THE IMPACT OF CULTURAL FACTORS ON THE DIAGNOSTIC PROCESS IN AUTISM: A COMPARISON OF LATINA AND EUROPEAN AMERICAN MOTHERS


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A dissertation submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Department of Psychology (Clinical Psychology).


Chapel Hill
2013

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# ABSTRACT

ALLISON B. RATTO: The Impact of Cultural Factors on the Diagnostic Process in
Autism: A Comparison of Latina and European American Mothers
(under the direction of J. Steven Reznick)

As the prevalence of autism spectrum disorder (ASD) has increased rapidly over

the past three decades, research on the diagnosis and treatment of the disorder has

advanced considerably. However, the role of culture in ASD has been largely neglected

in research. The present study evaluated the implications of cultural factors for ASD

screening and diagnosis by examining the parenting perceptions and diagnostic

experiences of 28 Latina and 28 European American mothers of children with ASD.  The

children of Latina mothers were found to have significantly later ages at diagnosis,

despite having similar ages at the time when mothers first developed concerns about their

child.  However, household income emerged as the strongest predictor of the child's age

at diagnosis. Latina mothers demonstrated significantly less knowledge of developmental

milestones and of ASD, and knowledge of ASD was found to be significantly correlated

with the time between mothers' first concerns and child's age at diagnosis.  There were

no significant differences in mothers' responses to measures of their child's ASD

symptomology, but Latina mothers were significantly more likely to report early

concerns about temperament.  The results of this study suggest that both socioeconomic

and culturally-based differences likely influence the early perception and diagnosis of

ASD.

## ACKNOWLEDGEMENTS

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# LIST OF ABBREVIATIONS AND SYMBOLS

ADI-R　　　　　Autism Diagnostic Interview-Revised

AFS　　　　　　Attitudinal Familism Scale

AKQ　　　　　　Autism Knowledge Questionnaire

ASD　　　　　　Autism Spectrum Disorder

BAS　　　　　　Bidimensional Acculturation Scale

CDC　　　　　　Centers for Disease Control

CIDD　　　　　Carolina Institute for Developmental Disabilities

DIF　　　　　　Differential Item Functioning

EA　　　　　　European American

FYI-R　　　　　First Year Inventory-Revised

IIT　　　　　　Infant Intentionality Tape

SCQ　　　　　　Social Communication Questionnaire

SD　　　　　　Standard deviation

SES　　　　　　Socioeconomic status

U.S.　　　　　United States of America

$\chi^2$　　　　　　Chi-squared

# CHAPTER 1

INTRODUCTION

Autism spectrum disorder (ASD) is defined by impairments in communication and social interaction, and the presence of restricted and stereotyped patterns of behavior and interest (American Psychiatric Association, 2000). Over the past three decades, the prevalence of ASD has increased dramatically, from an estimated rate of 1case per 1000 individuals in the 1980s to the substantially higher rate of 1 in 88 affected children under age 8 in the most recent study conducted by the Centers for Disease Control and Prevention (CDC, 2012).ASD is considered a lifelong disability that causes lasting difficulties in development and daily functioning, resulting in substantial costs for care to both families and society. The average private and public healthcare expenditures for an individual with ASD range from 2.5 to 8 times the average amount spent per individual without ASD (Johnson, Brown, Chang, Nelson, & Mrazek, 2011; Peng, Hatlestad, Klug, Kerbeshian, & Burd, 2009; Shimabukuro, Grosse, & Rice, 2008). Much of the cost for ASD-related care, however, is driven by expenses in adulthood (Ganz, 2007). Researchers have continually emphasized that early intervention can dramatically reduce these lifetime costs through improvements in adult outcomes.

In addition to poor social functioning, individuals with ASD are also at an elevated risk for co-morbid psychopathology throughout the lifespan, particularly anxiety and mood disorders, (Eaves & Ho, 2008; Kuusikko et al., 2008; Munesue et al., 2008; White & Roberson-Nay, 2009), as are their parents and caregivers (Abbeduto, Seltzer,

Shattuck, & Murphy, 2004; Boyd, 2002; Duarte, Bordin, Yazigi, & Mooney, 2005; Meltzer, 2011).  Children with ASD who benefit from early intervention develop significantly better communication and social skills, are more likely to be placed in mainstream education, and ultimately achieve greater levels of independence (Chasson, Harris, & Neely, 2007; Ganz, 2007). Higher levels of independence in adulthood are associated with greater well-being among both individuals with ASD and their family members (Keel, Mesibov, & Woods, 1997; Lounds, Seltzer, Greenberg, & Shattuck, 2007; Mawhood & Howlin, 1999; Renty & Roeyers, 2006). Early intervention has the potential to improve both short-term and long-term outcomes for individuals with ASD and their families. In order to increase the likelihood that all children can achieve better outcomes, the process of early screening and diagnosis must be improved. Although substantial progress has already been made in early screening for ASD, several challenges remain.

The average age at which an ASD diagnosis is assigned is approximately 4 years (CDC, 2012), but a stable diagnosis can be made as early as 2 years (Turner, Stone, Pozdol, & Coonrod, 2006). Early signs of ASD are undoubtedly present in infancy and toddlerhood, indicating that early identification is possible. Indeed, approximately 90% of parents of children with ASD report noticing differences in their children's development and behavior within the first two years of life (Chawarska et al., 2007; De Giacomo & Fombonne, 1998). These reports have been further substantiated by researchers through analyses of home video data and prospective studies of at-risk infants (Baranek, 1999; Boyd, Odom, Humphreys, & Sam, 2010; Chawarska et al., 2007). Despite the known presence of early risk signs and the increasing availability of

resources for identifying and treating ASD in early development, the prospective

identification of infants at risk for ASD is an on-going challenge.

As an initial obstacle, there is considerable variability in the presentation of ASD,

particularly in infancy and toddlerhood (Volkmar, Chawarska, & Klin, 2005). Some

parents report that their children seemed "different" from birth, but others report that

these differences did not appear until the child's first birthday or later (De Giacomo &

Fombonne, 1998). Additionally, the timing of symptom onset has not yet been

established and seems to vary somewhat across individuals (Bryson et al., 2007;

Chawarska et al., 2007). Core symptoms such as poor eye contact and lack of social

reciprocity may be present early on, or may initially appear intact and later become

impaired. The developmental process itself also complicates the task of early

identification, as expectations for appropriate socio-communicative behavior change with

age. Gesturing to an object using an open-handed reach, for example, is considered a sign

of socio-communicative competence before 9 months of age, but quickly becomes a sign

of impairment when it is not accompanied by eye contact, language, and a broader

repertoire of gestures (Colgan et al., 2006; Volkmar et al., 2004). Similarly, repetitive

motor mannerisms and repetitive object play are considered typical in early infancy and

only become a cause for concern when they continue into toddlerhood (Baranek, 1999;

Honey, Leekam, Turner, & McConachie, 2007).

Many behaviors and impairments that are readily apparent at older ages in ASD,

such as restricted interests and deficits in theory of mind, manifest in much more subtle

ways in early development or do not have clear precursors in infancy. Additionally, many

of the earliest symptoms of ASD, such as language delays and abnormal play, are not

specific to ASD, and are frequently observed in children with other developmental disorders (Baranek et al., 2005; Wetherby et al., 2004). Early identification is further complicated by the phenomenon of regression, defined as the loss of previously mastered developmental skills, most often in the domains of language and social interaction (Lord, Shulman, & DiLavore, 2004). Although regression is still not fully understood, it is estimated to occur in approximately 20% of children with ASD, presenting a significant obstacle to the process of early identification (Lord, 1995; Lord et al., 2004; Werner, Dawson, Munson, & Osterling, 2005).

In addition to the known challenges to early identification caused by the nature of ASD and the developmental process, there remain unknown challenges in the domain of culture. The field has made substantial advancements in research and treatment, but the role of culture in this disorder has been largely ignored (Daley, 2002). Although ASD occurs across cultural groups, there has been relatively little research into how the perception, experience, and manifestation of this disorder may differ by culture. However, researchers in the field have increasingly noted that culture may impact the process of diagnosis and screening for ASD in several ways (Daley, 2002; Wallis & Pinto-Martin, 2008). First, culture plays an important role in defining what constitutes socially appropriate behavior, the impairment of which is at the core of ASD. Expectations regarding eye contact and the initiation of conversations with others, for instance, are known to vary by culture, but have not yet been systematically studied in the context of ASD (Wallis & Pinto-Martin, 2008). Although the diagnostic criteria for ASD consistently refer to deficits in "socially appropriate" behaviors, currently available diagnostic instruments utilize U.S. and Western European standards of appropriate social

behavior. Existing measures may need to be modified or new measures developed in order to accurately diagnose, remediate, and study ASD in other cultural contexts.

Culture may also impact diagnosis through societal beliefs and expectations regarding child behavior and development. In India, for example, speaking later is often regarded as a sign of intelligence, rather than a cause for concern as it is in the U.S. and Western Europe (Daley, 2004). Additionally, some cultures consider a broader range of behaviors to be within the normal range, and thus may find repetitive or stereotyped behaviors to be less alarming (Draguns, 1995; Gutierrez, 2002; Nudelman, 1994). Culturally-based differences in symptom perception may cause diagnostic and screening instruments to function differently in these cultures, as has been found in some questionnaire measures of psychological constructs, including depression, anxiety, quality of life, language development and posttraumatic stress disorder (Hambrick et al., 2010; Huaqing Qi & Marley, 2009; Miles, Marshall, & Schell, 2008; Teresi, Ramirez, Lai, & Silver, 2008). These differences in symptom perception may affect the cross-cultural utility of questionnaires and other screening and diagnostic measures, through the potential presence of differential item functioning.  Differential item functioning (DIF) occurs when one or more items perform differently across groups in a systematic way, misrepresenting one of the groups' true value of the underlying variable being measured. When several items on a measure show evidence of DIF, the measure may be less accurate overall for one or more groups, resulting in inaccurate information (Teresi et al., 2008).  There are no published studies to date investigating the possibility of DIF by ethnicity on measures of ASD symptomology.  Therefore, it is unknown whether these

measures may also be subject to culturally-based DIF, and consequently be less accurate across cultural groups.

Cultural factors may also indirectly impact symptom perception by influencing the relative salience of behaviors to parents. ASD symptoms may simply be less prominent in some cultural contexts, as suggested in early studies that found significantly lower prevalence rates of ASD in the Jewish Kibbutz community. Although this finding was attributed to the communal nature of child-rearing better meeting children's attachment needs, it may also be that children with ASD are less burdensome and thus less noticeable when responsibilities for care are widely shared (Kaffman, 1972). These children may also be insulated from some of the environmental risk factors that have been hypothesized to play a role in ASD due to their more traditional lifestyle (Dawson, 2008; Kern & Jones, 2006). Additionally, parents from collectivist cultures, which place a strong emphasis on social and family bonds, may be more attentive to the child's social development, while those from individualistic cultures may be more attentive to cognitive development, leading to differences in symptom perception (Daley, 2004; Mandell & Novak, 2005). In a study of ASD in India, Daley (2004) found that 45% of parents reported that the first symptoms they noticed were social impairments, whereas parents in the United States overwhelmingly report first noticing language delays (Chawarska et al., 2007; De Giacomo & Fombonne, 1998). Similarly, a study of Latino children found that parents reported similar levels of socio-communicative symptoms for children with and without ASD, suggesting that these parents may be relatively more attentive to their children's social behavior than to other areas of functioning (Overton et al., 2007).

Differences in the relative emphasis placed on symptom areas may have important implications for the functioning of screening items and tools across cultural groups.

Cultural factors may also impact how providers perceive children. Studies of medical record data and diagnostic formulations have found that even when presented with the same symptom set, clinicians are more likely to assign stigmatizing diagnoses such as Oppositional Defiant Disorder, Psychotic Disorder, and Cultural Deprivation to ethnic minority children, and less stigmatizing diagnoses such as adjustment disorder, learning disabilities, and ASD to European American children (Begeer, Bouk, Boussaid, Terwogt, & Koot, 2009; Cuccaro et al., 1996; Mandell, Ittenbach, Levy, & Pinto-Martin, 2007). A national study of parent experiences with primary care physicians also found that pediatricians were less likely to ask about developmental and behavioral concerns with Spanish-speaking parents than with English-speaking parents, despite comparable levels of risk across these groups (Zuckerman, Boudreau, Lipstein, Kuhlthau, & Perrin, 2009). This is particularly worrisome given that Latino parents often expect their children to achieve developmental milestones on a later timeline (Schulze, Harwood, Schoelmerich, & Leyendecker, 2002), and therefore may not initially recognize developmental delays. Conversely, this finding may reflect greater assertiveness and comfort in interacting with providers among European American parents relative to Latino parents (Gannotti, Kaplan, Handwerker, & Groce, 2004).

Although the ways in which cultural factors may affect diagnosis of ASD are not yet clear, there are indisputable ethnic disparities in diagnosis of ASD, particularly in the United States. Ethnic minority children generally have diminished access to diagnostic and treatment services for ASD relative to children from European American families

(Liptak et al., 2008; Schieve et al., 2012).Studies of medical record data have also found that ethnic minority children receive ASD diagnoses significantly later than their European American peers on average, even after socioeconomic status (SES) has been accounted for (Granados, Puvvula, Berman, & Dowling, 2001; Mandell, Listerud, Levy, & Pinto-Martin, 2002).  Perhaps due to these delays in diagnosis, ethnic minority children have also been reported to have more severe forms of ASD than European American children, even within a sample of middle to upper-middle class families (Cuccaro et al., 2007; Tek & Landa, 2012).  In addition to delays in diagnosis, ethnic minority children are also at risk for misdiagnosis and underdiagnosis (Jarquin, Wiggins, Schieve, & Naarden-Braun, 2011). In the most recent report of a multisite U.S. study underway by the CDC, the overall prevalence of ASD among children under 8 years of age was estimated at 11.3 per 1000 (CDC, 2012). The prevalence rate was slightly higher among European American children, with 12.0 per 1000 meeting criteria for ASD (CDC, 2012). Significantly lower prevalence rates were reported among both African American and Latino children, at 10.2 per 1000 and 7.9 per 1000, respectively (CDC, 2012).  These findings are consistent with results across several years of surveillance data from the CDC, reporting significantly lower rates of ASD among Latino children relative to European American children (Pedersen et al., 2012). Thus, Latino children seem to be at particularly high risk of underdiagnosis and of never receiving appropriate intervention services (Overton, Fielding, & de Alba, 2007).

Indeed, even as the Latino population continues to be the fastest growing ethnic group in the U.S. (U.S. Census Bureau, 2010a), Latino children are consistently underrepresented in ASD prevalence rates (Overton et al., 2007; CDC, 2012). Although

Latinos make up approximately 21% of the students in U.S. public schools, they represent only 12.4% of children receiving services for ASD in the public school system (National Center for Education Statistics, 2008; U.S. Department of Education, 2008). In a recent analysis of national special education data, Latino children were found to have the greatest underrepresentation in the Autism category of special education services (Morrier & Hess, 2012). Moreover, an independent study conducted using data from Texas school districts reported that for each 10% increase in the proportion of Latino students in a district, there was a corresponding 11% decrease in children diagnosed with ASD (Palmer, Walker, Mandell, Bayles, & Miller, 2010). Even among diagnosed children with ASD, ethnic discrepancies are apparent. Latino children with ASD have more severe symptoms and impairment on average than their European American and African American peers (Liptak et al., 2008; Mandell, Novak, & Zubritsky, 2005). This finding may be reflective of delays in diagnosis and diminished access to treatment services, resulting in greater overall impairment for Latino children on the spectrum. Alternatively, it may also indicate that higher functioning Latino children on the spectrum may not receive ASD diagnoses, perhaps being misdiagnosed or never being identified as impaired.

Standardized cross-cultural research of ASD has not been conducted, so it is unknown whether the observed differences in prevalence rates are due to true population differences or are the result of societal factors. Based on the present understanding of ASD as a genetic, neurodevelopmental disorder, however, prevalence rates are widely assumed to be comparable across ethnic groups (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Grinker, 2007), and thus the disproportionate representation of Latinos

in the ASD population is believed to be due to other factors. At present, it is unknown what leads to underdiagnosis, but a number of factors likely contribute to this phenomenon. The most frequently advanced theory is that underdiagnosis of ASD among Latinos is primarily the result of broadly diminished access to healthcare among this group (Liptak et al., 2008; Schieve et al., 2012). Latino children and families have less access to and utilization of healthcare resources, particularly specialty care and mental health services (Alegría et al., 2002; Gannotti, Kaplan, Handwerker, & Groce, 2004; Liptak et al., 2008). This gap in care is partially driven by ethnic disparities in SES. Given that 25% of the U.S. Latino population lives below the poverty line and 20% report having no health insurance, low SES represents a significant contribution to the lack of access to healthcare among Latinos (Granados et al., 2001; Pew Hispanic Center, 2008; U.S. Census Bureau, 2010). Furthermore, because many ASD-related services are not covered by health insurance, even those who have health coverage may be unable to afford appropriate diagnostic and treatment services (Liptak, Stuart, & Auinger, 2006; Young, Ruble, & McGrew, 2009).

The limitations in care that result from low financial resources are often amplified among foreign-born Latinos by issues related to immigration. Recent estimates indicate that approximately 40% of Latinos living in the U.S. are foreign-born; these families are often lacking in economic resources, with nearly 50% lacking healthcare coverage and approximately 50% reporting an annual income of less than $20,000 (Pew Hispanic Center, 2008). Immigration status may also directly impact access to resources via legal concerns. Although data are understandably imprecise, an estimated 19% of Latinos are unauthorized immigrants, indicating that they either entered the U.S. without

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documentation or, more commonly, have remained in the U.S. past the time when their authorized residency expired (Pew Hispanic Center, 2010). Individuals residing in the U.S. without authorization are often reluctant to seek out services due to fears of deportation (Garrison, Roy, & Azar, 1999; Leidy, Guerra, & Toro, 2010). Despite the fact that many have the right to legally access healthcare and other services, particularly on behalf of children who are U.S. citizens, they may be unaware of these rights or distrustful of them, due to prior experiences with corrupt governments and fears of discrimination (Garrison et al., 1999).

Only two studies have been published examining differences in ASD prevalence in the United States by immigration status. Both reported that children of foreign-born Latino parents were significantly less likely to be diagnosed with ASD than were children of U.S.-born parents, even after controlling for ethnicity and SES (Croen, Grether, & Selvin, 2002; Schieve et al., 2012). Interestingly, these results are contrary to the patterns observed in Europe. Across several studies conducted in Britain and Scandinavia, immigrant mothers, particularly those born outside Europe, have been found to be at an increased risk of giving birth to children with ASD (Barnevik-Olsson, Gillberg, & Fernell, 2008; Gardener, Spiegelman, & Buka, 2009; Kamer, Zohar, & Youngmann, 2004; Lauritsen, Pedersen, & Mortensen, 2005). Some authors have suggested that the higher rates among immigrant mothers in Europe may be due to social stressors during pregnancy or to lower rates of immunization leading to maternal infections during pregnancy, both of which may in turn increase ASD risk (Gardener et al., 2009; Kolevzon,Gross, & Reichenberg, 2007). The consistency of findings in Europe suggests that the lower prevalence rates among U.S. immigrants may be a reflection of these

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families' diminished access to healthcare in the U.S., in contrast to the largely socialized healthcare systems in Europe (Palmer et al., 2010; Schieve et al., 2012). This theory is supported by an epidemiological analysis of ASD prevalence in California, which found that rates of ASD among Latino immigrants decreased relative to other groups following the passage of legislation that restricted access of illegal immigrants to public services (Fountain & Bearman, 2011). These results are particularly striking, as this same study found that prior to the passage of this legislation, the prevalence rate of ASD had been increasing at a faster rate among Latinos than among other ethnic groups.

Both foreign-born and native-born Latino families may also face barriers to care due to cultural differences (Welterlin & Larue, 2007). Language differences are often the most overt barriers to care for these families. Although many foreign-born Latino immigrants can speak English, over 70% speak English "less than very well," thus limiting their ability to communicate with healthcare professionals, particularly about complex topics such as symptoms of ASD (Pew Hispanic Center, 2008). Many healthcare facilities, particularly specialty clinics used to diagnose ASD, often lack bilingual clinicians and/or access to appropriate translation services (Welterlin & Larue, 2007). Although the use of translators can greatly improve the diagnostic process (Scheppers, van Dongen, Dekker, Geertzen, & Dekker, 2006), there are also concerns about conducting psychological assessments through translators, due to the complexities involved in making an ASD diagnosis. Thus, the lack of appropriate language services may be a significant obstacle to diagnosis and treatment.

Latino parents may also be limited by deficits in knowledge. As a general finding, mothers of low SES and those who have immigrated to the U.S. have been found to be

less knowledgeable regarding developmental milestones than high SES and U.S.-born mothers (Benasich & Brooks-Gunn, 1996; Bornstein & Cote, 2004; Conrad, Gross, & Fogg, 1992). Latino parents also tend to show deficits in developmental knowledge and timing relative to European American parents (Pachter & Dworkin, 1997; Savage, 1998; Schulze et al., 2002). Latina mothers generally expect children to achieve developmental milestones at later ages, particularly milestones related to independence and socioemotional development, which are key to ASD screening (Schulze et al., 2002; Zepeda & Espinosa, 1988). These delayed expectations may lead Latino parents to be less concerned by developmental delays, and thus less likely to seek out early services. Similarly, Latino parents may have less knowledge regarding specific signs and symptoms of ASD than parents of other ethnic backgrounds due to lower levels of education among this group (Pew Hispanic Center, 2008).

Cultural beliefs about children and parenting may also contribute to underdiagnosis and delays in diagnosis of ASD among Latinos. Parenting styles, beliefs, and practices differ along several dimensions across cultural groups (Forehand & Kotchick, 1996; Keller et al., 2006). One of the most consistent findings in this area is that Latina mothers tend to engage in higher levels of parental control, intrusiveness, and physical guidance behaviors relative to European American mothers (Arcia & Vazquez-Montilla, 2000; Halgunseth, Ispa, & Rudy, 2006). Latino parents also tend to place less value on encouraging self-help and independence skills in their children than do European American parents, which is often attributed to a cultural emphasis on protective care for children (Arcia & Vazquez-Montilla, 2000; Halgunseth et al., 2006). Latino parents often state that their role as a parent is to be an active and commanding force in

shaping their children's behavior, focusing particularly on instilling strong moral values in their children (Arcia &Johnson, 1998; Calzada, 2010). Instilling independence is often considered a less important goal, as familism/*familismo* (staying intimately connected as a family) is prioritized and generally includes the expectation that parents will closely monitor their children and perform many tasks for them (Arcia & Vazquez-Montilla, 2000).

The relatively higher degree of parental control and intrusiveness observed in this group appears to be at least partially attributable to differences in how these parents perceive their children. Studies of parental perceptions have reported that Latino parents tend to view their young children as inherently irrational, dependent upon others, and in need of strong guidance (Arcia & Johnson, 1998; Halgunseth et al., 2006). Latino parents are also less likely than European American and African American parents to hold young children accountable for misbehavior and to view infant behavior as intentional and purposeful (Halgunseth et al., 2006; Reznick, 1999). Latina mothers are more likely to respond to crying from very young children with extended cuddling and comfort routines than are European American mothers (Korn & Gannon, 1983; Zeskind, 1983). This view of children as needy and irrational may result in Latino parents being less concerned by unusual behaviors associated with ASD, as they ascribe less meaning to infant behaviors overall. Impairments in adaptive skills and self-regulation may also be less apparent, as these parents are less likely to expect and value these skills in their young children. It is important to note that while some of the research reviewed above has included both mothers and fathers, the vast majority relies heavily or exclusively on

mothers. Consequently, this conception of Latino parenting is likely to be most applicable to mothers.

**Hypotheses**

There is a concerning lack of knowledge and research regarding the role of culture in ASD. Nonetheless, prior research has demonstrated that Latino children are at increased risk for underdiagnosis and delays in diagnosis of ASD. These diagnostic disparities result in additional disparities in treatment and diminished access to early intervention services, resulting in poorer long-term outcomes and greater costs to individuals, families, and society. Additional research is needed to understand the multiple factors that may contribute to this phenomenon. The aim of the present study was to examine the ways in which sociodemographic and cultural factors may affect the diagnostic process for Latino children with ASD and their families. It was expected that Latino families of children with ASD would report significant disparities in diagnosis relative to European American families, and that cultural factors would significantly contribute to these disparities.

**Hypothesis 1.** It was hypothesized that Latino children would have more impairing experiences of ASD than European American (EA) children. Specifically, it was expected that Latino children would have later ages of ASD diagnosis, more severe symptoms of ASD, fewer weekly hours of therapeutic services, and fewer types of intervention relative to EA children.

**Hypothesis 2.** It was hypothesized that Latina mothers of children with ASD would significantly differ from their EA counterparts along several parenting dimensions. Specifically, it was expected that Latina mothers would demonstrate significantly less

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knowledge of ASD and would expect developmental milestones to occur significantly later than EA mothers. Latina mothers were also expected to ascribe significantly less intentionality to infants' behaviors and to endorse significantly greater levels of familism than EA mothers. It was expected that Latina mothers would be significantly more likely to report that the first concern they had about their child's development or behavior was in social skills. Finally, it was predicted that two parent-report measures of ASD symptoms would show evidence of differential item functioning by ethnicity. For this study, it was predicted that Latina mothers would be less likely to endorse repetitive/stereotyped behavior symptoms and more likely to endorse social symptoms, leading to DIF on measures of ASD symptoms.

**Hypothesis 3.** The final hypothesis of the study was that sociodemographic and cultural factors would have significant impacts on the diagnostic process. Specifically, it was hypothesized that mothers' lower household income, lower educational attainment, delayed developmental expectations, and lower levels of ASD knowledge would be significantly associated with a later age at ASD diagnosis and higher levels of current symptom severity among children. It was also hypothesized that lower levels of perceived infant intentionality among mothers would be significantly associated with lower levels of perceived repetitive/stereotyped behaviors and significantly later age of first concerns. Additionally, it was expected that greater endorsement of familism among mothers would be significantly associated with higher levels of perceived social impairment and a significantly greater likelihood of reporting their first concern about their child's behavior or development was related to social skills.

# CHAPTER 2

## METHODS

**Procedure**

Participants were recruited from the Research Participant Registry Core of the

Carolina Institute for Developmental Disabilities (CIDD), parent trainings and Latino

parent support groups of the Autism Society of North Carolina, and fliers distributed at

the CIDD and related events.  All participants were required to have a child with a

diagnosed autism spectrum disorder between the ages of 4 and 11 years-old.  After

consenting to be contacted by the research team, participants were contacted by phone to

schedule a participation date.  Participants were seen by the research team at their home

or other location of their choosing. All but 3 of the participants chose their home for the

site of the study visit. Of the three who chose other sites, two chose public places near

their home or work, and the other preferred to visit the research team at the study site. All

three participants who chose non-home locations were in the EA ethnic group.

After reviewing and signing the consent form with the research team member,

participants first completed an experimenter-administered demographic questionnaire,

followed by an experimenter-administered developmental questionnaire. Participants then

completed a series of questionnaires independently, with the research team member

available to answer questions as needed. Finally, all participants completed a qualitative

interview regarding their diagnostic experiences with their child (not analyzed in the

present study). All visits were conducted in the participant's primary language by the first

author and/or a trained research assistant. All measures, forms, and interviews were completed in the participant's primary language.

**Participants**

Participants included 28 Latina mothers and 28 EA mothers of children with a disorder on the autism spectrum, defined as Autism, Asperger syndrome, ASD, or Pervasive Developmental Disorder. Those with a diagnosis of Childhood Disintegrative Disorder were excluded, as this study specifically examined early concerns for ASD. A history of developmental regression was not exclusionary, as most children with developmental regression show some ASD symptoms prior to regression (Baird et al., 2008; Ozonoff, Williams, & Landa, 2005; Wiggins, Rice, & Baio, 2009). All EA mothers speak English as a primary language, and all Latina mothers speak Spanish as a primary language. All EA participants completed all study measures in English, while Latina participants completed all measures in Spanish. See Table 1 for a summary and comparison of relevant demographic characteristics. All EA mothers were born in the U.S., and all Latina mothers were foreign-born, with the majority (67.9%) being Mexican-born. Latina mothers had been in the U.S. for almost 12 years on average (mean=11.89, SD 5.31), ranging from 4 to 29 years. All visits were conducted in the family's home or in another location of the participant's choosing (e.g., workplace). EA mothers had significantly more years of education than Latina mothers and a significantly greater household income, even after eliminating an extreme outlier from the EA sample. There were no significant differences in children's ages, but EA mothers were significantly older than Latina mothers.

**Measures**

      **Demographic and Diagnostic Information.** All participants completed an experimenter-administered questionnaire in their primary language to gather relevant social demographic and diagnostic data, including age, ethnicity, country of origin, household income, and educational attainment. Participants also provided the age, gender, and psychological diagnoses of the target child. Additionally, mothers were asked to report their child's age (in months) when they first developed concerns about their child's behavior or development, what it was that concerned them, and the age at which their child was first diagnosed with ASD. Mothers were also asked to list the types of services and weekly hours of services their child received, as well as what concerns or goals they currently had for their child's development.

      **Developmental Expectations.** All participants completed an experimenter-administered questionnaire of expected ages for achieving developmental milestones. Each mother was asked to state the age in months at which she believed a typical infant achieves each of 25 developmental milestones (e.g., crawling, first words).

      **Autism Knowledge.** All participants completed an updated version of the Autism Knowledge Questionnaire (AKQ: Kuhn &Carter, 2006). The AKQ is a 43-item questionnaire that uses a true/false format to assess parent knowledge of autism diagnosis, symptoms, treatment, and epidemiology. In previous studies, the AKQ has demonstrated acceptable internal consistency ($\alpha$=.79), though a ceiling effect has been found in at least one sample of predominantly European American mothers (Kuhn & Carter, 2006). The AKQ was translated into Spanish by the primary author and back translated by a bilingual doctoral student in clinical psychology for accuracy.

**Autism Spectrum Symptoms.** All parents were asked to complete the Social Communication Questionnaire (SCQ: Rutter, Bailey, & Lord, 2003). The SCQ is a 40-item parent-report measure of social and communication skills relevant to a diagnosis of ASD, designed to be used as a screening instrument. Parents respond yes or no to each item, and a total score (range 0-40) is generated by summing responses to each item. The SCQ is available in Current and Lifetime forms; the Current form was used in the present study. The SCQ has good internal consistency for children age 4-10 ($\alpha$=.84-.89) and has established convergent validity with the ADI-R (Rutter et al., 2003). At the recommended cutoff of 15, the SCQ has a sensitivity of .85 and specificity of .75 (Rutter et al., 2003). Although a measure such as the Social Responsiveness Scale (Constantino, 2002) would be a more appropriate measure of ASD severity, the SCQ is the only well-validated measure of ASD for this age range that has been translated into Spanish. The use of the SCQ in this study also allowed for investigation of potential DIF in the most widely used screening instrument for this population.

Parents were also asked to complete the First Year Inventory-Retrospective (FYI-R: Watson et al., 2007). The FYI-R is a retrospective version of the FYI, a parent report measure of infant risk for autism spectrum disorder at 12 months. The FYI-R generates a total risk score for a child on the basis of parent-reported behaviors, using a quasi-logarithmic scale that assigns higher risk scores to children whose parents report higher levels of atypical behavior. Risk scores across the 8 constructs of the FYI-R are then summed to generate a total risk score. At a cutoff score of 15, the FYI-R has a sensitivity of .92 and specificity of .78, resulting in a positive predictive value of .74 and a negative predictive value of .93 (Watson et al., 2007). The FYI-R is moderately correlated with

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autism symptom severity in preschool (r=.54) as measured by the Social Communication

Questionnaire and the Autism Diagnostic Interview-Revised. The FYI-R was previously

translated into Spanish by the author, using back translation by a bilingual developmental

psychologist for accuracy.

**Familism.** All participants were asked to complete the Attitudinal Familism Scale

(AFS: Steidel & Contreras, 2003). The AFS is an 18-item measure of endorsement of

familism (*familismo*) along four dimensions: familial support, familial

interconnectedness, familial honor, and subjugation of self to family. The AFS has

adequate internal consistency ($\alpha$=.83) and is negatively correlated with acculturation to

U.S. mainstream values. The AFS was simultaneously developed and validated in both

English and Spanish.

**Parent Perception of Infant Intentionality.** All parents watched a standard set

of 28 video vignettes, known as the Infant Intentionality Tape (IIT: Feldman & Reznick,

1996). Each video shows a mother and 8-month-old infant playing together. Parents were

asked to rate the behavior of the infant in each video on a scale from 1 to 8, where 1

corresponds to "absolutely sure baby does not mean to do this" and 8 corresponds to

"absolutely sure baby means to do this".  Prior to watching the videos, parents were given

a standard introduction in their primary language explaining the concept of intentionality

and the rating scale. The IIT has high internal consistency ($\alpha$=.91) and is highly

correlated with parent perceptions of their own infant's intentionality (r=.57).

**Acculturation.** All participants completed the Bidimensional Acculturation Scale

(BAS: Marin & Gamba, 1996). The BAS is a 24-item measure of acculturation for use

with Hispanic/Latino populations, developed with a Mexican-American and Central

American sample. It assesses cultural identification with both the English-speaking/U.S. and Spanish-speaking/country of origin groups, through proficiency and use of language and electronic media usage, generating total scores for both cultural dimensions. The BAS has high internal consistency ($\alpha$=.90 for Hispanic dimension, $\alpha$=.96 for non-Hispanic dimension) and shows moderate to high correlations (r=.33-.70) with age at arrival in the U.S., length of residence in the U.S., and generational status. The BAS is available in both English and Spanish.

**Data Analytic Approach**

Student's t-tests were used for initial analysis of differences between groups on demographic variables and measures. Multiple linear regression analyses were used to test hypotheses regarding differences between the Latino and EA samples, while controlling for the effects of household income and maternal education. Logistic regression analyses were also utilized to determine if ethnicity was a significant predictor of certain outcomes (e.g., type of ASD diagnosis, type of maternal first concern). Additionally, Pearson correlations were utilized to examine associations between linear variables.

# CHAPTER 3

## RESULTS

**Hypothesis 1**

It was hypothesized that Latino children would have significantly older ages at symptom recognition and diagnosis, fewer weekly service hours and types of intervention, and higher symptom severity, as measured by the SCQ. Independent samples t-tests were conducted to evaluate each of these hypotheses, followed by multiple linear regression analyses to control for the effects of annual household income. An extreme outlier with an annual income of $500,000 (>4 SD from the next highest value) was eliminated from the EA group in all analyses that included annual income as a variable. The means for each group on the following variables are summarized in Table 2.

There were no significant differences reported in the age at which Latina and EA mothers developed concerns about their child. The results of multiple linear regression analyses indicated that neither annual household income nor maternal ethnicity significantly predicted the age at which mothers reported first being concerned about their child. The children of Latina mothers were diagnosed at older ages on average, at a level approaching statistical significance (t= -1.93, p<.06). The results of hierarchical multiple linear regression analyses indicated that ethnicity was not statistically significantly associated with age at diagnosis, but that annual income was (F=6.08, p<.02, $R^2$=.10), as illustrated in Figure 1. Latina mothers also reported a statistically

significantly greater period of time between first becoming concerned about their child

and the time of their child's diagnosis (t= -2.23, p<.05). Ethnicity was statistically

significantly associated with time to diagnosis (F=4.99, p<.03, $R^2$=.09), but the results of

hierarchical regression analyses indicated that these differences were better accounted for

by annual salary (F=6.38, p<.02, $R^2$=.11). There were no statistically significant

differences reported in the number of visits required to obtain a diagnosis between the

two groups, nor did annual income significantly predict this outcome. Within-group

analyses were conducted to determine if acculturation influenced age at first concerns,

age at diagnosis, or time to diagnosis within the Latina group. Stepwise linear regression

analyses were conducted including both the participant's score for affiliation with Latino

culture and the score for affiliation with U.S. culture. The results indicated that higher

affiliation with Latino culture was statistically significantly associated with later child

age's at mother's first concerns (F=5.07, p<.03), as seen in Figure 2, accounting for

approximately 16% of the variance ($R^2$=.16). Neither acculturation score was

significantly associated with age at diagnosis or time to diagnosis.

Contrary to hypotheses, there were no statistically significant differences in the

number of types of intervention that children received, and Latina mothers reported that

their children received more hours of intervention per week on average than did EA

mothers, at a level approaching statistical significance (t= -1.80, p<.08). However,

neither annual income nor ethnicity predicted hours of intervention in hierarchical

multiple regression analyses at a statistically significant level. There were no significant

differences in ASD severity between the groups as measured by the SCQ, and multiple

linear regression analyses indicated that neither income nor ethnicity significantly

predicted SCQ scores. Logistic regression analyses were then conducted to determine if ethnicity and/or annual income significantly predicted a child's spectrum diagnosis, as a proxy measure of severity. The results indicated that ethnicity, but not annual income, significantly increased the likelihood of being diagnosed with autism, as opposed to Asperger syndrome/high-functioning autism, autism spectrum disorder, or pervasive developmental disorder-not otherwise specified ($\chi^2$=10.10, p<.001). A log-odds ratio of 6.92 was found, indicating that children of Latina mothers were almost 7 times more likely to be diagnosed with autism than children of EA mothers, as illustrated in Figure 3.

Differences by ethnicity in the age at which a child said his/her first words and the age at which a child achieved toilet-training were evaluated as a second proxy of severity, using independent samples t-tests and survival analyses. Children of Latina mothers were reported to begin speaking at statistically significantly later ages on average (t= -2.72, p<.009), but there were no significant differences in age at toilet training. Because several children had not yet achieved speech or toilet-training, and thus were excluded from t-test analyses, survival analyses were used to further evaluate group differences in achievement of these milestones. The results indicated that children of Latina mothers achieved toilet training at significantly later ages (Log-rank =4.54, p<.03), and spoke their first words at later ages, at a level approaching statistical significance (Wilcoxon $\chi^2$=3.11, p<.08), as illustrated in Figures 4 and 5, respectively. It should be noted that these data were gathered via parent report and therefore may reflect true differences in achievement of these milestones, but may also be influenced by parent perception and recall. However, there were no statistically significant differences by ethnicity in the reported ages at which children achieved walking, as measured by either t-test analyses

(t= -1.58, *ns*) or survival analyses (Wilcoxon $\chi^2$=.90, *ns*). If the observed differences in the reported age of onset of talking and toilet training were due primarily to differences in parent recall, it is likely that differences in age of onset of walking would have been observed as well.

**Hypothesis 2**

It was expected that Latina mothers would have significantly less knowledge of ASD and developmental milestones. Latina mothers were also expected to endorse higher levels of perceived infant intentionality and familism. The means for each sample are summarized in Table 3.   As predicted, the results of independent samples t-tests indicated that Latina mothers demonstrated significantly less knowledge of ASD, as measured by the total number of items answered correctly on the AKQ (t=5.61, p<.001). Latina mothers also responded "I don't know" to significantly more items on the AKQ (t= -2.87, p<.001) than did EA mothers.  Hierarchical multiple regression analyses were conducted, entering mother's education into the model first and then adding ethnicity, to evaluate whether ethnicity was a significant predictor of ASD knowledge after controlling for education.  Adding maternal ethnicity into the model significantly improved its accuracy (F=1.69, p<.02), indicating that mothers' ethnicity was significantly associated with ASD knowledge, even after controlling for education (see Figure 6).  Notably, the full model including both maternal education and ethnicity predicted over half of the variance in AKQ scores ($R^2$=.51, F=27.04, p<.001).  The full model including maternal education and ethnicity also significantly predicted the number of AKQ items answered, "I don't know," (F=5.28, p<.008), but accounted for a much smaller proportion of the variance ($R^2$=.17).  Maternal ethnicity did not significantly

improve the model after controlling for education; however, after an extreme outlier in "I don't know" responses was removed from the EA group (>3 SD from the next highest value), maternal ethnicity became a statistically significant predictor (F=1.97, p<.007).

Knowledge of developmental milestones was assessed using the absolute value of the difference between mothers' estimation of the typical age at which a milestone is achieved and the actual age at which the milestone is expected to be achieved. Absolute value scores were used so as to capture mothers' overall accuracy and avoid a "balancing out" effect from mothers who may have overestimated some items and underestimated others. Thus, on this measure lower scores indicated more accuracy in developmental knowledge, as they reflected a smaller difference between a mother's estimated age and the true average. Scores for each of the items were then averaged to calculate the mean number of months between the participant's estimates and the correct response. As predicted, EA mothers demonstrated significantly better knowledge of the timing of developmental milestones overall, based on the results of independent samples t-tests (t= -2.65, p<.01). On average, EA mothers' estimates were off by 3.33 months, while Latina mothers' estimates were off by 4.13 months. These disparities were particularly notable on the items assessing knowledge of adaptive skills, such as feeding and toilet-training (t= -2.10, p<.04). The results of hierarchical multiple linear regression analyses indicated that although maternal ethnicity was associated with developmental knowledge at a statistically significant level, these differences were better accounted for by maternal education (F=11.47, p<.001), as illustrated in Figure 7. Similar results were obtained on the subscale of adaptive skills, with maternal education emerging as the best predictor of

knowledge of adaptive skill development (F=5.53, p<.02).  However, neither model accounted for a large proportion of the variance in scores ($R^2$ = .18, .09, respectively).

An examination of means and medians obtained prior to converting scores to absolute values (i.e., scores reflective of over- and under-estimations) indicated that Latina mothers generally believed that developmental milestones would be achieved at older ages than did EA mothers, in line with study hypotheses. Notably though, all participants tended to estimate that developmental milestones are reached at earlier ages than the true average, perhaps indicating that these mothers are over-correcting based on the developmental timeline of their child with ASD.  Among Latinas, the results of stepwise multiple regression analyses indicated that developmental knowledge was predicted by a model including education, acculturation to Latino culture, and acculturation to U.S. culture (F=3.18, p<.05).  However, the strongest predictors were maternal education (t= -2.91, p<.008) and acculturation to the U.S. (t=2.43, p<.02). The full model accounted for a substantial proportion of the variance ($R^2$=.28).

There were no significant differences by ethnicity in mothers' perceived infant intentionality (t=.27, *ns*). Neither education nor ethnicity emerged as significant predictors of mothers' ratings of infant intentionality in hierarchical multiple linear regression analyses. However, among Latina mothers, those who reported higher levels of affiliation with Latino culture tended to perceive infants as being less intentional, based on the results of Pearson correlations (r= -.47, p<.01). As predicted, Latina mothers endorsed significantly higher levels of familism than EA mothers (t= 6.95, p<.001).  The results of hierarchical multiple linear regression analyses indicated that maternal ethnicity significantly improved the prediction of familism scores, even after controlling for the

effects of maternal education (F=6.14, p<.001). The full model including both education and ethnicity predicted familism scores at a statistically significant level (F=30.31, p<.001), accounting for over half the variance ($R^2$=.53).

It was expected that Latina mothers would be significantly more likely than EA mothers to report that their first concern about their child's development was related to social skills. This hypothesis was evaluated using logistic regression analyses to predict endorsement of each category of "first concern" from ethnicity (see Figure 8). Contrary to hypotheses, maternal ethnicity was not a statistically significant predictor of reporting a first concern for social development. However, maternal ethnicity did significantly predict endorsement of abnormal temperament as the first concern ($\chi^2$= 5.81, p<.02). The results indicated that Latina mothers were approximately 9 times more likely than EA mothers to report that their first concern about their child's development was for temperament (log-odds ratio =9.00).

Logistic regression analyses were used to test for DIF on the SCQ, using the total score on the scale, ethnicity, and the interaction of these variables to predict the likelihood of item endorsement (Swaminathan & Rogers, 1990). Ordinal regression using the same predictors was used to test for DIF on the FYI-R, as responses to the FYI-R are provided on a rating scale, rather than dichotomously as on the SCQ. A Bonferroni correction was used to control for Type I error due to multiple analyses. No items showed significant DIF on either the SCQ or the FYI-R using this method. However, two items on the SCQ did show evidence of DIF at a level approaching statistical significance. The item "use of another's hand as a tool" showed possible uniform DIF (B=7.37, $\chi^2$=5.86, p<.02), as did "interest in parts of a toy" (B=5.12, $\chi^2$=3.76, p<.05),

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though these results were not significant after applying the Bonferroni correction. Uniform DIF occurs when items function differently across groups in a consistent way at all levels of the underlying variable (i.e., ASD severity). In this case, Latina mothers seemed more likely to endorse both of these items, regardless of their child's underlying level of ASD severity. This is in contrast to non-uniform DIF, in which the extent to which items function differently across groups differs at different levels of the underlying variable. For example, one group may be more likely to endorse an item only when they have a very low level of the underlying variable, but not at higher levels of the underlying variable. Although these results did not attain statistical significance in the present analyses, they may indicate that a more powerful, IRT-based analysis in a larger sample might reveal DIF by ethnicity on these items.

**Hypothesis 3**

It was expected that maternal knowledge of ASD and of developmental milestones would be significantly associated with the child's age when mothers' first developed concerns, the child's age at diagnosis, and the time between the mother's first concerns and her child's diagnosis. Contrary to hypotheses, there were no significant associations between developmental knowledge and child's age at mother's first concern, child's age at diagnosis, or time-to-diagnosis. Knowledge of ASD was statistically significantly associated with time-to-diagnosis ($r= -.31$, $p<.02$), such that higher knowledge of ASD was associated with less time between child's age at first concern and child's age at diagnosis (Figure 9). There was also a negative correlation approaching statistical significance between knowledge of ASD and child's age at diagnosis ($r= -.24$,

p<.08), such that higher knowledge of ASD was associated with an earlier age of diagnosis.

The results of hierarchical multiple linear regression analyses indicated that maternal knowledge of ASD and developmental milestones were not statistically significant predictors of child's age at mother's first concern or child's age at diagnosis. Maternal knowledge of ASD was a statistically significant predictor of time-to-diagnosis (F=5.55, p<.02), but this only accounted for a small proportion of the variance ($R^2$=.09). After controlling for the effects of maternal education and annual income, maternal knowledge of ASD was no longer a statistically significant predictor of time-to-diagnosis.

It was also expected that higher valuation of familism would be associated with higher endorsement of social symptoms on the FYI-R and the SCQ. Contrary to hypotheses, familism was not a statistically significant predictor of endorsement of social symptoms on either of these measures. However, the results of Pearson correlations indicated that higher familism scores were associated with statistically significantly higher scores on the FYI-R subscales of sensory processing (r=.29, p<.03), regulatory patterns (r=.29, p<.03), and repetitive play (r=.27, p<.05). Perceived infant intentionality was not statistically significantly associated with scores on any of the subscales of the SCQ or the FYI-R. Contrary to hypotheses, higher valuation of familism was not associated with an increased likelihood of a mother reporting that social development was her first concern.

**Exploratory Analyses**

As part of the demographic questionnaire, mothers were also asked to report on their current concerns about their child, as well as their current goals for their child. A

trained interviewer asked mothers to share their current concerns and goals and transcribed mothers' responses for later coding. There were no limits on the number of goals and concerns mothers were asked to list. An a priori coding system was developed based on common areas of ASD treatment and then adapted in response to unanticipated responses. Mothers' responses were coded using the following 11 categories: social skills, communication, pretend play, disruptive behavior, academic, adaptive skills, motor skills, medical/physical development goal, repetitive behavior, safety, and "other." Logistic regression analyses were used to evaluate whether ethnicity significantly predicted the type of concerns and goals mothers reported for their children. Latina mothers were found to be significantly more likely to report concerns about their child's communication skills ($\chi^2$=9.88, p<.002), as well as to be significantly more concerned about adaptive skills at a level approaching significance ($\chi^2$=2.64, p<.10). In contrast, EA mothers were more likely to report concerns about their child's academic performance, at a level approaching statistical significance ($\chi^2$=2.95, p<.09). EA mothers were significantly more likely to identify social skills as a goal for their child ($\chi^2$=5.85, p<.02), while Latina mothers were more likely to identify communication as a goal for their child, at a level approaching significance ($\chi^2$=3.46, p<.06). These outcomes may be a reflection of mothers' values for their children, but may also be an additional indication of differences in ASD severity between the two groups.

**CHAPTER 4**

DISCUSSION

The goal of the present study was to examine the impact of cultural and sociodemographic factors in the Latino community on the screening, diagnosis, and impact of ASD. As reported in previous studies, Latino children and children with lower SES were diagnosed at later ages and experienced greater delays between the time mothers reported first being concerned about their child and the time of diagnosis. Notably, there were no significant differences by ethnicity in the average age at which mothers developed concerns about their child. This may be an indication that Latina mothers and those of lower SES have more difficulty navigating the systems necessary to obtain a diagnosis for their child, or that providers and/or health care systems are less responsive to the concerns of these mothers. Additionally, within-group analyses indicated that higher levels of acculturation to Latino culture were associated with later ages at first concern. This finding may indicate that mothers with higher affiliation to Latino culture are more accepting of differences in early development and therefore are less likely to be concerned about early delays and symptoms. However, the measure of acculturation used in the present study utilizes use of English and Spanish language and media to assess levels of acculturation to U.S. and Latino culture, respectively. Consequently, this result may also indicate that there are fewer messages about early childhood development embedded in Spanish-language media, and these mothers are

therefore less knowledgeable about early childhood development and less able to recognize developmental differences in their children.

It was predicted that Latina mothers would be more likely than EA mothers to report that their first concern for their child's development was in social functioning. Contrary to hypotheses, Latina mothers were more likely to report concerns for their child's temperament as their first concern. This finding may be related to the notion of *Marianismo*, which is a Latino cultural concept of womanhood that sees the Virgin Mary as the ideal woman, and thus emphasizes self-sacrificing motherhood and care for the family as central to a woman's identity. In prior studies, Latina mothers of adults with ASD have been found to place more emphasis on their identity as a mother, and as a result to be more satisfied than EA mothers to have their adult children living at home with them (Magana & Smith, 2006). While parenting an infant, this cultural ideal may lead Latina mothers to place more importance on their child's temperament, perhaps seeing their child's temperament as a reflection of their own efforts as a mother and their value as an individual. The greater likelihood to report concerns about temperament may influence how treatment providers respond to mothers and whether they believe ASD screening is warranted. Future studies should evaluate whether endorsement of *Marianismo* and the centrality of motherhood to one's identity are associated with an increased focus on temperament, particularly within this population. It may also be useful to investigate what primary care providers see as potential warning signs of ASD, as well as how they respond to parental concerns about temperament.

Although no differences in ASD severity were detected using the SCQ, proxy measures of severity including type of spectrum diagnosis, age at talking, and age at toilet

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training all indicated that Latino children had more severe forms of ASD than their EA counterparts. It is unsurprising that these differences were not captured by the SCQ, as it is intended as a cutoff diagnostic measure, rather than a severity measure. The finding that Latino children seem to be more severely impaired than their EA peers (using proxy indicators) may indicate that delays in diagnosis, and thus in intervention, result in more profound impairments for these children. It may also be that Latino children with milder forms of ASD are less likely to be detected, either by parents or by professionals. Broad-based population studies are needed to determine whether there are undiagnosed children with ASD within the Latino community. Although the CDC has made efforts to include children from all ethnicities in their prevalence studies, these studies have not been specifically designed to address the question of ethnic differences in prevalence rates. Recruitment of ethnic minority participants is more difficult than recruitment of EA participants (Yancey, Ortega, & Kumanyika, 2006), and recruiting ethnic minority participants, particularly Latinos, often requires more community-based methods and personal contact (Cabral et al., 2003; Rodríguez, Rodríguez, & Davis, 2006). This finding was replicated in the present study, as EA participants were easily recruited from a university-based research registry, while Latina participants were almost entirely recruited through personal contacts made through parent support groups and workshops. Determining whether ethnic differences in prevalence rates are due to true differences or to outside factors will likely require the use of targeted recruitment procedures and research staff with extensive knowledge of cultural differences.

As predicted, Latina mothers demonstrated significantly less knowledge of ASD, even after controlling for education. Although this deficit was widely suspected, this

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study has provided the first empirical evidence of diminished knowledge of ASD among this population. This is in sharp contrast to an earlier study of the MAKQ, which found a ceiling effect among a sample of predominantly EA mothers of children with ASD (Kuhn & Carter, 2006). The finding of deficits in ASD knowledge in the present Latina sample was particularly striking, as this sample was taken entirely from mothers whose children had been diagnosed with ASD on average more than 4 years prior to study participation. Furthermore, Latina mothers were recruited primarily from Spanish-language parent support groups and workshops, indicating that this sample was likely representative of the most highly involved Latina mothers, who would be expected to have the greatest knowledge of ASD. Latina mothers were also significantly less knowledgeable about the timing of developmental milestones, although this difference was better accounted for by educational disparities. These findings suggest that greater education about early development and ASD is needed in the Latino community. Greater outreach to Spanish-speaking parents of diagnosed children with ASD may also be necessary, given the significant deficits in ASD knowledge among the mothers of already diagnosed children in the present study. Although these variables did not significantly predict timing of mothers' first concerns or age at children's diagnoses in regression analyses, there were significant correlations found between these variables. This finding may suggest that increasing knowledge of early development and awareness of ASD in this group may lead to earlier ages of diagnosis.

As reported in prior research, Latina mothers endorsed higher levels of familism; however, in contrast to previous findings, there were no significant differences reported in perceived infant intentionality. This finding may indicate that the experience of having

a child with ASD alters the perception of early development in a way that is more powerful than culturally-based influences. Parents of children with developmental disorders are often reminded that their children may not fully understand the implications of their behavior, particularly in the treatment of disruptive behaviors in this population (Brookman-Frazee, Stahmer, Baker-Ericzén, & Tsai, 2006). This experience may lead to these parents perceiving less intentionality overall in children, thus decreasing culturally-based differences in these beliefs. Future studies should examine differences in perceived infant intentionality and knowledge of developmental milestones among Latina and EA mothers of children with ASD, children with developmental delays, and typically developing children to evaluate this theory. It is also notable that previous research using the infant intentionality tapes was conducted with parents whose children were less than 1 year of age (Feldman & Reznick, 1996). The results of the present study may indicate that parents of older children perceive infant behaviors differently than do parents of infants.

There was no evidence of DIF by ethnicity on either the SCQ or the FYI-R, although two items on the SCQ suggested possible DIF. This finding may indicate that mothers' perception of ASD symptoms is invariant across cultures, perhaps because ASD symptoms are so aberrant from typical behavior that they are less subject to cultural influences on symptom perception. However, it is important to note that the recommended approach for evaluating DIF is the use of analyses based on IRT within a much larger sample than was available in the present study. Therefore, while these results suggest that cultural differences do not have a strong impact on the functioning of these measures, further studies should be conducted using more powerful and

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sophisticated statistical procedures to evaluate the possibility of DIF on these and other measures of ASD symptomology.

It was also hypothesized that lower perceived infant intentionality and higher endorsement of familism would be correlated with decreased endorsement of repetitive/stereotyped behaviors and increased endorsement of social symptoms. These hypotheses were not supported. Interestingly, associations were found between endorsement of familism and higher scores on the subscales of sensory processing, repetitive play, and regulatory patterns. The higher scores reported for sensory processing and repetitive play impairments may be associated with familism because these behaviors are clear markers of abnormality, separating the child from the family and others. Mothers who endorse high levels of familism may be particularly sensitive to their child's abnormal behaviors that interfere with "fitting in" socially.

One of the broader contributions of the present study is an illustration of the feasibility and importance of including ethnic minority children and families in ASD research. The underrepresentation of ethnic minority individuals in ASD research is often noted but seldom addressed. Through its focus on Latino families and cultural factors in ASD, the present study provided information about the relevance of ethnicity and culture to ASD broadly and about the unique experience of this underserved group. Latino families are available and willing to participate in ASD research. It is vital that we broaden the participant base in ASD research in order to produce research that is representative of all children and families coping with this disorder, rather than only the most easily accessible.

Although this study offers several important contributions to the research on ASD, there were also several limitations that should be noted. This is one of a very few studies that has specifically targeted Latino families of children with ASD, and the sample size was thus relatively small. This fact limited the ability to detect subtle effects, and in particular, the ability to test for DIF.   Additionally, this study retrospectively investigated the cultural factors that may influence the diagnostic process in ASD. Although this provides an important starting point, prospective studies of families actively undergoing the process of ASD screening and diagnosis would likely be better able to answer the questions posed in the present study.  Larger prospective studies would also allow us to determine whether current screening procedures fail to identify Latino children with milder forms of ASD as at-risk.  Future studies should also examine differences between families of children with other developmental delays, those with typical developing children, and those of children with ASD.  There may be important differences between how mothers of children with ASD or other developmental disorders perceive their children, relative to those with typically developing children.

In summary, the present study found several important differences between the experiences of Latino and EA families of children with a diagnosed ASD.  Children of Latina mothers were generally diagnosed later than their EA peers and appeared to be more severely impaired.  Latina mothers also demonstrated less knowledge of ASD and of developmental milestones than their EA counterparts.  Additionally, Latina mothers were also likely to report early concerns about their child's temperament.  This study suggests that greater education about ASD is needed within the Latino community and

that providers may need additional training in communicating with Latino parents about their children's development and risk for ASD.

Table 1

*Demographic Characteristics by Ethnicity.*

|  | European American Mean (SD) | Latina/Hispanic Mean (SD) |
|---|---|---|
| N | 28 | 28 |
| Child Age (Years) | 7.49 (1.68) | 7.42 (1.56) |
| Maternal Age (Years) | 38.96 (3.45)* | 35.32 (6.62)* |
| Annual Household Income † | 89,625.48 (35188.59)** | 31,768.29 (24845.03)** |
| Median Income | 99,000.00 | 22,100.00 |
| Maternal Education (Years) | 16.14 (1.33)** | 9.93 (4.28)** |
| Weekly Intervention Hours | 3.61 (.89) | 6.91 (2.16) |
| Child Age at Diagnosis (Months) | 34.07 (11.89)* | 41.57 (16.73)* |

*p< .05
**p< .001

† Note: An extreme outlier in the EA group with an annual income of $500,000 was eliminated from this line of the table and from all relevant analyses.

Table 2

*Autism Characteristics by Ethnicity.*

|  | European American Mean (SD) | Latina/Hispanic Mean (SD) |
|---|---|---|
| N | 28 | 28 |
| Child Age at First Concern (Months) | 16.61 (10.06) | 14.55 (10.70) |
| Child Age at Diagnosis (Months) | 34.07 (11.89)* | 41.57 (16.73)* |
| Time to Diagnosis (Months) | 17.46 (11.50)* | 27.02 (17.92)* |
| Visits to Obtain Diagnosis | 2.61 (1.62) | 2.46 (.88) |
| Types of Intervention | 3.96 (1.43) | 4.14 (3.60) |
| Weekly Intervention Hours | 3.61 (.89) | 6.91 (2.16) |
| SCQ Total Score | 17.07 (5.82) | 18.11 (5.29) |
| Child Age at First Words (Months) | 22.38 (15.22)** | 38.00 (23.50)** |
| Child Age at Toilet Training (Months) | 49.76 (11.67) | 56.68 (20.74) |

*p< .05
**p<.01

Table 3.

*Maternal Knowledge and Perceptions by Ethnicity.*

|  | European American Mean (SD) | Latina/Hispanic Mean (SD) |
|---|---|---|
| N | 28 | 28 |
| ASD Knowledge Items Correct (Range 0-41) | 37.21 (3.68)** | 30.39 (5.10)** |
| ASD Knowledge Items Answered "I Don't Know" (Range 0-41) | 1.75 (2.94)** | 4.89 (4.71)** |
| Developmental Milestones Knowledge: Average Months from Correct | 3.33 (.97)* | 4.13 (1.26)* |
| Perceived Infant Intentionality (Range 28-224) | 151.54 (22.25) | 153.21 (23.68) |
| Familism (Range 18-180) | 103.11 (18.00)** | 138.07 (18.91)** |
| Acculturation to Latino Culture (Range 12-48) | 13.54 (2.81)** | 44.04 (3.65)** |
| Acculturation to U.S. Culture (Range 12-48) | 47.68 (1.70)** | 22.32 (7.60)** |

*p<.01
**p<.005

Figure 1.

*Child Age at Diagnosis by Annual Household Income.*
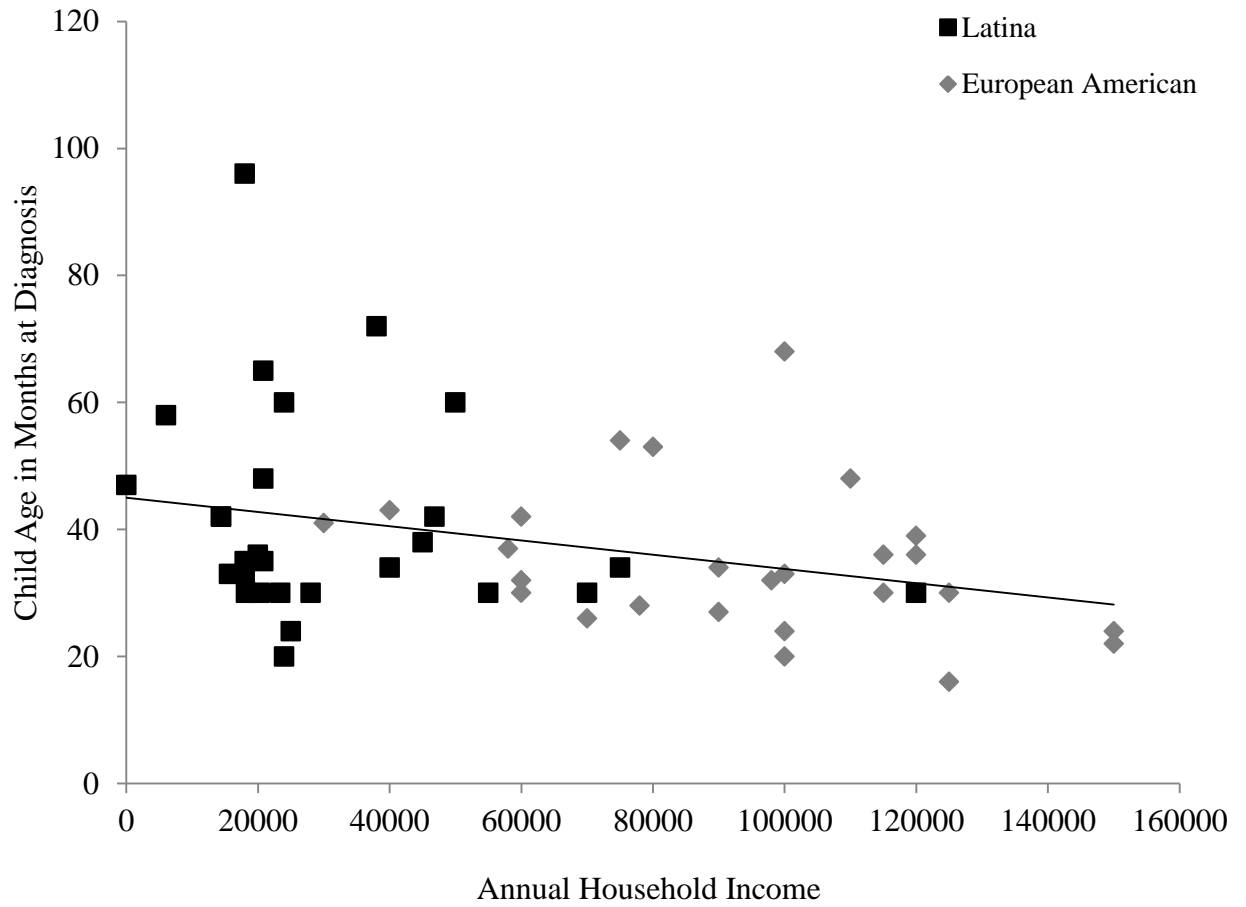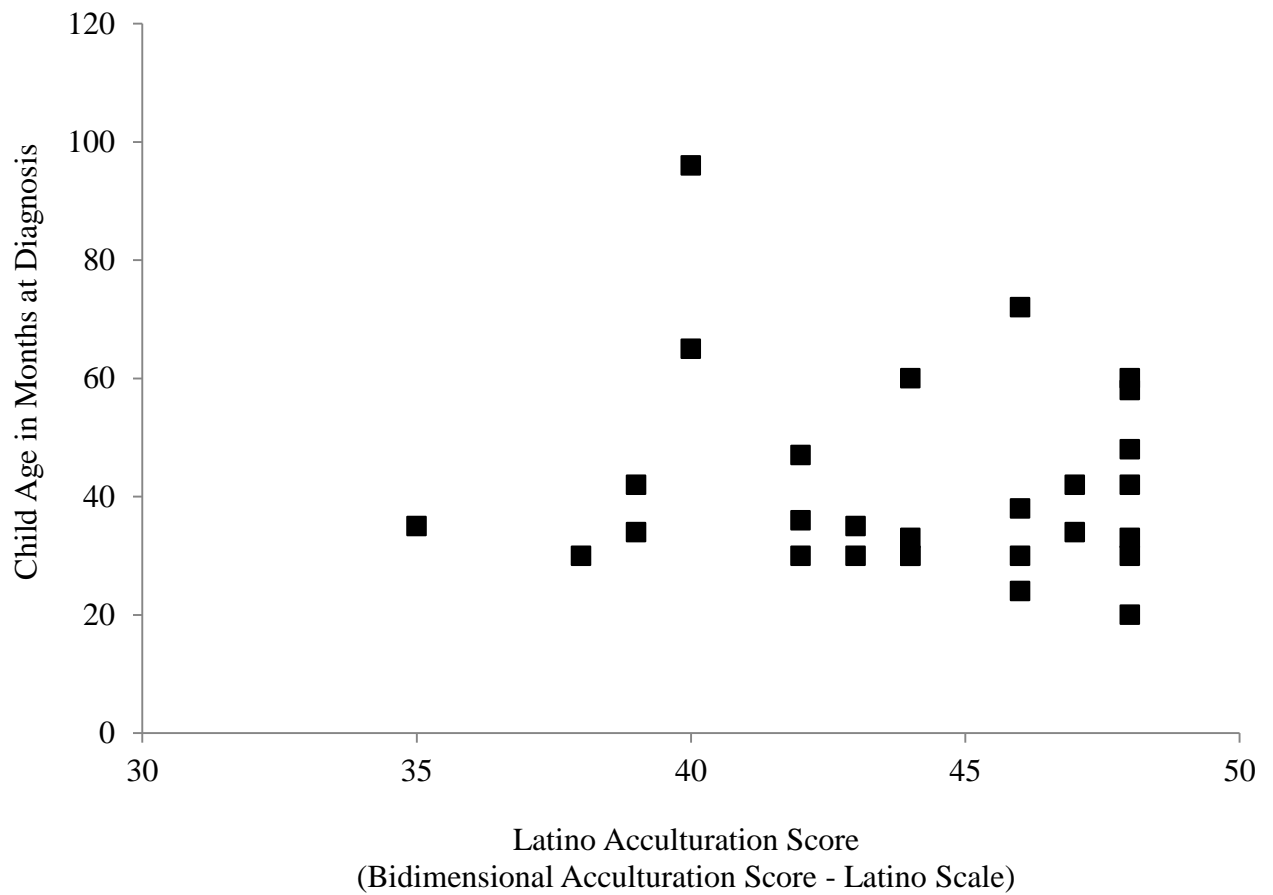


F=6.08, p<.02

$R^2 = .10$

*Note: Extreme outlier of $500,000 was eliminated from analyses

Figure 2.

*Child's Age at Mother's First Concern by Mother's Degree of Affiliation with Latino Culture among Latina Mothers Only.*
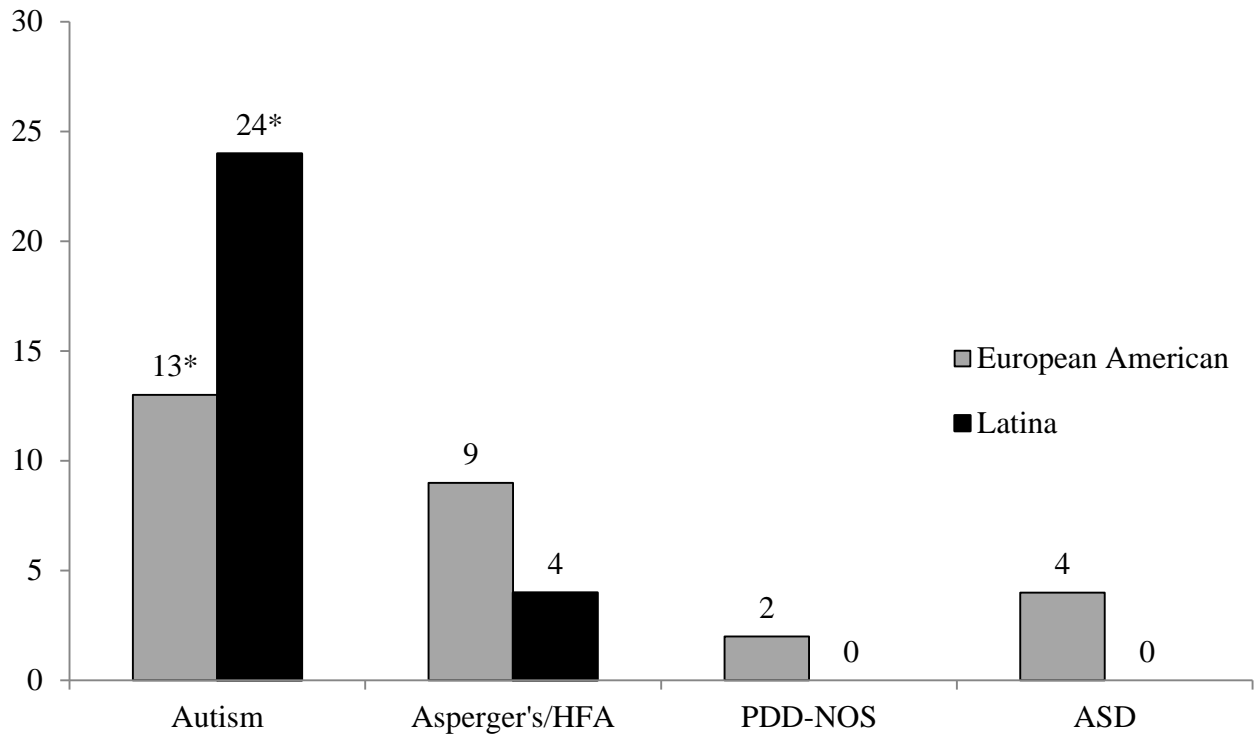


F=5.07, p<.03

$R^2$=.16

Figure 3.

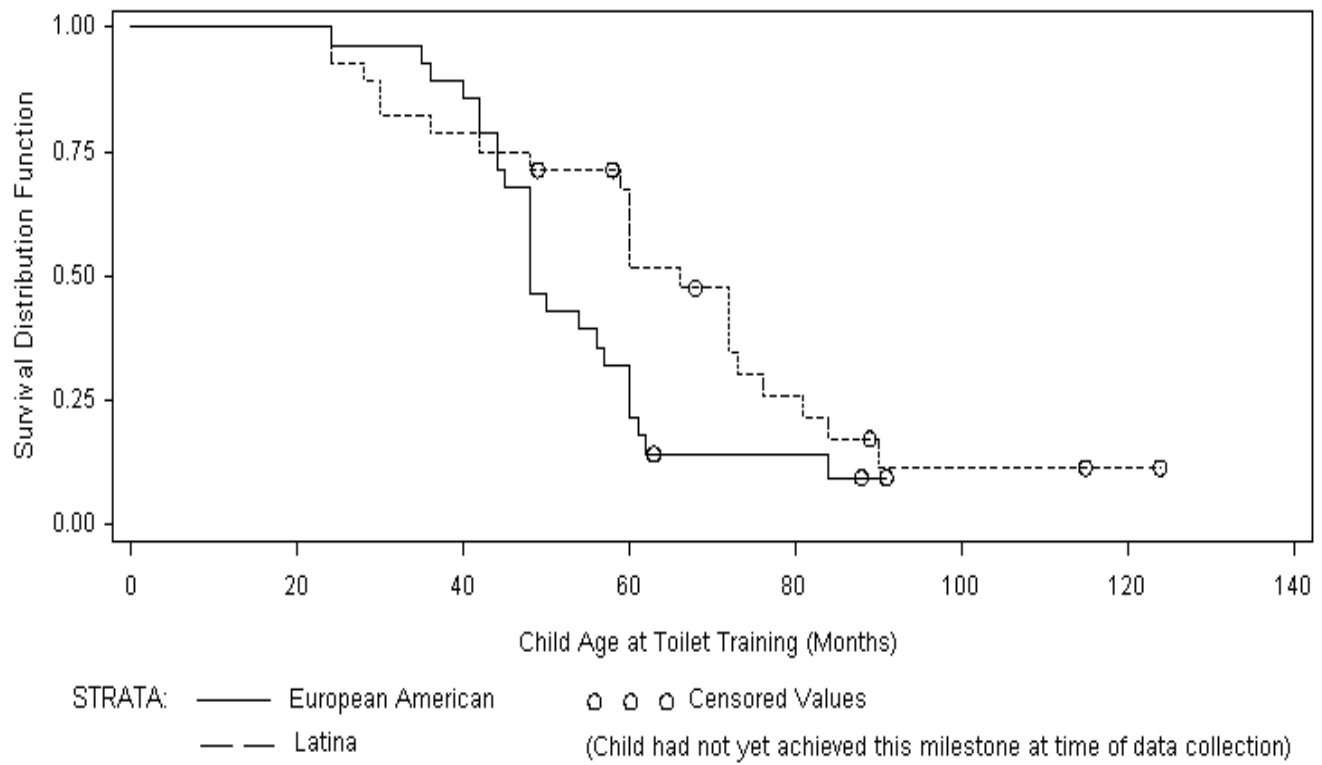*Autism Spectrum Diagnoses by Maternal Ethnicity.*



$*\chi^2 = 10.10$ (p<.001)

Log-odds ratio = 6.92

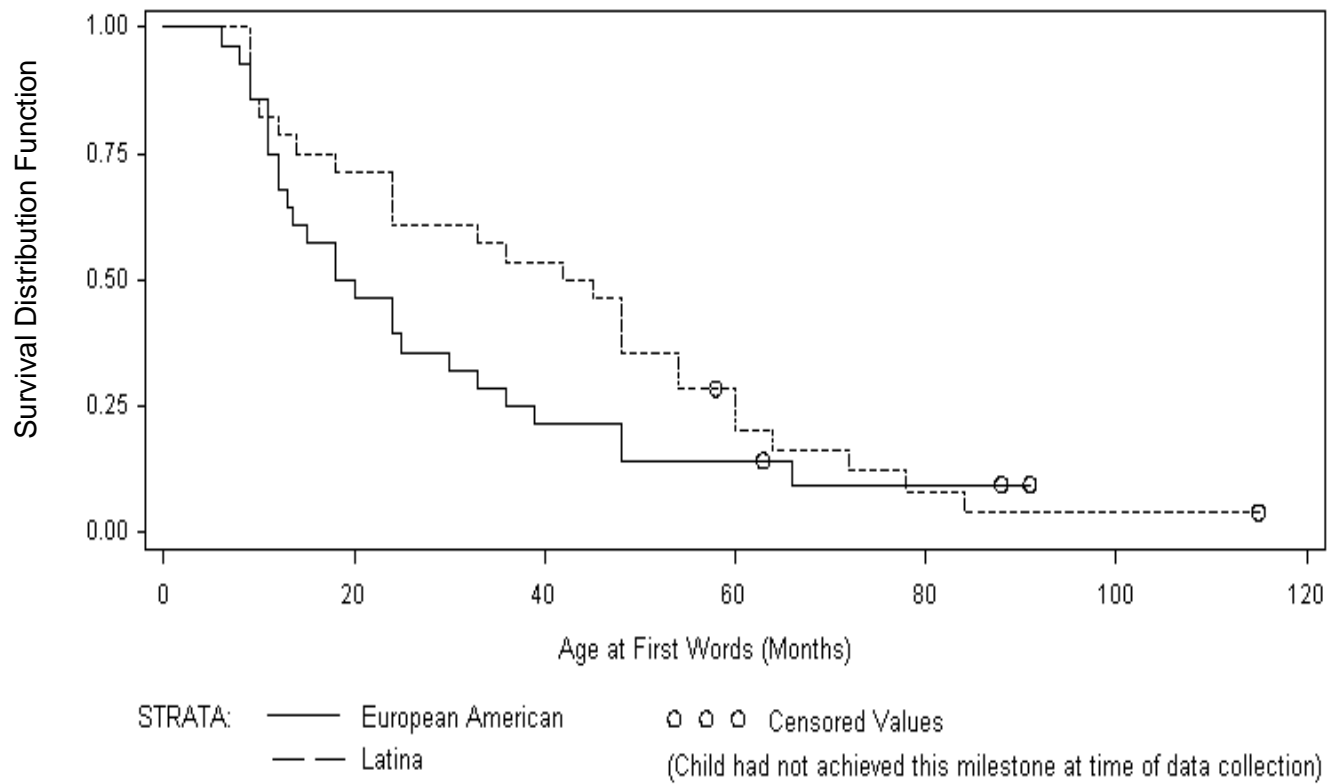Figure 4.

*Survival Analysis of Child's Age at Toilet Training Stratified by Maternal Ethnicity.*



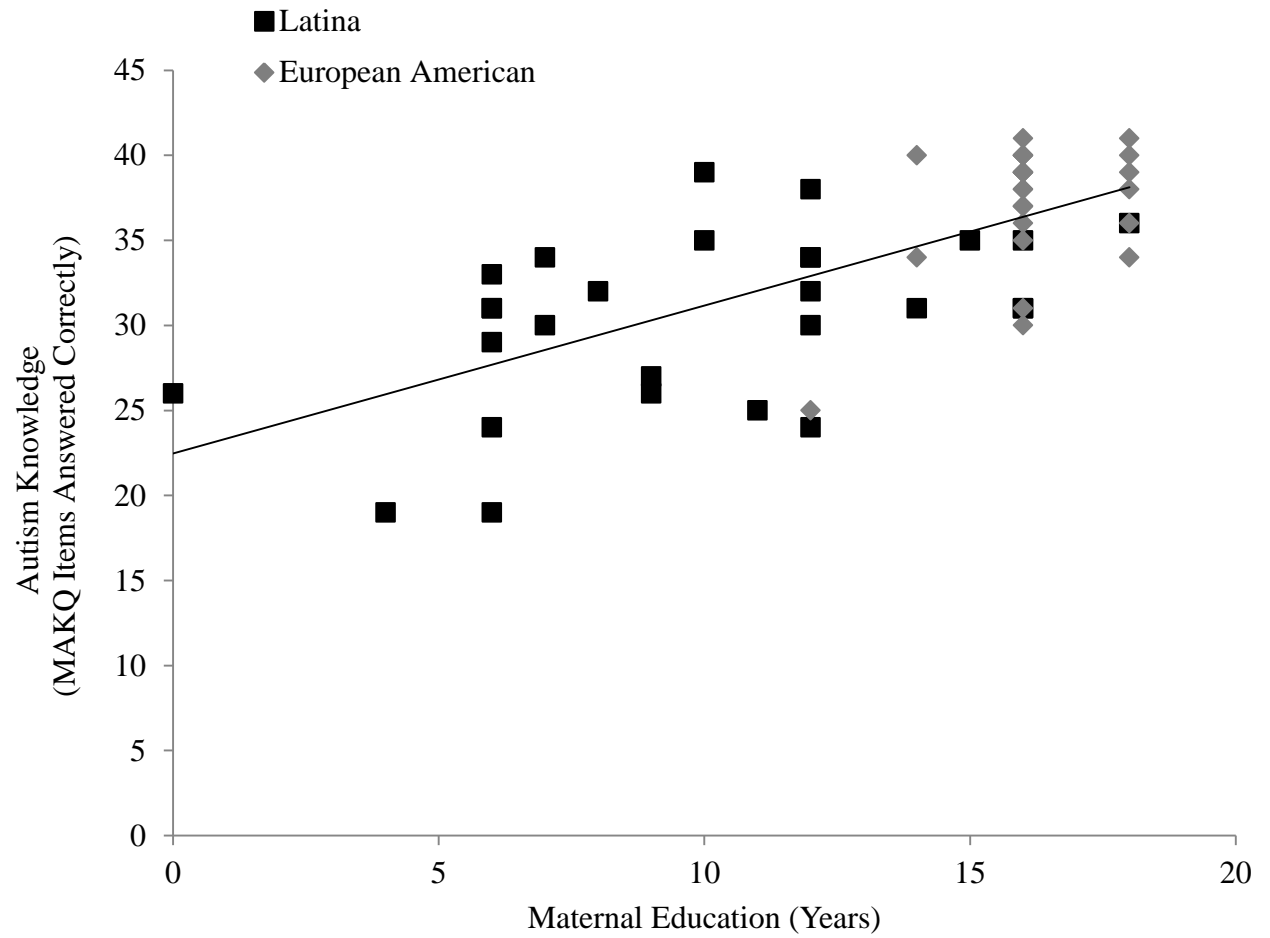Log-rank $\chi^2$=4.54, p<.03

Figure 5.

*Survival Analysis of Child's Age at First Words Stratified by Maternal Ethnicity.*



Wilcoxon $\chi^2$ = 3.11, p<.08

Figure 6.

*Association between Education, Ethnicity, and Mothers' Knowledge of ASD.*



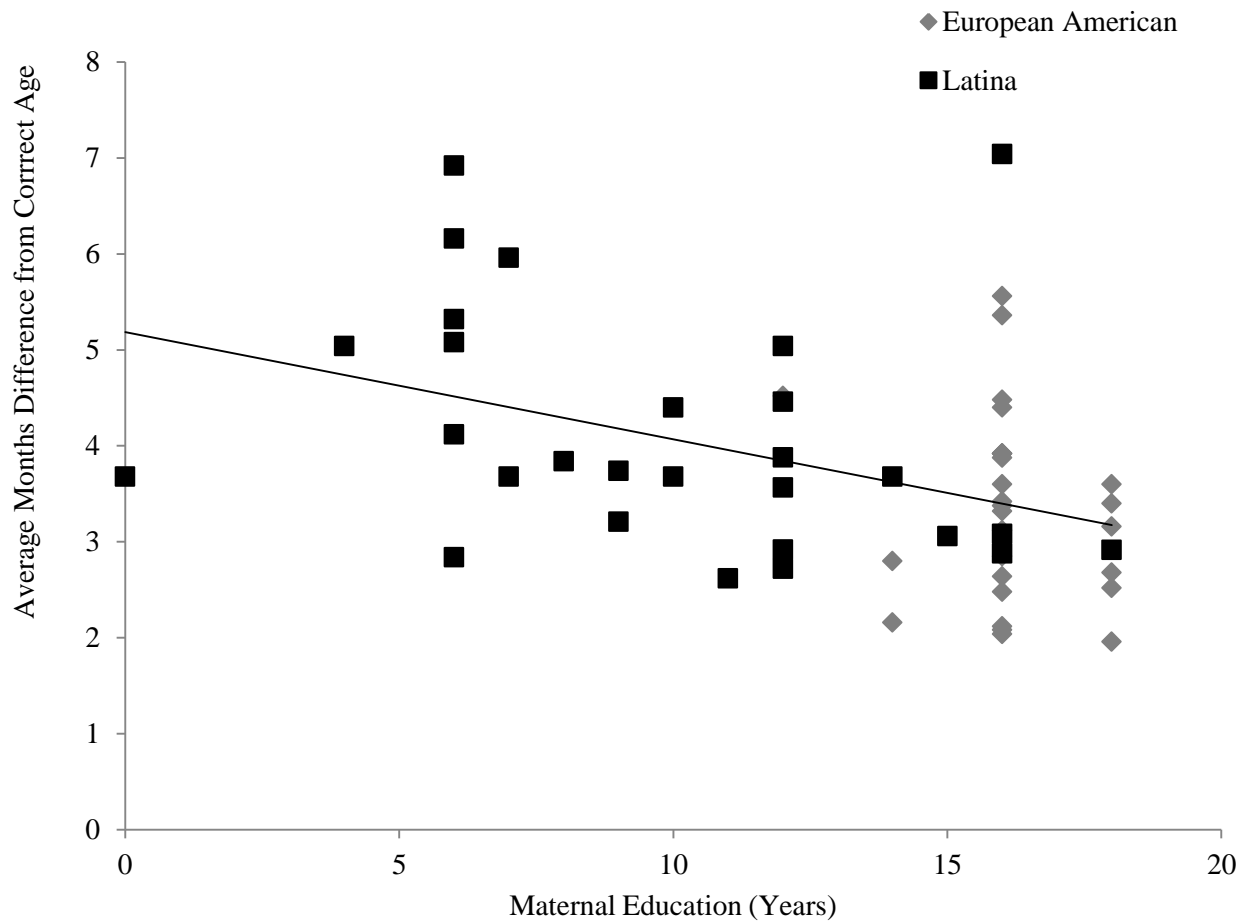F=27.04, p<.001

$R^2$=.51

Figure 7.

*Association between Maternal Education and Knowledge of Developmental Milestones.*
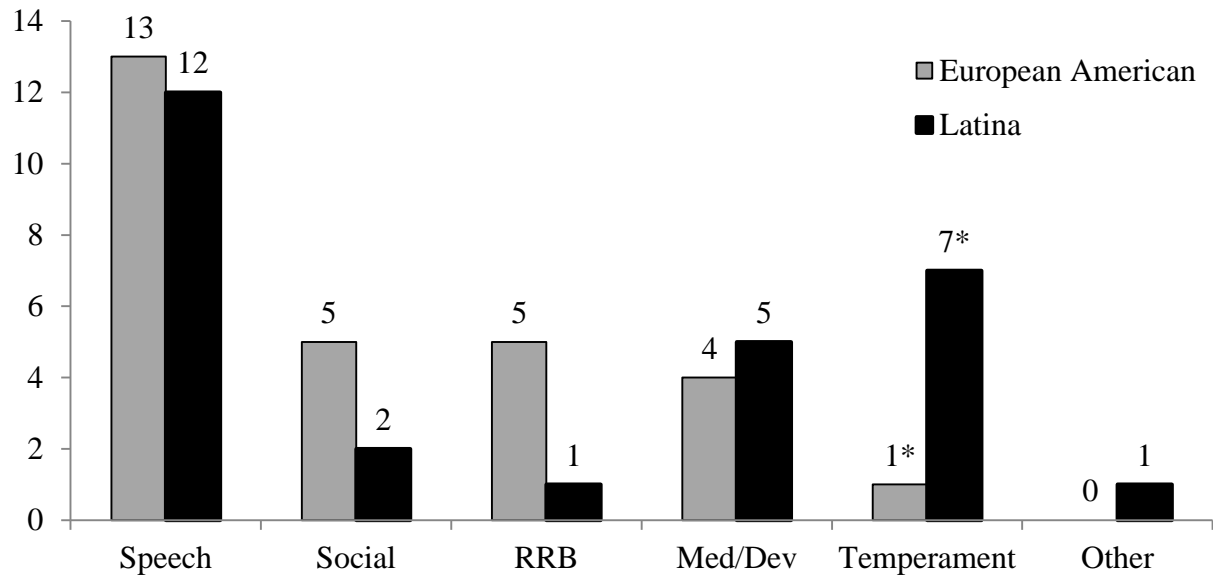


F=11.47, p<.001

R$^2$=.18

Figure 8.

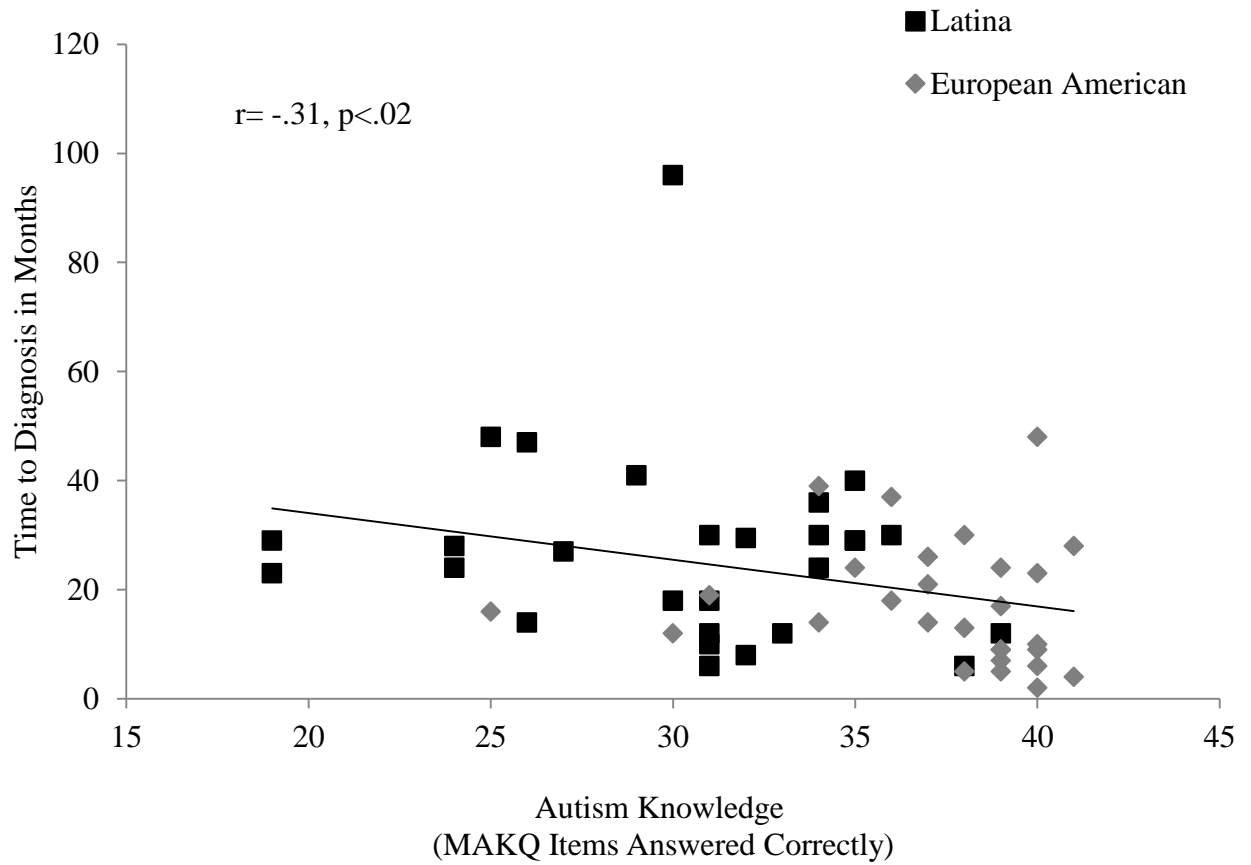*Mothers' First Concerns about Child by Ethnicity.*



$*\chi^2 = 5.81$, p<.02

Log-odds ratio = 9.00

Figure 9.

*Time between Mother's First Concern and Child's Diagnosis by Maternal Knowledge of ASD.*

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