

INVESTIGATING DISPARITIES IN THE AGE OF DIAGNOSIS OF AUTISM  
SPECTRUM DISORDERS

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## **ABSTRACT**

**TWYLA PERRYMAN: Investigating Disparities in the Age of Diagnosis of Autism Spectrum Disorders**  
(Under the direction of Linda R. Watson)

Research has documented later ages of diagnosis of Autism Spectrum Disorders (ASD) for children from minority backgrounds. In an effort to understand what may lead to differences in age of diagnosis or recognition of symptoms, researchers have mainly examined child related factors such as severity, co-existing medical conditions, or cognitive skills. However, very few studies have explored the impact parental factors such as empowerment levels, or reactions to and attributions of symptoms, have on the age of diagnosis of ASD. The objectives of this study were to investigate timing of diagnosis for African American and White children with ASD while examining associations between caregiver related factors, cultural group, and age of diagnosis. Using survey methods, a total of 168 North Carolina families were recruited and met inclusion criteria for the study. Caregivers reported on diagnostic factors, empowerment, and views related to initial ASD-related symptoms. There were no statistically significant group differences found in the age at diagnosis of ASD. Factors associated with age of diagnosis were: severity of symptoms, caregivers' level of worry about initial ASD symptoms, and caregivers' attributions of the symptoms to behavioral problems. These findings highlight the value of caregivers' roles in the early identification of ASD, and provide implications for promoting public awareness of symptoms related to ASD.

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## **CHAPTER 1**

### **Introduction**

#### *Statement of the Problem*

Utilization of appropriate early intervention (EI) services for children with Autism Spectrum Disorders (ASD), which affect the development of social and communication skills, is contingent upon accurate and early identification. Longitudinal research has demonstrated that EI for children with ASD may improve overall outcomes and enable them to lead lives closer to those of non-disabled peers (Harris & Handleman, 2000; Kasari, Paparella, Freeman, & Jahromi, 2008; Turner, Stone, Pozdol, & Coonrod, 2006). Unfortunately, research has also shown that children with minority backgrounds may be receiving later autism diagnoses than White children (Mandell, Listerud, Levy, & Pinto-Martin, 2002). Conceivably, this discrepancy could result in differences in the utilization of EI and other important support services. With advances in our ability to identify autism symptoms earlier than 3 years of age (Baranek, 1999; Osterling & Dawson, 1994; Turner et al., 2006), disparities in children's age at diagnosis warrant both attention and scrutiny. Understanding why these differences exist will help the communities at large (e.g. medical, allied health, childcare providers, and families) address discrepancies in the utilization of EI services.

### *Diagnostic Features and Screening Practices*

Autism Spectrum Disorders (ASD) are a subset of neurodevelopmental disorders now estimated to affect 1 in 150 children (Centers for Disease Control [CDC], 2007). ASD is characterized by a triad of observable features involving qualitative impairments in communication skills and social interactions, and restricted or repetitive behaviors or interests (American Psychiatric Association [APA], 2000). At present, biological or genetic testing to diagnose ASD is not possible; therefore, diagnoses are based on clinical features.

Several screening tools can be used to detect both general developmental delays and more specific impairments associated with ASD in young children. Ideally, medical professionals such as pediatricians or general practitioners would use them during regular checkups and refer for comprehensive evaluation those children who screen positive for delays or difficulties with social interaction and communication (Johnson, Myers, & the Council on Children with Disabilities, 2007). However, research has demonstrated that fewer than 10% of physicians routinely test for ASD (DosReis, Weiner, Johnson, & Newschaffer, 2006). In large samples, screeners have been shown to identify a significant number of children who may be at risk for ASD as early as 18 to 24 months of age (Robins & Dumont-Mathieu, 2006; Kleinman et al., 2008). Although these screeners are not perfect measures, they can serve as an effective first step in early detection of developmental difficulties.

Physicians should combine screenings with their clinical judgment while also understanding that it is best to refer for comprehensive assessment if ASD is even marginally suspected. Physicians should use parental concerns as another measure of risk and refer children who fail screenings or show symptoms of ASD to psychologists, psychiatrists,

neurologists, or other clinicians for further assessment with specialized diagnostic instruments. In short, early diagnosis of ASD may be largely dependent upon routine observations made by health care professionals and/or parents seeking assistance.

#### *Previous Research on Age of Diagnosis*

Early diagnosis of ASD is important for two major reasons. First, parents often begin to have concerns about their child's development between the ages of 1 to 2 years of age (De Giacomo & Fombonne, 1998; Howlin & Moore, 1997). However, these parents usually do not have an explanation or support for dealing with symptoms associated with ASD. Some have reported feeling desperate for answers and many felt relieved upon receiving a diagnosis (Mansell & Morris, 2004). Receiving a diagnosis also can encourage parents to tap into resources developed specifically for families of children with ASD such as local societies (e.g. Autism Society) or informal family support groups. Additionally, these parents may receive formal support from the early intervention system (e.g. service coordinators, respite, interventionists).

The second reason for the significance of early diagnosis stems from findings that it can lead to early intervention, which in turn can lead to better social and language outcomes. In one study, school-aged children who had received more intensive early speech and language intervention services, compared to a group with later diagnoses and later intervention services, had higher cognition and language skills (Turner et al., 2006). Another study observed that specialized services at younger ages increased placement in regular education settings, perhaps due to academic performance closer to that of typically developing peers (Harris & Handleman, 2000).

Prior to the recent advances in early diagnosis, research into the diagnosis of ASD documented the average age at diagnosis to be well over 6 years (Howlin & Moore, 1997; Mandell et al., 2002) and even later for children from minority populations (Mandell et al., 2002). In fact, the latter study found that African American and Latino children were diagnosed 1.4 to 2.0 years later than White children (Mandell et al., 2002). This study derived its data from existing Medicaid and other health records. A study published in 2005 did not find a significant age discrepancy between samples of White caregivers and caregivers from minority backgrounds who have children with ASD (Mandell, Maytali, & Zubritsky, 2005). Instead, children from households with lower incomes received a diagnosis of ASD later than those from families whose incomes were greater than 100% above the poverty level. However, in contrast to Mandell's earlier findings, the overwhelming majority of the participants were White (84%), had an income level greater than 200% above the poverty level, and responded via Internet to the survey. The methods of participant selection and response (Internet survey) yielded a sample from a different population than the previous study, thus limiting the comparison of the two studies. Given the differences in methodology utilized in the studies, evidence suggests that an age-of-diagnosis gap may persist for non-White racial or ethnic groups who experience low socioeconomic status (SES), relative to Whites who have low-SES. This age gap may continue even as the overall age of diagnosis decreases due to advancements in assessments and increased awareness.

In response to the apparent increase in the prevalence of ASD, the Centers for Disease and Control (CDC) have established a Multisite Monitoring Network for the Prevalence of ASD (<http://www.cdc.gov/Features/CountingAutism>) comprised of several

national research sites that monitor the prevalence rates of ASD through record reviews. However, findings about differences in the prevalence of ASD among ethnic/racial groups based upon reports from the various monitoring sites have been inconsistent. Three of the four sites with access only to health records found a significantly higher prevalence among non-Hispanic white children when compared to non-Hispanic black children, whereas only two of the ten with access to both health and education records found this significant difference between the two racial groups (CDC, 2007). Although these data represent rough estimates of prevalence, one implication may be that sites that have access to both health and education records include more minorities in their prevalence rates because these children were identified later, through the educational process instead of the healthcare system (which typically has earlier contact with young children and their families). Currently, the consensus among national health authorities is that all racial/ethnic groups are equally susceptible to ASD (CDC, 2007), which implies that there are no differences in the prevalence of ASD as a function of race or ethnicity. As stated above, it is premature to conclude that an age of diagnosis gap no longer exists for children from racial and ethnic minority populations and/or low SES populations who have ASD, and this is an issue that warrants further investigation.

#### *Theoretical Framework and Caregiver Related Factors Influencing Age of Diagnosis*

In an effort to understand the cause of reported disparities in the age of diagnosis of ASD among minority populations, researchers have suggested several possible reasons. These explanations have mainly proposed that external factors such as those related to accessing the health care system, experiences with health care providers, presence of support systems, and SES contribute to the discrepancy; however, to date they lack supporting

scientific evidence (Mandell et al., 2002). Further, researchers have not considered the potential impact of internal factors on age of diagnosis. Internal factors are related to personal beliefs, values, and behaviors. Caregivers' views about the behaviors related to ASD, which may determine when and if medical assistance is sought, can be influenced by factors such as culture and knowledge of expectations for child development. For this study, race will serve as a proxy for underlying variations associated with culture (i.e. shared meanings, values, and experiences among a group of people). The effect of cultural factors on the processes leading to help-seeking has been examined in the field of mental health. Cauce et al. (2002) presented a theoretical framework for understanding how cultural and contextual factors may determine help-seeking behaviors for mental health services. According to their framework, differences in cultural and family variables will likely affect all three interrelated stages along the help seeking pathway: problem recognition (epidemiologically defined need or perceived need), the decision to seek help, and the selection of help-providers. In other words, varied experiences among groups can lead to different interpretations of challenging behaviors in children, influencing how caregivers deal with these behaviors (e.g. seeking help or attempting to deal with behaviors with formal support). In the current study, two internal factors (caregiver reactions to and attributions of ASD symptoms) related to the problem recognition stage of the help-seeking model (Cauce et al., 2002) were measured and analyzed for cultural differences and associations with age of diagnosis of ASD.

Although no published studies have investigated the potential impact of cultural beliefs on the diagnosis or treatment of autism, research has shown that culturally linked



attitudes affect how different cultural populations respond to other disabilities such as Attention Deficit Hyperactivity Disorders (ADHD); Bussing, Schoenberg, Rodgers, Zima, & Angus, 1998). Investigating cultural differences in the context of other developmental and learning disorders may increase our understanding of how they influence identification of and intervention in ASD.

If a caregiver recognizes and interprets that behaviors may be related to developmental challenges, a third internal factor, caregiver empowerment, may play a major role in early identification of ASD. Although the concept of caregiver empowerment has traditionally been examined in the domain of early intervention (Dunst, 1985; Dunst, 2000; Thompson, Lobb, Elling, Herman, Jurkiewicz, & Hulleza, 1997), it has significant implications for early diagnosis. One survey of caregivers found that a significant minority reported major difficulties obtaining a referral for evaluation and had to exert considerable pressure on their practitioner to receive one (Howlin & Moore, 1997). Therefore, a caregiver's ability to respond to challenges, access resources, and control outcomes (i.e. empowerment) may impact how successfully appropriate referrals can be obtained for very young children, especially if the physician or other medical providers do not share the same concerns. The current study will expand on the Cauce et al. (2002) help-seeking model by examining the contribution of empowerment in the help-seeking process eventually leading to ASD evaluation and diagnosis

Finally, it is important to recognize that child-related factors (e.g. severity of ASD symptoms, other medical conditions) may also influence when parents seek professional help (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; Giacomo & Fombonne, 1998). If a

child's behaviors are intense enough to interfere significantly with everyday functioning, parents may become concerned earlier. Additionally, symptoms such as delayed expressive language development may trigger parental concern over more subtle symptoms such as lack of gesture use. Parents of children with more severe or noticeable symptoms may be more zealous and persistent in their search for explanations. Clearly, the timing and magnitude of parental concern can directly impact diagnosis of ASD.

### *Summary*

This body of research suggests many important issues regarding reported age disparities in the diagnosis of ASD and demonstrates a substantial gap in the current knowledge base. This study hypothesizes that internal factors, such as caregiver empowerment, magnitude of concerns, and attribution of initial ASD symptoms, can influence the age of diagnosis in addition to external factors. Investigating both types of variables will improve understanding of the origins of this health disparity.

The knowledge gained from examining internal factors can be used to improve and frame public health initiatives to increase earlier identification and access to early intervention services. In the efforts to design outreach and public awareness programs, it will be increasingly important to document, understand, and directly address barriers to early diagnosis of ASD. Parents, educators, and healthcare providers armed with this knowledge will be able to promote proactively earlier diagnosis of developmental disorders and autism. These efforts may include offering community workshops that teach advocacy skills, typical development, and warning signs for ASD to new parents and community providers.

### *Research Questions*

The proposed research will be guided by the overarching question, “What factors influence the age of diagnosis of autism?”. The specific questions to be addressed include:

1. Is there a difference in the age of diagnosis of ASD between African American and White children in North Carolina?
2. Are there differences in the level of empowerment, level of worry about initial ASD symptoms, and attributions of initial ASD symptoms between African American and White caregivers?
3. Can age of diagnosis be predicted by SES, caregiver empowerment, level of worry about initial ASD symptoms, attributions of initial ASD symptoms, or severity of symptoms?

## **CHAPTER 2**

### **Review of the Literature**

#### *Overview of Chapter*

On average, ASD is diagnosed after 3 years of age (Mandell et al., 2005; Goin-Kochel, Mackintosh, & Myers, 2006). However, because research has shown that it can be diagnosed earlier, this study will consider an early diagnosis as one that occurs prior to the third birthday. The following literature review will provide a summary of research related to early diagnosis of ASD. First, studies examining the prevalence of ASD will be presented to show the wide-reaching impact it can have on the lives of children and families. After introducing current trends in prevalence rates, it is important to describe the complexities involved in diagnosing this disorder in order to demonstrate how various factors can lead to a later age of diagnosis. Therefore, this literature review will outline the diagnostic features of ASD as well as the typical tools used in the screening and diagnostic process. Because the expression of ASD symptoms can be more subtle early in life, the accuracy of screening and diagnostic tools may be impacted when used with younger populations--especially if these young children experience regression or loss of skills. For this reason, and because successful advocacy for earlier diagnosis is contingent upon demonstrating its stability over time, the stability of ASD diagnosis prior to the age of 3 will also be discussed. Promoters of early diagnosis realize its benefits for the families of children affected by ASD, as well as for the

children themselves. Accordingly, studies of positive effects associated with early diagnosis will be reviewed. After outlining the procedures, complexities, and benefits of early diagnosis, this review will summarize previous research about the age of diagnosis of ASD. Then, this review will present research that examines the role of physicians and parents in early diagnosis, highlights the importance of caregivers' concerns as a catalyst for early diagnosis, and reveals long-term trends in the age of diagnosis and lingering gaps in the literature base. Finally, implications for caregiver-related factors that affect age of diagnosis will be discussed, along with a summary of research about caregiver empowerment and caregivers' beliefs about developmental and learning disabilities.

### *Epidemiology and Prevalence of ASD*

Historically, autism was viewed as a relatively rare disorder affecting the social development of children. Recent reports of increases in prevalence, however, have resulted in greater attention to and public awareness of ASD. Here it is important to distinguish between incidence and prevalence, which are often mistakenly interchanged. Prevalence refers to reported cases at a specific time whereas incidence refers to the rate of new cases within a period of time (Volkmar, Lord, Bailey, Schultz, & Klin, 2004, p. 139). Because of the difficulty in accurately counting all new cases, ASD is most often reported in terms of prevalence.

Examples of growth in the prevalence of ASD are numerous in the literature. In California alone, the reported proportion of children receiving ASD services increased from 0.6 to 1.5 per thousand between 1987 and 1994 (CDC, 2007). In Minnesota, the reported prevalence of ASD in 8-year-olds increased from 2 to 6.6 per thousand from 1997 to 2002

(CDC, 2007). Similar trends are being reported all over the United States. In fact, the number of children in the U.S. receiving special education services under a diagnosis of ASD increased 500% from the 1991–1992 school year to the 1998–1999 school year (CDC, 2007). As noted above, the current estimation for ASD prevalence in the United States is 1 out of 150 children (CDC, 2007). By far, the most baffling question for researchers, parents, and physicians is, “What is causing the observed increase of ASD prevalence?”

Researchers have postulated a number of factors that partly contribute to or complicate the investigation of increased prevalence of ASD. They include: (a) changes in diagnostic practices, (b) increased awareness, (c) earlier diagnosis, (d) issues of study design, and (e) diagnostic substitution (Volkmar et al., 2004). Diagnostic substitution has been given two definitions in the literature. It is said to occur when a child is given a label of ASD (as opposed to a label of mental retardation) for educational or intervention purposes (Volkmar et al., 2004). It has also been said to comprise children who would have received a label of mental retardation in the past but have been diagnosed with ASD due to changes in diagnostic practices (Parner, Schendel, & Thorsen, 2008).

To date, very few studies have measured the effects of changes in the diagnostic process on the prevalence of ASD. A recent study in Denmark examined how shifts in the age of diagnosis (i.e. from later to earlier) may impact the reported prevalence rate. Researchers who designed a cohort study of 2,649 children born between 1994 and 1999 using data from a national registry concluded that earlier diagnosis in the younger cohorts artificially inflated differences in the observed prevalence rate among younger cohorts

(Parner et al., 2008). When the length in follow-up was increased, the differences in prevalence decreased.

Even with changes in diagnostic practices, researchers in British Columbia have been able account partially for the reported increase in the prevalence of ASD due to variables such as diagnostic substitution (Coo et al., 2007). Thus, it is possible that a combination of factors are contributing to the reported rise in the prevalence of ASD, including a true increase in the occurrence of ASD. Therefore, researchers caution against concluding that an earlier age of diagnosis (Parner et al., 2008) or diagnostic substitution are solely responsible for increases in the prevalence of ASD. While it is encouraging to note that overall progress in the early diagnosis of ASD may be occurring, information about factors that contribute to or hinder early diagnosis is still lacking. Furthermore, it has not been determined if children from all minority and lower SES backgrounds are benefiting from earlier diagnosis at the same rate as non-minority or higher SES groups.

#### *Review of Literature on Defining Features and Diagnosis*

The following section will present the diagnostic features of ASD. Providers and clinicians qualified to diagnose ASD compare behaviors observed in children to the following clinical features during the diagnostic process.

#### *Autism Spectrum Disorders Classifications*

Autism spectrum disorders are a group of developmental disabilities that can cause impairments in social interaction and communication. This group includes autistic disorder, Asperger's disorder, and pervasive developmental disorders not otherwise specified (PDD-NOS). The latter condition (PDD-NOS) includes atypical autism. Combined with two other

developmental disabilities, Rett syndrome and childhood disintegrative disorder, these five conditions make up the broad diagnosis category of pervasive developmental disorders (PDDs). This study will cover the three diagnoses that are generally included as ASDs rather than all of the conditions under the PDDs. Additionally, for consistency with the terminology typically used by other researchers, children diagnosed with autistic disorder will be referred to as “children with autism.”

ASDs are diagnosed according to three types of observed clinical features listed in both the *Diagnostic and Statistical Manual for Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR; APA, 2000) and the *International Classification of Mental and Behavioral Disorders* (ICD-10; World Health Organization [WHO], 2007). The three categories of features are: (a) deficits in social interactions, (b) impairments in communication, and (c) the presence of restrictive, repetitive, and stereotyped patterns of behaviors. Each clinical category is accompanied by a list of diagnostic symptoms that describe specific impairments associated with ASD.

To receive a diagnosis of autistic disorder based upon the DSM-IV or ICD-10 criteria, children must exhibit a total of six or more diagnostic symptoms for all three categories. At least two of those symptoms must be from the social interaction category and at least one symptom must come from each of the other two feature categories (communication and restrictive repetitive and stereotyped behaviors). For social interaction, diagnostic symptoms are: (a) impairments in nonverbal communication, (b) failure to develop peer relationships, (c) not seeking to share enjoyment or interests, and (d) lack of social or emotional reciprocity. For communication development, the first diagnostic symptom is delay or lack of



spoken language development without alternative, compensatory modes (i.e. gestures or signs). For individuals who are verbal, diagnostic symptoms are: (a) impairment in the ability to initiate or sustain conversations, (b) stereotyped and repetitive use of language, and (c) lack of spontaneous pretend and social imitative play. Finally, restrictive and repetitive stereotyped behavior symptoms are listed as: (a) preoccupations, (b) inflexibility with routines and rituals, (c) motor mannerisms, and (d) persistent preoccupation with parts of objects. For a diagnosis of autistic disorder, significant delays or abnormal functioning must be present in at least one of the following prior to the third birthday: (a) social interaction, (b) language as used in social communication, or (c) symbolic or imaginative play.

Asperger's disorder is often distinguished from autistic disorder by higher intelligence quotients and no evidence of a clinically significant speech or language delay (Filipek, 1999; Folstein, 1999). However, children with Asperger's still exhibit poor flexibility in their use of language and have significant difficulty with abstract language. A diagnosis of PDD-NOS (synonymous with atypical autism [ICD-10]) is reserved for children who do not meet the full criteria for autistic disorder or Asperger's disorder. For example, children with PDD-NOS may meet criteria for only 2 out of 3 of the diagnostic categories (but must exhibit problems in the category of social interaction), or may exhibit only 5 symptoms overall rather than exhibiting a total of 6 symptoms (Filipek, 1999; Folstein, 1999). Other reasons that these children may not meet criteria for autistic disorder include late age of onset, atypical symptomatology, or subthreshold symptomatology (DSM-IV-TR, 2000).

### *Early Symptoms and Early Diagnosis of ASD*

The process leading to early diagnosis of ASD begins with the recognition of early symptoms by either parents and/or health care providers. Guided by the DSM-IV and ICD-10 diagnostic criteria, investigators have used various techniques and study designs to determine early indicators of ASD. These include retrospective video observations and longitudinal designs that follow infants with higher genetic risk for developing autism (younger siblings of children with ASD). Symptoms associated with ASD can be divided into two categories: negative symptoms (the absence of behaviors that typically occur during development) and positive symptoms (the presence of atypical behaviors during development). The following section will present research focusing on behaviors observed in fairly young children (under 3 years of age) whom either had been diagnosed with ASD or would eventually go on to receive a diagnosis of ASD.

*Social interactions in children with ASD under 3 years of age.* Researchers have observed unique social interaction characteristics in young children with ASD. Young children later diagnosed with ASD show less empathy (Charman et al., 1997; Dawson et al., 2004) and fewer warm, joyful, expressions (Wetherby et al., 2004). Other studies have documented that such children are less responsive to their names being called or other social stimuli (Baranek 1999; Osterling & Dawson 1994; Zwaigenbaum et al., 2005). These children also look less at others' faces during social interactions and demonstrate atypical eye contact as well (Osterling & Dawson, 1994; Zwaigenbaum et al., 2005). Additionally, children with ASD generally do not share interests by pointing to or otherwise indicating

objects in their environment (i.e. joint attention), nor do they coordinate eye gaze between objects and/or people (Charman et al., 1997; Dawson et al., 2004; Osterling & Dawson, 1994; Wetherby, Watt, Morgan, & Shumway, 2007; Wetherby et al., 2004). Furthermore, children with ASD do not imitate others' actions to demonstrate a perception of social contexts and routines (Charman et al., 1997; Zwaigenbaum et al., 2005). Generally speaking, infants with ASD may present as young children who are less responsive to people, who may not initiate social interactions, and who may exclude others from their activities.

*Communication and language in children with ASD under 3 years of age.* The expressive language development of young children later diagnosed with ASD include fewer communicative gestures such as pointing, waving, or head nodding than children who are developing typically (Dawson et al., 2004; Osterling & Dawson 1994; Mitchell et al., 2006; Zwaigenbaum et al., 2005). These children also tend to vocalize less (Zwaigenbaum et al., 2005), produce vocalizations lacking consonants, and have unusual prosody or pitch patterns (Wetherby et al., 2004).

Overall, the patterns of communication were also abnormally lower in children with ASD, leading to less requesting and commenting (Wetherby et al., 2007), a finding consistent with studies surveying parents of children diagnosed with ASD. For example, language development is one of the initial concerns most reported by parents (Howlin & Moore, 1997). Because children with ASD usually score lower on standardized language measures (Mitchell et al., 2006; Zwaigenbaum, 2005), it is likely that many have also experienced delays in their production of words/phrases. In fact, many children with ASD fail to develop conversational speech (Filipek, 1999; Folstein, 1999).

Children later diagnosed with ASDs also are found to have a more limited understanding of phrases (Wetherby, 2007; Zwaigenbaum, 2005). A deficit in receptive language may reflect both abnormal social responsiveness or appropriateness and problems with comprehension of linguistic meaning. Ultimately, it may be difficult to separate comprehension and social skills in young children with ASD. In sum, findings support that young children with ASD demonstrate fewer communication acts including gestures, vocalizations, and words/phrases. Also, when these children do communicate, their messages may have an unusual quality, such as atypical pitch patterns or utterances devoid of social reciprocity (Filipek, 1999; Folstein, 1999; Wetherby, 2007).

*Repetitive behaviors in children with ASD under 3 years of age.* Repetitive and stereotyped behaviors (RSB) in children with ASD have been traditionally associated more with older children (4 to 5 years of age) than younger ones (Moore & Goodson, 2003; Charman et al., 2005; Watt, Wetherby, Barber, & Morgan, 2008). A recent study challenged this prevailing notion. In their examination of repetitive/stereotyped behaviors in children between the ages of 18 and 24 months, Watt et al. (2008) found that children who were later diagnosed with ASD had significantly higher frequencies and durations of repetitive and stereotyped behaviors than comparison groups with either developmental disabilities (DD) or typical development (TD). The subset of RSBs with objects that appeared to distinguish children with ASD from the other groups were: (a) repetitively banging or tapping objects on a surface, (b) rocking or flipping objects back and forth, (c) swiping objects away repetitively, (d) spinning, wobbling, or rolling objects, (e) moving or placing objects in a stereotypical manner or place, and (f) clutching objects for longer than expected.

Surprisingly, children in the groups with DD or TD demonstrated lining up and stacking objects while the group with ASD did not. The RSBs associated with body movement which differentiated the groups included: (a) repetitively banging the table surface, (b) rubbing the body, and (c) stiffening or posturing hands and fingers. Notably, all of the groups in the study exhibited RSBs, but by varied magnitudes and amounts.

Loh et al. (2007) also examined RSBs in infant siblings of children ASD (aged 12 to 18 months), during the administration of an observational instrument. Compared to typically developing children, the infant siblings who were later diagnosed with ASD exhibited more arm-waving at 12 months. This study limited coding of behaviors to a defined body topography (e.g. different kinds of arm movements), so its findings do not reflect all RSBs demonstrated by the participants but nevertheless document early differences in at least one type of RSB.

These studies suggest that RSBs may be present in very young children; however, it is possible that RSBs are more difficult to detect in younger children unless observers are specially trained to document their occurrences. Watt et al. (2008) credit a larger sample size, more precise observational methods, and systematic sampling for the contrasts between their findings and earlier studies. It may be possible that RSBs increase over time and become more apparent as children approach 4 and 5 years of age. These findings are important to the broader domain of refining and developing screening instruments capable of detecting subtle RSBs.

*Object and symbolic play in children with ASD under 3 years of age.* Young children with ASD display deficits in object and symbolic play skills, which may stem from their lack

inability to imitate adults during routines and play scenarios. For instance, researchers have documented that during assessments, young children (approximately 20 months of age) with ASD did not imitate the play actions of the examiner (Charman et al., 1997). These children also had less flexibility when playing with objects and did not demonstrate symbolic play (e.g. substituting objects for other objects) to the extent expected for their age or cognitive functioning level. In fact, Charman et al. (1997) stated that none of the children with ASD in their study demonstrated symbolic play skills. In contrast, one third of the children with other developmental disorders and two-thirds of those with typical development demonstrated symbolic play skills. Atypical play and interaction with objects may not only originate from difficulty with participation in social contexts but may also reflect the presence of repetitive, stereotyped behaviors. After all, if children are more interested in spinning, banging, or clutching objects, they are probably less likely to use the objects as intended or in a more creative manner that incorporates abstract thinking.

*Temperament and self-regulation in children with ASD under 3 years of age.* Very few studies have investigated the overall temperament of infants who later meet criteria for ASD. Gomez and Baird (2005) achieved this by asking parents of children between the ages of 3 and 14 years (M=8.4 years) to complete, retrospectively, a temperament scale describing their child's behavior at 12 months of age. Based upon these reports, children with ASD were shown to have significantly more self-regulatory difficulties compared to typically developing children. Similarly, a study of infant siblings of children with ASD (whom later also received a diagnosis of ASD) indicated that parents commonly report an overall lower

activity level at 6 months of age followed by more frequent and intense distress reactions to stimuli at 12 months (Zwaigenbaum et al., 2005).

*Sensory regulation in children with ASD under 3 years of age.* The temperament of children with ASD may be connected with how they process sensory stimuli. When viewing home videos of infants later diagnosed with ASD, Baranek (1999) noted more social touch aversions and the need for more intensity before they would respond to many auditory or visual stimuli. Additionally, another study demonstrated that when infants later diagnosed with ASD were presented with competing visual images, they fixated on one and failed to disengage visual attention to look at the other image (Zwaigenbaum et al., 2005). Overall, the above studies give the impression that young children with ASD may have a mixed and atypical profile of sensory reactions that includes less response to some stimuli but unusually high sensitivity or responsiveness to other sensations. However, this profile may change over time, as demonstrated by the variation in parental ratings of under-activeness at 6 months and abnormal distress reactions at 12 months (Zwaigenbaum et al.). Clearly, more studies are needed about the expression of sensory regulation in young children.

#### *Screening Tools and Diagnostic Instruments*

To identify children with ASD at earlier ages, researchers have developed screening tools based upon documented symptoms in young children with ASD. Screeners can be categorized based upon two factors: breadth and levels. Broad screeners assess general cognitive or behavioral development and classify a wide range of developmental difficulties, whereas disorder-specific screeners target a specific disorder or class of disorders (Robins & Dumont-Mathieu, 2006). Broad screeners are meant for use in physicians' offices and other

general clinical settings to identify children who may be at risk for developmental disabilities, including ASD; consequently, they are cost- and time- effective. They are not specific for ASD, however, which requires more testing to confirm a diagnosis. Examples of broad screeners include: (a) Parents' Evaluation of Developmental Status ([PEDS]; Glascoe, 2003); (b) The Ages and Stages Questionnaires ([ASQ]; Squires, Potter, & Bricker, 1995); and (c) The Denver Developmental Screening Test ([DDST]; Frankenburg, Van Doorninck, Liddell, & Dick, 1976; Frankenburg, Fandal, & Thornton, 1987; Frankenburg & Bresnick, 1998). Another increasingly popular screening tool is the Communication and Symbolic Behavior Scales Developmental Profile (CSBS-DP; Wetherby and Prizant, 1993). The CSBS is more specific for the assessment of communicative competence and social language development. While these screeners are likely to detect some of the developmental difficulties associated with ASD or help to identify behaviors that may suggest a need for further ASD-specific testing, empirical proof of their effectiveness in screening for ASD has not been published.

In terms of ASD-specific screeners, a rating system consisting of levels is used to distinguish between the intended settings or targeted populations. For example, Level I tests are meant to screen the general population for signs and symptoms of ASD (Robins & Dumont-Mathieu, 2006; Watson, Baranek, & Dilavore, 2003). Level I screeners are usually brief and are most likely to be used in a physician's office. By contrast, Level II screeners are used with a selected group of children who have been referred for further testing and are considered to be at higher risk for ASD (Robins & Dumont-Mathieu, 2006; Watson et al., 2003). As one would expect, the Level II instruments are more time-consuming and more



likely to be used by clinicians in a child development assessment setting (e.g. speech-language pathologists, psychologists, developmental therapists). Finally, Level III tools are specialized diagnostic instruments designed to not only diagnose ASD but also discriminate among its variants (Watson et al., 2003). Therefore, these instruments are used primarily in clinics that specialize in diagnosing ASD in children.

With the development of screening instruments, researchers have conducted studies to examine their accuracy. As with such tools developed for other purposes, ASD screeners are evaluated using four criteria: (a) sensitivity, (b) specificity, (c) positive predictive value, and (e) negative predictive value. Sensitivity corresponds to the proportion of actual cases of ASD who are successfully identified by the screener (American Speech Language Hearing Association [ASHA], 2006). Specificity represents the proportion of children without ASD who are successfully identified as no-risk (ASHA, 2006). Calculation of accurate sensitivity and specificity values require extensive follow-up of the screened sample in order to determine the subsequent diagnostic status of the children (i.e., meeting or not meeting the criteria for an ASD). Positive predictive value represents the proportion of tested children who are identified as at-risk who also failed the follow-up testing, whereas negative predictive value equals the proportion of children identified as no-risk who also passed the follow-up testing (ASHA, 2006).

*Reported accuracy of screeners.* Currently, a handful of ASD-specific screeners have been empirically evaluated for accuracy. One of the first to be developed and tested with a large-scale sample is the Checklist for Autism in Toddlers (CHAT; Baron-Cohen, Allen, & Gillberg, 1992). The CHAT, which was originally designed to detect only autism, is

considered a Level I screener. Created for use with children as young as 18 months and specifically designed for use within the U.K. health care system, the CHAT consists of a parent questionnaire and a clinician observation component. Follow-up studies for the CHAT have shown it to be highly specific for autism but with low sensitivity (Baird et al., 2000); the test missed about 50 percent of the children who were later identified as having ASD. To improve sensitivity, the CHAT was later modified (Modified Checklist of Autism in Toddlers; M-CHAT; Robins, Fein, & Barton, 1999) by researchers in the United States to include additional socially relevant items such as social referencing and comprehension. The clinician observation component was removed as well.

The M-CHAT, one of the instruments recommended by the American Pediatric Association (Johnson et al., 2007), screens for all variants of ASD (Robins & Dumont-Mathieu, 2006) and is considered to be a Level I and Level II screener. It consists of a parent questionnaire and an additional parent interview when children fail the initial survey. In contrast to the CHAT, the M-CHAT is intended for an older screening age (24 months). Some studies investigating its accuracy have reported that the parent questionnaire portion has a low positive predictive value and therefore has an increased possibility of identifying children with other developmental disorders or misidentifying children who pass the follow-up testing (Robins, Fein, Barton, & Green, 2001; Robins & Dumont-Mathieu, 2006; Kleinman, Robins, Ventola, et al., 2008). For instance, Robins et al. (2001) reported that 56% of the children identified as “at risk for ASD” by the M-CHAT were later classified as “not at risk for ASD” after follow-up phone interviews with parents. Likewise, Kleinman et al. (2008) indicated that only 38% of the children who failed the M-CHAT screening (without

the telephone interview) were later diagnosed with ASD. Therefore, the follow-up interview for children who initially fail the screening is essential for increasing the M-CHAT's accuracy and eliminating false positives.

Another screener that employs the parent questionnaire format is the Pervasive Developmental Disorders Screening Test, Second Edition ([PDDST-II]; Siegel 1998). The PDDST-II was developed to screen at all three levels in children 18 months and older; at this time, large-scale study results for the PDDST-II are not available.

Although screeners routinely employ a parent questionnaire or interview format, one ASD specific-screening tool is based upon clinician observation during a play session. The Screening Tool for Autism in Two-Year Olds ([STAT]; Stone, Coonrod, & Ousley, 2000) was designed for children aged 24 to 35 months. The STAT's design makes it a Level II screener and requires professionals to be specially trained in its use (Stone, Coonrod, Turner, & Pozdol, 2004). An early examination of the STAT for a group of children between the ages of 2 and 3 years resulted in relatively high sensitivity (92%) and good specificity (85%) values among children referred due to concerns about their development and behaviors (Stone et al. 2004). However, in a more recent study of younger, referred children under two years of age, the test's sensitivity (95%) remained high but its specificity (73%) was significantly lower (Stone, McMahon, & Henderson, 2008), which indicates an increased risk of over-identification for very young children. When the analysis was repeated without 12- and 13-month-olds from the original sample, specificity (83%) improved to an adequate level. Thus, the youngest children in the sample accounted for most of the false positives. It should also be noted that when the STAT is used with children under 2 years of age, the

threshold for missed items must be lowered in order to achieve a balance between sensitivity and specificity.

*Screeners for children under 18 months.* Despite the difficulties associated with assessing very young children, researchers continue to develop tools in hopes of detecting risk for ASD as early as possible. One example is the First Year Inventory (FYI; Baranek, Watson, Crais, & Reznick, unpublished), which was developed to screen children at 12 months of age for risk of ASD or other social-communication-sensory disorders. The FYI is a 63-item parent questionnaire about the relative frequency of targeted developmental behaviors, both typical and atypical (Reznick, Baranek, Reavis, Watson, & Crais, 2007). It produces risk scores across eight different constructs within two developmental domains (social-communication and sensory-regulation); higher risk scores in more domains indicate increased likelihood of developmental abnormalities or ASD. Pilot data based upon a sample of 1,486 children suggest that the FYI has potential for identifying children who may later be diagnosed with ASD (Baranek, Brown, Reznick, Watson, Crais, & Childress, 2009). Another recently developed tool is the Early Screening of Autistic Traits Questionnaire (ESAT; Dietz, Swinkels, Van Daalen, Van Engeland, & Buitelaar, 2006), a 14-item caregiver questionnaire intended for use with 14–15-month-old children. Preliminary estimates indicate that the ESAT may have low to moderate sensitivity and specificity (Dietz et al., 2006) and that it is less accurate at detecting the milder variants of ASD (related to sensitivity) or screening out children with other developmental disabilities or delays (related to specificity). True specificity and sensitivity have not been calculated for either tool; the above findings only reflect estimates. Nonetheless, promising efforts are ongoing to develop screeners for

children under 18 months. Further research to evaluate the performance of these tools will of course be required.

In summary, research findings imply that it is more difficult to distinguish between ASD and developmental disabilities using screening tools with very young children (i.e. ages 12 to 24 months) than with older children. For children under the age of 2, there appears to be an increased chance of over-identification when screeners are used. However, it is safe to conclude that these screeners can help detect social or developmental delays/difficulties and also when further monitoring or testing is warranted. For now, researchers continue to grapple with the delicate balance between increasing the sensitivity of their instruments (so children do not go undiagnosed) and reducing false positives that can cause parents unnecessary anxiety. Many suggest that instruments with higher sensitivity rather than higher specificity may be more desirable (Stone et al., 2008). This preference may be based on the premise that it is worse for children with ASD to miss early intervention opportunities than it is for parents to experience some anxiety until further testing rules out ASD. On the other hand, the public health costs of evaluating large numbers of young children who do not actually have ASD or other developmental problems presents both practical issues of affordability and ethical issues regarding the best use of health care dollars (ASHA, 2006; Stone et al., 2008).

*Guidelines for screening procedures.* In response to increased national attention paid to ASD and the desire to detect ASD earlier, the American Academy of Pediatrics (AAP) has issued specific guidelines for screening by medical providers. One comprehensive policy report presents an algorithm outlining suggested screening procedures and measures

(Johnson et al., 2007). The AAP encourages physicians to screen all children with a broad, standardized developmental screening tool at specific intervals such as 9, 18, and 24 months. It is further suggested that doctors add ASD-specific screeners to their assessments at both 18- and 24-month visits, regardless of whether parents or other family members raise developmental concerns. The AAP report lists four risk factors to prompt physicians through the algorithm and provides advice on appropriate referrals or subsequent actions. They are: (a) siblings with ASD, (b) parental concern, (c) another caregiver's concern, or (d) pediatrician concern. According to the AAP, a risk factor score higher than 2 or positive results on an ASD screening tool should warrant immediate referral for a comprehensive evaluation and early intervention services. For children younger than 18 months with deficits in social communication/interaction skills, the AAP lists the Infant/Toddler Checklist from the Communication and Symbolic Behavior Scales Developmental Profile ([CSBS-DP]; Wetherby and Prizant, 1993) as a possible ASD screening tool.

*Diagnostic instruments.* Two comprehensive (Level III) assessment tools are currently considered the gold standards for diagnosis of autism: the Autism Diagnostic Observation Schedule ([ADOS]; Lord, Rutter, DiLavore, & Risi, 1999) and the Autism Diagnostic Interview - Revised ([ADI-R]; Lord, Rutter, & Le Couteur, 1994). As noted above, Level III assessments can be used to distinguish between variants of ASD (e.g. autism or PDD-NOS). The ADOS is a semi-structured, standardized assessment of communication, social interaction, and play skills, consisting of four modules that evaluate individuals at various developmental levels, ages (ranging from infants to adults), and communication abilities. The ADI-R, a semi-structured diagnostic parent interview that assesses child

behaviors related to ASD, contains questions about early development, communication, social interactions, and behavioral patterns that are scored in terms of both current and past behaviors. Several studies have shown that diagnoses made by trained assessors using the ADOS and ADI-R have been relatively accurate and stable for the autism spectrum as a whole for children two years of age and older (Charman et al, 2005; Lord et al., 2006; Turner & Stone, 2006).

### *Regression and Early Diagnosis*

A phenomenon which further complicates early diagnosis of ASD is regression, which is generally defined as a change in or loss of previously acquired behaviors or skills for a duration of 3–6 months (Ozonoff, Williams, & Landa, 2005; Tuchman & Rapin, 1997). The percentage of parents reporting regression has ranged from 20 to 50 percent, with larger studies reporting a midpoint of 30 percent (Ozonoff et al., 2007). Because language is one of the most commonly reported skills lost as a result of regression, most studies classify language loss as a defining feature of regression. Some researchers have expanded their definition to include the loss of social communicative gestures, imitation, or motor or adaptive skills (Ozonoff et. al., 2007; Siperstein & Volkmar, 2004).

The onset of regression is usually gradual and may occur after two basic patterns of development during the first year of life: (a) a period of normal development or (b) mild delays or subtle symptoms followed by skill loss. Several researchers have suggested that the majority of the children who experience regression follow the latter developmental trajectory (Ozonoff et al.2007; Siperstein & Volkmar, 2004). Because regression is typically studied by interviewing or surveying parents about their child’s developmental history, identifying it can

be complicated by difficulty with or inaccurate parental recall. Using retrospective parental reports, Ozonoff et al. (2007) compared responses about children who experienced regression of communicative and social skills to responses about children with early-onset autism (children with ASD whose parents did not report regression). At the time of survey administration, the sample children were between 3 and 9 years old, with a mean age of 6 years. Based upon retrospective parent reports about the behaviors exhibited by the children prior to 18 months of age, significant group differences on six skills were found: (a) orienting to name call, (b) showing objects, (c) looking at others during social interactions, (d) joint attention behaviors, (e) referential pointing, and (f) initiating social interactive games. As a group, children who experienced regression demonstrated more of these desired social behaviors than those with early-onset autism. However, further examination of individual profiles revealed that several of the children who experienced regression after 18 months of age were nevertheless missing some critical social behaviors (e.g. joint attention, showing, social games, or early pretend play) when they were 18 months. Thus, while the regression group was more socially developed than the early-onset group, the development of many children within the first group was not considered typical before 18 months. More in-depth investigation of regression may be warranted because of its potential impact upon early diagnosis and screening outcomes. If children have subtle delays or demonstrate expected behaviors and eventually lose them, the risk of late diagnosis may be increased.

#### *Stability of Early Diagnosis*

Another possible challenge to the detection of ASD prior to 3 years of age is instability of the diagnosis at later ages, including changes within the autism spectrum or



moving on or off the autism spectrum altogether. Researchers have investigated ASD diagnosis stability by conducting follow-up studies with children who have already been diagnosed. Moore and Goodson (2003) found that 15 out of 19 children diagnosed between 2 and 3 years of age via the ADI-R (Lord et al., 1994) retained their original position along the autism spectrum after follow-up assessments at ages 4 and 5. The other four children moved to different variants within the autism spectrum, (two who had been diagnosed with atypical autism were later diagnosed with autism and two children diagnosed with autism at 2 years meet criteria for atypical autism at 4 years ). These researchers did not indicate whether the children were initially referred as a result of receiving high scores on a screening instrument, or due to parental or other concerns.

Similarly, Charman et al. (2005) examined the stability of ASD diagnoses for 26 children originally diagnosed at 2 years of age, who were seen for follow-up assessments at age 7 years.. The diagnoses for 22 of children remained the same (based upon clinical judgment) at 7 years. In terms of the other four children, three met criteria for atypical autism and one did not meet criteria for any ASD at 7 years of age. The parents of the one child who was not clinically diagnosed with ASD at age 7 years had reported significant concerns about behaviors between 2 and 3 years of age; parental symptom reports about this child had fallen to near zero on the ADI-R after age 4. The researchers noted that this child was a younger sibling of an older child diagnosed with ASD. Therefore, Charman et al. (2005) suggested that the earlier over-reporting of symptoms may have been influenced by the presence of an older sibling with autism. These results imply that the ADI-R is a better diagnostic tool when used to assess younger children with more pronounced symptoms.

A third longitudinal study of diagnostic stability (Turner et al., 2006) found that 22 of 25 children (88%) diagnosed with ASD at age 2 (using clinical diagnosis and the ADOS-G; Lord et al. 2000) remained in the autism spectrum at age 9. One of the three children who left the spectrum demonstrated evidence of a learning disorder and behavioral problems. By contrast, a later study by the same team found evidence of lower stability of ASD diagnosis for children who were first diagnosed at age 2. In fact, the proportion of children who retained an ASD diagnosis at follow-up (conducted at age 4) was only 63% percent (Turner & Stone, 2007). Although this sample was slightly younger than the one from the previous longitudinal study, the authors expressed surprise at the difference in their findings and suggested alternative explanations: (a) over-diagnosis at age 2, (b) diagnostic improvement as a result of participation in early intervention, or (c) sample-specific differences. All of these are possible and over-diagnosis cannot be ruled out, given that research has shown less specificity of screeners for very young children. Additionally, brain plasticity in younger children can increase the benefits of early intervention, possibly resulting in communication and functioning closer to typical levels (Turner & Stone, 2007). Notably, the majority of the children who failed to meet ASD criteria at age 4 continued to show a range of developmental problems in language and cognition.

Diagnostic stability also has been examined on a larger scale. Comparison of a sample of 172 children referred for evaluation at 2 years with re-examination at age 9 revealed an overall diagnostic agreement of 76% for autism disorder versus non-autism (i.e., other variants of ASD) and of 90% for autism spectrum versus non-spectrum (Lord et al., 2006). The exact numbers for diagnostic categories at 2 years of age were 84 with autism, 46

with PDD-NOS, and 42 non-spectrum, compared to 9 years of age when 100 children were diagnosed with autism, 35 with PDD-NOS, and 37 non-spectrum. The non-spectrum category included both children later diagnosed with other developmental delays and children who received no diagnosis at all. Differences between the other studies described above and the Lord et al. (2006) study include a larger sample size and the use of the ADOS (Lord et al., 1999) in addition to parent interviews (ADI-R; Lord et al., 1994) for diagnostic assessments.

The consensus of these studies suggests that diagnosis of ASD between 2 and 3 years of age is relatively reliable and stable for ASD as a whole but less stable for the ASD variants. That is, children who did not retain their original diagnosis typically moved from one diagnostic category to another within the autism spectrum and, occasionally, some moved off the spectrum. Many of the latter were found to have other disorders or disabilities (e.g. language disorder) or special circumstances (e.g., an older sibling with ASD). Currently, specificity of ASD diagnostic categories is more difficult to determine at earlier ages but the situation may be improved by more training for clinicians and additional evaluations (e.g. play assessments and observations).

#### *Benefits of Early Diagnosis*

Evidence supporting the benefits of early diagnosis and early intervention for ASDs is continuing to emerge. Some studies suggest that gains in social competence, independence, family support can be attributed to earlier diagnosis and intervention. The following section reviews such literature.

*Increased family support.* Early diagnosis accompanied by formal family support and intervention services can be highly beneficial for parents. Although the initial impact of diagnosis can be difficult, many parents report a feeling of relief associated with finally understanding why their children were exhibiting certain behaviors (Mansell & Morris, 2004; Osborne & Reed, 2008). In fact, during a focus group interview, some parents stated that they ceased blaming themselves for their child's behaviors and no longer considered themselves to be "bad parents" after their child was diagnosed with ASD (Osborne & Reed, 2008). In another study, many parents expressed that the diagnosis both led them to a better understanding and acceptance of their child's behaviors and allowed them to adapt their family life while accessing practical services (Mansell & Morris, 2004). Parents also reported negative factors associated with diagnosis, including a sense of loss, uncertainty about their child's future, and confusion about availability of services. Nonetheless, the majority of parents indicated that having a diagnosis was useful and several wished that their child had been diagnosed earlier (Mansell & Morris, 2004).

*Impact of early diagnosis on social and language outcomes.* Early diagnosis not only benefits families of children with ASD; growing evidence also suggests that it leads to better social and language skills at later ages for the children themselves. This phenomenon is likely correlated with earlier entry into EI or specialized programs. Harris and Handleman (2000) found that children who entered an intensive specialized program at younger ages (prior to 48 months) were more likely to be in regular education settings at a later age. Indeed, only the children who entered the program before 50 months of age were eventually placed in a regular classroom; the rest continued to receive special education services. In a

similar study, Turner et al. (2006) observed similar outcomes for children diagnosed at age 2 during follow-up assessments at 9 years of age. After splitting their sample into two groups of outcomes, higher and lower based upon cognition and language skills at follow-up, these researchers found that children in the higher outcome group were diagnosed at younger ages and participated in more hours of speech-language therapy (between the ages of 2 and 3) than children in the lower outcome group. However, children diagnosed at younger ages did not receive more total hours of intervention than those diagnosed at older ages. Therefore, the researchers suggest that the timing of intervention onset may be more important than the overall amount of intervention received, which may imply that increased brain plasticity at younger ages can boost the impact of EI services.

When considering the effectiveness of early diagnosis, it is also important to examine the type of intervention services delivered to young children with ASD. Intervention that directly targets the core characteristics and challenges associated with ASD (ASHA, 2006) may be more beneficial than services that target general speech and language delays. In a randomized control study, children with ASD who received treatments focused on improving joint attention or symbolic play skills showed better language skills than a control group receiving only an adult-directed behavioral form of intervention (Kasari et al., 2008). These results, documented 12 months after the intervention study was completed, highlight the potential importance of focusing treatment upon core deficits associated with ASD. A diagnosis or even suspicions of ASD (rather than another type of developmental disorder) may signal clinicians to tailor intervention to the deficits known to be uniquely associated with ASD.

*Cost benefits of early diagnosis.* Due to improved outcomes, early intervention may reduce the long-term societal costs associated with addressing the needs of individuals with ASD. Some researchers who have approached this subject with cost-benefit analyses of Early Intensive Behavioral Intervention (EIBI) propose that for children who derive minimal effects from early intervention or no intervention, associated lifetime costs and expenditures can be more than \$4 million each (Jacobson, Mulick, & Green, 1998). For each child who receives EIBI and achieves partial or near-normal functioning as a result, projected savings may range between \$1 million and \$1.5 million (Jacobson et. al, 1998; Jacobson & Mulick, 2000). These estimates in cost reductions are thought to stem from increased independence and participation in general society.

*Studies Investigating Age of Diagnosis of Autism Spectrum Disorders*

Given the desire to identify children who have ASD as early as possible to maximize their long-term outcomes, it is not surprising that researchers began to examine the age of diagnosis of ASD. Beginning in the mid- to late 1990s, researchers published findings on the diagnostic experiences of families of children with ASD. A well-known study surveyed more than 1,200 U.K. families starting in 1993 (Howlin & Moore, 1997). Researchers documented that the average age of diagnosis was more than 6 years even though parents had tended to become concerned between 1 and 2 years of age. On average, parents tended to wait another six to seven months before actively seeking help or advice (around age 2 or 3); 25 percent reported waiting up to 12 months before seeking help or even expressing their concerns to a professional. Howlin and Moore (1997) also found that only about 8 percent of the parents received a diagnosis upon their initial visit; 25 percent were assured that there were no

problems and they “should not worry.” An additional 10 percent were told to “wait and see” or to return if the problems persisted. In hindsight, a significant proportion of parents (49 percent) reported dissatisfaction with the diagnostic process. Understandably, this dissatisfaction strengthened with later ages of diagnosis.

Similarly, a study conducted in 1999 in a major U.S. metropolitan area found the average age of ASD diagnosis was more than 6 years (Mandell et al., 2002). Based upon reviews of records from 406 Medicaid-eligible children, the average age of diagnosis for White children (n=118 or 29%) was 6.3 years compared to 7.9 years for African Americans (n=242 or 56%) and 8.8 years for Latinos (n = 33 or 8%). Not only did this significant gap in the age of diagnosis for minority children remain even after adjusting for gender and time of eligibility for Medicaid, but researchers found that African American children made more visits to healthcare professionals before receiving a diagnosis of ASD. These findings suggest that factors other than, or in addition to, SES are affecting the age of diagnosis of ASD. A follow-up study of factors associated with diagnosis timing (Mandell et al., 2005) revealed different results: from a sample of 969 children, no significant age discrepancy emerged between Whites and minorities. Instead, a later age of diagnosis was associated with rural residence, lower SES, and higher language abilities or functioning at assessment. For this study, the average age of diagnosis was 3.1 years for autism, 3.9 years for PDD-NOS, and 7.2 years for Asperger’s Disorder. However, it is important to consider that data collection methods and overall participant demographics for the latter study differed from the one published in 2002. For example, in the 2005 study, the majority of the participants were White (84%), had higher income levels, and responded via the Internet. The participants were

recruited through a mailing to 273 caregivers of children with ASD. The caregivers had previously participated in quality improvement program sponsored by the state of Pennsylvania and agreed to participate in the study. As a result of the methods and demographics, whether the age of diagnosis for all minority children has decreased to a level equivalent with White children remains unclear.

A more recently published study observed a similar decrease in age of diagnosis. A sample of 494 parents of children with ASD from various countries was recruited via advertisements and announcements made on behalf of the researchers by autism organizations (e.g. local chapters of the Autism Society of America, National Autistic Society, Cure Autism Now; Goin-Kochel et al., 2006). A survey of these parents showed the average age at diagnosis across all variants of ASD to be 4.5 years. When grouped by diagnostic category, on average, children with autism were diagnosed at 3.4 years compared to those with PDD-NOS at 4.2 years and Asperger's Disorder at 7.5 years. Goin-Kochel et al. (2006) did not document a difference in the average age of diagnosis among racial/ethnic groups; however, similar to the Mandell et al. (2005) study, the majority of the sample was White (88%) and responded via the Internet.

In looking at racially/ethnically based differences in type of diagnoses, a group of researchers participating in the autism surveillance project with the CDC suggested that White children were significantly more likely to be diagnosed with Asperger's than African American children (Wiggins, Baio, & Rice, 2006). Furthermore, African American children were rated as more impaired based upon record reviewers' (trained clinicians') coding of functioning related to documented social, communication, behavioral, and adaptive skills.



Their sample consisted of 115 children, 8 years of age during the specified study year, diagnosed with ASD living in a large urban setting. Records for their study were obtained through school departments, the state human resources department, local hospitals, clinics, and diagnostic centers. The Wiggins et al. (2006) study also did not find differences in the average age of diagnosis as a function of race/ethnicity. Nonetheless, based upon the differences in diagnostic variants and level of functioning, it is plausible their sample reflects a lack of identification and diagnosis of higher functioning African American children.

Differences in ASD diagnosis and referrals among ethnic minority groups have also been studied in Europe. One project conducted in the Netherlands examined both the representation of ethnic Dutch minorities (Moroccan and Turkish) in ASD institutions and the likelihood of referrals for these groups (Begeer, Bouk, Boussaid, Terwogt, & Koot, 2009). When comparing the expected number of minority children (based upon prevalence estimates) to the actual number of children utilizing institutions that treat ASD, these researchers found an under-representation of the minority groups. This team also surveyed pediatricians (N = 82; 14 men, 68 women) using vignettes of children who differed in ethnic background and ASD features. The physicians were recruited through a child healthcare society in the Netherlands. Based upon spontaneous written judgments, the pediatricians were significantly less likely to reference ASD after viewing vignettes containing children from ethnic minority backgrounds compared to those containing children from the Dutch majority. Instead, the pediatricians attributed the behaviors to other causes or origins. By contrast, when the pediatricians were asked to indicate possible underlying disorders for the same vignettes from a list of diagnostic categories, the bias was no longer significant. That is,

when using a more structured rating approach, the pediatricians were equally likely to assign ASD diagnostic categories as possible causes for both the ethnic minorities and Dutch majority group. This study indicated that the under-identification of ethnic minorities may be related to referral bias, especially when pediatricians are relying on subjective clinical judgment more than on structured methods.

### *Physician Knowledge and ASD Management Practices*

Conventional wisdom dictates that pediatricians and primary care physicians have a vital role in the early diagnosis of ASD. As indicated in the aforementioned studies, they are often the first resources parents consult when they have concerns about their child's development. Furthermore, physicians may see children prior to any other child care providers (e.g. preschool teachers, daycare providers) due to regularly scheduled medical visits. Accordingly, researchers have investigated the assessment, referral, and management practices for ASD. In a random sample selected from Maryland and Delaware pediatricians, 82% reported that they routinely screen for general developmental disorders (DosReis et al., 2006), but only 8% (n = 20) reported that they screen specifically for ASD on a regular basis. The number who screen is surprisingly low, considering that the caseload of 44% of the pediatricians contained 10 or more patients with ASD. For physicians who screened for ASD, the initiating events included: (a) parental concern, (b) suspicion of ASD during a routine examination, and/or (c) child failure of a general screen. According to DosReis et al. (2006), the most frequently reported reasons pediatricians did not use ASD specific screeners were lack of time and unfamiliarity with the instruments. Additionally, female physicians were more likely to administer developmental screenings than their male counterparts. If

children were suspected to have ASD, the most commonly reported course of action was a referral to a specialist; however, the likelihood of all pediatricians making a referral increased significantly with the age of the child. The proportion of physicians who reported that they would make a referral was 55% if the child was under 2 years of age, compared to 74% and 80% for children between the ages of 2–3 and 4–5. These findings echo another study investigating referral patterns of physicians for children presenting with developmental delays (Sices, Feudtner, McLaughlin, Drotar, & Williams, 2004). When considering vignettes about children with concerning delays and behaviors, physicians were more likely to make referrals for older children (more than 2 years) presenting an expressive language delay, or female children (Sices et al., 2004). Regarding social development, physicians were more likely to make referrals for avoidant behaviors (e.g. less responsive to others) than for disruptive behaviors (e.g. tantrums). When examining the influence of physician characteristics on referrals, Sices et al. (2004) reported that pediatricians were three times more likely to refer than family practice physicians, and male physicians were more apt to have a “watch and wait” attitude than female physicians. The consensus of these studies indicates that physicians may be more hesitant to make referrals for younger children even if they are presenting with signs that indicate developmental delays. Nor is it guaranteed that physicians routinely will screen for or even look for signs of ASD. In fact, they may have a limited knowledge of the various symptoms associated with ASD, particularly when those behaviors are manifested as disruptive behaviors. In combination, these factors can result in later diagnosis.

In summary, findings from previous research suggest disparities in the age of diagnosis among children from minority populations can not be ruled out and further examination of this issue is needed. Research has shown that differences in the age of diagnosis may stem from various factors including race (Mandell et al., 2002), SES (Mandell et al., 2005), child-related factors such as severity (Mandell et al., 2005; Goin-Kochel et al., 2006), and possibly physician practices (DosReis et al., 2006; Sices et al., 2004). However, little is known about the effect of factors associated to family factors such as caregiver's values and beliefs on the diagnosis of ASD.

#### *Review of Literature of Internal Factors or Independent Variables*

The aims of the proposed research are to explore possible disparities in the age of diagnosis of ASD between African American and White children in North Carolina, and examine how differences in caregiver factors (e.g. initial beliefs and attributions about symptoms, empowerment, and initial level of concerns about ASD symptoms) may affect timing of diagnosis. It seeks to go beyond the documentation of an age gap in diagnosis of ASD associated with race/ethnicity by attempting to understand how other, less obvious variables may influence earlier or later identification of ASD. In looking at these factors, this study will expand upon a theoretical help-seeking framework (Cauce et al., 2002) designed to consider cultural and contextual factors (e.g. family beliefs and values) on the utilization of mental health services. Cauce et al. (2002) proposes that help-seeking does not begin until a problem is recognized. The researchers define the problem recognition in two ways: an epidemiologically defined need or a subjective/perceived need. According to the authors, an epidemiologically defined problem or need reflects a symptom-focused approach based upon

disorder categories developed by the American Psychiatric Association's DSM-IV (APA, 2000). The inclusion of "perceived need" in their model also accounts for family or individual's perception of a problem/mental health need. Cauce et al. (2002) suggests that cultural and other contextual factors can play a key role in defining both epidemiologically assessed and perceived needs. The current study will examine problem recognition and perceived need for symptoms related to ASD by measuring caregivers': (a) recognition/knowledge of initial ASD symptoms and (b) beliefs/attributions about initial symptoms that turned out to be related to ASD symptoms.

Once a problem or need is recognized, the next steps along the help-seeking pathway are the decision to seek help and the selection of service providers or support systems (e.g. professionals or informal supports). The decision to seek help may be either coerced (e.g. required by a school to avoid undesired consequences such as expulsion of the child) or voluntary in nature (Cauce et al., 2002). Voluntary help-seeking is likely to be affected by cultural or familial variables (Cauce et al., 2002). However, empowerment or self advocacy may also influence the decision to seek help and service selection due to caregivers' views about their or other's ability to control outcomes and alleviate challenges for their children. Therefore, the current study will also consider the impact of caregiver empowerment on the help-seeking behaviors and age of diagnosis of ASD, thereby expanding the help-seeking model.

The previous section of the literature review discussed "external" or systemic factors (e.g. access, SES, physician knowledge/training) and child related factors associated with early diagnosis. Now the following section will focus on factors beyond the role of

physicians and child-related factors. As stated above, those “internal factors” could include caregivers’: (a) recognition/knowledge of initial ASD symptoms, (b) empowerment, and (c) beliefs about the symptoms that turned out to be related to ASD. Given that parental concerns can precipitate visits to physicians and referrals from physicians, it is important to explore how parents look at symptoms and behaviors associated with ASD. The following section presents research related to these factors.

### *Caregiver Recognition of ASD Symptoms*

Until all children are universally screened and monitored for ASD, caregivers’ concerns about children’s developmental progress will continue to facilitate early diagnosis. Given that the diagnosis of ASD is based upon observable features, it is important to consider parents’ recognition of associated behaviors. Studies investigating parental concern reported that certain medical conditions (e.g., neurological or auditory disorders) and developmental delays were associated with earlier recognition of ASD related symptoms (Baghdadli et al., 2003; Giacomo & Fombonne, 1998). Impairments labeled as developmental delays were: (a) impairments in daily living skills and social development, (b) speech/language impairments, and (c) cognitive impairments. The prior studies documented no link between age of recognition and SES, gender of the child, or severity of symptoms. Limitations of these studies included general measures of target variables, such as scores from the ADI-R to index severity (Lord et al., 1994) and reports of parental recognition of symptoms as a gross estimate of age of onset. These studies did not directly measure how parental recognition of ASD symptoms was related to children’s age at diagnosis. Both the Baghdadli et al., (2003) and Giacomo & Fombonne (1998) studies suggest that parents may be more sensitive to

general developmental deviations when they have greater impact on social and daily functioning or co-occur with other medical conditions.

A more recent study (Chawarska, Paul, Hannigen, Dichtel, & Volkmar, 2007) observed relationships between the type of parental concerns, the diagnostic category (e.g., autism, PDD-NOS), and the age of diagnosis of ASD. Parents of children diagnosed earlier with autism reported delayed onset of social smiling and independent walking. Additionally, parents of children with autism reported more concerns about issues related to delayed motor milestones and the presence of unusual sensory and stereotypic behaviors than parents of children with PDD-NOS. On the other hand, parents of children diagnosed with PDD-NOS reported more concerns regarding sleep, feeding, and overall activity levels than parents of children with autism. Chawarska et al. (2007) examined the relationship of one parental factor (maternal age) with age of diagnosis and discovered that mothers of children diagnosed with ASD at later ages were generally older and more likely to have a history of infertility. While Chawaska et al. looked at the connection between parental concerns and age of diagnosis, the general current understanding of the effect of parental beliefs and magnitude of concern about ASD-related symptoms upon diagnosis is still rather cursory.

*Symptoms most likely to be recognized by parents.* Based upon the available literature, a delay or abnormality in language development (particularly expressive language) is the most widely reported concern from parents prior to their child's diagnosis (Chawaska et al., 2007; DeGiacomo & Fombonne, 1998; Howlin & Moore, 1997; Young, Brewer, & Pattison, 2003). The next most commonly reported set of concerns comprise deficits in social development such as a lack of interest in other people, preferring to play alone, not looking at

others' faces, and unresponsiveness to social stimuli (Howlin & Moore, 1997; Young et al., 2003). Third, parents may express concern about disruptive behavior such as tantrums and agitation (Howlin & Moore, 1997). Researchers have found that the majority of parents do not express worry about repetitive, stereotyped behaviors (RSBs) prior to the age of 3 (Howlin & Moore, 1997; Young et. al, 2003). However, as indicated previously, RSBs may indeed be present at younger ages, but not with a magnitude noticeable to the lay person (Watt et al., 2008). Additionally, it appears that parents may not be as aware of pre-linguistic indicators of language development (e.g., gestures, play, and joint attention) as they are of spoken language delays and deficits.

Fundamentally, certain behaviors may result in earlier caregiver concerns and recognition of ASD- related symptoms in children. Which of the behaviors lead to earlier concerns and recognition can depend on their impact on the child's ability to function in everyday settings. However, caregivers' concerns about and recognition of ASD-related symptoms may also be influenced by culturally defined expectations and thresholds for developmental challenges.

#### *Cultural Differences and Developmental Disabilities*

Prior to consulting with medical professionals for referrals or information, caregivers' views about the origins and impact of ASD behaviors can shape decisions about seeking out medical advice. Undoubtedly, these views are partly formed from cultural experiences (Cauce et al., 2002).

*Defining culture.* An individual's cultural background and experiences inevitably influence how they view the world; however, the impact of culture on the recognition and



attribution of symptoms associated with ASD has not been explored in the literature. Although the literature defines culture in several ways, this study will combine two interpretations to characterize it. Johnson et al. (1997, p. 87) describe culture as representing a social group with “a shared language and set of norms, values, beliefs, expectations, and life experiences.” According to Triandis (1996, p. 408), culture consists of shared elements of perception, belief, evaluation, communication, and action among those who share a language, a historic period, and/or a geographic location. For this study’s purposes, culture is defined as a set of shared meanings, values, and experiences among a group of people. Culture is often paired with racial/ethnic identity within the United States, although it is important to understand that culture extends beyond these boundaries. Nonetheless, racial and ethnic categories still serve as useful general representations for shared experiences among various groups of people. This study employs racial/ethnic categories as a proxy for shared beliefs about developmental delays and disorders, recognizing that other factors beyond race/ethnicity influence an individual’s culture or beliefs (e.g. geographical location, country of origin, age, education, and social environment).

*Culture and explanatory styles.* Although very little research has been done in the area of ASD, scholars have investigated cultural influence on the symptom recognition and attribution of other conditions. One study regarding cultural differences in attitudes and explanatory styles for Attention Deficit Hyperactivity Disorders (ADHD) indicated that parents of African American children with ADHD were more apt to apply a behavior problem label or imply that their child was “bad,” whereas White parents were more likely to use specific medical labels when referring to their child’s condition (Bussing et al., 1998).

Additionally, fewer African American parents viewed their child's condition as permanent. These findings remained consistent even after controlling for SES. Other studies have also documented that African Americans may be more apt to view maladaptive behavior or cognitive delays exhibited by their children as a temporary condition that they will eventually "grow out of," or that they will "catch up" to lead more typical lives (Harry, Allen, & McLaughlin, 1995; Rao, 2000).

Such findings have important consequences in the broader domain of seeking medical advice and services. If caregivers do not attribute undesirable behaviors to underlying medical conditions, they may delay seeking early medical intervention when their child exhibits these behaviors. Furthermore, caregivers' thresholds for showing concern about symptoms related to developmental disabilities may vary. Studies have shown that African American families often hold different and perhaps broader views of "typical" development compared to professionals (Rao, 2000; Harry et al., 1995).

*Culture and attributions of intention.* Not only do minority parents' views of actual symptoms and the lifelong impact of developmental delays differ from majority-culture parents, their attributions of young children's intentions differ as well. Reznick (1999, p. 243) explains that intention is a term used to describe the mental state of a person who "intends to do something." Parents of infants may assign intentionality when their infant anticipates the outcome of an action, selects actions appropriate to goals, persists in actions to attain goals, and stops action when a goal is attained (Reznick, 1999). In his study of maternal attribution of infant intention, Reznick found that African American mothers rated infants as more negatively intentional than European-American mothers, and rated their own

children as more intentional than other parents on the measures of predicting specific behavior. He concluded that African American mothers may be more willing to view infants as having the capacity to be purposively difficult in order to obtain a goal and related this hypothesis to studies reporting that African American mothers are concerned with the possibility of “spoiling” an infant by providing too much attention. These findings have important implications in the broader domain of parents’ reactions to behavioral difficulties. Hypothetically, parents could attribute some disruptive symptoms accompanying ASD to negative intentionality of their child.

*Culture and attitudes about causes.* Minorities have also been shown to endorse biologically based causes such as genetic or chromosomal abnormalities less often than White Americans (Schnittker, Freese, & Powell, 2000; Cohen, Fine, & Pergament, 1998; Dyches et al., 2004; Bussing, Mills, & Garvan, 2007). On the contrary, Cohen et al. (1998) found that African Americans have attributed birth defects or disorders to more non-biologically based causes (e.g. eating the wrong foods, God’s will, or supernatural occurrences). Such findings have broad, important implications because they relate to the likelihood of seeking out medical advice and services. If caregivers do not believe that developmental difficulties are associated with medical conditions, they may delay finding early medical intervention if their child exhibits these behaviors. For example, if a parent attributes a disability or disorder to God’s will, their perception of treatment benefits may be less positive; partly, because they may believe that their child’s future outcomes are also beyond human control (Cauce et al., 2002). Similarly, caregivers who do not attribute symptoms and behaviors to medical or genetic origins may differ in their perceptions about

the benefits of treatment and their expectations of it. Like parents of children with ADHD (Bussing et al., 1998) or typical development (Reznick, 1999), some caregivers of children with ASD may initially attribute symptoms to behavioral disobedience, stubbornness, shyness, or slower but still typical development. In these instances, parents may initially attempt to deal with such behaviors using their own resources and behavior modification approaches (Rao, 2002).

*Cultural views on developmental disorders labels.* Cultural beliefs associated with the stigma that may accompany disabilities and their diagnostic labels also have been shown to be different among minorities, particularly with regards to mental illness diagnosis. African Americans may see labels associated with a diagnosis like autism as more stigmatizing and limiting for their children who may already be at risk for stereotyping (Gary, 2005). Indeed, Gary (2005) argues that a “double stigma” (i.e., minority group status and mental illness diagnosis), may cause a person to endure greater burdens in society. Accordingly, minority families may be more sensitive to the stigma of labels when compared to the majority group and show greater resistance to diagnostic processes that place their child at risk for labeling. In fact, several researchers have documented resistance to seeking professional help (Thompson, Brazile, & Akbar, 2004) or regret after seeking help (Harry et al., 1995; Rao, 2002) from African Americans due to perceived stigmatization and isolation associated with labels. Furthermore, these labels are often in direct conflict with how parents interpret or perceive their children’s behavior (Bussing et al., 1998, Harry et al., 1995). As such, African American parents may genuinely disagree with the notion of “disability” because they hold different views of typical development and expectations regarding

development than do professionals (Dyches et al., 2004; Rao, 2002). This reaction may be particularly present in cases where the child's developmental disability is accompanied by little to no physical impairment.

*Culture and help-seeking styles.* Along with considering cultural variations in recognition, attribution, and attitudes toward symptoms and disabilities, it is important to consider differences in help-seeking styles and how cultural beliefs can impact help-seeking behavior. Although research demonstrating differences in help-seeking styles between African Americans and White Americans for developmental disabilities is sparse, there are documented differences in the use of services such as mental health services by African Americans (Schnittker et al., 2000). For example, African Americans did not seek professional help at the same rates as White Americans; in fact, African Americans endorsed professional treatment significantly less than Whites, and were more likely to endorse spiritual assistance (Schnittker et al.).

The literature has suggested several culturally based factors that could impact help-seeking behaviors. In a model presented by Cauce et al. (2002), help-seeking does not begin until a medical or mental health issue is recognized (defined either epidemiologically or by perception). As highlighted earlier in this review, problem recognition or perceived need may vary as a function of both race and culture. In focus groups aimed at elucidating attitudes and expectations about mental health services, African Americans identified factors such as mistrust of professionals, lack of cultural sensitivity, and lack of knowledge as barriers to their help-seeking (Thompson et al., 2004). While the previous studies emphasize cultural factors that may inhibit the use of formal professional services, researchers should

not overlook forms of informal help-seeking (e.g. spiritual assistance, advice from family and friends). African American families may indeed feel that they are seeking and obtaining help, albeit in forms and from sources unlike those routinely used by Whites. In short, African Americans may not be as likely to attribute a diagnostic label, may have differences in perceptions and origins of behaviors, and may not initially seek formal professional services for children who are exhibiting symptoms of autism but instead may first look for help elsewhere.

#### *Caregiver Empowerment and Early Diagnosis of ASD*

If parents recognize concerning behaviors in their children and establish that there is a perceived need, the next step in the diagnostic process is consulting with professionals about their concerns. It is at this point that caregiver empowerment may play a significant role in the early identification of children with developmental disabilities such as ASD.

*Defining caregiver empowerment.* Empowerment has been defined in numerous ways, mostly stemming from psychologist Julian Rappaport's investigations of empowerment as a multi-level construct. Rappaport and Zimmerman (1988) defined empowerment as "linking matters of social policy and change to individual strengths and competencies, natural helping systems, and proactive behaviors (p. 726)." They further stated that empowerment is a process by which individuals master or control their own lives and participate in the environment around them.

Other researchers who have worked with families of children with disabilities have extended the concept of empowerment to the realm of early intervention. Carl Dunst (1985), who presented a definition of empowerment specific to the field of early intervention,

suggested that it involves the generation and allocation of power (decision making) in forms of access and control of physical, emotional, and instrumental resources. Additional researchers in the mental health field (Reich, Bickman, & Heflinger, 2004) have added the concept of “self-efficacy” to their overall explanation of empowerment by stating that self-efficacy refers to an individual’s perception of his or her capabilities for organizing and executing the courses of action required to attain designated types of performance. By combining these varied views of empowerment, one may define it as a person’s ability to respond to situations or challenges, access resources, and control outcomes, as well as the perceptions of his or her own abilities to do these things.

*Caregiver empowerment and referrals.* Although the effect of caregiver empowerment on ASD diagnoses has not been previously examined, the current study hypothesizes that higher levels of caregiver empowerment can increase the likelihood of earlier identification by leading to earlier referrals for comprehensive assessments. An initial consideration is that children with ASD have a wide range of symptoms, from very severe symptoms such as lack of speech/ language development and unresponsiveness, to more subtle symptoms such as aloofness or odd social interactions (Folstein, 1999). More subtle symptoms may not be apparent to the general public or even to medical practitioners who make referrals for diagnostic assessments. Indeed, high-functioning children have been shown to receive diagnoses later than lower-functioning children (Goin-Kochel et al., 2006; Mandell et al., 2005). Moreover, children with ASD often do not have obvious physical characteristics that accompany other developmental disorders such as Downs Syndrome or

Fragile X. Therefore, the relatively typical physical appearance of many children with autism may make them easier to miss in the process of early identification (Folstein, 1999).

Consequently, receiving appropriate referrals as a result of parental concerns could be problematic if the medical professional has a conflicting perception of the child's behaviors or wants to utilize a "watch and wait" approach (Howlin & Moore, 1997). Parents are particularly at risk for experiencing difficulty in the referral process if the child is very young (Sices et al., 2004; DosReis et al., 2006) or demonstrates more subtle symptoms (Goin-Kochel et al, 2006; Mandell et al., 2005). They may also have trouble convincing other family members, including spouses, that their concerns are valid, which could result in a lack of informal support. For less empowered caregivers, the above scenarios represent barriers that can decrease the likelihood of receiving a referral for a comprehensive evaluation. As demonstrated by Howlin and Moore (1997), parents may have to exert considerable pressure on physicians and show perseverance in order to receive a referral.

*Caregiver empowerment and physician-parent communication.* Another important aspect of empowerment is its relationship to communication challenges that can arise during the diagnostic process. After all, one's ability to respond to situations and access resources in may depend on being able to express differences in opinions and convince others to consider your views. In doing these things, caregivers can increase their allocation of power and involvement in the decision making process with clinicians. However, this may be difficult if there are communication barriers such as those that can arise from cultural and linguistic variations/mismatch. Research has shown that minorities may have more trouble communicating with their doctors because of differences in communication styles. Cooper-



Patrick et al. (1999) found that minority patients reported their visits with physicians were less reciprocal and that physicians involved them less in the decision making process compared to the experiences of White patients. This was especially so when the physician was of a different race than the patient(s). With regard to early diagnosis, parents may be less apt to voice concerns about their children or challenge any of their doctors' recommendations if there is a perceived lack of reciprocity and involvement during physician visits.

Clayman and Wissow (2004) conducted a study that investigated doctors' (mostly White residents') responses to words used by parents (mostly African Americans) to describe certain aspects of child behavior and discipline. Physician visits were tape-recorded and examined to identify potentially ambiguous words or cues used by parents about physical punishment (e.g. beat, smack, hit) or child attributes (e.g., bad, evil, greedy, spoiled). The choice of such words may indicate that parents are seeing or dealing with troublesome behaviors and interpreting them negatively, which may in some cases indicate underlying social and communication deficits associated with developmental disorders such as ASD. These researchers found that physicians may contradict or even ignore certain cues or statements. For example, when the words listed above were uttered during a visit, doctors seemed to ignore or dismiss them through contradiction (i.e. assuming meaning and then dismissing by proposing an alternative) in almost half of the sample. In fact, in only 11 percent of the visits did doctors actively seek to understand the parents by requesting elaboration of the words or phrases. Thus, when there is a mismatch in communication resulting in unintentional neglect or dismissal of concerns, higher levels of caregiver empowerment could trigger parental insistence on further discussion or at least

acknowledgement of their concerns. Ideally, more in-depth discussion about terms that describe a child's behaviors would open the door to increased family support, advice, guidance, and further evaluation if warranted.

*Caregiver empowerment and information seeking.* Another way that caregiver empowerment may influence early identification of autism is the possible association of empowerment with information seeking. Although there is a paucity of studies about the relationship between empowerment and information seeking, some researchers have investigated the relationship between health-related Locus of Control (LOC) beliefs and health-related information seeking. Logically, if LOC beliefs were mapped onto the concept of empowerment, individuals with high belief in internal control would show more empowerment and those with high belief in external control, who would show less. In general, LOC is related to an individual's perception of control over personal health outcomes. In initial models, LOC beliefs of individuals were classified on a two-dimensional scale, internality and externality (Wallston, Wallston, & Devellis, 1978). Individuals scoring high on internal control believe that actions within their control (e.g. self-care), also known as internal factors, are related to illness/health outcomes, whereas individuals scoring high on external control are more prone to believe that illness/health outcomes are related to fate, luck, or chance--factors beyond individual control. Some research has suggested that individuals with high beliefs in internal control are more likely to seek information and ask questions regarding a specific health condition (Wallston, Maides, & Wallston, 1976). Accordingly, parents who feel empowered might seek out more information about the health and developmental outcomes of their children and may also be more knowledgeable about

various resources discovered via their research efforts. Armed with this knowledge, such parents might seek help earlier, be more equipped to advocate for referrals, and be more likely to tap into available resources.

To summarize, highly empowered caregivers may have more confidence in their ability to obtain a desired outcome (Reich et al., 2004) such as an explanation for their child's behaviors. This confidence may be demonstrated by their perseverance to: (a) communicate concerns regardless of conversational breakdowns, (b) seek out information, and (c) receive a referral. Even after obtaining a referral, parents may still have to navigate an often- complicated medical system, communicate with specialists, and seek out second opinions, all of which require an understanding of one's options, determination, and a certain level of self -assurance. Thus, parents of children at risk for ASD may benefit from the higher levels of empowerment needed to overcome various barriers and challenges that may arise as they seek explanations for their children's behaviors or symptoms.

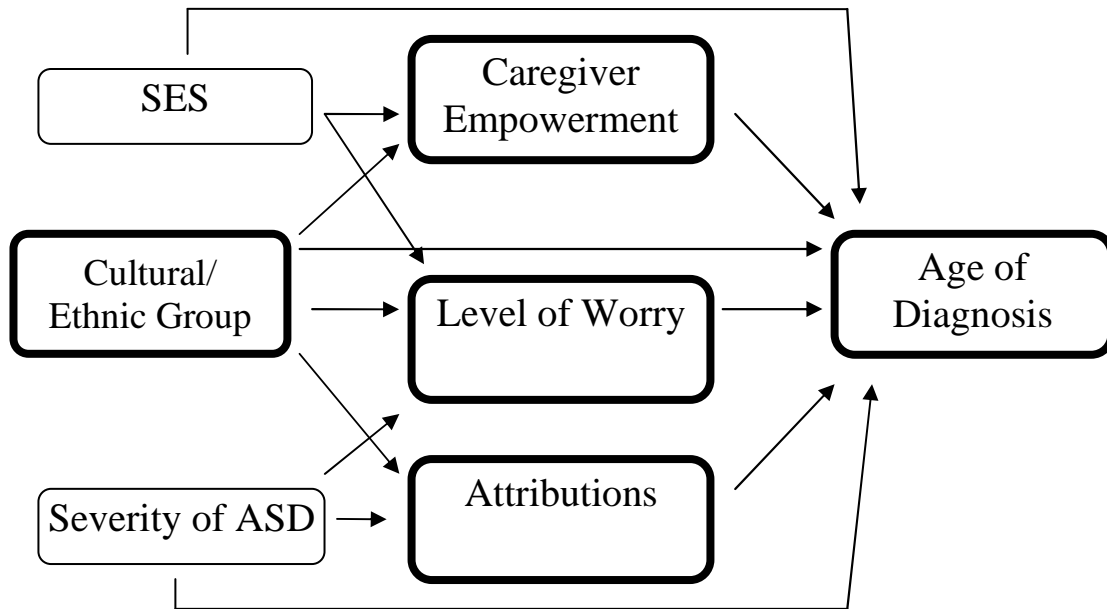
In conclusion, caregiver's recognition of or concerns about symptoms, attributions, and empowerment may play a significant role in the age of identification of children with ASD. They are important because of their capacity to encourage or hinder the help-seeking process leading to diagnosis. Observed differences in these factors may stem from cultural and environmental variations among caregivers.

#### *Purpose and Conceptual Model*

Given that problem recognition, attributions, and caregiver empowerment may affect when and how caregivers seek help for concerning behaviors exhibited by their children, the current study will examine the association between variability among these "internal" factors

and the age of diagnosis of ASD. Building upon the help-seeking model (Cauce et al., 2002), the current study will go beyond examining the association between child-related and “external factors” (e.g. SES, provider access or practices) and age of diagnosis. This will be accomplished by exploring the influence of caregiver empowerment in addition to problem recognition or “perceived need” on the early identification of ASD. For this study, initial attributions about symptoms and initial level of worry about ASD symptoms will serve as a proxy for the problem recognition construct. Figure 2.1 shows the conceptual model upon which the proposed study is based. Using this model may help explain discrepancies in the age of diagnosis of ASD among culturally different groups. It provides a framework to investigate how variations in values, beliefs, and levels of empowerment may affect a caregiver’s decision to seek help for their child’s developmental challenges. This information will facilitate the: (a) advancement of knowledge concerning barriers associated with early diagnosis of ASD, (b) design of public health campaigns to decrease the age of diagnosis, and (c) improvement in the utilization of early intervention services by minority families.

Figure 2.1 Conceptual Model of Independent and Outcome Variables



## **CHAPTER 3**

### **Methods**

#### *Sample Size and Subject Selection*

A total of 650 families on the University of North Carolina (UNC) Neurodevelopmental Disorders Research Center (NDRC) Autism Registry list were targeted for the initial mailing of informational packets, based upon a mixed sampling method, which contained fliers as well as response cards for contact information. All of the African American families (n = 250) who appeared to meet the inclusion criteria were sent these packets. The study purposely oversampled African American participants in order to increase their representation. For the White families, 400 were selected from 1,150 possibilities via a random number generator. The recruitment goal for the current study was 100 African American families and 100 White families, for a total of 200 families. An a priori power analysis determined that a sample size of 200 would yield adequate power for the planned analyses related to the research questions.

A total of 192 North Carolina caregivers (59 African American; 131 White; 2 other racial identities) of children with a current diagnosis of ASD were recruited for this study. A total of 191 caregivers were recruited through the UNC (NDRC) Autism Registry and one caregiver was recruited via a private practice agency (clinicians/ practitioners). The families on the NDRC registry had already agreed to be contacted for future research participation.

Inclusion criteria for the participants were that they be primary caregivers of a child with ASD and that they self-identify as either White or African American (Black). In addition, participants were only included if they had a child: (a) from 3 to 11 years old; (b) diagnosed with ASD at 12 months or older by a qualified medical professional, service provider, or agency (e.g. neurologist, psychologist, psychiatrist, Child Developmental Service Agency [CDSA], Treatment and Education of Autistic and Communication Handicapped [TEACCH] Center); (c) who is ambulatory, with no severe motor impairments, other genetic disorders, evidence of other neurological impairments, or significant co-existing medical conditions; and (d) with a Social Responsiveness Scale (SRS) total scale score consistent with a diagnosis of ASD. The SRS total scale score was used as an inclusion criterion because the current study was interested in including children who currently show features of ASD. Although the current study recognizes that children can have a diagnosis of ASD without meeting the criteria for SRS, use of this instrument helps to verify ASD diagnosis in a sample where the use of diagnostic assessment tools is not feasible. Therefore, it was deemed appropriate to use the SRS to confirm ASD diagnosis and to require such confirmation as an inclusion criterion.

#### *Demographic Characteristics of the Sample*

*Caregiver characteristics.* After the inclusion criteria were applied, a total of 168 (N= 50 African American and N= 118 White) families remained eligible for the study.

Participants were excluded due to the following reasons: (a) children's SRS scores were in below the ASD range (n=9); (b) children had co-existing genetic disorders, neurological, or significant medical conditions (n = 7); (c) children were over 11 years of age at the time of

the study (n=3); (d) children were diagnosed under 12 months of age (n = 2); (e) caregivers did not identify as African American or White but identified as “other” (n=2); and (f) caregiver sent in an incomplete survey package (n=1). Tables 3.1 and 3.2 summarize the demographic characteristics for the participants.

Table 3.1: Demographic Characteristics (Categorical Variables)

Participant Characteristics	African American		White	
	N	%	N	%
Gender (Female; Respondent)	46	92	111	94
Gender (Male; Child)	44	88	99	84
Educational Status (Maternal) *				
No High School Diploma or GED	4	8	0	0
Completed High School or GED	10	20	10	8.6
Some college or technical school	14	28	25	22
Associate Degree	9	18	16	14
Bachelors Degree	8	16	43	37
Graduate or Professional Degree	5	10	22	19
Place of Residency *				
Large City	9	18	9	8
Suburb	4	8	38	32
Small town or city	27	55	55	47



Participant Characteristics ( <i>continued</i> ).	African American		White	
	N	%	N	%
Rural Area	9	18	16	14
Marital Status *				
Married or Living as Married	29	58	108	91
Divorced or Widow(er)	6	12	8	7
Single or Never Married	15	30	2	2
Child Born Premature	12	24	25	21
Medical Problems (pregnancy, delivery, or early infancy				
	21	42	57	49
Place of Diagnosis				
TEACCH	23	46	46	39
State or Developmental Agency				
(CDSA, DEC) <sup>a</sup>	14	28	40	34
School System	5	10	7	6
Doctor's Office, Hospital, or Private	6	12	19	16
Child Received Another Initial Diagnosis	21	42	56	46

*Note.* <sup>a</sup> Children Developmental Services Agencies (CDSA); Division of Exceptional Children (DEC)

\* indicates significant differences between groups on demographic variable,  $p < .01$

Table 3.2: Demographic Characteristics (Continuous Variables)

Participant Characteristics	African American			White		
	M	SD	Range	M	SD	Range
Age (Respondent) <sup>a</sup>	37.16	6.53	22 - 58	38.24	5.98	23 - 65
Current Age (Child) <sup>a</sup>	7.40	1.74	3 - 11	6.86	2.2	3 - 11
Age of Diagnosis <sup>b</sup>	49.72	25.83	12 - 104	43.78	20.18	16 - 102
SRS Total Scale Score	81.30	8.95	62 - 90	81.61	8.90	61 - 90

Note. <sup>a</sup> measured in years <sup>b</sup> measured in months

Comparison of the demographic data for participants to census data for the state of North Carolina (2000) indicates that the current study's sample has higher educational levels. Approximately 40% of caregivers (mothers) in the current study had some college experience or an associate's degree. An additional 46% had obtained a bachelor's degree or beyond. According to the 2000 North Carolina census, around 28% adults over the age of 25 years had some college experience or an associate's degree and an estimated 22% had bachelor's or graduate degrees. Participants in the current study also had higher household income levels (36% were above \$80,000) when compared to estimates from the 2000 North Carolina census (19% of households were above \$75,000).

#### *Predictor Variables and Measures*

Three instruments were developed to measure the constructs of family empowerment, level of worry/concern about symptoms related to ASD, and attributions of initial ASD symptoms. The questionnaires were piloted using the cognitive interviewing technique

(Willis, 2005) with three caregivers whose children had a diagnosis of ASD or other developmental disorders. Families were identified for pre-testing through personal contact with organizations (e.g. First in Families), private practices, and clinicians. Families were asked to complete the survey independently and individually share their impressions and challenges they may have encountered with the survey. The respondents generally felt that the survey instruments were fairly easy to complete and suggested some minor changes in wording (these were taken into account when finalizing the instruments).

In addition to the three instruments developed to measure the symptoms and experiences listed above, caregivers completed a demographic questionnaire and questions relevant to ASD on the Social Responsiveness Scale ([SRS]; Constantino et al., 2003). The measures included in the questionnaire package are described in more detail below.

*Caregiver Empowerment Measure.* This was developed for the current study to assess empowerment in parents or other caregivers whose children were diagnosed with ASD. The content of the scale was loosely based upon items from the Family Empowerment Scale (Koren, DeChillo, and Friesen, 1992) and the Psychological Empowerment Scale (Akey, Marquis, & Ross, 2000). The wording of both scales was modified to match the target population of the current study. Parents were asked to respond to 15 items on the researcher-developed Perryman Caregiver Empowerment Scale (PCES; Perryman, 2008). The response format was a 4 point Likert scale in which 1 = never true for the respondent and 4 = always true for the respondent. These items measured the feelings of parents/caregivers about their ability to communicate with health professionals and obtain services to meet the unique needs of their children (see complete measure in Appendix A).

*Measurement of initial level of worry about autism symptoms.* The Initial Level of Worry (ILOW; Perryman 2008) instrument was developed to measure parents' perceptions of their initial concerns about symptoms typically related to ASD. The content of the measure was based upon previous studies of early symptoms and behaviors associated with ASD (Baranek, 1999; Osterling & Dawson, 1994; Reznick et al., 2007; Wetherby et al., 2004; Wetherby et al., 2007; Zwaigenbaum et al., 2005). The measure asked parents to gauge retrospectively their levels of worry about their child's early behaviors prior to diagnosis which may have resulted from ASD, prior to diagnosis. The items inquired about both the absence of typical behaviors and the presence of atypical behaviors, including: (a) object play, (b) response to social interaction and social stimuli, (c) play and engagement, (d) motor movements, (e) joint attention (pointing) behaviors, (f) eye contact and looking behaviors, (g) speech development, and (h) imitation skills. The response format for the measure of initial level of concern is a Likert scale in which 1 = not worried and 3 = very worried (see complete measure in Appendix B).

*Measurement of attributions of autism symptoms.* The Attributions of Autism Symptoms (AOAS; Perryman, 2008) instrument was developed to measure parents' initial thoughts about the causes of behaviors related to ASD. Parents were asked to retrospectively respond to items concerning behaviors which later turned out to be associated with ASD. The content of the scale was based upon previous research documenting differences in explanations of behaviors (Bussing et al., 1998; Cohen et Al., 1998). Items on the instrument asked if parents thought behaviors were caused by conditions/reasons such as: (a) another medical condition (hearing loss or brain injury), (b) disobedience or stubbornness, (c) slower

but typical development, (d) shyness, (e) uniqueness or personality differences, or (f) spiritual influences. The response categories for initial attributions of behaviors used a binary-scale format of yes, “I thought my child’s behavior may have been caused by this condition/trait” and no, “I did not think that my child’s behavior could have been caused by this condition/trait (see complete measure in Appendix C).”

*Measurement of demographic information.* Parents were asked to complete a survey requesting information on family demographics and their diagnostic experiences. The survey included questions that focused on: (a) caregiver and child racial or ethnic group affiliation; (b) educational level attainment and income (as a measure of SES); (c) type of residential setting (e.g. city or rural); (d) primary language spoken in home; (e) type of insurance coverage; (f) month and year of diagnosis of ASD; (g) agency or location where diagnosis of ASD took place (e.g. hospital, CDSA, TEACCH); (h) diagnoses given to the child prior to a diagnosis of ASD; (i) length of time between observing behaviors related to ASD and consulting professionals; (j) length of time between talking to a professional and receiving a diagnosis; and (k) approximate number of visits to medical providers before referral for diagnosis (see complete measure in Appendix D).

*Social Responsiveness Scale (SRS; Constantino et al., 2003).* The SRS is a 65-item rating scale that measures the severity of ASD symptoms as they occur in natural settings. The SRS was normed on a sample of more than 1,600 children and is appropriate for use with children from 4 to 18 years of age. Although the current study included 3-year-olds, the majority of the study sample ( $n = 158$ ) was 4 years or older. The SRS was validated by comparison with the Autism Diagnostic Interview - Revised (ADI-R; Lord et al., 1994),

which is considered one of the gold standards in establishing a clinical diagnosis of autism. The SRS provides a total scaled score that classifies behaviors along a range of normal to severe. The SRS also provides five subscale scores for the following areas: (a) social awareness, (b) social cognition, (c) social communication, (d) social motivation, and (e) autistic mannerisms. Strong correlations were found between the ADI-R and maternal-report SRS scores, with coefficients ranging from .65 to .77. Inter-rater reliability between teachers, mothers, and fathers ranged from .75 to .91. The current study used the cut-off score of 59 for total scaled score as an inclusion criterion; scores at or above this value indicated deficits in social and communication skills consistent with those associated with ASD according to Constantino et al.(2003).

#### *Data Collection Procedures*

The process for data collection through the NDRC Autism Registry is outlined below. The procedures employed a modified variation of the Dillman (2007) survey implementation method. After the initial mailing of the informational packets to targeted families, NDRC registry staff followed up with letters to nonresponders. They also called 100 African American families in order to encourage their participation and increase their representation. After caregivers expressed interest in participation by completing and returning response forms or indicating interest during phone calls, the NDRC registry staff immediately sent them a questionnaire package containing the following items: (a) an implied consent letter (outlining the purpose of the study, expectations of participants, rights, risks, and benefits); (b) a fact sheet (providing more detailed information about rights, possible risks, and benefits associated with participation); (c) the Social Responsiveness Scale (SRS); (d) the three

investigator-developed measures and the demographic survey (combined into an 8 x 11 survey booklet); (e) a letter containing brief instructions for completing the questionnaires; (f) an incentive of \$5 in cash; and (g) a stamped envelope addressed to the investigator.

Returned questionnaires were tracked via subject-numbers (assigned by the researcher) that linked the questionnaires with the caregiver response cards. In the fact sheet and implied consent letter, participants were assured that only the primary researcher would have access to their contact information (if follow-up calls were necessary), which was separated from the completed questionnaires prior to data entry and stored in locked cabinets.

Approximately three weeks after the initial mailing of the questionnaire package, caregivers who had not returned theirs were sent another letter detailing the uniqueness and importance of their contribution to the project, and encouraging them to complete and return the questionnaires.

After five to six weeks, caregivers who had not returned their questionnaire package received another reminder letter that extended the opportunity to participate in this research project. These letters also explained that replacement packages were available if the initial package had been misplaced. Finally, two to three weeks after the second follow-up letters were sent to nonresponders, the caregivers received another reminder, by phone from the researcher, to return their packages.

*Data management.* After caregivers returned their survey packages, responses were entered into a Microsoft Excel spreadsheet by a graduate student in speech and hearing sciences. The caregivers' responses for the demographic survey were coded into numerical values (e.g., no = 1, yes = 2) and entered into the database. For the instruments, numbers

corresponding to the responses on the Likert scales were entered into the database. Finally, the SRS (Constantino et al., 2003; raw and scaled) scores were entered into the database. Notes on missing values and other pertinent issues with the data were also recorded in the database. All data were then entered a second time and compared with the original data spreadsheet using Compare Spreadsheets for Excel software by Office Assistance LLC from share-it (<http://www.office-excel.com/>). This software generates a report that synchronizes and presents the original and double-entry spreadsheets side by side, visually highlighting differences in the data. Conflicts in the data were resolved by returning to the original questionnaires or instruments. The final database was directly exported into the statistical software program for analysis.

*Coding of the diagnostic date variable.* Caregivers were asked to give only the month and year of diagnosis to ease their process of recall. The default coding for day of diagnosis was the first day of the month mentioned by the caregivers. Rarely, the parents did not provide the month of diagnosis of ASD; in these cases, the default month used was July (first day) since it can be considered the mid-point of a calendar year. If caregivers listed two different years for diagnosis, the earlier year was chosen by default. Whenever information pertaining to diagnostic year or date of birth was missing, every effort was made to clarify or obtain it by calling caregivers. Only one case was lost as a result of not having information about diagnostic dates.



## **CHAPTER 4**

### **Results**

The aims of this research study are to investigate possible differences in age of diagnosis and caregiver factors based upon race and cultural differences, specifically between African American and White participants. Additionally this study seeks to examine how “internal” caregiver factors (e.g. empowerment, worry about initial symptoms, and pre-diagnosis attributions of behaviors) influence children’s age at ASD diagnosis. A power analysis will be followed by descriptive statistics for the variables, test statistics correlating with the research questions, and a regression analysis.

The planned analytical procedures related to the research questions include: using a generalized linear model to detect differences in age of diagnosis between groups and exploring variations in the “internal” factors using t-Tests for independent groups and Chi-square analyses. Because two of the measures of internal factors (e.g. caregiver empowerment and attributions) were developed as scales, a factor analysis will be conducted to identify constructs and subscales. Finally, associations between the “internal” factors, demographic variables (e.g. Severity and SES), and age of diagnosis will be examined using Pearson or Spearman correlations followed by a Hierarchical Linear Regression Model. Unless otherwise noted, all statistical analyses were completed using SPSS, version 16.0.

### *Power Analyses and Effect Sizes*

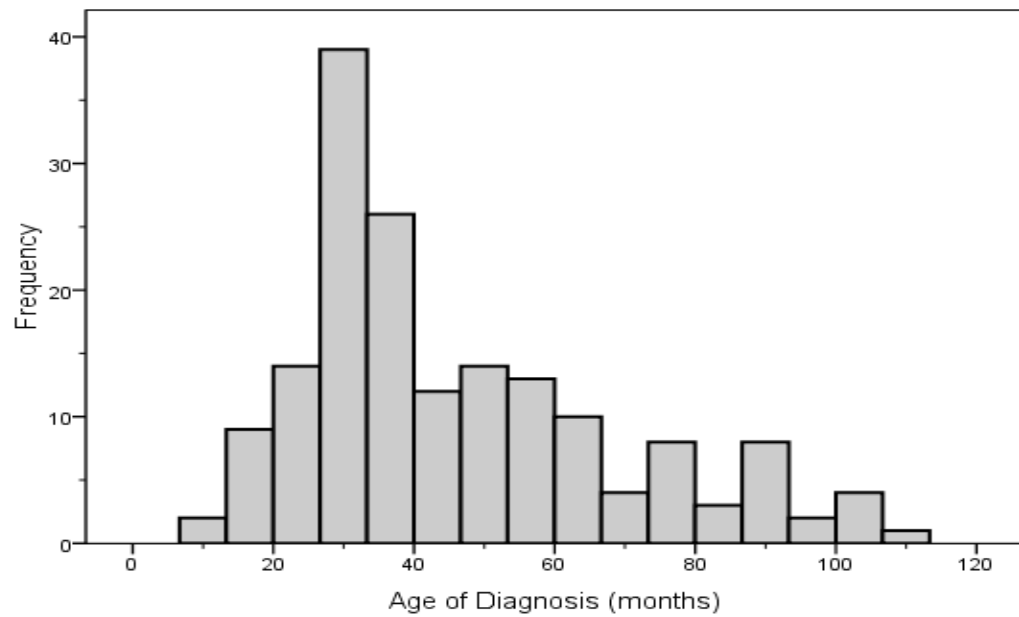
A power analysis was conducted to examine the strength of the current study to detect expected medium to small effects associated with age at diagnosis. Based upon previous research findings (Mandell, 2002), a medium effect would translate to differences of nine months. Using the *Power and Precision* software program, it was determined that the sample size was adequate to detect a medium to small effects of 0.49 with .80 power for comparison of group means. It was also determined that the sample size was sufficient to detect medium to small effects for including any one variable in a regression analysis, so increments in  $r$  squared would need to be only 0.048 to detect the targeted effect. Using a general rule of 10 cases of data per predictor (Field, 2005) the current sample size of 168 is more than adequate for regression models using the 1 to 13 predictor variables included in the models tested in the analyses of study data.

### *Data Screening for Outcome Variable: Age of Diagnosis*

The following section will provide results for analyses related to the outcome variable, age of diagnosis. These analyses were completed to test assumptions related to the outcome variable.

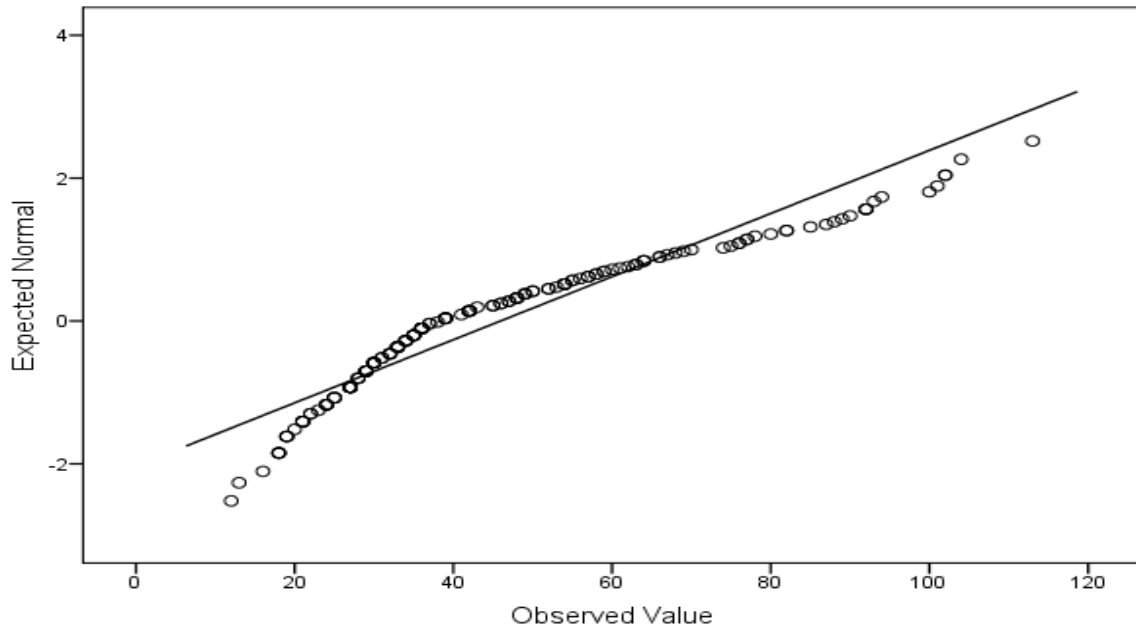
*Normality of distribution.* The second step in data analysis was obtaining descriptive statistics for the outcome variable, age at diagnosis of ASD. Normality of this age (stated in months) was first examined using visual inspection of a histogram (Fig. 4.1), which showed a slightly negatively skewed distribution; more children were diagnosed at younger ages. The mean age of diagnosis for the sample was 46 months with a standard deviation of 23. Based on these findings, the outcome variable appears to deviate from normal distribution.

Figure 4.1: Histogram of Age of Diagnosis of ASD for Entire Sample



The outcome variable was further examined for normality using a Q-Q plot generated via SPSS. A Q-Q chart plots the values one would expect from normal distribution (expected values) against the values actually seen in the data set (observed values). The expected values are on a straight diagonal line, whereas the observed values are plotted as individual points (Field, 2005). Figure 4.2 shows the graph of the Q-Q plot.

Figure 4.2: Normal Q-Q Plot Showing Age of Diagnosis (months)



Normally distributed data would fall exactly along the line; however, the plot shows that the outcome variable (age at diagnosis) has an s-shape and deviates from the line. The deviation from normality is likely caused by skewed distribution as shown in the histogram.

To further test and confirm deviation from normality for the outcome variable, both a Kolmogorov-Smirnov and a Shapiro-Wilk test were conducted. These tests compare the values in the sample to a normally distributed set of values with the same mean and standard deviation. Table 4.1 shows the results for the entire sample and Table 4. 2 summarizes results for the two comparison groups.

Table 4.1: Tests to Determine Normality of Outcome Variable

	Kolmogorov-Smirnov			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Age of Diagnosis	.15	168	.000	.91	168	.000

Table 4.2: Tests to Determine Normality of Outcome Variable by Groups

	Kolmogorov-Smirnov			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
A-A <sup>a</sup>	.12	50	.082	.93	50	.007
White	.17	118	.000	.90	118	.000

The significance of these tests and examination of the normal Q-Q plot both confirm deviation from normality in the distribution of the outcome variable. However, the extent of the impact of non-normality is lessened for this sample due to a larger N and more degrees of freedom. It should also be noted that as sample sizes increase, small differences in normality and variances can produce significant test results (Field, 2005).

*Homogeneity of variances and outcome variable.* A Levene's test was conducted to address the hypothesis that group variances are equal on the outcome variable (i.e., the

difference between the variances is zero). The Levene's test was significant, showing that  $F(1, 167) = 8.34, p < .01$ , indicating that the variances are significantly different. A second method was utilized to examine homogeneity of variances. The variance ratio for the two groups,  $F_{51, 118} = 1.79$ , was greater than the critical value for  $F = 1.48$ , indicating significant differences between the standard deviations of the groups. Taken together, these tests indicate heterogeneity of group variances.

#### *Analysis Related to Groups*

A preliminary step in examining group differences was comparing them on standardized measures. The purpose of this analysis was to assess group equivalence on variables with potential influence on overall study outcomes. De-identified scores on IQ tests and the Vineland Adaptive Behavior Scales ([VABS]; Sparrow, Balla, & Cicchetti, 1984) were available from the recruitment source for: (a) children whose caregivers completed the questionnaires and (b) children whose caregivers received a study invitation and flyer but chose not to participate (non-responders). Because standard measures were not available for all of the participants, the data represents the subset of children with scores in the recruitment source's database. Table 4.3 summarizes standardized measures for those who completed the study and the entire recruitment sample (participants and non-responders).

Table 4.3: Group Comparisons on Standardized Measures

Measures	African-American		White		<i>t</i>	<i>df</i>	<i>p</i>
	<i>M</i>	<i>SE</i>	<i>M</i>	<i>SE</i>			
Participants							
IQ	68.24 <sup>a</sup>	21.30	75.32 <sup>b</sup>	22.63	-1.59	107	.12
VABS	65.43 <sup>c</sup>	14.87	67.50 <sup>d</sup>	10.79	-.88	120	.38
Entire Recruitment Sample							
IQ	61.86 <sup>e</sup>	18.38	73.57 <sup>f</sup>	22.41	-5.40	344	.000
VABS	61.99 <sup>g</sup>	11.98	67.12 <sup>h</sup>	11.67	-4.41	424	.000

Note: <sup>a</sup>N=38 <sup>b</sup>N=71 <sup>c</sup>N=42 <sup>d</sup>N=80 <sup>e</sup>N=146 <sup>f</sup>N=210 <sup>g</sup>N=172 <sup>h</sup>N=254

As shown in Table 4.3, there were no significant differences in the IQ or VABS scores between the African American and White children who were study participants, although the average scores for the African American children were slightly lower than the White children on both measures. However, in the recruitment sample, African American children had significantly lower IQ and VABS scores than the White children.

The non-responders were also compared to study participants. On average, the IQ scores were significantly lower for non-responders ( $M = 66.96, SD = 21.07$ ) compared to those who participated ( $M = 72.85, SD = 22.34$ ) in the study  $t(354) = -2.39, p = .017$ . For the latter test, IQ scores were available for 247 of the non-responders and 109 of the participants. For the available VABS scores, the group average for non-responders ( $M = 64.30, SD = 11.91$ ) was also significantly lower than for participants ( $M = 66.93, SD = 12.26$ ),  $t(424) = -$

2.04,  $p = .042$ . For this comparison, VABS scores were available for 305 of the non-responders and 121 of the responders.

Similar comparisons were conducted within each of the African American and White groups. The average IQ scores were significantly lower for African American non-responders ( $M = 59.61$ ,  $SD = 16.78$ ) than African American study participants ( $M = 68.24$ ,  $SD = 21.30$ ),  $t(54) = -2.26$ ,  $p = .028$ . The IQ scores were available for 108 of the non-responders and 38 participants. With regard to VABS scores, African American non-responders ( $M = 60.88$ ,  $SD = 10.72$ ) also had lower scores than participants ( $M = 65.43$ ,  $SD = 14.87$ ), but this difference did not reach a level of significance  $t(55) = -1.84$ ,  $p = .07$ . For the latter comparison, VABS scores were available for 130 non-responders and 42 participants. These differences were not found within the White group, whose non-responders ( $M = 72.67$ ,  $SD = 22.32$ ) and participants ( $M = 75.32$ ,  $SD = 22.63$ ) had similar IQ scores,  $t(208) = -.81$ ,  $p = .42$ , based on available scores for 139 non-responders and 71 participants. White non-responders ( $M = 66.85$ ,  $SD = 12.13$ ) also had similar VABS scores when compared to White participants ( $M = 67.73$ ,  $SD = 10.63$ ),  $t(252) = -.56$ ,  $p = .58$ . For this comparison, scores were available for 175 of the non-responders and 79 of the participants.

The diagnostic codes were also available for group comparison. Chi-square analyses were performed to examine the likelihood of obtaining one diagnosis over another as a function of group membership. The DSM diagnostic codes differentiate between variants within ASD (i.e. Autistic, PDD-NOS, Asperger's Disorder). Differences between the two groups of study participants were seen in diagnostic codes,  $\chi^2 = (1, N=188) = 9.06$ ,  $p = .011$ . This finding appears to stem from the inclusion of proportionally more African-American



children with Asperger's Disorder (8%) than White children (1%). For example, within the entire recruitment sample, seven African-American children were diagnosed with Asperger's and six of those children were represented in this study. By contrast, within the entire recruitment sample there were 13 White children diagnosed with Asperger's and only one of them was represented in this study. However, when the entire recruitment sample was considered, there were no significant group differences for the diagnostic codes,  $\chi^2 = (1, N= 649) = 2.4, p = .30$ .

Codes representing other conditions or clinical impressions (e.g., mental retardation deferred, ADHD, communication disorders) were also available in the recruitment database. Children were assigned one or more of these codes in addition to a DSM diagnostic code, but group differences were found for only one, i.e., mental retardation deferred. Significantly more African American participants were assigned this diagnostic code in addition to a DSM code,  $\chi^2 = (1, N= 188) = 4.36, p = .03$  (one-tail). It should also be noted that more African American participants (14%) had a co-occurring diagnosis of mental retardation compared to White participants (8%), but this difference was not significant. The code of mental retardation deferred represents a clinical impression of cognitive skills based upon clinicians' interactions with the children during assessments at TEACCH referral centers. According to the clinical director of a referral center, it may be assigned during assessments when a child appears to have impairments in cognitive functioning. However, in such cases the child may be too young to receive a diagnosis or the center may be unable to provide a formal cognitive assessment for some other reason. In addition to the above circumstances, formal cognitive assessments may not be available from another source. Thus, while the mental retardation

deferred code is not a formal diagnosis, it does indicate serious clinical concern about cognitive impairments.

In summary, it appears African American children whose parents or caregivers participated in the study are slightly higher-functioning than the African American non-responders. Additionally, the African American group in this sample also contains a higher percentage of children who have a diagnosis of Asperger's Disorder, which is considered one of the less severe variants of ASD. Results suggest that the distribution of the African American group appeared to be more bi-modal, containing a higher proportion of children with diagnoses of mental retardation and mental retardation deferred but also a higher proportion of children with Asperger's, compared to the White group. Figures 4.3 through 4.6 show scatterplots of both cognitive IQ scores and VABS composite scores.

Figure 4.3: Scatterplot of IQ scores for African American Participants

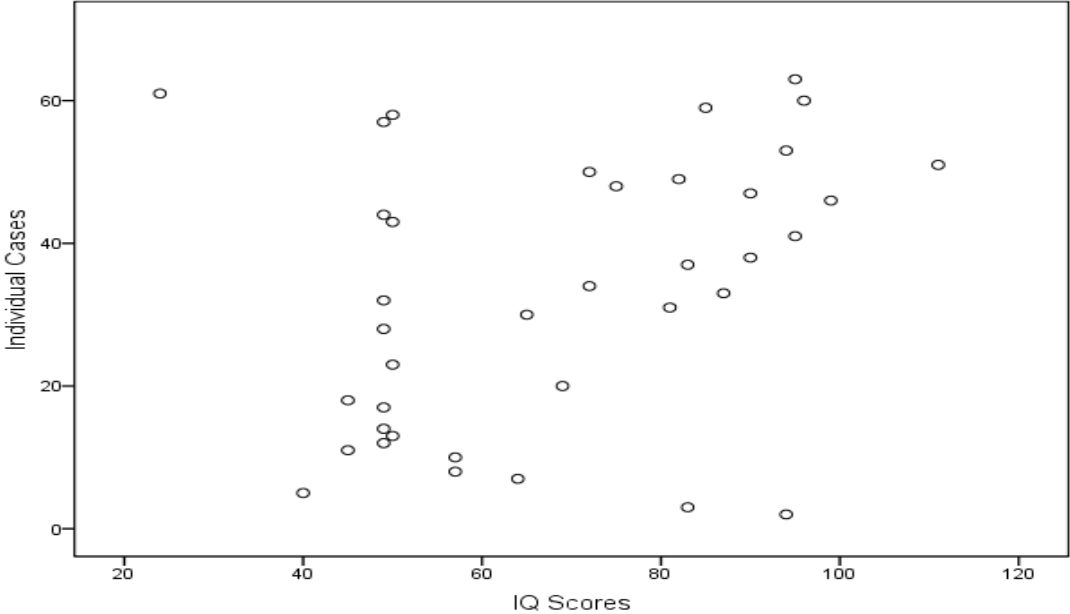


Figure 4.4: Scatterplot of IQ Scores for White Participants

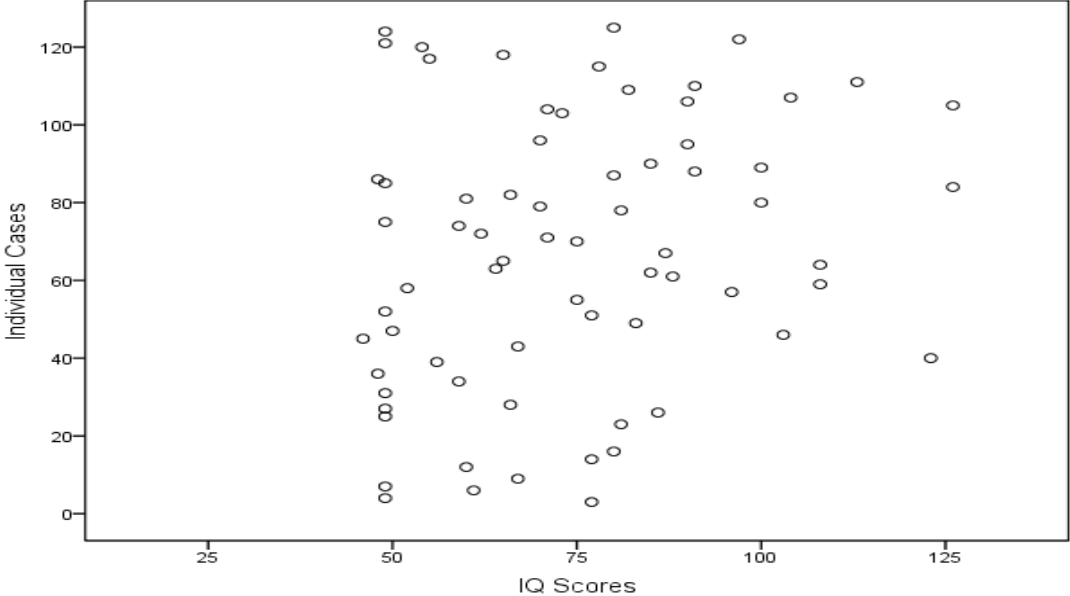


Figure 4.5: Scatterplot of Vineland Composite Scores for African American Participants

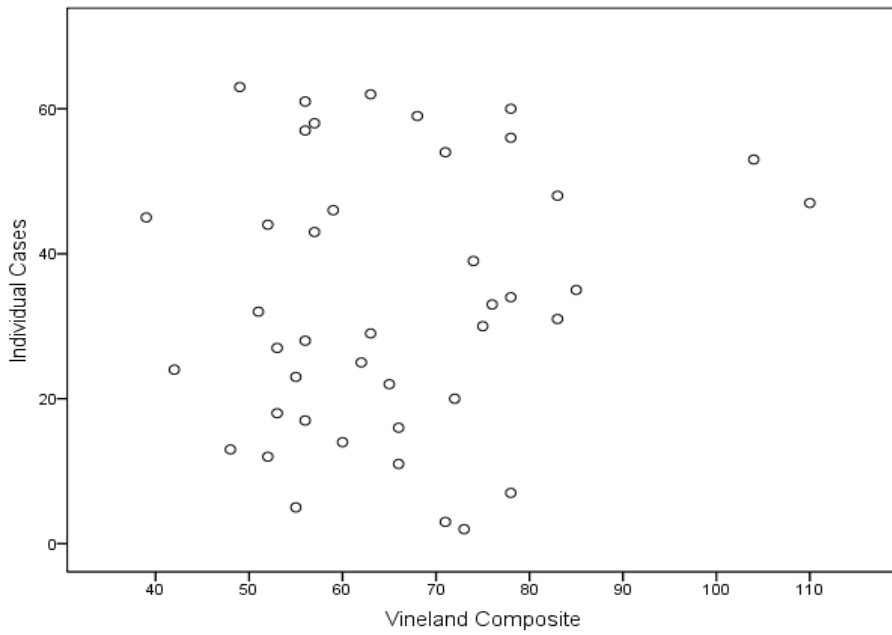
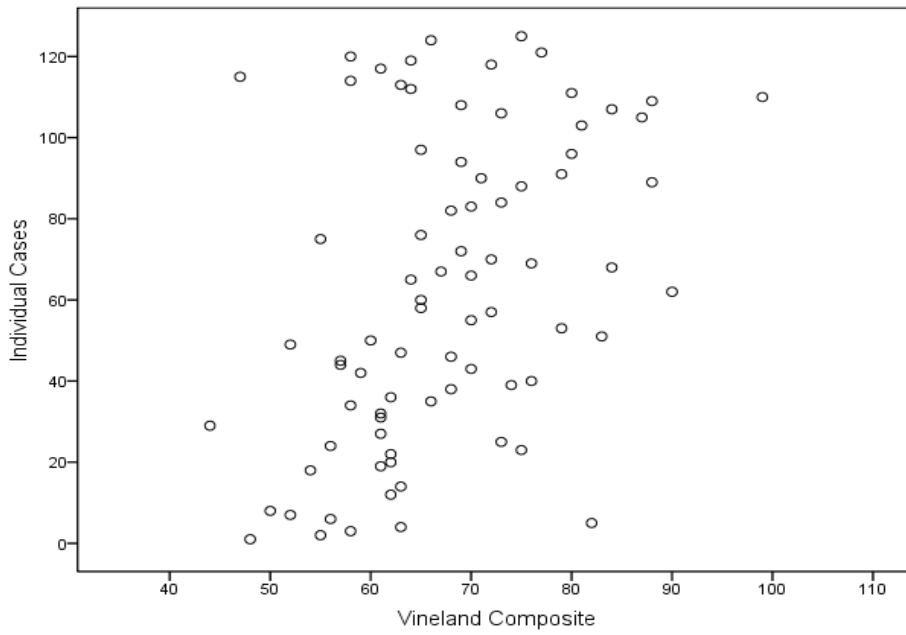


Figure 4.6: Scatterplot of Vineland Composite Scores for White Participants



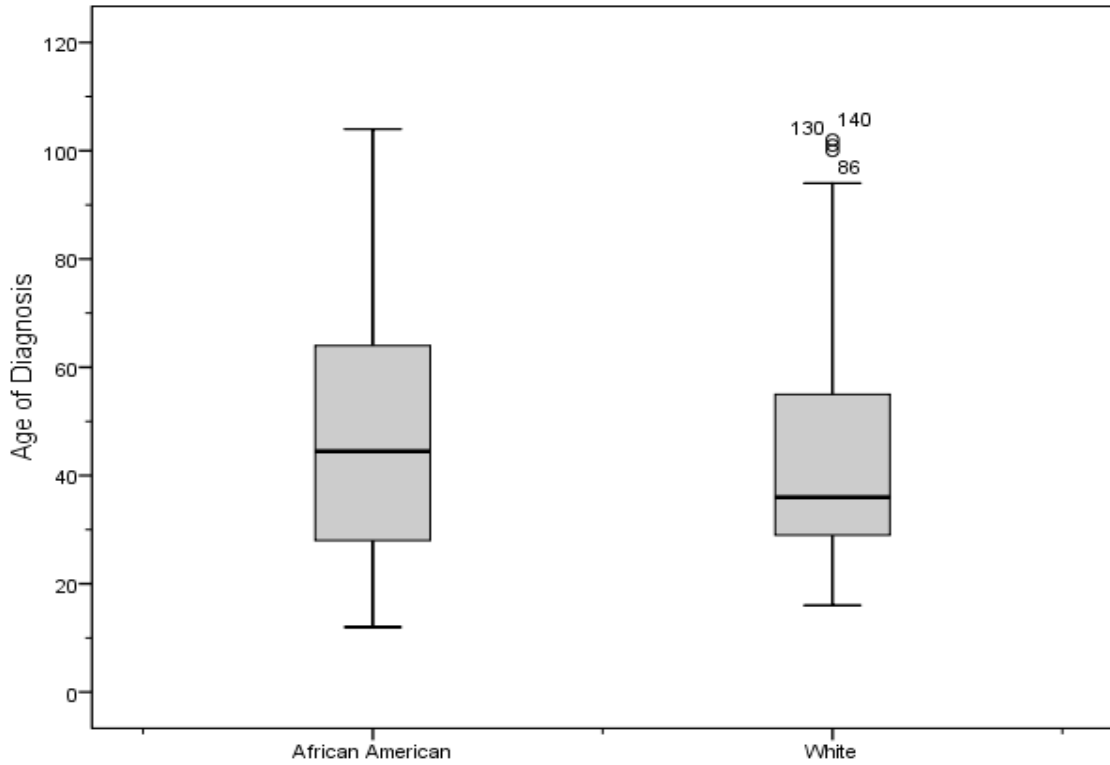
### *Analyses Related to Research Questions*

Results related to the specific research questions outlined in the current study are described in the following sections. Each of the three questions will be analyzed and presented separately.

*Research Question 1: Is there a later age of diagnosis of ASD for African American versus White children in North Carolina?*

Examination of the data for age of diagnosis revealed outliers in the White group (see Fig. 4.3). To attenuate the impact of outliers, non-normality, and heterogeneity of variances, a Generalized Linear Model was used to test the main effect of group differences on age at diagnosis. This procedure uses a log-linear regression which assumes a gamma distribution rather than normal error distribution for age at diagnosis (Nevill & Copas, 1991). Otherwise, the test is similar to an independent T-test of group means. A log-linear regression model was conducted to evaluate the hypothesis that African American children receive a diagnosis of ASD at later ages than White children. The test for main effects did not reach a level of statistical significance,  $\chi^2(1, N = 168) = 2.48, p = 0.115$ ; however, the difference in age of diagnosis was in the predicted direction, with the African American children having an average age of diagnosis approximately 6 months later than the White children. Indeed, the mean age of diagnosis for African American children in the sample was 49.72 (SD=25.83) months, compared to 43.78 (SD=20.16) for the White children. Figure 4.7 shows box plots graphs of the age at diagnosis as a function of group membership.

Figure 4.7: Boxplots of Age of Diagnosis (in months) for A-A and White Groups



As noted earlier, the African American group also had a larger standard deviation in age at diagnosis compared to the White group. The distribution of the two groups is slightly different because proportionally more children were diagnosed at a later age (right tail of distribution) in the African American group. Figures 4.8 (African American) and 4.9 (White) provide a visual depiction of the distributions for both groups on the outcome variable.

Figure 4.8: Distribution of Age of Diagnosis for African American Group

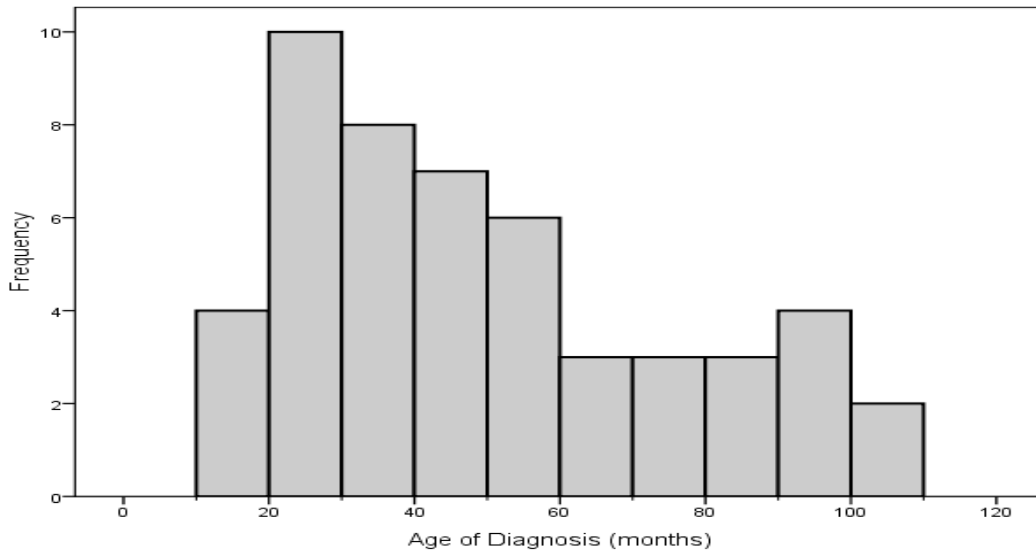
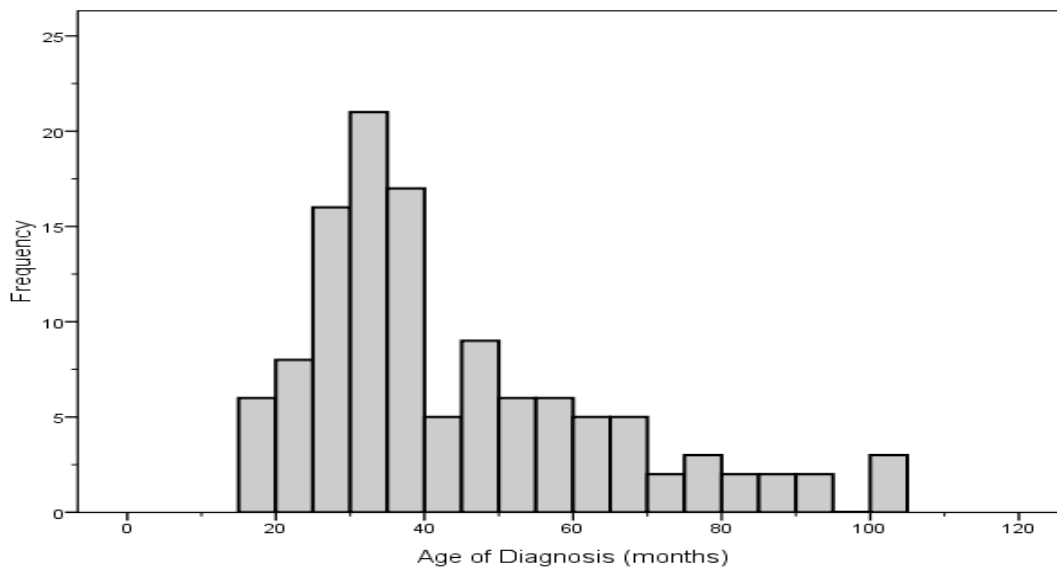


Figure 4.9: Distribution of Age of Diagnosis for White Group



*Research Question 2: Are there differences between African American and White caregivers' levels of empowerment, levels of worry about initial ASD symptoms, and attributions of symptoms?*

A preliminary step in examining the data for research questions 2 and 3 included conducting factorial analyses for the researcher-created Caregiver Empowerment (Appendix A) and Attribution of Autism Symptoms (Appendix D) measures to establish the subscales/constructs that will be used in group comparisons and the regression analysis.

*Data screening for Caregiver Empowerment measure.* Prior to running the factor analysis, the data were screened for sampling adequacy using a KMO (Kaiser-Meyer-Olkin) test, multicollinearity, and assumption that the correlation matrix is not equal to the identity matrix (Barlett test). The KMO measure represents the ratio of the sum of squared correlation between variables to the sum of squared correlations plus squared partial correlations between variables. The KMO statistic ranges from 0 to 1. A value closer to 1 indicates that the patterns of correlations are relatively compact and the factor analysis should yield distinct and reliable factors. A minimum value of .5 is recommended before proceeding with a factor rotation and analysis. The KMO for the Caregiver Empowerment items yielded a value of .89, which exceeds the minimum recommended value (Tabachnick & Fidell, 2007).

Next, the correlation matrix and determinant values were examined for extreme multicollinearity (i.e. variables that highly correlated and fail to provide unique contribution to the factor). First, the significance values (one-tail test) of the correlation matrix were



scanned to identify items that showed significant correlations (greater than .05) with the other items. Inspection of the correlation matrix showed that only one item was significantly correlated with more than two of the other items in the scale (n= 5). However, 10 other items did not have a significant correlation with the item in question; thus, the five correlations did not form a majority. As a result, this item was retained. When the magnitudes of the correlation coefficients were examined, none of the values exceeded .9, which would indicate nearly perfect correlation and failure to provide unique contributions.

As a final step in the investigation of multicollinearity, the determinant value was checked. The resulting statistic = .002, which exceeded the necessary value of .00001 (Field, 2005). These tests indicated no major problems with multicollinearity in the data. Finally, the Barlett's test of sphericity was conducted to test the hypothesis that the correlation matrix resembles an identity matrix (i.e., the off diagonal components are zero). If the population matrix resembles an identity matrix then it means that every variable correlates poorly with all other variables (i.e., all correlation coefficients are close to zero). In a non-significant test, the items correlate only with themselves and the correlation with other items is close to zero, meaning that the items have little in common and would not cluster together to form interpretable constructs (Field, 2005). The Barlett's test for the Caregiver Empowerment measure was significant,  $\chi^2 = (105) = 947.04$ ,  $p = .000$ , indicating that the correlation matrix is significantly different from the identity matrix.

*Factor analysis for the caregiver empowerment measure.* Initially, the dimensionality of the 15 items from the Caregiver Empowerment measure was analyzed via a principal axis extraction method. Three criteria were used to determine the number of factors to rotate: the

a priori hypothesis that the measure was three- dimensional, the scree test, and the interpretability of the factor solution. The scree plot (Fig. 4.10) indicated that the initial hypothesis of three dimensions was incorrect. Based upon the plot, two factors were rotated using a Varimax rotation procedure. The rotated solution, as shown in Table 4.4, yielded two distinct interpretable factors with double loadings of two items. Consequently, these two items were dropped and were not used to compute subscale scores for the instrument. The named Caregiver Empowerment factors used in the remaining analysis were: (a) control-services (CS) and (b) confidence-perseverance (CP). The cumulative item variance accounted for by both factors was 44%.

Figure 4.10: Scree plot for Caregiver Empowerment Measure

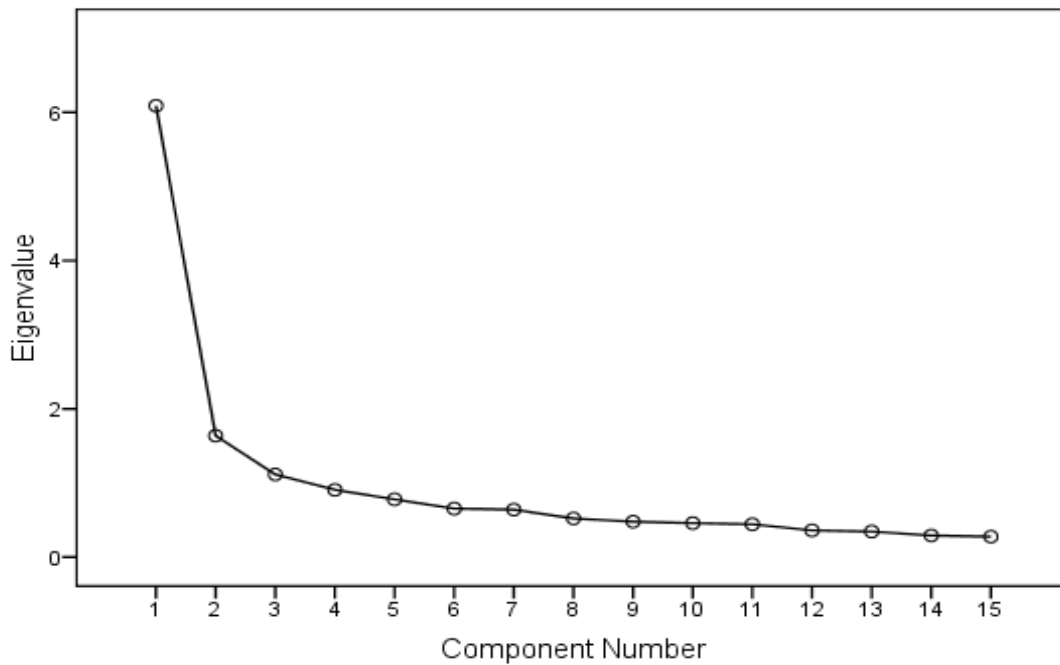


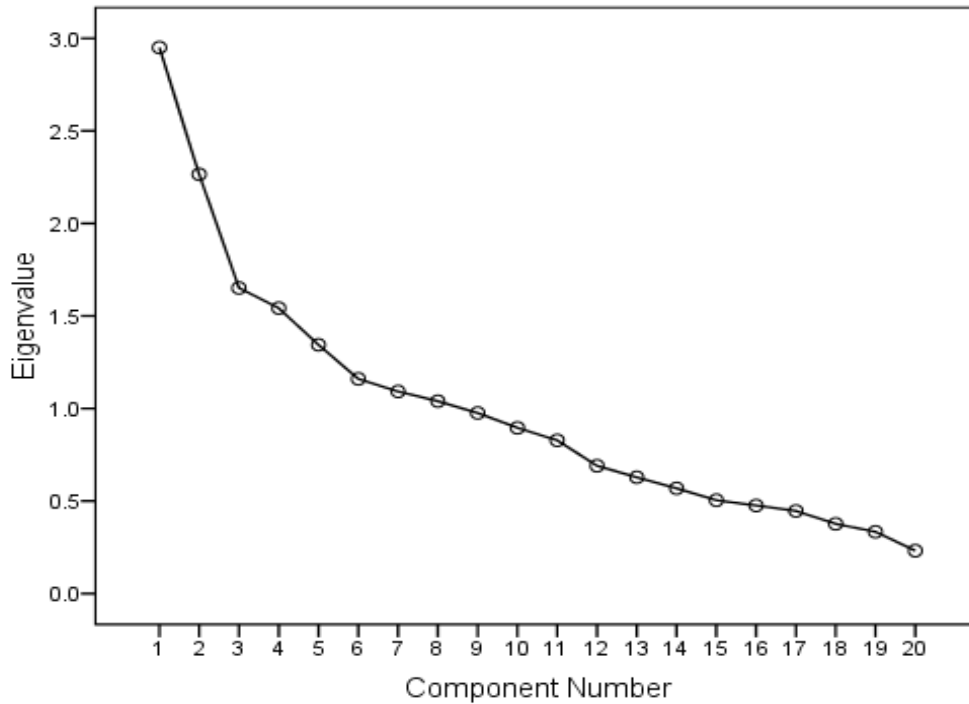
Table 4.4: Correlations Between the Two Factors for the Caregiver Empowerment Measure

Items	Factors	
	CS	CP
<b>Control-Services (CS) items</b>		
My child receives the type of services he/she needs.	<b>.79</b>	.09
It is easy for me to get the services my child needs.	<b>.74</b>	.14
It is easy for me to find information to help me make decisions for my child.	<b>.73</b>	.17
I feel like I have choices for meeting my child's needs.	<b>.65</b>	.20
I know where to go and who to talk to when I need to get help for my child.	<b>.54</b>	.24
My child's services are something I control.	<b>.54</b>	.33
Professionals understand me when I tell them about my concerns.	<b>.51</b>	.26
I am able to explain myself until my views are clearly understood.	<b>.50</b>	.31
<b>Confidence-Perseverance (CP) items</b>		
If I have a hard time getting any services for my child, I try something different.	.15	<b>.67</b>
If I cannot get the services my child needs, I keep trying.	.21	<b>.67</b>
I make a difference in the services my child receives.	.39	<b>.57</b>
If I do not get the response I want from one professional, I go to another one.	.02	<b>.57</b>
If it is hard for me to talk professionals, I find someone else to help me communicate.	.25	<b>.37</b>
<b>Double-Loaded Items</b>		
I feel sure I can take the steps needed to get services for my child.	.51	.52
I have the power to get what my child needs.	.51	.51

*Factor analysis for attributions of autism symptoms measure.* As with the previous measure, data were screened for sampling adequacy, multicollinearity, and assumptions. The KMO for the Attribution items produced a value of .61, which exceeds the minimum recommended value. Examination of the correlation matrix revealed several items that correlated with more than 10 out of the 20 items, indicating possible concerns with multicollinearity. However, inspection of the correlation coefficients did not reveal any values greater than .9 and the determinant value, statistic = .017, exceeded .00001. Therefore, all of the items were retained for the factor analysis with the understanding that some concerns with multicollinearity cannot be completely ruled out. Last, the Bartlett's test of sphericity was significant,  $\chi^2 = (190) = 606.92$ ,  $p = .000$ , indicating that the correlation matrix for the Attribution measure is significantly different from the identity matrix.

Dimensionality of 20 items from the attribution measure was analyzed using a principal axis extraction method. Three criteria were used to determine the number of factors to rotate: the a priori hypothesis that the measure was five-dimensional, the scree test, and the interpretability of the factor solution. The scree plot (Fig. 4.11) indicated that the initial hypothesis for five dimensions was appropriate. Based upon the plot, five factors were rotated using a Varimax rotation procedure.

Figure 4.11: Scree plot for Attribution Measure



Two of the items did not load onto any factors: (a) I thought my child's behaviors were associated with being "under a curse" and (b) I thought my child's behaviors were associated with a "hearing loss." Consequently, these two items were dropped and the factor analysis was conducted a second time. The rotated solution, as shown in Table 4.5, yielded five interpretable factors with weak loadings of three items (coefficient values  $<.30$ ). The named attribution factors used in the remaining analysis are: (a) behavioral problems (BP); (b) alternative explanations (AE); (c) family factors (FF); (d) external factors (EF); and (e) experiences/personality differences (EP). The cumulative item variance accounted for by all five factors was 34%.

Table 4.5: Correlations Between the Five Factors for the Attribution Measure

Items	Factors				
	BP	AE	FF	EF	EP
<b>Behavioral Problems (BP) items</b>					
needed more discipline	<b>.72</b>	.07	.03	-.05	-.07
was being stubborn or disobedient	<b>.72</b>	.09	.14	-.08	-.01
might be spoiled	<b>.51</b>	.06	-.04	-.07	.14
had a difficult personality	<b>.50</b>	.04	.15	.07	.00
<b>Alternative Explanations (AE) items</b>					
was behaving this way because of what he/she ate	.09	<b>.88</b>	.02	.07	-.01
had a food allergy	.01	<b>.78</b>	.16	.17	-.08
didn't have enough prayer	.15	<b>.31</b>	.23	.03	.06
<b>Family Factors (FF) items</b>					
had inherited these behaviors	.04	.13	<b>.75</b>	.17	-.11
was behaving like another member of my family	.08	.05	<b>.60</b>	-.11	.08
didn't have enough love and attention	.06	.22	<b>.27</b>	.03	.07
<b>External Factors (EF) items</b>					
had a disability	-.22	.02	.03	<b>.67</b>	.02
had a medical condition	.01	.11	-.04	<b>.66</b>	-.13
was made this way by God	.08	.16	.21	<b>.27</b>	.01

Items ( <i>continued</i> ).	Factors				
	BP	AE	FF	EF	EP
<b>Experiences/Personality (EP) items</b>					
was different from other children	.12	.03	.06	.04	<b>.57</b>
was a “late bloomer” or just delayed	-.18	-.01	-.25	.17	<b>.45</b>
was very shy	-.02	-.06	.02	-.17	<b>.41</b>
needed to spend more time with other children	.03	.24	.12	-.01	<b>.31</b>
would grow out of the behaviors	.24	-.04	.03	-.12	<b>.26</b>

Based upon the item groupings generated from the factor analysis, scores from the items were combined to create constructs for the Caregiver Empowerment measure and the Attribution of Autism Symptoms measure. The subscale scores from these constructs were used in the following analyses:

*Caregiver levels of empowerment.* An independent *t*-test was conducted to examine differences between the scores of African American and White caregivers on the two subscales of the Empowerment measure. On average, the African American caregivers had similar scores on the Control-Services Construct ( $M = 23.29, SE = 4.80$ ) compared to White caregivers ( $M = 22.62, SE = 4.27$ ), which suggests that the two groups of parents had similar perceptions regarding their own level of control and the adequacy of services they could access for their children. The small difference in means was not significant  $t(164) = .89, p = .38$ . The African American caregivers also reported comparable levels of perseverance and

confidence in obtaining services for their children (Confidence-Perseverance Construct;  $M = 15.55$ ,  $SE = 2.82$ ) compared to White caregivers ( $M = 15.10$ ,  $SE = 2.80$ ). This comparison was not significant  $t(156) = .93$ ,  $p = .35$ . The degrees of freedom are smaller in the comparison of the latter construct due to the exclusion of cases with missing values. Individual scale items were also examined for group differences, with only one producing significant results. A chi-square analysis showed that African American caregivers were less likely to report knowing where to go and who to talk to when needing to get help for their children compared to White parents,  $\chi^2(3, N = 168) = 10.71$ ,  $p = .013$ .

*Levels of worry about initial ASD symptoms.* An independent  $t$ -test was conducted to examine the differences between the scores of African American and White caregivers on the Level of Worry measure. Similar levels of worry were reported by African American ( $M = 16.42$ ,  $SE = 4.41$ ) and White caregivers ( $M = 16.36$ ,  $SE = 4.66$ ). The results of the test were not significant  $t(166) = .08$ ,  $p = .93$ . Analysis of individual items did not show group differences on caregivers' responses.

*Attributions of symptoms.* Independent  $t$ -tests were conducted to examine differences between the scores of African American and White caregivers for all five constructs of the measure. Similar patterns of attributions for initial autism-related symptoms were reported for both African American and White caregivers. The results did not reach significance for any of the five constructs (see Table 4.6).



Table 4.6: Group Comparisons of Five Constructs on Attribution Measure: t-Tests

Constructs	African-American		White		<i>t</i>	<i>p</i>	<i>df</i>
	<i>M</i>	<i>SE</i>	<i>M</i>	<i>SE</i>			
Behavioral (BP)	6.06	1.27	5.70	1.5	1.56	.12	111 <sup>a</sup>
Alternative (AE)	3.26	.63	3.43	.85	-1.45	.15	123 <sup>a</sup>
Family (FF)	3.68	.82	3.64	.94	.29	.77	166
External (EF)	4.84	1.13	4.57	.103	1.52	.13	166
Experiences (EP)	8.70	1.07	8.40	1.23	1.51	.13	166

<sup>a</sup> Differences in degrees of freedom resulting from unequal variances.

While differences were not found between groups on the five constructs, variations were found for some individual items using chi-square analysis. The following list details items in which group differences reached significance or trended toward significance.

1. There was a significant association between the group membership and whether or not caregivers attributed initial symptoms to something their child ate,  $\chi^2(1) = 4.6$ ,  $p=.023$  (one-tail). In terms of percentages, 17% of the White caregivers endorsed this item compared to 6% of the African American caregivers.
2. There was a significant association between group membership and whether or not caregivers were likely to attribute initial behaviors to their child being made this way

- by God,  $\chi^2(1) = 3.8, p=.038$  (one-tail). Indeed, 49% of the African American caregivers endorsed this item compared to 33% of the White caregivers.
3. There was a trend toward significance in the association between group membership and the attribution of initial behaviors to a need for more discipline,  $\chi^2(1) = 3.1, p=.056$  (one-tail). The proportion of African American caregivers endorsing this item was 58% compared to 43% of the White caregivers.
  4. There was also a trend toward significance in the association between group membership and the attribution of initial symptoms to their child being spoiled,  $\chi^2(1) = 2.8, p=.069$  (one-tail). More of the African American caregivers (37%) endorsed this item than the White caregivers (25%).
  5. Finally, there was a trend toward significance in the association between group membership and the attribution of initial symptoms being caused by food allergies,  $\chi^2(1) = 2.8, p=.07$  (one-tail). The percentage of White caregivers who endorsed this item was 20% compared to 10% of the African American caregivers.

*Research Question 3: Can age of diagnosis be predicted by SES, caregiver empowerment, level of worry about initial ASD symptoms, attributions of initial ASD symptoms, or severity of symptoms?*

As a preliminary step to the regression analysis, bivariate Spearman rank correlations were conducted to examine the relationships among the predictor and outcome variables. The results show that two of the correlations were significant. Level of worry about initial ASD symptoms was negatively correlated with the age of diagnosis of ASD,  $r(169) = -.22, p = .004$ . The behavioral construct of the attribution scale was positively correlated with the age of diagnosis of ASD,  $r(169) = .31, p = .000$ .

As part of the preliminary analysis, the variables of interest were examined for potential outliers and influence as well as assumptions surrounding homoscedasticity and multicollinearity. To rule out multicollinearity between the predictor variables, the variance inflation factor (VIF) was analyzed. A suggested VIF value of 10 (Myers, 1990) or an average VIF value substantially greater than 1 (Bowerman & O'Connell, 1990) may indicate multicollinearity. The screening statistics for the current regression analysis did not reveal any VIF values greater than 10; the average of the values was 2.5. The larger average VIF values and potential problems for collinearity arose from constructed dummy-coded (maternal education) variables. It should be noted that these variables will be entered into the regression model as one block in a separate step. Next, the data were screened to identify outliers and cases of influence on the predictor or outcome variables. Leverage values were generated in SPSS and compared to a cut-off value of three times the average leverage value (.25). This more inclusive cut-off value was used in order to avoid identifying a large number

of outliers (Field, 2005). None of the values exceeded this number or the more conservative cut-off value of two times the average leverage value (.17). These findings indicate that none of the cases were extreme enough to have a significant influence on the independent variables. A leverage scatter plot generated in SPSS confirmed this observation. The studentized residuals were inspected to identify any highly discrepant observations on the outcome variable in the context of the regression model. None of the values exceeded the recommended cut-off score of  $\pm 2$ , indicating that none of the observations were extreme enough to influence the outcome variable.

The Cook's and Mahalanobis distances were also examined to detect any cases of possible concern, because a case with a Cook's distance value exceeding 1 may have undue influence on the regression model as a whole (Field, 2005). In the current data, none of the Cook's distance values exceeded 1, suggesting that no one particular case is injecting bias into the model. Of the Mahalanobis measurements, only 6 cases had a distance value greater than 10 and none exceeded a critical value of 20–22 (values set for a sample size of 100 or 200); values of more than 22 would imply influential cases in the data (Field, 2005). Finally, residual plots of the predictor and outcome variables were examined to look for evidence of homoscedasticity (same residual variances) and linearity. One construct, Alternative Experiences from the Attribution of Autism Symptoms Measure, showed some heteroscedasticity but did not appear to be an extreme case. The Durbin-Watson statistic was 2.32 (recommended value 1–3, according to Field, 2005), indicating that for any two observations the residual terms were uncorrelated or independent. Because data screening of

the variables did not indicate significant violations to the assumptions of the regression model, no cases were deleted from the analysis.

Regression analysis. A hierarchical regression analysis was conducted upon the relationship between the predictor variables and the age at diagnosis. The predictor variables were: (a) severity (SRS total standardized score); (b) maternal educational level (dummy coded  $n= 4$ ); (c) scores on two constructs measuring caregiver empowerment; (d) caregiver level of worry about ASD symptoms; and (e) scores on five constructs measuring the attribution of ASD symptoms. In this study, maternal educational level served as proxy for socioeconomic status. Sequential entry of predictor variables into the model was based upon research showing that a child's level of functioning or severity of symptoms (Goin-Kochel et al., 2006; Mandell, et al., 2005) and SES (Mandell et al., 2005) may influence age at diagnosis. Race was not included in the model as a variable because it was examined independently and did not distinguish between the two groups on the outcome variable, age of diagnosis, or any of the researcher developed measures (i.e. internal factors); nor did the race variable have a significant correlation or association with the outcome variable.

The predictors were entered into the model in three steps: first the SRS total score, next the dummy- coded variables for maternal educational level, and finally scores on the researcher-developed measures of internal caregiver-related factors (i.e., two constructs of both Caregiver Empowerment and Level of Worry measure, as well as five constructs of the Attribution measure). The final model included all 13 predictor variables and was significant, with  $R^2 = .22$ ,  $F(8, 142) = 4.22$ ,  $p = .000$  and adjusted  $R^2 = .15$ . It thereby explained approximately 22% of the variance associated with the outcome variable of age at diagnosis.

The first step of the model trended toward significance and the last step was statistically significant. The first block (SRS; severity) resulted in an  $R^2 = .019$ ,  $F$  change (1, 154) = 2.91,  $p = .090$ , indicating that severity alone only explained 2% of the variance in age of diagnosis. The second block (maternal educational levels) did not produce significant change,  $R^2 = .034$ ,  $F$  change (4, 150) = .61,  $p = .653$ ; thus, maternal educational level only explained an additional 1% of the variance in age of diagnosis. Finally, entry of the third block (Empowerment, Level of Worry, and Attributions) produced a significant change in  $R^2$  as shown by the final model summary stated above. Individual examination of parameter estimates revealed that only three of the variables were significantly associated with the age of diagnosis of ASD: (a) SRS total scaled scores or child severity (b) caregivers' Level of Worry about ASD symptoms, and (c) caregivers' Attribution of Initial Autism Symptoms to behavioral problems. A summary is provided in Table 4.7.

Table 4.7: Hierarchical Regression Predicting Age of Diagnosis of ASD

<b>Variables</b>	<b><i>B</i></b>	<b><i>SE B</i></b>	<b><math>\beta</math></b>
Step 1			
Constant	18.20	16.13	
SRS total scaled score	.34	.20	.14
Step 2			
Constant	21.154	19.06	
SRS total scaled score	.32	.20	.13

<b>Variables</b> ( <i>continued</i> ).	<b>B</b>	<b>SE B</b>	<b>β</b>
Maternal Education Levels:			
High School Diploma or GED	-2.85	10.31	-.04
Some College	2.37	9.70	.05
Associates Degree	-6.34	10.10	-.10
Bachelors and Beyond	-2.32	9.37	-.05
Step 3			
Constant	9.86	25.89	
SRS total scaled score	.42	.20	.18*
Maternal Education Levels:			
High School Diploma or GED	-1.87	9.81	-.03
Some College	2.38	9.18	.05
Associates Degree	-4.02	9.46	-.07
Bachelors and Beyond	-5.61	8.83	-.13
Caregiver Empowerment:			
Control-Services Construct	.09	.46	.02
Confidence-Perseverance Construct	.44	.71	.06
Level of Worry About ASD symptoms	-1.39	.41	-.29**
Attributions of ASD symptoms:			
Behavioral Problems	4.64	1.19	.31**
Alternative Explanations	-3.78	2.28	-.14
Family Factors	-2.43	2.05	-.10
External Factors	1.35	1.67	.07
Experiences-Personality Factors	.92	1.41	.05

*Note.*  $R^2 = .02$  for Step 1;  $\Delta R^2 = .01$  for Step 2 ( $ps > .01$ );  $\Delta R^2 = .18$  for Step 3 ( $ps < .001$ )  
\*  $p < .05$ ; \*\*  $p < .001$

Partial residual plots of the outcome and predictor variables were produced during the regression analysis, in the form of scatterplots of the residuals for the outcome variable and each of the predictors when regressed separately on the remaining predictors (Field, 2005). These plots also show the linear relationship between the outcome variable (age at diagnosis) and the predictors, providing a graph of the gradient of the regression line. Figures 4.12 – 4.14 show the partial residual plots for the significant predictor variables entered into the regression model.

Figure 4.12: Partial Residual Plots for the Outcome Variable and SRS Total Scale Scores

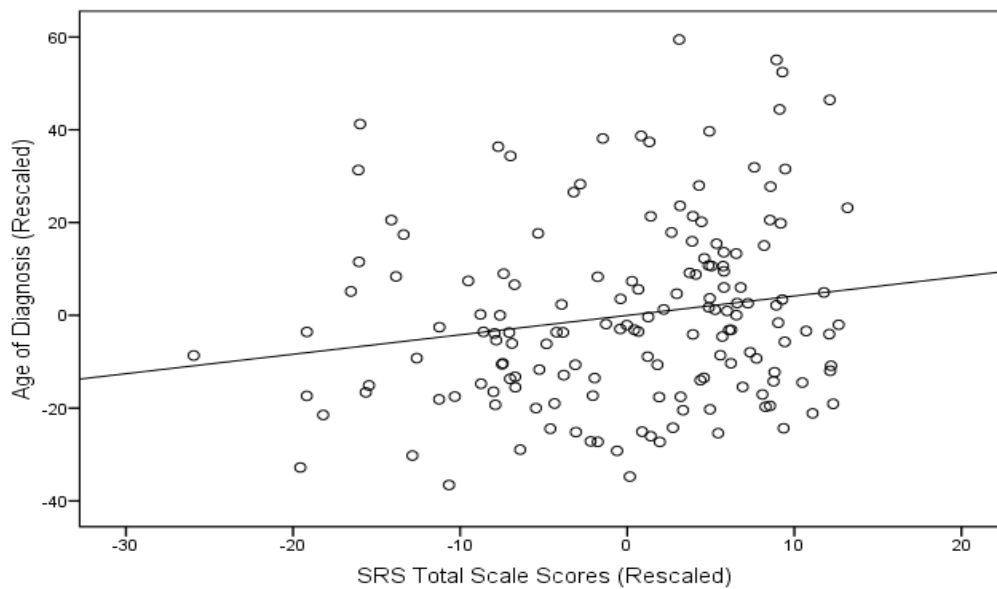




Figure 4.13: Partial Regression Plots for the Outcome Variable and Level of Worry Scores

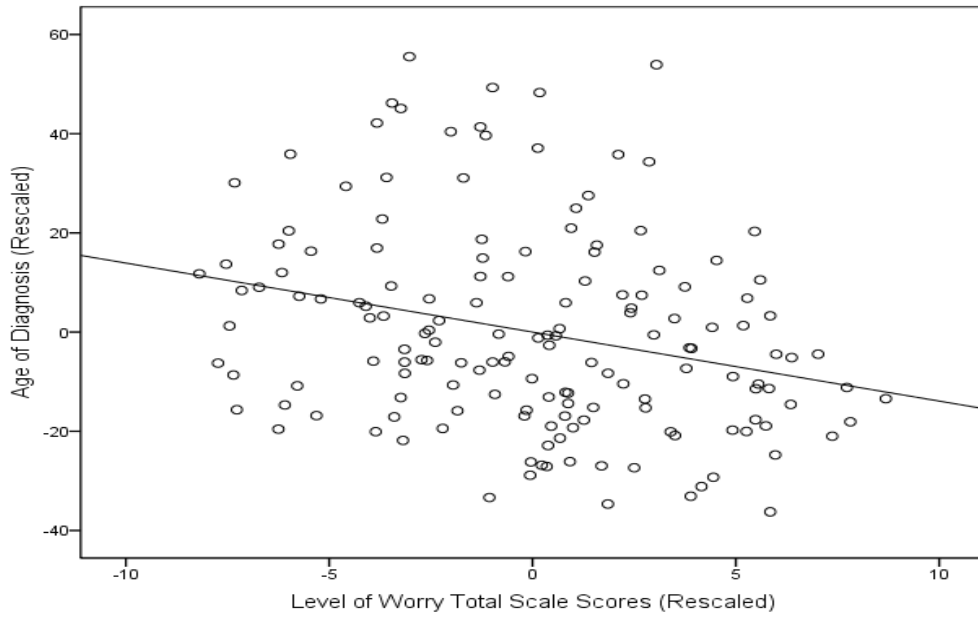
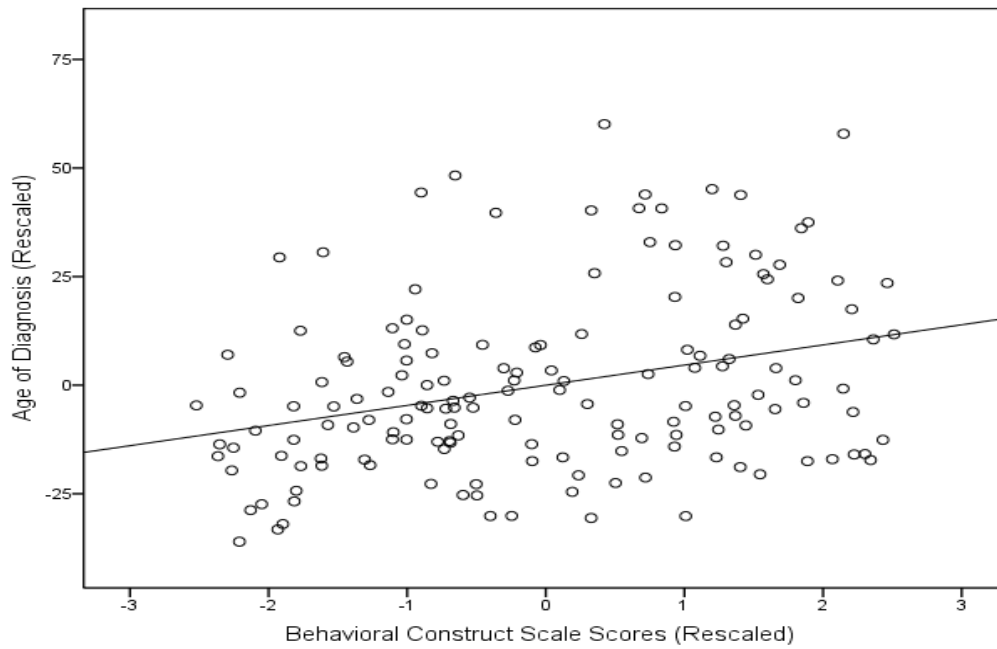


Figure 4.14: Partial Regression Plots for the Outcome Variable and Behavioral Construct



*Correlations of Independent and Outcome Variables with Demographic Variables*

This study also examined relationships among variables that may help explain its findings. Several significant correlations were found among some of the demographic, independent, and outcome variables. Table 4.8 summarizes correlations among the demographic and outcome variables.

Table 4.8: Correlations among Outcome and Demographic Variables

Demographic Variables	Age at Diagnosis
Child's current age	.44**
Child received another diagnosis prior to an ASD diagnosis	.40**
Length of time between talking to the initial professional about behavioral concerns and receiving a diagnosis	.31**
Length of time between the caregiver observing concerning behaviors and speaking with a professional	.20*

Note. N = 168. \*\*  $p < .05$  \*  $p < .01$

All of the demographic variables shown in Table 4.8 have significant positive correlations with the outcome variable, age of diagnosis. To summarize, children were more likely to have a later age of diagnosis if: (a) they were older, (b) they received a different diagnosis before being diagnosed with ASD, (c) there was a longer period of time between seeking help for concerning behaviors and diagnostic assessment for ASD, and (d) their

parents reported a longer period of time between seeing concerning behaviors and seeking help from professionals.

Demographic and independent variables were also examined for Pearson or Spearman rank correlations. The results that were significant and contributed to understanding the overall findings are listed below:

1. Caregiver's report of medical problems during pregnancy, infancy, or early childhood was positively correlated with the child receiving a different diagnosis prior to an ASD diagnosis,  $r(167) = .22, p = .005$ . These findings suggest that the presence of other medical conditions may increase the likelihood that children will receive other diagnostic labels before ASD is considered or diagnosed.
2. Caregiver's report of medical problems during pregnancy, infancy, or early childhood was also positively correlated with caregiver's scores on the level of worry about autism symptoms measure,  $r(167) = .18, p = .018$ , indicating the presence of health challenges associated with pregnancy or early childhood increased the likelihood that parents would be more concerned about deficits in social-communicative skills.
3. The presence of a cognitive impairment was significantly correlated with a child receiving a different diagnosis prior to an ASD diagnosis,  $r(162) = .22, p = .005$ .
4. The presence of a cognitive impairment was significantly correlated with SRS total scale score,  $r(162) = .18, p = .023$ , suggesting cognitive impairment is associated with more severe symptoms of ASD.
5. The length of time between talking to the initial professional about behavioral concerns and receiving a diagnosis was correlated with a child receiving a different

diagnosis prior to an ASD diagnosis,  $r(168) = .34, p = .000$ . Such children experienced a longer lag between the time their parents first spoke to a professional and their ASD diagnosis.

6. Maternal educational level was negatively correlated with caregiver's scores on the level of Worry about autism symptoms measure,  $r(166) = -.26, p = .001$ . This finding suggested that mothers with lower education levels worried more about autism symptoms than mothers with higher education levels.
7. Maternal educational level was positively associated with income,  $r(162) = .49, p = .000$ .
8. Income levels were negatively associated with the SRS total scale score,  $r(164) = -.17, p = .027$ , suggesting a tendency for children at lower income levels to exhibit more severe symptoms of ASD.
9. Caregivers' scores on the Behavioral Problems construct of the Attribution of Autism Symptoms were positively associated with a child receiving a different diagnosis prior to an ASD diagnosis,  $r(168) = .18, p = .02$ . In other words, caregivers who reported they attributed early autism symptoms to behavior problems also were more likely to report that their children received a different diagnosis prior to their ASD diagnosis.
10. Caregivers' scores on the Behavioral Problems construct of the Attribution of Autism Symptoms were correlated with the length of time between the caregiver observing behaviors that caused concern and consulting a professional,  $r(166) = .19, p = .017$ .

## **CHAPTER 5**

### **Discussion**

The purpose of this study was to identify possible disparities in the age of diagnosis of ASD among a sample of African American and White children in North Carolina and provide insight about factors influencing the age of diagnosis of ASD, specifically caregiver empowerment, perceptions, and beliefs about initial ASD-related symptoms across two racial groups. This discussion will review the major findings, interpret them, relate them to prior research, and consider some alternative explanations. The clinical relevance of the findings will also be discussed. Finally, the limitations of this study and suggested directions for future research will be presented.

#### *Age of Diagnosis of ASD*

The current study did not find significant differences in the age of diagnosis of ASD between African American and White children. Although this finding is consistent with more recent studies about age of diagnosis of ASD (Mandell et al., 2005; Goin-Kochel et al., 2006; Wiggins, 2005), it is inconsistent with an earlier study by Mandell et al. (2002) and conflicts with the hypothesis that racial-group disparities in age of diagnosis still exist based upon Mandell's findings.

Several reasons could explain why a significant difference was not found in the age of diagnosis among the sample used in the current study. The first and most obvious is that this

sample differs from Mandell et al. (2002), which was majority African American, Medicaid eligible, and not self-selected, but is more similar to the sample used by Mandell et al. (2005), which was majority Caucasian, mostly had income greater than 200% above poverty level, and responded via internet. Similar to the Mandell et al. (2005) sample, participants in current study were self-selected and had higher income levels (74% with a total household income of more than \$40,000). Therefore, this sample may have had more access to resources and information that could have impacted the families' abilities to get an earlier diagnosis for their children. It should be noted, however, that only 52% percent of the African American families in this study had a combined household income of more than \$40,000 (compared to 83% of the White caregivers). Thus, it may not be accurate to conclude that African American and White families or caregivers in this study had the same access. Caregiver decision to participate in the current study also may have been affected by child-related factors, particularly for the African American group. In the current study, scatterplots of cognitive IQ scores revealed that African American participants had a bimodal distribution with proportionally fewer children in the mild to moderate ranges of cognitive impairment. This discrepancy may be another by-product of self-selection, where African American caregivers are more apt to participate in research if their children have either high or relatively low cognitive functioning.

Another, related explanation for the influence of sample characteristics and the lack of differences across groups may involve the recruitment source for the current study. Participants in the NDRC autism registry are often referred by TEACCH or CDSA centers, both of which provide free diagnostic and assessment services for children at risk for ASD.

These free, specialized diagnostic services may reduce the incidence of unequal access to comprehensive services that is assumed to be based upon SES. In fact, a large proportion of this sample (75%) was diagnosed at TEACCH or CDSA sites. These sites, which are specific to North Carolina, may equalize the age of diagnosis across racial groups in this state compared to other states not offering such services. Alternatively, the NDRC autism registry may disproportionately reflect families who have accessed free public services for their children with ASD, given the large number of referrals from TEACCH and CDSA centers to the registry.

Third, and beyond the factors directly related to the study participants, is the possibility of a national system-wide improvement in detecting ASD at earlier ages due to increased awareness and better diagnostic tools. This explanation is supported by the overall decrease in the average age at diagnosis reported in recent studies of ASD (Mandell et al., 2005; Goin-Kochel et al., 2006; Wiggins, 2005) compared to earlier studies (Howlin & Moore, 1997; Mandell et al., 2002). In fact, there is a clear difference of one to two years in the average age at diagnosis between the earlier and later studies. The current study shows evidence of this trend via a positive correlation between children's age at diagnosis and current age. Thus, the age at diagnosis was later for children who were older in this sample. Additionally, the overall average age at diagnosis for the sample was between 3 and 4 years, well below the average age of 6 years reported by Mandell et al. (2002) and Howlin and Moore (1997). This system-wide improvement may not only have brought about earlier identification but may also have closed the gap in age at diagnosis between children in minority and majority populations.

The above reasons may partially explain why the current study did not find statistically significant differences in age at diagnosis between racial groups; however, whether the six-month difference between diagnosis of White and African American children is clinically significant must be considered. Full attention to this question requires consulting studies that have examined longitudinal outcomes (e.g. skills, educational placement, IQ) for children who were diagnosed and/or entered early intervention at younger ages. Stone et al. (2006) found higher cognitive and language skills for children who were diagnosed earlier and received more hours of speech-language therapy between ages 2 and 3. At their age 9 follow-up, this team found that children in their higher outcomes group had been diagnosed slightly earlier and received more speech-language therapy between ages 2 and 3. By contrast, children in the lower outcomes group had been diagnosed slightly later and received less hours of speech-language therapy between ages 2 and 3. Proportionally, the majority of the children (70%) diagnosed prior to 30 months were in the higher outcomes group at age 9, while the majority of children (72%) identified after 30 months were in the low outcomes group.

Another well-known study (Harris & Handleman, 2000) documenting relationships between age of admission into an intervention program and eventual school placement found that children who started the program at earlier ages (prior to 48 months) were more likely to be placed in inclusive regular education settings than those who started later. Similarly, Harris and Handleman also found a correlation between higher IQs (at admission) and later outcomes (placement in regular education settings). Although they did not find a correlation between age and cognitive functioning at the beginning of the program, an association



between starting age and IQ was found when children left the program. In other words, the children who started the program when they were younger had higher IQs at discharge than those who started later.

It appears that younger ages or higher cognitive and language skills at the start of intervention services can influence gains in skills and functioning at later ages. The above studies indicate that even slight differences in age at diagnosis and cognitive skills may equal large effects for younger children. The six-month difference in age at diagnosis found in the current study can translate to 52 hours of direct early intervention services (at two hours per week) or 78 hours (at three hours per week). Also, these estimates do not include placement into specialized preschool programs, or parent-provided intervention, both of which would further increase the hours of intervention an identified child could receive in a six month time period. Because initial IQ scores are beyond clinical control, factors such as younger ages at identification and increased amounts of intervention should be maximized. Given that Turner et al. (2006) observed average differences of only 4 months in age of diagnosis and 71 hours of speech and language therapy (between ages 2 and 3) between the higher- and lower-functioning groups, a six-month delay in diagnosis could very well be clinically significant especially in terms of later outcomes.

#### *Caregiver Empowerment*

As with the findings about age at diagnosis, the current study did not find differences between African-American and White caregivers on the Caregiver Empowerment measure. The groups responded similarly to a majority of the items, with the exception of one: African Americans were less likely to report knowing whom to consult and where to go to get help

for their children. This difference resonates with findings of another study about access to healthcare health services for children with ASD. According to Liptak et al. (2008), African Americans and Latinos were more likely to have difficulty obtaining important medical advice by phone and were less likely to receive timely medical care. On the other hand, the Liptak (2008) study also found that African American children did not have difficulty obtaining care from a specialist. It may, however, take African American caregivers longer to find an entry point into those specialized services based upon findings from the current study.

Instrument design and collection methods could partially explain why differences were not found on the measure as a whole; rather than assessing pre-diagnosis levels, it was designed to measure current levels of Caregiver Empowerment. Having a child with ASD, in and of itself, may positively influence the overall empowerment levels of all caregivers. For example, parents who learn about their child's diagnosis may access resources and support (Mansell and Morris, 2004), which makes them feel more empowered. Resources can include advice from other parents and professionals, family support, and intervention. Thus, although pre-diagnosis differences in empowerment may exist, parents' experiences following their child's ASD diagnosis could equalize the overall feelings of empowerment or abilities to obtain services for their children.

#### *Caregiver Level of Worry*

The current study found no race-based differences between caregivers' levels of worry about autism symptoms, which indicates that both groups may have had similar levels of worry about ASD-related behaviors. However, this finding may be explained by limitations in the instrument's ability to measure underlying differences between African

American and White parents/caregivers. According to Devellis (2003), a scale's capacity to measure variability between respondents is improved by an increase in the number of items and response categories. In the current research, eight items in the caregiver worry measure provided three response categories, which may have reduced the potential to detect differences between the two racial groups under examination.

#### *Attribution of Symptoms*

As with the other two researcher-created measures, group differences were not observed between the five constructs in the caregiver's attributions of symptoms measure. Again, this may be due to the design of the pilot instrument (e.g. number of response categories, number of items in each construct, and wording). Although differences were not found among the constructs, comparisons of individual items demonstrated variability between the groups. For example, White caregivers were more likely than African American caregivers to endorse the attributions related to nutritional or dietary issues. On the other hand, African American caregivers tended to be more likely to attribute initial behaviors to two of the behavioral problem items (being spoiled and needing more discipline). The latter finding is similar to other studies reporting that African American mothers are more likely to attribute certain child behaviors to behavioral problems such as being spoiled or stubborn (Bussing et al., 1998; Reznick, 1999). African Americans in the current study were also more likely to attribute initial troubling behaviors to their child being made this way by God, which is also similar to findings of previous studies (Cohen et al., 1998; Cauce et al., 2002).

### *Regression Findings*

The factors shown to be associated with age at diagnosis were severity of the child's (current) symptoms, level of caregiver worry about early ASD-related symptoms, and the attribution of pre-diagnosis symptoms to behavior or discipline problems. The current study shows that severity alone did not account for much of the variance in age at diagnosis; in fact, its impact did not reach statistical significance until the third step in the regression analysis. These findings support the importance of caregivers' roles in early identification and provide insight about which factors may hinder or promote earlier detection of ASD. In the past, studies investigating events leading to caregiver concerns were limited by variables that examined general child-related characteristics (e.g., severity, medical conditions, functioning). Similar to the current study, previous research found that severity (Baghdadli et al., 2003) or the presence of medical problems or cognitive impairments (De Giacomo & Fombonne, 1998) influence concerns about child development.

The association between caregiver variables and children's age at diagnosis has implications for professional surveillance of developmental concerns related to ASD. Parents' beliefs and reactions to ASD-related symptoms may shape how they present their concerns to physicians. As demonstrated in the current study, the children of parents who attributed ASD-related symptoms to discipline-based behavioral problems were more likely to receive a later diagnosis. This finding may be the consequence of parents presenting concerns in a way that minimizes their complexity or influences physicians' assessment of them. In another scenario, attributions of behaviors to behavioral problems may have deterred parents from raising their concerns to their child's physicians, resulting in parents

attempting to deal with the behaviors on their own. Either way, it has important implications for early diagnosis because previous research has shown that physicians are less likely to refer children for comprehensive ASD testing if behaviors are disruptive or appear to be related to behavior problems (Sices et al., 2004). Furthermore, if parents believe that their children's behaviors are related to behavior problems instead of an underlying medical issue, their levels of concerns may be lower, causing them to delay seeking medical advice or assistance. Indeed, findings from the current study suggest the magnitude of caregiver concern is inversely related to age at diagnosis of ASD (i.e., parents less worried about early symptoms had children who were diagnosed later).

The current study also found some interesting connections between caregiver-related factors and demographic variables. For example, although Caregiver Empowerment did not appear to be directly associated with age of diagnosis of ASD, it may have had an indirect impact. This possibility is suggested by the negative correlation between the Caregiver Control and Services construct and the length of time between first consultation with professionals and receiving a diagnosis. Parents who reported higher levels of control in intervention services received a diagnosis more quickly after speaking with a professional. Another interesting finding is an association between levels of initial worry and maternal educational levels. Mothers' levels of worry were inversely related to higher educational levels (as educational levels increased, initial worry about autism-related symptoms decreased). This finding is surprising, given that parental concerns about many of the items may have required knowledge about typical child development that would be associated with individuals with higher educational levels. An alternative explanation is that caregivers with

lower incomes, as a whole, were reporting on children who were more impacted by ASD. Indeed, the current study found a negative correlation between SRS scores (more severe ASD symptoms) and familial income. Thus, levels of worry may have been higher for parents/caregivers with lower household incomes because they were reporting on children who were more affected by ASD. Another explanation is that parents with lower levels of education and income have fewer resources and access to professionals to help them address the needs of children showing developmental difficulties, which in turn may lead to more worry about their children's overall development. By this logic, initial symptoms may have had a greater impact on the families and caregivers with lower incomes and educational levels and thereby increased their levels of worry. In fact, Liptak et al. (2009) found that families with lower incomes rated their children's autism as more severe. Based upon these findings, it is clear that the link between concerns and income should be further explored in future research.

### *Study Limitations*

Some limitations associated with the current study may impact generalization of the results. First, because the study consisted of a self-selected sample from one recruitment source, there may have been unmeasured differences between families who signed up for the registry or decided to participate in the study and those who did not. Based upon group comparisons of demographic factors, it does appear the children of study participants may have had slightly higher IQ scores and functioning than those whose caregivers did not participate in the study, and that this difference was of greater magnitude among African American participants. As a group, it also appears that study participants (both African

American and White) may have had a slightly higher average income than the general population. Although it is not uncommon for self-selected research participants to have higher than average educational levels or incomes (Dillman, 2007), this may have influenced the outcome of this study. Fortunately, the two main referral sites associated with the chosen recruitment source offer free diagnostic assessment for ASD, which would likely lessen the possibility that the sample is not representative due to access issues or inability to pay for diagnostic services.

Another limitation related to the representativeness of the sample stems from children who have still have not been identified, children whose parents elect not to participate in research, or children whose parents are unaware of opportunities to participate in research. These factors may especially affect African Americans or other minorities who may be at higher risk for having less access to quality healthcare or diagnostic services. Furthermore, African Americans may be more reticent to participate in studies, including surveys (Dillman, 2007), as a result of historically-based mistrust of researchers.

Third, there may have been some response errors as a result of caregivers' recall or "forward telescoping." It is possible that some parents' estimations of parameters such as month/year of diagnosis or other temporal events were less accurate than others. For example, a handful of parents had to be contacted for clarification on diagnosis dates because they failed to list any information or listed information that was not easily interpreted (e.g., listing two different years; in this case, if the parents could not be reached, the default was to use the earliest year they supplied). Fortunately in most instances, vague answers about age at diagnosis could be clarified by phone.

Responses to items associated with level of worry or attribution measures (caregivers' memories about their own thoughts, behaviors, and attitudes prior to diagnosis) were more likely to be affected by "forward telescoping". For some respondents, pre-diagnosis attitudes or reactions could have been influenced by post-diagnosis knowledge and concerns. For example, parents may have misplaced their current worry and knowledge about their child's play deficits into the requested pre-diagnosis recall period. In surveys of this type, most response errors likely are related to sincere mistakes, but some responses could have been biased by satisficing or social desirability. Satisficing respondents do not seek to understand the question completely, just well enough to provide a plausible answer (Tourangeau, Rips, & Rasinski, 2000). In this case, parents or caregivers may not have tried to recall their beliefs or attitudes with enough depth to increase the accuracy of their responses. On the other hand, social desirability influences when participants feel the need to present themselves in a favorable light (Tourangeau et al., 2000), as when parents refuse to endorse some initial beliefs due to fear of being negatively judged even though the items are representative. The current study tried to reduce this potential source of "response modification" by asking parents not to put any identifying information directly on the questionnaires and by using subject numbers. Thus, only the researcher would be able to link their questionnaires back to the family if necessary for clarifying missing data.

Finally, generalization of this study may also be limited by the use of pilot instruments that had not been tested before in survey research. Because these instruments are a work in progress, measurement error may have been introduced into the dataset. For example, two items in the attribution measure failed to load onto any of the factors, as well as



weak loading of three other items. Future research using this method should modify this measure by writing additional items and dropping items that showed little or no commonality with other items. Additionally, more response categories for both the level of worry and attribution measures may help to distinguish between racial, ethnic, or other groups of people. All of the researcher-created instruments will need further examination and refinement in additional studies. Limitations were also noted for the other instrument used in this study (SRS; Constantino et al., 2003) because some parents with nonverbal children had difficulty completing items that assumed verbal communicative abilities. As a result, parents didn't know how to respond to the questions presented on the form.

### *Clinical Implications*

Findings from this study have important implications in the context of clinical practice and for increasing early diagnosis for children and families impacted by ASD. Having presented evidence showing that attributions and magnitude of concerns about early ASD related symptoms may affect when a child is diagnosed, a worthy question is how can we influence these internal factors? As demonstrated in the current study, caregiver attribution of behaviors to another source, such as behavioral problems, can lengthen the interval between initial observations and diagnosis. According to Koegel et al. (2005), it is important to emphasize the range of symptoms exhibited by very young children at risk for ASD, including the absence of specific typical behaviors. The absence of emotional regulation or the ability to calm oneself when upset may indicate underlying developmental problems. The current study suggests that both physicians and caregivers may benefit from visual examples (e.g. workshops, videos, or trainings) which contrast disruptive ASD-related

behaviors with disruptive behaviors exhibited by typically developing children or by children with other diagnoses or delays. Indeed, children in the current study with other initial diagnoses, including ADHD, or medical concerns in utero, during delivery, or in early infancy received later diagnoses. Increasing both physicians' and clinicians' understanding of the array of behaviors associated with ASD, may lead them to ask parents a broader range of questions and detect symptoms that may resemble other conditions. Thus, much more work is needed to expand caregivers' and physicians' conceptual picture of young children with ASD.

### *Suggestions for Future Research*

Research looking at the relationship between caregiver factors and diagnosis of ASD should continue, with the goal of eliminating under-identification and late diagnosis. One suggestion for future studies is examining pre-diagnostic views (perhaps from parents in the initial stages of the help-seeking or diagnostic process) and knowledge about ASD-related behaviors in caregivers from different racial/ethnic groups. Measuring pre-diagnostic views would eliminate any potential "forward telescoping" of post-diagnosis attitudes and concerns thereby providing a more accurate picture of individuals' first impressions of ASD-related behaviors. Culturally different views about ASD symptoms may be more detectable in a general sample of caregivers who do not possess advanced knowledge about or personal experience with autism.

Findings from the current study may also have implications in the realm of early intervention. For instance, future studies can examine the influence of "internal" factors on intervention choices and treatment outcomes. The affect of these factors may be greater for

younger children whose parents play a significant role in service delivery via clinician training and models. Similar to age of diagnosis, caregiver implementation of clinician recommendations and guidelines may be partially determined by attributions or level of worry about ASD-related behaviors. Furthermore, internal factors may have the ability to influence caregivers' perceptions of treatment benefits. For example, if caregivers continue to attribute some ASD-related symptoms to behavioral problems after diagnosis, they may believe that other strategies (e.g. reprimand) will work better than those suggested by interventionists.

Another direction for future research as indicated by the current study is examination of how community practices influence the identification and referral of children showing ASD-related symptoms, particularly minority children. While the 6 month delay in average age of diagnosis for African American children in the current study was not statistically significant, it may have repercussions for later outcomes (Turner et al., 2006). Even slightly later diagnoses can lead disadvantages later in life for minority children with ASD. Previous research has shown that subtle biases (stemming from racial/cultural differences) can emerge if physicians are not using standardized methods to assess behaviors and/or parental concerns (Begeer et al., 2009) and has also suggested that many pediatricians and family practitioners are not using ASD-specific instruments. Worse, a sizable minority are not using any developmental screeners (Dos Reis et al. 2006). Similarly, it will also be important to examine how caregivers' presentation of symptoms, concerns, and requests for help can influence recommendations or referrals. If physicians and clinicians are aware of how variations in attributions/concerns may impact caregivers' choice of words describing

possible developmental challenges, they can modify their responses and encourage a more in-depth dialogue with parents. Future studies should attempt to identify if communication mismatches or ambiguity in the description of behaviors hinder referrals for comprehensive assessments. Reducing biases and interaction barriers related to cultural and/or communication differences can only improve surveillance efforts and earlier identification of ASD.

### *Conclusions*

The present study provides new information about the importance of parental concerns and attributions in the quest to identify children at risk for ASD at younger ages. While a variety of factors still appear to impact the age of diagnosis of ASD, the role of caregivers cannot be underestimated, especially in the absence of routine ASD screening by medical care providers. Still, the major findings of the current study suggest the average age at diagnosis is decreasing for children with ASD. Although statistically significant differences in age of diagnosis were not found between groups, African American children were diagnosed with ASD an average of six months later than White children. This gap may be large enough to be clinically significant because it may delay entry of African American children into EI services. Furthermore, examining the reasons for overall differences in IQ scores and VABS scores between African American children and White children with ASD in the recruitment sample of this study is of urgent concern, as it may suggest that African American children are negatively impacted by unequal access to early intervention services that support better cognitive and adaptive outcomes.

This study supports the hypothesis that caregivers' attributions of and reactions to initial ASD-related symptoms impact children's age at diagnosis of ASD, above and beyond SES and severity of symptoms. On the other hand, caregiver empowerment seems not to be as strongly or directly associated with age at diagnosis as previously thought. It may, however, have more importance after parents have initially expressed concerns to professionals and are on their way to receiving a diagnosis. Parents who are more empowered may be able to reduce the number of different professionals seen and get a referral to a diagnostic specialist sooner. Finally, the current study provides evidence for the importance of regular developmental and ASD-specific screenings by medical providers, regardless of caregiver or physician concern. Making these practices routine could eliminate the potential for lack of awareness of symptoms or biases from either caregivers or physicians to delay early diagnosis.

## Appendix A:

### Caregiver Empowerment Measure

<b>Caregiver Empowerment Scale</b>	<b>Never</b>	<b>Sometimes</b>	<b>Usually</b>	<b>Always</b>
1. If I do not get the response I want from one professional, I go to another one.	1	2	3	4
2. I have the power to get what my child needs.	1	2	3	4
3. If I cannot get the services my child needs, I keep trying.	1	2	3	4
4. I feel sure I can take the steps needed to get services for my child.	1	2	3	4
5. If it is hard for me to talk with professionals, I can find someone else to help me communicate.	1	2	3	4
6. My child's services are something I control.	1	2	3	4
7. Professionals understand me when I tell them about my concerns.	1	2	3	4
8. I am able to explain myself until my views are clearly understood.	1	2	3	4
9. I make a difference in the services my child receives.	1	2	3	4
10. I know where to go and who to talk to when I need to get help for my child.	1	2	3	4
11. If I have a hard time getting any services for my child, I try something different.	1	2	3	4
12. I feel like I have choices for meeting my child's needs.	1	2	3	4
13. It is easy for me to get the services my child needs.	1	2	3	4
14. My child receives the type of services he/she needs.	1	2	3	4
15. It is easy for me find information to help me make decisions for my child.	1	2	3	4

## Appendix B:

### Caregiver Level of Worry Measure

*Think back to the time between your child's 1<sup>st</sup> and 3<sup>rd</sup> birthday.*

**Were you ever worried that your child ...**

- 1. did not respond when you called his or her name?**

Not Worried	Worried	Very Worried
1	2	3

- 2. did not point at interesting things like a plane in the sky, a fun toy, a cartoon character on TV, or pictures of people or things?**

Not Worried	Worried	Very Worried
-------------	---------	--------------

- 3. often made unusual movements with his or her fingers, hands, or arms or showed unusual body positions?**

Not Worried	Worried	Very Worried
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- 4. did not enjoy or participate in activities, such as games or pretend play, like other children his or her age?**

Not Worried	Worried	Very Worried
-------------	---------	--------------

- 5. did not copy or imitate things you did with an object, such as tapping a spoon on the table or feeding a stuffed animal?**

Not Worried	Worried	Very Worried
-------------	---------	--------------

- 6. did not look at your eyes/face when you talked to him or her?**

Not Worried	Worried	Very Worried
-------------	---------	--------------

- 7. played with objects or toys in an unusual way such as spinning them, lining them up, rubbing them, or scratching them?**

Not Worried	Worried	Very Worried
-------------	---------	--------------

- 8. did not babble or talk like other children his or her age?**

Not Worried	Worried	Very Worried
-------------	---------	--------------

## Appendix C:

### Caregiver Attribution Measure

*When parents first see behaviors that later turn out to be part of an autism spectrum disorder, they may have various thoughts about those behaviors. These thoughts may change over time, however; we are asking that you think back to your initial beliefs about your child's behaviors that caused your concern. Again, we will use the initials ASD to refer to Autism Spectrum Disorders.*

**When my child first showed behaviors that turned out to be ASD, I wondered if my child ...**

*(Circle one for each item)*

1. had a medical condition (including one related to how the brain works).....	No <sub>1</sub>	Yes <sub>2</sub>
2. needed more discipline .....	No	Yes
3. had a disability.....	No	Yes
4. would grow out of the behaviors.....	No	Yes
5. was just a little different from other children.....	No	Yes
6. had a hearing loss .....	No	Yes
7. was very shy .....	No	Yes
8. had a difficult personality .....	No	Yes
9. was behaving like another member of my family.....	No	Yes
10. was a "late bloomer" or just delayed.....	No	Yes
11. might be spoiled .....	No	Yes
12. was under a curse .....	No	Yes
13. needed to spend more time with other children.....	No	Yes
14. was behaving this way because of what he/she ate .....	No	Yes
15. was made this way by God.....	No	Yes
16. was being stubborn or disobedient.....	No	Yes
17. had inherited these behaviors.....	No	Yes
18. didn't have enough prayer .....	No	Yes
19. didn't have enough love and attention.....	No	Yes
20. had a food allergy .....	No	Yes
21. Other _____	No	Yes



## Appendix D:

### Demographic Survey

*Please respond to each of the questions as best you can. Your responses will be kept confidential. If you have more than one child with autism, give answers for the oldest child with autism. We will use the initials ASD to refer to Autism Spectrum Disorders. ASD includes the range of diagnosis applied to children with social communication difficulties (such as Autism, PDD-NOS, and Aspergers)*

1. Please list the age and gender of each of your children from oldest to youngest (with and without ASD)

Child Number	Gender (M or F)	Age (in years)	ASD (Yes or No)
1 (Oldest)			
2			
3			
4			
5			
6			
7			
8			
9			

2. What is your gender?

- Male  
 Female

3. What is your age? \_\_\_\_\_

*All of the following questions are for your oldest child with ASD.*

4. Child's Date of Birth: \_\_\_\_\_ (mm/dd/yyyy)

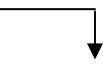
5. What is your relationship to the child?

- Mother  
 Father  
 Grandmother  
 Grandfather

Other (Specify): \_\_\_\_\_

**6. a. Was your child born prematurely?**

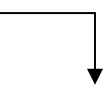
No (*Go to Question 7*)

Yes 

**b. (If yes) How many weeks premature? \_\_\_\_\_ weeks**

**7. Were there any significant medical problems during pregnancy, delivery, or early infancy with this child?**

No (*Go to Question 8*)

Yes 

If yes, list specific problems: \_\_\_\_\_

**8. Does your child have any of the following genetic conditions? (*Check all that apply*)**

Fragile X

Retts Syndrome

Down Syndrome

Sclerosis

Neurofibromatosis

Cognitive Impairments or Mental Retardation

Other (Specify): \_\_\_\_\_

**9. What month and year was your child diagnosed with ASD?**

Month \_\_\_\_\_

Year 200\_\_\_\_

**10. At the time of diagnosis, what type of medical insurance did you have for your child? (Check all that apply)**

- No Insurance
- Medicaid
- Health Choice
- Private Insurance (e.g. blue cross, blue shield)
- Other (Specify): \_\_\_\_\_

**11. Where was your child diagnosed? (Check One)**

- School System
- State or Developmental Agency (such as the CDSA-Children's Developmental Services Agencies or DEC-Developmental Evaluation Centers)
- TEACCH (Treatment and Education of Autistic and related Communication Handicapped Children)
- Doctor's Office or Hospital
- Private agency/practice (such as a Psychologist or Psychiatrist)
- Other (Specify): \_\_\_\_\_

**12. Did your child have any other diagnosis before being diagnosed with autism?**

- No
- Yes (If yes) What was the diagnosis? \_\_\_\_\_

**13. After you started seeing behaviors that later turned out to be part of his/her ASD, how long was it before you talked to a professional about these behaviors? (*Check One*)**

- 0-3 months
- 4-6 months
- 7-12 months
- More than a year

**14. After you talked to a professional about these behaviors, how long was it before your child was diagnosed with ASD? (*Check One*)**

- 0-3 months
- 4-6 months
- 7-12 months
- More than a year

**15. How many different professionals did you see before your child was diagnosed with ASD? (*Check One*)**

- 1-2 professionals
- 3- 4 professionals
- 5-6 professionals
- Over 6 professionals

**16. Are you Hispanic?**

No

Yes

**17. What is your race? (Please check the best match)**

Black/ African American.....	<input type="checkbox"/>	
White/Caucasian.....	<input type="checkbox"/>	
American Indian/Alaskan Native.....	<input type="checkbox"/>	
Asian.....	<input type="checkbox"/>	
Other.....	<input type="checkbox"/>	 Specify: _____

**18. What is the highest level of education obtained ...**

**by the child's mother?**

No High School Diploma or GED	<input type="checkbox"/>
High School Diploma or GED	<input type="checkbox"/>
Some college or technical school	<input type="checkbox"/>
Associate Degree	<input type="checkbox"/>
Bachelors Degree	<input type="checkbox"/>
Graduate or Professional Degree	<input type="checkbox"/>

**by the child's father?**

No High School Diploma or GED	<input type="checkbox"/>
High School Diploma or GED	<input type="checkbox"/>
Some college or technical school	<input type="checkbox"/>
Associate Degree	<input type="checkbox"/>
Bachelors Degree	<input type="checkbox"/>
Graduate or Professional Degree	<input type="checkbox"/>

**19. What is your estimated total household income?**

Less than \$20,000 per year	<input type="checkbox"/>
\$20,000 to \$39,999 per year	<input type="checkbox"/>
\$40,000 - \$59,999 per year	<input type="checkbox"/>
\$60,000 to \$79,999 per year	<input type="checkbox"/>
\$80,000 to \$99,999 per year	<input type="checkbox"/>
\$100,000 or more per year	<input type="checkbox"/>

**20. Are you employed?**

- No
- Part time
- Full time

**21. What is your current martial status? (*Check One*)**

- Married
- Living as married
- Divorced
- Single/ Never Married
- Widow(er)

**22. Which of the following best describes where you live? (*Check One*)**

- Large city
- Suburb of city
- Small town or city
- Rural Area

**THANK YOU FOR YOUR HELP**

*Before you complete this survey, is there anything else that you would like to tell us about your experience with your child that we have failed to ask? Please use the space below to write your comments.*

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