8. **Videotaping:** You and your child will be videotaped by the clinician during the evaluation session. These videotapes will be kept by project staff in a locked room and will be saved indefinitely. These videotapes will be accessible only to research staff, unless otherwise specified by you. We may ask your permission to use segments of these videotapes for educational purposes; however, this is optional.

I acknowledge that I have read and fully understand the above explanation of the project, all of my questions have been satisfactorily answered, and I give permission for my child to participate in this research project. If I have any questions about my rights as a participant in this research, or if I feel I have been placed at risk, I can contact the chair of the human subjects committee, institutional review board, through the vice president for the office of research at [phone number].

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Signature of Parent Date

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ACUERDO PARA PARTICIPAR EN UN ESTUDIO DE INVESTIGACIÓN CLÍNICA

Título del Proyecto: Proyecto FIRST WORDS [Primero Palabras]: Identificación Temprana del Habla, Lenguaje, Comunicación y Trastornos del Espectro del Autismo.

Investigador Principal: Amy M. Wetherby, Ph.D., CCC-SLP [NOMBRE CUKED]

Su niño está siendo llamado a participar en un proyecto de investigación en la forma en que se describe a continuación en este formulario. Todo este tipo de proyectos se llevan a cabo en la Universidad, están regidos por los reglamentos tanto del Gobierno Federal como los de la Universidad del Estado de la Florida. Estos reglamentos exigen que usted otorgue su consentimiento firmado para que su niño pueda participar en el proyecto.

El personal de investigación que va a evaluar a su niño le explicará a usted, en detalle, el propósito del proyecto, los procedimientos a ser usados y los beneficios potenciales y posibles riesgos de la participación. Usted podrá formular cualquier pregunta que le ayude a entender el proyecto. Más adelante le ofrecemos una explicación básica del proyecto. Por favor lea esta explicación y discuta con el personal de investigación cualquier pregunta que pudiera tener.

Si usted decide entonces que su niño puede participar en el proyecto, por favor firme este formulario en presencia de la persona que le explicó el proyecto. Usted recibirá una copia de este formulario para sus archivos.

1. Naturaleza y Propósito del Proyecto: El propósito de este estudio es el de determinar si los trastornos de comunicación pueden ser identificados en niños muy pequeños que demuestran retrasos en el desarrollo temprano de la comunicación. La tardanza en empezar a hablar es con frecuencia el primer síntoma evidente para los padres y profesionales de niños que tienen trastornos de comunicación. Dado que los niños generalmente comienzan a adquirir vocabulario entre los 12 y 18 meses de edad, un niño podría no ser referido por su retraso de lenguaje hasta los 20 o 24 meses en el mejor de los casos; sin embargo lo más común es que sea después de los 30 meses. Este estudio longitudinal de desarrollo de comunicación en niños y niños proporcionará información sobre el valor de predicción de nuestra lista de verificación y de medidas tempranas de comunicación social y desarrollo de juegos en relación con la actuación en evaluaciones de seguimiento. Esperamos que este proyecto de investigación ayude a desarrollar mejores herramientas para orientar en la referencia de niños con retraso de habla, lenguaje, comunicación, espectro del autismo y otros trastornos de desarrollo en edades más tempranas. La identificación temprana podría llevar a tratamiento y soporte más temprano para los niños y sus familias, lo cual tendría un efecto positivo en el desarrollo de los niños.

2. Explicación de los Procedimientos: A usted y a su niño se les pedirá que participen en varios procedimientos como parte del proyecto. Nosotros le proporcionaremos un cuestionario para completar y proporcionar información acerca de cómo su niño se comunica y juega con objetos. Su niño participará en una evaluación que tomará aproximadamente de 30 a 40 minutos. En esta sesión las actividades incluyen procedimientos estándar de evaluación para niños pequeños, a fin de medir el enfoque visual, los gestos, sonidos, palabras, comprensión y juego. Esto implica la presentación de juguetes y materiales de interés para incentivar al niño a comunicarse y la presentación de instrucciones simples. Nosotros le pediremos autorización para grabar la sesión de evaluación en un video, a fin de ayudarnos a calificar el comportamiento acertadamente. Le daremos un resumen de los resultados de la evaluación. Si su niño presenta alguna alerta de trastornos de espectro del autismo.
nosotros le invitaremos a una evaluación de diagnóstico para identificar o descartar el espectro del autismo. Nosotros podríamos pedirle que regrese para una evaluación de seguimiento a los 3 o 6 meses, a fin de darle seguimiento al desarrollo de su niño. Si embargo, la evaluación de diagnóstico para autismo y la visita de seguimiento son opcionales y usted puede decidir rehusarlas más adelante. Nosotros guardaremos el video de esta sesión de evaluación a fin de continuar estudiando las medidas precisas de comunicación social y juego de su niño en el transcurso de este proyecto longitudinal. Dado que este estudio es de naturaleza exploratoria, es posible que el personal de investigación revise la grabación de su niño más tarde para calificar medidas más precisas de comunicación social y de juego. Las calificaciones de su niño en el cuestionario y clasificación del video serán parte de la base de datos del Proyecto FIRST WORDS y podrán ser utilizadas para estudiar indicadores tempranos de desarrollo típico y retrasos de comunicación.

3. Incomodidades y Riesgos: Todos los procedimientos que se van a utilizar son usados generalmente con niños pequeños de uno a dos años de edad. Por lo tanto, estos no incluyen actividades que pudieran causar incomodidad o poner a su niño bajo ningún tipo de riesgo. Sin embargo, si su niño se sintiera molesto por alguna razón, la evaluación será suspendida y reprogramada con su permiso.

4. Beneficios: Usted y su niño podrían beneficiarse por su participación en este proyecto de varias maneras. Primero, nosotros le daremos información acerca del desarrollo de la comunicación social y de juego de su niño. Segundo, los resultados de este estudio ofrecerán información para profesionales en relación a los patrones de desarrollo temprano de la comunicación, lo cual ayudará a la identificación temprana de los retrasos de comunicación en los niños. Esta información conllevará el prestar servicios más tempranos y apropiados a niños pequeños y sus familias.

5. Confidencialidad: Todos los registros relacionados con este proyecto serán manejados y resguardados de conformidad con las normas clínicas estándares para todos los registros de pacientes y se mantendrán en confidencialidad en la medida en que lo permita la ley. Los reportes de investigación no contendrán información que identifique a los niños, o a sus familias.

6. Rechazo/ Retiro: En cualquier momento durante su participación en este estudio, usted tendrá la oportunidad de rehusarse a participar en cualquiera de los procedimientos, o de retirarse del estudio en cualquier momento, sin prejuicio o efecto sobre usted y su niño. Si usted quisiera retirar los registros de su niño de la base de datos de la investigación en cualquier momento en el futuro, llame al proyecto: [Número de contacto] y háganoslo saber.

7. Riesgos: Nosotros no anticipamos ningún riesgo inusual como resultado directo de la participación en este proyecto, ya que todos los procedimientos de prueba son parte del grupo de pruebas clínicas estándar de rutina.

8. Grabaciones de video: Usted y su niño serán video-grabados por el clínico durante la sesión de evaluación. El personal del proyecto mantendrá las grabaciones en un salón bajo llave y se guardarán indefinidamente. Estas grabaciones solo estarán accesibles para el personal de investigación, a menos que usted especifique lo contrario. Nosotros podríamos pedir su autorización para usar partes de estas grabaciones con propósitos educativos, sin embargo esto es opcional.

Yo certifico que he leído y entiendo plenamente la explicación anterior del proyecto, que todas mis preguntas han sido contestadas satisfactoriamente y doy el permiso para que mi niño participe en este proyecto de investigación. Si tengo alguna pregunta acerca de mis derechos como participante en este proyecto, o si siento que he sido puesto en riesgo, yo puedo ponerme en contacto con el presidente del comité de sujetos humanos de la junta institucional de revisión, a través del vicepresidente para la oficina de investigación llamando al [Número de contacto].

Firma de Padre o Guardian Legal: [Firma]
Fecha de Hoy: [Mes] / [Día] / [Año]

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AGREEMENT TO PARTICIPATE IN A CLINICAL RESEARCH STUDY

Project Title: FIRST WORDS Project: Early Identification of Speech, Language, Communication, and Autism Spectrum Disorders

Principal Investigator: Amy M. Wetherby, Ph.D., CCC-SLP

Your child is being asked to participate in a follow-up research project as described in this form below. All such research projects carried out at the University are governed by the rules of both the federal government and Florida State University. These rules require that you give your signed agreement for your child to participate in this project.

The research staff who will evaluate your child will explain to you, in detail, the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask any questions you have to help you understand the project. A basic explanation of the project is written below. Please read this explanation and discuss with the research staff any questions you might have.

If you then decide that your child may participate in the project, please sign this form in the presence of the person who explained the project to you. You will be given a copy of this form to keep.

1. Nature and Purpose of the Project: The purpose of this study is to determine if communication disorders can be identified in very young children who demonstrate delays in early communication development. Being late in talking is often the first symptom evident to parents and professionals of children with communication disorders. Because children usually begin acquiring words between 12 and 18 months of age, a child may not be referred for a language delay until at best 20 to 24 months, but more typically, after 30 months. This longitudinal study of communication development in infants and toddlers will provide information on the predictive value of our checklist and early measures of social communication and play development in relation to performance on follow-up evaluations until 5 years of age. We hope that this research project will help to develop better tools to guide referrals of children at risk for speech, language, communication, autism spectrum, and other developmental disorders at earlier ages. This project will also help estimate the percentage of children born in the panhandle of Florida who have communication disorders. Early identification may lead to earlier treatment and support for children and families, which would have a positive effect on a children's development.

2. Explanation of Procedures: You and your child will be asked to participate in a number of procedures as part of this project. We will be giving you questionnaires to complete to provide information about your child's development and experience. Your child will participate in an evaluation lasting approximately 60-90 minutes scheduled on one or two days. Activities during the session include standard assessment procedures for young children to measure social communication, language, nonverbal cognitive and emergent literacy skills. This involves the presentation of toys and interesting materials to encourage our child to communicate and will require your child to follow instructions, repeat sounds and words, name pictures, rhyme, and answer questions. We will ask your permission to videotape the evaluation session to help us

[Contact Information]

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score behavior accurately. We will give you a summary of the results of this evaluation. If your child shows any red flags of autism spectrum disorders, we will invite you for a diagnostic evaluation to identify or rule-out autism spectrum. We may also ask your permission to send a videographer to your home to videotape you interacting with your child during everyday routines for about an hour. This will allow us to see how your child communicates and interacts at home compared to our clinical setting. We may ask you to return to for a follow-up evaluation in 6 to 12 months in order to follow the development of your child. However, the diagnostic evaluation for autism, home videotape, and follow-up evaluation are optional, and you can decide to refuse at a later time. We will save the videotape of this evaluation session and the home visit so we can continue to study precise measures of social communication and play of your child over the course of this longitudinal project. Because this study is exploratory in nature, research staff may review your child’s videotape at a later time to rate more precise measures of social communication and play. Your child’s scores on questionnaires, standardized tests, and ratings of the videotape will become part of the FIRST WORDS Project database and may be used to study early indicators of typical development and communication delays in relation to developmental outcomes.

3. Discomforts and Risks: All of the procedures to be used are commonly used with toddlers and preschool children. Therefore, they do not involve activities that would cause discomfort to your child or put your child at any risk. However, if your child should become upset for any reason, the evaluation will be stopped, and rescheduled with your permission.

4. Benefits: You and your child may benefit from involvement in this project in a number of ways. First, we will provide you with information about your child’s social communication and play development. Second, the results of this study will provide information for professionals regarding patterns of early communication development, which will help with the early identification of communication delays in children. This information should lead to earlier and more appropriate services to young children and their families.

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7. Risks: We do not expect any unusual risks as a direct result of participation in this project, since all testing procedures are part of standard routine clinical test batteries.

8. Videotaping: You and your child will be videotaped by the clinician during the evaluation session, and if you agree, during a home visit. These videotapes will be kept by project staff in a locked room and will be saved indefinitely. These videotapes will be accessible only to research staff, unless otherwise specified by you. We may ask your permission to use segments of these videotapes for educational purposes; however, this is optional.

I acknowledge that I have read and fully understand the above explanation of the project, all of my questions have been satisfactorily answered, and I give permission for my child to participate in this research project. If I have any questions about my rights as a participant in this research, or if I feel I have been placed at risk, I can contact the chair of the human subjects committee, institutional review board, through the vice president for the office of research at [redacted].

Signature of Parent Date

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AGREEMENT TO PARTICIPATE IN A CLINICAL RESEARCH STUDY

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Principal Investigator: Amy M. Wetherby, Ph.D., CCC-SLP

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Tallahassee, Florida 32303

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score behavior accurately. We will give you a summary of the results of this evaluation.

We will also be completing a standardized diagnostic measure to identify or rule-out autism spectrum disorder which lasts about an hour. We will ask your permission to send a videographer to your home to videotape you interacting with your child during everyday routines for about an hour. This will allow us to see how your child communicates and interacts at home compared to our clinical setting. The home observation is optional. We may ask you to return to for a follow-up evaluation in 6 to 12 months in order to follow the development of your child. The follow-up evaluation is optional, and you can decide to refuse at a later time. We will save the videotape of this evaluation session and the home visit so we can continue to study precise measures of social communication and play of your child over the course of this longitudinal project. Because this study is exploratory in nature, research staff may review your child’s videotape at a later time to rate more precise measures of social communication and play. Your child’s scores on questionnaires, standardized tests, and ratings of the videotape will become part of the FIRST WORDS Project database and may be used to study early indicators of typical development and communication delays in relation to developmental outcomes. If you choose to participate in the diagnostic evaluation for autism, information obtained about your child as part of this study will be shared with the National Institutes of Health National Database for Autism Research (NIH NDAR). The information will include standardized test scores, observation ratings, and information provided on questionnaires. The information will be available for researchers to use in research about autism and other social communication disorders to answer questions about etiology, diagnosis, development, and response to treatment. All personal details identifying you or your child will be removed before information becomes a part of this database. No video records will be provided to NDAR. **If you do not want you or your child’s research information to be used in this way, you should not participate in the diagnostic evaluation for autism.**

3. **Discomforts and Risks**: All of the procedures to be used are commonly used with toddlers and preschool children. Therefore, they do not involve activities that would cause discomfort to your child or put your child at any risk. However, if your child should become upset for any reason, the evaluation will be stopped, and rescheduled with your permission.

4. **Benefits**: You and your child may benefit from involvement in this project in a number of ways. First, we will provide you with information about your child’s social communication and play development. Second, the results of this study will provide information for professionals regarding patterns of early communication development, which will help with the early identification of communication delays in children. This information should lead to earlier and more appropriate services to young children and their families.

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Signature of Parent Date
APPENDIX D

INFORMED CONSENT

INFORMATION SHEET AND INFORMED CONSENT

Project Title:
FIRST WORDS Project: Early Social Communication Characteristics of Autism Spectrum Disorders in Diverse Cultures in the US and Africa

SPONSOR:
National Institutes of Health

Principal Investigator:
Amy M. Wetherby, Ph.D., Florida State University

Telephone Number: [redacted] or toll free [redacted]
Email: [redacted]

Co-Investigators:
Roy Richard Grinker, Ph.D., George Washington University
Nola J. Chambers, Ph.D., University of Witwatersrand, South Africa
Shuaib Kauchali, Ph.D., Department of Paediatrics and Child Health, Nelson R Mandela School of Medicine, University of Natal, South Africa

To the Participant: This consent form may contain words that you do not understand. Please ask the research assistant to explain any words or information that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

Tallahassee, Florida 32301
Tele: [redacted]  Fax: [redacted]

Hello, my name is _____________ (name of research assistant). We are doing research about communication skills in children between 18 and 36 months of age. In this study we want to learn about children's communication and what can go wrong in its development.

We are asking for your permission to include your child in this study. Your agreement is entirely up to you. I will explain to you, in detail, the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask any questions you have to help you understand the project. A description of the project is written below. Please read this description and let me know any questions you have. If you decide that your child may participate in the project, please sign this form. I will give you a copy of this form to keep.

**Purpose of the study.** The purpose of this study is to identify very young children who have social communication problems. These include difficulties looking and smiling at people, difficulties communicating with gestures, sounds or words, or difficulties playing like other children their age. When these problems all occur together, the condition is called an autism spectrum disorder. For some children these difficulties can be very mild, and for others they can be more noticeable. We would like to identify these difficulties early in development, between 18 months and 3 years old, so we can give the parents of affected children some help in teaching their children how to communicate better while they are still young. Some children who have good communication skills will also be asked to participate in this study so that they can be compared to children who are having difficulties in this area.

**Procedures.** This study is taking place in the US and South Africa. We hope to find at least 15 children with these problems and 15 children who are developing fine in both places. Families will be recruited from community clinics, local hospitals and child care centers in Immokalee. If you agree to be in this study, I will first ask you some questions about your child’s communication skills. This will take about 30 minutes. After you answer these questions, I would like to see how your child communicates at home. I would like to come to your home to take a video of your child communicating with you or other family members in your daily activities at home. I will also present some toys to see how your child plays with them and communicates with me. You or your child’s caregiver will be present the whole time and can be part of the video. The visit for the video will take about 1 hour.

After this visit to your home, we would like to do one more evaluation with your child here at your local hospital or clinic. This evaluation will be to determine if your child has an autism spectrum disorder or not. The evaluation will take about 1 hour and there will be toys to see how your child communicates and plays. There are no medical tests in this evaluation. If I identify any communication problems in your child, I will give you information about early intervention services in your community that your child may be eligible for. I will help to refer you for early intervention services if you are interested.

**Risks and benefits.** All of the procedures are commonly used with young children. Therefore, they do not involve activities that would cause discomfort to your child or put your child at any risk. However, if your child should become upset for any reason, the evaluation will be stopped, and rescheduled with your permission. You and your child may benefit by being in this project in a number of ways. First, we will provide you with information about your child’s social communication and play development. We will also refer you to other service providers in your community who will be able to help you. Second, the results of this study will provide information for professionals about patterns of early communication development, which will help with the early identification of communication delays in children. This information should lead to earlier and more appropriate services to young children and their families.

**Confidentiality.** All records relating to this project will remain confidential to the extent allowed by law. Any research reports will carry no identifying information of children or families.

Refusal/Withdrawal. Your decision to let your child be part of this study is completely up to you (i.e., voluntary). Deciding not to take part will in no way affect your child’s care at this hospital or clinic. At any time during your involvement in this study, you can decline to participate in any procedures or you can withdraw from the study altogether without prejudice or effect on you or your child. If you would like to remove your child’s records from the research database at any time in the future, call the project at [redacted] or [redacted] to let us know.

Videotaping. You and your child will be videotaped by the clinician during the evaluation session, and during the home visit. These videotapes will be kept by project staff in a locked room and will be saved indefinitely. Digital files of these videotapes will also be stored on a secure computer network that is encrypted and password protected. These videotapes or digital files of the videos will be accessible only to research staff, unless otherwise specified by you. We may ask your permission to use segments of these videotapes for educational purposes, however, this is optional. A copy of the videotape will also be viewed by research staff in the United States or Africa, but they will not be given your name or any other information that will identify you. These researchers will help us decide if your child has an autism spectrum disorder or not. Any information about your child’s development uncovered as a result of your participation in this study will be held in strict confidence. You will be informed of any findings of importance to your child but this information will not be disclosed to anyone else without your written permission.

Use of my child’s information. We will save the videotape of the evaluation session and the home visit so we can continue to study precise measures of social communication and play of your child over the course of this longitudinal project. Because this study is exploratory in nature, research staff may review your child’s videotape at a later time to rate more precise measures of social communication and play. Your child’s scores on questionnaires, standardized tests, and ratings of the videotape will become part of the FIRST WORDS Project database and may be used to study early signs of typical development and communication delays in relation to developmental outcomes. If you choose to participate in the diagnostic evaluation for autism spectrum disorder, information obtained about your child as part of this study will be shared with the National Institutes of Health National Database for Autism Research (NIH NDAR). The information will include standardized test scores, observation ratings, and information provided on questionnaires. The information will be available for researchers to use in research about autism and other social communication disorders to answer questions about the cause, diagnosis, development, and response to treatment. All personal details identifying you or your child will be removed before information becomes a part of this database. No video records will be provided to NDAR. If you agree to be in this study, that means that your child’s research information will be used in this way. If you change your mind later, we can ask to remove your child’s data from NDAR. However, NDAR cannot get back information that was shared before you changed your mind.

Reimbursement for the study. You will receive a $50 gift card after completing each of the three measures: 1) for answering questions during the first interview about your child’s communication, interests, and activities; 2) for the home visit; and 3) for participation in the evaluation session at the local clinic. This is to thank you for your time and to help if you need to get a babysitter or with travel costs to our clinic. You will receive the $50 gift card for each measure you complete, even if you do not complete all three. You will get gift cards totaling $150 if you participate in all three measures.

Problems or Questions. Further information about this study may be obtained from Dr. Amy Wetherby by phone at [redacted] or toll free at [redacted] or by email at [redacted]. If you have any questions about your rights as a participant in this research, or if you feel you have been placed at risk, you can contact the chair of the human subjects committee, institutional review board, through the vice president for the Office of Research at Florida State University at [redacted].

Informed Consent for Parents / Legal Guardians: I have read and fully understand the above description of the project, all of my questions have been answered, and I give permission for my child to participate in this research project.

I understand that if I participate in this study:

☐ I will be asked questions about my child’s communication, interests, and activities.

☐ A video will be made of my child interacting with me at home to see how my child communicates.

☐ My child will be evaluated at a clinic to test for autism spectrum disorder. I will be with my child and a video will be made of this evaluation.

☐ I will be given a $50 gift card for each measure completed with my child.

☐ The information I provide may help my child and other children get services earlier.

☐ The information I provide will be kept private and confidential to the extent allowed by law. The information will be used in research and will be part of a computer database without my child’s name.

☐ I do not have to participate if I do not want to.

☐ I have asked questions and have received answers.

☐ I consent to participate in the study.

______________________________    ____________________________
Child’s name                     Parent’s name

______________________________    ____________________________
Signature of Parent              Date

HOJA DE INFORMACION E INFORMACION DE CONSENTIMIENTO

Título del Proyecto:
Proyecto FIRST WORDS: Características de la Comunicación Social Temprana del Desorden del Espectro Autista en Diversas Culturas en Estados Unidos y Africa.

PATROCINADOR:
Institutos Nacionales de Salud

Investigador Principal:
Amy M. Wetherby, Ph.D., Universidad Estatal de Florida

Número Telefónico: [censored] o línea gratuita [censored]
Correo Electrónico: [censored]

Co-Investigadores:
Roy Richard Grinker, Ph.D., Universidad George Washington
Nola J. Chambers, Ph.D., University of Witswatersrand, South Africa
Shuaib Kauchali, Ph.D., Departamento de Pediatras y Salud Infantil, Escuela de Medicina Nelson R. Mandela, Universidad de Natal, South Africa

Al Participante: Esta forma de consentimiento puede contener palabras que usted no comprende. Por favor pida al asistente de investigación que le explique cualquier palabra o información que usted no comprenda claramente. Usted puede llevar a casa una copia sin firma de este documento para pensar acerca de él o discutir con su familia o amigos antes de tomar una determinación.
Hola, mi nombre es ___________ (nombre del asistente de investigación). Estamos haciendo una investigación acerca de habilidades de comunicación en niños entre los 18 y 36 meses de edad. En este estudio queremos aprender acerca de la comunicación en niños pequeños y lo que podría ir mal en su desarrollo.

Estamos solicitando su permiso para incluir a su hijo en este estudio. Su aceptación depende enteramente de usted. Yo le explicaré detalladamente el objetivo de este proyecto, los procedimientos a ser utilizados, y los posibles beneficios y riesgos de su participación. Usted puede realizar cualquier pregunta que desee para ayudarle a entender mejor el proyecto. Una descripción del proyecto está por escrito más abajo. Por favor lea esta descripción y déjeme saber cualquier pregunta al respecto. Si usted decide que su hijo podría participar en este proyecto, por favor firme la presente forma. Le entregará una copia de esta forma para que usted la conserve.

Objetivo del estudio. El objetivo de este estudio es el de identificar niños muy pequeños que tienen problemas sociales de comunicación. Estos incluyen dificultades mirando y sonriendo a las personas, dificultades comunicándose con gestos, sonidos o palabras, o dificultades jugando con otros niños de su misma edad. Cuando todos estos problemas ocurren juntos, la condición se llama desorden del espectro autista. Para algunos niños, estas dificultades pueden ser muy leves, y para otros pueden ser muy notorias. Nos gustaría poder identificar éstas dificultades temprano en el desarrollo entre los 18 meses y los 3 años, de modo que podamos dar a los padres de los niños afectados, algún tipo de ayuda acerca de cómo educar a sus hijos, para ayudarles a comunicarse mejor mientras son todavía pequeños. Algunos niños que tienen buenas habilidades de comunicación serán también invitados a participar en este estudio, de modo que podrán ser comparados con otros niños que tienen dificultades en esta área.

Procedimientos. Este estudio se está llevando a cabo en Estados Unidos y el Sur de África. Esperamos encontrar en ambos lugares, al menos 5 niños con éstos problemas y 15 niños cuyo desarrollo es correcto. Las familias serán reclutadas a través de las clínicas de la comunidad, hospitales locales y centros de cuidado en Immokalee. Si usted está de acuerdo en ser parte de este estudio, primero le haré unas preguntas acerca de las habilidades comunicacionales de su hijo. Esto tomará alrededor de 30 minutos. Después de que usted haya contestado éstas preguntas, me gustaría venir a su hogar para hacer un video de su niño mientras se comunica con usted y otros miembros de la familia en las actividades cotidianas del hogar. También le presentaré algunos juguetes para ver como su niño juega con ellos y se comunica conmigo. Usted o la persona a cargo del cuidado de su hijo, estará presente todo el tiempo y podrá formar parte del video. La visita para la filmación del video tomará alrededor de 1 hora.

Después de ésta visita en su hogar, nos gustaría hacer otra evaluación con su niño en su hospital o clínica local. Esta evaluación será necesaria para determinar si su hijo tiene un espectro autista o no. La evaluación tomará alrededor de 1 hora y habrá juguetes para ver como su niño se comunica y juega. No hay ningún tipo de estudio médico en esta evaluación. Si yo identifico algún tipo de problemas de comunicación en su hijo, le daré información acerca de servicios de intervención temprana en su comunidad para los cuales su hijo pudiera calificar. Le ayudaré a referir a su hijo a los programas de intervención temprana si usted está interesado.

Riesgos y beneficios. Todos los procedimientos a utilizarse son habitualmente utilizados con niños pequeños. Por lo tanto, no involucrarán actividades que causarán molestia a su niño o lo podrán en algún tipo de riesgo. De cualquier modo, si su hijo se sintiera molesto por algún motivo, la evaluación será cancelada y podrá ser fijada para una nueva fecha con su autorización. Usted y su hijo se pueden beneficiar de éste proyecto de muchas maneras. Primero, le proveeremos información acerca del desarrollo de la comunicación social y del juego de su hijo. Lo referiremos a otro proveedor de servicio de la comunidad que puede ayudarle. Segundo, los resultados de éste estudio arrojarán información para profesionales, acerca de los patrones de desarrollo de la comunicación temprano, lo que ayudará a la identificación de los retrasos de comunicación en los niños. Esta información será de utilidad para ofrecer servicios más tempranos y más apropiados para niños pequeños y sus familias.

Confidencialidad. Todos los registros relacionados a este proyecto se mantendrán de manera confidencial de acuerdo a las normas regidas por ley. Ningún reporte de ésta investigación ofrecerá información de los niños o sus familias.

Denegación/ Retiro. Su decisión de permitir que su hijo sea parte de éste estudio depende completamente de usted (es voluntaria). Si decide que su hijo no participe de él, ésta decisión no afectará para nada los servicios ofrecidos a su hijo en éste hospital o clínica. En cualquier momento durante su participación en éste estudio, usted puede negar su participación en cualquier procedimiento o se puede retirar del estudio sin que ésto ocasione ningún perjuicio o efecto en usted o su hijo. Si le gustaría retirar los registros de su hijo de ésta investigación en cualquier momento en el futuro, por favor llame al o para dejarnos saber de su decisión.

Grabación en video. Usted y su hijo serán grabados en video por el personal de la clínica durante la sesión de evaluación, y durante la visita a su hogar. Estos videos serán mantenidos por el personal al cargo del proyecto en una habitación con seguridad y serán guardados de forma indefinida. Archivos digitales de éstas Cintas de video serán también guardadas en una red segura de computación que está codificada y protegida por una contraseña. Estas Cintas de video o archivos digitales estarán accesibles sólo para el personal de investigación, a menos que usted autorice a alguien más. Posiblemente solicitaremos su permiso para utilizar segmentos de éstos videos para objetivos educacionales, de cualquier modo; esto es opcional. Una copia de la cinta de video será también revisada por el personal en los Estados Unidos o África, pero ni su nombre ni otra información que le identifique, será divulgada. Estos investigadores no ayudarán a decidir si su hijo tiene el desorden de espectro autista o no. Cualquier información del desarrollo de su hijo puesta al descubierto por este estudio, se mantendrá bajo estricta confidencialidad. Usted será informado de cualquier descubrimiento de importancia acerca de su hijo, esta información no será compartida con nadie más sin su previo consentimiento por escrito.

Uso de la información de mi hijo. Durante el curso de este proyecto longitudinal, guardaremos el video de la sesión de evaluación y la visita a su hogar, de modo de poder continuar estudiando medios precisos de medición de la comunicación social y juego de su hijo. Debido a que este estudio es de naturaleza explorativa, el personal de investigación puede revisar el video de su hijo más adelante, para calificar métodos más precisos de comunicación social y juego. Los resultados de su hijo en el cuestionario, pruebas estandarizadas, y calificaciones de la cinta de video serán parte de la base de datos de FIRST WORDS y pueden ser utilizadas para estudiar señales tempranas de desarrollo típico y retrasos en el desarrollo de la comunicación, basados en los resultados de desarrollo. Si usted decide participar en la evaluación de diagnóstico del desorden de espectro autista, la información obtenida acerca de su hijo como parte de estudio, será compartida con los Institutos Nacionales de Salud Base de Datos Nacional para la investigación del Autismo (NIH NDAR). La información incluirá resultados estandarizados del examen, calificaciones de observación, e información proveída en los cuestionarios. La información estará disponible para los investigadores para utilizarse en investigaciones acerca del autismo y otros desórdenes de comunicación, también para contestar preguntas acerca de la causa, diagnóstico, desarrollo, y respuesta al tratamiento. Todos los detalles personales que identifiquen a usted o su hijo serán retirados antes de que la información se convierta en parte de la base de datos. Ningún registro de video será entregado al NDAR. Si usted está de acuerdo en ser parte de éste estudio, eso significa que los registros de información de su hijo serán utilizados de ese modo. Si usted cambia de parecer más adelante, podemos solicitar que los datos de su hijo sean removidos del registro de NDAR. Como sea, NDAR no puede recuperar información que ya ha sido compartida antes de que usted cambiara de parecer.

Reembolso por el estudio. Usted recibirá una tarjeta de regalo de $50 después de haber completado cada una de las tres mediciones: 1) por contestar preguntas durante la primera entrevista acerca de la comunicación de su hijo, intereses, y actividades; 2) por la visita a la casa; y 3) por la participación en la sesión de evaluación en la clínica local. Esto es por agradecerle por su tiempo y para ayudarle si usted necesita una niñera o para cubrir los costos del transporte a la clínica. Usted recibirá la tarjeta de regalo de $50 por cada mediación completada, incluso si no completa las tres. Usted recibirá un total de $150 si participa en las 3 mediciones.
Problemas o Preguntas. Mayor información acerca de éste estudio puede ser obtenida de parte de la Dr. Amy Wetherby por teléfono al [número] o línea gratuita al [número] o por correo electrónico al amy.wetherby@med.fsu.edu. Si usted tiene alguna pregunta acerca de sus derechos como un participante en esta investigación, o si siente que ha sido puesto en riesgo, usted podrá contactar al representante del comité de asuntos humanos, la junta de revisión institucional, a través del vice presidente para la Oficina de Investigaciones en la Universidad del Estado de la Florida al (850) 644-8633.

Informe de Consentimiento para Padres/Guardianes Legales:
Yo he leído y entendido completamente la presente descripción del proyecto, todas mis preguntas han sido contestadas, y doy permiso para que mi hijo participe en éste proyecto de investigación.

Entiendo que si participo en éste estudio:

____ Me harán preguntas acerca de la comunicación de mi hijo, intereses, y actividades
____ Un vídeo de mi hijo será realizado mientras interactúa conmigo en la casa, para mostrar como se comunica mi hijo.
____ Mi hijo será evaluado en la clínica para evaluar el desorden del espectro autista. Yo estaré con mi hijo y un vídeo será realizado de esta evaluación.
____ Me seré otorgada una tarjeta de regalo de $50 por cada medición completada con mi hijo.
____ La información que proveo puede ayudar a mi hijo y otros niños, para obtener servicios a edades más tempranas.
____ La información que proveo se mantendrá privada y confidencial de acuerdo a las medidas requeridas por la ley. La información será utilizada para investigación y será parte de una base de datos digitales que no utilizará el nombre de mi hijo.
____ No estoy obligado a participar si yo no lo deseo así.
____ He hecho preguntas y recibido respuestas.
____ Doy mi consentimiento para participar en éste estudio.

_____________________________   ________________________
Nombre del Niño                       Nombre del Padre

_____________________________
Firma del Padre                      Fecha

REFERENCES


BIOGRAPHICAL SKETCH

Sheri T. Stronach received her B.A. and M.S. degrees in Communicative Disorders from the University of Wisconsin – Madison and her Ph.D. from Florida State University under the direction of Dr. Amy M. Wetherby. She has had a variety of clinical and research experiences working with adults and children with communication disorders, and has presented research at national and international levels. Her primary research interests include typical and atypical social communication development across cultures, early identification of autism spectrum disorder, and cultural adaptations for early intervention services. Sheri will begin a position at the University of Minnesota – Twin Cities in the fall of 2013 as an Assistant Professor in the Department of Speech, Language, and Hearing Sciences.