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# A Mixed Method Study of Diagnostic and Adaptive Functioning Challenges in African American Preschool-Aged Children with Autism Spectrum Disorders

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2015

Abstract

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MOT, Nova Southeastern University, 2002

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Dissertation Submitted in Partial Fulfillment
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# Abstract

Children with Autism Spectrum Disorder (ASD) are known to experience performance and participation challenges, with early diagnosis being critical for improved outcomes. Children from ethnic minority backgrounds tend to receive their diagnoses later, even when symptomatology is similar. This mixed methods study explored symptom severity, functional difficulties, and age at diagnosis for ASD and to describe the functional challenges encountered by preschool-aged children with ASD of African American descent. The International Classification of Functioning, Disability, and Health along with the Model of Human Occupation were the theories used for this study to conceptualize functional challenges and other potential factors. Research questions addressed symptom severity, degree of functional challenges, and age of diagnosis, and to gather family perspectives regarding functional challenges for preschool-aged children of African American descent. Data consisted of subpopulation responses from the 2009-2010 National Survey for Children with Special Healthcare Needs (*N* = 224) and locally-conducted interviews with parents (*N* = 3). No significant relationships were found using general linear model between age at diagnosis and symptom severity or degree of functional challenges. Qualitative themes included the diagnosis process, routines and transitions, communication, family and home environment, and school and community environments. Educators and health care providers need to enhance screening for early signs of ASD and consider racial and cultural implications related to performance and participation challenges. Social change implications include the development of effective and targeted awareness campaigns and improved diagnostic and intervention services for children with ASD from minority backgrounds and their families.

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# Table of Contents

# List of Tables

# List of Figures

# Chapter 1: Introduction to the Study

## Introduction

Children from ethnic minority backgrounds, such as African American and Hispanic, generally receive their diagnosis of Autism Spectrum Disorder (ASD) later than non-minority children, typically after the age of four (Daniels & Mandell, 2014; Valicenti-McDermott, Hottinger, Seijo, & Shulman, 2012). As a result, they may miss critical windows associated with neuroplasticity where early intervention would be most beneficial for acquiring adaptive functioning skills (Berger et al., 2013; Dawson, 2008). Further research is needed to address these disparities and gain a better understanding of the factors that may influence later presentation of symptomology and diagnosis of children of African American descent. Below is an overview of a mixed methodology study where factors associated with disparities in the diagnosis of adaptive functioning challenges in preschool-aged children of African American descent from were explored. A background for the study is provided, followed by a description of the problem and purpose of the study. Additionally, the research questions, theoretical framework, nature of the study, definitions, assumptions, scope and delimitations, and limitations are discussed. The chapter concludes with the significance of the study and a summary.

## Background

As more assessments have been made available and because early intervention can be critical for achieving positive outcomes, children are being diagnosed at earlier ages with ASD (Matson, Rieske, & Tureck, 2011). In spite of early diagnosis, children from ethnic minority backgrounds have been found to receive their diagnosis later than children from other backgrounds (Daniels &Mandell, 2014; Valicenti-McDermott et al., 2012). Additionally, children with ASD of African American descent have not been included in a sufficient number of research studies to provide a perspective on the influence race and culture may have on adaptive functioning (Jang, Matson, Cervantes, & Goldin, 2013; Mandell et al., 2009). Although a later diagnosis of ASD in children from African American backgrounds has been noted, research has not been conducted to explore influential factors beyond maternal education and socioeconomic status. The purpose of this mixed methods study was to further explore the disparities in age of diagnosis and provide a description of the functional challenges encountered by African American preschool-aged children with ASD.

## Autism and Early Diagnosis

The diagnosis of ASD continues to increase, with the current prevalence being 1 in 66 children (Centers for Disease Control and Prevention [CDC], 2014). As diagnostic procedures continue to improve, children are being identified earlier, with a diagnoses made as early as 2 years of age noted to remain stable (Chawarska, Klin, Paul, Macari, & Volkmar, 2009; Daniels & Mandell, 2014; Kleinmanet al., 2008; Sutera et al., 2007).Identification of infants at risk for ASD have also been made prior to 12 months of age, with increasing success for predictability (Flanagan, Bauman,& Landa, 2012; Samango-Sprouse et al., 2015). The core deficits related to ASD symptomology are reportedly similar, with subtle differences noted across individuals from different backgrounds (Grinker, Yeargin-Allsopp, & Boyle, 2011; Cuccaro et al., 2007). Overall, individuals with ASD present performance and participation impairments as a result of difficulties with adaptive functioning, such as communication, social interaction, behavior challenges, and sensory processing disorders (Brock et al., 2012; Lane, Molloy, & Bishop, 2014; Kanne et al., 2011; Perry, Flanagan, Geier, & Freeman, 2009). However, children from minority backgrounds have been found to be misdiagnosed or receive their diagnosis at a later age than non-minority children (Burkett, Morris, Manning-Courtney, Anthony, & Shambley-Ebron, 2015; Ennis-Cole, Durodoye, & Harris, 2013; Valicenti-McDermott et al., 2012).

With early identification and assessment practices, children with ASD can have access to interventions that may ameliorate the symptoms of autism and empower families to address the associated challenges of parenting a child with a disability (Estes et al., 2009). However, early diagnosis and service utilization may vary due to numerous factors, such as socioeconomic status, availability and coverage of services, awareness and acknowledgement of developmental delays, and comfort level with practitioners based on previous encounters with health and educational professionals (Daniels & Mandell, 2014; Ennis-Cole et al., 2013). In spite of awareness campaigns and early intervention initiatives, children with ASD from minority backgrounds are diagnosed later and face an increased challenge as a result of delays in diagnosis (Ennis-Cole et al, 2013; Mandell et al., 2009; Valicenti-McDermott et al., 2012).

Early diagnosis is important for addressing the functional difficulties encountered by individuals with ASD as there are optimal age windows for the consolidation of developmental skills, and therefore reaping the full benefits of early intervention can be critical for a chance at improved outcomes and quality of life (Berger, Rohn, & Oxford, 2013; Dawson, 2008). Although some researchers have proposed possible factors associated with delays in diagnosis such as maternal education, socioeconomic status, and access to resources, there is little research that explores this in detail (Daniels & Mandell, 2014; Ennis-Cole et al., 2013; Irvin, McBee, Boyd, Hume, & Odom, 2012; Mandell et al., 2009). More research is needed to further identify associated factors with ASD diagnostic delays, such as those of African American descent, as well as to explore the functional challenges of ASD that may be associated with race and culture.

## Problem Statement

There have been numerous initiatives such as training opportunities for professionals and media campaigns for the public to increase awareness of the early signs and associated symptoms of ASD (American Psychiatric Association [APA], 2013a; CDC, 2014). With the update to the *Diagnostic and Statistical Manual of Mental Disorders-5th Edition (DSM-5)*, new diagnostic criteria were established and symptom severity is now provided with a diagnosis of ASD (APA, 2013b). According to the new criteria, individuals with ASD must present with challenges related to the following: (a) social interaction and communication, and (b) restricted and repetitive behaviors, activities, and interests. These symptoms must present during early childhood and collectively impair functional participation and performance. Although the symptoms are defined similarly across individuals, those from minority backgrounds have been noted to often receive their diagnoses at later ages (Ennis-Cole et al, 2013; Mandell et al., 2009; Valicenti-McDermott et al., 2012).

Information regarding the relationship between racial and cultural influence and lived experiences of individuals to a diagnosis of ASD is scarce. Researchers have proposed various factors that may contribute to the age that individuals from minority backgrounds are diagnosed with ASD. Commonly identified in these proposed factors are socioeconomic status, maternal education level, access to quality care, and service utilization (Daniels & Mandell, 2014; Ennis-Cole et al., 2013; Irvin et al., 2012; Mandell et al., 2009). Additionally, subtle differences have been noted with the presentation of symptomology, with more significant concerns reported regarding socialization, communication, and behavior challenges (Horovitz, Matson, Rieske, Kozlowski, & Sipes, 2011; Jang, Matson, Cervantes, & Goldin, 2013; Mayes & Calhoun, 2011; Tek & Landa, 2013). Delays in diagnosis pose significant challenges to accessing and utilizing early intervention services during the preschool years. As this is a critical period in early childhood development, delayed diagnosis can compromise the opportunity for improved outcomes (Berger et al., 2013; Dawson, 2008; Irvin et al., 2012). Few studies exist that include African Americans as a representative sample and address the presentation of symptoms associated with ASD as well as concomitant disparities in early childhood diagnosis (Jang et al., 2013; Mandell et al., 2009). To gain a better understanding of the implications that race and culture may have on delays in ASD diagnosis, more research is needed that explores the functional participation and performance challenges of preschool-aged children of African American descent.

## Purpose of the Study

The purpose of this mixed methods study was to explore symptom severity, functional difficulties, and age at diagnosis for ASD, as well as describe the functional challenges encountered by preschool-aged children of African American descent with ASD. The intent was to explore factors related to later diagnosis of ASD in preschool-aged children of African American background at a national level, as well as describe adaptive functioning challenges to performance and participation from a local perspective. Researchers have documented delays in age of ASD diagnosis for minority children, as well as variance in the performance and participation challenges they face regarding performance and participation (Tek & Landa, 2012).However, few have provided information on a national level (CDC, 2011a). Additionally, little research is available that has included African Americans as the primary sample to study the influence of race and culture on symptom presentation and service utilization (Cuccaro et al., 2007; Sell, Giarelli, Blum, Hanlon, & Levy, 2012).Using a mixed methods approach, I investigated the relationship between race and diagnostic disparities based on parental report of symptom severity and adaptive functioning challenges from a national data set. Additionally, I explored adaptive functioning difficulties of preschool-aged children of African American descent with ASD from a qualitative perspective using interviews that were conducted locally. With children from minority backgrounds being diagnosed with ASD later than those from other backgrounds, it is critical to explore possible influences that may affect timely diagnosis.

## Research Questions and Hypotheses

Previous researchers have identified that individuals from minority backgrounds often receive a diagnosis of ASD later than non-minority children. Therefore, the aim of this study was to gain insight into possible factors related to this disparity, as well as to understand the lived experiences from the perspective of parents of preschool-aged children of African American descent with ASD. The research questions for this mixed method study were as follows:

1. How does symptom severity relate to age of diagnosis?

2. How does the degree of reported functional challenges relate to age of diagnosis?
3. How do parents describe adaptive functioning challenges related to performance and participation?

It has been hypothesized that symptom severity and degree of functional challenges may be related to age of ASD diagnosis for children of African American descent. The dependent variable for this study was age at diagnosis, with parental report of severity of ASD and degree of functional difficulties being the independent variables. The null hypotheses are that age of diagnosis is not influenced by either ASD symptom severity ($H_0 1$) or adaptive functioning challenges ($H_0 2$). In turn, the alternate hypotheses are as follows: age at diagnosis is influenced by ASD symptom severity ($H_a 1$) and/or degree of functional challenges ($H_a 2$). I hoped to gain an understanding of the relationship that symptom severity and functional challenges may have with delays in diagnosis through the use of a general linear model, as well as qualitatively via parental perspectives regarding adaptive functioning challenges in preschool-aged children with ASD.

## Theoretical and Conceptual Framework

The Model of Human Occupation (MOHO) is a theoretical framework where contributory factors that either support or inhibit the different ways in which people participate in activities are described (Kielhofner, 2008). Kielhofner (2008) posited that in addition to the social environment, three components that are dynamically interrelated influence participation: volition, habituation, and performance capacity. Volition refers to individual motivation, habituation is related to patterns and routines, and performance capacity depicts the various skills and abilities inherent to the individual that may influence participation. Culture also is said to play a role in participation and performance patterns. Together, Kielhofner proposed that understanding this dynamic interplay could help identify the different reasons why an individual may be successful or limited in their ability to perform and participate in daily activities.

Similarly, the World Health Organization (WHO) has established the International Classification of Functioning, Disability, and Health (ICF), which is based on a biopsychosocial model and can be used as a framework to conceptualize functioning (WHO, 2002). According to ICF, functioning is influenced by a variety of factors that determine one's health and quality of life. Disability and function are based on the interaction between individual and contextual factors, all which can support or hinder how an individual is able to perform and participate in various settings (WHO, 2013). As such, ICF has been used internationally to classify and study disability in various countries. It serves as a conceptual framework for describing disability across the lifespan and cultures.

The intent of this study was to explore the relationship race and culture may have with adaptive functioning and early diagnosis of ASD in preschool-aged children of African American descent. Using the theoretical framework of Kielhofner's (2008) MOHO, as well as the tenets proposed in ICF, functional challenges based on parental report could be explored in minority populations to elucidate the disparities and functional challenges reported. Through applying these concepts to this study, I hoped that insight could be gained into the various individual and contextual factors that parents of preschool-aged children with an ASD identification face in regard to their child's functional performance and participation. In addition, I hoped to further understanding of how symptom severity and degree of functional challenges with ASD children may be associated with delays in diagnosis. A more thorough explanation of the major tenets of MOHO and ICF as they relate to this study are provided in the next chapter.

## Nature of the Study

Mixed methodology is a research approach that allows for the collection of quantitative and qualitative data with the aim of providing a better understanding of a particular phenomenon (Creswell, Klassen, Plano Clark, & Smith, 2011; Creswell & Plano Clark, 2011). This approach can be beneficial to explore concepts where unexpected results are found from quantitative studies, as well as investigate sociocultural phenomenon (Creswell, Klassen, Plano Clark, & Smith, 2011; Klingner & Boardman, 2011). A mixed methods approach was used to gain insight into the diagnostic disparities related to preschool-aged children of African American descent with ASD and further explore the adaptive functioning challenges reported by parents. Information from parents who previously completed a national survey was analyzed. Additionally, information was gathered locally through interviews regarding preschool-aged children with ASD of African American background to depict the lived challenges and functional difficulties based on parental report. Mixed methodology can be used to first analyze a national data set and then explore local perspectives.

### Quantitative Component

Quantitative measures were used through reviewing responses provided by parents of children with special needs on the2009-2010 National Survey of Children with Special Health Care Needs (CDC, 2011a). During the administration of the National

Survey of Children with Special Health Care Needs (NS-CSHCN), parents provided responses to various questions to determine types of disabilities and degree of impairment. Questions of interest to this study included whether age at diagnosis had any relationship with symptom severity and adaptive functioning challenges. The dependent variable for this study was age at diagnosis, with independent variables consisting of parental report of severity of ASD and degree of functional difficulties. The null hypotheses are that age of diagnosis is not influenced by either ASD symptom severity ($H_0$1) or adaptive functioning challenges ($H_0$2). In turn, the alternate hypotheses are as follows: age at diagnosis is influenced by ASD symptom severity ($H_a$1) and/or degree of functional challenges ($H_a$2).Data from the public 2009-2010 NS-CSHCN dataset were analyzed using descriptive statistics and regression analysis, including general linear model, to answer the research questions.

### Qualitative Component

Qualitative measures were employed through conducting interviews with parents of preschool-aged children with ASD of African American backgroundto depict adaptive functioning challenges. Of particular interest were the answers to the following question: What adaptive functioning challenges related to performance and participation are reported by parents of preschool-aged children with ASD of African American background. Parents of African American background who had a child with a diagnosis of ASD at 6 years of age or younger were solicited through a recruitment letter provided to local community pediatric therapy service providers, such as therapy clinics and behavioral intervention companies. Parents were interviewed and responses being coded to determine major themes and concepts. Conducting interviews with at least four local parents was thought to allow for a first-hand account of challenges encountered and an opportunity to expand upon the questions posed in the NS-CSHCN. Through triangulation, I hoped that this information from the interviews would add to the data gathered from the quantitative component. A more detailed description of the quantitative and qualitative components of this explanatory sequential mixed method study can be found in Chapter 3.

## Definitions

*Adaptive functioning*: Skills necessary for an individual to function in everyday activities, such as communication, social interaction, self-help, and overall independence with age-appropriate tasks (Perry et al., 2009; Paul et al., 2014).

*Biopsychosocial*: A useful model of disability. ICF is based on this model;it is one that yields an integration of medical and social aspects of disability. ICF provides, by this synthesis, a coherent view of different perspectives of health: biological, individual, and social. (WHO, 2002, p. 9).

*Culture:* "Beliefs and perceptions, values and norms, customs and behaviors that are shared by a group or society and are passed from one generation the next through both formal and informal education; within most cultures there are also a variety of subcultures" (Kielhofner, 2008, p. 95).

*Environmental factors:* Social attitudes, architectural characteristics, legal and social structures, as well as climate and terrain (WHO, 2002, p. 10).

*Functioning: "*All body functions, activities, and participation" (WHO, 2002, p. 2)

*Habituation*: Organizational process for occupation due to recurrent patterns, including personal roles, routines, and habits (Boyer et al., 2008; Kielhofner, 2008; Model of Human Occupational Clearinghouse, 2013)

*Occupation*: "the doing of work, play, or activities of daily living [such as self-care and self-maintenance] within a temporal, physical, and sociocultural context" (Kielhofner, 2008, p. 5)

*Occupational participation:* Engaging in work, play, or activities of daily living that are part of one's socio-cultural context and that are desired and/or necessary to one's well-being (Kielhofner, 2008, p. 101)

*Participation: "*Involvement in a life situation" (WHO, 2002, p. 10).

*Performance*: The ability to do things based on an individual's mental and physical makeup and personal experience (Boyer et al., 2008; Kielhofner, 2008; Model of Human Occupational Clearinghouse, 2013)

*Personal factors:* Gender, age, coping styles, social background, education, profession, past and current experience, overall behavior pattern, character, and other factors that influence how disability is experienced by the individual (WHO, 2002, p. 10)

*Skills:* Observable, goal-directed actions that a person uses while performing (Kielhofner, 2008, p. 109).

*Volition*: Motivation for occupation, being comprised of individual values, interests, and personal perception of being effective at a task (Boyer et al., 2008; Kielhofner, 2008; Model of Human Occupational Clearinghouse, 2013)

## Assumptions

Although constructed around effective methodological approaches for mixed methods studies, this study presents assumptions. Information related to age at diagnosis in relation to severity of ASD and degree of functional performance and participation challenges were obtained from the NS-SCSHCN(CDC, 2011a), as well as from interviews with at least four local parents. It was assumed that the participants in the study had been and were credible in their responses, being open and honest in answering the questions posed to them (Plano Clark & Creswell, 2008; Teddlie & Tashakkori, 2009).

## Scope and Delimitations

The focus of this study was on diagnostic disparities related to age at diagnosis, as well as challenges reported in preschool-aged children with ASD of African American background. Researchers have identified that the diagnosis of ASD can be made and considered to be stable as early as two years of age. However, children of minority background often receive their diagnosis at a later age than non-minority children, resulting in delays in access to early intervention services that could have led to improved functional outcomes (Gourdine, Baffour, & Teasley, 2011; Mandell et al., 2009). Additionally, differences have been noted in the presentation of behavioral and communication deficit symptomology in children of African American descent with ASD, as well as perceptions of symptoms based on parental report (Horovitz et al., 2011; Jang et al., 2013; Mayes & Calhoun, 2011; Tek & Landa, 2013). To explore these concepts further, the population of focus in this study was African American preschool-aged children6 years of age or younger with a reported diagnosis of ASD.

For the qualitative interviews, I chose parents of preschool-aged children between the ages of 2 and 6 years old. Individuals of minority backgrounds, particularly African American, are seldom included to a degree that would result in a large sample that is representative of the general population (Carr & Lord, 2013; Cuccaro et al., 2007; Gourdine & Algood, 2014; Sell et al., 2012). The specific focus was on recruiting parents of African American descent who in responding to the survey and recruitment letter identified their child as having a current diagnosis of ASD. Thus, the scope of this study included exploring potential causes of late diagnosis, such as reported severity of autism and significance of functional challenges. Quantitative means were utilized to explore these constructs from a national dataset using telephone contact. This limited the generalizability of the results to the larger population, as variances in family resources may have affected either access to having a landline or availability when the call was placed. Additionally, using interviews conducted with local parents of African American background for the qualitative component of this study further impeded the transferability of findings to the larger population due to purposeful sampling and the use of a small number of local parents from a southern state in the United States.

## Limitations

In using an existing national dataset from the 2009-2010 NS-SCSHCN, responses were already provided and interviews were conducted by multiple interviewees through telephone calls. Although a script was used for the interviews, including further instructions for explanations to clarify questions, limitations still exist with this approach. As a result, the information obtained from the telephone interviews may be representative of only those participants on a national level who possessed a landline or cellular phone numbers. In addition, responses may be confined to individuals who were available during the time of the call and willing to complete the survey at that moment.

The interview used for the NS-SCSHCN as well as the assessments used for the qualitative component of this study, had adequate construct validity, measuring what they were designed and developed to assess (Creswell & Plano Clark, 2011; Teddlie & Tashakkori, 2009). The information regarding the validity of these measures is provided in a subsequent chapter. However, information obtained through interviews is subjective, relying solely on parental report. As a result, the credibility of the information obtained may be questioned because of subjectivity. With the NS-SCSHCN survey, interviewers attempted to clarify responses through expansion of questions in accordance with the script. Following the interviews, member checking was used in an attempt to clarify responses, which has been reported to be effective at improving validity (Creswell & Plano Clark, 2011; Fielding, 2012).

Regarding the mixed method design of this study, quantitative measures were used to analyze the survey data, with qualitative techniques employed with an interview-based design. Participants in the NS-SCSHCN survey had no previous relationship with those conducting the interview and a script was used to variance in the questions posed. With the interviews, biases may have existed in regards to my previous experience working with children from various backgrounds with ASD. As a result, purposeful sampling was utilized to select parents of preschool-aged children from African American background in the southern United States who had no pre-existing awareness of or relationship with me. Additionally, previously standardized measures with closed and open-ended questions were utilized for the interview. Triangulation of data from quantitative and qualitative assessments completed during the study was used to gain a global picture of the adaptive functioning challenges experienced by the parent participants who were selected for the quantitative and qualitative interviews. Through these efforts, it was hoped that biases were reduced and the validity of the results were not compromised throughout the conducting and analysis components of this study.

## Significance

Through this research study, positive social change is promoted by revealing the perspective of parents of preschool-aged children of African American descent with ASD regarding diagnostic disparities and the performance and participation challenges their children face. The aim was to provide a large-scale picture of the age at diagnosis in relation to reported symptom severity and functional challenges, as well as a description of adaptive functioning challenges based on interviews with local parents of pre-school aged children with ASD. Various factors may impede early diagnosis, including parental concern related to developmental challenges, socioeconomic status, maternal education, and availability of resources in the area where the family resides (Daniels & Mandell, 2014; Ennis-Cole et al., 2013; Irvin et al., 2012; Mandell et al., 2009). Information obtained from this mixed methods study may be useful to guide assessment practices and intervention approaches in home, community, and school settings to promote improved early diagnostic practices and access to early intervention services for minority children with ASD.

## Summary

Early intervention services are critical for improved outcomes in children with ASD (Boyd, Odom, Humphreys, & Sam, 2010; Irvin et al., 2012). However, receiving a diagnosis later in life limits the opportunity for access to early intervention in a timely manner.  Researchers have indicated that children from minority backgrounds receive their diagnosis later than non-minority children, which in turn impedes utilization of early intervention services for improved functional outcomes (Ennis-Cole et al., 2013; Gourdine et al., 2011; Mandell et al., 2009; Mandell et al., 2010; Valicenti-McDermott, et al., 2012).  The exploration of disparities in age at diagnosis and factors related to adaptive functioning difficulties in minority populations is scarce in the current literature (Daniels & Mandell, 2014; Sell et al., 2012).  Thus, the aim of this mixed methods study was to explore diagnostic delays in African American preschool-aged children with ASD through analysis of an existing national dataset, as well as depict the adaptive functioning challenges of preschool-aged children of African American background based on parental interviews.  Chapter 2 includes a review of the current literature regarding ASD, with a focus on symptomology, diagnostic practices, and presentation in the African-American population.

# Chapter 2: Literature Review

## Introduction

Individuals with Autism Spectrum Disorders (ASD) present with core deficits in the areas of communication, social participation, behavior, and sensory processing. As a result, families of individuals with autism spectrum disorder are faced with many challenges due to difficulties with functional performance and participation in everyday activities. Recent studies have explored these participation patterns and functional impairments in childhood and adolescence. However, few studies have been published exploring the relationship between the severity of one's disorder on and the functional performance and participation capacities of preschoolers (Paul et al., 2011; Perez-Robles, 2009). Although some assessments may have previously considered severity level, the reclassification of ASD in the revised *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM-5) now requires severity level specifications. Additionally, there is a lack of reporting of performance and participation challenges from the perspectives of minorities such as African Americans, where the influence of cultural, societal, and socioeconomic differences that may affect those factors have been described.

The purpose of this mixed methods study was to explore symptom severity, functional difficulties, and age at diagnosis for ASD children, particularly functional challenges encountered by preschool-aged children with ASD from African American backgrounds. The review of literature discussed in this chapter covers recent research topics related to adaptive functioning challenges of children with ASD with a primary focus on toddlers and children from African American backgrounds. Included are articles from peer-reviewed journals, books, and resources obtained from a variety of electronic databases, including those completed within the past five years, and related seminal literature. Databases used for this review available through Walden University's library and other professional resources consisted of CINAHL, ERIC, MEDLINE, Ovid, PubMed, and Science Direct. Specific keywords used alone or in conjunction with others in these searches included the following: *ASD*, *autism*, *African American*, *Black*, *minority*, *function*, *adaptive*, *performance*, *participation*, *preschool*, *toddler*, and *early childhood*. The results of this review indicate a need for further studies related to performance and participation of preschool-aged children with ASD from various backgrounds and the possible influence of race and culture.

Discussed in this literature review are the theoretical framework for understanding performance and participation from the perspective of MOHO and ICF. An overview of ASD is also provided, with a focus on prevalence, diagnosis, and symptomology. Additionally, studies that relate to functional challenges in early childhood are discussed. Below is a review of current literature with a focus on the challenges related to functional performance and participation patterns of individuals with ASD, highlighting the need for further research related to preschool-aged children with ASD from African American backgrounds.

## Theoretical Framework

The theoretical frameworks that served as the basis for this study were MOHO and the biopsychosocial model proposed by the WHO for conceptualizing health, disability, and function. MOHO was pioneered by Kielhofner and further developed through collaboration with other professionals (2008). MOHO is a concept for understanding the performance and participation patterns of individuals with a focus on human occupation. Provided in WHO's constitution and ICF are concepts related to health and functional impairments that can be applied internationally. Together, these concepts formed the basis for describing participation and performance challenges of individuals with ASD and their influence on adaptive functioning with respect to this mixed methods study.

## Model of Human Occupation

MOHO is designed to inform human occupation concerning individual performance and participation. Kielhofner (2008) described human occupation as being comprised of three distinct areas, which include activities of daily living, productivity, and play. These occupations serve as a means to be actively involved in a task within a particular timeframe and context, allowing for interactions with the environment and others. Thus, occupation is best defined as encompassing "a wide range of doing that occurs in the context of time, space, society, and culture [where] temporal, physical, social, and cultural contexts pose conditions that invite, shape, and inform human occupation (Kielhofner, 2008, p. 5). Human occupations are a unique experience for every individual and are influenced by a multitude of factors that influence the ability to be productive, engage in leisure, and complete various activities of daily living.

Provided in MOHO is an explanation of the motivation, patterning, and performance factors associated with individual occupations. Human operations occur in various social and physical environments and are inherently comprised of three components that are interrelated and influence occupational participation: volition, habituation, and performance capacity. "Volition refers to the motivation for occupation, habituation refers to the process by which occupation is organized into patterns or routines, and performance capacity refers to the physical and mental abilities that underlie skilled occupational performance" (Model of Human Occupational Clearinghouse, 2013). Volition includes an individual's values, interests, and personal causation, which is the personal perception of being effective at a task. Habituation occurs as a result of recurrent patterns, such as routines, habits, and personal roles. Performance capacity is dependent on individual skill-based factors related to motor, process, communication, and interaction skills (Boyer et al., 2008). Kielhofner (2008) asserts that human occupations can best be understood through considering the concepts of habituation, volition, performance capacity, as well as environmental contexts.

The environment is comprised of social, cultural, and physical dimensions that either foster or inhibit functional performance and participation (Boyer et al., 2008). It consists of the people, places, and objects with which individuals interact and provides opportunities that support or interfere with an individual's ability to participate and perform various occupations (Kielhofner, 2008). Included in MOHO are systems theory approaches to aid in describing how the dynamics of human occupations including volition, habituation, and performance capacity were impacted by the interplay of human qualities and environmental factors. Patterns of doing, such as performance and participation, are all shaped by these interconnected components. As a result, occupations occurring in a supportive environment with positive outcomes will result in behaviors being repeated. In turn, change and adaptation will occur in response to less favorable results and promote the reshaping and development of new occupational patterns of performance and participation (Kielhofner, 2008). Occupational performance and participation are continuously being shaped by the dynamics of volition, habituation, performance capacity, and the environment.

Similar to the environment, culture also plays a role in an individual's participation and performance of human occupations (Kielhofner, 2008). All components inherent in MOHO and previously discussed are influenced by culture, as individual's thoughts, actions, roles, and perceptions about their surroundings are molded by culture. "Culture shapes what kinds of abilities are important, what kinds of meanings are tied to actions, what pastimes are enjoyed, and what one should strive after in life" (Kielhofner, 2008, p. 34). As a result, personal customs and beliefs may influence the volitional, habitual, performance capacities, and environmental factors of an individual's occupations and functioning within society. Kielhofner (2008) provided through MOHO a construct for determining the various internal and external factors that may influence an individual's performance and participation.

**Research and MOHO.** Since the development of MOHO, researchers and clinicians have applied this model to their studies and clinical practice in an effort to gain insight into participation challenges of individuals with various conditions that negatively affect function. MOHO has been used as a framework for research related to performance assessment and program development internationally for children and adults, primarily in the areas of mental health and with individuals with various disabilities (Basu, Jacobson, & Keller, 2004; Bowyer, et al., 2008;Kramer, Kielhofner, Lee, Ashpole, & Castle, 2009). Relating to autism, Restalt and Magill-Evans (1994) used the theoretical basis of MOHO to study challenges with play skills in preschoolers. Prevalent studies utilizing MOHO have been conducted with regards to the clinical utility of assessments developed for use in practice based on the model (Bowyer, Kramer, Kielhofner, Maziero-Barbosa, & Girolami, 2007; Kramer, et al., 2009). Common assessments used with the pediatric population that appear in research include the Child Occupational Self-Assessment and the Short Child Occupational Profile (Harney & Kramer, 2007; Romero Ayuso, & Kramer, 2009). As a result of such research, clinicians primarily in the field of occupational therapy employ MOHO in practice through clinical reasoning and utilization of related MOHO assessments (Keopenen & Launiainen, 2008; Kielhofner, 2008; Kramer, Bowyer, O'Brien, Kielhofner, & Maziero-Barbosa, 2009).

## International Classification of Functioning, Disability, and Health (ICF)

ICF contains definitions for functioning, disability, and health that can be used to understand influential factors related to performance and participation from a biopsychosocial model (WHO, 2002). The biopsychosocial model is a combination of individual, biological, and social frames of reference for conceptualizing disability and function, which are dependent on interactions between contextual factors and individual factors that affect conditions of health.

> Among contextual factors are external environmental factors (for example, social attitudes, architectural characteristics, legal and social structures, as well as climate, terrain and so forth); and internal personal factors, which include gender, age, coping styles, social background, education, profession, past and current experience, overall behavior pattern, character and other factors that influence how disability is experienced by the individual. (WHO, 2002, p. 10)

Human functioning is said to be dependent on the interaction at three distinct levels, namely an individual body part or system, the entire person, and the context. Disability occurs as a result of dysfunction at either one or more of these levels and presents as functional impairments, limitations in activity, and restrictions in participation.

The WHO (2006) aims to present disability as a common feature of existence that everyone has the potential to experience at any given time due to health challenges. According to the World Health Organization, health is defined as follows:

> a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity… Healthy development of the child is of basic importance [and] the ability to live harmoniously in a changing total environment is essential to such development." (WHO Constitution, p. 1, 2006).

As such, individuals with disabilities like ASD may present with health impairments as they struggle with development and optimal functioning in their environment due to internal and external challenges. Difficulties with performance and participation may negatively influence an individual with ASD's ability to engage with others and the environment, as well as one's overall ability to function and experience healthy development.

**Research and ICF.** ICF has been used in various research studies, alongside public policy initiatives and clinical practice, to provide a conceptual framework for discussing and determining functional abilities and challenges (Björck-Åkesson et al., 2010; Francescutti et al., 2009; WHO, 2010). Additionally, it has been used as a systematic means for data collection at the population level related to disability, functioning, and participation across cultures and countries (WHO, 2013). In 2006, ICF for Children and Youth (ICF-CY) was developed to help with the application of a universal terminology related to infancy through adolescence, being recommended to merge back into ICF in 2010 (WHO, 2007; WHO, 2012). Since then, ICF-CY has been used to assess the functional and participation challenges of children across multiple contexts (Adolfson, Malmqvist, Pless, & Granlund, 2011; Coster et al., 2011; Ibragimova, Granlund, & Bjorck-Akesson, 2009; Simeonson, 2009). Recently, researchers have used ICF framework to specifically study the challenges of individuals with ASD, demonstrating the validity of its use with this population (Gan, Tung, Yeh, Chang, & Wang, 2014; Gan, Tung, Yeh, & Wang, 2013; Poon, 2011). An overview of ASD, including functional challenges and diagnostic criteria identified through recent research, appears below.

## Overview of Autism Spectrum Disorders

Autism Spectrum Disorder (ASD) is a developmental disability that negatively affects social participation, communication, and behavioral functioning, with differing degrees of impairments exhibited by affected individuals (APA, 2013b; CDC, 2014). ASD is prevalent in individuals of various races and socioeconomic groups, being diagnosed in 1 in 68 children and noted to occur 5 times more frequently in boys (CDC, 2014). In May 2013, the American Psychiatric Association (APA) published new diagnostic criteria for ASD in the revised DSM-5 to clarify the diagnosis of ASD (APA, 2013a). Under the previous edition, individuals were diagnosed as having any of the following four disorders: Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). With the updated DSM-5, changes were made to eliminate sub-classifications under the autism spectrum and allow for one uniform diagnosis of ASD (APA, 2013a). For individuals who previously had a well-substantiated diagnosis under the former DSM, they should be given the new diagnosis of ASD.

## Diagnostic Criteria for ASD

The most recent DSM-5 now includes one diagnostic category for ASD, with the reclassification of other related conditions (APA, 2013a). Those with known genetic and medical conditions, such as Rett Syndrome and Fragile X, are categorized as their own disorder. The use of PDD-NOS and Asperger's Disorder were eliminated and consolidated under the ASD category. Additionally, those individuals who do not meet the criteria for ASD and have challenges with using verbal and nonverbal communication socially are now diagnosed under Social Communication Disorder (APA, 2013b). Professionals are encouraged to consider the degree to which an individual exhibits such difficulties that meet the above noted symptomology and determine the most appropriate diagnosis, whether ASD or a better suited one.

For an individual to be diagnosed with ASD, they must demonstrate deficits primarily in social communication and interaction, as well as exhibit restricted repetitive behaviors, interests, and activities (APA, 2013b). Social impairments must be present across multiple contexts and may include non-verbal and verbal behaviors, challenges with social interactions and relationships, and difficulties with situational appropriateness. Restricted and repetitive behaviors now encompass a sensory component, where maladaptive and hyper- or hypo-responsiveness to environmental stimuli and sensory input are considered. Additionally, stereotyped movements, rigidity in routines, ritualistic behaviors, and restricted interests are behaviors that must be reported or observed. Also specified in the DSM-5 are further criteria for such symptoms to have been present during early development and not be a result of global developmental delays or intellectual disability (APA, 2013b). The above-described symptomology for ASD should result in significant impairments that affect occupational, social, and overall functioning.

In addition to symptoms, severity levels for the degree to which an individual's functioning is impaired is now included in the DSM-5 (APA, 2013a). Severity levels range from level 1 to 3, with each providing specific examples as to the degree of support required. Level 1 implies minimal functional impairment regarding social communication and restricted, repetitive behaviors, where an individual may have verbal abilities, but demonstrate atypical social overtures and behavioral inflexibility in one or more contexts. Level 2 includes marked impairments with verbal and non-verbal communication and frequent behavior challenges that impede functioning, resulting in the need for substantial support. Challenges described in Level 3 imply the most significant amount of support required because of severe impairments in social communication and behaviors (APA, 2013b). By providing such criteria related to severity levels, it may help in understanding the degree to which an individual's functioning in impaired as a result of a uniform diagnosis of ASD (APA, 2013a).

With the changes to diagnostic criteria for ASD, there is a proposed benefit of a more accurate description of the symptoms that should be present and the degree to which functioning is impaired (APA, 2013a). Symptoms can now be viewed on a continuum, with accompanying severity levels as to the manner in which social communication and interaction, as well as restrictions in participation, require different degrees of support. Criticism has been expressed regarding the recent changes, with some voicing concerns of individuals losing their current diagnoses, as well as discontinuation of access to needed services (APA, 2013a; Wing, Gould, & Gillberg, 2011). As a result, the DSM-5 is recommended in conjunction with other screening and diagnostic measures to determine a diagnosis of ASD from a global and holistic perspective (APA, 2013a; APA, 2013b).

## Diagnostic Assessment of ASD

The diagnosis of children suspected of having ASD can be a difficult process, as professionals seek to rule out other co-occurring symptoms and determine a diagnosis that allows a child and family to access the services they need (Close, Lee, Kaufmann, & Zimmerman, 2012; Ennis-Cole et al., 2013). Additionally, developmental, neurological, and psychiatric problems often co-exist in individuals with ASD, such as intellectual disabilities, sensory processing difficulties, speech and language difficulties, motor skill deficits, epilepsy, and anxiety disorders. It is critical for professionals to know the early signs of ASD, as well as consider related disorders and cultural factors (Close et al., 2012; Zwaigenbaum et al., 2009). It is recommended that diagnosis be a comprehensive process, considering multiple forms of data sources and information, while also exercising cultural sensitivity (Ennis-Cole et al., 2013; Matson et al., 2011). There are various resources available through the Centers for Disease Control, as well as other professional trainings, to assist professionals in developing competency in identifying the early signs of ASD (CDC, 2013; Boyd et al., 2010).

Professional practitioners use a variety of assessments to assist in the screening and diagnostic process for identifying ASD and can reference professional resources to help foster their skills for early detection of ASD (Boyd et al, 2010; Reszka, Boyd, McBee, Hume, & Odom, 2014). Early screenings before and around 18 months of age, as well as at 24 months, are recommended in efforts to allow for early implementation of services (Barton, Dumont-Mathieu, & Fein, 2012). Common screeners used in early identification of ASD include the following: Checklist for Autism in Toddlers (CHAT) Modified Checklist for Autism in Toddlers (M-CHAT), Quantitative Checklist for Autism in Toddlers (QCHAT), Baby and Infant Screen for Children with Autism Traits (BISCUIT), First Year Inventory (FYI), Screening Tool for Autism in Two-Year Olds (STAT), and Communication and Symbolic Behavior Scales Developmental Profile (CSBSDP. For comprehensive diagnostic purposes, practitioners often use the following caregiver questionnaires and observational measures: Autism Diagnostic Observation Schedule (ADOS), Autism Diagnostic Interview-Revised (ADI-R), Childhood Autism Rating Scale (CARS), and Social Responsiveness Scale (SRS), Repetitive Behavior Scale-Revised (RBS-R), and Child Behavior Checklist (CBCL) (Boyd et al., 2010; Matson et al, 2011; Zwaigenbaum et al., 2009). Using various screening and assessments tools, practitioners can assess an individual’s skills and help to make an early diagnosis for access to early intervention services.

## Age of ASD Diagnosis and Disparities

A diagnosis of ASD can be made by the second year of life, with early intervention being critical during this period to address the core deficits in social, communication, and adaptive functioning skills (Chawarska et al. 2009; Rogers 2009). Following a review of studies published from 1990 to 2012, Daniels and Mandell (2014) reported the mean age for diagnosis for ASD to range from 38 to 120 months, with a noted decrease across time. Researchers have reported that parents may even begin noticing symptoms as early as 6 to 8 months of age, with diagnosis between the ages of 1 and 3 becoming the standard (Mandell et al., 2010; Matson, Beighley, & Turygin, 2012; Valicenti-McDermott et al., 2012). Some identified factors associated with earlier diagnosis include higher socioeconomic status, greater severity of symptoms, and previous familial interactions with educational and health systems (Daniels & Mandell, 2014).

In spite of the campaigns and initiatives for the early identification of ASD, disparities exist with some populations being misdiagnosed or receiving a diagnosis at later ages (Ennis-Cole et al., 2013; Valicenti-McDermott, et al., 2012). Although there is no reported difference in clinical characteristics and exhibited symptomology based on ethnicity or socioeconomic status, individuals from minority groups have been found to receive their diagnosis at later ages (Ennis-Cole et al., 2013; Mandell et al., 2009). Children of Hispanic and African American backgrounds have been found to be more likely to receive their diagnosis of ASD after the age of 4, even after adjusting for various demographic factors related to education, insurance, and family history. Additionally, children who are born in another country or were born to foreign-born parents are reportedly referred for evaluations later (Valicenti-McDermott et al., 2012). With the disparities in referrals for assessment and later age for receiving an ASD diagnosis, it is important for practitioners to consider the influence race and culture may have on this process and potential differences in participation and performance challenges. Below is a discussion of recent studies that identify challenges faced by individuals with ASD, with further emphasis on the early childhood years.

## ASD and Adaptive Functioning Challenges in Early Childhood

According to ICF (WHO, 2002), an individual's ability to function and participate are affected by a variety of factors, including personal and environmental contributors. Similarly, Kielhofner (2008) proposed with MOHO that participation and performance could be affected by volitional, habitual, capacities for performance, and contextual factors. As a result, children with ASD present with challenges that negatively affect their ability to function in the home, school, and community settings due to individual capacities and environmental factors. Researchers have conducted studies to explore the participation and performance challenges encountered by individuals with ASD, as well as the influence this may have on parenting and family dynamics. It has been found that raising an individual with functional impairments as a result of having an ASD can negatively influence the family dynamics and increase parental stress (Estes et al., 2009; Myers, Mackintosh, & Goin-Kochel, 2009; Rao & Beidel, 2009). Additionally, participation in age-appropriate activities, such as school, family gatherings, and community outings, also poses challenges due to difficulties with communication, social participation, motor skills, cognitive abilities, adaptive behavior, and sensory processing difficulties (Fournier, Hass, Naik, Lodha, & Cauraugh 2010; Lane, Young, Baker, & Angley, 2010; LaVasser & Berg, 2011). Below is a discussion of recent studies highlighting the reported difficulties in early childhood of individuals with ASD as it relates to adaptive functioning.

### Overview of Adaptive Functioning Challenges

Participation is described by the WHO (2002) as being essential for development and consists of involvement in life experiences. With participation being impacted by personal and environmental factors (Kielhofner, 2008; WHO, 2002), individuals with ASD are said to have difficulties with communication, social interaction, and restricted repetitive behaviors, interests, and activities (APA, 2013b). Researchers have explored these constructs to further define functional difficulties encountered by individuals with ASD and identify interventions to help improve upon those challenges encountered with adaptive functioning. Adaptive functioning, also referred to as adaptive behavior or skills in the literature, consists of those skills necessary for an individual to function in everyday activities, such as communication, social interaction, self-help, and overall independence with age-appropriate tasks (Perry et al., 2009; Paul et al., 2014). Age, cognitive level, behavior, sensory processing, and symptom severity are variables that reportedly influence participation and performance with adaptive functioning (Lane et al., 2010; Paul et al., 2014).

Little research currently exists that considers the relationship between adaptive functioning in the preschool-age population and other variables, including age, symptom severity, and cognitive abilities (Perry et al., 2009). As children are being diagnosed with ASD at younger ages, it is critical that researchers begin to focus on adaptive functioning difficulties in the toddler and preschool-age population in order to determine challenges and progress with participation and performance over time. Acquiring adaptive skills in early childhood may be one of the most import goals during this time, as they serve the foundation for independent functioning and are based on communication, socialization, motor, and self-care skills (Oakland & Algina, 2011). The American Association on Intellectual and Developmental Disabilities (2013) recommends measuring adaptive functioning based on conceptual, practical, and social skills essential for performance in everyday activities. These skills are defined as follows:

> 1. Conceptual skills: language and literacy; money, time, and number concepts; and self-direction.
> 2. Social skills: interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.
> 3. Practical skills: activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone. (American Association on Intellectual and Developmental Disabilities [AAIDD], 2013, para. 4)

Various assessments are currently available to professionals to identify adaptive functioning skills exhibited in early childhood.

Standardized assessments used to determine an individual’s adaptive functioning include measurement of the domains recommended by the AAIDD, with Vineland Adaptive Behavior Scales (VABS), Adaptive Behavior Assessment System (ABAS), and Behavior Assessment System for Children (BASC) being most common. Across studies, the VABS is the most popular adaptive functioning assessment used (Lopata et al., 2013). Parents, caregivers, and teachers are instrumental in providing information on a child’s daily functioning and are often asked to complete these assessments. Using these assessments, adaptive functioning difficulties have been noted in early childhood, with there being a continuing challenge with these skills as a child progresses in age (Baghdadli et al., 2012). Lopata et al. (2013) have identified some variances in the scores reported through cross-comparison analysis of the VABS, ABAS, and BASC. Their findings indicated that children with high functioning ASD had significant discrepancies between their IQ and adaptive functioning, tended to have higher reported adaptive composite scores based on the VABS, and higher adaptive social scales on the BASC. They found that the ABAS was more sensitive in determining adaptive skill challenges in comparison to the other measures. As a result, a comprehensive assessment is critical that involves both observation and caregiver report to yield a more accurate picture of a child's adaptive functioning abilities and encountered difficulties.

Perry et al. (2009), building upon earlier studies in the area of adaptive functioning, have identified profiles of children with ASD related to cognitive abilities and adaptive functioning based on the VABS, highlighting the variance in previous studies. Their findings of children under the age of 6 indicated that individuals with ASD having severe and profound cognitive impairments presented with adaptive functioning above their cognitive scores. In contrast, children with less severe cognitive impairments presented with adaptive functioning abilities significantly lower than their cognitive age equivalents. As a result, Perry et al. have suggested a pattern for an "autism profile" based on the domains measured on the VABS related to age equivalents, where "Motor is highest, followed by Daily Living and Communication (except in the two highest functioning groups), and then Socialization lowest" (p. 1072). Higher functioning children with ASD exhibited a profile where communication skills were highest, followed by motor skills and daily living skills respectively, with socialization being the lowest. Autism severity levels reportedly had a significant impact on adaptive functioning, resulting in more pronounced impairments when confounded by cognitive challenges. Additionally, variance in adaptive functioning was noted and attributed to developmental level and age.

Similarly, Kanne et al. (2011) described a profile of functioning in children with ASD based on functional outcomes. Their study consisted of 1,089 verbal individuals with ASD who were classified as “high functioning,” ranging in age from 4-17 with cognitive abilities in the average range for verbal and nonverbal skills. Kanne et al. found that as a child increased in age, so did the degree of impairment with adaptive functioning in comparison to their mental age. Increases in intellectual functioning were positively correlated with increased adaptive functioning, although the strength of such results was less predictive with interpersonal relationship and language responsivity skills. Of importance was the poor association with adaptive behavior and severity of autism symptoms based on clinical observation, whereas stronger associations were noted based on parental report. Parents indicated increased challenges with socialization skills and social communication as a result of increased severity in symptomatology, although this pattern may diminish with increasing age. Overall, the greatest degree of impairment was related to socialization skills, with moderate delays in activities of daily living and communication.

In addition to the core deficit areas of communication and social interaction, sensory processing difficulties have also been identified in individuals with ASD, with researchers reporting challenges with adaptive behavior as a result (Lane et al. 2010; O’Donnell, Deitz, Kartin, Nalty, & Dawson, 2012). Included in the *Diagnostic Classification of Mental Health and Development Disorders of Infancy and Early Childhood: Revised Version* (Zero to Three, 2005) are aberrant responses to sensory stimuli that fall under the diagnosis of Regulation Disorders of Sensory Processing (RDSP). Three categories exist within the diagnosis of RDSP: hyper-responsive, hypo-responsive, and sensory seeking/impulsivity. In the current *DSM-V*, irregular sensory responses, such as atypical interests in sensory features of the environment and hyper-or hypo-reactivity to stimuli, are now considered when making a diagnosis of ASD (DSM-V, 2013). As a result of sensory processing disorders, an individual may lack awareness of, seek excessive opportunities to interact with, or respond negatively to certain environmental stimuli. These may include certain sounds, visual stimuli, tactile experiences, olfactory stimuli, oral input, proprioception, and vestibular input (Lane et al., 2014; Reynolds, Bendixen, Lawrence, & Lane, 2011). Challenges with sensory processing related to avoidance, seeking, or poor awareness have resulted in difficulties with self-regulation, which negatively affects adaptive functioning (Brock et al., 2012; Hazen, Stornelli, O'Rourke, Koesterer, & McDougle, 2014; Lane et al., 2010; O'Donnell et al., 2012).

The findings of researchers regarding functional profiles of individuals with ASD and the challenges with adaptive functioning can be beneficial to practice. It is documented that individuals with ASD may present with adaptive functioning challenges in the areas of communication, social interaction, behavior challenges, and sensory processing (Brock et al., 2012; Lane et al., 2014; Kanne et al., 2011; Perry et al., 2009). Additionally, they may present with varying profiles of sensory responsivities and temperament due to numerous factors, including development, behavior, and cognitive abilities (Baranek et al., 2006; Hepburn & Stone, 2006; Hilton et al., 2010; Watson et al., 2011). However, caution should be used with these results due to variance from previously reported profiles and changes in intellectual functioning over time (Brock et al., 2012; Kanne, et al., 2011; Klin et al., 2007; Matson & Shoemaker, 2009; Perry et al., 2009). Individuals with ASD may demonstrate strengths and challenges with certain aspects of adaptive functioning, as varying degrees of impairments may be exhibited by each individual and across different contexts. These findings do have clinical relevance and are useful to assist with program development and guide the implementation of intervention approaches in efforts to improve an individual's adaptive functioning.

## ASD and Adaptive Functioning Challenges inPreschool-Aged Children

Studies on the functional challenges of preschoolers with ASD are few, although evidence supports the stability of a diagnosis as early as 2 years of age (Chawarska, et al, 2009; Kleinmanet al., 2008; Sutera, et al., 2007). Recently, children under the age of three have been studied to assess their adaptive behavior skills and monitor developmental trajectories. In a study of toddlers under the age of two diagnosed with ASD, Paul et al. (2011) discussed their findings of adaptive behavior challenges reported by caregivers of children under the age of 2 on the VABS. Those with ASD demonstrated significant differences concerning receptive language when compared to other children with non-autistic developmental delays (Paul et al., 2011; Ventola, Saulnier, Steiner, Chawarska, & Klin, 2014). Paul et al. found that receptive communication was related to severity of autistic symptoms more than cognitive abilities. While challenges in language and communication are present also in children with developmental delays, certain characteristic differences are more significant in children with ASD, particularly with respect to joint attention, imitation, facial expression, social interest in others, gesture usage, and initiation and response to communication (Paul et al., 2011; Ventola et al., 2014). Additionally, adaptive living skills related to performance of basic self-care tasks, such as feeding, dressing, and bathing, were notably impacted more than other children with developmental delays (Paul et al., 2011).

Adaptive functioning challenges related to behavior have also been attributed to negative reports of participation for preschool aged children with ASD (Lavasser & Berg, 2011; Pérez-Robles et al., 2013). In a qualitative study of preschool children with ASD between the ages of 3 and 6years, LaVasser and Berg (2011) explored child, family, and environmental factors that parents reported as reasons for impairment in participation. Of importance is their finding of behavior to be the most significant challenge to participation. Although opportunities may be provided, parents indicated that behaviors, such as refusal, tantrums, limited interest, and difficulties with following directions, frequently impeded participation. As a result, factors beyond cognition and communication challenges such as those related to behavior may influence adaptive functioning.

Sensory-related factors involving difficulties to respond appropriately to sensory input in the environment, have also been reported to influence adaptive behavior in children under the age of 6 years with ASD (LaVasser & Berg, 2011; Pérez-Robles et al., 2013). It has been noted that children with ASD exhibit temperament patterns because of sensory modulation patterns in distinct from that of typically developing children, with less significant differences than children with developmental delays (Brock et al., 2012). Hypo-responsivity, diminished behavioral responses to sensory stimuli, is commonly reported in children with ASD, as well as hyper-responsivity, exaggerated responses that may be observed as avoidance or aversive reactions to certain stimuli (Baranek, David, Poe, Stone, & Watson, 2006; Schoen, Miller, & Green 2008). Ben-Sasson et al. (2007) explored sensory modulation difficulties in toddlers with ASD, indicating low registration of information, followed by avoidance, as the most significant challenges. Similar to the findings of Kanne et al. (2011) regarding variance with clinician versus parental reports of degrees of impairment, Ben-Sasson et al. found that parental report of findings was consistent across measures and differed from clinical observation results. Overall, preschool children with ASD present with various challenges, including those related to sensory processing, that negatively impact performance and participation with adaptive functioning.

## ASD and Adaptive Functioning Challenges in African American Preschool-Aged Children

The core symptoms of ASD related to atypical social, communication, sensory, and behavioral patterns have been documented across cultures and races, although subtle differences may exist with regards to individual presentation (Cuccaro et al., 2007; Mandell et al., 2009). Recent studies have identified the various challenges preschool-aged children with ASD experience that negatively impact adaptive functioning (Paul et al., 2011; Ventola et al., 2014). With diagnosis occurring at an earlier age, children under the age of two are even being included in research studies to explore these challenges further to allow for early identification and intervention (Chawarska et al., 2009; Matson et al., 2012; Rogers, 2009). While the diagnosis of ASD has been found to be stable even when given as early as 2 years old, minority populations, such as those from African American backgrounds, continue to receive a diagnosis later in life (Ennis-Cole et al., 2013; Mandell et al., 2009; Mandell et al., 2010; Valicenti-McDermott, et al., 2012).

Additionally, few studies provide a representative sample where minorities are included to a significant degree to assess possible race and cultural implications to the presentation of ASD symptomology (Cuccaro et al., 2007; Sell et al., 2012).

In the few studies where researchers have focused on minority populations, subtle differences have been noted in the manifestations of deficit areas, as well as children being given other diagnoses prior to that of an ASD (Gourdine, Baffour, & Teasley, 2011; Mandell et al., 2009). Tek and Landa (2013) reported similarities in the core features of children with ASD from minority backgrounds with others, finding difference concerning more significant delays related to communication and language. In a study conducted by Herlihy et al. (2014), lower socioeconomic status served as a predictor of later age at the time of evaluation for ASD, resulting in severity of delays upon diagnosis. Additionally, yearly household income and maternal education predicted adaptive functioning difficulties related to communication, social, and motor skills. Differences related to presence and severity of challenging behavior have also been identified, with children from African American backgrounds reportedly having higher scores for aggression (Horovitz et al., 2011; Jang et al., 2013; Mayes & Calhoun, 2011). Perceptions of disability in minority populations may also be a factor, delaying the time in which assistance is sought to address concerns (Carr & Lord, 2013). In order for early intervention to take place, standardization of screening processes and promoting access to services in minorities to address the disparities in early diagnosis of ASD are recommended (Gourdine et al., 2011; Herlihy et al., 2014). Researchers have identified numerous factors that contribute to the presentation of symptomology of ASD, with race and culture seldom being explored. As tools are more readily available for diagnosis and the incidence of ASD continues to rise, it is critical that race and cultural concerns be explored in order to gain a better understanding and effectively serve minority populations.

## Summary

There is a vast amount of research currently available and underway to explore the functional challenges encountered by individuals with ASD, although not specific to race and cultural influences. Recently, researchers are now delving into the exploration of the adaptive functioning challenges of preschool-aged children with ASD, as diagnosis as early as 2 years of age has proven to be stable (Chawarska et al., 2009; Kleinman et al., 2008). With ICF serving as a uniform terminology for classifying functioning across countries, research is now available where the difficulties of individuals with ASD concerning functioning on an international basis are explored. This leads to hope for a better understanding of the impact of ASD on quality of life and can assist with public policy and program development (Björck-Åkesson et al., 2010; Coster & Khetani, 2008; Francescutti et al., 2009; WHO, 2013). Both personal and environmental challenges have been identified as having an influence on one's adaptive functioning (Rosenberg, Bart, Ratzon, & Jarus, 2013). However, challenges exist with understanding this perspective from individuals of minority backgrounds, as they represent a small sample of individuals included in current research (Cuccaro et al., 2007; Mandell et al., 2009).

Of the numerous studies conducted with individuals with ASD, few include a significant sample of individuals from minority backgrounds (Carr & Lord, 2013; Gourdine & Algood, 2014; Sell et al., 2012). It has been noted that individuals from minority backgrounds, such as African American and Hispanic, receive their diagnosis at a later age than children from other backgrounds (Ennis-Cole et al., 2013; Gourdine et al., 2011; Mandell et al., 2009; Mandell et al., 2010; Valicenti-McDermott, et al., 2012). Researchers have hypothesized that this may be attributed to differences in socioeconomic status, educational background, access to quality healthcare and educational services, and parental identification and expressed concern for developmental delays (Daniels & Mandell, 2014; Ennis-Cole et al., 2013; Irvin et al., 2012; Mandell et al., 2009). Further research is needed to explore the challenges of participation and performance concerning the influence race and culture may have on the presentation and identification of symptomology, especially with individuals from minority backgrounds (Daniels & Mandell, 2014; Ennis-Cole et al., 2013; Gourdine & Algood, 2014).

# Chapter 3: Methodology

## Introduction

The purpose of this mixed methods study was to explore symptom severity, functional difficulties, and age at diagnosis for ASD, as well as describe the functional challenges encountered by preschool-aged children with ASD from African American backgrounds. Early intervention is critical for improved outcomes, making early diagnosis of ASD important for increased opportunities for service utilization. However, children from minority backgrounds often receive their diagnoses later, even when symptomatology of ASD is considered to be similar in presentation across races. As a result, I chose to explore possible correlations of factors associated with later diagnosis in children of African American background with ASD using a national dataset, such as symptom severity and degree of functional challenges, as well as describe the functional challenges on an individual level using interviews conducted with at leastfour families. In this chapter, the methodological approach for this research study is discussed, including the setting, design of the study, rationale, and methodology procedures and concerns.

## Setting

There were two components of data collection and setting, national andlocal. The quantitative component of the study consisted of the participants who completed the 2009-2010 NS-CSHCN, specifically parents of children with special needs who identified their child as having a current diagnosis of ASD. Because it was a national survey, all 50 states and the District of Columbia were included in a cross-sectional telephone study completed through phone interviews. There were 40,242 interviews completed overall with parents who had at least one child 17 years old or younger in their household during the completion period of July 2009 through March 2011. Of those completing the survey, there were 347 parents who indicated that their child had a current diagnosis of ASD. However, responses for severity level were only provided by 224 parents, which was the target sample for this study. In accordance with the recommendations for the codebook of the NS-CSHCN, subpopulation features using statistical software was used rather than selecting only these responses to preserve the integrity of the data.

For the qualitative component, local families from a southern state in the United States of African American background were selected. However, previous researchers have pointed out the difficulty in recruitment of African Americans to be represented in research (Carr & Lord, 2013; Gourdine & Algood, 2014; Sell et al., 2012). As a result, the aim was to recruit the parents of at least four local families to participate in the study. However, due to attrition, only three parents participated in the qualitative component of this study. Together, these research components addressed both a population representative of a national sample and personal accounts from parents of African American background.

## Research Design and Rationale

Mixed methodology using an explanatory sequential design was chosen for this study, as it allows for an integrative approach of both quantitative and qualitative research methods (Bryman, 2006; Fielding, 2012). The purpose of this research study was to explore factors that may have a relationship with later age of diagnosis of ASD in children of African American background, as well as to describe the lived perspective of adaptive functioning challenges based on parental reports. The research questions for this study were as follows:

1. How does symptom severity relate to earlier age of diagnosis?
2. How does degree of reported functional challenges relate to earlier diagnosis?
3. How do parents describe adaptive functioning challenges related to performance and participation?

Thus, this study combined the use of quantitative and qualitative research approaches in an effort to explore factors that may influence age at diagnosis for ASD and explore parental reports of adaptive functioning challenges in children of African American descent with ASD.

With mixed methodology, the illustration and explanation of quantitative findings can be expounded upon using qualitative methods (Bryman, 2006; Fielding, 2012). In a study where an explanatory sequential design is used, two distinct phases occur in the research process: (a) quantitative phase where data are collected and analyzed and (b) qualitative phase to understand the quantitative data more deeply (Creswell & Plano Clark, 2011; Guest, 2013). As a result, a sequential explanatory design was chosen for this study to first analyze a national dataset and further elaborate on these findings using interviews. A sequential approach was employed as follows: QUAN→QUAL (Guest, 2013; Leech and Onwuegbuzie, 2009; Teddlie & Tashakkori, 2009).

Mixed methodology is an approach to research that involves the use of both quantitative and qualitative research paradigms when it is important to choose a design that would provide the best means to answering the research questions and allow for quality inferences to be made (Creswell & Plano Clark, 2011; Fielding, 2012; Guest, 2013; Teddlie & Tashakkori, 2009). Additionally, mixed methodology can be used to explore unexpected quantitative results in further detail through employing qualitative measures (Creswell, et al., 2011; Klingner & Boardman, 2011). An explanatory sequential approach was chosen primarily as a result of having access to a national dataset with little in-depth information to in order to understand the responses provided therein.

To address the research questions, first quantitative methods were used to analyze the responses provided in the 2009-2010 NS-CSHCN Survey using subpopulation features of statistical software. Using information form a large national sample afforded a representative sampling of the general population with regards to age at diagnosis in relation to symptom severity and degree of functional impairments. This was followed by a qualitative approach using interviews with local parents to address the final research question. Interviews are considered to be a powerful tool in that they allow for individual interactions between the researcher and the study participant. Using sequential mixed methodology allowed for the results of the quantitative study to be expounded upon through qualitative interviewing (Guest, 2013;Leech and Onwuegbuzie, 2009; Teddlie & Tashakkori, 2009). Through employing an explanatory sequential design, I aimed to examine the diagnostic disparities and adaptive functioning challenges of preschool-aged children from African American backgrounds who have been diagnosed with ASD.

## Role of the Researcher

For this study, I served as the sole researcher, collecting the qualitative data and analyzing the quantitative data. Having worked in the rehabilitation field for over 16 years, primarily as an occupational therapist, and having provided services to individuals of various ages with ASD, it may be presumed that personal biases may have compromised my role in this study. To account for any biases and probable relationships with the families selected for the qualitative component, the participant parents chosen for the interviews had no prior interactions with me, either personally or professionally. Recruitment of participants excluded anyone receiving services in my current or previous work environments. Additionally, the interview was confined to open-ended and structured questions in accordance with existing assessment measures that related to the study. These efforts were taken to address the potential for bias in participant selection and throughout the data collection and analysis process.

## Methodology

This research study was approved by the Institutional Review Board of Walden University (IRB # 01-16-15-0102048). Mixed methodology is a research approach that allows for the collection of quantitative and qualitative data, with the aim of providing a better understanding of a particular phenomenon (Creswell & Plano Clark, 2011; Guest, 2013). A mixed methods approach was used to gain insight into the diagnostic disparities and adaptive functioning challenges of preschool-aged children with ASD of African American background. Information was analyzed from parents who completed a national survey, as well as gathered from at least four parents of African American background recruited locally from the southern United States. Quantitative measures were used through reviewing responses provided by parents of children with special needs on the NS-CSHCN (CDC, 2011a). Qualitative measures were employed through conducting interviews with parents of preschool-aged children of African American descent with ASD.

## Quantitative Participant Selection

Participants for this study included parents who had a child with special needs, using secondary analysis of the NS-CSHCN data from July 2010 through March 2011. Random sampling involves an equal probability for an individual to be chosen as a potential participant in a research study (Plano Clark & Creswell, 2008). Initially, families who were identified as having a child with special needs were randomly selected from across the nation to participate in the NS-CSHCN. Random sampling was further used to address the issue of families having more than one child with special needs. One child from households that included multiple children with special needs were selected, with parents providing responses to survey questions as it solely related to that individual (Centers for Disease Control and Prevention, 2011a).

From this random sample, responses from parents of children with autism were identified. Further subgrouping of the responses provided on the NS-CSHCN was not advised, as the information that may be gathered from this approach may conflict with the research design and potentially provide misconstrued data (Centers for Disease Control and Prevention, 2011b). As a result, the developers of the NS-CSHCN study recommended using features of statistical analysis software, such as subpopulation (SUBPOPN), to compare participants based on other potential subgroups. Respondents from the NS-CSHCN were categorized based on demographic responses identifying them as being of African American background and having a child with a diagnosis of ASD. Based on preliminary exploration of the data, there were 224 parents who identified themselves as having a child of African American background with a current diagnosis of ASD and provided responses regarding severity level and degree of adaptive functioning challenges. However, subpopulation of the NS-CSHCN data was used to maintain the integrity of the data in accordance with the associated codebook.

### Qualitative Participant Selection

Mixed methodology sampling procedures may involve having a larger sample for the quantitative component and a smaller size for the qualitative (Guest, 2013; Teddlie & Tashakkori, 2009). With interviews being used for the qualitative component of this study, purposive sampling was utilized to identify at least four parents locally. The aim was to identify at least four parents of preschool-aged children 6 years of age or younger with a diagnosis of ASD of African American background. Recruitment efforts were aimed at community partners, clinical and community-based therapy providers who provide services to preschool-aged children with ASD and agree to allow solicitation of their families for participation in this study. Community partners were provided with a Letter of Support, which served as an attestation of their agreement for allowing recruitment of families from their establishment for participation in this research study. In order to be included in the study, parents were informed of the nature of the study and signed a consent form, with an emphasis on voluntary participation and an explanation of the minimal risks for participation. Interviews consisting of structured and open-ended questions with related probes were then conducted with parents using components of the Short Child Occupational Profile (SCOPE), with member checking to verify accuracy of responses.

### Quantitative Instrumentation

Surveys are a common way to gather information from individuals that can provide information about their experiences and views (Creswell & Plano Clark, 2011). The quantitative data will consist of information gathered from the NS-CSHCN (Centers for Disease Control and Prevention, 2011a). This survey consisted of multiple questions that referred to age at diagnosis and adaptive functioning challenges, as well as demographic information that provided information regarding parental race. Of particular interest were those responses provided by parents of children with an ASD of African American background.

The responses provided by parents on the NS-CSHCN allowed for information to be gathered on the age of diagnosis, severity of symptoms, and adaptive functioning challenges of preschool-aged children with ASD. The specific questions on the NS-CSHCN that related to the research questions of this study, with their respective code, were as follows:(a) “K2Q35D-How old was [S.C.] when a doctor or other health care provider first told you that [he/she] had autism or ASD”; (b) “K2Q35C-Would you describe [his/her] autism or ASD as mild, moderate, or severe” (Centers for Disease Control and Prevention, 2011a, p. 27); and (c) “C3Q03-Do [S.C.]’s (medical, behavioral, or other health conditions/emotional, developmental, or behavioral problems) affect [his/her] ability to do things a great deal, some, or very little”(Centers for Disease Control and Prevention, 2011a, p. 16). I analyzed responses from parents of children with a reported diagnosis of ASD who were of African American background to address the research questions.

Reliability and validity are means by which quantitative data can be assessed for quality, with multiple sources helping to strengthen the results  (Guest, 2013; Teddlie & Tashakkori, 2009).  The NS-CSHCN has been conducted over several years, consisting of initial administration in 2001 and subsequently in 2005-2006 and 2009-2010. Revisions to the survey have taken place, with changes being made to include more variables to assess the health care status, needs, and challenges of children with special needs (CDC, 2011b).  Updates to the 2009-2010 survey relevant to this study included the addition of questions related to whether a doctor had identified a child as having an ASD, as well as severity of ASD.  The psychometric properties for the NS-CSHCN Screener have been researched and determined to be good, with internal reliability being reported at .76 (Carle, Blumberg, & Poblenz, 2011).

## Qualitative Instrumentation

Interviews using structured and open-ended questions are one means of collecting qualitative data (Creswell & Plano Clark, 2011).  The intent of the qualitative component of this study was to explore the impact contextual, familial, and individual factors may have on performance and participation.  For the purpose of exploring the above constructs, the following interview-based SCOPE assessment was chosen.  SCOPE contains questions that seek parental input regarding factors that support or hinder their child’s participation and performance capacities.

SCOPE is an assessment that was developed based on MOHO for the pediatric population (Bowyer et al., 2007; Kramer et al., 2009).  It consists of multiple questions that help to gather information about factors that may impact participation in daily occupations.  There are different formats of SCOPE, soliciting various types of information from observation, checklists, and interviews. For the purpose of this study, the Parent Report Form and Parent Interview Extended Format of SCOPE was used with permission, as parents could provide information on their child's strengths and challenges, as well as expound on their perceived reasons for their child's participation and performance challenges.

The Parent Report Form and Parent Interview Extended Format are designed to solicit information on a child's adaptive functioning abilities based on parental report. The Parent Report Form is designed to aid in gathering information regarding what activities and environments are considered as strengths or challenges for a child, as well as asks for specific examples and additional comments. The Parent Interview Extended Format is a comprehensive interview component of SCOPE that allows for parents to expound on answers provided in the Parent Report Form. Additionally, responses provided for these interview questions can allow for a more in-depth understanding of the child's strengths and challenges, as well as the role personal abilities, family, and the environment may play. SCOPE has been demonstrated as a reliable tool to assess participation patterns in children (Bowyer et al., 2007; Kramer et al., 2009).

## Data Collection Procedures

As previously stated, this study used an explanatory sequential design, where quantitative national survey data was first explored and followed by qualitative interviews locally. The study was non-experimental in nature, as data from the NS-CSHCN was used to determine diagnostic disparities and adaptive functioning challenges of preschool-aged children with ASD of African American background with regards to age at diagnosis. In total, 40,242 parents of children with special needs provided information based on this survey, which were sub-categorized based on demographic information related to race and child's age at time of diagnosis. Preliminary review of the data returned 224 valid respondents from parents who met the criteria of interest for this study: having a child with a current diagnosis of ASD and being of African American background. Employing a sequential design, quantitative data was first collected from existing parental responses on the NS-CSHCN as it relates to children of African American descent with an ASD diagnosis. This information was made available to the public following the completion of the study on the website of the CDC, including the data files and codebook (Centers for Disease Control and Prevention, 2011b). Additionally, local interviews with parents of preschool-aged children with ASD of African American background took place for the qualitative component.

This study consisted of two distinct parts: 1) quantitative data analysis of the NS-CSHCN and 2) interview with at least four local parents using components of the NS-CSHCN and SCOPE. Participants in the NS-CSHCN were recruited from the national population, with a total of 40,242 parents of children with special needs providing responses that were made publicly available on the CDC's website and 224 meeting the criteria of interest for this study. The parents for the qualitative interviews were recruited locally from various pediatric therapy clinics and community based therapy service providers. An interview was conducted in the community at a location agreed upon by the parent, which was a private room in a local library. The interview was based on prior existing structured questions, with a few open-ended questions in an effort to reach saturation around the subject matter of the study. Interviews were recorded digitally and stored on a secure online database for later transcription and analysis. Together, the responses on the NS-CSHCN and interviews conducted with locally recruited parents helped to answer the following research questions:

1. How does symptom severity relate to earlier age of diagnosis?
2. How does degree of reported functional challenges relate to earlier diagnosis?
3. How do parents describe adaptive functioning challenges related to performance and participation?

## Quantitative Data Analysis Plan

Quantitative measures utilize the analysis of numerical data to support or dispel a hypothesis (Teddlie & Tashakkori, 2009). For the quantitative component of this research study, analysis of the results from the NS-CSHCN using SPSS® Version 21-Complex Samples consisted of descriptive statistics and regression analysis. The information gleaned from this analysis was used to identify the degree to which symptom severity and adaptive functioning challenges relate with age at diagnosis in preschool-aged children with ASD of African American background. To describe the severity of ASD reported by parents, frequency counts were provided for the categories of mild, moderate, or severe with regards to reported ASD symptom severity. Regression analysis was used to determine the degree to which the variables of severity of ASD and adaptive functioning challenges are related to age at diagnosis. The use of general linear regression allowed for a better understanding of parental responses regarding variables that may have an influential correlation with age at diagnosis to address the research questions of this study regarding delays in diagnosis and adaptive function challenges.

### Qualitative Data Analysis Plan

Responses from parents with preschool-aged children who had an ASD diagnosis were recorded during the interview process and later transcribed. Parents were then asked to verify the transcriptions, as well as the final interpretation of the results, through member checking. Initially, the data was explored to gain an understanding of the responses provided based on possible a priori codes and the development of a codebook. The data was then analyzed for themes and coded using qualitative coding software, NVivo 10, aiding with applying categorical strategies to organize the data from parental responses (Fielding, 2012; Teddlie & Tashakkori, 2009). The results were discussed with reference to the common and divergent themes that emerged, with tables and figures used as needed. In the end, the findings from the interviews were integrated with the results from the quantitative component through triangulation, with the aim being to illustrate influential factors associated with diagnostic disparities and adaptive functioning challenges from the perspective of African American preschool-aged children with ASD.

## Threats to Validity

Threats to validity can generate from confounding factors associated with external and internal validity (Creswell & Plano Clark, 2011; Teddlie & Tashakkori, 2009). With respect to the quantitative component of this study, there may be internal validity concerns associated with factors other than symptom severity and adaptive functioning challenges that may influence delays in ASD diagnosis. Previous researchers have identified factors that may influence delays in diagnosis, socioeconomic status, maternal education level, and access to resources (Carr & Lord, 2013; Horovitz et al., 2011; Mandell et al., 2009). This was accounted for through considering the degree to which diagnostic age is related with symptom severity and functional challenges. Additionally, external validity challenges related to the generalizability of the study are accounted for by using a large national sample, aiding in the generalizability of the quantitative findings. However, it has been noted that African Americans are generally not represented to a strong extent in research (Cuccaro et al., 2007; Sell et al., 2012). Thus, further research has been recommended where minorities are included to a representative degree in samples to aid in generalizability of findings from research studies (Cuccaro et al., 2007; Mandell et al., 2009; Sell et al., 2012; Tek & Landa, 2013).

With minorities, such as African Americans, not comprising a significant degree of participants in samples, it is important to explore approaches that address this issue and identify potential factors that may influence presentation of symptomology, as well as diagnostic disparities (Mandell et al., Sell et al., 2012). As a result, the qualitative component was critical to obtain an in-depth perspective from an individual of African American background regarding the focus of this study. Credibility concerns with regards to the qualitative component of this study were addressed using saturation, member checking, and data triangulation. Saturation was gained by thoroughly performed structured interviewing and open-ended questions to answer the related research question. Additionally, member checking was used to verify the accuracy of the information obtained from the interview and record review following data analysis. Triangulation included the analysis of data from both the quantitative and qualitative components of this study. Together, these strategies were employed to address the potential threats to validity related to the research findings.

## Issues of Trustworthiness

With research, trustworthiness poses an issue that researchers must address to establish the accuracy and credibility of their findings (Creswell & Plano Clark, 2011). When surveys are used in research, it is hoped that participants are truthful with their responses and interviewers record them accurately. To address trustworthiness of the qualitative data, member checking was implemented following data analysis, as study participants were asked to verify the accuracy of my interpretation of their responses. During completion of the NS-CSHCN, interviewees also utilized this approach after asking questions, as well as expounded on questions when posed based on a script (CDC, 2011b). Following analysis of both the quantitative and qualitative data, information was triangulated to help to strengthen the confidence of the results (Creswell & Plano Clark, 2011;Fielding, 2012; Plano Clark & Creswell, 2008).

## Ethical Procedures

Ethical procedures were employed throughout the process of this research study, in accordance with ethical research practices and gaining approval through the Institutional Review Board (IRB). The safety and confidentiality of each participant was maintained through de-identification of information. Data was stored electronically and password protected where possible. Hard copies of data were stored in a locked filed cabinet or box and shredded once electronically uploaded. Upon IRB approval, data was collected following ethical guidelines and in accordance with policies for utilization of the 2009-2010 NS-CSHCN dataset. Recruitment procedures for the qualitative case study component were on a voluntary basis, with consent forms being provided to outline procedures, study requirements, confidentiality concerns, potential risks and benefits of study participation, and other pertinent information. There was no compensation provided for participation in this study and any conflicts of interest were fully disclosed and avoided when possible.

## Summary

In this explanatory sequential study, the diagnostic disparities and adaptive functioning challenges of preschool-aged children with ASD of African American background were explored. Mixed methodology using a quantitative approach followed by qualitative measures were employed to gain an understanding of influential factors related to delays in diagnosis and functional challenges on a national and local scale. The sample for this study consisted of responses from the 2009-2010 NS-CSHCN, as well as interviews with parents of children 6 years of age or younger with ASD of African American background who resided in the southern United States. The aim was to explore how ASD symptom severity and adaptive functioning challenges may be related with later age for ASD diagnosis, as well as expound on these findings through in-person interviews to inform practice and improve opportunities for early intervention services as a result of earlier ASD diagnosis in minority populations.

# Chapter 4: Results

## Introduction

The purpose of this mixed methods study is to explore factors associated with later diagnosis of ASD in preschool-aged children of African American background at a national level, as well as describe adaptive functioning challenges related to performance and participation from a local perspective. This study was conducted to answer the following research questions:

1. How does symptom severity relate to earlier age of diagnosis?
2. How does degree of reported functional challenges relate to earlier diagnosis?
3. How do parents describe adaptive functioning challenges related to performance and participation?

These questions were answered from a quantitative perspective with the use of descriptive and correlational statistics and with qualitative interview results being analyzed for themes and coded. Included in this chapter is a description of the participants, including the setting and demographics. Additionally, details about the data collection process, data analysis, results, and comments regarding trustworthiness of the data are presented.

## Setting

The setting for this study consisted of two components, one national through the use of a public data set and one local in a southern state. The quantitative component of the study consisted of the participants who previously completed the 2009-2010 NS-CSHCN, which was representative of parents from all 50 states and the District of

Columbia who identified as the parent of a child with special healthcare needs. Chosen specifically for the quantitative component of this study were a sub-population of respondents who were parents of children with ASD and of African American background. Additionally, parents were recruited from a southern state to be interviewed for the qualitative component of the study. Although the local sample was small, the data set used for the quantitative component was representative of the national population.

For the qualitative component, local families from a southern state in the United States were recruited to participate in face-to-face interviews. With previous researchers pointing out the difficulty in recruitment of African Americans and having them represented in research (Carr & Lord, 2013; Gourdine & Algood, 2014; Sell et al., 2012), community-based partners who indicated they were providing services to children of African American descent 6 years of age or younger who had a current diagnosis of ASD were asked to assist with local study recruitment. The local and national setting together allowed for a population that is representative of a national sample and also provided for personal accounts on a smaller level from parents residing in a southern state.

## Demographics

The demographics of the participants recruited for this study included adults who identified themselves as having a child of African American background with ASD. As the coding book for the NS-CSHCN required that the data across states for a specific population only be analyzed using sub-population to maintain the integrity of the random sampling, the results consisted of 102 respondents who met my inclusion criteria. The mean age for diagnosis of ASD was 6, which represented a delay in comparison to reports from previous studies related to diagnostic disparities in ASD (Ennis-Cole et al., 2013; Mandell et al., 2009; Valicenti-McDermott et al., 2012). In keeping the sampling process of the initial data set of 40,242, a representative sample of parents of children of African American descent with ASD under the age of 6 were included.

The qualitative study participants were all mothers of children of African American background with a diagnosis of ASD; those with children currently attending a preschool program were recruited for the study. Challenges with recruiting parents whose child was under the age of 6 were encountered, which was consistent with the findings of previous researchers who have identified that children from minority backgrounds often received an ASD diagnosis at a later age (Ennis-Cole et al, 2013; Mandell et al., 2009; Valicenti-McDermott et al., 2012). Initially, the number of participants recruited included 5 mothers, with 2 of them being unable to complete the study at the time the interviews began. The participants' children were all 5 years of age or younger, with those whose parents completed the study being between the ages of 3 and 5. The mean age for diagnosis of the local sample was 3 years of age ($\bar{x} = 3$; $n = 3$). See Table 1 below for information regarding the biological age and age of ASD diagnosis for the participants' children, with the parents' names being changed for confidentiality.

Table 1

*Qualitative Data: Child's Current Age and Age at Diagnosis*

| Participant | Current age | Age of ASD diagnosis |
|---|---|---|
| QI1 (Ava) | 3 years, 2 months | 2 years old |
| QI2 (Janette) | 3 years, 10 months | 3 years old |
| QI3 (Sharon) | 5 years, 1 month | 4 years old |

*Note*. QI=Qualitative Interview *(N= 3)*

The parents who participated in this study were similar in several ways regarding their background. Two of the mothers emigrated from Africa and the third mother was African American, with all of them relocating to this area. All three mothers were married and had quit their jobs in order to address the needs of their child with ASD. Also, they were all currently attending college to obtain a master's degree. Although similar in background, their stories regarding their child with ASD included some differences, as well as commonalities. Their stories are discussed in the qualitative results section.

## Data Collection

The collection of data was completed in two separate phases, as the quantitative data already existed and the qualitative data required recruitment procedures to obtain participants for interviews who met the study criteria. Data was collected using a sequential approach as follows: QUAN→QUAL (Teddlie & Tashakkori, 2009). Permission to have access to the quantitative data set of the NS-CSHCN was established through the use of a data use agreement. This data was collected through landline or cell phone calls placed from July 2009 through March 2011, which consisted of a national survey of parents who were randomly selected from the 50 United States and the District of Columbia. Interviewers used the NS-CSHCN as a script and data was entered in response to the questions posed to the study participants. This data was made publicly available along with to a codebook for individuals who wanted to use this data for research while maintaining the fidelity of the data for different types of analysis. The national data set was sub-populated using SPSS® Version 21-Complex Samples to identify a random sample of parents who indicated that they had a child under the age of 6 with ASD who was of African American background.

The qualitative data was collected over the periods of March 2015 through May 2015, with 3 out of the 5 parents completing the study. Local therapy service providers to preschool aged children with special needs who were contacted and communicated intent to be a community partner for allowing access to their clients assisted with the recruitment process by making flyers available to their current clients. Those who met the criteria and were interested contacted the researcher, with a time, date, and location being established to conduct the interview at a local library. Participants were interviewed using SCOPE-Parent Interview Extended Format and then asked to complete the SCOPE-Parent report Form. Of the participants in the qualitative component of the study, 3 parents completed the interview and 2 parents completed the Parent Report Form. Two families were unable to complete the study due to one relocating and the other withdrawing from the study. An analysis of the results of the quantitative and qualitative data appears below.

## Data Analysis

Using a mixed methods approach allows for different types of data to be collected to address research questions. Since the types of data were different for the two components of the study, two different approaches were used for the data analysis. It was initially proposed to analyze the quantitative following gathering a sub-population using spearman correlations. However, due to limitations of the various statistical software packages, the analysis method was changed to general linear model, as spearmen correlations could not be used with the subpopulation feature of various software packages.  In accordance with the specifications of the NS-CSHCN codebook, the data was sub-populated using SPSS® Version 21-Complex Samples software package to determine the relationship between age of diagnosis with either severity of symptoms and degree of functional challenges. Age of diagnosis served as the dependent variable, with severity of ASD and degree of functional challenges serving as independent variables. The results of the quantitative data analysis appear in the subsequent section.

The interviews for the qualitative data were recorded and later transcribed, with questions being used from SCOPE Extended Parent Interview to gather information from parents who had a preschool aged child of African American background with a diagnosis of ASD.  Additionally, parents completed SCOPE Parent Report Form, was administered to confirm the areas stated as challenges and weaknesses during the interview.  Two of the three parents interviewed completed this form.  The transcribed text was then analyzed using NVivo 10 to determine themes that emerged in the data in response to the interview questions. Of particular interest were the reported challenges with participation and performance as they related to their child with ASD’s ability to function in different roles, contexts, and capacities in the home and community setting, as well as the supports that the families identified as helpful.  The interviews were coded and emergent themes were identified throughout, which included the following categories:  diagnosis, transitions and routines, communication, and the home, school, and community settings to promote performance and participation. Discussed below are the results of both the quantitative and qualitative data.

# Results

The results of this study are reported below in two separate sections, with one being for the quantitative and then the qualitative results. Quantitative data were analyzed using SPSS Complex Samples Version SPSS® Version 21 following the recommendations for the NC-CSHCN codebook for establishing a sub-population in order to run statistical analysis. General linear model was used to determine the influence of ASD severity and degree of functional challenges reported by parents in relation to age at initial diagnosis for ASD. The qualitative data were analyzed using NVIVO 10, where transcribed results from the qualitative interviews were entered and coded according to emergent themes based on participant responses to questions on the SCOPE Extended Parent Interview. Below are the results for the quantitative and qualitative data.

## Quantitative Data Results

The quantitative data from the NS-CSHCN was analyzed to answer the first two research questions:

1. How does symptom severity relate to earlier age of diagnosis?
2. How does degree of reported functional challenges relate to earlier diagnosis?

Parents interviewed on the NS-CSHCN provided responses to questions asked to gather information on the age at which their child was diagnosed, severity of ASD, and degree of functional challenges. General linear model was used to analyze the quantitative data to determine the relationship between age at diagnosis with respect to symptom severity and degree of functional challenges.  See Figure 1 for the results of parental reports related to symptom severity with regards to their child's ASD diagnosis.

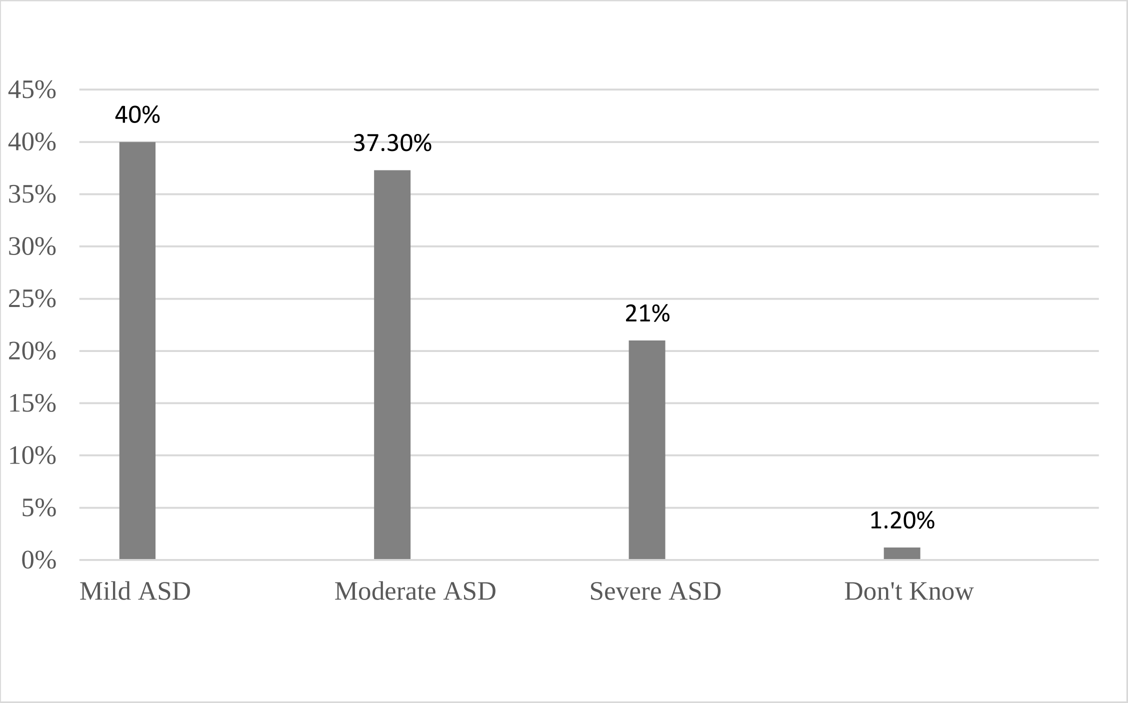

*Figure 1.*Severity level of ASD reported by parents on the NS-CSHCN
Graphic shows that parents indicated their child's severity level to be as follows: Mild-40%, Moderate-37.3%, Severe-21%, and Don't Know-1.2%.

The respondents from the NS-CSHCN indicated their child's ASD severity level along a range of Mild to Severe, with 1.2% indicating that they did not know.  The mean age of diagnosis made by a healthcare provider for children with ASD of African American background was 6 year old ($\bar{x}$= 6.27; n = 102).  The majority of parents indicted that their child had mild (40%) to moderate (37.3%) ASD, with fewer reporting severe (21%) symptoms.  It should be noted that the guidelines for reporting severity of ASD with diagnosis was first included in the DSM-5 (APA, 2013b), making it unclear whether these reports were the subjective understanding of parents regarding their child's ASD severity or what was given by the diagnosing healthcare provider.

In addition to reporting their child's symptom severity, parents were also asked to indicate their child's degree of functional challenges. The question posed to parents was "Do [medical, behavioral, or other health conditions/emotional, developmental, or behavioral problems] affect [his/her] ability to do things a great deal, some, or very little?" All subpopulation respondents provided an answer to this question, with the majority of respondents indicating that their child had challenges doing things as a result of their child's symptoms related to ASD. Below in Figure 2 is a summation of their reported results.

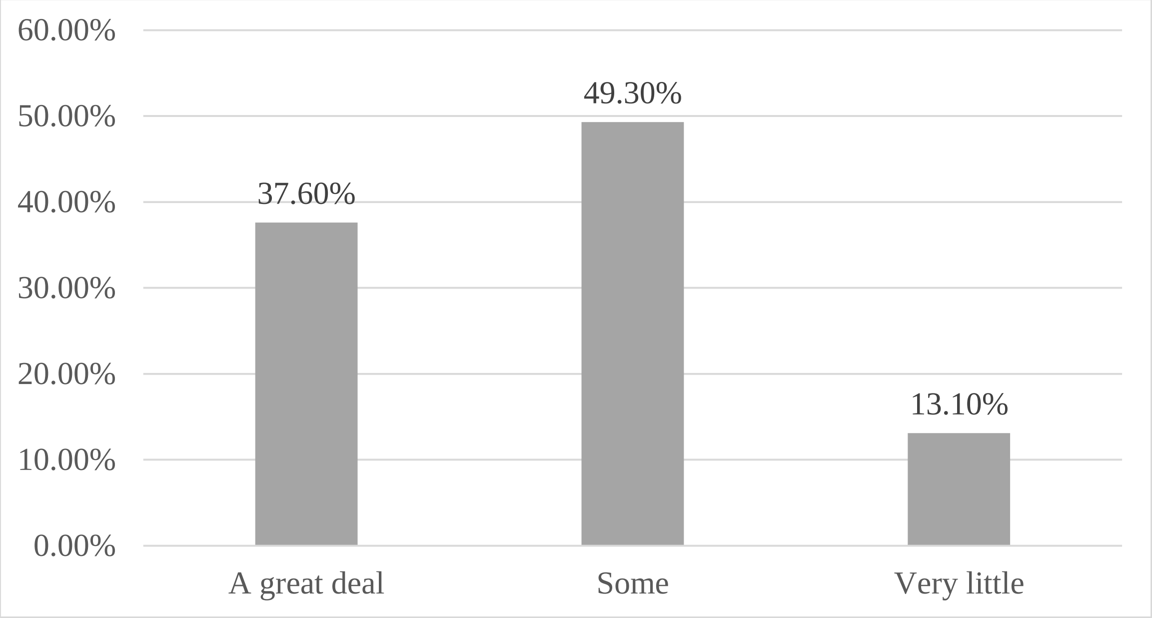

*Figure 2.Degree of functional challenges reported by parents on the NS-CSHCN Graphic shows that parents indicated their child's functional challenges as follows: A great deal: 37.6%; Some: 49.3%; and Very little: 13.1%.*

The degree of functional challenges differed across the respondents, with the majority of parents indicating that their child had some (49.3%) degree of difficulty. A great deal (37.6%) was the second most frequent response, with fewer parents indicating very little (13.1%) challenges. With the new classification approach for ASD in the DSM-5 (APA, 2013b), diagnosing healthcare professionals can specify the degree of support that is needed based on the reported challenges by parents. As this survey was completed prior to the DSM-5 revision, these results may also be based on subjective parental report rather than what was stated by the diagnosing healthcare provider.

To test the hypotheses and examine the influence of ASD symptom severity and degree of functional challenges on age at diagnosis, analysis using general linear model was performed. A subpopulation of respondents who indicated their child's race to be African American was generated from the larger national data set of the NS-CSHCN according to the data codebook. The results of the regression with symptom severity ($p$= .733) and degree of functional challenges ($p$= .866) were not significant. This suggests that age at diagnosis for ASD was not related to having more severe functional challenges or severity of ASD symptomatology. There was no predictable connection evident to indicate an influential relationship, leading to the possibility that other factors may be involved that result in a later diagnosis of ASD for children of African American background. As a result, we do not reject the null hypothesis that age of diagnosis is influenced by symptom severity or degree of functional challenges due to the insignificance of the statistical findings. The results of this analysis using general linear model to determine any significance between symptom severity or degree of functional challenges and age at diagnosis appear in Table 2.

Table 2

*Quantitative Data: General Linear Model Results*

| Independent variable | Wald F | Sig. |
|---|---|---|
| Question 1: ASD Severity | .428 | .733 |
| Question 2: Function | .144 | .866 |

*Note.* $R^2$= .005

## Qualitative Data Results

The qualitative data was transcribed and coded to answer the final research question: How do parents describe adaptive functioning challenges related to performance and participation? Following transcription of the qualitative interviews, data was coded for themes using NVivo 10. The interview questions consisted of those from the SCOPE-Parent Interview Extended Format. Responses from parents centered around providing insight into the adaptive functioning challenges of preschool-aged children from African American backgrounds with ASD, particularly those skills necessary for an individual to function in everyday activities, such as communication, social interaction, self-help, and overall independence with age-appropriate tasks. For confidentiality purposes, the parents' names were changed to Ava, Janette, and Sharon. Below are themes that emerged from their responses related to adaptive functioning challenges around the categories of diagnosis, transitions and routines, communication, and the home, school, and community settings to promote performance and participation.

**Diagnosis Process.** The situations under which the parents interviewed indicated their child was diagnosed shared some similarities, with them all being diagnosed by neurologists. Similarly, all indicated that concerns with communication prompted them to seek out assistance to address their child’s developmental challenges. While Ava and Janette expressed a delay in their child’s speech development, Sharon reported a regression with her son losing skills:

> We realized he was losing his voice because there were so many words that he had and when we say the same words, like when he saw the train tracks, he would usually say "train track." But you say the same words “train tracks,”it’s like he doesn't even know what that is. So compared to the tapes we had before he was say a year to 16 months and to when he was 18 months, there was a huge difference.

As a result of developmental concerns, two parents who participated in this study were referred to a neurologist by their pediatricians once symptoms of ASD were identified, whereas one was receiving therapy and a therapist made the referral to see a neurologist.

Since communication was a key concern for all of them, these parents sought out help and their children were able to get their ASD diagnosis between the ages of 2 and 4. While Ava and Sharon were clear about their child’s diagnosis and what it meant, Janette struggled with whether her child had ASD or some other disorder following the initial diagnosis. Initially, she reported that her pediatrician indicated that her son should be saying more words at that age, but there was not a referral for any follow up. When Janette and her family relocated, their new pediatrician referred them to seek out early intervention services and they had an evaluation completed at that time. However, the early intervention staff indicated that they could not make a diagnosis and referred her back to her pediatrician, who then sent them to a neurologist. Ava reported that the neurologist indicated that her child had “a case of Pervasive Developmental Disorder, but in order to get services we have to label it as Autism." She reported that she and her husband saw that he had some of the symptoms, although mild. All parents accepted their child's diagnosis and sought out therapy to address their adaptive functioning concerns.

**Routines and Transitions.** Parents indicated that routines were an integral part of their day, which served to either inhibit or promote performance and participation based on adherence to them. Ava, Janette, and Sharon all indicated that their children had a set routine throughout the week. Keeping to that routine and having some predictability in their schedules helped their children to function. When changes were made to that routine, parents indicated that their children would have meltdowns and tantrums. While Sharon and Janette primarily adhered to their routines to prevent these, Ava took a different approach. Ava reported that her son:

> likes to follow the routine, but [she tries] to break those routines now and then so he understands you can do it either way**…**He likes to follow patterns and routines, but he is adjusting to us not really allowing him to do the same things over and over. He is kind of breaking away from that.

On the contrary, Sharon and Janette chose to adhere to their children's routines as best they could in order to minimize difficulties as a result of changes in routine. Each parent took an approach that worked best for their family dynamic and child's needs.

Similar to routines, response to transitions was an aspect of daily functioning that was of concern for each parent. Times of transition were reported to be a challenge for all parents, resulting in tantrums when they occurred. Each parent approached transitions in a way that helped to prepare their child for upcoming transitions in anticipation of the challenge encountered as a result of change. Sharon indicated:

> If it's something very new, it's going to be a challenge. Of course again, if it's routine, he knows, he just knows. He has his time clock in his brain. But if it's new, you prepare him. So, I give him time. If I ever go and demand he does it immediately, we are going to meet a great war. So prepare him.

Likewise, Ava indicated transitions were frustrating for her son and that she used distractions, such as a toy, and continued to prompt him along when encountering tantrums during transitions. Over time, Janette expressed that she has seen improvements in this area, but still prepared her son when possible for upcoming transitions. Transitions were a noted difficulty for all of these parents and each prepared their child in advance to promote participation.

**Communication.** With communication being one of the key concerns that prompted parents to seek assistance for their child, each of these parents expressed that this area was one of the most difficult aspects limiting their child’s participation and performance. Themes that emerged around their responses highlighted the negative impact their child’s communication challenges had on expressing their feelings and needs, as well as with relationships with family members and peers. All of the children had a few words and would use them to make basic requests, but they resorted to tantrums when the ability or vocabulary was not there to make their requests or feelings known. Common strategies used by all parents were to anticipate their child’s needs or make a variety of choices available to select or point to; otherwise, the child would go and get what it was that they needed if it was accessible.

With regards to relationships, challenges with communication were said to limit interactions with family members and peers, as well as be associated with negative experiences. Ava and Sharon had other children and their sons were able to play to some degree with their older siblings. Sharon indicated that it was easier for her son to play with her other children rather than peers, as his siblings would make attempts to engage in rough house play or simple games with him and were aware of his challenges. She shared that peer interactions were more difficult due to communication challenges, turn taking, and following the rules of games, with her son’s play skills just beginning to emerge in this area. Sharon said:

> I would say that he's at the teaching stage. Prior to that he was not able to do that. Yeah he's able to take turns now. But because he's not verbal, he doesn't understand a lot of children’s games, like the tag game. He doesn't understand that if you’re tagged then you get to chase the other person. He just wants to be chased all the time. So most times, you see children get fed up.They figure he's not playing by the rules so they find other friends. So he doesn't quite get that when you are tagged you need to chase the other person or something like that.

Although Sharon’s son had awareness of other peers and was interested in interacting with them, difficulties with communication and other areas of adaptive function limited his performance and participation.

Similar to Sharon’s experience, Ava expressed that her son had siblings to interact with, but her son would wait, although with frustration, for a toy to become available to play with rather than engage in parallel or cooperative play with his siblings. She stated, “He plays his part; he doesn't have much words to express himself.” On the other hand, Janette's son was an only child and did not have siblings to routinely interact with. Additionally, she expressed that she did not have much family in the area and it was difficult to make friends with other children due to her son's communication challenges. As a result, communication skills were a primary challenge identified as limiting participation and performance for their children in relationships.

**Family and Home Environment.** As a result of the individual difficulties that their children faced in association with their ASD diagnosis, each of the parents interviewed indicated that they faced challenges that impacted their family and home environment. All of the parents were married and made the decision at some point to stop working in order to meet the needs of their children and families while their husbands continued to work. Ava shared:

> Before, we didn't understand his needs. So I'm working, his father is working; we were rarely home. Around that time, we realized that I would have to be there to help support; he needs things. So we have made a lot of changes at home to make it safe and to improve things.

Sharon expressed that it was difficult for her to work and manage the various schedules of her children, especially with the additional therapies that her son with ASD received on a weekly basis. As all parents were also enrolled in college, they relied on the support of their spouses, extended family, and friends while they furthered their education and met the various needs of their family. Based on their responses, meeting their families' needs in addition to the unique needs of their children with ASD, such as attending therapies, was a challenge and required some adjustments to their roles and routines.

The physical environments of their homes were expressed as being important to support and not hinder their child's performance. Janette had recently relocated to the area and was living in an apartment with her family. She shared that she had made the inside of her home as safe as possible to prevent her son from eating things he should not and promoting his independence, such as having open access to the bathroom when he needed to use the potty and making preferred toys readily available. Additionally, she provided visual supports throughout the house to facilitate communication through the use of pictures. Similarly, Sharon and Ava placed pictures in central locations, such as on the refrigerator and in their child's bedroom, to help with making requests and communicating needs. Janette also used a visual schedule to help facilitate transitions in the home, allowing for a visual representation of their routine as a reference. As communication and transitions were some of the largest concerns for all families, providing an environment where their child could have access to preferred items, communicate, and be safe were of importance.

In order to improve the safety of their environment and to support their child's performance and participation, two of the parents, Ava and Sharon, had moved to different homes. Ava discussed how she was initially fearful in her first rental home due to the lake that was in the backyard and her son frequently escaping from the house. When her family decided to purchase a home, they had to take this, as well as their son's challenges with certain textures, into consideration. She described it as follows:

> So when we were buying a house, we realized that he likes to run out. When we open the door, he wants to run out to see whatever we are trying to shield him from. We decided to get a house with no water in the backyard. So once we

> opened the door the first time we got to the new house, he wanted to run out until he saw the grass; the grass was kind of hindering him. But after a few therapies to address textures, he is not afraid of the grass anymore; he can just walk out and go walking without sandals. For him, it's like a free world for him now.

Ava sought out a home that would allow her child to run around outside and be safe and had the resources available to purchase a home in a cul-de-sac that met her family’s needs, stating that it has “created a big improvement.”

Like Ava, Sharon sought to make their new home safe for their son to explore and meet his overall needs. She expressed the importance of having an area where he could run around, both indoors and outdoors. Another priority for her was to have a designated room where her son could have all of his toys and learning materials, as she was a Montessori teacher. Overall, she felt that her home was a “physically safe space.” Each family took their child’s need to perform and participate in their daily activities into consideration and made the necessary adjustments, given their respective resources, to provide a safe environment that would promote their children’s performance and participation.

**School and Community Environments: Challenges and Supports.** Whereas parents had more control over their home environments, they each expressed some overall strengths and concerns with the school and community environments. All of their children were attending a special needs preschool programs within their county, as well as receiving additional therapy services after school. They each expressed how the school was a benefit to their children, as well as a great support to them by providing various resources. Janette’s son attended a preschool program specifically for children with ASD, which she felt was of great benefit:

> The autism preschool has a lot of stuff going on for families. They give a lot of resources to us and they send it home in his folder. So they are helpful in that area [and] doing a great job keeping the kids active and having things for families to participate in.

Similarly, Ava expressed appreciation for the collaboration she felt with her son’s school, as she felt he had an individualized plan to address his needs:

> At school, actually they did an evaluation based on his needs, and they drew a program directly to support his needs. We have a 3 months plan that we set up goals and then we work towards achieving those goals. So every 3 months I go to the school. We plan whatever it is they will be doing and they work towards that. So when I go for the evaluation, we would see which ones he has mastered or perfected and which ones he hasn’t. So we keep on setting goals and reaching the goals as we go.

All of the parents commented that their children’s school helped to support their communication challenges outside of the school setting by providing visuals that were used in the classroom to also be used at home. In this respect, the school served as a good resource to address one of their key areas of concerns.

Although their children’s schools were touted as a great resource, these parents also identified some of the shortcomings. Janette expressed that the teachers often used terms that she did not understand when talking about supports and strategies. She stated, “there are a lot of terms that I am not familiar with that [his teacher] says to me on a daily basis. And I tell her, look, I don't know what you are saying and you have to break it down to me." Sharon expressed mixed feelings towards her son's classroom, as she found they were helpful in some respects, but not others. She said:

> The intensive class that he is at, they have very few students. So I would say there isn't much of an expectation when you have very few students. He used to be the only one for a long time [and now] there are 3 or maybe 4. But then I hear they take him to another class, a bigger class, so that he can have more social relations.

Ava, for the most part, felt her son's school was very supportive, outside of minor incidents where he had some difficulties with changes in teachers and routines that she was not previously notified about. Overall, these parents found their children's schools to be of benefit to their child's development.

The community was also discussed during the interviews, with these parents expressing some of the strengths and weaknesses in the community. They shared that the neighborhood playground and libraries had various opportunities for their child and family to take part in. All of these parents visited their neighborhood playgrounds, with some having more favorable experiences than others. Ava particularly appreciated that she lived in a diverse neighborhood with people from various backgrounds.She stated:

> I think that he is learning that the other kids are different from him because our neighbors are mainly white and the others speak spanish. So he is learning that they are not like him, but he can still play with them.

Ava and Sharon found the playgrounds to be a good outlet for their child to explore, get some exercise, and attempt to interact with peers. However, Janette found it to be more of a challenge due to safety concerns. She indicated, "we live in an apartment complex, so they have a playground there, but I don't like it because he keeps picking up stuff and putting it in his mouth, [including] the sand. However, Janette found that the programs offered through the local university had a bit more to offer than what was directly in her neighborhood, although minimal.

Outside of their local neighborhoods and into the larger community, each parent idenified some of their challenges. Janette stated:

> I don't think for the most part that this area has a lot going on for children on the spectrum. I think the university is doing a great job keeping the kids active and having things for families to participate in. But I don't know if we are like other states; they got it going on with stuff.

Sharon expressed that she had challenges with visiting stores, as her son had sensitivities to loud noises. In the car, they would not turn on music as a result, but she had less control over this when visiting stores.

> With the community, it is not their fault that they have to play music when I go in the store. He finds that a problem. What can I do? Tell them to put off the music? So I just tell him, listen, it's okay. They'll play music and then we will be done and leave. Music is a problem in stores and in public.

Ava shared that her biggest challenge was her son's fear of animals, as well as new places and experiences. Although there were some weaknesses and strengths identified, each of the families sought out opportunities to promote their children's performance and participate in the community.

The qualitative participants shared their personal accounts of the performance and participation challenges of their children with ASD. The emergent themes from their responses were grouped around the following categories: diagnosis process, routines and transitions, communication, family and home environment, and school and community environments.  Together, the perspectives shared can provide some initial insight into the diagnostic process, current challenges, and supports that have helped in addressing the challenges that parents of preschool-aged children with ASD from minority backgrounds face in their home, school, and community environments.

## Evidence of Trustworthiness

To address issues of trustworthiness, member checking and triangulation were implemented following data collection.  With the quantitative data, interviewees for the NS-CSHCN used member checking when confirming answers and asking participants to expound on answers that were provided to questions (CDC, 2011b).  During the qualitative interviews, participants were asked to clarify responses and allowed to ask questions if they did not understand the questions posed during the interview. Additionally, parents completed SCOPE Parent Report Form, which was used to confirm the areas stated as challenges and weaknesses during the interview; two of the three parents interviewed completed this form.  Following completion of the qualitative interviews, families were contacted by phone to review their responses, with opportunities to confirm what was conveyed.  Triangulation occurred after analysis of both the quantitative and qualitative data to add more insight into the age at diagnosis and factors that may impact adaptive functioning for individuals with ASD of African American background.  As the quantitative data was from a national data set that was previously collected and the null hypothesis was accepted, the qualitative data was used to add some insight into the functional challenges that led to early diagnosis and the functional challenges families reported (Creswell & Plano Clark, 2011; Plano Clark & Creswell, 2008).

## Summary

The purpose of this mixed methods study was to answer the following research questions:

1. How does symptom severity relate to earlier age of diagnosis?
2. How does degree of reported functional challenges relate to earlier diagnosis?
3. How do parents describe adaptive functioning challenges related to performance and participation?

Based on the analysis of the quantitative data using a general linear model, no evidence was found to support that severity level of ASD or degree of functional challenges were a predictor of earlier age at diagnosis. A weak level of significance was found for both reported ASD severity level (*p*= .733) and the degree to which their child's ASD influenced functional performance (*p*= .866). As a result, the null hypothesis was accepted for both of the quantitative research questions.

To address the qualitative research question regarding the adaptive functioning challenges reported by families, coding of the qualitative interviews allowed for descriptions of their personal accounts around particular themes. Their responses were presented with respect to challenges and supports around the following themes that emerged: diagnosis process, routines and transitions, communication, family and home environment, and school and community environments. Discussed in the next chapter is an interpretation of the findings and limitations of the study. Additionally, recommendations for future research and implications to practice and promoting social change are included.

# Chapter 5: Discussion, Conclusion, and Recommendations

## Introduction

As the purpose of this study was to explore factors associated with later diagnosis of ASD in preschool-aged children of African American background, mixed methodology was used to gather information from both a national and local perspective. The quantitative component consisted of analysis of a national dataset from the 2009-2010 NS-CSHCN to answer the following research questions:

1. How does symptom severity relate to age of diagnosis?
2. How does degree of reported functional challenges relate to age of diagnosis?

Using interviews from local parents who identified themselves as having a preschool-aged child of African American background with a diagnosis of ASD, the component consisted of measures to answer the final research question:

3. How do parents describe adaptive functioning challenges related to performance and participation?

Following analysis and coding of the data, there was not found to be any significant relationship with the first two research questions, with the final research question allowing for an opportunity to gain some insight into the adaptive functioning challenges reported by parents of preschool-aged children with ASD from African American backgrounds.

As noted previously, the findings from the quantitative study were not significant, with convergent and divergent responses being reported by respondents in the qualitative component of the study. The results from the quantitative component of the study resulted in the null hypothesis being retained, as there was no significant relationship found between ASD symptom severity or degree of functional challenge with respect to earlier age of diagnosis. The following themes emerged based on results from SCOPE-Parent Interview Extended Format: *diagnosis process, routines and transitions, communication*, *family and home environment*, and *school and community environments*. Although the quantitative findings were insignificant, parents communicated their personal accounts of adaptive functioning challenges and identified helpful supports through their responses to the interview questions.

## Interpretation of Findings

Proposed in both ICF (WHO, 2002) and MOHO (Kielhofner, 2008) are various factors to be considered that may impact an individual's adaptive functioning. Defined in ICF are personal and environmental contributors that may influence an individual's ability to function and participate. Similarly, volition, habituation, individual performance capacities, and contextual factors are noted to be contributors that may influence adaptive functioning, according to MOHO. In answering the quantitative research questions, age at diagnosis was not found to be related to the factors proposed in the hypotheses, such as ASD symptom severity or degree of functional challenges as reported by parents. On the contrary, the responses provided by parents during the qualitative interviews indicated various personal and environmental factors that led these parents to seek out a diagnosis for their children's developmental concerns, with communication challenges being at the center of their concerns. Together, the theoretical frameworks of ICF and MOHO helped to gain a better understanding in order to conceptualize the challenges reported by parents to obtain a diagnosis of ASD at an early age.

## Age at Diagnosis

Although symptom severity or degree of functional challenges were not found to be factors that related to an earlier age of diagnosis based on results from the quantitative component of the study, the parents of the preschool-aged children from African American backgrounds interviewed for qualitative component of this study were able to obtain an early diagnosis of ASD for their children. These parents reported that their children were diagnosed between ages of 2 and 4, having been referred to a neurologist as a result of concerns primarily related to poor communication skills. This was younger than the average age found in previous studies or from analysis of the quantitative data, which was 6 years old (Ennis-Cole et al., 2013; Gourdine et al., 2011; Mandell et al., 2009; Mandell et al., 2010; Valicenti-McDermott, et al., 2012).

In a recent study where the mean age of diagnosis was analyzed based on results of the 2009-2010 NS-CSHCN, Jo et al. (2015) found a continued tendency of children from non-Hispanic Black and Hispanic backgrounds who were reported to have mild to moderate ASD to have been diagnosed at a later age. However, they also found that children with more severe symptomatology, such as language regression, received their ASD diagnoses closer to 2 to 3 years of age. Regression in language skills was reported by one of the parents interviewed for the qualitative study, with her son receiving his ASD diagnosis at the age of 3. This trend towards an earlier age of diagnosis has been also confirmed by other recent studies using national surveys that compared means for age of diagnosis based on race (Daniels and Mandell, 2014;Emerson, Morrell, & Neece, 2015).

## Factors Related to Later Age at Diagnosis

There have been various contributory factors to later age of diagnosis reported in minority populations. Among these have been socioeconomic status, maternal education, and access to healthcare (Daniels & Mandell, 2014; Ennis-Cole et al., 2013; Jo et al., 2015). Although not addressed in the quantitative study, the parents interviewed for the qualitative study were all of higher socioeconomic status, were completing first or second higher education degrees, had private insurance, and were able to access healthcare and local specialty providers to receive therapy. All were able to seek out a diagnosis from a neurologist based on referrals from their therapy service providers or local early intervention programs. These families included in the qualitative component of the study had similar socioeconomic statuses to parents who participated in previous research studies that were said to have an increased likelihood of obtaining an earlier diagnosis of ASD for their children (Daniels & Mandell, 2014; Mandell et al., 2010; Matson, Beighley, & Turygin, 2012; Valicenti-McDermott et al., 2012). Their children received their ASD diagnoses between the ages of 2 and 4.

Whereas socioeconomic status, maternal education, and access to healthcare have been the primary factors investigated by researchers, culture has also been identified as a factor but with little research occurring in this area (Burkett et al., 2015; Ennis-Cole et al, 2013; Gourdine et al, 2011; Grinker et al., 2011). In a recent study on the influence of culture on ASD diagnosis and treatment, Burkett et al (2015), found that multiple cultural elements influenced diagnostic disparities. Based on qualitative findings of interviews with families, they identified community awareness of ASD and a lack of acceptance of the diagnosis as contributory factors to later diagnosis of ASD in children from African

American backgrounds. Additionally, they found that some parents indicated a lack of trust with regards to healthcare providers, as well as a level of disrespect for their concerns or child-rearing practices. Similarly, Gourdine et al. (2011) found that families from African American backgrounds may feel intimidated by healthcare professionals as a result of interpersonal relations, varying viewpoints, and professional jargon. Parents interviewed in this study were proactive and persistent in their approaches to obtain a diagnosis for their child, even when the process resulted in seeing multiple professionals to finally receive that diagnosis.

## Adaptive Functioning Challenges

The symptomatology of ASD has not been found to differ across races, although subtle difference in presentation may be evident (Horovitz et al., 2011; Jang et al., 2013; Mayes & Calhoun, 2011, Tek & Landa, 2013). Parental reports of adaptive functioning challenges for their children with ASD of African American background based on the qualitative interviews were consistent with those described in the literature, with challenges in communication being the hallmark indicator for their developmental concerns (Cuccaro et al., 2007; Horovitz et al., 2011; Jang et al., 2013; Mandell et al., 2009; Mayes & Calhoun, 2011; Tek & Landa, 2013). Although it would appear that these families had an easier time at obtaining a diagnosis for their children, one of the parents indicated that she had been to several professionals before finally receiving an ASD diagnosis for her son. She indicated that her child’s pediatrician made the initial referral and she then followed up with his recommendations. However, she was referred to her local early intervention program and then on to a neurologist. As her son’s symptoms were considered mild, she reported that a formal diagnosis of ASD was only made so she could obtain services.

Similarly, Jarquin, Wiggins, Schieve, and Van Naarden-Braun (2011) found that Non-Hispanic Black children were often identified when their symptoms were more severe. In their study, school systems rather than healthcare providers primarily made the diagnosis, which was noted to occur after being diagnosed with an intellectual disability. The trajectory for those families whose children may present with subtler or slight variances in symptoms can result in misdiagnosis or go overlooked, resulting in delays in diagnosis (Burkett et al., 2015; Tek & Landa, 2013; Daniels and Mandell, 2014). Commonly reported by all of the participants in the qualitative component of the study were challenges with communication. Children with milder symptoms of ASD have often been under-diagnosed in minority populations, which does not help to promote follow-up with recommendations for further assessments (Daniels and Mandell, 2014; Gourdine et al., 2011; Herlihy et al., 2014).

## Limitations

As with research using small qualitative samples and post analysis of previous data, there are some limitations to note with this study. Convenience sampling was used for the qualitative component of the study, resulting in the sample participants not being representative of the larger population of parents and children with ASD. With the qualitative study, there were only three parents that interviewed, although the initial goal was for five. Five parents were recruited, but two parents of girls with ASD were not able to complete the study. Having a small sample that consisted of parents of boys limits the transferability of these findings to the larger population across gender.

Additionally, the quantitative component of the study also did not include responses from many respondents who indicated that they were of African American background. This has been an identified concern of researchers in previous studies, as minorities are seldom represented in a large number in research studies (Carr & Lord, 2013; Cuccaro et al., 2007; Gourdine & Algood, 2014; Sell et al., 2012). Surveys were also the means for data collection and conducted over the phone, which may have presented with some limits to the quantity and backgrounds of those participants who responded. These limitations should be considered when interpreting the results of this mixed methods study.

## Recommendations

Diagnostic disparities in ASD, although recently reported to be improving, continue to persist in minority populations (Burkett et al., 2015; Daniels and Mandell, 2014; Gourdine et al., 2011; Herlihy et al., 2014; Jo et al., 2015). The aim of this mixed methods study was to identify possible causes for later ages at diagnosis for children from African American backgrounds, as well as some of the adaptive functioning challenges reported by parents. Based on the findings of the quantitative and qualitative results of this study, future areas for research can be proposed. Below are recommendations for further research based on the findings of this mixed methods study and within the context of the current literature.

Recent advances in identification of early risk factors prior to 12 months of age, such as poor motor control and increased head circumference, are promoting early detection of children who may be at risk for ASD (Flanagan, et al., 2012; Samango-Sprouse et al., 2015). Recently, researchers have been finding a trend where ASD is diagnosed earlier across races, although inconsistently reported (Burkett et al., 2015; Daniels and Mandell, 2014; Ho et al., 2015). The reason for this inconsistency has not been clearly identified and early diagnosis continues to be critical to early intervention for improved outcomes (Berger, Rohn, & Oxford, 2013; Boyd et al., 2010; Mandell et al., 2010; Jarquin et al., 2011; Valicenti-McDermott et al., 2012). Further studies should consider the role race and culture may play in later diagnosis of ASD in minority populations to address such disparities.

As found in this study and previous research, those children presenting with mild or more subtle signs of ASD often go undiagnosed (Daniels and Mandell, 2014; Jarquin et al., 2011). Additionally, even when identified early through screenings, families from minority backgrounds may not follow up with recommendations to seek further information beyond the initial screening process (Khowaja, Hazzard, & Robbins, 2015). Various factors may be associated with this lack of follow-up by families, including feelings of mistrust of healthcare providers or fear of the social stigma associated with a diagnosis of ASD. Burkett et al., 2015; Ennis-Cole et al, 2013; Gourdine et al, 2011; Grinker et al., 2011). One parent in this study shared how her initial concerns for her child’s development were dismissed or the severity of them not recognized by her healthcare provider. Research to further investigate the role interpersonal relationships may have between families and their healthcare providers, as well as perceptions associated with a diagnosis of ASD in minority communities, may be beneficial to address challenges with follow-up regarding diagnostic disparities related to ASD in minority populations.

Challenges and supports related to adaptive functioning within the home, school, and community were identified by parents of preschool-aged children with ASD from African American backgrounds in this study. As the sample size was small, the results of this study are difficult to generalize, but do allow for some preliminary insight into their experiences. The various challenges reported by children with ASD have been studied and reported, with subtle differences with the presentation of ASD symptoms and the diagnostic process for individuals with minorities being noted (Gourdine, Baffour, & Teasley, 2011; Mandell et al., 2009; Paul et al., 2011; Tek & Landa, 2013; Ventola et al., 2014). However, previous researchers have identified that minorities are seldom included to a large degree in research studies, with these subtleties not being further explored (Cuccaro et al., 2007; Sell et al., 2012). Future studies are recommended where the adaptive functioning challenges in the home, school, and community environments of minority populations from a qualitative perspective on a larger scale are explored. Together, these recommendations for further investigation into the cultural and interpersonal factors related to diagnostic delays, as well as the possible adaptive functioning challenges unique to minority populations, are warranted and can have implications for earlier diagnosis and the opportunity to seek early intervention services for improved functional outcomes.

## Implications

The results of this study in conjunction with the latest research around diagnostic disparities in minority populations present various implications for positive social change. Although the results of the quantitative component of the study did not indicate significant relationships with symptom severity or degree of adaptive functioning challenges, these results can be understood as demonstrating the need for further research into this area to address the delays in diagnosis of ASD in minority populations. Socioeconomic, maternal education, and access to care have all been explored, but studies to investigate how cultural and interpersonal aspects may influence these delays are lacking.

Additionally, there have been various efforts targeted at the community to increase awareness of ASD. Recently, there has been a trend noticed by some researchers towards earlier diagnosis of ASD in various races and ethnicities. However, the reported social stigma felt by minorities, difficulty with relating to healthcare providers and having their concerns heard, and challenges noted with accessing services should be taken seriously. The development and implementation of these public initiatives to promote awareness of ASD should be constructed with potential cultural factors in mind, as minorities have been identified as having poor follow-up following initial screenings for ASD to seek out confirmatory diagnosis and early intervention services.

To increase the reach of awareness campaigns, it is critical for community initiatives to target those populations who may not be inclined or able to access information through traditional means, such as pamphlets or educational handouts. Interpersonal efforts should be aimed at partnering with local agencies, churches, preschools, and other organizations that are directly connected to members of the community. The participants in the qualitative component of this study had higher educational backgrounds and socioeconomic statuses, which is not representative of the general minority population. Caregivers who may be of lower socioeconomic status or educational backgrounds may need more support for accessing and applying information aimed at increasing knowledge of ASD symptoms and other developmental milestones. Awareness initiatives need to have an outreach campaign to facilitate the dissemination of information to minority populations that are sensitive to their racial, cultural, socioeconomic, and educational backgrounds, as well as relevant and accessible to such populations. This also applies to recruitment efforts for including minorities as a representative sample in research studies, with such factors being taken into consideration with methodological approaches for research study designs.

As early intervention is critical for improved outcomes, diagnostic delays in any population can have significant negative consequences for those who miss out on the critical window to benefit from early intervention services. Healthcare providers and parents alike can strive to identify subtle and more significant symptoms of ASD in the early stages of life. As often recommended by their various professional associations and community health boards, healthcare and educational providers should be diligent in adhering to and promoting routine screening of children during those critical early years and beyond for early signs of ASD. Diagnosis in a timely manner is instrumental in allowing families to seek out early intervention services, which would provide them with the resources and programs to address their child’s adaptive functioning challenges. However, some families may live in an area where there are not enough programs offered and providers available in an area, which was identified by one of the participants in the qualitative component of this study.

To address the potential for a lack of resources and services, communities and service providers should aim to work collaboratively together to orchestrate programs that are inclusive in nature and can benefit children of all abilities, regardless of whether they have a formal diagnosis or not. The U.S. Department of Health and Human Services and U.S. Department of Education (2015) released a policy statement for increasing inclusive opportunities beginning in infancy and preschool programs for children with disabilities in high-quality educational programs. Inclusion is an important component to foster social change in all facets of society, as families can feel supported not only within formal school and clinical service programs, but in the larger community as a whole. The ideal situation would be to promote awareness, acceptance, and quality diagnostic and intervention services for individuals with ASD, as well as other diagnoses. Such efforts should be aimed at reducing the social stigma that may be attached and creating a supportive society that embraces differences and helps to promote the adaptive functioning abilities of all children.

## Conclusion

The purpose of this mixed methods study was to explore factors related to the diagnostic disparities and adaptive functioning challenges of preschool-aged children of African American background with ASD. The results of the quantitative component were insignificant with respect to symptom severity and degree of functional challenges as a possible factor for delays in diagnosis. Of benefit were the responses from the qualitative interviews, as parents were able to obtain their diagnosis between the ages of 2 and 4 years old for their child and share their current challenges and supports. Early diagnosis of ASD is critical, as the importance of early intervention services for improved functional outcomes has been recognized. Further research and initiatives to address delays in diagnosis and access to early intervention service in a timely manner is needed.

Additionally, larger representation of minorities is needed in research studies, including qualitative studies with larger sample sizes. In order to promote positive social change, cultural factors specific to minority populations, as well as the subgroups inherent within, need to be considered in order to develop programs and services that are effective at meeting societal needs.

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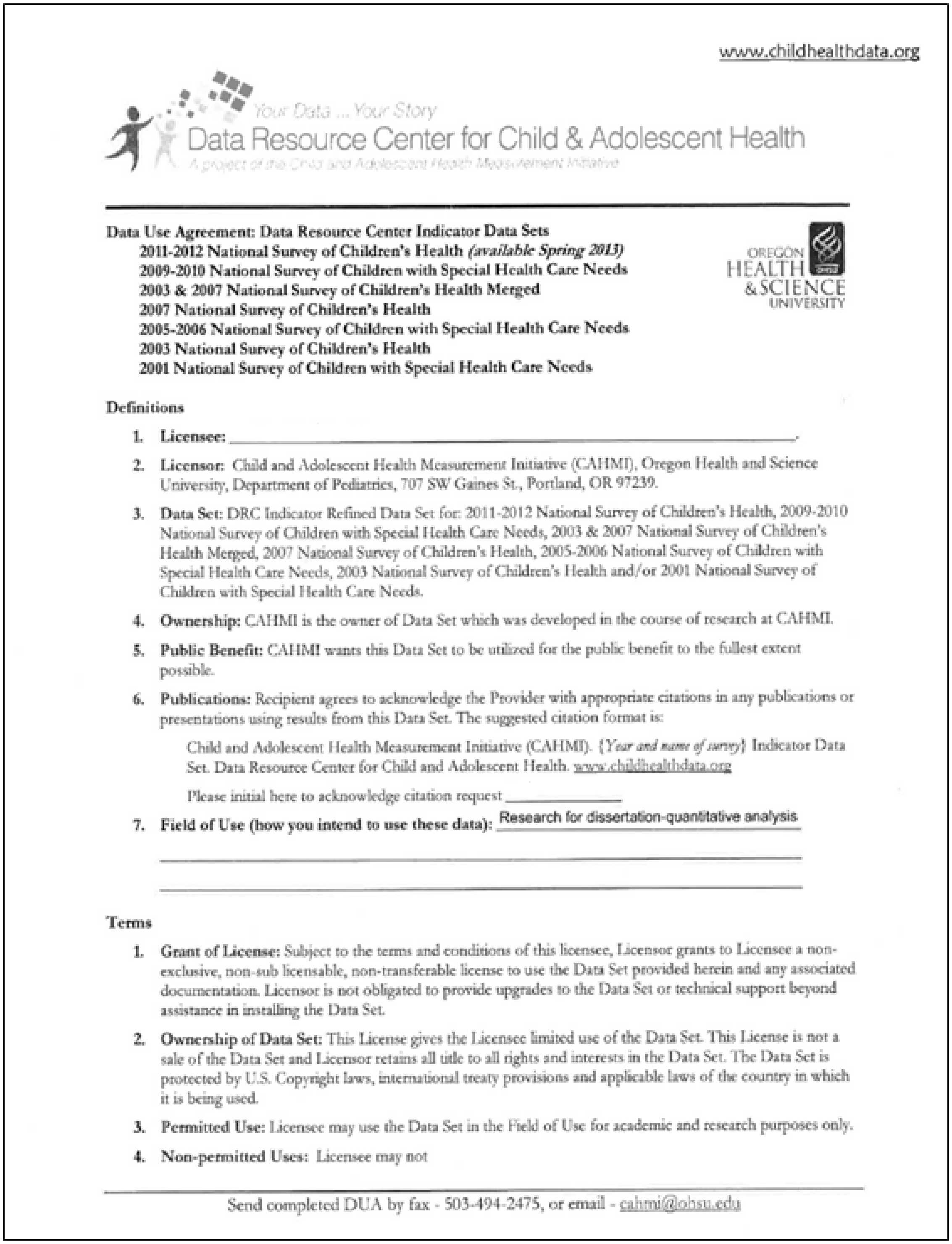
# Appendix A: Data Use Agreement



www.childhealthdata.org

Your Data ... Your Story
Data Resource Center for Child & Adolescent Health
A project of the Child and Adolescent Health Measurement Initiative

OREGON HEALTH & SCIENCE UNIVERSITY

**Data Use Agreement: Data Resource Center Indicator Data Sets**
**2011-2012 National Survey of Children's Health *(available Spring 2013)***
**2009-2010 National Survey of Children with Special Health Care Needs**
**2003 & 2007 National Survey of Children's Health Merged**
**2007 National Survey of Children's Health**
**2005-2006 National Survey of Children with Special Health Care Needs**
**2003 National Survey of Children's Health**
**2001 National Survey of Children with Special Health Care Needs**

**Definitions**

1. **Licensee:** ________________________________.
2. **Licensor:** Child and Adolescent Health Measurement Initiative (CAHMI), Oregon Health and Science University, Department of Pediatrics, 707 SW Gaines St., Portland, OR 97239.
3. **Data Set:** DRC Indicator Refined Data Set for: 2011-2012 National Survey of Children's Health, 2009-2010 National Survey of Children with Special Health Care Needs, 2003 & 2007 National Survey of Children's Health Merged, 2007 National Survey of Children's Health, 2005-2006 National Survey of Children with Special Health Care Needs, 2003 National Survey of Children's Health and/or 2001 National Survey of Children with Special Health Care Needs.
4. **Ownership:** CAHMI is the owner of Data Set which was developed in the course of research at CAHMI.
5. **Public Benefit:** CAHMI wants this Data Set to be utilized for the public benefit to the fullest extent possible.
6. **Publications:** Recipient agrees to acknowledge the Provider with appropriate citations in any publications or presentations using results from this Data Set. The suggested citation format is:

   Child and Adolescent Health Measurement Initiative (CAHMI). {*Year and name of survey*} Indicator Data Set. Data Resource Center for Child and Adolescent Health. www.childhealthdata.org

   Please initial here to acknowledge citation request ______________
7. **Field of Use (how you intend to use these data):** Research for dissertation-quantitative analysis

**Terms**

1. **Grant of License:** Subject to the terms and conditions of this licensee, Licensor grants to Licensee a non-exclusive, non-sub licensable, non-transferable license to use the Data Set provided herein and any associated documentation. Licensor is not obligated to provide upgrades to the Data Set or technical support beyond assistance in installing the Data Set.
2. **Ownership of Data Set:** This License gives the Licensee limited use of the Data Set. This License is not a sale of the Data Set and Licensor retains all title to all rights and interests in the Data Set. The Data Set is protected by U.S. Copyright laws, international treaty provisions and applicable laws of the country in which it is being used.
3. **Permitted Use:** Licensee may use the Data Set in the Field of Use for academic and research purposes only.
4. **Non-permitted Uses:** Licensee may not

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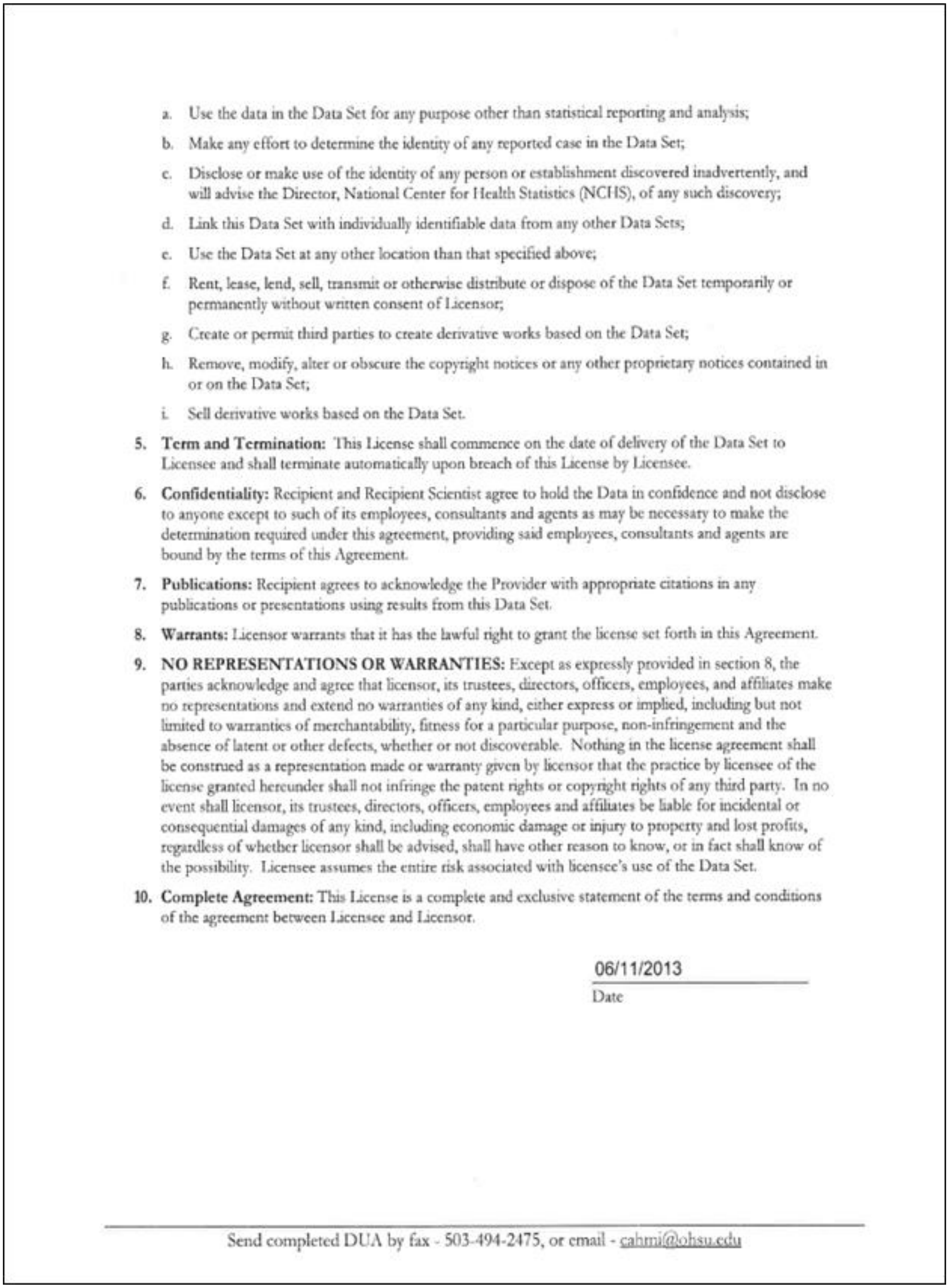


a. Use the data in the Data Set for any purpose other than statistical reporting and analysis;

b. Make any effort to determine the identity of any reported case in the Data Set;

c. Disclose or make use of the identity of any person or establishment discovered inadvertently, and will advise the Director, National Center for Health Statistics (NCHS), of any such discovery;

d. Link this Data Set with individually identifiable data from any other Data Sets;

e. Use the Data Set at any other location than that specified above;

f. Rent, lease, lend, sell, transmit or otherwise distribute or dispose of the Data Set temporarily or permanently without written consent of Licensor;

g. Create or permit third parties to create derivative works based on the Data Set;

h. Remove, modify, alter or obscure the copyright notices or any other proprietary notices contained in or on the Data Set;

i. Sell derivative works based on the Data Set.

5. **Term and Termination:** This License shall commence on the date of delivery of the Data Set to Licensee and shall terminate automatically upon breach of this License by Licensee.

6. **Confidentiality:** Recipient and Recipient Scientist agree to hold the Data in confidence and not disclose to anyone except to such of its employees, consultants and agents as may be necessary to make the determination required under this agreement, providing said employees, consultants and agents are bound by the terms of this Agreement.

7. **Publications:** Recipient agrees to acknowledge the Provider with appropriate citations in any publications or presentations using results from this Data Set.

8. **Warrants:** Licensor warrants that it has the lawful right to grant the license set forth in this Agreement.

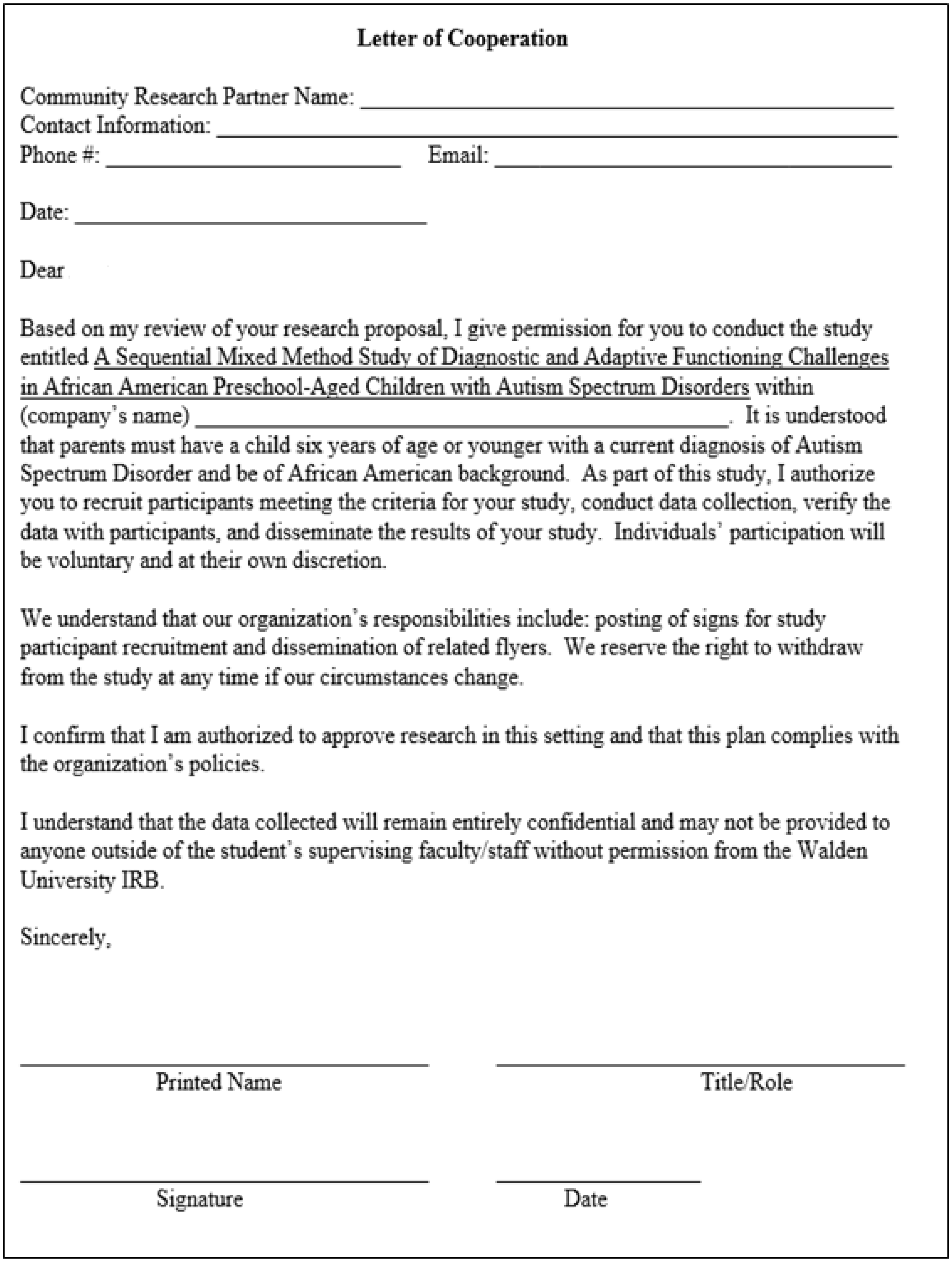
9. **NO REPRESENTATIONS OR WARRANTIES:** Except as expressly provided in section 8, the parties acknowledge and agree that licensor, its trustees, directors, officers, employees, and affiliates make no representations and extend no warranties of any kind, either express or implied, including but not limited to warranties of merchantability, fitness for a particular purpose, non-infringement and the absence of latent or other defects, whether or not discoverable. Nothing in the license agreement shall be construed as a representation made or warranty given by licensor that the practice by licensee of the license granted hereunder shall not infringe the patent rights or copyright rights of any third party. In no event shall licensor, its trustees, directors, officers, employees and affiliates be liable for incidental or consequential damages of any kind, including economic damage or injury to property and lost profits, regardless of whether licensor shall be advised, shall have other reason to know, or in fact shall know of the possibility. Licensee assumes the entire risk associated with licensee's use of the Data Set.

10. **Complete Agreement:** This License is a complete and exclusive statement of the terms and conditions of the agreement between Licensee and Licensor.

06/11/2013
Date

Send completed DUA by fax - 503-494-2475, or email - cahmi@ohsu.edu

# Appendix B: Letter of Cooperation



**Letter of Cooperation**

Community Research Partner Name: ______________________________
Contact Information: ______________________________
Phone #: ______________________ Email: ______________________

Date: ______________________

Dear

Based on my review of your research proposal, I give permission for you to conduct the study entitled A Sequential Mixed Method Study of Diagnostic and Adaptive Functioning Challenges in African American Preschool-Aged Children with Autism Spectrum Disorders within (company's name) ______________________________. It is understood that parents must have a child six years of age or younger with a current diagnosis of Autism Spectrum Disorder and be of African American background. As part of this study, I authorize you to recruit participants meeting the criteria for your study, conduct data collection, verify the data with participants, and disseminate the results of your study. Individuals' participation will be voluntary and at their own discretion.

We understand that our organization's responsibilities include: posting of signs for study participant recruitment and dissemination of related flyers. We reserve the right to withdraw from the study at any time if our circumstances change.

I confirm that I am authorized to approve research in this setting and that this plan complies with the organization's policies.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the student's supervising faculty/staff without permission from the Walden University IRB.

Sincerely,

______________________________ ______________________________
Printed Name Title/Role

______________________________ ______________
Signature Date

# Appendix C: Recruitment Flyer and Postcard

PLEASE be a part of an Autism Research Study!

Who?

African American parents of children 6 years old or younger with Autism

What?

Participate in an interview about your child and complete a questionnaire

Why?

To understand delays in diagnosis and functional challenges