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Asperger's Syndrome in African American Children

Suzette Bailey
Walden University

Walden University

College of Health Sciences

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Suzette Bailey

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Review Committee
Dr. Shari Jorissen, Committee Chairperson, Public Health Faculty
Dr. Chester Jones, Committee Member, Public Health Faculty
Dr. James Rohrer, University Reviewer, Public Health Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
2018

Abstract

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MSN, Walden University, 2011

BSN, Chamberlain College of Nursing, 2009

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

The prevalence of autism in the United States is 1 in 68 children. African American children are less likely to receive advance testing to confirm the diagnosis of Asperger's Syndrome (AS) compared to other ethnic groups. The purpose of this study was to determine if demographic factors (parental education level, family annual income, marital status of custodial parent(s), parent ethnicity, number of children in home, other children with disability, family location, mother age at time of birth, gender of child, birth status of child, adoption status and age, child order, and other disability) have any predictive relationship to AS diagnosis among African American children in the Washington Metropolitan area. A quantitative correlational study of a cross-sectional nature was conducted using a survey to collect data from parents of children age 3-16 (*n*= 187) who may or may not have a confirmed autism diagnosis. Bronfenbrenner's ecological theory provided an understanding of how environmental factors may be related to a diagnosis of AS. Chi-square analyses were conducted and statistically significant higher frequencies of diagnosis were found in parents with no other child with a disability, later born children, and parents who have been married. Logistic regressions analysis resulted in parental marital status being found to be a statistically significant predictor of a child having an official AS diagnosis. There is a critical need to train health care professionals working in underserved communities where minority groups may reside about AS. Results from this study may provide information to develop policies, community-based services, and programs that ensure that children can receive an accurate AS diagnosis regardless of factors such as race, ethnicity, or socioeconomic status.

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Dedication

I will like to dedicate this dissertation to my family, who has been very supportive while I pursued this doctorate. It was not easy; however, the support and encouragement I received from my husband (Livern), children, and extended family members were exceptional. Thank you for your understanding during this process.

To my mom, who called me daily to inquire if I had done any work on my dissertation. These conversations were helpful because it motivated me to keep going. To my dad who provided words of wisdom and encouragement – it meant a lot to me. To my sister Gillian, who often asked how far I have reached in my dissertation, I am so thankful for your inquiries. To Dr. Kehinde Abiodun, my colleague, who started the program with me, I am appreciative for your support.

To my deceased grandmother who told me to pursue my doctorate and that I can do it with God’s help.

I dedicate this dissertation to my wonderful children Blair, Damien, Darren, Tyler, Ariel, and Justin who allowed me to pursue my dreams.

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I will like to thank God for keeping me focused throughout the years and allowed me the opportunity to finish this dissertation. I am so grateful that God helped me reach this major milestone in my academic achievement.

I would like to acknowledge my siblings, extended family members, and friends who supported and encouraged me as I pursued my dream to earn this degree.

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Chapter 1: Introduction to the Study

Asperger's Syndrome (AS) is a neurological developmental disorder characterized by impairment in social interaction and a repetitive, stereotyped pattern of behavior (American Psychiatric Association [APA], 2000; Leekam, Prior, & Uljarevic, 2011; Weber, 2008). The National Institute of Neurological Disorders and Stroke [NINDS] (2013, 2016) noted that symptomology of AS consists of repetitive behaviors demonstrated in children diagnosed with the disorder. AS, also called high-functioning autism (HFA), is on the "mild end" of the autistic spectrum with an average to above average intelligence and normal development of speech and language (American Academy of Child and Adolescent Psychiatry [AACAP], 2013, 2015; NINDS, 2013, 2016).

Autistic disorders are conditions that cause developmental delay in basic skills, ability to socialize with others, communication, and use of imagination (APA, 2000; Baio, 2012; NINDS, 2013, 2016). In 2014, the Centers for Disease Control and Prevention (CDC) estimated that the prevalence of AS in the United States is one in 110 children. Currently, the prevalence of AS in the U.S. is one in 68 children (14.7 per 1,000 8-year old) (CDC, 2014). African American children are less likely to receive advance testing to confirm the diagnosis of AS in comparison to the rate of advanced testing in Caucasian children (Gourdine, Baffour, & Teasley, 2011). African American children are being diagnosed at a later age because of inconsistencies in diagnostic instruments/tools used to make the diagnosis of AS (Gourdine et al., 2011).

This chapter presents a synopsis of the background of the problem, statement of the problem, nature of the study, and the rationale for this study. The research question and hypotheses are also provided. The significance of the study, assumptions, delimitations, and the definitions of terms used in this study are provided. Implications for social change are provided in this chapter as well. A more detailed discussion of the literature is provided in Chapter 2.

Background

Autistic disorders are conditions that cause developmental delay in a child's basic skills, ability to socialize with others, communicate, and use of imagination (APA, 2000; Baio, 2012; NINDS, 2013, 2016). In 2013, the American Psychological Association (APA) removed AS from the *American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders Fifth edition* (DSM-5) and grouped AS with other similar disorders under the term Autism Spectrum Disorder to make diagnosis more accurate and consistent (AACAP, 2015; APA, 2013). NINDS noted that the ability to diagnose (AS is complicated by the lack of a standardized diagnostic test (2013, 2016). There are several screening instruments in current use, each with its criteria, and depending on what instrument is been used the same child could receive varying diagnoses (NINDS, 2013, 2016). In 2014, CDC estimated that the prevalence of AS in the United States is one in 110 children. Currently, the prevalence of AS in the U.S. is one in 68 children – a 30% increase in 2 years (CDC, 2015).

Researchers have shown that although AS is diagnosed at the same rate among racial groups, African American children are diagnosed later than Caucasian children

(Gourdine et al., 2011). African American children that visited a clinician for the first time were 2.6 times less likely to receive a diagnosis of AS in comparison to Caucasian children (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007). Mandell et al. (2007) found that African American children were 5.1 times more likely to receive an adjustment disorder diagnosis and 2.4 times more likely to be diagnosed with conduct disorder – compared to Caucasian children. Children with AS were diagnosed at 7.2 years compared to 3.9 years for children diagnosed with pervasive developmental disorder, and poor children received a diagnosis 0.9 years later than those with parental incomes more than 100% above the poverty level (Mandell & Novak, 2005). Because of delayed diagnosis, African American children may require prolong intensive interventions due to variation in diagnosis compared to Caucasian children. Differences in diagnosis may be related to factors such as ethnicity, culture, variations in parental descriptions of symptoms (Nowell, Brewton, Allain, & Mire, 2015; Ravindran & Myers, 2012; Thomas, et al., 2012), clinician interpretation/expectations, and/or symptom presentation (Gourdine et al., 2011; Mandell et al., 2007).

Researchers have shown that AS can be accurately diagnosed in children as young as 2 years old (Charman et al., 2005; Lord et al., 2006; Kozlowski, Matson, Horovitz, Worley, & Neal, 2011; Rezendes & Scarpa, 2011); however, diagnoses are usually made among school-aged children (Christensen et al., 2016; Filipek et al., 2000; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell, Novak, & Zubritsky, 2005a; Pinto-Martin & Levy, 2004). Delays may be related to inadequate screening practices (Fernell & Gillberg, 2010; Giannoni & Kass, 2010; Pinto-Martin & Levy, 2004; Sices, Feudtner, McLaughlin, Drotar, & Williams, 2003), clinicians' delayed response to parental concerns (Caronna, Augustyn, & Zuckerman, 2007; Ozonoff et al., 2009; Steiner, Koegel, Koegel, & Ence, 2013; Zuckerman, Lindly, & Sinche, 2015), inadequate screening tools/instruments (CDC, 2016; Charman & Gotham, 2013; Dumont-Mathieu & Fein, 2005; Huerta & Lord, 2012), and lack of awareness of AS symptoms (Heidgerken et al., 2005; Carrington, et al., 2014).

Disparities in diagnosis at an earlier age for African American children may be related to late entry and limited access to specialty care (Feinberg, Silverstein, Donahue, & Bliss, 2011; Guevara, Mandell, Rosatin, Zhao, & Hadley, 2006; Mandell et al., 2010). Baio (2014) noted that results from the 2010 Autism and Developmental Disabilities Monitoring (ADDM) Network Surveillance found that those who were diagnosed with AS on their first visit were more likely to be among Caucasian children (14%, p<0.01) compared to Black children (4%) and Hispanic children (5%). Caucasian children were diagnosed with autistic spectrum disorder at 6.3 years old, compared to 7.9 years for African American children, and 8.8 years for Hispanic children (Mandell et al., 2002; Daniels & Mandell, 2014). Other researchers have shown that after an accurate diagnosis of AS, minority families with limited education or lower incomes had difficulty with access to an early intervention system (Gourdine et al., 2011; Thomas et al., 2012).

Children with AS usually function at a higher level than children with autism and tend to display repetitive or what are unusual or eccentric behaviors (AACAP, 2015). Classic symptomology of AS include hand wringing and finger twisting, as well as unusual preoccupations, and repetitive or restrictive behaviors (Leekam et al., 2011;

Ronald, Happe, Dworzynski, Bolton, & Plomin, 2010). The newly revised definition includes children who display problems with social communication, social recognition, social imagination and understanding, as well as social interaction difficulties (AACAP, 2015; APA, 2013).

Children with AS may respond inappropriately to verbal and nonverbal cues, have difficulty building friendships with age appropriate peers, be overly dependent on routines, sensitive to changes in the environment, or remain focused on a specific item or items (AACAP, 2015; NINDS, 2013). Additionally, they often have difficulty interacting with others in social situations, social imagination and understanding, or conversations (AACAP, 2015; APA, 2000; Dworzynski, Happe, Bolton, & Ronald, 2009; Leekam et al., 2011). Another symptom a child with AS tend to possess includes a lack of eye contact during communication with other people (NINDS, 2013). For example, they may have an inability to maintain facial expressions and gestures or understand the body language of others. They may respond inappropriately to conversations or misread nonverbal cues. Other limitations include limited range of interest and motor coordination problems (Pandit, 2011). One positive aspect of children diagnosed with AS is the ability to be exceptionally talented or skilled in an area of interest, such as in music or math (NINDS, 2013).

Problem Statement

African American children are less likely to receive advance testing to confirm the diagnosis of AS in comparison to the rate of advanced testing of Caucasian children (Gourdine et al., 2011). As a result, African American children are being diagnosed at a later age and this considerable delay in diagnosis of AS in African American children is a major cause for concern (Gourdine et al., 2011; Mandell et al., 2002). Factors that can influence the rate of diagnosis of AS among African American children are lack of access to healthcare, lack of private pediatricians, high socioeconomic status, parental concerns, and family interactions with the health care systems prior to diagnosis (Daniels & Mandell, 2014; Zuckerman et al., 2015). Without enhanced parental and provider education on early recognition of AS symptoms, there may be a delay in early diagnosis and subsequent treatment interventions for children (Daniels & Mandell, 2014). There is not a consensus in the research regarding the reasons that African American children are diagnosed with AS at a lower rate than Caucasian children. Later diagnosis of AS among African American children results in treatments and interventions to be delayed which negatively impacts the quality of life going forward (Feinberg et al., 2011; Magana, Parish, Rose, Timberlake, & Swaine, 2012; Mandell et al., 2002). The lack of early diagnosis of AS in African American children in comparison to Caucasian children is a major problem that needs to be addressed by analyzing the predictive relationship between demographic factors. If the problem is not addressed, the disproportionate under-diagnosis of AS in African American children will continue to rise and the delay in diagnosis of AS will continue to cause these children to not get the therapy they need in a timely manner (CDC, 2014).

Purpose of the Study

The purpose of this study was to determine if demographic factors have any predictive relationship in the rate of AS diagnosis among African- American children in the District of Columbia, Maryland, and Virginia (DMV) and if so, to what extent. The variables were quantitatively examined using a self-administered survey designed to gather information from African American parents of children with and without a confirmed diagnosis of AS. A delayed AS diagnosis can result in delayed treatment and interventions and prolonged intensive interventions (Gourdine et al., 2011; Mandell et al., 2002; Mandell et al., 2007). When children with AS do not get the medical care that they need, their quality of life can be significantly reduced. The results of this study can provide insight into the relationship that may exist between race and other demographics factors in the diagnosis of children with AS. Understanding the predictive relationships between demographic factors and rates of diagnosis can assist health care providers to determine the barriers that various groups; specifically, African Americans may face in obtaining a proper diagnosis for their children so that those barriers can be eliminated. Results from this study may provide information to develop policies, community-based services, and programs that ensure that children can receive an accurate AS diagnosis regardless of factors such as race, ethnicity, or socioeconomic status.

Research Question and Hypotheses

To explore if there are demographic factors that have a predictive relationship in the rate of diagnosis of AS in African American children, the following research questions and hypotheses guided this study:

Research Question 1: What family socioeconomic factors predict the diagnosis of Asperger’s Syndrome in African American children who exhibit symptomology of Asperger’s syndrome?

$H_0$1: There are no statistically significant predictive relationships between family socioeconomic factors (parental education level and family annual income) and the AS diagnosis status of children who exhibit symptomology of AS.

H_a1: There are statistically significant predictive relationships between family socioeconomic factors (parental education level and family annual income) and the AS diagnosis status of children who exhibit symptomology of AS.

Research Question 2: What family structural factors predict the diagnosis of Asperger's Syndrome in African American children who exhibit symptomology of Asperger's syndrome?

$H_0$2: There are no statistically significant predictive relationships between family structural factors (marital status of custodial parent(s), parental ethnicity, number of children in home, other children in home with disability/chronic illness, where family lives) and the AS diagnosis status of children who exhibit symptomology of AS.

H_a2: There are statistically significant predictive relationships between family structural factors (marital status of custodial parent(s), parental ethnicity, number of children in home, other children in home with disability/chronic illness, where family lives) and the AS diagnosis status of children who exhibit symptomology of AS.

Research Question 3: What child demographic factors predict the diagnosis of Asperger's Syndrome in African American children who exhibit symptomology of Asperger's syndrome?

$H_0$3: There are no statistically significant predictive relationships between child demographic factors (mother's age at time of birth; gender of child; birth status of child—single/multiple, adoption status, and age of adoption of child; child order in family; other disability/chronic disease diagnosis) and the AS diagnosis status of children who exhibit symptomology of AS.

H_a3: There are statistically significant predictive relationships between child demographic factors (mother's age at time of birth; gender of child; birth status of child—single/multiple, adoption status and age of adoption of child; child order in family; other disability/chronic disease diagnosis) and the AS diagnosis status of children who exhibit symptomology of AS.

Independent variables: For these research questions, the independent variables are family socioeconomic factors (parental educational level and family annual income), family structural factors (marital status of custodial parent(s), parental ethnicity, number of children in home, other children in home with disability/chronic illness, where family lives), and child demographic factors (mother's age at time of birth, gender of child, birth status of child – single/multiple, adoption status and age of adoption of child, child order in family, other disability/chronic disease diagnosis).

Dependent variables: The dependent variable is the rate of AS diagnosis (0=no official diagnosis; 1=documented diagnosis).

Theoretical Framework for the Study

The theoretical framework that was used in this study was Bronfenbrenner's ecological theory (1979). Ecological theory, or ecological systems theory, describes the exterior forces that impact human development in relation to the proximity of those forces to the individual (Kazdin, 2000). These environmental forces are separated into five systems: the microsystem, the mesosystem, the exosystem, the macrosystem, and the chronosystem (Shaffer & Kipp, 2014). Each of these five systems has a role in promoting or hindering the rate of AS diagnosis in children. The microsystem describes the environmental factors that have the closest proximity to and direct interaction with a person (Berk, 2000). These include factors such as home and family, church, school, and the neighborhood. These factors may influence people or groups of people to believe certain ideas or have certain values about autism, AS, mental health, or doctors and medical care in general. The mesosystem describes the interaction or connectedness between all the factors that make up the microsystem (Berk, 2000). Churches, school systems, and communities may unify to offer support and provide resources for healthcare. The exosystem refers to the environmental factors that affect a person but do not have a direct part in the person or child's life (Berk, 2000). These factors may include mass media, family, friends, and neighbors, the school board, or health and community-based services. Families and communities may receive information about AS through the media such as television and the internet and make value judgments based on that information. The chronosystem describes how these systems change over time, thus changing their influence on the person (Shaffer & Kipp, 2014).

Bronfenbrenner's ecological theory (1979) was an appropriate theoretical framework for this study because it provides an understanding of how environmental factors can influence whether an African American child is diagnosed with AS. This theory identifies factors such as family dynamics and income, school, and community-based resources that can influence whether a family has the information, desire, and/or capability to obtain adequate testing to diagnose a child with AS (Bornstein & Bradley, 2003; Fernell & Gillberg, 2010; Golden & Earp, 2012; Magana et al., 2012). Researchers have applied this theory when analyzing the role of environmental factors in families' health outcomes, such as health education, diagnoses, development, use of services, and psychological well-being (Bornstein & Bradley, 2003; Golden & Earp, 2012; Shaffer & Kipp, 2014). Other theories that were considered for this study were the self-efficacy theory (Bandura, 1977) and cognitive dissonance theory (Festinger, 1957); however, both theories help to explain internal motivations for behavior and do not aid in understanding the outside influential factors affecting behavior as it relates to healthcare. Bronfenbrenner's ecological theory (1979) provided an adequate framework for conceptualizing the influence of factors that may have a relationship with the rate of AS diagnosis in African American children.

Nature of the Study

This research study utilized a quantitative, cross-sectional, correlational design to determine the demographic factors that can be used to predict the relationship of AS diagnosis in African American children. Data was collected from families living in the DMV area using a researcher-designed survey, the Autism Spectrum Screening Questionnaire (ASSQ) (Ehlers, Gillberg, & Wing, 1999), and the Childhood Autism Spectrum Test (CAST) (Williams et al., 2008). The quantitative method was an appropriate research method for this study because it allowed me to effectively analyze demographic data (income level, educational level, parental age, marital status, etc.) which was represented quantitatively and its relationship with the rate of diagnosis of AS in African American children. To answer the research question, I examined the relationships of various demographic factors with the rate of AS diagnosis in African American children and determine the predictive relationships of those demographic factors and the rate of AS diagnosis in African Americans; therefore, a quantitative research method and a multiple logistic regression analysis was appropriate for determining if demographic variables can be used to explain the variation in rates of AS diagnosis in African American children and, if so, to what extent.

Definitions of Terms

The following terms and definitions are used in this study:

Asperger's Syndrome: Asperger's syndrome (AS; also known as Asperger's Disorder, or Asperger's) is a neurological and developmental disorder that affects the ability to effectively socialize and communicate (APA, 2013; Leekam et al., 2011; Weber, 2008). Children with Asperger's have an obsessive focus on a topic and routinely perform behaviors or task in the same way repeatedly. In 2013, the APA changed how Asperger's is classified in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) and it is now classified as autism spectrum disorders (ASD) (APA, 2013). AS is considered a high-functioning form of ASD and the symptoms are considered less severe than other forms of ASD.

Autism Spectrum Disorder (ASD): Autism spectrum disorder is a term used to describe various neurological and developmental disorders such as Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified, Rett's syndrome, Childhood disintegrative disorder, and autism (PDD-NOS) (APA, 2013). Characteristics of ASD include repetitive behaviors, social problems that include difficulty communicating and interacting with others. There are two types of main symptoms that consist of restricted/repetitive behaviors and social communication/interaction behaviors (APA, 2013; National Institute of Mental Health, 2016).

Felt-stigma (self-stigmatization): Felt stigma can be internal or self-stigmatization. It denotes shame and discrimination that prevents individuals from talking about their experiences or seek help (Scambler, 1998). Felt stigma relates to the feelings of shame, embarrassment, or the fear of rejection by others (Gray, 2002).

Genetics: Genetics refers to genes, heredity, a variation in living organisms. When parents pass certain genes to their children this biological process is known as heredity (Mandal, 2013). Children acquire genes from their biological parents and these genes express specific traits. These traits may be physical for example; hair, eye color, or skin color (Mandal, 2013; White & Rabago-Smith, 2011).

Socioeconomic status (SES; occupation, income, and education level): It is an economic and sociological combination of an individuals' or family's work experience, economic and social position in comparison to others based on income, education, and occupation (Conger, Conger, & Martin, 2010). It conceptualizes the social standing or class of an individual or group. It also examines the socioeconomic status that reveals the inequities in access to resources (APA, 2016).

Assumptions

In this study, the researcher attempted to better understand if demographic factors have a predictive relationship with the rate of diagnosis of AS in African American children. There are several assumptions that have been made to conduct this study. Firstly, it was assumed that the alacrity of the participants that responded in this study did not bias the study. Instead, the assumption was that participants' in this study were who they purported to be, and they completed the survey honestly and accurately. This assumption was important to the validity of the study. Secondly, it was also assumed that participants were able to use a computer and have access to the Internet; as well as possess the skills necessary to use an email account. In addition, it was assumed that the respondents' computer was equipped to access the electronic survey in its originally designed form to solicit valid responses to the survey item. This assumption was important to the sampling for participants as computer accessibility, or lack thereof, does not pose a barrier to participation so that participants' answers may be regarded as valid and depict their actual circumstances. Finally, it was assumed that the ecological theory by Bronfenbrenner (1979) was the most appropriate theoretical framework to use in determining if there were factors that had a predictive relationship in the rate of diagnosis of AS among African American children.

Scope and Delimitations

The research question in this study focused on the factors that had a potential relationship with the rate of AS in African American children. The population for the study was chosen from the District of Columbia, Maryland, and Virginia area. This area consisted of a high rate of African American families and was a good area to access participants for this study. Participants' included parents who had children age 3 to 16 years old with and without a confirmed diagnosis of AS or who display symptomology of AS in the DMV area. Children with and without a formal diagnosis are crucial to be able to analyze the predictive relationships between the rate of AS diagnosis and the demographics outlined in the research question. A demographic questionnaire, the ASSQ (Ehlers et al., 1999), and the CAST (Williams et al., 2008) were used to collect data for this study. Power analysis of 0.85, an alpha level of 0.05, a medium effect size (odds ratio = 1.75), Pr(Y=1/X=1) Ho = 0.2, two-tailed test, and a binary X-distribution (Hsieh et al., 1998) were used to compute the G*Power 3.1.9.2 (Faul, Erdfelder, Buchner, & Lang, 2009) a post hoc, which yielded a sample size of 187 participants. I aimed to exceed the sample size of 187 during recruitment to ensure that there were an equal number of participants in each group (with and without a confirmed diagnosis of autism). Other researchers used both similar and larger sample sizes (Baron-Cohen et al., 2009; Lai, Lombardo, Chakrabarti, & Baron-Cohen, 2013; Rivet & Matson, 2011; Sun et al., 2014); therefore, a target sample size of 187 participants was appropriate for this study.

Limitations

There were limitations that may impact this study. The first limitation may be the sampling method of participants. Purposeful convenience and snowballing sampling methods were used to solicit participants for the study. Snowball sampling aided in accessing the target population (Atkinson & Flint, 2001), but this method may also cause the participants to not be as diverse as the population they represent. Autism is a broad topic; however, this study was limited to the demographic factors that have been outlined in the research questions. Therefore, this was taken into consideration when generalizing about the rate of AS diagnosis based on demographics.

Significance

Potential outcomes of this study included identifying barriers to early AS identification/diagnosis and enhancing strategies to address the need for improved recognition and documentation of symptoms of AS among African American children. Identifying and addressing barriers to diagnosis may lead to a decrease in the age when African American children receive their first evaluation for a diagnosis of AS, so they can be enrolled in community-based support services at an earlier age (CDC, 2014). Results from this study could raise awareness in parents, teachers, psychologists, speech pathologists, and pediatricians regarding the disparities in AS diagnosis so that warning signs of AS will not be overlooked. Early diagnosis could lead to access to programs that focus on individualized treatment and appropriate interventions to help children function more independently and socially (Fernell, Eriksson, & Gillberg, 2013; Lindgren & Doobay, 2011). Additionally, individualized treatment plans may be appropriate for children who do not have AS; diagnostic tools can aid in the identification of symptomology which can be addressed through interventions. The CDC (2014) noted that early and accurate diagnoses may lead to future potential of African American children improvement in “social interaction, improved communication, social, play, and behavioral functioning” (Tek & Landa, 2012, p. 1967) so these children could be able to function and enjoy a better quality of life socially.

Summary

The prevalence of autism has significantly increased over the years and African American children are disproportionately being diagnosed at a decreased rate in comparison to other ethnic groups (Mandell et al., 2002). There are limited studies available on the diagnosis of AS in African American children and the factors associated with the rate of diagnosis. By determining if there are factors that have any predictive relationships in the rate of diagnosis of AS among African American children; the results of this study may help to add pertinent information to the body of knowledge available in the literature. Asperger’s syndrome demonstrates deficits in social interaction, verbal and nonverbal communication, and repetitive behaviors or interests (APA, 2013). Misdiagnosis and being deprived of the opportunity to receive early diagnosis and intervention may significantly impact the lives of African American children (CDC, 2006, 2014, 2016; Mandell et al., 2007). Furthermore, the results from this study may assist parents, school administrators, physicians, and other healthcare professionals that develop and implement policies for children with autism.

Chapter 2 provides an in-depth examination of the literature in relation to the factors that may have predictive relationships in the rate of diagnosis of AS in African American children. In Chapter 2, I also examine how the various independent variables found in the literature is associated with the diagnosis of autism in children. Chapter 3 describes the methodology that was used to address the research question and conduct this study. The chapter also focuses the instruments and procedures that were utilized to conduct this study. Chapter 4 provides the analysis and data collection method. It also provides the results of the study, which used a quantitative method to gather data. Chapter 5 provides an overview of the research, discussion of the results, and implications of the study.

Chapter 2: Literature Review

Introduction

AS is a neurological developmental disorder characterized by impairment in social interaction and a repetitive, stereotyped pattern of behavior (APA, 2000; Leekam et al., 2011; Weber, 2008). The NINDS (2013, 2016) noted that symptomology of AS consists of repetitive behaviors demonstrated in children diagnosed with the disorder. AS, also called HFA, is on the mild end of the autistic spectrum with an average to above average intelligence and normal development of speech and language (AACAP, 2015; NINDS, 2013, 2016).

Autistic disorders are conditions that cause developmental delay in basic skills, ability to socialize with others, communicate, and use imagination (APA, 2000; Baio, 2012; NINDS, 2013, 2016). The (CDC, 2014) estimated that the prevalence of AS in the United States is one in 110 children. Currently, the prevalence of AS in the U.S. is one in 68 children (14.7 per 1,000 8-years old) (CDC, 2014). African American children are less likely to receive advance testing to confirm the diagnosis of AS in comparison to the rate of advanced testing in Caucasian children (Gourdine et al., 2011). African American children are being diagnosed at a later age because of inconsistencies in diagnostic instruments/tools used to make the diagnosis of AS (Gourdine et al., 2011).

In this chapter an overview of the theoretical perspective is presented, history and behaviors associated with autism and AS is reviewed including the prevalence of autism, early diagnosis and intervention services, as well as the economic cost, diagnostic process, ethnicity, quality of clinician and school services associated with autism. In addition, factors related to autism and AS is discussed to determine if there are factors that have the potential to impact the rate of diagnosis of AS in African American children.

Literature Search Strategy

The research databases that were searched for recent research related to the topic included: JSTOR, Google Scholar, The U.S. National Library of Medicine, and ProQuest. The following health-related websites were also searched: The Autism Research Center (ARC), AACAP, CDC, and the National Institute of Mental Health (NIMH). The Google search engine was used in all cases except when data was specific to use within a proprietary search engine or database. Progressive development of keywords occurred throughout the process, and initial sets of keywords included: *African American health outcomes, African American autism, African American diagnosis, autism, autism criteria, autism diagnosis tools, African American Caucasian autism, under-diagnosis African Americans, ethnic health outcomes, racial disparity diagnosis, health disparity racial,* and *disparity in autism diagnosis among African American and Caucasian.* Additional keywords and terms such as *Asperger's, autism, black children, ASD, diagnosis and autism, child,* and *youth* were later developed and included in the appendix.

A review of the literature included health-related websites, peer-reviewed journal articles, books, national databases of health statistics, and related research. The period reviewed was 1995 to 2015 but 80% of the sources used were from the last 5 publication years which restricted the data to the latest developments in autism diagnosis focused on racial outcomes. A total of 85 separate works was reviewed and referenced in this study.

Approximately 70% of the studies were quantitative and the remaining 30% were qualitative or theory related. Research that was addressed includes information about African American health outcomes, autism, disparities in racial health outcomes, and the difficulty of diagnosing autism due to a lack of reliable tools, and the current role a combination of unreliable tools and late diagnosis play in African American health outcomes as related to autism.

Theoretical Framework

Bronfenbrenner's ecological theory (1979) was used to conduct this study. This theory also known as the ecological systems theory, defines and looks at the child's development within the context of the system of relationships that help form the child's environment. Bronfenbrenner's theory describes complex layers of environment, each influencing the child's development (Berk, 2000). The ecological system theory describes the exterior forces that impact human development in relation to the proximity of those forces to the individual (Kazdin, 2000). There are five systems that separates these environmental forces: the microsystem, the mesosystem, the exosystem, the macrosystem, and the chronosystem (Shaffer & Kipp, 2014). The rate of AS diagnosis in children is being hindered or promoted by these five systems. The microsystem describes the component that is adjacent to the child and incorporate the structures with which the child has the most contact (Berk, 2000). This system beset the relationships and interactions a child has with his immediate environment (Berk, 2000). These structures include aspects such as home and family, church, school, and the neighborhood. The microsystem has the greatest impact on the child. These layers may influence people or groups of people to believe certain ideas or have certain values about autism, AS, mental health, or doctors and medical care in general. The mesosystem describes the interaction or connectedness between all the factors that make up the microsystem. For instance, the connection between the child's parents and teachers, churches, school systems, and communities may unify to offer support and provide resources for healthcare. The exosystem is the larger social system that defines the community-based systems and activities in which the child does not function directly (Kumi-Kyereme, Awusabo-Asare, Biddlecom, & Tanle, 2007). This layer impact the child's development by interacting with some structures in the microsystem (Berk, 2000). These factors may include mass media, extended family networks, friends, and neighborhood community context, the school board, or health and community-based services. Families and communities may receive information about AS through the media such as television and the internet and make value judgments based on that information. The exosystem is expected to compliment the main role of parents and other family members within this system (Kumi-Kyereme et al., 2007). The chronosystem describes how these systems change over time, thus changing their influence on the person (Shaffer & Kipp, 2014). Aspects of this system can be external (timing of a parents' death), or internal (physiological changes that occur with aging of a child). Children may react differently to environmental changes and be more prone to determine how change can influence them (Berk, 2000).

Bronfenbrenner's ecological theory (1979) was an appropriate theoretical framework for this study because it provided an understanding of how environmental factors can influence whether an African American child is diagnosed with AS. This theory identifies factors such as family dynamics and income, school, and community-based resources that can influence whether a family has the information, desire, and/or capability to obtain adequate testing to diagnose a child with AS (Bornstein & Bradley, 2003; Fernell & Gillberg, 2010; Golden & Earp, 2012; Magana et al., 2012). Bronfenbrenner (1979) noted that human development is when a growing person acquires an extended, different and valid conception of the ecological environment, and thus becomes motivated (p. 27). Several researchers have applied this theory when analyzing the role of environmental factors in families' health outcomes, such as health education, diagnoses, development, use of services, and psychological well-being (Bornstein & Bradley, 2003; Golden & Earp, 2012; Shaffer & Kipp, 2014). Self-efficacy theory (Bandura, 1977) and cognitive dissonance theory (Festinger, 1957) were other theories that were considered for this study; however, both theories help to explain internal motivations for behavior and do not aid in understanding the outside influential factors that affect behavior as it relates to healthcare. This theoretical framework was suitable for conceptualizing the influence of aspects that may impact the rate of AS diagnosis in African American children.

Literature Review

The topics discussed in this literature review includes the diagnosis of AS and its prevalence, behaviors associated with AS including demographic factors of income level, family structure, geography, socioeconomic factors, education level of parents, environment, and genetics.

History of Asperger's Syndrome

AS is a neurological and developmental disorder characterized by impairment in impairment in social interaction and a repetitive, stereotyped pattern of behavior (APA, 2000; Leekam et al., 2011; Weber, 2008). NINDS (2013, 2016) noted that symptomology of AS consists of repetitive behaviors demonstrated in children diagnosed with the disorder. Children with AS can range from mild to severe with their symptoms. Additionally, children with AS can exhibit serious deficiency in social and communication skills. Other behaviors that are associated with AS include: difficulty judging personal space and understanding others' feelings, difficulty reading and interpreting social cues, socially and emotionally inappropriate responses (Asperger Autism Spectrum Education Network [ASPEN], 2017).

AS was first described in the 1940s by Asperger, who observed autism-like behaviors and difficulties with social and communicative skills in boys who had normal intelligence and language development (Autism Society, 2015). Frith described individuals with Asperger's as having a dash of autism (Autism Society, 2015; Frith, 1989). Asperger's syndrome was added to the APA *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* in 1994 as a separate disorder from autism (APA, 2000). Many professionals consider Asperger's as a less severe form of autism (Boyle et al., 2011). In 1994, the APA (1994) identified a set of Pervasive Developmental Disorders referred to as ASDs. These disorders include Autistic Disorder, Asperger's Disorder, and PDD-NOS (APA, 2013). In 2013, the DSM-5 was realized with significant changes to criteria and categories of ASDs (APA, 2013). APA replaced Autistic Disorder, AS and other pervasive developmental disorders with the umbrella diagnosis of autism spectrum disorder (APA, 2013; Autism Society, 2014, 2015).

The logic behind the change from the *DSM-IV* diagnoses to the DSM-5 diagnoses is that there was no consistency in the way AS or PDD-NOS diagnosis criteria was applied (Lutz, 2013). The consensus from the task force that included several research clinicians that were selected for their expertise in AS and trained in using standardized instruments; was that the diagnosis children received depended largely on where they were diagnosed (Lutz, 2013). It was hoped that the new DSM-5 criteria would create common language clinicians could use when they speak with parents, school systems, and other healthcare professionals which will ultimately be helpful for everyone involved (Lord et al., 2012). Kite, Gullifer, and Tyson (2013) found that 22% of parents who participated in their study supported the proposed DSM-5 changes while 28% of parents who participated expressed some level of uncertainty because autism is considered to be more severe than AS. Parents also associated negative outcomes with having a child diagnosed with AS to chronic stressors, such as the severity of the child's behavioral problems (Abbeduto et al., 2004; Anderson, 2010; Cachia, Anderson, & Moore, 2016; Duarte et al., 2005; Hastings, 2003; Rivard, Terroux, Parent-Boursier, & Mercier, 2014), or as the stressors cumulate daily (Bristol, 1987; Krakovich, McGrew, Yu, & Ruble, 2016; Neff & Faso, 2014).

A diagnosis of AS is typically applied to individuals with no intellectual disability or language deficit, pervasive developmental disorder, not otherwise specified (typically given to individuals' who may not meet all the criteria for autism), and childhood disintegrative disorder (applies to children who develop normally and then experience severe regression after three years) are now incorporated into the single diagnosis of autism spectrum disorder (Lutz, 2013). The decision of the APA to make these changes in the DSM-5 has caused some anxiety in parents which range from a mild concern to outrage (Lutz, 2013). Over 8,000 people signed an online petition conducted by the Global and Regional Asperger's Syndrome Partnership to denounce the changes made in DSM-5 (Lutz, 2013). The Asperger's Association of New England also received 5,400 signatures in their petition from concerned parents about the APA's decision to omit AS from a single diagnosis in the DSM-5 (Lutz, 2013).

Behaviors Associated with Asperger's Syndrome (AS)

AS is a lifelong developmental disability defined by diagnostic criteria that include deficits in social communication and social interaction and restricted, repetitive patterns of behavior, interests, or activities (APA, 2013). The initial signs and symptoms of AS are usually not apparent in the early developmental period and social deficits and behavioral patterns might not be recognized as symptoms of AS until the child is unable to meet social, educational, occupational, or other important life stage demands (Baio, 2014).

Children with AS are higher-functioning individuals (compared to children with autism) with severe impairments in social interaction, communication, imaginative abilities, and tend to display repetitive or what are considered unusual or eccentric behaviors (AACAP, 2015). A classic symptom of AS includes hand wringing and finger twisting, as well as unusual preoccupations, and repetitive or restrictive behaviors

(Ronald et al., 2010). The newly revised definition includes children who display problems with social communication, social recognition, social imagination and understanding, as well as social interaction difficulties (AACAP, 2015; APA, 2013).

According to the DSM-5 diagnostic criteria for 299.00 Autism Spectrum Disorder consists of three major criteria with subsections that should be met before a diagnosis of AS could be made (APA, 2013). ASD is characterized by 1) deficits in social communication and social interaction and 2) restricted, repetitive patterns of behavior, interest, and activities (APA, 2013). Both components are required for a diagnosis of ASD; otherwise, a diagnosis of social communication is made if repetitive patterns of behaviors and interest are not present (APA, 2013).

Children with AS may respond inappropriately to verbal and nonverbal cues, have difficulty building friendships with age appropriate peers, be overly dependent on routines, sensitive to changes in the environment, or remain focused on a specific item or items (AACAP, 2015; NINDS, 2013, 2016). Asperger's children often have difficulty interacting with others in social situations, social imagination and understanding or conversations (AACAP, 2015; APA, 2000; Dworzynski et al., 2009; Leekam et al., 2011). They also tend to possess a lack of eye contact during communication with other people and cannot maintain facial expressions, gestures, or understand the body language of others (NIMH, 2011). Other limitations include a limited range of interest and motor coordination problems (Pandit, 2011). One positive aspect of children diagnosed with AS is the ability to be exceptionally talented or skilled in an area of interest such as in music or math (NINDS, 2013). Children with AS are viewed as naïve, inappropriate, lack empathy, and have difficulty socializing and interacting with their peers.

AS children often misinterpret, and have difficulty understanding, the verbal or nonverbal intentions of other individuals' they are communicating with (Fletcher-Watson, McConnell, Manola, & McConachie, 2014). APA (2000) found that school-age children who have an ability to express themselves verbally may hide the severity of their ability to communicate socially. The inability to communicate socially tends to be more evident over time in AS children. During adolescence, children may adapt or learn certain strengths that they use routinely to assist with their verbal abilities to compensate for their deficit (APA, 2000). Social knowledge may allow children diagnosed with AS to have an awareness of their language and social skills and may be able to monitor and adjust accordingly during an interaction with peers (Baron-Cohen, Tager-Flusberg, & Cohen, 2000; Chevallier, Kohls, Troiani, Brodkin, & Schultz, 2012; Eren, 2015; Quill, 2002, Sillman et al., 2003). Practitioners should ensure that deficiency in social and communicative skills related to AS be recognized so an accurate diagnosis is made at an early age, so children can receive the appropriate intervention and services at school and other community-based centers (Autism Speaks, 2015; Glicksman, 2012; Zwaigenbaum et al., 2015).

Prevalence of Asperger's Syndrome

The ADDM Network began collecting data in 2000 to provide estimates of the prevalence of ASD and other developmental disabilities (CDC, 2014). The prevalence of the ASD has continued to increase since tracking began (Baio, 2014; CDC, 2015).

Fombonne and Tidmarsh (2003) conducted a review of epidemiological studies and found prevalence rates ranged from 0.03 to 4.84 per 1,000, with the ratio of autism to AS averaged 5:1. This, combined with a conservative prevalence estimate for autism of 1.3 per 1,000, indirectly suggested that the prevalence of AS may be approximately 0.26 per 1,000 (Fombonne, 2007). Part of the variance in estimates is associated with the differences in diagnostic criteria (Mattila, Kielinen, Jussila, & Linna, 2007). However, in 2012, the estimated prevalence of ASD among 11 ADDM Network sites was 14.6 per 1,000 children aged 8 years old (Christensen et al., 2016). Continued surveillance by ADDM Network is vital to enhance strategies that effectively addresses the need for standardized measures. These measures could assist with early diagnosis of children with ASD among all ethnic and racial groups. Early diagnosis leads to better outcomes by ensuring that children receive services for individualized treatment and programs.

The prevalence of autism and other developmental disorders has been on the rise based on the data that is currently available. The CDC (2014) had estimated that the prevalence of ASD in the United States was one in 110 in 2006, which increased to 1 in 68 by 2010. ASD is approximately five times more common among boys (1 in 42) than among girls (1 in 189) (CDC, 2014). Autism is considered the fastest growing developmental disability and it is estimated that more than 3.5 million Americans live with an ASD (Buescher, Cidav, Knapp, & Mandell, 2014; Christensen et al., 2016). Researchers have shown that, among identical twins, if one child has ASD then the other child will more than likely be affected about 36% to 95% of the time versus 0% to 31% of the time in nonidentical twin pairs (Hallmayer et al., 2011; Ronald et al., 2006;

Rosenberg, Yenokyan, McGready, Kaufmann, & Law, 2009; Taniai, Nishiyama, Miyahci, Imaeda, & Sumi, 2008). Parents who have a child with ASD have a 2% to 18% chance of having a second child who is also affected (Ozonoff et al., 2011; Sumi, Taniai, Miyachi, & Tanemura, 2006). Windham et al. (2011) found that disparities exists with the prevalence of ASD across racial and ethnic groups, including lower reported rates among African American and Hispanic children compared to non-Hispanic White children.

Diagnosis and Intervention Services for Asperger's Syndrome

The number of diagnoses of AS has increased in recent years but it is unclear if the prevalence has increased in the general population or if clinicians/professionals are better at detecting it (Autism Society, 2015). When AS and autism were separate disorders under the *DSM-IV*, the symptoms for both disorders were the same. Children with AS do not present with delays in communication and language and to receive a diagnosis of AS, a child must have normal language development and normal intelligence (Autism Society, 2015).

Early diagnosis of AS plays a major role for parents and children with autistic disorders in terms of receiving intervention and treatment needed to help their ability to function independently (CDC, 2015; Christensen et al., 2016; Handleman & Harris, 2000; National Research Council [NRC], 2001; Wiggins, Baio, & Rice, 2006; Zwaigenbaum et al., 2015). Early intervention services have shown to help children from birth to three years old learn important skills. These services include therapy to help children walk, talk, and interact with others (CDC, 2015). In this context, parents should speak with their child’s pediatrician as soon as possible if they think their child has AS or other developmental disorders (CDC, 2015).

Clinicians and parents should collaborate so that symptoms of AS could be observed and monitored for an accurate diagnosis to be made early. According to the Autism Society of America (2015), diagnosis of AS and other autistic spectrum disorders should be conducted by a multidisciplinary team including but not limited to pediatricians, psychologists, psychiatrists, speech pathologists, and other professionals with the expertise to diagnose autism. Additionally, health care providers should use the criteria set forth by the DSM-5 and the International Classification of Diseases – Tenth Edition (ICD-10), together with instruments/tools so that diagnosis of AS can be accurately made (Charman & Gotham, 2013; Filipek et al., 2000; Huerta & Lord, 2012). Furthermore, clinicians can educate parents on the signs and symptoms of AS and this could help children with AS get the interventions and treatments needed that may facilitate or influence their achievement outcome (CDC, 2015). Variables such as family socioeconomic factors (parental educational level and family annual income), family structural factors (marital status of custodial parent(s), parental ethnicity, number of children in home, other children in home with disability/chronic illness, where family lives), and child demographic factors (mother’s age at time of birth, gender of child, birth status of child – single/multiple, adoption status and age of adoption of child, child order in family, other disability/chronic disease diagnosis) in the family are important because these variables could be essential to determine the diagnosis of AS among African American children in the Washington Metropolitan area.

Asperger’s Syndrome (AS) Diagnostic Process

Researchers have shown that Asperger’s syndrome can be accurately diagnosed in young children (Charman et al., 2005; Christensen et al., 2016; Lord et al., 2006; Rezendes & Scarpa, 2011); however, diagnoses are usually made among children of school age (Filipek et al., 2000; Mandell et al., 2002; Mandell et al., 2005a; Pinto-Martin & Levy, 2004). Delays may be related to inadequate screening practices (Fernell & Gillberg, 2010; Huerta & Lord, 2012; Magana et al., 2012; Pinto-Martin & Levy, 2004; Sices et al., 2003), clinicians’ delayed response to parental concerns (Caronna et al.,2007; Ozonoff et al., 2009; Steiner et al., 2013; Zuckerman et al., 2015), inadequate screening tools/instruments (Dumont-Mathieu, & Fein, 2005), and lack of awareness of AS symptoms (Heidgerken, Geffken, Modi, & Frakey, 2005). The National Institute of Neurology and Stroke noted that the ability to diagnose Asperger’s Syndrome (AS) is complicated by the lack of a standardized diagnostic test (2013). There are several screening instruments in current use, each with its criteria, and depending on what instrument is been used the same child could receive varying diagnoses (NINDS, 2013).

Early identification of autistic developmental disorders is crucial to the well-being of children and their families (CDC, 2015). Hence, it is imperative that primary-care professionals use the recommended guidelines to appropriately screen children for ASD (American Academy of Pediatrics [AAP], 2006). Any concerns identified during the well-child preventive care visits should be addressed immediately with recommended standardized screening instruments. In addition, early identification should warrant further developmental and medical evaluation, diagnosis, and treatment including early developmental intervention and services (AAP, 2006; CDC, 2015). Research suggest that the Checklist for Autism in Toddlers and the Autism Screening Questionnaire are the best screening tools available and the American Academy of Neurology [AAN] and the Child Neurology Society [CNS] have both recommended these instruments as effective developmental screening tools (2006). Other screening tools include the Ages and Stages Questionnaire, BRIGANCE® Screens, Child Development Inventories, and the Parents' Evaluations of Developmental Status (AAN, 2006; CNS, 2006). Due to a lack of sensitivity and specificity, the Denver-II (DDST-II) and the Revised Denver Pre-Screening Developmental Questionnaire (R-DPDQ) are not recommended for primary-care developmental surveillance (AAN, 2006; CNS, 2006).

Researchers have shown that autism can be identified by 18 months and a health care professional can make an accurate diagnosis that is reliable by the age of 2 (Hess & Landa, 2012; Macari et al., 2012; Martinez-Pedraza & Carter, 2009; Landa, Gross, Stuart, & Faherty, 2013; Lord et al., 2006; Ozonoff et al., 2010; Zwaigenbaum, 2010). Nevertheless, children who could receive an early diagnosis do not receive a diagnosis until they are much older (Malhi & Singhi, 2012; Mandell et al., 2005; Lord et al., 2006). Due to this delay, children with ASD may not receive treatment and intervention services in a timely manner which may greatly improve their overall developmental delays/disabilities (CDC, 2015). The American Academy of Pediatrics (AAP) recommended that children be screened at 9 months, 18 months, 24 and/or 30 months for autism developmental disabilities during regular pediatric well-child visits (2006). They have also recommended that pediatricians should screen children who were preterm, have a high risk for ASD, or have a sibling with autism, or if the child present with symptoms of autism (AAP, 2015). The Autism A.L.A.R.M. guidelines were developed by American Academy of Pediatrics and the American Academy of Neurology to help physicians with the autism screening process. This policy was developed to ensure that children receive routine and appropriate screening in a timely manner (AAN, 2006; AAP, 2006).

Diagnostic delays of Asperger's syndrome and other autistic disorders can be significant and may be impacted by the quality of the screening instruments and tools used. Thus, it is paramount that physicians use the recommended screening instruments and parent questionnaires to assess and diagnose developmental delays in children. Sices et al. (2003) found that only 50% of physicians used the recommended screening instruments and parent questionnaires compared to other physicians who do not use the recommended screening instruments. Bryson, Rogers, and Fombonne (2003) found that early diagnosis of autism is often impacted by the lack of early screening instruments.

There are many diagnostic tools available to assess ASD; however, CDC noted that no single tool should be used by itself to make a diagnosis of ASD (2015). Diagnostic tools rely on parental/caregiver input or description of their child's development as well as a professional's observations of the child's behavior (CDC, 2015). In some instances, referrals by a specialist may be needed for further assessment and diagnosis for some children. These specialists include neurodevelopmental, developmental/behavioral pediatricians, neurologists, geneticists, and early intervention programs and services (CDC, 2015).

Pediatricians should listen to parental description regarding the developmental milestones of their children and should avoid ignoring parents’ concerns about developmental delays among their children during well-child office visits (Scherzer, Chhagan, Kauchali, & Susser, 2012). Radecki, Sand-Loud, O'Connor, Sharps, and Olson (2005) hypothesized that fewer than half of pediatric physicians use formal screening tools. Bethell, Reuland, Schor, Abrahms, and Halfon concluded in their study that only one-fifth of children received parent-centered developmental screening in a 12-month period (2011). Additionally, various factors ultimately influence/impact the acceptance and practice of early detection and intervention (Scherzer et al., 2012). These factors include attitudes of physicians and awareness, ineffective training, and doubtfulness regarding early detection or non-acceptance of early treatment (Angie, Zwaigenbaum, Nicholas, & Sharon, 2015; Mousmanis & Watson, 2008; Siu, 2016). Pediatricians should ensure that all children receive routine and ongoing screening for social-development and social relationships. Early and continuous screening could help identify potential problems and evaluators should pay attention to delays in social development when conducting assessments. Early screening could identify children who may already have developmental delays. Earlier diagnosis means earlier intervention, which is closely associated with better outcomes.

In 2013, the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM-5) removed Asperger’s Syndrome from the psychiatrist handbook and grouped AS with other similar disorders under the term Autism Spectrum Disorder to make diagnosis more accurate and consistent (AACAP, 2015; APA, 2013). The main purpose of the DSM-5 is to provide standard guidelines for clinicians to use for the diagnosis of different psychological disorders and conditions (APA, 2015; Autism Research Institute, 2015). One of the most significant changes to the DSM-5 is the separate diagnostic labels of Autistic Disorder, Asperger's Disorder and PDD-NOS which were replaced under one umbrella term Autism Spectrum Disorder (APA, 2013). Thus, severity level would be based on the amount of support needed, due to challenges with social communication, restricted interests, and repetitive behaviors (Lorenz & Heinitz, 2014).

Stigmatization Associated with Asperger's

The diagnosis of Asperger's syndrome presents challenges for parents as they have to cope with the demands associated with their child's disability and the social stigma that comes along with it (Gray, 1993, 2002). Researchers have found that stigma affects parents with autistic children (Baxter, 1989; Birenbaum, 1970; Farrugia, 2009; Gray, 1993, 2002, 2008; Sarris, 2015; Voysey, 1975). Gray (2002) conducted a study about the different types of stigma parents with AS experience and found that 75% of parents' experience felt stigma due to an autistic child. Felt stigma can be internal or self-stigmatization. It denotes shame and discrimination that prevents individuals from talking about their experiences or seek help (Scambler, 1998). Basically, felt stigma relates to the feelings of shame, embarrassment, or the fear of rejection by others (Gray, 2002). The parents were embarrassed when their child acts socially inappropriate in public (Gray, 2002). In addition, 50% of parents' experienced enacted stigma (Gray, 2002). Enacted stigma (external or discrimination) refers to the experiences of unfair treatment by others

(Scambler, 1998). This stigma refers to the actual rejection or discrimination an individual face (Gray, 2002).

Gray (2002) found that many parents experienced both felt and enacted stigma from others and mothers were more likely to experience stigma than fathers (Gray, 2002). The author also found that most mothers and a few fathers encountered avoidance, hostile staring, and rude comments from others (Gray, 2002). Gray noted that parents of children who were more aggressive were more likely to experience stigma than parents of children who did not engage in aggressive behaviors (2002). According to Link and Phelan (2006), stigma may cause families to avoid seeking AS diagnosis and services for their children, or from participating in community activities.

Economic Cost of Asperger's Syndrome

Services related to autism cost the citizens of the U.S. \$236-\$262 billion dollars annually (Buescher et al., 2014). A significant amount of this cost is associated with the services provided to adult patients with Asperger's which accounts for \$175-\$196 billion dollars in comparison to \$61-\$66 billion for services provided to children (Buescher et al., 2014). Lifelong costs could significantly be reduced by at least two-thirds with early diagnosis and intervention (Järbrink, 2007). Researchers in Sweden examined the societal economic impact and found that societal cost per child were \$50,000 annually and parents of ASD children spent approximately 1000 hours caring for children with the disorder which ultimately impacted quality time spent with family (Järbrink, 2007). Early diagnosis is instrumental because treatment and interventions may significantly decrease the cost of providing services to individuals diagnosed with ASD. In the U.S. the cost of autism over the lifespan of an individual with an intellectual disability is $2.4 million or $1.4 million for an individual without an intellectual disability (Autism Speaks, 2014; Buescher et al., 2014).

The economic burden associated with caring for a child with ASD is substantial with most of the cost going towards the educational systems such as special educational services (Horlin, Falkmer, Parsons, Albrecht, & Falmer, 2014; Klin et al., 2015; Lavelle et al., 2014). The National Center for Education Statistics [NCES] indicated that educating a child without ASD averaged about $12,000 annually while it costs approximately $8,600 extra annually to educate a child with autism (Lavelle et al., 2014). Lavelle et al. (2014) found that parent-reported children with ASD had statistically significant higher levels of health care associated visits and prescription use compared with children without ASD. Researchers found that ASD accounted for $3,020 (95% confidence interval [CI]: $1,017 - $$4,259) higher health care cost and $14,061 (95% CI: $4,390-$24,302) higher aggregate non-health care costs and $8,610 (95% CI: $6,595-$10, 421) higher school costs (Lavelle et al., 2014, p. 520).

Based on these findings it is vital that children with ASD be diagnosed early so that appropriate treatment and interventions could be offered to help them develop to their fullest potential. Children born to parents of African Americans who are disproportionately affected based on their socioeconomic status may suffer inadvertently due to lack of access to quality services (Johnson & Theberge, 2007; Mazurek et al., 2014; Milteer & Ginsburg, 2012; Nowell et al., 2015). Early intervention helps improve the lives of ASD children significantly; therefore, it is paramount that services be offered early. Researchers have suggested that there is a significant economic cost associated with ASD and it varies in terms of demographics (Horlin et al., 2014; Klin et al., 2015; Lavelle et al., 2014).

Ethnicity and AS Diagnosis

Diagnosis by ethnicity. Differences in diagnosis may be related to factors such as ethnicity, culture, variations in parental descriptions of symptoms, clinician interpretation/expectations, and/or symptom presentation (Gourdine et al., 2011; Mandell et al., 2007). When adjusted for age, sex, and the time between Medicaid eligibility and diagnosis, Black children consistently spend longer periods under observation before being officially diagnosed and beginning treatment (CDC, 2006; Mandell et al., 2002, 2009). Caucasian children are more likely to receive a diagnosis of autism than African Americans (odds ratio [OR] = 0.79; 95% confidence interval [CI] = 0.64, 0.9) and Hispanics (OR = 0.76; CI = 0.56, 0.99) (Mandell, 2009). Later diagnosis of African American children means that treatment is delayed, and it will take longer for these children to receive services that will improve their lives.

Other researchers have shown that after an accurate diagnosis of AS, minority families with limited education or lower incomes had difficulty with access to an early intervention system (Feinberg et al., 2011; Gourdine et al., 2011; Magana et al., 2012). African American children are also less likely to receive an ASD diagnosis than children of any other ethnic background (Mandell et al., 2002, 2009). This is inconsistent with the prevalence of autism, which has a statistically consistent presentation across all ethnic populations (Durkin et al., 2010). Children of other ethnic backgrounds tend to go misdiagnosed which adds to the disparity. This occurs even when children of other ethnic backgrounds meet the same criteria for autistic diagnosis that would occur in White children (Ratto et al., 2016; Soto et al., 2014; Yeargin-Allsopp et al., 2003). Racial and ethnic disparities extend to other areas of ASD, such as, research, treatment, and advocacy. Thus, understanding ASD in all ethnic background could help children reach their full potential through early intervention and individualized treatment.

Thomas et al. (2012) found that White, Asian, and non-Hispanics were found to be diagnosed more frequently with autism than black non-Hispanics and Hispanics (12.5, 14.0, 9.0, and 8.5/1000, respectively). Access to health services that would evaluate and positively diagnose autism was negatively correlated with being Black or Latino (Liptak et al., 2008). The ongoing body of evidence suggests diagnostic bias when evaluating ethnic groups, with White children consistently receiving a higher rate of diagnosis than their peers (CDC, 2006; Mandell et al., 2002, 2009; Ratto et al., 2016; Yeargin-Allsopp et al., 2003).

Other factors that illustrate there is a problem with the diagnosis of AS among African American children are the lack of access to healthcare, lack of private pediatricians, high socioeconomic status, parental concerns, and family interactions with the health care systems prior to diagnosis (Daniels & Mandell, 2014). Community resources and State policies also play a role in early diagnosis. Without enhanced parental and provider education on early recognition of AS symptoms, there may be a delay in early diagnosis and subsequent treatment interventions for children (Daniels & Mandell, 2014; Koegel, Koegel, Ashbaugh, & Bradshaw, 2014).

It is important to have a regular primary care physician who can assess the child for changes so that an accurate diagnosis can be possible to ensure that early intervention and special education services such as an Individualized Educational Plan (IEP) (Albrecht, Skiba, Losen, Chung, & Middelberg, 2012; Eldevik et al., 2009; Reichow, 2012) can be initiated for African American children diagnosed with AS. Early diagnosis is critical and education services provided in some rural school districts are under-funded (Albrecht et al., 2012). This presents a major challenge in terms of getting the services needed to provide early testing. African American children living in poverty are more likely to attend a school district that has endured major cutbacks and restructuring due to neighborhoods that have experienced foreclosure and thus, funding for services at schools may be limited or decreased as a result (Dymond, Gilson, & Myran, 2007; Oliff & Leachman, 2012).

Age of diagnosis by ethnicity. The disparity between White children that receive a diagnosis of autistic disorder versus Black children that receive the same is statistically significant (Mandell, 2002). White children on Medicaid receive this diagnosis at 6.3 years of age, while Black children on Medicaid receive it at 7.9 years of age (Mandell, 2002). White children are more likely to begin treatment for this disorder younger than Black children. When adjusted for age, sex, and the time between Medicaid eligibility and diagnosis, Black children consistently spend longer periods under observation before being officially diagnosed and beginning treatment (Daniels & Mandell, 2014). Caucasian children are more likely to receive a diagnosis of autism than African

Americans (odds ratio [OR] = 0.79; 95% confidence interval [CI] = 0.64, 0.9) and Hispanics (OR = 0.76; CI = 0.56, 0.99) (Mandell, 2009).

African American children that visited a clinician for the first time were 2.6 times less likely to receive a diagnosis of AS in comparison to Caucasian children (Mandell et al., 2007). Mandell et al. (2007) found that African American children were 5.1 times more likely to receive an adjustment disorder diagnosis and 2.4 times more likely to be diagnosed with conduct disorder when compared to Caucasian children (p. 1795). African American children are diagnosed later than Caucasian children (Gourdine et al., 2011). Children with AS were diagnosed at 7.2 years compared to 3.9 years for children diagnosed with a pervasive developmental disorder, and poor children received a diagnosis 0.9 years later than those with parental incomes more than 100% above the poverty level (Mandell & Novak, 2005). Because of delayed or incorrect diagnoses, African American children may require prolonging intensive interventions due to variation in diagnosis compared to Caucasian children.

Other researchers also supported the conclusion that disparities in diagnosis at an earlier age for African American children may be related to late entry and limited access to specialty care (Guevara et al., 2006; Mandell et al., 2010). CDC (2014) also noted similar results from the 2010 Autism and Developmental Disabilities Monitoring (ADDM) Network Surveillance. They found that those who were diagnosed with AS on their first visit were more likely to be among Caucasian children (14%, $p<0.01$) compared with Black children (4%) and Hispanic children (5%) (p. 8). Increasingly, the research community found that Caucasian children were diagnosed with AS at 6.3 years old, compared with 7.9 years for African American children (Mandell et al., 2002, p. 1447).

They are also more likely to receive this diagnosis than children of any other ethnic background. This is inconsistent with the prevalence of autism, which has a statistically consistent presentation across all ethnic populations (Durkin et al., 2010). Children of other ethnic backgrounds tend to go misdiagnosed which adds to the disparity. This occurs even when children of other ethnic backgrounds meet the same criteria for autistic diagnosis that would occur in White children (Yeargin-Allsopp et al., 2003).

Geography and AS Diagnosis

Urban children generally are diagnosed with AS earlier than rural children (Lauritsen et al., 2014) as rural children receive a diagnosis 0.4 years later than their urban counterparts (Mandell, 2005). Urban regions are positively associated with greater access to medical care and treatment (Lauritsen et al., 2014). In turn, early diagnosis of autism is positively associated with geographic regions where there is a higher concentration of neurologists, psychiatrists, and specialists dealing with such disorders (Kalkbrenner, 2011). This suggests the need to target specific forms of service wherever specialists are not prevalent to diagnose autism at an earlier stage. In general, the prevalence of autism in metropolitan areas has increased (Yeargin-Allsopp, 2003). However, this may be a result of the greater availability of specialists concentrated within an urban region (Kalkbrenner, 2011). Caucasians also tend to be geographically clustered together, and that clusters of specialists tend to cluster in these geographic regions. This produces a higher rate of diagnosis within certain geographic regions (Palmer et al., 2011).

Socioeconomic Status & Asperger's Diagnosis

There is a positive association of AS diagnosis with socioeconomic status (SES). Researchers compared diagnostic rates against socioeconomic status, and an increase in diagnosis was found to be positively correlated with an increase in SES (Delobel-Ayoub et al., 2015; Durkin et al., 2010; King & Bearman, 2011; Nowell, 2015). The existence of diagnostic disparity when examining children of differing income levels suggested an ongoing diagnostic bias impacting a fair diagnosis of ASD (Durkin et al., 2010). The availability of specialists that would evaluate and diagnose autism was negatively correlated with poverty (Liptak et al., 2008).

Parents from a low SES background reported it was more difficult to have their children diagnosed, although these reports were ameliorated by the aid of services such as Medicaid (Flores & Lin, 2013; Morsy & Rothstein, 2015). Researchers found the ongoing existence of diagnostic bias when examining a separate group of 586 boys and girls (Thomas et al., 2012). Thomas et al. (2012) found a positive correlation between high SES and ASD diagnosis. Although the gap between diagnosis in high SES children and low SES children diminished slightly, the disparity remained statistically significant over the years with a median age of autism diagnosis with 95% [confidence interval] CI for median by birth cohort (Fountain et al., 2011).

Children of families in higher income brackets not only received a greater number of evaluations but also received an earlier diagnosis than their low SES peer. The association between a higher SES background and access to a greater number of specialists was reinforced by Palmer and colleagues (2010) who observed that the density of these specialists was concentrated in areas where there were higher populations of non-Hispanic Whites, which in turn was associated with higher SES. Other researchers confirmed this analysis in their studies and found that children who belonged to a higher SES received more services such as applied behavior analysis (ABA) based treatment, speech-language therapy (SLT), and occupational therapy (OT), compared to children who belonged to a lower SES group and received fewer types of services (Cooper, Heron, & Heward, 2007; Irvin, McBee, Boyd, Hume, & Odom, 2012). The body of literature suggests an ongoing connection between SES, ethnic makeup, and geography (Cooper et al., 2007; Durkin et al., 2010; Flores & Lin, 2013; Irvin et al., 2012; Liptak et al., 2008; Morsy & Rothstein, 2015; Thomas et al., 2012).

Education Status of Parent(s) & Asperger’s Diagnosis

Examination of education levels of parents revealed another disparity in autism diagnosis. Fountain et al. (2009) found that children with highly educated parents were more likely to be diagnosed autistic than children of parents with lower levels of education. In another study that used ten cohorts of California children based on their zip codes, researchers discovered that children of highly educated parents were diagnosed with autism earlier than children of parents with less education; and this effect elevated over the years as parents’ educational status increased (Fountain, King, & Bearman, 2011). Autism clustering tends to occur in regions where parental education remains high (Van Meter, 2010). Higher education is associated with a higher income level.

Researchers have suggested that parents from lower income brackets are less likely to seek services, resulting in a lower rate of diagnosis (Eiraldi & Diaz, 2010; McCabe, 2002; Reyno, & McGrath, 2006). The tie between education and income level is difficult to divide and leads to parallel observations of low-income, low-education parents experiencing lower access to specialists and a lower rate of diagnosis (Eiraldi & Diaz, 2010; Fountain et al., 2009; Fountain et al., 2011; McCabe, 2002; Reyno & McGrath, 2006).

Environmental Factors & Asperger's Diagnosis

Environmental presence of toxins is linked to autism, for example, mercury, is positively correlated with a higher prevalence of autistic diagnoses (Dickerson et al., 2016; Lyall, Schmidt, & Hertz-Picciotto, 2014; Ng, Montigny, Ofner, & Doce, 2017; Rossignol, Genuis, & Frye, 2014). In an examination of studies released by the Texas Education Department, for every 1,000 pounds of environmentally released mercury, there was a 61% increase in the rate of autism (Palmer, Blanchard, Stein, Mandell, & Miller, 2006). This association between mercury and autism was reevaluated by DeSoto (2007) who detected higher levels of mercury in the blood levels of those diagnosed along the autistic spectrum. Epidemiologic evidence has also shown that there is no causal relationship between thimerosol-containing vaccines and autism. Despite this evidence, concerns still arise over pediatric exposure to mercury and administration of vaccines (Hurley, Tadrous, & Miller, 2010).

Researchers studied the records of over 7000 women in Los Angeles county and found that women who were exposed to increased amount of air pollution levels for ozone and particulate matter had a 12% - 15% greater chance of having an autistic child than women who lived in areas that had cleaner air and were not exposed to this particulate matter during their pregnancies (Becerra, Wilhelm, Olsen, Cockburn, & Ritz, 2013). Conversely, researchers examined the relationship between traffic-related air pollution, air quality, and autism, in the Childhood Autism Risk from Genetics and the Environment (CHARGE) study in California among 279 children with autism and 245 control children with typical development (Volk, Lurmann, Penfold, Hertz-Picciotto, & McConnell, 2013). Volk et al. (2013) found that maternal residence at the time of delivery was more likely to be living near a freeway for cases than controls. Children with autism were more likely to live in areas that had higher exposure to traffic-related air pollution during gestation (AOR, 1.98 [95% CI, 1.20-3.31]) and during the first year of life (AOR, 3.10 [95% CI, 1.76-5.57]) (Volk et al., 2013). In addition, researchers examined shared mechanisms between autism pathophysiology and the effects of pesticides exposure, along with neuroexcitability, oxidative stress, and immune functions (Shelton, Hertz-Picciotto, & Pessah, 2012). Researchers have suggested a link between the environmental presence of mercury, increased levels of mercury in the blood system, higher exposure to traffic-related pollution during gestation, and higher rates of autism (Becerra et al., 2013; DeSoto & Hitlan, 2007; Palmer et al., 2006; Shelton et al., 2012; Volk et al., 2013). Environmental factors were added for background purposes only; however, it will not be studied as an independent variable in this study.

Country of Origin and Asperger's Syndrome (AS)

The prevalence of autism has been reported to be highest among non-Hispanic children in the United States (Wheeler, 2014). Researchers at the UCLA Fielding School of Public Health found that a mother's place of birth may be a risk factor of her having an autistic child (Becerra et al., 2014). These researchers used data from Los Angeles County which consisted of a large amount of racially diverse immigrants. When compared to children of White American women, 76% of children of foreign-born Black women, Central or South American, Filipino and Vietnamese they had a higher risk of autism. African American and Hispanic women children also had a higher risk as well. The results of the study concluded that maternal race/ethnicity and nativity were associated with diagnosis and severity of autism (Becerra et al., 2014).

Paternal/Maternal Parental Age at Birth of Child & Risk of Autism

Paternal age. Many in the scientific community have increasingly suggested that autism is related to certain genetic mutations most likely inherited from the father (Neale et al., 2012; O'Roak et al., 2012; Sanders et al., 2012). Researchers completing empirical studies have increasingly suggested that autism is most likely associated with parental age, specifically, an increased paternal age (Julie, Hamdan, & Rouleau, 2011). Campbell and Eichler (2013) used whole-exome sequencing (decodes protein in children and parents) a precise method used to detect genetic mutations in multiple genes that may be associated with autism. They acknowledged and supported the growing evidence that purported that as the father's age increases that there is an increased chance the child may develop some form of autism (Campbell & Eichler, 2013).

D'Onofrio et al. (2014) agreed with the findings of increased paternal age and its association with autism. These authors found that many psychiatric disorders are higher in children born to older fathers. Medical records from 1973-2001 were analyzed and researchers found a strong association between a father's age at childbearing age and disorders such as autism, ADHD, and bipolar disorder (D'Onofrio et al., 2014). Researchers have indicated that the likelihood of autism continuously increased with paternal age. They emphasized that in comparison to a child born to a 24-year-old father, a child born to a 45-year-old father was 3.5 times more likely to have autism, 13 times more likely to have ADHD, and 25 times more likely to have bipolar disorder (D'Onofrio et al., 2014). While researchers have cautioned that although older parents are at an increased risk of having a child with autism or other developmental disorders, blaming parents should be avoided because there may be underlying factors or mechanisms that may cause this increased risk (Autism Speaks, 2015).

Experts continue to argue that autism spectrum disorders and other developmental disabilities vary and may likely be caused by genetics and environmental factors (CDC, 2015; Huquet, Ey, & Bourgeron, 2013; Liu, King, & Bearman, 2010; NINDS, 2015). Genome sequencing continues to be an effective tool for scientists to use to uncover specific mutations in DNA associated with autism (Michaelson et al., 2012; Szego & Zawati, 2016). Researchers compared siblings with autism and those without autism and found that siblings who had autism had two different mutations that disrupted the gene SCN2A [Sodium channel, voltage-gated, type II, alpha subunit] (Sanders et al., 2012).

SCN2A is a gene that codes for the alpha subunit of voltage-gated, type II sodium channels, which is highly expressed in the brain (Tavassoli et al., 2014).

Other researchers found that genetic mutations in a child with autism were absent in both parents and thus were not likely associated with autism (Geschwind, 2011; O'Roak et al., 2012; Sanders et al., 2012). Researchers found that fathers’ age, not necessarily the mothers’ age, would more likely increase the risk of new hereditary mutations in children (Kong et al., 2012). Additionally, each year as the father’s age increases at the conception phase of a child it caused two new single nucleotide polymorphisms. As a result, researchers conceded that paternal mutations accounted for 94% and 97% of all the genetic variation that eventually pass on to their child/children (Kong et al., 2012).

Maternal age. Advanced maternal age has been linked to various developmental disorders such as Down’s syndrome (Buxbaum & Hof, 2013; Hollander, Kolevzon, & Coyle, 2011; Moisse, 2010; Myrskyla & Fenelon, 2012; World Health Organization, 2015). Researchers at the University of California Davis Health System [UCDHS] examined the relationship between parental age of over 12,000 children diagnosed with autism between 1990 and 1999 (UCDHS, 2010). They found that the link between maternal ages had a statistically significantly higher risk of having a child with autism, despite the father’s age (UCDHS, 2010). Mothers over 40 years had a 50% higher risk of having a child with autism in comparison to mothers 25 to 29 years old (UCDHS, 2010). However, researchers in Iceland disputed this notion and argued that it was the age of the father that was more likely to be associated with autism in children (Kong et al., 2012).

After researchers compared the whole genome sequences of 78 trios (father, mother, and child) they noted that the average father's age in the study was 29.7 which ranged from 18 to 40.5 in the trios (Kong et al., 2012). A child in each trio had 63.2 new mutations where 55.4 came from the father and 14.2 derived from the mother. Mutations rose monotonically with father's age with 2.01 mutations per year and doubling every 16.5 years (Kong et al., 2012).

Conversely, Sandin et al. (2016) recently disputed this notion and claimed it was advanced maternal and paternal age that both caused an increased risk of autism among children. In their analysis, they found that maternal age, paternal age, and parental age gaps all influenced autism risk independently. Rates of autism were 66% higher among fathers who were 50 years of age compared to dads in their 20s. Rates were 15% higher among mothers who were in their 40s in comparison to mothers who were in their 20s (Sandin et al., 2016). Researchers have suggested that there is an association between increased paternal age as well as maternal age and autism together with other developmental disorders in children born to fathers of an older age (Sandin et al., 2016).

Family Genetics and Asperger's Syndrome (AS)

Autism is a developmental disorder that typically appears before a child turns three (Mandell et al., 2005). The causes of autism are unclear; however, researchers have begun to identify some risk factors for the disorder (Rodriquez & Thompson, 2015). Landa, of the Kennedy Krieger Institute's Center for Autism and Related Disorders indicated that family history is a primary known risk factor for autism (Rodriquez & Thompson, 2015). Researchers have found that Autism tends to run in family and having a child with autism increases the risk of having another child with an autistic disorder (Bartlett et al., 2014). A study of 79 families with one child with autism and another child with a language impairment found that there is a genetic link to autism in children and language problems in other family members (Bartlett et al., 2014).

Parents who have a child with autism have a 2% to 18% chance of having another child with autism (Ozonoff et al., 2011; Sumi et al., 2006). Genetic changes in a small region of two chromosomes increased the risk of both autism and language impairment (Bartlett et al., 2014). This link may explain why half of family members with ASD also show some form of language impairment as well (Autism Speaks, 2015). DiGuiseppi et al. (2010) suggested that there is a genetic link to autism that includes an increased prevalence of chromosomal abnormalities, nervous systems abnormalities, and language difficulties which seems to be prevalent in families with autistic children.

Researchers found that ASD tends to occur more often in people who have certain genetic or chromosomal conditions (CDC, 2015; Guerra, 2011; LePage & Courey, 2014). Approximately 10% of children with autism are also identified as having comorbid conditions such as Down syndrome, fragile X syndrome, tuberous sclerosis or other genetic and chromosomal disorders (Cohen et al., 2005; DiGuiseppi et al., 2010; Hall, Lightbody, & Reiss, 2008; Zecavati & Spence, 2009). Genetic and genomic research could advance understanding into ASD in ways that could lead to improved diagnosis and treatment.

Sex Differences, Race/Ethnicity and Birth-order of Child & AS

One of the most predominant features of autism is a higher prevalence in males (Baron-Cohen et al., 2011; Bolte, Duketis, Poustka, & Holtmann, 2011; Giarelli et al., 2010; Szatmari et al., 2012; Werling & Geschwind, 2013, 2015). Boys are affected with ASD at a rate of (1 in 42) to (1 in 189) among girls, at least five times more according to CDC (2014). The 2010 Autism and Developmental Disabilities Monitoring (ADDM) Network surveillance found that the prevalence of ASD based on sex, race, and ethnicity differed statistically significantly from the 11 states that provided data. After data were combined, the estimated prevalence of ASD among Caucasian children was 15.8 per 1,000 which was statistically significantly greater among black (12.3 per 1,000) and Hispanic children (10.8 per 1,000) (Baio, 2014; CDC, 2014). All states reported a significantly higher prevalence among white children compared to Black or Hispanic children (CDC, 2014). This information confirmed that White children are often diagnosed at a higher rate in comparison to Black or Hispanic children.

African American families may differ in size, number of siblings and sex distribution, birth order and recognizable patterns that create various comparison base on an individuals’ situation (Bandura, 1986; 1994). These factors could be statistically significantly and may have an impact on the disproportionate rate of diagnosis of ASD among African American children in comparison to children from other ethnic groups (Bandura, 1994). Giarelli et al. (2010) conducted a population-based cohort study to examine sex differences rate among children affected with ASD regarding age at diagnosis and other features and found that there were no differences between sex at first diagnosis of ASD or evaluation (Giarelli et al., 2010). However, they confirmed that boys were diagnosed with ASD more frequently (OR = 0.76, p = .004) (Giarelli et al., 2010).

The timing of treatment and intervention may impact or delay early intervention which could be crucial for the child's development (CDC, 2015; Fernell, Eriksson, & Gillberg, 2013). Stampoltzis et al. (2012) looked at the developmental, familial and educational characteristics of 91 children diagnosed with ASD from a school district in Athens, Greece. They found that the boy to girl diagnostic ratios was 4.3:1 while the average age of diagnosis was 6 years old which signified a delay in early detection of ASD (Stampoltzis et al., 2012). Werling and Geschwind (2015) used recurrence patterns in multiplex families and concordance rates in 305 twin pairs from the Autism Genetics Resource Exchange (AGRE) to determine if the risk in 1,120 multiplex nuclear families followed a female protective model. The researchers chose the first two affected children from each family, and randomly selected one autistic twin per pair, as probands (Werling & Geschwind, 2015). They found that there was a statistically significantly higher recurrence in males (47.5%) than in females (21.1%) and in siblings of female (44.3%) versus siblings of male probands (30.4%). (Werling & Geschwind, 2015). They also found that sex-differential recurrence was also robust in dizygotic twin pairs (males = 61.5%, females = 19.1%) (Werling & Geschwind, 2015).

Marital Status/Family Structure/Behaviors and Asperger's Syndrome (AS)

Autism spectrum disorders (ASDs) are associated with communication challenges, misunderstanding of social cues, and lack of emotional understanding, which affects every relationship in the family (Sicile-Kira, 2010). A child diagnosed with an autism spectrum disorder places enormous pressure and stress on the family in various ways (Autism Society, 2006; Bluth, Roberson, Billen, & Sams, 2013; Haag, Bird, & Weiss, 2016; Meadan, Halle, & Ebata, 2010). Parents and caregivers must place their primary focus on caring for children with ASD. These children will need to attend doctors' visit, therapy, and other schedule treatment and intervention sessions. As a result, these can put stress on parents' marriage, work, other children, finances, and personal relationships as well as responsibilities (Bluth et al., 2013; Hartley et al., 2010; Weiss, Wingsiong, & Lunsky, 2013, 2014).

It has been estimated that the divorce rate is in the 80% range in families with children who have autism (Bolman, 2006). However, Freedman, Kalb, Zablotsky, and Stuart (2012) used data from the 2007 National Survey of Children's Health to explore family structures of children with ASD as compared to children without ASD. They limited the data to children between the ages of 3 to 17 years and used a sample of 77, 911 children, of whom 913 were reported to have ASD diagnoses which were a representation of children in the U.S (Freedman et al., 2012). The researchers revealed no statistically significant difference between the percentage of children with ASD and the percentage of children without ASD (64% and 65% respectively) who lived with both their biological or adoptive parents, as opposed to living with single parents, step parents, etc. (Freedman et al., 2012). In contrast, Hartley et al. (2010) found that the divorce rate among parents of children with ASD were 23.5% while parents of children without ASD and other developmental disorders were 13.8%.

Parents must re-evaluate their lives and priorities because the focus shifts towards the child diagnosed with ASD (Autism Society, 2015; Sawyer et al., 2010; Sicile-Kira, 2004). Financial situations need to be prioritized so money would be available to provide treatment and interventions necessary for the child. A child with ASD needs complicates familial relationships, especially with other siblings (Gau et al., 2012). Hence, it is important for parents to educate and inform other siblings about the diagnosis and the complications it may introduce (Brendel et al., 2014). Parents should also help other siblings understand the challenges that the child with autism faces. Parents should seek help with coping by involving other members of the extended family as well. This could be accomplished by creating a network whereby parents and siblings could call upon when needed (Autism Speaks, 2015; Desai, Divan, Wertz, & Patel, 2012).

There are physical and psychological stressors that are associated with having a child with ASD (Davis & Carter, 2008). Parent-child conflicts can be a regular occurrence for families dealing with an autistic child (Davis & Carter, 2008; Sicile-Kira, 2004). A child with autism may not be able to express their needs in a manner that is understandable, and parents may have to play the guessing game to provide the child’s needs (Autism Speaks, 2015, Haney, 2013). In these instances, the child can become frustrated and this frustration can lead to aggressive or self-injurious behaviors that threaten the safety of the child and other family members. Likewise, parents are concerned about stereotypic and compulsive behaviors that may appear peculiar and interfere with functioning and learning (Autism Society, 2006; Green, 2013).

Individuals that lack appropriate play and social skills may increase the stress level for family members (Bluth et al., 2013). These individuals require constant structure and the home environment may not be quite feasible to accommodate (Ennis-Cole, Durodoye, & Harris, 2013; Weiss et al., 2014). Eating habits of children diagnosed with autism can be very stressful for parents as well (Autism Speaks, 2015). Williams, Dalrymple, and Neal (2000) found that 69% of ASD children were reluctant to try new foods while another 46% had rituals that surrounded their eating habits. Choosing a wide variety of foods can be a challenge and becomes very frustrating for parents (Palmer & Shore, 2012). All these issues and behaviors are physically exhausting and emotionally draining for families (Palmer & Shore, 2012). A child with ASD that display behaviors can impact the marital relationship (Bluth et al., 2013). Parents may lack quality time to spend together, socialize with other families in the neighborhood, or attend community events as a family (Bluth et al., 2013; Thompson, Kerr, Glynn, & Linehan, 2014). Maladaptive behaviors may prevent families from these social experiences due to fear of being stigmatized by other families who do not understand the challenges of dealing with an autistic child (Sicile-Kira, 2006). Researchers have suggested that autism is associated with stress and it is a major cause for stressors on family relationships and structure; however, more information need to be provided in terms of divorce rate among parents of children with autism (Bluth et al., 2013; Davis & Carter, 2008; Meadan et al., 2010).

Summary

Autism is a serious neurological disorder that affects a child’s ability to communicate and interact with others. It also impedes a child’s language and communication skills (APA, 2000; Leekam et al., 2011; Weber, 2008). Autism is on the rise in the U.S. and the current prevalence is 1 in 68 (CDC, 2014). CDC reported a 78% increase in autism prevalence since 2002 (2014). Despite the increased prevalence and knowledge of autism, many African American children are not being diagnosed at an earlier age in comparison to their Caucasian counterparts (Gourdine et al., 2011). The literature suggested that the late diagnosis/identification of autism among African American children are due to inconsistencies in the diagnostic process (Gourdine et al., 2011). In fact, while the DSM-5 is used by medical and other professionals to diagnosed autism, children from a low socioeconomic status may be disproportionately affected due to lack of a primary care physician, health care insurance, and other community-based services.

The literature also suggested that demographic factors may have a predictive relationship in the diagnosis of ASD among African American children. Variables such as family socioeconomic factors (parental educational level and family annual income), family structural factors (marital status of custodial parent(s), parental ethnicity, number of children in home, other children in home with disability/chronic illness, where family lives), and child demographic factors (mother's age at time of birth, gender of child, birth status of child – single/multiple, adoption status and age of adoption of child, child order in family, other disability/chronic disease diagnosis) are important to consider when diagnosis of ASD is made. The literature also suggested that early diagnosis of ASD is crucial for intervention and treatment that could help children learn important skills to meet their daily needs (CDC, 2015). When a diagnosis is delayed for African American children, this could delay interventions and treatments that could help the child develop at a functional level (CDC, 2015). In this instance, it is imperative that a multidisciplinary approach is conducted to include psychologists, psychiatrists, pediatricians, speech pathologists, occupational therapists, and other professionals who could accurately make a diagnosis of ASD (Autism Society, 2015).

Several studies have addressed the independent variables economic status (Buescher et al., 2014; Järbrink, 2007; Lavelle et al., 2014), and ethnicity (Becerra, 2014; CDC, 2014; Gourdine et al., 2011; Guevara et al., 2006; Mandell et al., 2007; Mandell & Novak, 2005; Mandell et al., 2010) individually as it relates to the disparities in early diagnosis of ASD among African American children. This evident gap in the literature was clearly addressed by this study.

Furthermore, there were studies that examined maternal and paternal age (Julie et al., 2011; Campbell & Eicher, 2013; D' Onofrio et al., 2014), genetics (Bartlett et al., 2014; Cohen et al., 2005; DiGuiseppi et al., 2010; Hall et al., 2008; Zecavati & Spence, 2009), geography (Kalkbrenner et al., 2011; Mandell, 2005; Palmer et al., 2011; Yeargin-Allsopp, 2003), socioeconomic status (Durkin et al., 2010; Liptak et al., 2008; Thomas et al., 2012), educational level (Fountain et al., 2010; Van Meter et al., 2010), sex differences and race (Baio, 2014; Giarelli et al., 2010), and marital status (Bolman, 2006; Freedman et al., 2011; Williams et al., 2000) individually as they pertained to the diagnosis of ASD. However, an extensive research of the literature did not reveal any study that had examined the above variables together or how they may/may not have a predictive relationship in the diagnosis of ASD. This study may contribute or fill the gap in the literature by examining these variables together, using the Bronfenbrenner's ecological systems theoretical framework to address the lack of early diagnosis of AS among African American in comparison to Caucasian children. This study analyzed the predictive relationship between (1) family socioeconomic factors, (2) family structural factors, and (3) child demographic factors, and how these factors may be related to the diagnosis of AS among African American children in the Washington Metropolitan area.

Chapter 3 described the methodology that was used to address the research question. Chapter 3 also discussed the procedures and instruments related to this study. The research design used in this study was also described.

Chapter 3: Research Methodology

Introduction

African American children may not reach their full capability due to misdiagnosis of AS and could be deprived of an opportunity to receive adequate treatments or interventions (CDC, 2006; CDC, 2014; Mandell et al., 2007). The purpose of this research study was to determine if there are socioeconomic and demographic factors such as parental age at birth of a child, educational level, income level, and parents’ ethnicity that are related to the diagnosis of AS in African American children. This chapter includes a description of the research design, the participants, instruments created and utilized to conduct this study.

Research Design & Rationale

Research Questions & Hypotheses

To explore if there are demographic factors that have a predictive relationship in the rate of diagnosis of Asperger’s Syndrome (AS) in African American children, the following research question and hypotheses guided this study:

Research Question 1**:** What family socioeconomic factors predict the diagnosis of Asperger’s Syndrome in African American children who exhibit symptomology of AS?

$H_0$1: There are no statistically significant predictive relationships between family socioeconomic factors (parental education level and family annual income) and the AS diagnosis status of children who exhibit symptomology of AS.

H_a1: There are statistically significant predictive relationships between family socioeconomic factors (parental education level and family annual income) and the AS diagnosis status of children who exhibit symptomology of AS.

Research Question 2**:** What family structural factors predict the diagnosis of AS in African American children who exhibit symptomology of Asperger's syndrome?

H_02: There are no statistically significant predictive relationships between family structural factors (marital status of custodial parent(s), parental ethnicity, number of children in home, other children in home with disability/chronic illness, where family lives) and the AS diagnosis status of children who exhibit symptomology of AS.

H_a2: There are statistically significant predictive relationships between family structural factors (marital status of custodial parent(s), parental ethnicity, number of children in home, other children in home with disability/chronic illness, where family lives) and the AS diagnosis status of children who exhibit symptomology of AS.

Research Question 3**:** What child demographic factors predict the diagnosis of AS in African American children who exhibit symptomology of AS?

H_03: There are no statistically significant predictive relationships between child demographic factors (mother's age at time of birth, gender of child, birth status of child—single/multiple, adoption status and age of adoption of child, child order in family, other disability/chronic disease diagnosis) and the AS diagnosis status of children who exhibit symptomology of AS.

H_a3: There are statistically significant predictive relationships between child demographic factors (mother's age at time of birth, gender of child, birth status of child—

single/multiple, adoption status and age of adoption of child, child order in family, other disability/chronic disease diagnosis) and the AS diagnosis status of children who exhibit symptomology of AS.

Independent variables: For these research questions, the independent variables were family socioeconomic factors (parental educational level and family annual income), family structural factors (marital status of custodial parent(s), parental ethnicity, number of children in home, other children in home with disability/chronic illness, where family lives), and child demographic factors (mother's age at time of birth, gender of child, birth status of child – single/multiple, adoption status and age of adoption of child, child order in family, other disability/chronic disease diagnosis).

Dependent variables: The dependent variable was the rate of AS diagnosis status (0=no official diagnosis; 1=documented diagnosis).

Research Design

This research study utilized a quantitative, cross-sectional, correlational design to determine the demographic factors that can be used to predict the relationship of AS diagnosis in African American children. As the dependent variable was binary (0=no official diagnosis; 1=documented diagnosis), multiple logistic regression was used to explore these relationships. This quantitative method was relevant to use with this study because it allowed the researcher to effectively measure the independent variables/factors (income level, educational level, parental age, marital status, etc.) that may have a predictive relationship with the diagnosis of AS in African American children. This study specifically used the correlational quantitative research design which aimed to determine the extent of a relationship between two or more variables by using statistical data (McLeod, 2008). Correlational research designs are used to identify trends and patterns in data, but it does not go far enough in its analysis to prove causation for the observed patterns (McLeod, 2008). Cause and effect are not part of this type of research study; instead, data, relationships, and distributions of variables are the ones that are studied because interpreting causal relationships is limited (Shaughnessy, Zechmeister, & Zechmeister, 2015). Correlational research designs do not require manipulation of the variables; they are only identified and studied as they occur in their natural setting (McLeod, 2008).

A correlational design is an association or, more precisely, a measure of the extent to which two variables are related. When using a correlation design, the researcher identifies variables and looks for a relationship between them (McLeod, 2008). Correlational designs pertain to the systematic examination of the nature of relationships, or associations, between and among variables, rather than direct cause-effect relationships; they are usually cross-sectional (Burns & Grove, 2005; Walker, 2005). Researchers used a correlational design to examine whether changes in some variable/variables are associated with changes in different variable/variables, possibly resulting in covariance. With correlations, the researcher examines the direction, degree, magnitude, and strength of the relationships or associations (Burns & Grove, 2005; Walker, 2005).

Some strengths of correlational studies allow for examination of variables that may be unethical or impractical to test experimentally (McLeod, 2008). Correlational designs are quick and easy, and the researcher can easily see if there is a relationship between the variables and whether there is a relationship between two variables worthwhile for further exploration. In addition, it is a simple and objective method of describing the strength of a relationship between two variables (Bewick, Cheek, & Ball, 2003; McLeod, 2008). Correlational study designs do not equal or imply causation and they are difficult to establish cause and effect (McLeod, 2008). They can also be misused, and it is quite difficult to make an accurate conclusion about the causes of the relationship. Hence, correlational study designs limit the researcher to go beyond the data that is provided (McLeod, 2008).

Methodology

Population

Participants in this study included parents of children age 3 to 16 years old who demonstrated symptomology of AS but who may or may not have been diagnosed with AS and who reside in the DMV area. This area has the largest Black population of more than 2 million African Americans (Census Bureau, 2011). This population was appropriate for this study because researchers have shown that there is a higher rate of AS diagnosis and African American children are diagnosed at a significantly older age in comparison to Caucasians (Mandell & Novak, 2005; Mandell et al., 2007).

Sampling & Sampling Procedures

The sample for this study included parents of children with and without a formal diagnosis of AS living in the DMV area. Purposeful convenience (Patton, 1990) and snowball sampling (Atkinson & Flint, 2001; Goodman, 1961; Vogt, 1999) were used to recruit parents of children with and without a formal diagnosis of autism from a physician. Purposeful sampling, a nonprobability sampling technique, was used to identify a population of interest and develop a method of selecting cases without advanced knowledge (Cohen & Crabtree, 2006). This means that purposive sampling focuses on a distinct aspect or aspects of a population that are of significance which will allow me to answer the research question (Laerd Dissertation, 2012). The logic and power of purposeful sampling depend on the selection of information-rich cases for in-depth studies (Patton, 1990). In addition, purposeful convenience sampling is fast, easy, inexpensive, and increased the participation pool (Patton, 1990). Snowball sampling, a nonprobability sampling technique, is an approach used to locate information-rich key informants or critical cases for a study (Goodman, 1961; Vogt, 1999), by depending on participants' social network to access specific populations (Browne, 2005). This type of sampling usually identifies cases of interest from people who know other people and what cases information are rich. Snowball sampling was used to increase participants by allowing parents who participated in the study the opportunity to recruit their friends and acquaintances as participants (Voicu, 2011).

This sampling strategy was most appropriate for attaining participants that met the study criteria (Atkinson & Flint, 2001). Snowball sampling involved contacting parents of children with and without AS with whom I would not ordinarily have contact. Additionally, organizations and healthcare facilities must abide by the HIPAA Privacy Rule (US Department of Health and Human Services, 2016); hence, it was critical that parents provide the information of their children with and without a diagnosis of AS because this was necessary to obtain participants for the study. I also used criteria set by the DSM-5 (APA, 2013) to recruit parents of children with and without a formal diagnosis of AS.

The inclusion criteria included Black or African American parents of children who display AS symptomology with and without a formal diagnosis of AS from a physician (APA, 2013). If a child had a confirmed diagnosis of AS this child was also included in the study even if there was a diagnosis of another developmental disorder. Black or African American parents were given a screening and demographic form to identify their race and other demographics, the ASSQ (Ehlers et al., 1999), and the CAST (Williams et al., 2008) questionnaires so they could select the answers based on the symptoms they may or may not observe in their child. In the case where the child has two parents, data was collected from only one so as not to duplicate data for one child. Children from single-parent households were included in the study; however, data was only collected from one parent of the child.

The parents of children between the age group 3 to 16 years were chosen to participate in this study. Researchers have shown the average AS diagnosis occurs at 7.2 years of age, with poor children receiving the diagnosis 0.9 years later than the average (Mandell & Novak, 2005; Mandell et al., 2007). Additionally, the diagnoses of ASD, such as pervasive developmental disorder have usually occurred at an average of 3.9 years of age (Mandell & Novak, 2005). The selected age range ensured that parents of children who were diagnosed at an early age were included, but also parents of those with a late diagnosis were included as well. In addition, age 3 as the starting age range was appropriate because to make a diagnosis, the child must possess difficulty in at least one area of communication, socialization, or restricted behavior and it must be present prior to the age of 3 (Child Development Institute, 2015; National Institute of Health, 2011). Additionally, selecting parents of children within this age range ensured that the parents could complete the diagnostic tools included in this research study. Parents were asked on the demographic form if their child displays any of the symptomology associated with ASD.

The exclusion criteria included parents of children under 3 or children above 16 years old who may or may not display AS symptomology, parents who did not identify their race as African American, parents under 18 years old, as well as parents who were unable to read or write English. Parents of children under 3 years of age or 16 years of age and above fell outside of the age range identified for the study. If a child was outside of the participants' age, the parent was thanked for their participation and exited from the study. Parents who did not read or write in English were not included in the study because the questionnaire was administered in written format, which required comprehension of written English to answer the survey items appropriately. Also, the questionnaire was not translated into any other languages. Parents under the age of 18 years were also exited from the survey. Those who did not identify their ethnicity as Black or African American parents were not included and were thanked for their participation and exited from the study.

Sample size. The necessary sample size was calculated by using power analysis (Cohen, 1992) for a logistic regression based on the guidelines set in G*Power 3.1.9.2

software program (Faul et al., 2009). Logistic regression analysis is the preferred statistical test used to conduct a study when the dependent variable is dichotomous (binary) and the researcher is looking for predictive relationships between multiple variables (Statistics Solutions, 2016). *Z*-test was used to compute the sample size using a binomial X distribution (Hsieh et al., 1998) for a logistic regression and to determine a sufficient sample size an alpha of 0.05, a power of 0.80, a medium effect size (odds ratio = 1.75), Pr(Y=1/X=1) Ho = 0.2, and a two-tailed test was used. Based on the preceding assumptions, the desired sample size needed to achieve sufficient power of 0.80 (Cohen, 1992) was 187 participants.

Cox (1958) developed multiple logistic regression, a statistical method for analyzing a dataset in which there are one or more independent variables that determine an outcome. The outcome is measured with a dichotomous variable (in which there are only two possible outcomes). Multiple logistic regression examines the relationship between two quantitative variables and the odds of an outcome occurring or not (Bewick, Cheek, & Ball, 2003). Thus, multiple logistic regression analysis is applied when there is a single dichotomous outcome and more than one continuous-level independent variable (Cox, 1958; Kelley & Maxwell, 2003; McDonald, 2014). The researcher aimed to exceed the sample size of 187 during recruitment to ensure that there were an equal number of participants in each group (with and without a confirmed diagnosis of autism). This was crucial to ensure that during the data analysis process – if any data must be removed due to missing components, then the minimum sample size was still met.

Procedures for Recruitment, Participation, and Data Collection

Procedure for recruitment. For this research study to be conducted, I obtained permission from Walden University Institutional Review Board (IRB Approval number: 03-23-17-0197250) and the physician/director of the Melwood Family Dentistry in Upper Marlboro, Maryland. I also posted flyers on bulletin boards at various public locations (libraries, grocery stores, gyms/recreational facilities, laundromat, drug stores, and book stores) in the DMV where participants were recruited. Participants were also recruited from local churches and community centers in the DMV area. Qualtrics.com participant pool was used to recruit participants as well as Walden's participant pool when permission was granted. No potential participants were directly approached for recruitment for this study by the researcher.

Parents of children diagnosed with and without autism were introduced to the study and asked to complete the instruments and demographic forms. Flyers and packages containing the (consent form, screening and demographic questionnaires, ASSQ, and CAST questionnaires) were posted in the waiting room at the physician office so potential participants could obtain. Participants were informed that participation was voluntary, and they could discontinue at any time during the survey as part of the informed consent process. Signatures of participants were not collected as filling out the surveys constituted giving informed consent. Parents were asked to fill out an online self-administered screening/demographic questionnaire. By using an online format to recruit participants, I aimed to increase the participation pool. For the analysis to be effective, a total of 187 participants were recruited for those with and without a confirmed diagnosis of autism. Therefore, I aimed to exceed the sample size by recruiting an equal amount of the sample size for both groups from the DMV area that was effective for the analysis of the study.

Participants of children who may/may not display symptomology of AS and met inclusion criteria received information from the flyer about the research study and how they could access the online forms. Participants were informed that the information they provided was used for the study only and would not be shared with other outside entities. Those who preferred to fill out the forms via paper received a package in an envelope that contained the informed consent, demographic questionnaire, and a self-addressed stamped envelope for return of the documents. No signatures or identifying information was collected from any of the participants. Data was collected and retrieved over a 5-week period or until the necessary sample size was obtained. Participants were informed about the period in which the completed forms should be returned. Participants who filled out the forms incorrectly were counted as missing data and were not included in the study. Upon returning the completed demographic forms, participants were thanked for their participation in this study and given information on how they could access the study when it was finished. This study did not require any follow-up interview with participants and they could remain anonymous.

Data Collection

A package containing the informed consent, screening and demographic questionnaire, the ASSQ and CAST questionnaires, and a self-addressed stamped envelope was provided to participants who preferred a printed version of the questionnaire. Participants who preferred the electronic method were provided with information via the flyer to access the survey online using the website Qualtrics.com.

Instrumentation and Operationalization of Constructs

Participants were asked to fill out a self-administered demographics questionnaire to collect data regarding parental age, race, marital status, educational level, income, the number of children in the household, and birth order from eligible participants. Parental age refers to the age of the parent completing the survey at the time of the birth of the child with symptoms of AS. Parents were asked to identify their race and if they did not identify themselves as African American, these parents were exited from the survey. This measure was added because the snowball sampling method relies on word-of-mouth, which could result in the transfer of misinformation.

Parents also filled out the ASSQ and CAST questionnaires. Each questionnaire applied to a targeted age group; however, by utilizing both questionnaires in the study, parents were sure to complete the questionnaire that corresponds to their child’s age. A copy of the ASSQ is included as Appendix A, and a copy of the CAST is included as Appendix B. Permission to use the ASSQ is included as Appendix D. Additionally, permission to use the CAST instrument from the authors was not required, it is open access via the Internet and a copy of the instructions from the website is included as Appendix E. Both tests are available for free download per the authors on their website.

Demographics Questionnaire

I used a demographic questionnaire to gather information and collect data for this study. A sample of the questionnaire is provided in Appendix C. Online participants completed an electronic version of the demographic questionnaire as well. This demographic survey collected information about family socioeconomic factors (parental educational level and family annual income), family structural factors (marital status of custodial parent(s), parental ethnicity, number of children in home, other children in home with disability/chronic illness, where family lives), and child demographic factors (mother's age at time of birth, gender of child, birth status of child – single/multiple, adoption status and age of adoption of child, child order in family, other disability/chronic disease diagnosis).

This information was crucial to determine the independent variables needed for this study. This demographic questionnaire took about five minutes to complete and participants were instructed on how they could access the online version if needed. A paper demographic questionnaire format was provided for parents who did not wish to complete the online version. Participants' information collected from the demographic survey was protected and participants were informed that their information will remain private and will not be shared by other outside entities.

Table 1.
Assigned values of variables

Independent Variable	Dependent Variable
Parental age at birth of child ____	Asperger's Diagnosis Status
(numerical age)	0= Formal diagnosis
	1= No formal diagnosis

Child’s current age in years ____

(numerical age)

Child’s age at the time of diagnosis in years ____

(numerical age)

Geography

0= Maryland

1= District of Columbia

2= Virginia

Parents educational level (mother)

0= less than high school

1= high school graduate (includes equivalency)

2= some college, no degree

3= Associates degree

4= bachelor’s degree

5= master’s degree

6= Doctoral degree

Parents educational level (father)

0= less than high school

1= high school graduate (includes equivalency)

2= some college, no degree

3= Associates degree

4= bachelor’s degree

5= master’s degree

6= Doctoral degree

Mother’s race/ethnicity

0= White

1= Black or African American

2= Hispanic or Latino

3= Native American

4= Hawaiian or Pacific Islander

5= Two or more races

6=Prefer not to answer

Father’s race/ethnicity

0= White

1= Black or African American

2= Hispanic or Latino

3= Native American

4= Hawaiian or Pacific Islander

5= Two or more races

6= Prefer not to answer

Marital Status

0= never married/single

1= married

2= separated

3= divorced

4= widowed

Gender of child

0= male

1= female

Child birth-order in family

0= 1st

1= 2nd

2= 3rd

3= 4th

4= 5th

5= 6th

6= more than 6

Multiple birth

0= Single

1= Multiple

Number of children in family structure

Please specify number ________________

Family income level

Please indicate income amount ______________________

0= prefer not to answer

Family genetics

0= No

1= Yes

99= No non-genetically related siblings in home

Adoption status

0= No

1= Yes

If yes, actual age __________________

Disability among family members

Please specify_______________

0= prefer not to answer

Autism Spectrum Screening Questionnaire

The ASSQ, which consists of a 27-item questionnaire is used to screen, identify, and recommend children for further evaluation if needed to diagnose Asperger's syndrome (Ehlers et al., 1999). The ASSQ was constructed to evaluate children between the ages of 7 to 16 years with normal intelligence or mild mental retardation and is used as a screening measure for Asperger's syndrome. Responses on this survey range from *no*, *somewhat*, or *yes*. Each response was weighted to provide an overall score for this questionnaire. Areas that were assessed included social interaction, problems with communication, restricted/repetitive behaviors, clumsiness, and related behaviors (Ehlers et al., 1999). This questionnaire has 11 items that focus on social interaction, six items focus on communication problems, five items cover restricted and repetitive behavior and the remainder covers motor clumsiness and other associated symptoms (Ehlers et al., 1999). The ASSQ has shown previously to be reliable and has a good validity as a population screen for AS with the Bergen Child Study among 7 to 9 years old that showed a sensitivity of 0.91 and specificity of 0.86 (Posserud, Lundervold, & Gillberg, 2009).

Childhood Autism Spectrum Test

The second measure that was used was the CAST (Williams et al., 2008) a 37-item questionnaire, evaluation aimed at parents to assess the severity of Asperger's syndrome in children aged 4-11 years. This instrument is used to assess children who may have Asperger's syndrome and other related social and communication conditions.

The CAST have a scoring that ranges from 0-31. Autism-positive responses received a score of 1, and autism-negative responses received a score of 0 (Baron-Cohen, 2009). A score of 15 or higher is a cause for concern for possible autism spectrum disorder (Baron-Cohen, 2009). Responses to this questionnaire are limited to *yes* or *no*. Each response was weighted to provide an overall score for this questionnaire. The CAST has a moderate to good test-retest reliability (Allison et al., 2007; Williams et al., 2006). The CAST was used to study the prevalence of autism-spectrum conditions in school-aged children 5 to 9 years in Cambridgeshire (Baron-Cohen, 2009). In addition, the CAST had previously demonstrated good accuracy for use as a screening test, with high sensitivity in studies with primary school aged children in mainstream schools (Allison et al., 2007).

Data Analysis Plan

The version 21 Statistical Package for Social Sciences (IBM SPSS) was used to complete the data analysis for this study. Questionnaires that were administered via paper were hand scored and transferred to an Excel spreadsheet. Data was exported from Qualtrics.com to an Excel spreadsheet. Then data was imported from the Excel spreadsheet to SPSS. The data was analyzed for any missing data and adjusted accordingly so that the analysis only included complete survey responses. Next, descriptive statistics were analyzed. Multiple logistic regression was used to examine the dependent variable (with and without Asperger’s diagnosis) and the independent variables (parental age, marital status, educational level, income level, parents’ ethnicity etc.). The data was checked to ensure that all the assumptions for the test had been met, including independence, homogeneity of variance, linearity, and a normal distribution of data in both samples.

The frequency distribution was used to explore the response patterns of the independent variables and the dependent variable in this study. Frequency distribution summarizes the distribution of responses on a survey, and this was used to examine the nominal variables (Nachmias & Nachmais, 2008). Univariate analysis was used to examine the data and measure mean which is the total number of participants that responded *yes* or *no* to the demographic survey. Univariate analysis or statistics were used to measure the mean, median, and mode that represented the categorical frequency that will be observed (Goodwin, 1984; Statistic Solutions, 2016). Measures of tendency included mean, mode, and median. Mean was used to measure the total amount of observations, the median measured the distribution equally, and mode focused on the category of most observed frequency that appeared in the distribution (Laerd Statistics, 2013).

I used chi-square test to compare the dependent variables in the independent and categorical variables. Chi-square test was used to find the difference in frequencies of the dependent variable between the different categories of independent variables. Pearson’s Chi-square method was used to determine the statistical significance of the relationship with the categorical variable or variables and whether the relationship will be statistically significant beyond the 0.5 level (Palazzolo, 2010). The results of this test helped to determine if there were a difference in the two groups studied, children diagnosed with

AS and children not diagnosed with AS, based on the factors identified in the research questions.

The variance described how distributions were allotted, and standard deviation discussed homogeneity in the sampled population to formulate a normal distribution curve with the use of SPSS statistical software (Laerd Statistics, 2013). If the assumptions of the research study were met, they were measured by using bivariate or multivariate inferential statistics. Bivariate and multivariate techniques are advantageous to use in quantitative research because it is quick and cost-effective to execute (Statistic Solutions, 2016). I used multiple logistic regression to determine if the variables identified in the research question could be used to predict the relationship of the rate of AS diagnosis in the study sample. Prior to analysis, the data was screened for missingness and violation of assumptions. Then the results of the multiple logistic regression were analyzed to determine which, if any, of the factors, identified significantly, explained the rate of AS diagnosis in African Americans and, if so, to what extent. For logistic regression, the odds ratio (OR) helps to determine the extent to which the dependent variable varies in relation to each independent variable. This variable allowed me to determine the effect size for each of the demographic factors analyzed (Lomax & Hahs-Vaugh, 2012).

Threats to Validity

Creswell (2009) posited that internal and external are two types of threats to validity. These threats could weaken the researchers’ ability to make conclusions or inferences in their study. Thus, threats to internal validity are controlled by providing sufficient evidence that there is a relationship between the independent and dependent variables (Creswell, 2009). For the study results to be valid, the survey instruments must be valid and measure what they are intended to measure (Kimberlin & Winterstein, 2008). Since a researcher-designed demographic questionnaire was used for this study, this may have posed a threat to the validity of the study. Additionally, the survey tool forced respondents to select from prepopulated responses. This could cause a participant to select a response that does not accurately reflect their answer to the question asked. This could also have posed a threat to the validity of the study.

Respondents' bias is comprised of any error in a study that is a result of participants' inability or unwillingness to provide accurate responses or answers in a survey. This unwillingness or inability to answer responses accurately and honestly could occur due to unfamiliarity, respondents' fatigue, faulty recall, question format, or question context (Pelham & Blanton, 2006). To avoid respondents' bias, I ensured that questions were clear and to the point, making it easier for participants to answer honestly and accurately.

Ethical Procedures

The target population was taken into consideration to ensure that their vulnerability was not at risk and all ethical matters were addressed adequately. Agreement to gain access to participants' data and information was obtained from the Walden University IRB department to conduct this study. Participants were informed of their rights and privacy and clarification was given prior to completing the online and paper format survey using informed consent. No identifying information (for example name, email, social security number) was collected as part of the study to prevent any disclosures of sensitive medical data that may be disclosed in compliance with the HIPAA Act (US Department of Health and Human Services, 2016).

I provided my contact information (email address) so participants could contact me if needed. Informed consent forms were provided in the packages so each participant who received a paper version of the data collection tools were able to read the study's purpose and process in detail before they agreed to take part in the study. Participants needed to be able to speak and read in English because the study's purpose and procedures for collecting data were explained in the consent form prior to the questionnaires and forms being filled out. Participants who accessed the online version of the survey were provided with a website link in the flyer to access the survey online. The informed consent was provided at the beginning of the survey and it was explained that entering the survey and completing items indicated that they consented to participate in the study.

As part of the informed consent, participants were informed that their identity and personal information will remain secure and confidential and will not be shared with other parties. Additionally, participants were informed that the questionnaire included in this study will not serve as a diagnosis of AS or any other condition. Participants were informed that the instruments used in this study will aid in providing information about behaviors that the child may exhibit but are not to be considered as a method of diagnosing AS or Autism in their child. Scores from the instruments will not be shared with participants. If parents are concerned about behaviors their child exhibit, they were encouraged to discuss the behaviors with their primary physician. Data and personal information collected will be kept in a secure vault for a period of five years by the researcher. Dissemination of the data was shared with my advisor and committee member. Hence, participants were informed that their information will not be shared with other researchers. After a period of five years, the information will be destroyed. Participants were informed that participation is voluntarily, and their safety and personal concern was paramount. If any participant wanted to discontinue or opt out of the study, they could do so.

Summary

This research study used a quantitative, cross-sectional, analysis of variance method together with a purposeful convenience sampling, and snowball sampling methods to collect data. The survey instrument consisted of a demographic self-administered questionnaire, ASSQ, and CAST questionnaires. The data was analyzed to determine if there are factors that have a predictive relationship in the rate of AS diagnosis among African American children based on demographics. The use of validity instruments helped to reduce type II error and helped with internal consistency (Creswell, 2008). The analysis of variance design was deemed to be an appropriate method to explore the differences between these two groups (with and without AS diagnosis) based on demographic factors. Chapter 4 provided the results of the study when completed.

Chapter 4: Results

Introduction

The purpose of this study was to determine if demographic factors had any predictive relationships with AS diagnosis among African-American children in the DMV and if so, to what extent. Eligible participants were parents of children aged 3 to 16 years old who had demonstrated symptomology of AS but who may, or may not, have been diagnosed with AS and who reside in the DMV area.

The data used for analysis were from an online survey administered via the internet through Qualtrics.com that contained a demographic questionnaire, the ASSQ and CAST questionnaire. If the participant chose to fill out a paper version, then a self-stamped addressed envelope was provided for participants to return the survey when completed. Flyers were posted at the Melwood Family Dentistry office waiting room, so participants could access the survey link via the internet. The ASSQ is a 27-item survey that used to screen, identify, and recommend children for further evaluation if needed to diagnose AS (Ehlers et al., 1999). The CAST questionnaire is a 37-item survey, used to assess children who may have AS and other related social and communication conditions (Williams et al., 2008).

The independent variables were family socioeconomic factors (parental educational level and family annual income), family structural factors (marital status of custodial parent(s), parental ethnicity, number of children in home, other children in home with disability/chronic illness, where family lives), and child demographic factors (mother’s age at time of birth, gender of child, birth status of child – single/multiple, adoption status and age of adoption of child, child order in family, other disability/chronic disease diagnosis). The dependent variable was AS diagnosis status (0=no official diagnosis; 1=documented diagnosis).

The data was checked to ensure that all the assumptions for the test were met, including independence, homogeneity of variance, linearity, and a normal distribution of data. Multiple logistic regression was used to examine the relationship between the independent variables (parental age, marital status, educational level, income level, parents' ethnicity etc.) and dependent variable (with and without Asperger's diagnosis).

Research Questions and Hypotheses

RQ1. What family socioeconomic factors predict the diagnosis of AS in African American children who exhibit symptomology of AS?

$H_0$1. There are no statistically significant predictive relationships between family socioeconomic factors (parental education level and family annual income) and the AS diagnosis status of children who exhibit symptomology of AS.

H_a1. There are statistically significant predictive relationships between family socioeconomic factors (parental education level and family annual income) and the AS diagnosis status of children who exhibit symptomology of AS.

RQ2. What family structural factors predict the diagnosis of AS in African American children who exhibit symptomology of AS?

$H_0$2. There are no statistically significant predictive relationships between family structural factors (marital status of custodial parent(s), parental ethnicity, number of children in home, other children in home with disability/chronic illness, where family lives) and the AS diagnosis status of children who exhibit symptomology of AS.

H_a2. There are statistically significant predictive relationships between family structural factors (marital status of custodial parent(s), parental ethnicity, number of children in home, other children in home with disability/chronic illness, where family lives) and the AS diagnosis status of children who exhibit symptomology of AS.

RQ3. What child demographic factors predict the diagnosis of AS in African American children who exhibit symptomology of AS?

H_03. There are no statistically significant predictive relationships between child demographic factors (mother's age at time of birth, gender of child, birth status of child—single/multiple, adoption status and age of adoption of child, child order in family, other disability/chronic disease diagnosis) and the AS diagnosis status of children who exhibit symptomology of AS.

H_a3. There are statistically significant predictive relationships between child demographic factors (mother's age at time of birth, gender of child, birth status of child—single/multiple, adoption status and age of adoption of child, child order in family, other disability/chronic disease diagnosis) and the AS diagnosis status of children who exhibit symptomology of AS.

Chapter 4 presents the results of the data analysis methods following the collection and organization of the data, including details on the research questions and hypotheses, a description of the sample used for statistical analysis, and an exploration of the statistical tests used to observe the research questions and hypotheses. Chapter 4 concludes with a summary section.

Data Collection

A package containing the informed consent, screening and demographic questionnaire, the ASSQ and CAST questionnaires, and a self-addressed stamped envelope were provided to participants who prefer a printed version of the questionnaire. The package was made available in the waiting room at the Melwood Family Dentistry in Upper Marlboro, Maryland. Printed copies of flyers were available in the waiting room of the dentist office so participants could take a copy if they choose to. Flyers were distributed at various public places bulletin boards in the DMV area (grocery stores, libraries, churches, laundromats, gyms, etc.) and a survey link was provided on the flyer for participants to access the survey via internet. The survey was anonymous with no identifying information collected from participants. No in-person soliciting was conducted for this study. Participation was voluntary, and no monetary/gifts were promised to participants in exchange for participating in the study. To progress to the main survey, participants had to provide informed consent and meet the inclusion criterion of having an African American child. Those who did not consent or did not have a child who was African American were exited from the survey.

A power analysis was conducted to determine the ideal minimum sample size using G*Power 3.1.7 (Faul, Erdfelder, Buchner, & Lang, 2013). Based on a logistic regression with a medium effect size (odds ratio = 1.75), the desired sample size was 215. The survey became available in April 7, 2017 and data collection ended June 30, 2017. A total of 201 respondents completed the survey online. Twenty-two participants returned the self-stamped envelope with completed surveys and the responses were entered into the database containing the online survey data. Before conducting any analyses, responses were screened for completeness. Fourteen out of the 201 total responses (6.9%) were removed for incomplete data, bringing the total number of participants to 187. A post-hoc power analysis was conducted with the actual sample size of 187, medium effect size (odds ratio of 1.75), which indicated that the achieved power of the logistic regressions was 0.85 which was more than the minimum required of 0.80 power.

Results

Demographics

Table 2 shows a summary of demographics for the study participants, with the largest number living in Maryland (42.8%), and most mothers had at least some college education (73.8%) while only about half of the fathers had at least some college education (50.3%). Both the mothers (81.3%) and the fathers (66.8%) were predominantly African-American, which aligned with the focus of the study. Most of the children have at least one parent that went to college (77%) and less than half children have both of their parents that went to college (47.1%). Most of the race of the mothers (93.13%) and fathers (67.4%) of the children were Black/African-American, more than half (60.4%) having at least one African-American parent, only 16% have one White parent. Approximately half of the respondents were married (48.7%), with the rest being single (31.0%), divorced (10.7%), separated (7.0%), or widowed (2.7%).

The children were mostly male (65.0%) and the majority were either the first-born (34.2%) or second-born child in the family (35.9%). Most of the children in the present sample (83.8%) were single births and did not have adopted siblings (42.2%). Many of the children were not adopted (88.9%), thus adoption age (*M* = 3.55, *SD* = 2.09) was not included as a variable in the regression analysis for RQ3 (due to too many missing data points for those children who are not adopted). Around a quarter of the children (21.5%) had family members with disabilities, and there were less than half (44.9%) that have other disability. The mean age of the respondent (parent) at the time of the child's birth was 30.08 (*SD* = 8.78) and the mean family income was $69,550.21 (*SD* = $51,604.62). The mean current age of the child was 9.32 (*SD* = 3.69), with a mean age of 4.08 (*SD* = 0.82) at the time of diagnosis (for those with official diagnoses). On average, there were 2.04 (*SD* = 1.96) children in the family. For the dependent variable of interest, rate of AS diagnosis (0 = no official diagnosis; 1 = documented diagnosis), roughly half of the children in the sample (51.3%) had an official diagnosis of AS.

Table 2.

Summary of Demographics (N = 187)

Characteristic	*N*	Percent
Geography (N = 187)		
Maryland	80	42.8%
District of Columbia	62	33.2%
Virginia	45	24.1%
Parent's Education Level – Mother (N = 187)		

Characteristic	*N*	Percent
Less Than High School	10	5.3%
High School Graduate (or equivalent)	39	20.9%
Some College, No Degree	37	19.8%
Associates Degree	32	17.1%
Bachelor’s Degree	27	14.4%
Master’s Degree	27	14.4%
Specialist Degree	6	3.2%
Doctoral Degree	9	4.8%
Parent’s Education Level – Father (N = 187)		
Less Than High School	27	14.4%
High School Graduate (or equivalent)	66	35.3%
Some College, No Degree	39	20.9%
Associates Degree	19	10.2%
Bachelor’s Degree	17	9.1%
Master’s Degree	14	7.5%
Specialist Degree	3	1.6%
Doctoral Degree	2	1.1%
One parent was in College (N = 187)		
No	43	23%
Yes	144	77%

Characteristic	*N*	Percent
Both Parents Were in College (N = 187)		
No	99	52.9%
Yes	88	47.1%
Mother's Race/Ethnicity (N = 187)		
White	23	12.3%
Black or African American	152	81.3%
Hispanic or Latino	7	3.7%
Native American	2	1.1%
Hawaiian or Pacific Islander	1	0.5%
Two or more races	2	1.1%
Father's Race/Ethnicity (N = 187)		
White	15	8.0%
Black or African American	126	67.4%
Hispanic or Latino	15	8.0%
Native American	8	4.3%
Hawaiian or Pacific Islander	1	0.5%
Two or more races	22	11.8%
Parent Same Race of Black (N = 187)		
Both parents Black	74	39.6%
One Parent difference race	113	60.4%

Characteristic	*N*	Percent
One Parent is White (N = 187)		
No	157	84.0%
Yes	30	16.0%
Marital Status (N = 187)		
Never Married/Single	58	31.0%
Married	91	48.7%
Separated	13	7.0%
Divorced	20	10.7%
Widowed	5	2.7%
Gender of Child (N = 117)		
Male	76	65.0%
Female	41	35.0%
Child Birth-Order in Family (N = 117)		
1st	40	34.2%
2nd	42	35.9%
3rd	16	13.7%
4th	10	8.5%
5th	2	1.7%
6th	3	2.6%
More Than 6	4	3.4%

Characteristic	*N*	Percent
Multiple birth (*N* = 117)		
Single	98	83.8%
Multiple	19	16.2%
Family Genetics (N = 120)		
No	34	28.3%
Yes	7	5.8%
No Non-Genetically Related Siblings in Home	79	65.8%
Adoption Status (N = 117)		
No	104	88.9%
Yes	13	11.1%
Disability Among Family Members (N = 187)		
No	147	78.5%
Yes	40	21.5%
Other Disability (N = 117)		
No	33	17.6%
Yes	84	44.9%
Asperger's Syndrome diagnosis (N = 187)		
No	91	48.7%
Yes	96	51.3%
	M	*SD*

Characteristic	*N*	Percent
Parental age at birth of child (*N* = 117)	30.08	8.78
Child’s current age in years (*N* = 187)	9.32	3.69
Child’s age at the time of diagnosis in years (*N* = 47)	4.08	0.82
Number of children in family structure (*N* = 186)	2.04	1.96
Family income level (*N* = 187)	$69,550.21	$51,604.62
If Adopted, Actual Age of Adoption (*N* = 8)	3.55	2.09
ASSQ Score (*N* = 187)	32.11	28.50
CAST Score (*N* = 187)	13.78	9.91

Symptomatology and Diagnosis

To confirm that children with official diagnoses of AS showed the symptomatology of the syndrome, scores on the ASSQ and the CAST for children with and without official diagnoses were compared using binary logistic regression and chi-square test (chosen because of violations of the equal variances assumption and the assumption of normality; see Tables 3 and 4). The two questionnaires were scored according to standardized scoring methods and higher scores on either of the instruments indicate more symptoms of Asperger’s Syndrome. As was expected, children with official diagnoses ($M = 58.54$, $SD = 10.46$) scored higher on the ASSQ than children without ($M = 4.23$, $SD = 5.63$), $U = 3$, $p < 0.001$. Additionally, children with official diagnoses (*M* = 22.59, *SD* = 14.61) scored higher on the CAST than children without (*M* = 4.47, *SD* = 3.17), *U* = 10.00, *p* < 0.001.

Table 3.
Levene's Tests of Equality of Variances for Comparison of ASSQ and CAST Scores between Children with and without Official Diagnoses

Variable	*F*	*df*	*p*
ASSQ	34.30	1	< 0.001
CAST	14.96	1	< 0.001

Table 4.
Shapiro-Wilk Tests of Normality for Comparison of ASSQ and CAST Scores between Children with and without Official Diagnoses

Variable	Diagnosis Status	*W*	*P*
ASSQ	No Diagnosis	0.76	< 0.001
	Diagnosis	0.96	0.01
CAST	No Diagnosis	0.91	< 0.001
	Diagnosis	0.97	0.04

Chi-Square Analyses

For the analysis to address the research questions, the demographic factors were recoded. The variables of geography (0 = DC, 1 = Maryland/Virginia), sibling disability (0 = No, 1 = Yes), other disability (0 = No, 1 = Yes), child's gender (0 = Male, 1 = Female), multiple birth (0 = No, Single; 1 = Yes, Multiple), adoption status (0 = No, 1 = Yes), marital status of parents (0 = Single/Not married, 1 = Have been married), education level of parents (0 = high school education, 1 = college education), and race of parents (0 = White, 1 = Non-white), and other race variables of parent same race of Black (0 = No, 1 = Yes), one parent is White (0 = No, 1 = Yes), one parent was in college (0 = No, 1 = Yes),, and both parents were in college (0 = No, 1 = Yes); and Asperger's official diagnosis (0 = No, 1 = Yes) were dummy coded using two binary categories of 0 and 1. Number of siblings and parent’s age were continuous measured using the actual number of siblings and age, respectively. Child’s birth order was categorical measured with seven categories (0 = First Child, 1 = Later Child, 2 = 3rd, 3 = 4th, 4 = 5th, 5 = 6th, and 6 = More than 6).

Table 5.
Cross Tabulation Results of Asperger’s Syndrome Diagnosis Status of Children Versus Demographic Factors of Parents

Independent Variable	Category		Asperger's Official Diagnosis		Total
			0 No	1 Yes	
Sibling Disability	0 No	n	79	68	147
		%	86.80%	70.80%	78.60%
	1 Yes	n	12	28	40
		%	13.20%	29.20%	21.40%
Total		n	91	96	187
Other Disability	0 No	n	33	0	33
		%	68.80%	0.00%	28.20%
	1 Yes	n	15	69	84
		%	31.30%	100.00%	71.80%
Total		n	48	69	117
Child's Gender	0 Male	n	28	48	76
		%	58.30%	69.60%	65.00%
	1 Female	n	20	21	41

		%	41.70%	30.40%	35.00%
Total		n	48	69	117
Multiple Birth	0 No (Single)	n	42	56	98
		%	87.50%	81.20%	83.80%
	1 Yes (Multiple)	n	6	13	19
		%	12.50%	18.80%	16.20%
Total		n	48	69	117
Child's Birth Order	0 First child	n	23	17	40
		%	47.90%	24.60%	34.20%
	1 Later child	n	25	52	77
		%	52.10%	75.40%	65.80%
Total		n	48	69	117
Adoption Status	0 No	n	43	61	104
		%	89.60%	88.40%	88.90%
	1 Yes	n	5	8	13
		%	10.40%	11.60%	11.10%
Total		n	48	69	117
Marital Status	0 Single/Not Married	n	36	22	58
		%	39.60%	22.90%	31.00%
	1 Have been Married	n	55	74	129
		%	60.40%	77.10%	69.00%
Total		n	91	96	187
Mother's Education Level	0 High school education	n	25	24	49
		%	27.50%	25.00%	26.20%
	1 College education	n	66	72	138
		%	72.50%	75.00%	73.80%
Total		n	91	96	187
Father's Education Level	0 High school education	n	48	45	93
		%	52.70%	46.90%	49.70%

	1 College education	n	43	51	94
		%	47.30%	53.10%	50.30%
Total		n	91	96	187
Parent same race	0 No	n	49	64	113
		%	53.80%	66.70%	60.40%
	1 Yes	n	42	32	74
		%	46.20%	33.30%	39.60%
Total		n	91	96	187
One parent is White	0 No	n	81	76	157
		%	89.00%	79.20%	84.00%
	1 Yes	n	10	20	30
		%	11.00%	20.80%	16.00%
Total		n	91	96	187
One parent was in College	0 No	n	23	20	43
		%	25.30%	20.80%	23.00%
	1 Yes	n	68	76	144
		%	74.70%	79.20%	77.00%
Total		n	91	96	187
Both parents were in College	0 No	n	50	49	99
		%	54.90%	51.00%	52.90%
	1 Yes	n	41	47	88
		%	45.10%	49.00%	47.10%
Total		n	91	96	187

Prior to the analyses to address the research questions, a test of comparison was conducted to determine whether there were statistically significant differences in the AS diagnosis status of children by differences of demographic factors of parents. The demographic factors included sibling disability, other disability, child’s gender, multiple birth, child's birth order, adoption status, marital status of parents, education level of parents, and race of parents (parent same race of Black, one parent is White, one parent was in college, and both parents were in college). A chi-square test was conducted and a level of statistical significance of p<0.05 was used in the analysis.

The results of the chi-square tests were presented in Table 6. Chi-square test results showed that there were statistically significant differences in the AS diagnosis status of children by only sibling disability (X^2 (1) = -7.10, $p = 0.01$), other disability (X^2 (1) = 66.07, $p < 0.001$), child's birth order (X^2 (1) = 6.82, $p = 0.01$), and marital status (X^2 (1) = 6.05, $p = 0.01$).

- Parents with no other child with a disability (70.8%) have statistically significantly higher frequency of having children diagnosed with AS than those parents with other children with disabilities.
- Later born children (75.4%) have statistically significantly higher frequency of being diagnosed with AS first children.
- Parents who have been married to other parent at some point (77.1%) have a statistically significantly higher frequency of having children diagnosed with AS than those parents with marital status of never married.

Table 6.
Chi-Square Test Results of Relationship of Asperger's Syndrome Diagnosis Status of Children and Demographic Factors of Parents

Dependent Variable	Independent Variable	Pearson Chi-Square Value	df	Asymp. Sig. (2-sided)
Asperger's Syndrome diagnosis	Sibling Disability	7.10	1	0.01*
	Other Disability	66.07	1	0.00*
	Child's Gender	1.57	1	0.21

Multiple Birth	0.84	1	0.36
Child's Birth Order	6.82	1	0.01*
Adoption Status	0.04	1	0.84
Marital Status	6.05	1	0.01*
Education of Mother	0.15	1	0.70
Education of Father	0.64	1	0.42
Parent same race	3.21	1	0.07
One parent is White	3.36	1	0.07
One parent was in College	0.52	1	0.47
Both parent was in College	0.29	1	0.59

*Statistically significant difference at level of significance of $p<0.05$

Research Question 1. What family socioeconomic factors predict the diagnosis of Asperger's Syndrome in African American children who exhibit symptomology of Asperger's syndrome?

Null hypothesis 1 ($H0_1$). There are no statistically significant predictive relationships between family socioeconomic factors (parental education level and family annual income) and the Asperger's Syndrome diagnosis status of children who exhibit symptomology of AS.

To explore this research question, a binary logistic regression was performed with AS diagnosis as the dependent variable and mother education level, father education level, and family income as the independent variables (predictor). The dummy codes for the independent variables of mother education level and father education level; and the continuous measure of actual family income were used in the binary logistic regression. Predictors were entered in the model (and all later models) using a forced entry method. There are several assumptions that must be true for the test to be valid. A binary logistic regression assumes independence of errors, which was true for the present data, as each case represents a single unrelated participant. Additionally, a binary logistic regression assumes that none of the independent variables in the present data set are highly correlated with one another (Hosmer, Lemeshow, & Sturdivant, 2013). To assess whether multicollinearity was an issue in the present data set, VIF and tolerance statistics were obtained. As can be seen in Table 7, all VIF values were well under 10 and tolerance values over 0.1 (following the guidelines of Bowerman and O'Connell (1990) and Myers (1990)), indicating that multicollinearity was not an issue, and the analysis could proceed as planned.

Table 7.
VIF and Tolerance Values for the Binary Logistic Regression Model for Research Question 1

Variable	VIF	Tolerance
Mother Ed	0.73	1.37
Father Ed	0.71	1.41
Family Income	0.76	1.38

The results of the logistic regression model (Table 8) showed that mother education level (Wald (1) = 0.003, *p* = 0.96), father education level (Wald (1) = 0.34, *p* = 0.56), and family annual income (Wald (1) = 0.07, *p* = 0.80) did not have a statistically significant predictive relationship with AS diagnosis status of children. Based on these results, the null hypothesis that there are no statistically significant predictive relationships between family socioeconomic factors (parental education level and family annual income) and the AS diagnosis status of children who exhibit symptomology of AS was retained.

Table 8.
Model Coefficients for Binary Logistic Regression Analysis with Asperger's Syndrome Diagnosis as the Dependent variable and Mother's Education Level, Father's Education Level, and Family Income as Predictor Variables

Variable	*B* (SE)	*Wald*	*p*	Odds Ratio
Intercept	-0.09 (0.30)	0.09	0.76	0.91
Mother Education	-0.02 (0.39)	0.003	0.96	0.98
Father Education	0.20 (0.34)	0.34	0.56	1.23
Income	<0.001 (<0.001)	0.07	0.80	1.00

Note: $R^2 = 0.04$ *(Cox & Snell). Model* $X^2(3) = 0.71$, p = 0.87.

Research Question 2. What family structural factors predict the diagnosis of Asperger's Syndrome in African American children who exhibit symptomology of Asperger's syndrome?

Null hypothesis 2 ($H0_2$). There are no statistically significant predictive relationships between family structural factors (parental marital status, parental race, the number of siblings of the child, disability among family members, and geography) and the Asperger's Syndrome diagnosis status of children who exhibit symptomology of AS.

To explore this research question, a binary logistic regression was performed with AS diagnosis as the outcome variable and marital status, mother's race, father's race, the number of siblings of the child, disability among family members, and geography as the predictor variables. The dummy codes for the independent variables of marital status, mother's race, father's race, disability among family members, and geography; and continuous measure of the number of siblings of the child were used in the binary logistic regression. VIF and Tolerance statistics were obtained for the model and indicated that there were no issues of multicollinearity (see Table 9).

Table 9.
VIF and Tolerance Values for Binary Logistic Regression Model for Research Question 2

Variable	VIF	Tolerance
Marital Status	0.99	1.01
Mother Race	0.96	1.04
Father Race	0.94	1.07
# Siblings	0.70	1.42
Family Disability	0.72	1.40
Geography	0.92	1.09

One participant was excluded from this analysis due to missing father race data resulting in 186 total remaining participants. The results of the regression model (Table 10) showed that only parental marital status (Wald (1) = 4.14, $p = 0.04$) had a statistically significant predictive relationship with AS diagnosis status of children. The null hypothesis that there are no statistically significant predictive relationships between family structural factors (parental marital status, parental race, the number of siblings of the child, disability among family members, and geography) and the AS diagnosis status of children who exhibit symptomology of AS was rejected and the alternative hypothesis accepted. Based on the odds ratio, specifically, children are more likely to have an official diagnosis of AS if the mother has been married. Per the results of the logistic regression (see Table 10) a mother who is married is 1.98 times more likely to have a child diagnosed with AS than a mother who is single or has not been married.

Table 10.
Model Coefficients for a Binary Logistic Regression Analysis with Asperger's Syndrome Diagnosis as the Dependent Variable and Marital Status, Mother's Race, Father's Race, number of Siblings of the Child, Disability among Family Members, and Geography

Variable	*B* (SE)	*Wald*	*p*	Odds Ratio
Intercept	0.44 (0.82)	0.29	0.59	1.55
Marital Status	0.69 (0.34)	4.14	0.04	1.98
Mother's Race	-0.77 (0.62)	2.32	0.13	0.46
Father's Race	-0.61 (0.10)	0.96	0.33	0.54
Family Disability	0.17 (0.45)	3.02	0.08	1.18
Number of Siblings	0.58 (0.34)	1.63	0.20	1.78
Geography	-0.13 (0.82)	0.14	0.71	0.88

Note: $R^2 = 0.10$ *(Cox & Snell). Model* $X^2(6) = 19.23$, p = 0.004.

Research Question 3. What child demographic factors predict the diagnosis of Asperger's Syndrome in African American children who exhibit symptomology of Asperger's syndrome?

Null hypothesis 3 ($H0_3$). There are no statistically significant predictive relationships between child demographic factors (mother's age, child's gender, multiple birth status, adoption status, birth order, and other disabilities) and the AS diagnosis status of children who exhibit symptomology of AS.

To explore this research question, a binary logistic regression was performed with AS diagnosis as the outcome variable and the mother's age at time of birth, the child's gender, whether there was a multiple birth, the adoption status of the child, the child's birth order, and whether the child presented with any other disability as the predictor variables. The regular coding for the independent variables of the child's gender, whether there was a multiple birth, the adoption status of the child, and whether the child presented with any other disability; continuous measure of the mother's age at time of birth; and regular categorical coding of the child's birth order were used in the binary logistic regression. VIF and Tolerance statistics indicated that multicollinearity was not an issue for this model (Table 11).

Table 11.
VIF and Tolerance Values for Binary Logistic Regression Model for Research Question 3

Variable	VIF	Tolerance
Mother Age	0.70	1.43
Child Gender	0.96	1.04
Multiple Birth	0.92	1.08
Adoption Status	0.95	1.06
Birth Order	0.65	1.55
Other Disability	0.84	1.19

Seventy participants did not provide birth order information and were excluded from the analysis, bringing the remaining total to 117 participants. The results of the regression model (Table 12) showed that the demographic variables of mother age, child gender, multiple birth status, birth order, and other disabilities did not have a statistically significant predictive relationship with AS diagnosis status of children. The null hypothesis that there are statistically significant predictive relationships between child demographic factors (mother's age, child's gender, multiple birth status, adoption status, birth order, other disabilities) and the AS diagnosis status of children who exhibit symptomology of AS was retained.

Table 12.
Model Coefficients for a Binary Logistic Regression Analysis with Asperger's Syndrome Diagnosis as the Dependent Variable and Mother's Age at Time of Birth, Child's Gender, Multiple Birth, the Adoption Status of the Child, Child's Birth Order, and Child's Other Disability as Predictor Variables

Variable	*B* (SE)	*Wald*	*p*	*Odds Ratio*
Intercept	-21.78 (6923.19)	0.00	1.00	0.00
Mother Age	0.02 (0.04)	0.19	0.67	1.02
Child Gender	0.20 (0.66)	0.09	0.77	1.22
Multiple Birth	0.59 (0.84)	0.50	0.48	1.81
Adoption Status	0.81 (1.14)	0.50	0.48	2.24
Birth Order	-0.50 (0.80)	0.39	0.54	0.61
Other Disability	22.94 (6923.19)	0.00	1.00	$9.19e^{9}$

Note: $R^2 = 0.50$ *(Cox & Snell). Model* $X^2(6) = 80.81$, $p < 0.001$.

Summary

The main purpose of this study was to determine if demographic factors had any predictive relationship in the rate of AS diagnosis among African-American children in the DMV and if so, to what extent. Results of the analyses showed that overall, only family structural factor (Research Question 2) of parental marital status was predictive of the likelihood of a child having an official AS diagnosis at statistically significant levels with a mother who is married being 1.98 times more likely to have a child diagnosed with AS, as a mother who is single or has not been married. Both family socioeconomic factors (Research Question 1) and child demographic factors (Research Question 3) were not predictive of the likelihood of a child having an official AS diagnosis at statistically significant levels. Chapter 5 consists of interpretations of the findings, limitations of this study, recommendations for future research studies, and implications for positive social change. I will discuss in more detail what the data mean for the current study, and how the results can be used for future studies pertaining to demographic factors and the extent of their predictive relationship in the rate of AS diagnosis among African-American children in the DMV area.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This study was completed to evaluate the relationships between demographic factors with AS diagnosis among African American children in the DVM area. AS is a neurological development disorder that causes development delay in basic skills, in the ability to socialize with others, and in communication, among others (APA, 2000; Baio, 2012; NINDS, 2013, 2016). The capability to diagnose AS is complicated by the lack of a standard diagnostic test (NINDS, 2013, 2016) and African American children who visited a clinician for the first time were 2.6 times less likely to receive a diagnosis of AS compared to Caucasian children (Gourdine et al., 2012). Inconsistency in diagnosis at an early age for African American children may be caused by late entry to the healthcare system and limited access to specialty care for children with autism. Minority families with limited education or lower incomes had been found to face obstacles with access to an early intervention system (Feinberg et al., 2011; Gourdine et al., 2011; Guevera et al., 2006; Thomas et al., 2012). Those who were diagnosed with AS on their first visit were mostly Caucasian children (14%), Hispanic children (5%), and Black children (4%) (Biao, 2014). By improving access to affordable health care enables children from all ethnic background to receive early screening for AS diagnosis and aides in timeliness of treatments and interventions.

A chi-square test analysis was performed prior to the additional statistical analyses related to the research questions and the results indicated that there are statistically significant differences in the AS diagnosis status of children who have parents with no sibling with disability (68; 70.8%), whose parents have other disabilities (69; 100%), who is not the first child (52; 75.4%), and who has married parents (74; 77.1%) compared to those children who do not possess the above conditions.

To explore if there were demographic factors that have predictive relationships to the diagnosis of AS) in African American children, I wanted to answer three research questions:

RQ 1: What family socioeconomic factors predict the diagnosis of Asperger's Syndrome in African American children who exhibit symptomology of Asperger's Syndrome?

With the use of multiple logistic regression analyses on data obtained from the parents of 187 African American children aged 3 to 16 years old who had displayed symptomology of AS but who may or may not have been diagnosed with AS was conducted. Socioeconomic factors, as defined by the mother's educational level, father's educational level, and family income, do not predict the diagnosis of AS of African American children at statistically significant levels so the null hypothesis was retained.

RQ 2: What family structural factors predict the diagnosis of Asperger's Syndrome in African American children who exhibit symptomology of Asperger's Syndrome?

Family structural factors including marital status, mother's race, father's race, the number of siblings of the child, disability among family members, and geography are related to the diagnosis of AS of African American children at statistically significant levels, so the null hypothesis was rejected and the alternative accepted. Children are more likely to have an official diagnosis of AS if the mother is married (Wald (1) = 4.14, p = 0.04), as compared to if the mother is single.

RQ 3: What child demographic factors predict the diagnosis of Asperger's Syndrome in African American children who exhibit symptomology of Asperger's Syndrome?

Demographic factors of the mother's age at time of birth, the child's gender, if there was a multiple birth, the adoption status of the child, the child's birth order, and if the child presented with any other disability, do not have a statistically significant relationship with the diagnosis of AS in African American children so the null hypothesis was retained.

Interpretation of the Findings

My findings, specifically that socioeconomic factors (mother's educational attainment, father's educational level, and family income) do not have a statistically significant predictive relationship with the diagnosis of AS in African American children, seemingly contradict the work of previous researchers. Delobel-Ayuob et al. (2015), Durkin et al. (2010), King and Bearman (2011), Nowell et al. (2015), and Palmer et al. (2010) observed that there exists a statistically significant positive correlation of AS diagnosis with socioeconomic status given that the density of specialists was concentrated in areas where there were higher populations of non-Hispanic Whites, which in turn was associated with higher socioeconomic status. Children of families in higher income brackets not only received more number of evaluations but were diagnosed earlier than their peers with lower socioeconomic status. Lehti et al. (2015)

studied the association between parental socioeconomic status and ASD and concluded that the connection between socioeconomic status and ASD differs by the disease's subtypes and by the family's service use. King and Bearman (2011) discovered that autism's prevalence rates began to increase at a slower rate and diagnosis became less sparse among families with high socioeconomic status, the community-level socioeconomic status slope also began to decline. The influence of socioeconomic status began to fade as knowledge about autism and the capacity for discovery saturated the entire population and health care enrollment expanded to the point where the system became less selective (King & Bearman, 2011).

My conclusions (child demographic factors such as mother's age at time of birth, gender of child, birth status of child, adoption status of child, child order in family, and other disability) do not have a statistically significant predictive relationship with the diagnosis of AS of African American children, seem to contradict those of previous researchers as well (Buxbaum & Hof, 2013; Hollander, Kolevzon, & Coyle, 2011; Moisse, 2010; Myrskyla & Fenelon, 2012; World Health Organization, 2015). A strong point of interest is that the "other disability" variable did not seem to have a relationship with the diagnosis of AS in children, given that several researchers had supported such claims (Badawi et al., 2016; Bartlett et al., 2014; Gillberg et al., 2015; Ozonoff et al., 2011; Rodriguez, 2015; Sumi et al., 2006; Timonen-Soivio et al., 2015).

Expectations of children's behavior vary across cultures and manifestations of developmental disabilities may not be identified as disorders by some parents (Fountain et al., 2011). Cultural differences in the perception of developmental problems may influence both parent report and clinician diagnostic practices (Nowell et al., 2015). Symptoms of ASD exist on a continuum of severity, and doctors may overlook the symptoms because of African American parents' perception of the condition (Nowell et al., 2015). Developmental progression of skills such as language may be looked at by health care professionals to be the consequence of second language acquisition for children who came from other countries or English is not the primary language spoken in the home (Nowell et al., 2015). This may result in parents not identifying an issue and/or reporting this to a physician for testing and diagnosis.

Family structural factors (such as parental marital status) have a statistically significant and positive relationship with the diagnosis of AS in African American children that is consistent with the findings of previous researchers (Eiraldi & Diaz, 2010; McCabe, 2002; Reyno & McGrath, 2006). ASDs are associated with communication challenges, misunderstanding of social cues, and lack of emotional understanding, which affect every relationship in the family (Sicile-Kira, 2010). A child diagnosed with AS brings enormous pressure and stress on the family in various ways due to special care that must be given to children with this condition which may result in dissolution of marriages/relationships (Autism Society, 2006; Baeza-Velasco et al., 2013; Bluth et al., 2013; Meadan et al., 2010). On the other hand, marriage may also be strengthened because of the parents having to go through the ordeal together (Bluth et al., 2013). Freedman et al. (2011) reported that they did not find any evidence in which children with AS were at an increased risk in having their parents divorced as compared to children without AS.

Per the results of the Chi-square test analyses, one of the statistically significant differences among the diagnosis of AS among African American children found in this study is the genetic component. There is a statistically significant difference in the AS diagnosis status of children who have another disability or has a sibling who has disability compared with those who have none. Disabilities not caused by accident or illness generally have a history in families and having a child with autism increases the risk of having another child with an autistic disorder (Bartlett et al., 2014). Timonen-Soivio et al. (2015) suggested that there was a statistically significant connection between autism and congenital anomalies. Furthermore, the linkage between childhood autism and congenital anomalies is stronger among children with intellectual disability as compared to those without intellectual disability (Timonen-Soivio et al., 2015). It was discovered a linkage between glycine encephalopathy, a genetic or inherited condition which results to abnormally elevated levels of amino acids in the brain and subsequently affects cognitive functions, and the development of autism disorder (Badawi et al., 2006; Weir et al., 2006). The association between birth defects and autism disorder may be caused by underlying genetic and/or environmental factors common to both autism and birth defects, or birth defects may make a child susceptible to autism (Dawson, Glasson, Dixon, and Bower, 2009). Most children diagnosed with AS in the population developed additional psychiatric or neurodevelopmental ailment, and more than half had ongoing comorbidity, with Attention Deficit Hyperactivity Disorder (ADHD) and depression being the most common (Gillberg et al., 2015). Lastly, autism disorders and schizophrenia spectrum disorders share multiple phenotypic similarities as well as risk factors and have been described to co-occur at elevated rates (Chrisholm, Lin, Abu-Akel, and Wood, 2015). Children with early onset schizophrenia commonly have a history of ASDs, and such patients develop serious psychosocial impairments that may progress well into their adolescence and adulthood (Chrisholm et al., 2015).

The theoretical framework employed in this study, Bronfenbrenner’s (1979) ecological theory, is well supported in this research as well. The ecological theory states that external forces impact human development in relation to the closeness of those forces to the individual (Bornstein & Bradley, 2003; Fernell & Gillberg, 2010; Golden & Earp, 2012; Magana et al., 2012). The theory further states that environmental factors such as family, family dynamics, income, school, and the community, among others, affect an individual (Bornstein & Bradley, 2003; Golden & Earp, 2012; Shaffer & Kipp, 2014). The person’s own biological composition may also be considered part of those factors which shape him/her. As demonstrated in this study, several external factors affect the diagnosis of AS among African American children. Specifically, family structural and child demographic components play a large part in AS diagnosis.

Limitations of the Study

This study has several limitations. The first limitation was the sampling method employed in this research. Purposeful convenience and snowballing sampling methods were used to enlist participants for the study. Snowball sampling facilitated in accessing the target population, but this method also resulted to having participants not being able to represent the diversity of the population (Atkinson & Flint, 2001). In 2016, the estimated population of Maryland is 6,068,511; African American (30.7%); Virginia’s population is 8,411,808; African American (19.8%); and the District of Columbia has a population of 681,170; African American (47.7%) (United States Census Bureau, 2016). Because my data collection focused solely on African American children born in the DMV, the results of this study is not representative of the entire population. The data did not capture the fact whether these children differ from children who were born elsewhere and later moved to the states mentioned above. Moreover, the DMV have all well-established health care support systems that provide diagnoses and services to children with AS; therefore, it might be expected that there will be less inequality and subsequently lower prevalence rates for minority groups. Against this background, the DMV may be considered a conservative case.

Moreover, given that the basis of this study's data is quantitative in nature, and is heavily dependent on the responses made by the participants, there may exist information bias. It is a general conception that reality is distorted when seen through a questionnaire (Fadness, Taube, & Tylleskar, 2009). Answering questionnaires requires the participants to remember past events and recall usually deteriorates with time; which may lead to inaccuracy of what is being reported (Fadness et al., 2009).

Recommendations

This study promoted the need to determine if similar patterns of socioeconomic concurrence can be established elsewhere. Further studies involving different racial ethnic groups should be considered with the goal of strengthening recruitment strategy to cover diverse population. Such consideration will help greatly in fortifying the conclusion that divergence in the access to health care has been achieved in the DMV. Otherwise, there may be some ethnic groups that are not yet achieving optimum health care assistance. Health care facilities must be wary of the structural support challenges that families belonging to the minority may be experiencing, as ethnic groups are susceptible to perceptive challenges arising from loss of social ties and proliferation of social stigma (Padilla & Perez, 2003). If fragmented and dispersed services for diagnosing autism exist in communities heavily populated by ethnic minorities, these issues must be addressed (Padilla & Perez, 2003). Moreover, access inequality to medical services specific to AS diagnosis, if present, must be given focused attention to improve pathways in which all medical services will be available to everyone, regardless of their ethnic group.

Racial discrepancies in AS diagnosis must be curbed as well. Even before a child gets to be diagnosed, a clinician already has a certain expectation about the probability of AS manifesting in White and non-White children (Nowell et al., 2015). Children from non-White demographic groups, particularly those from non-English-speaking families, may respond dismally on standardized measures of cognitive functioning, which may further be accredited to a cultural test bias (CDC, 2006; Mandell et al., 2002, 2009; Ratto et al., 2016; Yeargin-Allsopp et al., 2003). Consequently, many children from non-English-speaking families may be misdiagnosed with intellectual disability, all the while ignoring the possibility that what they have is an autism spectrum disorder (Padilla & Perez, 2003).

Parental concerns from individuals originating from minority groups may be dismissed or not taken seriously by health care professionals. Health care providers must eliminate this diagnostic bias by being aware of cultural differences among groups and be able to bring out answers from parents who may initially be hesitant to open to discussion. Established health care practitioners should recognize the importance of considering diversity in clinical practice (Nowell et al., 2015). For example, Texas State Board of Examiners of Psychology now requires licensees to get three hours of continuing education credit in multicultural practice (Nowell et al., 2015). Providing health care professional specific training in attribution biases, giving them focus on the cognitive strategy of individuation such as versus categorization, and increasing the awareness of the existence and implications of under-identification and misidentification of children from the minority populations have the potential to address potential diagnostic biases (Nowell, 2015).

The same can be extended to teachers as well. Given the hours that they spend with the children, they would be able to observe patterns in the child's behavior that may be a cause for concern. Cultural bias is a conduct that is usually overlooked (Ennis-Cole, Durodoye, & Harris, 2013). Teachers should refrain from this kind of mindset and advise the child's parents if they see any uncommon behavior, whatever that may be.

The types of disorders and symptoms of AS vary by age and there is a need to further develop age-specific procedures which will fit toddlers, children, adolescents, and adults with AS. They symptoms of autism, including such as communication and language impairments, may not be truly reflective of the disorder (Autism Society, 2015). Language problems in children may signify another ailment other than ASD and it would be beneficial to extend the research on this subject by exploring developmental history from infancy to cover all disciplines related to autism and other communication disorders (Padilla & Perez, 2003). The early developmental history will greatly help in defining the connection with ASD.

Following up the growth of these children into their adolescence and adulthood should be explored as well since the true depth of social impediment is most of the time not fully revealed until the person is exposed to the demands of adulthood. It is from the viewpoint of adult life that it is viable to deduce what types of education and support during the individual's early years would have been advantageous in preparing the person for the post school years (Gillberg et al., 2015). Research into the variables driving to a myriad of outcomes in adult life may give practical insights to the field of autism. Most intervention programs are targeted towards children, but it must not be forgotten that children affected with AS have more difficulty in forming social relationships than with their peers and which may have caused impediments while growing up (Gillberg et al., 2015). Knowing such standpoint will contribute to the design of more effective and enduring early intervention programs for children affected with AS.

Implications

Identifying the variables that have a relationship with AS identification/diagnosis and enhancing strategies to address the need for improved recognition and documentation of symptoms of AS among African American children, are two of my contributions to existing literature. Addressing barriers to diagnosis may lead to a decrease in the age when African American children receive their first evaluation for a diagnosis of AS, so they can be enrolled in community-based support services at an earlier age (CDC, 2014).

It was noted that early and accurate diagnoses may lead to future potential of African American children improvement in “social interaction, improved communication, social, play, and behavioral functioning,” (Tek & Landa, 2012, p. 1967) so these children could be able to function and enjoy a better quality of life socially (CDC, 2014). With the right intervention, the child may be able to develop acceptance and appreciation of his difficulties (CDC, 2014; Tek & Landa, 2012). They could learn strategies that may help them cope with their word retrieval problems and appropriate language formulation. Children with AS originally have issues with social interaction, proper intervention may prompt the child to be willing to engage in social organizations that interest them (Rao, Beidel, & Murray, 2007).

There may exist an AS diagnostic bias in children from underserved population due to most variables considered in this study being insignificant (CDC, 2006; Mandell et al., 2002, 2009; Ratto et al., 2016; Yeargin-Allsopp et al., 2003). Given the technological rise in the world today, new avenues for AS diagnosis become available for clinicians to effectively recognize the presence of such disorder; hence, eliminating such bias. Health care professionals may explore the use of medical technology such as MRI to determine if AS is present in the individual. For those children in families who speak a language other than English, there is a high chance that health care providers may indicate language delays to second language issues; thus, failing to scrutinize the presence of other early signs of AS (Timonen-Solvio et al., 2015).

In addition, results from this study may provide information to develop policies, community-based services, and programs that could bring about social change. This change could ensure that children receive an accurate AS diagnosis regardless of factors such as race, ethnicity, or socioeconomic status. Results may contribute to the existing literature regarding AS, which promote early diagnosis as one of the key elements to its treatment. Early diagnosis could lead to access to programs that focus on individualized treatment and appropriate interventions to help children function more independently and socially (Fernell, Eriksson, & Gillberg, 2013; Lindgren & Doobay, 2011). Within this context, parents should first and foremost be knowledgeable about the symptomology of AS. Freedman et al. (2011) noted that AS presents itself in several ways and at numerous different points, and parents should recognize this fact. Parents of children with AS are given the key role of coaches in their child's development of social and emotional skills (Freedman et al., 2011). Recreational stories, conversation coaching, social blending, and predicting are just a handful of the multitude of parenting tools that can enlarge a child's comfort zone and social success. Doctors must not easily minimize or dismiss concerns raised by parents in terms of the toddler’s behavior as a normal part of early child development. Doctors must be adequately educated about development delays and their corresponding warning signs in relation to AS.

Teachers can also misread common symptoms of AS, such as insistent preoccupations, as obstructive refusal to follow their instructions. Lack of social exchange may be mistaken as selfishness or intentional uncaring behavior (Cole, 2014). Notwithstanding that when schools are completely informed of the child's diagnosis, it enables the child’s parents to champion for their child. It also makes sure that teachers have the required resources and knowledge to insightfully react to Asperger’s behaviors which materialize at school. Without proper diagnosis, parents lack the legal entitlements to guarantee that their child acquires these precautions and provisions. Furthermore, special education should be established around the child’s individual needs. Educational setting for children with AS should provide sufficient opportunity for individualized technique, individual consideration, and small work groups (Aldred, Green, & Adams, 2004). A fundamental aspect of the available educational infrastructure involves the accessibility of a communication specialist with keen interest in pragmatics and social skills training, and who can fashion communication and social skills training mediation an intrinsic part of all school activities (Aldred et al., 2004). More so, there should be a conscious effort to encourage the attainment of real-life skills in addition to academic goals. Real-life skills may include adaptive competence, which is a less-naturally developed ability in children with AS than their normal counterparts. The school should be willing to adapt a specialized curriculum for students with AS to deliver flexible and fair opportunities for success, as well as to foster the gain of a positive self-concept and self-sufficiency (Aldred et al., 2004).

There is a critical need to train health care professionals, especially those working in underserved communities where families belonging to minority groups may reside, about the prevalence and symptomology of AS (Ennis-Cole et al., 2013). Since we are dealing with an ethnic group, clinicians must be mindful of the cultural differences among families. As such, the 3-fold multicultural competencies must be applied, as composed by personal awareness, cultural knowledge, and appropriate skills (Cole, 2014). Health professionals should take time and effort to evaluate their thoughts, feelings, and actions about autism before they can work effectively with families who have children affected by the disorder (Cole, 2014). To be effective, counselors must comprehend autism from the perspective of the family since there are numerous emotions that may be required to address first before a family can handle and accept an autism diagnosis.

Counselors are highly encouraged to scrutinize how cultural identities influence clients and avoid casting negative assumptions about families who have a child diagnosed with AS (Ennis-Cole et al., 2013). An interesting implication of the cultural element in counseling is for health professionals to familiarize themselves with the culturally infused verbal and nonverbal communication styles of the family so that they can be effective in their occupation. Finally, appropriate skills connote that professionals must be flexible in the application of theories and skills (Cole, 2014). An approach that worked in one family may not work in another given the diversity of families. Generally, the most vital component of the intervention program for children with AS is the demand to augment communication and social competence. This attention does not indicate a societal pressure for the need to fit in or an effort to suppress individuality and distinction. On the contrary, this emphasis represents the implication of this study that most individuals with AS are not introvert by choice. Comorbidity of AS with other disorders, such as depression, entails that there is a great chance, as children develop toward adolescence, for them to develop a pessimistic attitude because of the individual’s increasing awareness of personal insufficiency in group situations, and of reoccurring episodes of failure to make and maintain relationships (Chrisholm et al., 2015; Matson & Cervantes, 2014). A need to explicitly teach social and communication skills must be met for children with AS to lead a high-quality life. Having such training shall equip the child with the necessary tools in coping with social and interpersonal circumstances.

Conclusion

Summing-up, the diagnosis of AS in African American children has a statistically significant relationship with family structural factors, specifically parental marital status. The lack of conclusive factors that affect the rate at which African American children are diagnosed with AS suggests that there may still be diagnostic bias. Health care professionals have a perceived expectation about the probability of an African American child being diagnosed with AS. More work is required to ensure that all children with AS, regardless of their conditions in life, are identified immediately and be provided with successful interventions beginning at a young age.

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Appendix A

High-Functioning Autism Spectrum Screening Questionnaire (ASSQ)

This child stands out from other children of his/her age in the following ways:

1. is old-fashioned or precocious
    - No
    - Somewhat
    - Yes
2. is regarded as an ‘eccentric professor’ by the other children
    - No
    - Somewhat
    - Yes
3. lives somewhat in a world of his/her own with restricted idiosyncratic intellectual interests
    - No
    - Somewhat
    - Yes
4. accumulates facts on certain subjects (good rote memory) but does not really understand the meaning
    - No
    - Somewhat
    - Yes

5. has a literal understanding of ambiguous and metaphoric language (i.e. takes things literally; troubles understanding expressions or metaphors)
   - ○ No
   - ○ Somewhat
   - ○ Yes
6. has a deviant style of communication with a formal, fussy, ‘old-fashioned’ or ‘robot-like’ language (i.e. talks differently than other children, in a formal or stilted way)
   - ○ No
   - ○ Somewhat
   - ○ Yes
7. invents idiosyncratic words and expressions (i.e. makes up his or her own words, expressions or names for things)
   - ○ No
   - ○ Somewhat
   - ○ Yes
8. has a different voice or speech
   - ○ No
   - ○ Somewhat
   - ○ Yes
9. expresses sound involuntarily; clears throat, grunts, smacks, cries or screams
   - ○ No

- ○ Somewhat
- ○ Yes

10. is surprisingly good at some things and surprisingly poor at others
    - ○ No
    - ○ Somewhat
    - ○ Yes

11. uses language freely but fails to make adjustments to fit social contexts or the needs of different listeners
    - ○ No
    - ○ Somewhat
    - ○ Yes

12. lacks empathy (i.e. tends to see things only from his/her own perspective, and has troubles seeing things from other's perspective)
    - ○ No
    - ○ Somewhat
    - ○ Yes

13. makes naïve and embarrassing remarks
    - ○ No
    - ○ Somewhat
    - ○ Yes

14. has a deviant style of gaze (e.g. may range from not looking people in the eye, to the other extreme of staring directly at people to the point it makes them uncomfortable)

    - ○ No
    - ○ Somewhat
    - ○ Yes

15. wishes to be sociable but fails to make relationships with peers

    - ○ No
    - ○ Somewhat
    - ○ Yes

16. can be with other children but only on his/her terms

    - ○ No
    - ○ Somewhat
    - ○ Yes

17. lacks best friend

    - ○ No
    - ○ Somewhat
    - ○ Yes

18. lacks common sense

    - ○ No
    - ○ Somewhat
    - ○ Yes

19. is poor at games; no idea of cooperating in a team, scores ‘own goals’

○ No

○ Somewhat

○ Yes

20. has clumsy, ill coordinated, ungainly, awkward movements or gestures

○ No

○ Somewhat

○ Yes

21. has involuntary face or body movements (i.e. any tics?)

○ No

○ Somewhat

○ Yes

22. has difficulties in completing simple daily activities because of compulsory repetition of certain actions or thoughts (i.e. any habits that s/he just has to do?)

○ No

○ Somewhat

○ Yes

23. has special routines; insists on no change (i.e. may need to have exactly the same change; troubles with even the slightest change in his/her environment, or routines or activities)

○ No

○ Somewhat

- ○ Yes

24. shows idiosyncratic attachment to objects (i.e. may get strangely attached to objects as if they were people)
    - ○ No
    - ○ Somewhat
    - ○ Yes
25. is bullied by other children
    - ○ No
    - ○ Somewhat
    - ○ Yes
26. has markedly unusual facial expression
    - ○ No
    - ○ Somewhat
    - ○ Yes
27. has markedly unusual posture
    - ○ No
    - ○ Somewhat
    - ○ Yes

Appendix B

The Childhood Autism Spectrum Test (CAST)

Please read the following questions carefully and circle the appropriate answer. All responses are confidential.

1. Does s/he join in playing games with other children easily?	Yes	No
2. Does s/he come up to you spontaneously for a chat?	Yes	No
3. Was s/he speaking by 2 years old?	Yes	No
4. Does s/he enjoy sports?	Yes	No
5. Is it important to him/her to fit in with the peer group?	Yes	No
6. Does s/he appear to notice unusual details that others miss?	Yes	No
7. Does s/he tend to take things literally?	Yes	No
8. When s/he was 3 years old, did s/he spend a lot of time pretending (e.g., play-acting being a superhero, or holding teddy's tea parties)?	Yes	No
9. Does s/he like to do things over and over again, in the same way all the time?	Yes	No
10. Does s/he find it easy to interact with other children?	Yes	No
11. Can s/he keep a two-way conversation going?	Yes	No
12. Can s/he read appropriately for his/her age?	Yes	No
13. Does s/he mostly have the same interests as his/her peers?	Yes	No
14. Does s/he have an interest which takes up so much time that s/he does little else?	Yes	No
15. Does s/he have friends, rather than just acquaintances?	Yes	No

16. Does s/he often bring you things s/he is interested in to show you?	Yes	No
17. Does s/he enjoy joking around?	Yes	No
18. Does s/he have difficulty understanding the rules for polite behaviour?	Yes	No
19. Does s/he appear to have an unusual memory for details?	Yes	No
20. Is his/her voice unusual (e.g., overly adult, flat, or very monotonous)?	Yes	No
21. Are people important to him/her?	Yes	No
22. Can s/he dress him/herself?	Yes	No
23. Is s/he good at turn-taking in conversation?	Yes	No
24. Does s/he play imaginatively with other children, and engage in role-play?	Yes	No
25. Does s/he often do or say things that are tactless or socially inappropriate?	Yes	No
26. Can s/he count to 50 without leaving out any numbers?	Yes	No
27. Does s/he make normal eye-contact?	Yes	No
28. Does s/he have any unusual and repetitive movements?	Yes	No
29. Is his/her social behaviour very one-sided and always on his/her own terms?	Yes	No
30. Does s/he sometimes say “you” or “s/he” when s/he means “I”?	Yes	No
31. Does s/he prefer imaginative activities such as play-acting or story-telling, rather than numbers		

or lists of facts? Yes No

32. Does s/he sometimes lose the listener because of not explaining what s/he is talking about? Yes No

33. Can s/he ride a bicycle (even if with stabilisers)? Yes No

34. Does s/he try to impose routines on him/herself, or on others, in such a way that it causes problems? Yes No

35. Does s/he care how s/he is perceived by the rest of the group? Yes No

36. Does s/he often turn conversations to his/her favourite subject rather than following what the other person wants to talk about? Yes No

37. Does s/he have odd or unusual phrases? Yes No

SPECIAL NEEDS SECTION

Please complete as appropriate

38. Have teachers'/health visitors ever expressed any concerns about his/her development? Yes No

If Yes, please specify...

39. Has s/he ever been diagnosed with any of the following?

Language delay Yes No

Hyperactivity/Attention Deficit Disorder (ADHD) Yes No

Hearing or visual difficulties Yes No

Autism Spectrum Condition, incl. Asperger's Syndrome Yes No

A physical disability Yes No

Other (please specify) Yes No

Appendix C

Screening & Demographic Questionnaire

Screening Items:

1. What is your child’s ethnicity?

   0=White

   1=Black or African American

   2=Hispanic or Latino

   3=Native American

   4=Hawaiian or Pacific Islander

   5=Two or more

   6=Prefer not to answer

2. Please specify what ethnicities are included in the “two or more”. (only displayed if first screening item is “two or more”:

   0=White

   1=Black or African American

   2=Hispanic or Latino

   3=Native American

   4=Hawaiian or Pacific Islander

3. Is your child between the ages of 3 and 16?

   0=no

   1=yes

Demographic Form

Parental Information:

1. Are you the mother or father of the child?

   0=father

   1=mother

2. What was the mother's age at the birth of child? _____ (specify age)

3. Are you the primary custodial parent (if child lives between homes of parents)?

   0=no

   1=yes

4. What is the marital status if primary custodial parent of child or if the child lives in only your home or marital status of the parent who is the primary custodial parent of the child)?

   0=never married/single

   1=married

   2=separated

   3=divorced

   4=widowed

5. What is the mother's education level?

   0=Less than high school

   1=High school graduate (includes equivalency)

   2=Some college, no degree

   3=Associate degree

   4=Bachelor's degree

5=master’s degree

6=Specialist degree

7=Doctorate degree

6. What is the father’s education level?

    0=Less than high school

    1=High school graduate (includes equivalency)

    2=Some college, no degree

    3=Associate degree

    4=bachelor’s degree

    5=master’s degree

    6=Specialist degree

    7=Doctorate degree

7. What is the mother’s ethnicity?

    0=White

    1=Black or African American

    2=Hispanic or Latino

    3=Native American

    4=Hawaiian or Pacific Islander

    5=Two or more races

    6=Prefer not to answer

8. What is the father’s ethnicity?

    0=White

1=Black or African American

2=Hispanic or Latino

3=Native American

4=Hawaiian or Pacific Islander

5=Two or more races

6=Prefer not to answer

Family Information:

1. Where does your family live?

   0=Maryland

   1=District of Columbia

   2=Virginia

2. What is your annual family income? (actual income) ______
3. How many children reside in your household? ______
4. Do any of the child’s genetically related siblings have an official diagnosis of any disability or chronic illness?

   0=no

   1=yes

5. Do any of the child’s non-genetically related siblings have an official diagnosis of any disability or chronic illness?

   0=no

   1=yes

   99=no non-genetically related siblings in home

Child Information:

1. What is the current age of your child? (actual age) ______
2. What is the gender of your child?

   0=male

   1=female
3. Was your child adopted?

   0=no

   1=yes

   a. If yes, at what age was your child adopted? (actual age) _____
4. Was the child a single or multiple birth?

   0=single

   1=multiple
5. If you have more than one child, what place in the order of your children is the child? For example, if you have 5 children in your family and the child is the middle (3rd) child the order would be "3". ______
6. Does your child have an official diagnosis of Asperger's Syndrome?

   0=no

   1=yes

   a. If yes, at what age did your child receive the diagnosis? (actual age) ____
7. Does your child have any other diagnoses of a disability or chronic illness?

   0=no

   1=yes

a. If yes, at what age did your child receive the diagnosis? (actual age) _____

Appendix D

Permission Email to use ASSQ Instrument

no-reply@gu.se <no-reply@gu.se>
2:47 AM (10 hours ago)
to christopher.gi., me
Följande meddelande är skickat via GU: s webb:
Dear Sir,

My name is Suzette Bailey and I am a doctoral student at Walden University pursuing a PhD in Public Health. I am in the process of writing my dissertation topic "Asperger's Syndrome in African American children" and will like to request permission from you to use the Autism Spectrum Screening Questionnaire (ASSQ) as one of the instrument in my research study please.

I have included my email and telephone contact information. Please let me know if I will be granted permission to use the ASSQ instrument in my research study.

Thank you.

Yours faithfully,

Suzette Bailey.

Telefon: 1-240-706-3336

E-post: suzette.bailey@waldenu.edu

Meddelandet skickades från:

Websida: http://gillbergcentre.gu.se/english/research-staff-%26-associates/gillberg--christopher/

IP-nummer: 130.241.151.213

Webbläsare: Mozilla/5.0 (Windows NT 10.0) AppleWebKit/537.36 (KHTML, like Gecko) Chrome/53.0.2785.116 Safari/537.36

Christopher Gillberg christopher.gillberg@gnc.gu.se >4:41 AM (8 hours ago)

to Ingrid, me

Please feel free to use the ASSQ in your research. Please note that we want you to be notified of any results you may publish before they appear in print!

All good wishes and good luck,

Chris Gillberg

Appendix E

Open Access for use of CAST

ARC TESTS

Downloadable Tests

Various tests have been devised by ARC for use in the course of our research. Some of these tests are made available here for download.
You are welcome to download these tests provided that they are used for genuine research purposes and provided due acknowledgement of ARC as the source is given.

Translations

If you have translated any of the ARC tests and are happy to be contacted by other researchers to obtain a copy of your translation, please contact the **webmaster**.
Please see our **Terms and Conditions for translations**.

Please note

Our tests are posted on our website to enable free access to academic researchers. None of them are diagnostic: No single score on any of our tests or questionnaires indicates that an individual has an Autism Spectrum Condition (ASC). If you are concerned that you, or a friend or relative, may have ASC, please discuss these concerns with your GP or family doctor or ask the **National Autistic Society** (NAS) or equivalent charity in your country, for advice.

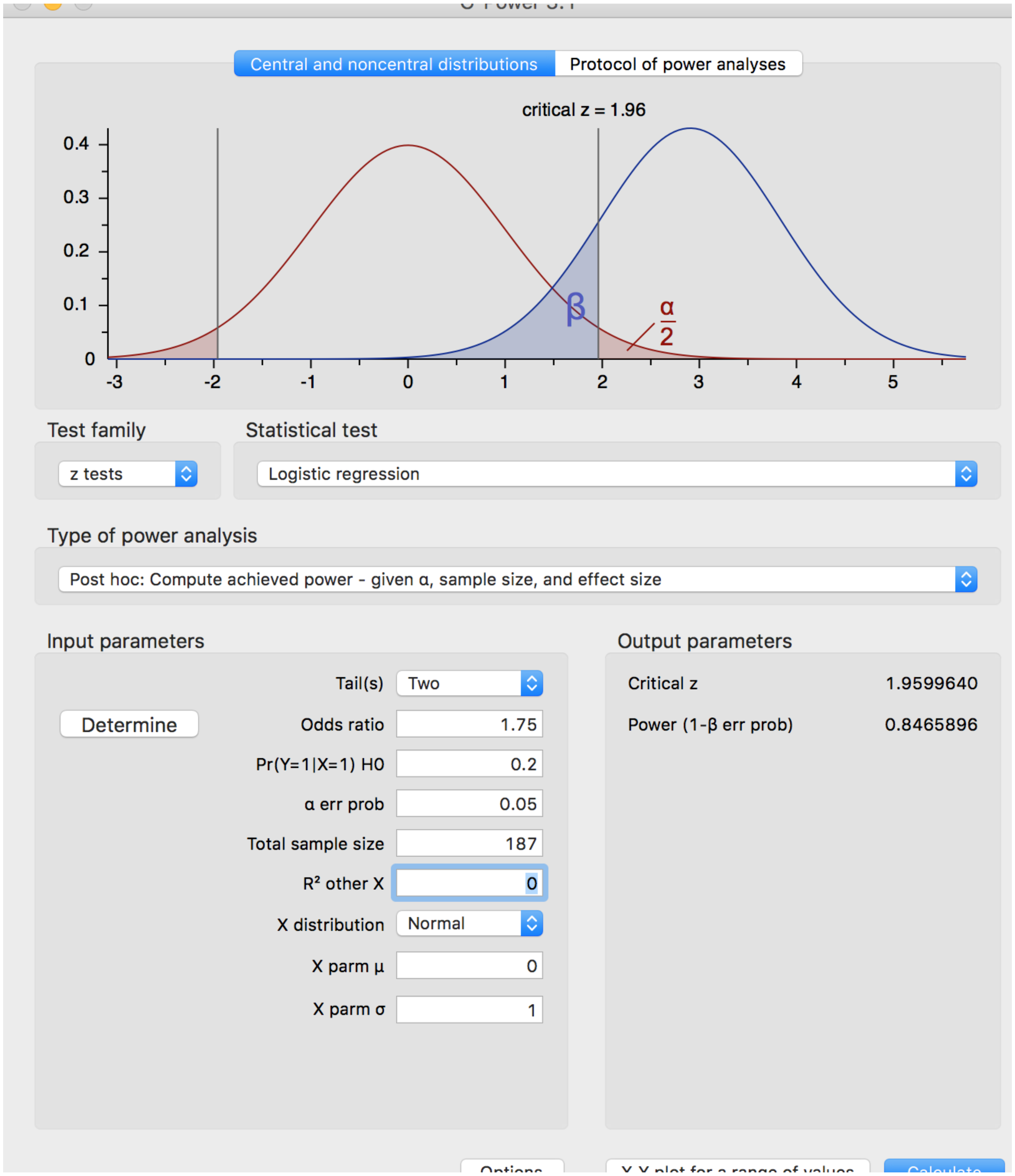
Childhood Autism Spectrum Test (CAST)

Formerly known as the Childhood Asperger Syndrome Test.

https://www.autismresearchcentre.com/arc_tests

Appendix F

Post-Hoc Power Analysis Results



Test family: z tests

Statistical test: Logistic regression

Type of power analysis: Post hoc: Compute achieved power – given α, sample size, and effect size

Input parameters

Tail(s): Two
Odds ratio: 1.75
Pr(Y=1|X=1) H0: 0.2
α err prob: 0.05
Total sample size: 187
R² other X: 0
X distribution: Normal
X parm μ: 0
X parm σ: 1

Output parameters

Critical z: 1.9599640
Power (1-β err prob): 0.8465896