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Exploring Disparities in Underrepresented Minority Groups of Children Diagnosed with Autism Spectrum Disorders Using the Biopsychosocial Theoretical Model

Varleisha Gibbs
varleisha.gibbs@student.shu.edu

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EXPLORING DISPARITIES IN UNDERREPRESENTED MINORITY GROUPS OF
CHILDREN DIAGNOSED WITH AUTISM SPECTRUM DISORDERS USING THE
BIOPSYCHOSOCIAL THEORETICAL MODEL

By: Varleisha Gibbs

Dissertation Committee

Dr. Genevieve Pinto-Zipp (Chair)

Dr. Deborah Deluca

Dr. Terrence Cahill

Submitted in partial fulfillment of the requirements for the degree
of Doctor of Philosophy in Health Sciences Seton Hall University

2017

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"Exploring Disparities in Underrepresented Minority Groups of Children Diagnosed with
Autism Spectrum Disorders Using the Biopsychosocial Theoretical Model"

By

Varleisha D. Gibbs

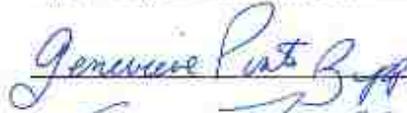
Dissertation Committee

Dr. Genevieve Pinto-Zipp (Chair)

Dr. Deborah DeLuca

Dr. Terrence Cahill

Approved by the Dissertation Committee:

	Date: <u>3/2/17</u>
	Date: <u>3/2/17</u>
	Date: <u>3/2/17</u>

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To my husband, I wish to say thank you. I could not have possibly cared for two children, my grandmother, and work as a chair of an inaugural occupational therapy program without a strong support! If I could share my degree with him, I would.

I want to thank my children. Dakota and Tennessee, I apologize for the long hours behind my laptop. I hope my work ethic inspires you.

I would like to thank my cheerleaders, the Freeman family. My sister, Vacinqua, grandmother, Thelma, and all of my brothers, aunts, uncles and cousins, and sister friends. Thank you for always being supportive and proud.

To my chair, Dr. Zipp, I say thank you for staying by my side all of these years. I recall leaving the program to pursue my clinical doctorate. Thank you for leaving the door open for me to return. I would also like to thank Dr. Deluca and Dr. Cahill for agreeing to take part in my journey. Your honesty and expertise pushed me to enhance my scholarship.

DEDICATION

I wish to dedicate this dissertation to my late mother, Vanest Freeman. She had me during her first year of college. I entered the world and soon after entered academia. My mother enrolled me in the campus program at her college. She taught me how to love learning. After years of going to college, and entering into my profession, we both agreed I seemed addicted to school. We often joked that I could stop going to school after I received my second graduate degree. My mother passed away before I could complete this dissertation. Yet, I know she is still proud!

ABSTRACT

Exploring Disparities in Underrepresented Minority Groups of Children Diagnosed with Autism Spectrum Disorders Using the Biopsychosocial Theoretical Model

Varleisha Gibbs

Seton Hall University, 2017

Dissertation Chair: Dr. Genevieve Pinto-Zipp

Background and Purpose of the Study

The rate of Autism continues to rise nationally. However, disparities in the age of diagnosis amongst underrepresented minority groups, still remains a major concern. Research supports that racial and ethnic disparities are key factors influencing noted age of diagnosis discrepancies. Traditionally, the medical community has used the biomedical or disability model, as revealed in the Diagnostic Statistical Manual of Mental Disorders, to explore diagnostic differences. However, these models limit the healthcare professional's ability to examine elements outside of pathology. In attempt to address the issue with a broader perspective, this study explored the various factors impacting the noted disparity in the age of diagnoses of Autism Spectrum Disorder (ASD), in underrepresented minority groups. The Biopsychosocial model provided a comprehensive view to examine and define the disparities in the diagnostic process.

Methods

For this study, the researcher employed a retrospective Cohort Design to conduct a secondary data analysis on the Survey of Pathways to Diagnosis and Services, 2011 survey data. The database houses past parental telephone interviews and self-administered surveys regarding personal recounts before and along the journey towards children receiving the ASD diagnosis. After obtaining data access, the principle investigator (PI) conducted data cleaning, and stratification. The PI implemented a random selection process to identify 150 subjects for the groups, Caucasian and Underrepresented Minorities (URM) groups for further review.

Results

The findings resulted in non-significant differences in age of diagnosis, age of concern, and child's age at which parent consulted with a medical professional. However, an apparent discrepancy existed in the age of concern and age of diagnosis for both groups. Furthermore, parental educational level correlated to the child's age for when the parent consulted a medical professional. Lastly, URM group parents reported more concerns regarding symptoms and behaviors of their child as compared with Caucasian children.

Discussion/Conclusion

The findings of this study highlight a key concern regarding a notable gap between the child's age when parents sought out consultation with a medical professional, based upon their observed concerns, and the child's age of diagnosis amongst all racial groups. Thus, healthcare professionals must expand their awareness of the multi-faceted influences that may reduce the gap between the child's age when concerns are noted and their age when a diagnosis occurs. The findings offer two theoretical models to explore. The study observations provide insight that more personal factors, possessed by the parent and child, result in a higher age of concern, seeking of a medical professional, and age of diagnosis. Personal factors include the components of the theoretical model; Society and Medical Professionals, Culture, Community and Family, Primary Caregiver, and Symptomatology. Based upon the inferences gleaned from this work, future research should address the two-person factors and explore use of more qualitative methodology.

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CHAPTER I

INTRODUCTION

Background of the Problem

The Autism and Developmental Disabilities Monitoring Network (ADDM) collects data from various sites located within the United States regarding the prevalence of Autism (Centers for Disease Control and Prevention, 2014). Recent outcomes suggest that 1 out of 68 children nationally as having a diagnosis of Autism. Furthermore, current data identified disparities in the rate of diagnosis based upon race, with Caucasian children being diagnosed at a much higher rate than minority counterparts. While the prevalence of the diagnosis of Autism continues to grow, the disparity in the diagnosis in URM based upon race and ethnical background is alarming. Thus leading us to question, “What factors influence the observed disparities noted in the diagnosis amongst underrepresented minority groups specific to the diagnosis rate and timeframe of Autism diagnosis?”

Informed by the literature and the revised Biopsychosocial model as an overarching framework this investigation explored several predetermined factors. Specifically, the author evaluated factors affecting underrepresented minority (URM) parental perceptions of early ASD symptoms. The perceptions of the URM, related to the behavioral characteristics associated with the diagnosis of Autism may further impact the intervention services provided and when they are employed. Other factors may include, how physicians are viewed by URM groups and their abilities to effective communicate

with URM groups in general, may be a factor impacting the low rates/late diagnosis of Autism in URM groups. Additionally, socioeconomic status and possible biological factors may also impact the diagnosis rate of Autism in racial/ethnic groups.

Autism Presentation

The Autism Spectrum Disorder (ASD) diagnosis is characterized by a variety of neurodevelopmental behaviors. Over the years, the ASD definition evolved. Initial descriptors highlighted the varying challenges in speech, social, and behavior skills (Kanner, 1943). When Kanner (1943) first coined the term, the intention was to appease curiosity of a group of puzzling symptoms in children. Such children displayed peculiar behaviors and skills. They had an affinity for music, unusual recall abilities, yet were self-absorbed. The perplexing condition also presented a desire to spin objects, a lack of response to affection, and rigidity to change. Additionally, symptoms consisted of repetitive verbal utterances and behaviors, echolalia, and over responsiveness to sensory stimuli.

Prior to Kanner, experts initially compared the diagnosis to childhood schizophrenia. Kanner (1943) correlated the symptoms to the high intellect of the parents and their lack of warm-heartedness. In years to follow, experts debunked and theorist embraced a consideration of neurobiological causes. A myriad of symptoms and severity levels led to an acknowledgement of the condition's complexity (Wing & Gould, 1979). Currently, the diagnostic criteria categorizes the symptoms of earlier times as social communication and repetitive restrictive behaviors (American Psychiatric Association, 2013). They encompass the primary deficits of the diagnosis. Yet, the detection of these

ASD symptoms is complex.

Early Detection

Early detection is crucial to enhance treatment outcomes for the Autism diagnosis (Durand, 2005; Scott & Baldwin, 2005). Such diagnoses should occur between the ages of 18 and 24 months for optimal outcomes. Upon review of the literature a correlation is noted between the timing or lack of diagnosis of Autism and one's culture, race, and ethnicity (Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell, Ittenbach, Levy, & Pinto-Martin, 2007; Mandell, Wiggins, Amstein, Carpenter, Daniels, DiGuseppi, Durkin, Giarelli, Morrier, Nicolas, Pinto-Martin, Shattuck, Thomas, Yeargin-Alsopp, & Kirby, 2009; Fountain, King, & Bearman, 2011). This ultimately impacts early treatment options. In 2014, the Centers for Disease Control issued a publication revealing this disparity. Caucasian children displayed a likelihood of an Autism diagnosis around 30% more than African American children and almost 50% more than those of Hispanic descent. (Center for Disease Control, 2014). In general, URM children have disproportional occurrences of documented Autism diagnosis when compared to white children (Mandell, et al., 2009; Liptak, et.al, 2008). This occurrence exists despite consistency in the phenotype of the ASD across cultures.

Literature suggests possible parental and cultural influences (Bultas, Johnson, Burkett, & Reinhold, 2016). Studies make assumptions relating to parental concern and detection as correlated to parental culture (Bernier, Mao, & Yen, 2010). How a parent reacts to the signs and symptoms of ASD may be highly dependent upon culture. Due to the variation and subtlety of symptom severity, symptom detection is particularly challenging. In addition, social stigma may also play a role regarding if, and when,

parents seek professional help regarding concerns with their child's development (Oswald & Haworth, 2014). Despite these assumptions, how the person's culture and beliefs influence that detection is absent from the literature. What is known is that a delay in acknowledgement of ASD can be detrimental hampering the outcomes of missed intervention. Certain URM groups have more severe symptoms, and maintain preventable symptoms (Burkett & Morris, 2015). Conversely, this concern significantly diminishes with the implementation of culturally competent care.

Therefore, the role of the parent and physician is critical. Physicians must screen for ASD between 18 to 24 months (Bultas, Johnson, Burkett, & Reinhold, 2016). Yet, the diagnostic processes are complex and require appropriate actions. There are red flags that indicate the need to move beyond the screening process and initiate appropriate diagnostic procedures (Figure 1).

- By 12 months:
 - No babbling
 - No gesturing
- By 6 months
 - No single words
- By 24 months
 - No two-word spontaneous phrases (excluding echolalia)
- Any Age
 - Any loss of any language or social skills

Derived from Bultas, Johnson, Burkett, & Reinhold, 2016

Figure 1. Indications for Referral for ASD

The Diagnostic Process

Having ASD correlates to possible difficulty communicating with others including both verbal and non-verbal communication skills (American Psychiatric Association, 2013). Hence, those with ASD often participate in inappropriate conversations, and lack the ability to read social cues (American Psychiatric Association, 2013). Rigid behaviors such as reliance on routines and inflexibility to change also align with the ASD diagnosis. Routines frequently encompass abnormal activities with obsessions with objects and unusual repetitive behaviors (American Psychiatric Association, 2013).

The diagnosis also includes unusual interest and response to sensory stimuli. The term 'spectrum' acknowledges the variation in severity of the symptoms between individuals. Some individuals have low intellectual ability with others displaying extremely high intellect (Grzadzinski, Huerta & Lord, 2013). In addition, dysfunctional secondary symptoms, such as self-injurious behaviors and psychiatric co-morbidities, exacerbate impairments for some with ASD (Fakhoury, 2015).

Diagnosis of ASD did not occur until the late 1980's (American Psychiatric Association, 1978). The psychometric properties of the diagnostic process have a history of good sensitivity and poor specificity. The assessment occurs through very subjective means of observation and completion of rating scales by medical professionals (Fakhoury, 2015). Commonly utilized, the Autism Diagnostic Observation Schedule (ADOS) evaluates social and communication deficits. In addition, the Autism Diagnostic

Interview-Revised (ADI-R) collects information based on parent report (Fahoury, 2015). The M-Chat is a validated tool available free of charge for use by medical professionals and specialist. It is intended for children ages 16 to 30 months of age (Robins et. al, 2014). A 23-item questionnaire allows parents to provide feedback on their child's behavior. The developers indicate a high false positive rate for the M-Chat. The M-Chat R provides a more extensive two-stage process to enhance the sensitivity of the tool (Robins et. al, 2014). However, specificity remains inadequate.

The various assessments for diagnosis depend on parent perception and provider observation of behavior. The information gathered then informs the medical professional to provide a formal diagnosis. Unlike common medical conditions such as those relating to cancer and cardiac health, ASD lacks technological innovation in the diagnostic process (King & Bearman, 2011). The obtained information is subjective. Consequently, misdiagnoses are possible.

Common Assessment Tools Utilized During the Dx Process	Assessment Details
Autism Diagnostic Observation Schedule (ADOS) evaluates social and communication deficits (Fakhoury, 2015)	<ul style="list-style-type: none"> Standardized behavioral observation and coding Social and communication deficits For varying age and developmental levels (Retrieved from http://www.wpspublish.com)
Autism Diagnostic Interview-Revised (ADI-R) (Fakhoury, 2015)	<ul style="list-style-type: none"> Standardized interview and response coding Children 2y/o or older and adults (Retrieved from http://www.wpspublish.com)
Childhood Autism Rating Scale (CARS) (Fakhoury, 2015)	<ul style="list-style-type: none"> Two 15-item rating scales completed by the clinician (each designed for a different population); and an unscored Parent/Caregiver Questionnaire Children 2y/o or older and adults (Retrieved from http://www.wpspublish.com)
The Modified Checklist of Autism in Toddlers (M-CHAT) (Robins, Fein, & Barton, 2009)	<ul style="list-style-type: none"> Designed to be administered to parents/guardians and interpreted by pediatric providers (Retrieved from https://www.m-chat.org/)

Figure 2. Summary of commonly utilized assessment tools in the diagnostic process.

Statement of the Problem

While, the presence of disparities in the Autism diagnosis between Caucasian and URM groups is supported in the literature a multifaceted investigation of why is imperative if we seek to address it. While several studies have inferred a possible connection between personal factors and culture, societal influences, and parental perspectives, they fail to establish evidence supporting such assumptions.

Based upon the current available literature, what is missing is an evidenced based driven investigation focusing on personal factors. Culture, parental perspective, variations in symptomatology, and the connection to socioeconomic status (SES) require a formal

analysis to inform reasoning behind delayed diagnosis. Improved acknowledgement of undiagnosed ASD can determine proper and timely intervention. Such findings may support a reduction of cost and time required for the delivery of therapeutic services secondary to treatment of ASD.

Purpose of the Study

The purpose of the study was to explore the assumptions related to personal factors regarding the disparities in the ASD diagnosis using a nationwide database. Disparities of concern included variations in the timeliness and accuracy of diagnosis between Caucasian and URM children groups. The investigation also targeted the child's age at the time of diagnosis, child's age at the time of parental concerns regarding possible signs and symptoms, and the child's age when parents sought out a healthcare provider. Additionally, child's access to healthcare, parental perceptions regarding their experience during the diagnostic process, and feelings regarding the ASD diagnosis were explored to provide further insight into personal factors relating to a timely and accurate diagnosis.

Variables

The independent variables of this study were the child's race and socioeconomic status including poverty level and parental education. Dependent variables were child's age at the time of diagnosis, when parental concerns were noted, when parents sought out a medical professional, and access to healthcare. Additionally, parental perceptions regarding the diagnostic experience and the ASD diagnosis specific to their child was explored qualitatively to provide additional insight.

Research Questions

Overarching Research question:

Does parental race and /or socioeconomic status influence the child's age at the time of diagnosis, child's age when parental concerns are identified, and child's age when a medical professional is sought out by parents of children from underrepresented minority groups specific to Autism?

Research questions 1 through 3 address the comparison of racial groups regarding timeliness of diagnosis and health care access.

RQ1 : Does parental race and/or socioeconomic status influence the Childs Age at Diagnosis, Childs Age when Concerns Identified, and Childs Age a Medical Professional was sought amongst underrepresented minority groups specific to Autism?

HA_{1A}: Caucasian children receive a significantly more timely diagnosis of ASD when compared to URM children.

HA_{1B}: There is an association between race and when ASD diagnosis is received from a medical specialist.

HA_{1C}: There is a significant difference between Caucasian and URM groups as to when parents express concern for ASD and the time of an ASD screen.

HA_{1D}: There is a significant relationship between age of diagnosis of ASD And SES.

HA_{1E}: There is a significant relationship between child's age when concerns identified, and child's age when medical professional was sought and parental socioeconomic status.

HA_{1F}: There is a significant relationship between age of diagnosis of ASD and parental education level.

RQ2: Does a significant association exist between age of diagnosis of ASD and access to health coverage?

HA₂: A significant association will exist between age of diagnosis of ASD and access to health coverage.

Research questions 3 through 5 address the parental perceptions towards their diagnostic experience and symptomatology displayed by their children.

RQ3a-h: What differences exist between URM and Caucasian parents and their perception of the causes, treatments, and prognoses for their child's ASD diagnosis?

Rq3a: Do parents agree that the doctors and other health care providers that child sees are able to meet their needs?

Rq3b: Do parents agree that the services their child receives from doctors and other health care providers are able to meet their needs?

Rq3c: Do parent agree the condition is likely to be lifelong rather than temporary?

Rq3d: Do parents agree the problems related to their child's condition can be prevented or decreased with treatment?

Rq3e: Do parents agree they have the power to change their child's condition?

Rq4f: Do parents get upset when they think about their child's condition?

Rq3g: Do parents agree their child's condition is genetic or hereditary?

Rq3h: Do parents agree their child's condition was caused by something the child was exposed to in utero, that is, before they was born?

RQ4-5: Parents were asked questions relating to the symptoms their child had during the time of their diagnosis.

RQ4: What parental concerns exist for parents of children diagnosed with ASD regarding their child's symptoms and behaviors?

RQ5: Are there common themes amongst ethnic groups in relationship to symptoms and behaviors revealed by children diagnosed with ASD?

Theoretical Foundation

As we begin to explore possible reasons for this disparity, current research findings offer insight into several factors. By applying the Biopsychosocial model, exploring parental perceptions regarding symptom detection correlates to investigating their social influences. Parents from URM groups may not have the same perceptions regarding milestones as compared to Caucasian parents (Tek & Landa, 2012). However, while one might assume that parental knowledge, perceptions, and beliefs towards ASD may influence their awareness of signs and symptoms, and its potential impact on a

child's participation in their life, limited evidence is available. Furthermore, analysis of SES and access to healthcare, through a national study, requires a systematic approach.

The Biopsychosocial model addresses biological, psychological, cognitive and social risk factors that contribute to a specific illness (McGill, 2011). Such a model contradicts the narrow biomedical model. While it may be difficult to identify a single answer regarding the disparity in diagnosis of Autism, the Biopsychosocial model provides an opportunity to analyze differentials based upon the various contributions. The model has proven valid in predicting specific mental health diagnoses (McGill, 2011). In addition, the model supports identification of subtypes.

The field of psychology embeds the Biopsychosocial model in its history. Engel (1997) was an active researcher in the area of psychosomatic medicine. Yet, he developed a Biopsychosocial model to apply to all areas of medicine. Engel's model attempted to address the psychological and social factors contributing to health.

Engel (1977) developed the levels of organization, a systems hierarchy to organize the Biopsychosocial model (*Figure. 3*).

**SYSTEMS HIERARCHY
(LEVELS OF ORGANIZATION)**

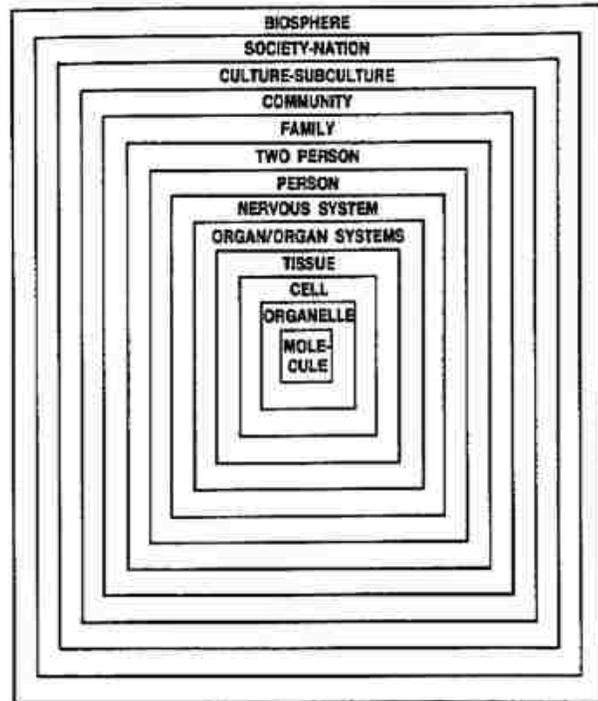
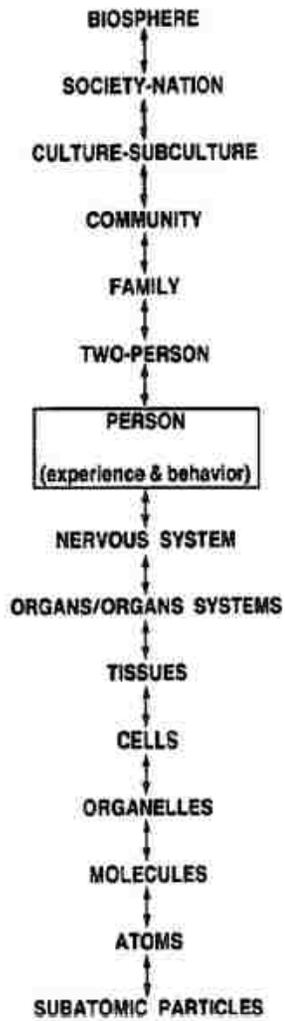


Figure 3. Engle’s schematic view as a multifaceted natural system as a hierarchy and continuum. (Retrieved from Van Oudenhove & Cuypers, 2014)

The person lies within the mid-level of the levels of organization. The model starts with biosphere followed by society-nation and culture-subculture. Next, lie the community, then family, two-person, and lastly the person (experiences and behaviors). The underlying physiological components round out the model. The nervous system is followed by organs/organ systems, tissues, cells, organelles, molecules, atoms, and subatomic particles Engel, 1977). This study suggests the use of this theoretical model to examine healthcare professional's role in diagnosing, parental perceptions, and socioeconomic status. Lastly, differences in presentations, between racial/ethnic groups, are assessed.

The Biopsychosocial model has been affective in identifying conditions with specific neurological or genetic symptoms (McGill, 2011). Yet, previous diagnostic methods are limited to a biomedical model. When diagnosing, it is important to take into account multiple aspects of the individual. However, this is lacking when diagnosing Autism. Historically, a disability model looks at an individual's pathological presentations for diagnosing. The Diagnostic and Statistical Manual of Mental Disorders (DSM) is limited due to utilizing a disability model as a foundation (Bricout, Porterfield, Tracey, and Howard, 2004).

The Biopsychosocial model has been found to be effective in gaining an understanding behind mental health disorders (McGill, 2011). The model allows for proper analysis of phenomena surrounding diagnostic processes as well as treatment of conditions. However, its application in the exploration of the ASD diagnosis to date is absent in the literature. Hence, the limitations of the model are unknown. The benefits of

its application, concerning the ASD diagnosis, are purely an assumption. The feasibility and possible benefits of this theoretical model is further explored in the discussion section.

CHAPTER II

REVIEW OF RELEVANT LITERATURE

Parental Perception

King, Hurd, Hajek & Jones (2009) illustrate how one is perceived needs and perception regarding the healthcare system are potential barriers. They reviewed a macro and micro view of one's environmental influences relating to health outcomes. Where people live correlates with the type and quality of healthcare received. Societal influences impact if a person actually utilizes, or seeks out, available resources. While their research primarily focused on community influences, the findings may relate to race as well. For example, even in the presence of available resources and access to care, URM may perceive a lack of support regarding their healthcare needs. Hence, researchers must take the concept of perception into account while exploring disparity in healthcare.

The history and bias of an individual, racial/ethnic group, or those from similar socioeconomic status feed the perceived notion of lack of access and necessary support when faced with the possible diagnosis of ASD. Therefore, the perception of inadequate healthcare resources hampers attention to healthcare concerns. King, Hurd, Hajek & Jones (2009) suggest taking into account three factors: *Knowledge, Attitudes, and Practices*. History feeds *Knowledge*. The URM groups have an unfortunate history with the healthcare system in the United States. Attitudes correlate to one's cultural

perception regarding acknowledgement and acceptance of mental health disorders. Lastly, practices relates to the utilization of services by particular racial groups. Again, services may be available. However, the desire for an individual to utilize the services can affect health care.

The available literature exploring when a parent begins to become concerned regarding their child is limited. Two studies specify findings regarding race and a correlation to the ability to accurately detect symptoms. African-American and Hispanic children's parents have an age of concern that is 1.56 to 1.94 months later than the white non-Hispanic subjects (Rosenberg, Landa, Law, Stuart, & Law (2011). Limitations in the findings require further research as less than 3% of the observations were of minority subjects. The second study is by Mandell et al. (2009). Findings associate a disparity in age of diagnosis for African Americans, Hispanic, and other non-White ethnicities with those groups showing a lower confidence interval to predict the presence of an Autism diagnosis (Caucasian 1.00, Blacks 0.79, Hispanics 0.76, Other 0.65) (Mandell et al., 2009). While the study did not specify parental perceptions, subtle symptoms may be missed by certain racial groups such as the lack or absence of eye contact, non-verbal communication, and inappropriate social behavior (Ennis-Cole, Durodoye, & Harris, 2013).

To further explore this concept, perspectives regarding the cause of Autism provide additional background. African Americans reveal a belief in dietary causes such as processed food and contamination. Caucasian populations identify physical elements, and perhaps immunizations as potential causes for Autism (Pitten, 2008). In addition, theories suggest that URM groups may view language delays as temporary allowing time

for the child to outgrow the deficit (Ennis-Cole, Durodoye, & Harris, 2013). With this limited data, along with research on misdiagnosis, African American parents' delay in reporting concerns to physicians may correlate to the disparity in diagnosis.

To gain a better understanding regarding parental perception and diagnosis of ASD, De Alba and Bodfish (2011) sought to investigate the time lapse from when a parent developed concerns regarding their child in comparison to time and age of diagnosis. They performed an internet-based survey method researching the hierarchy of the various concerns of symptomatology reported by parents. The Autism Registry in Northern Carolina provided a database of families dealing with ASD. In addition, review of the literature provided additional insight on problem. The investigators identified core symptoms of autism. Such symptoms consisted of language delay and dysfunction, social delay and dysfunction, and restricted and/or repetitive behaviors or interest (De Alba & Bodfish, 2011). Additional symptoms included challenges within the areas of gastrointestinal, feeding, and sleep.

The 17-question survey obtained demographic information, questions regarding the initial ASD diagnosis, and prioritizing of the importance of the symptoms (De Alba & Bodfish, 2011). Of the 2491 solicitations, 438 families completed and submitted their surveys. The results revealed parental concerns at the time of diagnosis. The majority of parents saw social problems, such as interacting with others, as primary concerns. Concerns regarding expressive language, and unusual behaviors, were secondary and third most commonly reported themes. Hence, primary social concerns outweighed secondary medical concerns. Therefore, the societal influences of culture possibly align with the variation in diagnosis between URM and non-minorities.

Studies on Parental Perceptions	Results
King, Hurd, Hajek & Jones (2009)	How one perceived their healthcare needs and personal perceptions towards the healthcare, system may be potential barriers to appropriate quality care.
Rosenberg, Landa, Law, Stuart, & Law (2011)	African-American and Hispanic children's parents have an age of concern regarding their child's development that is 1.56 to 1.94 months later than the white non-Hispanic subjects.
Mandell et al. (2009)	African Americans groups, Hispanic groups, and other non-White ethnicities showed a lower confidence interval to predict the presence of an Autism diagnosis.
Ennis-Cole, Durodoye, & Harris (2013)	Subtle symptoms may be problematic and overlooked such as the lack or absence of eye contact, non-verbal communication, and inappropriate social behavior. URM parents may view language delays as temporary.
Pitten (2008)	African Americans reveal a belief in dietary causes such as processed food and contamination. Caucasian populations identify physical elements, and perhaps immunizations as potential causes for Autism.
De Alba and Bodfish (2011)	Parental concerns at the time of diagnosis primarily related to social problems rather medical. Social interaction, unusual behaviors, and expressive language were important factors as reported by parents.

Figure 4. Key supportive studies in parental perceptions towards the ASD diagnosis.

Physician Perception

How the physicians' diagnosing behaviors relate to the disparity issue is crucial in completing the picture. Particularly, for African American children diagnosis frequently results in a variety of conditions other than Autism (Mandell, et. al., 2007). Studies reveal misdiagnosis, across ethnicities, of ADHD at 21.4%, followed by conduct-related disorders at 12.1%, adjustment disorder at 9.6%, and cognitive disorders at 7.9%. Specific to African-American children, they are twice more likely to receive a diagnosis of conduct disorder (15.7% vs. 6.7%). Caucasian children are approximately 5 times less likely to receive a diagnosis of Adjustment Disorder (2.5% vs. 12.8%) (Mandell et al, 2007). Mandell (2009) acknowledges the effects of physician perspective. The physician's assumptions that another diagnosis is present correlate to if they conduct crucial assessment for the Autism diagnosis. With performing a regression analysis on 2,586 eight-year-old children, lacking the diagnosis of Autism, results revealed that 58% of the children actually had the diagnosis.

Inadequate screening processes could be a reason for this disparity. Researchers Dosreis, Weiner, Johnson, and Newschaffer (2006), studied Autism screening and management practices among general pediatric providers. From a sample of n=255, researchers discovered through self-report that 82% routinely screened for developmental delays. However, only 8% routinely screened for Autism Spectrum Disorder. From the 8% who did routinely screen, 90% did so due to parental concern and suspicion of Autism during a routine examination. Again, this is of great concern if the parent reporting lacks the knowledge relating to symptom recognition (Dosreis, et al., 2006).

Perhaps more concerning is that nearly two thirds of physicians indicate being unfamiliar with Autism screens, almost half-referring patients to a specialist, and expressing lacking sufficient time to screen for Autism (Dosreis, et al., 2006, p. S91). Lack of awareness, and training of physicians, affects their ability to appropriately diagnosis Autism.

Similar to the perceptions of the parents, the parent-practitioner relationship and communication present significant importance.

In our current society, parents seeking medical assistance rely physicians to inform them about conditions and diagnoses, seeing them as experts. The assessment, screening, and treatment process must include parent interview. While parent report may reveal beneficial information, it may also cause a major hindrance. Parents may place emphasis on areas of concern differently than what the physician identifies as important in identifying and treating the condition. Ultimately, a misfit may occur.

Angell & Solomon's (2014) research exposed a disconnection from what African American parent report compared to what evaluators documented in their records. Misinterpretation of the parents' concerns led to late diagnosis, misdiagnosis, and inappropriate treatment planning for service delivery. The qualitative outcome measures provided insight on the parents' experiences. Some shared perceptions that the evaluator did not view them as knowledgeable. Parents also expressed upset in the evaluators' inaccurate translations of their statements. On the other end, primary care physicians (PCP) reported difficulty in screening for ASD in certain minority groups.

The PCPs perceived Latino parents as having a lack of knowledge of the disorder (Zuckerman et al., 2013). Therefore, screening presented challenges especially with

language barriers. Despite having large Spanish speaking populations, many PCP's did not offer screenings in Spanish. Limitations existed in the PCP's ability to assess risk for ASD. When referrals did formalize, access to specialists posed significant challenges. Hence, Zuckerman et al. (2013) and Angell & Solomon (2014) uncover a splintered and often unsuccessful alliance between minority parents and healthcare providers.

To expand upon this concept, Zuckerman, Lindly, & Sinche (2015) investigated age of parental concerns as compared to timeliness of discussing such concerns with a medical professional. Their analysis related more to provider perception. The researchers analyzed the response of the medical providers. The 2011 national 'Pathway Survey' consisted of data from 1420 parents of children with ASD and 2098 with intellectual/developmental disabilities (ID/DD). The researchers randomly selected subjects from a previous study.

The methodology included the analysis of three time points throughout the child's diagnostic history. The time points were age of parental concerns, age when initial discussion occurred with a medical professional, and lastly age of those diagnosed with ASD (Zuckerman, Lindly, & Sinche, 2015). Provider responses to parental concerns consisted of proactive or reassuring/passive responses. Conducting developmental tests, making a referral to a specialist, and discussing concerns with the child's school comprised the proactive response actions. The reassuring/passive response actions consisted of provider's indication that nothing was wrong, it was too early to tell, or the child might outgrow the concerns.

Zuckerman, Lindly, & Sinche (2015) revealed that children with ASD were less

likely to receive proactive provider responses. Such results were significant with the ASD population being 14% less likely to report proactive provider responses (AIRR, 0.86; 95% CI, 0.77-0.95). Hence, those with ASD reported receiving all three reassurance/passive responses 30% more than those with ID/DD (AIRR, 1.30; 95% CI, 1.15-1.47). Furthermore, the children with ASD had higher socioeconomic status, private insurance, more educated parents, and were in a 2-parent family. In addition, those diagnosed with ID/DD had a mean age of concern of 3 years of age as compared to 2.1 years of age for those diagnosed with ASD. Those with ASD reported a 2.7-year delay in diagnosis from the initial discussion with medical providers.

Physician Perceptions	Results
Mandell et al. (2007)	Studies reveal misdiagnosis, across ethnicities. Common misdiagnoses were ADHD, followed by conduct-related disorders, adjustment disorder, and cognitive disorders. Specific to African-American children, they are twice more likely than other children to receive a diagnosis of conduct disorder.
Mandell (2009)	With performing a regression analysis on 2,586 eight-year-old children, lacking the diagnosis of Autism, results identified that 58% of the children actually had the diagnosis.
Dosreis, Weiner, Johnson, and Newschaffer (2006)	Of pediatric physicians only 8% routinely screened for Autism Spectrum Disorder. Screening was primarily due to parental concern and suspicion of Autism during a routine examination.
Angell & Solomon's (2014)	Misinterpretation of the parents' concerns led to late diagnosis, misdiagnosis, and inappropriate treatment planning for service delivery.
Zuckerman et al. (2013)	The PCPs perceived Latino parents as having a lack of knowledge of the disorder leading to challenges in the screening process especially with language barriers.
Zuckerman, Lindly, & Sinche (2015)	Parents having children with ASD reported medical providers were less likely to be proactive in addressing their concerns regarding their child's development and behavior. Those families with ASD reported receiving reassurance/passive responses regarding their concerns.

Figure 5. Key supportive studies in physician perceptions during the ASD diagnostic process.

Socioeconomic Status

An in depth view of the literature identifies variations in the age of diagnosis when accounting for SES and level of education. Mortality rates and quality of health care, for various conditions, have a direct connection to SES (King & Bearman, 2011). Children with more educated parents/mothers are more likely to be diagnosed at an earlier age (Fountain, King, & Bearman, 2011; Mandell, et al, 2009). Higher levels of education may allow one to exploit the use of innovative practices such technological advances and improved care delivery models. Available services for those with SES may become limited due over saturation of accessible care providers. Furthermore, African-Americans and Hispanics having the highest rates of teen pregnancies, and lower maternal education attainment, within the United States, the correlation of age of diagnosis to these factors is concerning (CDC, 2014). Younger maternal ages, and lower maternal education attainment, show significant association to older ages of Autism diagnosis (Shattuck, et al., 2009). Parents who are more educated may have increased knowledge and awareness of Autism symptoms and signs. This may result in early diagnosis and treatment, in comparison to parents with lower education attainment, who may not be knowledgeable about Autism and its behavioral characteristics.

In regards to socioeconomic status (SES), individuals receiving long-term government assistance, particularly federal healthcare, are three times more likely to receive some other diagnosis (Mandell, et.al, 2007). A person's SES proves to correlate to if a physician screens for Autism (Gibson, 2007). Furthermore, it is revealed that the

younger median ages of a mother, born outside the United States, and having government provide insurance display later ages of diagnosis (Fountain, et al., 2011). Through requiring assistance with rendering care to their children, the mothers reduce contact with the child. Therefore, there are reduced opportunities to possibly detect symptoms (Ennis-Cole, Durodoye, & Harris, 2013). Furthermore, Tek & Landa (2012) revealed the absence of individuals with lower economic status from research. Hence, literature suggested that higher SES might predict symptom detection (Tek & Landa, 2013). The gap in the age of diagnosis between the highest and lowest SES children remains (Fountain, et al., 2011) thus this requires additional research to gain a more generalized view of the sample population.

SES in Relation to the ASD Dx	Results
King & Bearman (2011)	A person's context, specifically the neighborhood in which they live, directly influence and impact the prevalence of diagnoses and health outcomes.
Fountain, King, & Bearman (2011)	There is a significant difference in age of diagnosis based on SES. Those having parents with higher educational levels received a diagnosis significantly earlier than those without.
Shattuck, et al. (2009)	Younger maternal ages, and lower maternal education attainment, showed a significant association to older ages of Autism diagnosis.
Mandell, et.al (2007)	Individuals receiving long-term government assistance, particularly federal healthcare, are three times more likely to receive some other diagnosis
Gibson (2007)	A person's SES proves to correlate to if a physician screens for Autism.
Fountain, et al. (2011)	The younger median ages of a mother, born outside the United States, and having government provide insurance display later ages of ASD diagnoses.
Ennis-Cole, Durodoye, & Harris (2013)	Parents requiring assistance with rendering care to their children reduces contact with the child. Therefore, there are reduced opportunities to possibly detect symptoms of ASD.
Tek & Landa (2012)	The study acknowledged the absence of individuals with lower economic status from research. It suggested that higher SES may predict symptom detection of ASD.

Figure 6. Key supportive studies in the influence of SES in relation to the ASD diagnosis.

Symptom Presentation

When researching trends in clinical presentation of Autism between racial/ethnic groups, slight differences emerge. Children from URM groups are more likely to have lower communication scores presenting with delayed or atypical language. Tek & Landa (2013) performed the first study on 84 families investigating ethnic differences in the characteristics of ASD in toddlers. Previously collected pre-treatment data provided information to compare 19 minority and 65 non-minority children with ASD. Standardized testing included a parent questionnaire, clinician developmental rating scale, and the Autism Diagnostic Observation Schedule-Generic (ADOS; Lord et al., 1999). Socioeconomic status (SES) further provided demographic information to consider during analysis (Tek & Landa, 2013). Measures assessed receptive and expressive language, cognitive, social, and motor skills.

The results revealed upper-middle class made up the majority of subjects having ASD. Hence, the minority and non-minority groups did not have significant differences. Tek & Landa (2013) suggested that higher SES correlates to symptom detection. Despite variation of the samples, minority children scored lower in language and communication on the parent and clinician assessments. Such findings led the researchers to suggest a possible phenotype relating to ethnicity and ASD symptom presentation. However, the subject size and sample bias led to significant study limitations. Yet, Becerra et al. (2014) identified similar findings. While differences were revealed for language, behavioral differences presented, children from URM groups tended to have outbursts that are more

emotional. The study occurred in California and included foreign-born mothers. While the findings again pose significant bias, and lack generalizability to the national ASD population, it is important to assess how these differences in presentations correlate to the rate and age of diagnosis.

Symptom Presentation of the ASD Dx	Results
Tek & Landa (2013)	Minority children scored lower in language and communication on the parent and clinician assessments. Providing possible differences in presentation of minorities versus non-minority children with ASD.
Becerra et al. (2014)	Children from URM groups tended to have outbursts that are more emotional.

Figure 7. Key supportive studies in the symptom ASD diagnosis between racial groups.

DSM-5

Traditionally, the DSM is used to diagnosis Autism. The physician's charge is to observe the child to determine diagnose, or rule-out, Autism. Yet, the process often results in a delay in, or temporary, diagnosis (Bricout, Porterfield, Tracey, and Howard, 2004). With concern that the DSM over generalizes symptoms without taking into account race/ethnicity and culture, the tool requires analysis (American Psychiatry Association, 2013).

Recent epidemiological studies, performed on the DSM, aimed to identify cross-cultural variations in diagnosis presentations. As a result, the DSM lacks consideration of one's culture and social diversity. There are efforts now to implement a cultural formulation interview and list of culturally diverse diagnostic criteria. The newly developed components provided a launch pad to address cultural differences. However, the DSM-5 changes did not indicate an inclusion of the Autism diagnosis. In addition to such a concern, the controversial changes to the Autism diagnosis cause additional reason for alarm.

In response to the rising rates, and an attempt to provide more specificity to the diagnosis of Autism, the DSM-IV was modified (Maenner et al., 2014). Physician's lack of confidence in diagnosing could be another cause for the changes. Yet, a biomedical model again applies when looking at the diagnostic process. The current DSM-5 has a major revision that it collapses the diagnosis into simply Autism rather a spectrum of disorders (American Psychiatric Association, 2013). The DSM-5 eliminates the Autism

diagnoses of PDD-NOS and Asperger's disorder from the categories (Figure 8). Expert's suspects that the previous utilization of the minimal criteria set for those former categories resulted in over diagnoses (Maenner et al., 2014). Retrospective studies reveal a lower percentage of children, previously diagnosed with Autism, fitting the new DSM-5 criteria (Kulage, Smaldone, Cohn, 2014).

<p>Criteria A: Persistent social communication and social interaction deficits in multiple contexts. Includes deficits in all three areas: Social-emotional reciprocity. Nonverbal communicative behaviors used for social interaction. Developing, maintaining, and understanding relationships.</p> <p>Criteria B: Restricted, repetitive patterns of behavior, interests, or activities. Includes at least two: Stereotyped or repetitive movements, use of objects, or speech. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior. Highly restricted, fixated interests that are abnormal in intensity or focus. Hyper- or hyporeactivity to sensory input or unusual sensory environment interest.</p> <p>Criteria C: Symptoms were present in early developmental period.</p> <p>Criteria D: Symptoms correlate with clinically significant impairments in social or occupational functioning.</p> <p>Criteria E: Impairments are not better explained by intellectual disability or global developmental delay. Clinician specifies the following: With or without intellectual impairment. With or without language impairment. Any associated or known medical or genetic condition. Any associated neurodevelopmental, mental or behavioral disorder.</p> <p>Severity rating:</p> <p>Level 1: Requires support.</p> <p>Level 2: Requires substantial support.</p> <p>Level 3: Requires very substantial support.</p> <p><i>Adapted from Autism criteria found in the Diagnostic and Statistical Manual for Mental Disorders, edition 5 (American Psychiatric Association, 2013).</i></p>
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Figure 8. DSM-V ASD Diagnostic Criteria

- Autism spectrum disorder versus Autistic disorder (autism)
- One single diagnostic condition versus different conditions (i.e. Asperger's Disorder, Autism, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder not otherwise specified)
- Varying severity levels of symptoms acknowledged in the DSM-5
- The addition of social communication disorder into the DSM-5 in the absence of restricted repetitive behaviors.

(American Psychiatric Association, 2013)

Figure 9. Changes from DSM-IV-TR to DSM-5 domains

Research suggests that there will be a 30% decrease in the rate of diagnosis of Autism (Kulage, Smaldone, Cohn, 2014). Literature reports that those children who previously diagnosed with Asperger's disorder ranged from 0% to 83% for meeting the new criteria (Mattila et al, 2011; McPartland et al, 2012; Gibbs et al, 2012). Children who diagnosed as PDD-NOS resulted in 17% to 50% meeting the new criteria (Mattila et al, 2011; Taheri & Perry, 2012; McPartland et al, 2012; Gibbs et al, 2012). Those with a previously received diagnosis of Autism Spectrum Disorder had a higher correlation to the DSM-5, ranging from 76% to 90%. (Mattila et al, 2011; Taheri & Perry, 2012; McPartland et al, 2012; Gibbs et al, 2012).

After reviewing the data, it was observed that the prevalence of Autism decreases when the DSM-5 is applied (Maenner et al., 2014). The individuals that previously fit the criteria of Asperger's Disorder and PDD-NOS have the lowest predicted chances to fit the new criteria. Clinical case studies on individuals currently in the Early Intervention system reveal extreme practitioner and parental concern (Harstad, Mauras, Weissman, Augustyn, 2014). Younger children not presenting with significant communication concerns, and who lack repetitive and restricted behaviors, may not be diagnosed (Kulage, Smaldone, Cohn, 2014). With screening assessments not being sensitive enough to detect dysfunction, children may fall through the cracks.

The concern regarding the DSM-5 reducing the rates of Autism diagnoses is extremely concerning for URM groups. Given the historic over generalized model of the DSM, one must question the implications for the URM groups. Research established that such individuals have lower rates and ages of diagnosis. Ethnicity, maternal age,

educational attainment, and SES are themes that have significant correlations to rates of diagnosis of Autism (Mandell, et.al, 2007;, et al., 2011; Mandell, et al, 2009; Shattuck, et al., 2009; King, & Bearman, 2011). Without taking into account a Biopsychosocial model, the DSM changes may significantly affect the URM populations. Not surprising, current research has not addressed how the changes in the DSM-5 might affect URM groups.

DSM-5 Influence on the ASD Dx	Results
Maenner et al. (2014)	Previous DSM editions led to over diagnosis of ASD. The DSM-5 criteria leads to a reduction of ASD cases.
Kulage, Smaldone, Cohn (2014)	Retrospective studies reveal a lower percentage of children, previously diagnosed with Autism, fitting the new DSM-5 criteria (Kulage, Smaldone, Cohn, 2014).
Mattila et al (2011)	Revealed a 58.3% reduction in the ASD through application of the DSM-5 criteria.
McPartland et al. (2012)	Revealed a 39.4% reduction in the ASD through application of the DSM-5 criteria.
Gibbs et al (2012)	Revealed a 23.4% reduction in the ASD through application of the DSM-5 criteria.
Harstad, Mauras, Weissman, Augustyn, (2014)	Clinical case studies on individuals currently in the Early Intervention system reveal extreme practitioner and parental concern regarding the changes in the DSM-5 criteria for ASD.

Figure 10. Key supportive studies in the release of the DSM-5 and its impact on the ASD diagnosis.

Significance of the Study

While the prevalence of ASD continues to grow nationally, disparities in the rate and age of diagnosis are apparent between URM and non-minority populations. The traditional biomedical-based model of healthcare does not offer insight to healthcare providers that can assist them in addressing these disparities. The Biopsychosocial model sets a template for examining possible causes.

This study examines the apparent challenges to the diagnostic process. Parental perception and physician observation pose significant difficulty. If parents are the individuals relied upon to report to healthcare practitioners, they need to recognize the symptoms of ASD to express concern. Yet, there appears to be a gap in their knowledge and physician response to ASD symptoms. Research revealed educational level, and cultural disparities as other causal factors. Yet, acknowledgement of the lack of symptom recognition is extremely limited in the literature. Further research on the perspectives of URM groups, as relating to symptoms of Autism, is necessary for early detection.

Finally, the newly implemented DSM-5 has resulted in new concerns regarding this disparity. Now more than ever, physicians' screening methods require evolution to an approach such as the proposed Biopsychosocial model. It is crucial to continue exploration of the identified health disparity to enhance treatment outcomes, and quality of life, for children and families dealing with ASD. Investigation should include social

and cultural influences as well as possible differences in symptom presentations between cultural groups.

CHAPTER III

METHODOLOGY

Design

For this dissertation, a retrospective Cohort Design occurred through use of secondary data analysis of the Survey of Pathways to Diagnosis and Services, 2011. Cohort studies allow researchers to observe collected data related to a specific group rather cohort. Retrospective studies review prior data to provide an historical view to inform current issues or inquiries. This study design is essential to the exploration of diagnoses and epidemiology (Doll, 1980).

Database

The study reviewed past parent surveys regarding personal recounts before and during child's receipt of ASD diagnosis. The analysis addressed the overarching research question.

Does parental race AND /OR socioeconomic status influence the Childs Age at Diagnosis, Childs Age when Concerns Identified, and Childs Age a Medical Professional was sought amongst underrepresented minority groups specific to Autism?

The Pathways to Diagnosis data consisted of 4,032 parental interviews of parents having children with an ASD diagnosis, intellectual disabilities, or developmental disabilities.

Variables

Dependent Variables

Dependent variables in this study consisted of the child's age of receipt of the ASD diagnosis. To further explore the parental influences relating the diagnostic process, parental age of concern was an additional dependent variable. In order to further explore the parental influence on the diagnosis, this study included the age they sought out a medical professional as a dependent variable.

Independent Variables

The child's race and family's socioeconomic status were independent variables for this dissertation study. Socioeconomic status consisted of parental educational and poverty levels.

Procedures

To gain access to the database, this researcher completed a request for data resources center indicator data set. Following review of the form by the Child and Adolescent Health Measurement Initiative (CAHMI), they forwarded a data use agreement form which was completed by the investigator and returned. The CAHMI approved the data agreement form and provided a link to the requested data set.

Data Mining

Following approval to access the data, the researcher performed data mining to clean and stratify the samples. The data required initial mining to determine relevant variables. It consisted of subjects having a diagnosis of ASD as well as intellectual disabilities (ID) and developmental disabilities (DD). Of the sample, 1420 revealed a diagnosis of ASD. Once determining the relevant subjects, this researcher then identified the factor variables. Data consisted of Caucasian children, African-American, and other. This study aimed to investigate the disparity between Caucasian children and URM. Hence, the data required for the development of a new variable. The URM group merged both the African-American and other subjects.

Once establishing the groups, an *A Priori* occurred through application of G*Power software for the independent t-test indicated two tails, a medium effect size of 0.5, and selected power of 0.95 (Appendix A). The significance alpha level was 0.05. The analysis resulted in a minimum sample size of 210 subjects. Further analysis occurred for the Chi-Square analysis. *A Priori* through application of G*Power software for the Chi-Square analysis applied a medium effect size of 0.3, and selected power of 0.95. The significance alpha level was 0.05. The analysis resulted in a minimum sample size of 220 subjects (Appendix A).

Secondary to missing data, within the variables, as well as unbalanced groups, the researcher randomly selected 300 subjects following stratification. Data mining further required review of the 2011 Survey of Pathways to Diagnosis and Services database to

select appropriate questions related to the indicated variables. The database consisted of raw data from a study supported by the Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) of the U.S. Department of Health and Human Services (HHS) under Cooperative Agreement U59MC27866, The National Maternal and Child Health Data Resource Center. There were two inclusion criteria for the sample. (1) Diagnosis of autism spectrum disorder (ASD), intellectual disability (ID), and/or developmental delay (DD). (2) Child aged 6 -17 years at time of Pathways interview. Researchers randomly selected telephone numbers, within the United States, from July 2009 through March 2011. Through telephone conversation, researchers inquired if the household had a child living there with special healthcare needs. If they met the inclusion criteria, the interviewer identified them as a Child with Special Health Care Needs (CSHN).

The total respondents having identified as CSHN were 7,572. Researchers randomly selected and re-contacted 6,090 of the CSHN households between February 2011 through June 2011. Those families performed a telephone interview survey. Researchers completed 4,032 telephone interviews. Of those interviewed, 3,997 families agreed to receive a mailed self-administered questionnaire to complete and return. Of those mailed, 2,988 returned completed Strengths and Difficulty and Child's Social Behavior questionnaires.

Relevant telephone interview questions included sections on parental concerns. Ten questions addressed what the parent experienced before their child's receipt of the ASD diagnosis. Such questions required the parent to reflect on past knowledge. Questions addressed the diagnostic process related to the parent's experience during the time their child received the ASD diagnosis. Inquires also resulted in information about the type of doctor or health care provider who originally determined the child's diagnosis. Interviewers also queried about school professionals' role in the diagnostic process. In addition, to address the impact of health insurance and access, questions focused on parental perception to having their child's healthcare needs met. Parents also answered questions regarding health care coverage including insurance, prepaid plans, and government plans.

The self-administered survey further addressed parental perceptions. The survey consisted of inquires from *The Strengths and Difficulties Questionnaire* by Robert Goodman. Parents answered questions regarding their perceptions towards their child's current healthcare services and educational services. Questions also explored parental perceptual towards the prognosis of the disorder. Such questions occurred during telephone interview. However, they reappeared during the self-administered questionnaires as well. Inquires addressed parents, siblings, race, and ethnicity (in relation to Hispanic or non-Hispanic).

Following review of the survey questions, development of a chart then mapped out relevant inquiries (Figures 11). Furthermore, this researcher determined the type of variables to help determine required statistical tests. The dependent variables of age of

concern, age sought out a medical professional, and age of diagnoses were continuous variables. Those variables required cleaning as some ages were displayed in years and others months. Once converting the data to months, a new dataset emerged. The new dataset included stratified data only including those with the ASD diagnosis. Random selection then identified 150 subjects from both groups, Caucasian and URM groups.

Research question	RQ1 : Does parental race AND/OR socioeconomic status influence the Childs Age at Diagnosis, Childs Age when Concerns Identified, and Childs Age a Medical Professional was sought amongst underrepresented minority groups specific to Autism?	
Hypotheses:	<p>H1a: Caucasian Children Receive A SIGNIFICANTLY MORE Timely Diagnosis OF ASD WHEN Compared To URM Children.</p> <p>H1b: There Is An Association Between Race And WHEN ASD DX IS RECEIVED From A Medical Specialist.</p> <p>H1c: There is a significant difference between Caucasian and URM groups as to when parents express concern for ASD and the time of an ASD screen.</p> <p>H1d: There Is A Significant Relationship Between Age Of Diagnosis Of ASD And Socioeconomic Status.</p> <p>H1e: There is a significant relationship between child's age when concerns identified, and child's age when medical professional was sought and parental socioeconomic status.</p> <p>H1f: There Is A Significant Relationship Between Age Of Diagnosis Of ASD And Parental Education Level.</p>	
	Data	Type of Data
	<p>Question:</p> <p>Did the doctors, health care providers, or school professionals ever tell you that child had any of the 3 conditions: Asperger's, pervasive developmental disorder or autistic disorder?</p>	Nominal
	<p>How old was child when you were first told he/she had ASD?</p> <p>How old was the child when you first wondered if there was something not quiet right with their development?</p> <p>How old was the child when you first talked to a doctor or health care provider about your concerns?</p>	<p>Scale</p> <p>Nominal</p>

	<p>Question:</p> <p>What type of doctor first diagnosed child with autism spectrum disorder?</p>	Nominal
	<p>Question:</p> <p>After parent expressed concerns, did the doctor or health care provider conduct a developmental test?</p>	Nominal
	<p>Question:</p> <p>After parent expressed concerns, did doctor or health care provider refer the child to a specialist?</p>	Nominal

Figure 11. Data type chart and review of variables used to inform required statistical tests for research question #1.

Research question	RQ2: Does a significant association exist between age of diagnosis of ASD and access to health coverage?	
Hypotheses:	H ₂ : A significant difference will exist between age of diagnosis of ASD and access to health coverage.	
	Data	Type of Data
	Question: Does [name] have any kind of health care coverage, including health insurance, prepaid plans such as hmos, or government plans such as Medicaid?	Nominal
Research question	RQ3: Is there an Association between the initial revealing of parental concern regarding the child's development and racial group for children with ASD?	
Hypotheses:	H ₃ There is a significant association between the initial revealing of parental concern regarding the child's development and racial group for children with ASD.	
	How old was the child when you first wondered if there was something not quiet right with their development?	Scale
	Non-Hypothesis Testing Data: Descriptive	
	<ul style="list-style-type: none"> • RQ4A-H: What differences exist between URM and Caucasian parents and their perception of the causes, treatments, and prognoses for their child's ASD diagnosis? • RQ5a: What parental concerns exist for parents of children diagnosed with ASD regarding their child's symptoms and behaviors? • RQ5b: Are there common themes amongst ethnic groups in relationship to symptoms and behaviors revealed by children diagnosed with ASD? 	
	Questions:	

<p>Do parents agree that the doctors and other health care providers that child sees are able to meet their needs?</p> <p>Do parents agree that the services their child receives from doctors and other health care providers are Able to meet their needs?</p> <p>Do parents agree the condition is likely to be lifelong rather than temporary?</p> <p>Do parents agree the problems related to their child's condition can be prevented or decreased with treatment?</p> <p>Do parents agree they have the power to change their child's condition?</p> <p>Do parents get upset when they think about their child's condition?</p> <p>Do parents agree their child's condition is genetic or hereditary?</p> <p>Do parents agree their child's condition was caused by something the child was exposed to in utero, that is, before they was born?</p> <p>Parents were asked questions relating to the symptoms their child had during the time of their Diagnosis:</p> <p>Based on your child's behavior over the last 6 months, would you say the following statements are Not True, Somewhat True, or Certainly True?</p> <ul style="list-style-type: none"> • Considerate of other people's feelings? • Restless, overactive, cannot stay still for long? • Often complains of headaches, stomach-aches or sickness? • Shares readily with other children, for example toys, treats, pencils? • Often loses temper? 	
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Figure 12. Data type chart and review of variables used to inform required statistical tests for research questions.

	<ul style="list-style-type: none"> · Rather solitary, prefers to play alone? · Generally well behaved, usually does what adults request? · Many worries or often seems worried? · Helpful if someone is hurt, upset or feeling ill? · Constantly fidgeting or squirming? · Has at least one good friend? · Often fights with other children or bullies them? · Often unhappy, depressed or tearful? <p>In the last two months, please indicate the extent to which your child's behavior occurs regularly, infrequently or does not occur/ does not apply: Talks confusedly; jumps from one subject to another in speaking?</p> <ul style="list-style-type: none"> · Generally liked by other children? · Easily distracted, concentration wanders? · Nervous or clingy in new situations, easily loses confidence? · Kind to younger children? · Often lies or cheats? · Picked on or bullied by other children? · Often offers to help others (parents, teachers, other children)? 	
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	<ul style="list-style-type: none"> · Thinks things out before acting? · Steals from home, school or elsewhere? · Gets along better with adults than with other children? <ul style="list-style-type: none"> · Many fears, easily scared? · Good attention span, sees chores or homework through to the end? <ul style="list-style-type: none"> · Only talks about things that are often concern to him/her? · Does not fully understand what is being said to him/her, for example, tends to miss the point? · Frequently says things that are not relevant to the conversation? · Does not understand jokes? · Takes things literally, for example, does not understand certain expressions? · Is extremely naïve; believes anything you say? · Overreacts to everything and everyone? · Flaps arms/hands when excited? · Makes odd, fast movement with fingers or hands? · Sways back and forth? · Does not look up when spoken to? · Acts as if others are not there? · Lives in a world of his/her own? 	
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Figure 13. Review of non-hypothesis testing of variables used to inform research questions #3-5.

	<ul style="list-style-type: none"> · Makes little eye contact? · Dislike physical contact, for example, does not want to be touched or hugged? · Does not seek comfort when he/she is hurt or upset? · Does not initiate play with other children? · Has little or no need for contact with others? · Does not respond to attempts by others to initiate contact, for example, does not play along when asked? · Is usually sensitive to certain sounds, for example, always hears certain sounds earlier than other people? · Is extremely pleased by certain movements and keeps doing them, for example, turning around and around? · Smells objects? · Constantly feels objects? · Is fascinated by certain colors, forms, or moving objects? · Has difficulty doing two things at the same time, for example, he/she cannot dress and listen to parent at the same time? · Cannot tell if he/she is at the beginning, middle, or end of an activity? · Does things without realizing the goal, for example, constantly has to be reminded to finish things? · Shows sudden mood changes? · Gets angry quickly? 	
--	---	--

	<ul style="list-style-type: none"> · Stays angry for a long time, for example, when he/she does not get his/her way? · Cannot be made enthusiastic about anything; does not particularly like anything? · Does not show his/her feelings in facial expressions and/or body posture? · Does not realize when there is danger? · Barely knows the difference between strangers and familiar people, for example, readily goes with strangers? · Is disobedient? · Cannot be corrected when he/she has done something wrong? · Has difficulty taking in information; information is heard but does not sink in? · Makes careless remarks, for example, remarks that are painful to others? · Does not appreciate it when someone else is hurt or sad? · Makes a fuss over little things; "makes a mountain of a mole-hill"? · Does not know when to stop, for example, goes on and on about things? 	
--	--	--

Figure 14. Continued review of non-hypothesis testing of variables used to inform research questions #3-5.

Following data cleaning, the newly formed dataset allowed for distribution analysis and test of homogeneity. Review of the data type determined a need for non-parametric testing for the categorical variables. The figure below maps out the process and categorization of the variables informing statistical analysis.

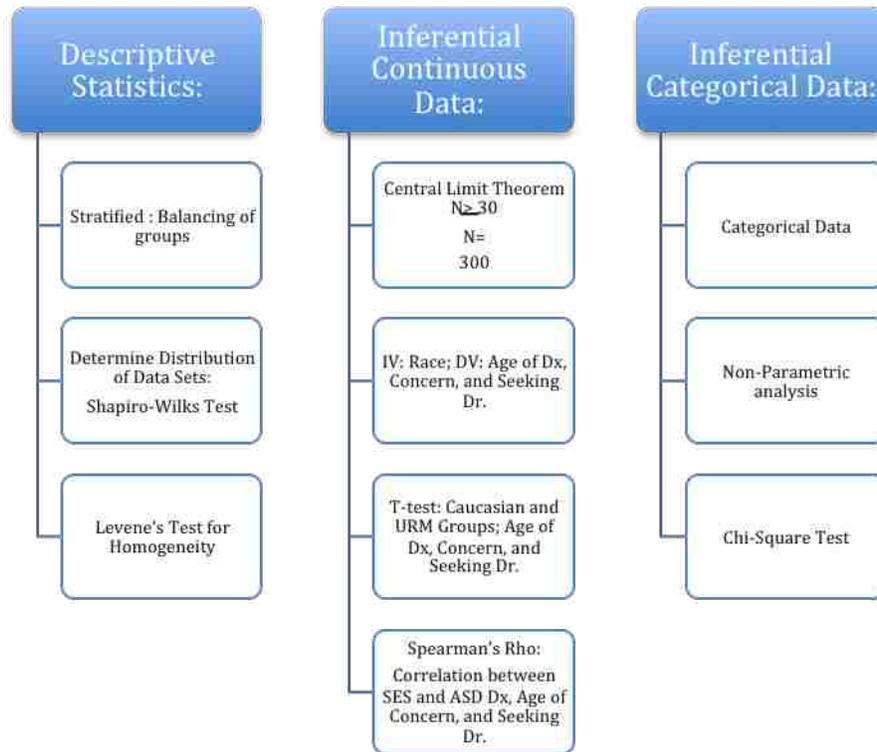


Figure 15. Process and statistical analysis based on data type.

Data Analysis

Proper selection of the statistical tests occurred following review of the variables as outlined in the previous section. Data analysis included application of a t-test of two independent means. Such analysis supported the investigation of the probability of differences in the age of diagnoses between Caucasian and URM children. Age, being continuous data, allowed for t-test analysis with an alpha level for the analysis of $p \leq 0.05$. Hence, there was a 5% risk of identifying a difference that did not truly exist. Lastly, the use of the t-test assisted the examination of a possible difference between Caucasian and URM groups regarding the child's age when parents first acknowledged concern about the child's development.

The selection of the Chi-Square test was appropriate in determining if an association existed between the categorical data. The variable sets examined possible associations between the child's race and if the child received an ASD diagnoses by a specialist. The alpha level for this analysis was also $p \leq 0.05$. Furthermore, having two categorical variables, the Chi-Square analysis through cross tabulation was necessary.

Next, the study required use of a Spearman's Rho statistical analysis to investigate if there was a significant relationship between age of diagnosis of ASD and socioeconomic status (SES). Having one continuous data type, and one ordinal, the analysis required use of the Spearman's Rho versus a Pearson's r correlation. The Spearman's Rho also allowed for analysis of the relationship between the child's age

when parental concerns were first identified, and the child's age when a medical professional was sought. Examination of the relationships between the child's age and parental socioeconomic status, and parental education level, also required such statistical analysis. The alpha level for the analyses remained at $p \leq 0.05$ for all statistical tests.

Lastly, examination of parental perception occurred through the self-administered questionnaires. Parents answered questions regarding their perspectives towards their experiences before, during, and after the ASD diagnosis. Non-hypothesis testing involved descriptive statistics to analyze their responses. To this end, both inferential and descriptive analysis informed the overarching research question: *“Does parental race and /or socioeconomic status influence the child's age at diagnosis, child's age when concerns identified, and child's age a medical professional was sought amongst underrepresented minority groups specific to Autism?”*

CHAPTER IV

RESULTS

Characteristics of the Sample

The study sample size was 300; 150 subjects for each group. An overview of the demographic data determined descriptive statistics for the sex of the samples, parental education, poverty level, and region of residence for both the Caucasian and URM groups. The two groups had similar demographics relating to the sex of the child. The majority of the sample was male at 77.33%. For parental educational level, the majority of parents had higher than a high school education. Caucasian parents reported having more than a high school education at 85.3% and 80.7% for the URM parents.

The poverty levels of both groups were comparable as approximately 80% of parents reported being above the poverty level indicating higher levels of income based upon family size. Regarding the place of residence, both groups were primarily from the Western regions of the United States, followed by Southern regions, accounting for 60% of the sample in total.

A post-hoc G*Power analysis on the t-test, with a medium effect size of 0.5, $p > 0.05$, resulted in a power of 0.99. Therefore, the resulting power was high. For the test of correlation having a medium effect size of 0.6, the power was 0.99. Hence, the statistical power was again high. (Appendix B)

Utilization of the Shapiro-Wilk test revealed variations from normality for both the Caucasian and URM sample groups. Conducted tests of normality for race, and age of receiving the ASD diagnosis, demonstrated that the data was positively skewed. Normality testing for the child's age, at the time of initial parental concern, and when the parents first spoke with a medical professional regarding the concerns, are illustrated in Figures 16-21. Given the positive skewedness, the data lacked normal distribution with the tail towards the right of the peak and the mass towards the left. Despite the tests for normality indicating significance, the Central Limit Theorem applied due to the large sample size being greater than 30 subjects.

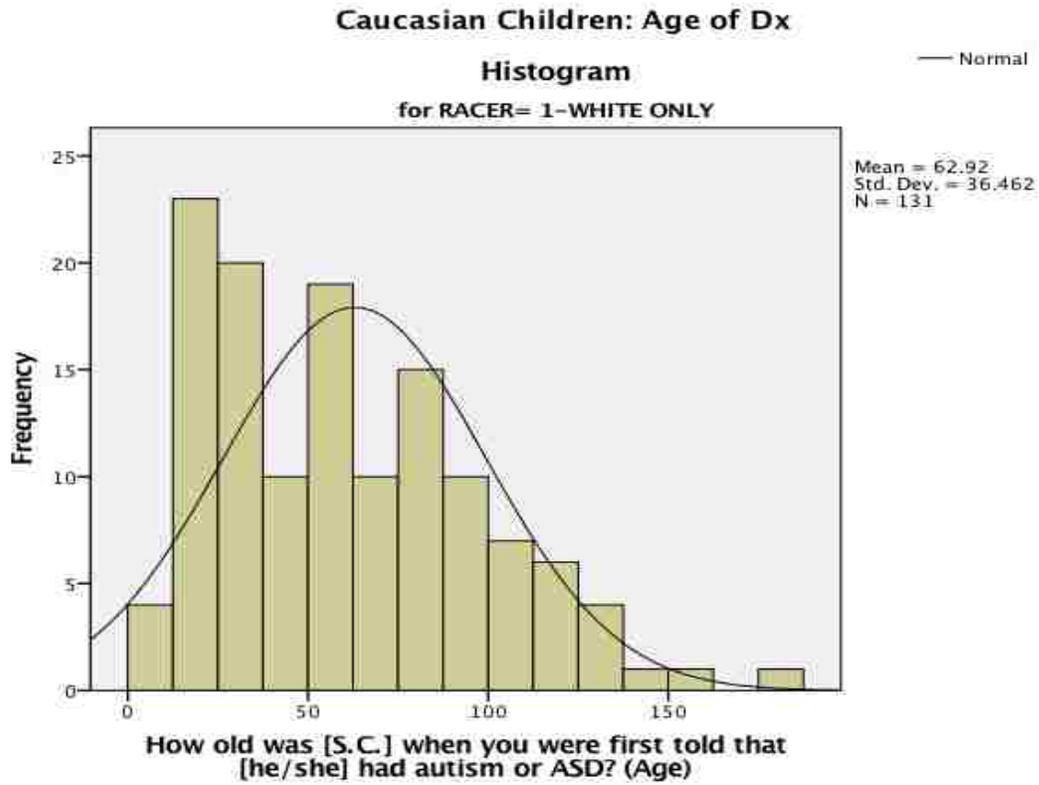


Figure 16. Tests of Normality: Age of Diagnosis for Caucasian Subject Group.

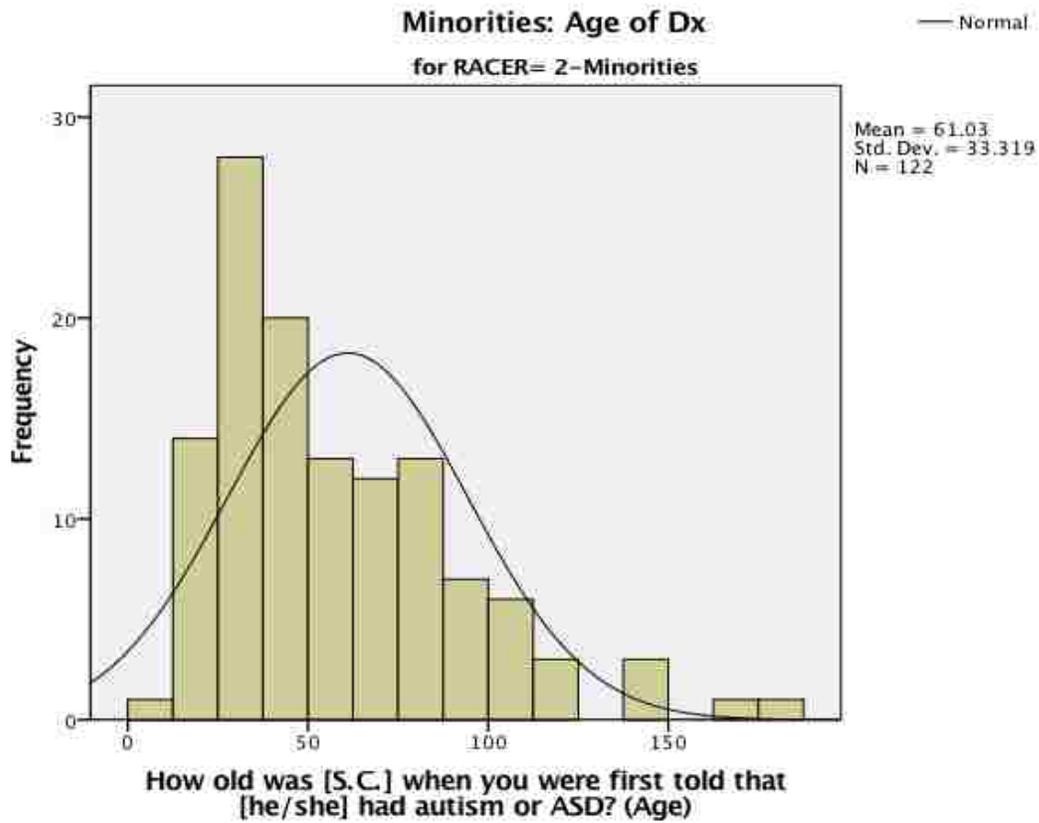


Figure 17. Tests of Normality: Age of Diagnosis for URM Subject Group.

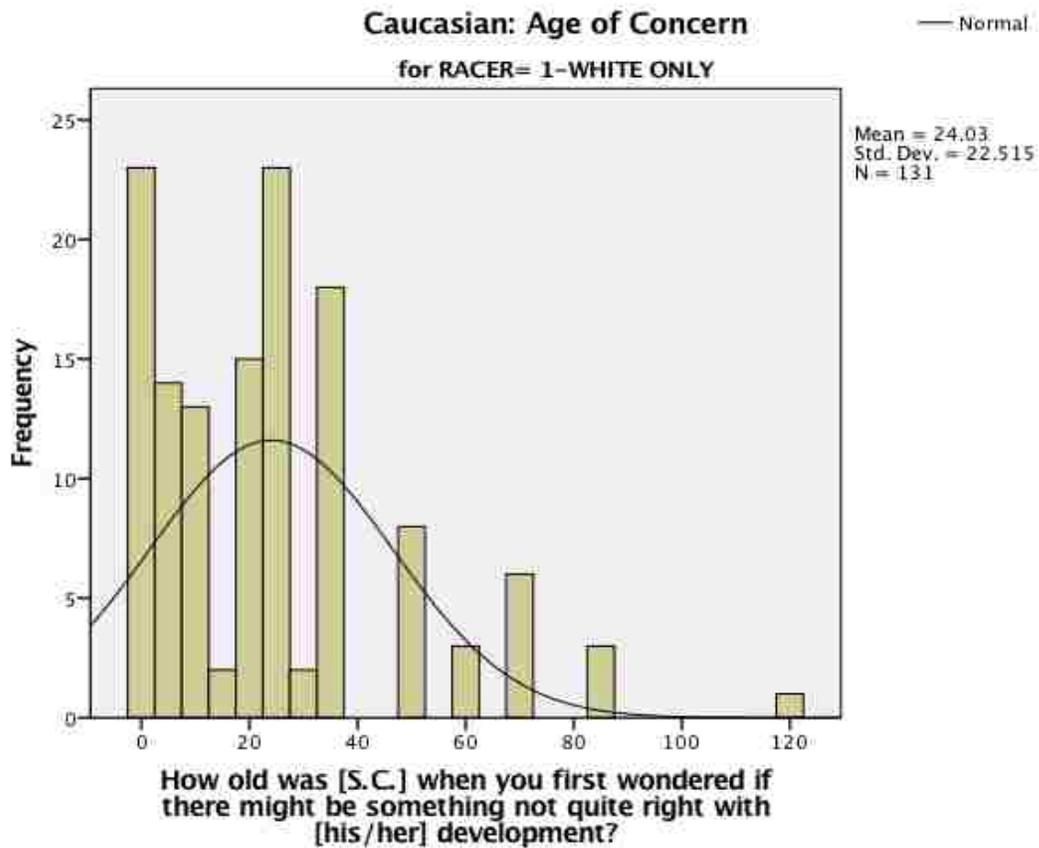


Figure 18. Tests of Normality: Age of concern for Caucasian Subject Group

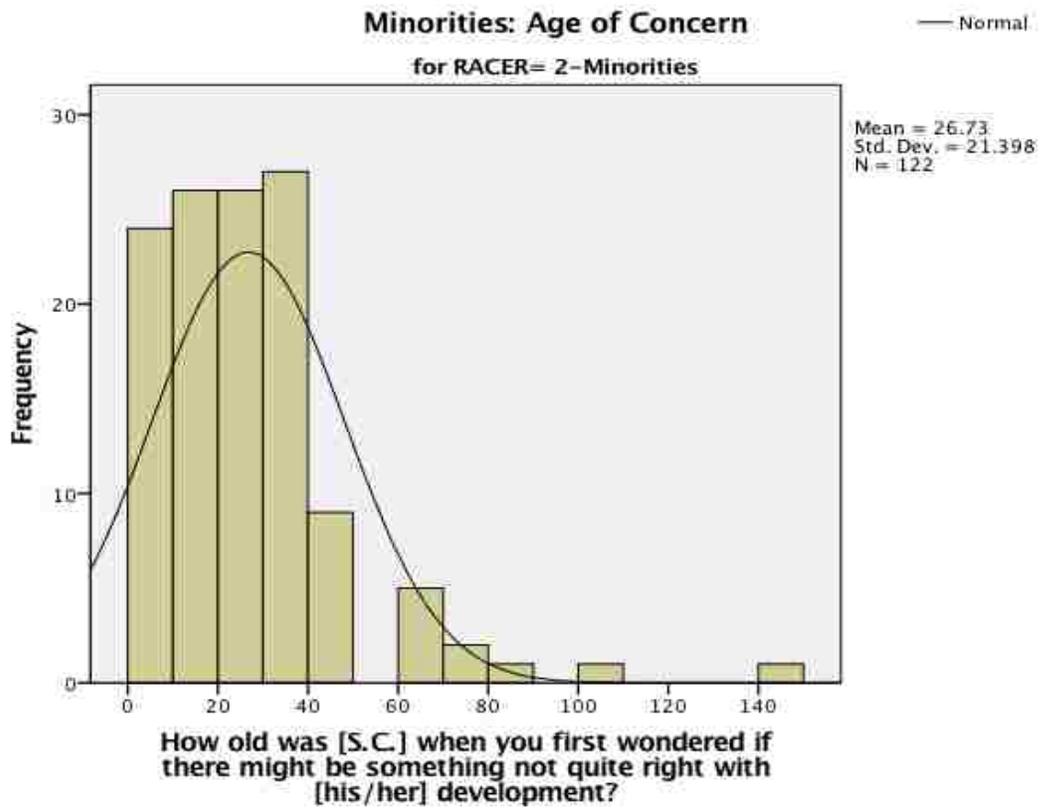


Figure 19. Tests of Normality: Age of concern for URM Subject group.

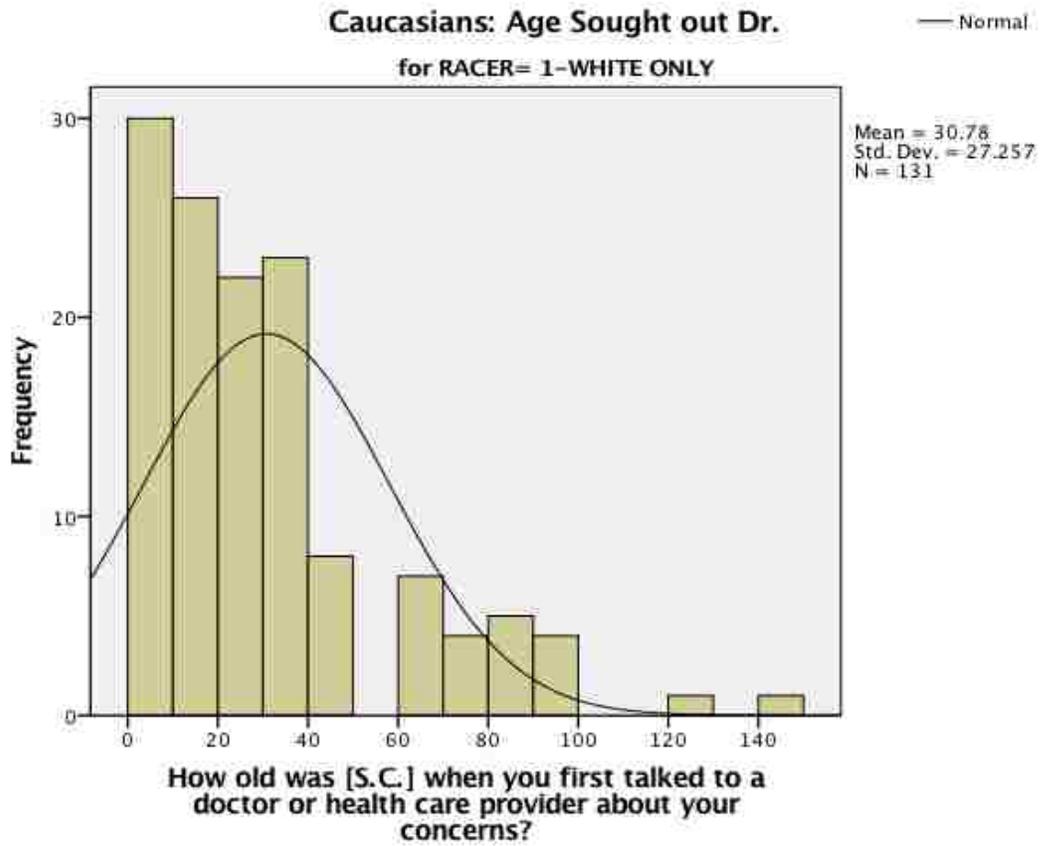


Figure 20. Tests of Normality: Age Sought out Medical Professional for Caucasian subject group

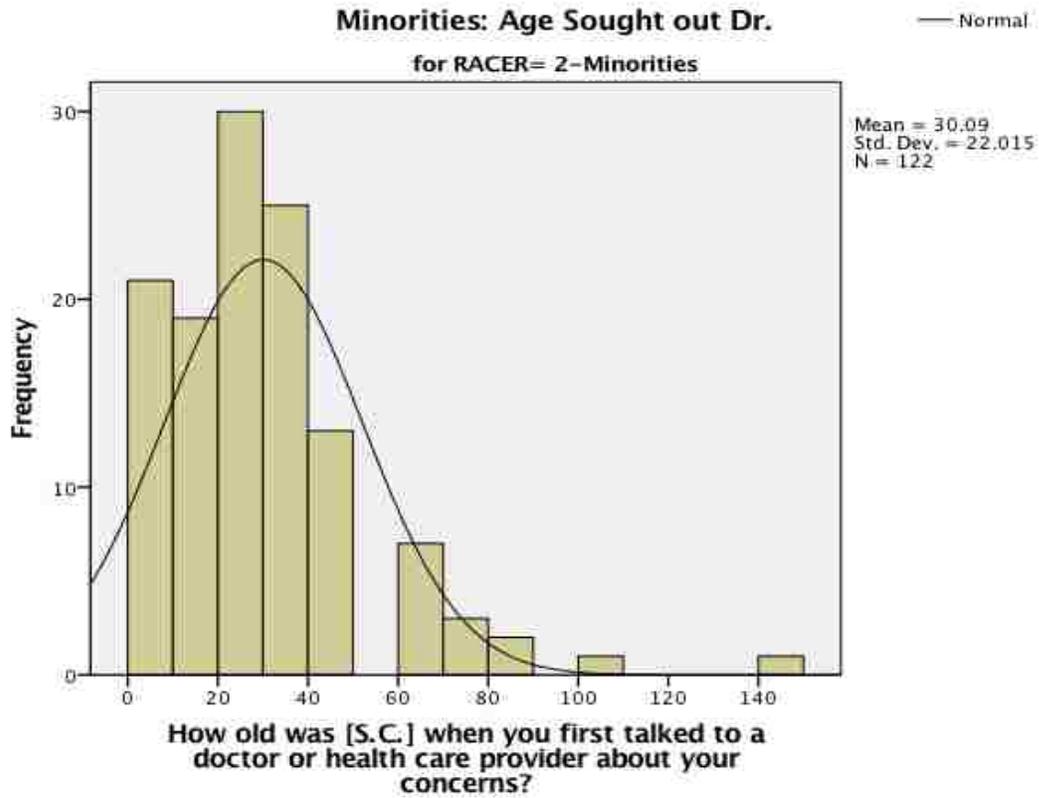


Figure 21. Tests of Normality: Age Sought out Medical Professional for URM subject group

Quantitative Findings

To explore the parental experiences at the time of diagnosis, the use of cross tabulation assisted in analysis of responses to the following questions:

- “Did the doctor or health care provider conduct a developmental test?”
- “How did that doctor or health care provider respond to your concern? –Made a referral to a specialist?”
- “How did that doctor or health care provider respond to your concern? -Said nothing was wrong/the behavior was normal?”

The questions referred to when parents originally sought out a medical professional based on their concerns. While there was not a significant association to race, 108 parents (from both groups) reported not having a developmental test conducted (Table I). Furthermore, 95 parents reported not having necessary referrals made to specialists (Table II). Lastly, 63 parents shared that the initial doctor indicated “nothing was wrong” with their child (Table III) .

Table I

Parental response to the question, “Did the doctor or health care provider conduct a developmental test?”

		0 - NO	1 - YES	6 - DON'T KNOW	
Derived. Race of target child	CAUCASIAN	40	54	0	94
	URM	68	115	1	184
Total		108	169	1	278

Table II

Parental response based on the question, “How did that doctor or health care provider respond to your concern? –Made a referral to a specialist?”

		0 - NO	1 - YES	6 - DON'T KNOW	Total
Race of target child	CAUCASIAN	43	51	0	94
	URM	52	131	1	184
Total		95	182	1	278

Table III

Parental response based on the question, “How did that doctor or health care provider respond to your concern? -Said nothing was wrong/the behavior was normal?”

		0 - NO	1 - YES	6 - DON'T KNOW	Total
Race of target child	CAUCASIAN	76	18	0	94
	URM	138	45	1	184
Total		214	63	1	278

Further analysis of cross tabulation explored the means for age of concern, and age a medical professional was sought, as compared to the age of diagnosis. Based upon the data there appears to be an overall gap, regardless of group assignment, in timing of diagnosis from age of concern, speaking to a medical professional, and receiving a diagnosis for both groups. On average, parents expressed concern around two to three years of age. Yet, a diagnosis did not occur until around the age of five years (Table IV).

Table IV

Age of Concern, Sought Medical Professional, and ASD Diagnosis.

			Statistics		
Derived. Race of target child			How old was [S.C.] when you first wondered if there might be something not quite right with [his/her] development?	How old was [S.C.] when you first talked to a doctor or health care provider about your concerns?	How old was [S.C.] when you were first told that [he/she] had autism or ASD? (Age)
CAUCASIAN	N	Valid	150	141	140
		Missing	0	9	10
	Mean		23.15	31.06	63.81
	Sum		3473	4379	8933
URM	N	Valid	150	138	133
		Missing	0	12	17
	Mean		25.37	29.20	62.08
	Sum		3806	4030	8256

In preparation for inferential data analysis of the hypotheses, the non-normality of the data required addressing. As previously stated, the Central Limit Theorem was applied based on the sample size of 300 subjects, despite the skewedness of the data. Hence, the research questions addressing mean differences between the groups implemented a t-test (Lumley, Diehr, Emerson & Chen, L., 2002). Non-parametric statistics addressed the other variables, as they were qualitative and not continuous in nature.

The results report findings for each research question. Research question #1: Does parental race and/or socioeconomic status influence the child's age at diagnosis, child's age when concerns identified, and child's age a medical professional was sought amongst underrepresented minority groups specific to Autism? The hypothesis failed to reject the null hypothesis based on the following findings.

The age the child received the ASD diagnosis did not reveal significance in the means between both groups $t(271) = .40, p > 0.05$ (Table V). There was not an association between race and when ASD diagnosis was received from a medical specialist $\chi^2(2, N = 157) = 0.70, p = .70$. The results failed to reject the null hypotheses (Table VI). Caucasian and URM groups did not reveal a significant difference as to when parents expressed concern for ASD $t(298) = -0.88, p > 0.05$ (Table VII). Also, there was not a significant difference between Caucasian and URM groups as to when parents spoke to a medical professional to perform an ASD screen $t(277) = 0.60, p > 0.05$. Furthermore, there was not a relationship between the child's age at diagnosis and parental socioeconomic status (rho

(271)= -0.00, $p > .05$), nor when the parent first spoke to a medical professional (ρ (256)= -0.07, $p > .05$) (Tables VIII). However, there was a significant relationship between child's age when concerns identified and child's age when medical professional was sought and parental socioeconomic status. The findings indicate a weak negative correlation between parental educational level and age when the parent sought out a medical professional (ρ (277)= -0.11, $p < .05$) (Table IX).

Table V

T-test Race and Age of Diagnosis.

		Independent Samples Test					t-test for Equality of Means			
		Levene's Test for Equality of Variances				Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
		F	Sig.	t	df				Lower	Upper
How old was [S.C.] when you were first told that [he/she] had autism or ASD? (Age)	Equal variances assumed	2.283	.132	.402	271	.688	1.732	4.305	-6.744	10.208
	Equal variances not assumed			.403	270.500	.687	1.732	4.295	-6.724	10.188

Table VI

Race and Received Diagnosis from a Specialist.

Crosstab

Count		Derived. Race of target child		Total
		Caucasian	2-URM	
What types of other doctors, health care providers, or school professionals told you that [S.C.] had autism or ASD? - A specialist pediatrician such as a developmental pediatrician	0 - NO	68	72	140
	1 - YES	9	6	15
	6 - DON'T KNOW	1	1	2
Total		78	79	157

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	.708 ^a	2	.702
Likelihood Ratio	.712	2	.700
Linear-by-Linear Association	.121	1	.728
N of Valid Cases	157		

a. 2 cells (33.3%) have expected count less than 5. The minimum expected count is .99.

Table VII

T-test Race and Age of Concern

		Independent Samples Test								
		Levene's Test for Equality of Variances					t-test for Equality of Means		95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
How old was [S.C.] when you first wondered if there might be something not quite right with [his/her] development?	Equal variances assumed	.680	.410	-.881	298	.379	-2.220	2.521	-7.181	2.741
	Equal variances not assumed			-.881	297.582	.379	-2.220	2.521	-7.181	2.741

Table VIII

T-test Race and Sought out a Medical Professional.

		Independent Samples Test								
		Levene's Test for Equality of Variances				t-test for Equality of Means				
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
How old was [S.C.] when you first talked to a doctor or health care provider about your concerns?	Equal variances assumed	2.949	.087	.601	277	.548	1.854	3.082	-4.214	7.922
	Equal variances not assumed			.602	274.516	.548	1.854	3.079	-4.207	7.914

Table IX

Spearman's Rho SES and Age of Diagnosis.

Correlations

			DERIVED. Highest education level of parents in household (3 categories)	How old was [S.C.] when you were first told that [he/she] had autism or ASD? (Age)
Spearman's rho	DERIVED. Highest education level of parents in household (3 categories)	Correlation Coefficient	1.000	-.003
		Sig. (2-tailed)	.	.955
	N		300	273
	How old was [S.C.] when you were first told that [he/she] had autism or ASD? (Age)	Correlation Coefficient	-.003	1.000
		Sig. (2-tailed)	.955	.
	N		273	273

Table X

Correlation of age of diagnosis and poverty level.

Correlations

		How old was [S.C.] when you were first told that [he/she] had autism or ASD? (Age)		DERIVED. Poverty level of this household based on DHHS guidelines (9 categories)
Spearman's rho	How old was [S.C.] when you were first told that [he/she] had autism or ASD? (Age)	Correlation Coefficient	1.000	-.079
		Sig. (2-tailed)	.	.208
		N	273	257
DERIVED. Poverty level of this household based on DHHS guidelines (9 categories)	DERIVED. Poverty level of this household based on DHHS guidelines (9 categories)	Correlation Coefficient	-.079	1.000
		Sig. (2-tailed)	.208	.
		N	257	278

Table XI

Spearman's Rho Sought out Medical Professional and SES.

Correlations

			How old was [S.C.] when you first talked to a doctor or health care provider about your concerns?	DERIVED. Highest education level of parents in household (3 categories)	DERIVED. Poverty level of this household based on DHHS guidelines (9 categories)
Spearman's rho	How old was [S.C.] when you first talked to a doctor or health care provider about your concerns?	Correlation Coefficient	1.000	-.119*	-.071
		Sig. (2-tailed)	.	.047	.256
		N	279	279	258
	DERIVED. Highest education level of parents in household (3 categories)	Correlation Coefficient	-.119*	1.000	.354**
		Sig. (2-tailed)	.047	.	.000
		N	279	300	278
	DERIVED. Poverty level of this household based on DHHS guidelines (9 categories)	Correlation Coefficient	-.071	.354**	1.000
		Sig. (2-tailed)	.256	.000	.
		N	258	278	278

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Correlations

Summary of the findings for research question #1

The statistical tests addressed the alternative hypotheses for the first research question. “Does parental race and/or socioeconomic status influence the child’s age at diagnosis, child’s age when concerns identified, and child’s age a medical professional was sought amongst underrepresented minority groups specific to Autism?” The non-significant findings rejected the notion that Caucasian children received a significantly more timely diagnosis of ASD when compared to URM children. There was not a significant association between race and when ASD diagnosis was received from a medical specialist. Furthermore, there was not a significant difference between Caucasian and URM groups as to when parents expressed concern for ASD and the time of an ASD screen. Additionally, the null was retained regarding the hypothesis suggesting a relationship between age of diagnosis of ASD and socioeconomic status. There was not a significant relationship between the child’s age when concerns identified, the child’s age when medical professional was sought, and parental poverty level. However, there was a weak relationship between parental educational level and seeking out a medical professional. Yet, there was not a significant correlation between age of diagnosis of ASD and parental education level.

Summary of the findings for research question #2

The second research question was as follows. “Does a significant association exist between age of diagnosis of ASD and access to health coverage?” There was not a significant association between age of diagnosis of ASD and access to health coverage ($\rho(270) = 0.11, p > .05$) (Table XII).

Table XII

Spearman's Rho Age of Diagnosis and Health Coverage.

Correlations

			How old was [S.C.] when you were first told that [he/she] had autism or ASD? (Age)	Has any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid
Spearman's rho	How old was [S.C.] when you were first told that [he/she] had autism or ASD? (Age)	Correlation Coefficient	1.000	.118
		Sig. (2-tailed)	.	.051
		N	273	272
	Has any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid	Correlation Coefficient	.118	1.000
		Sig. (2-tailed)	.051	.
		N	272	299

Summary of the findings for research questions #3-5

To capture the variations between the sample groups, examination of the response rates provided more insight for the remaining research questions. Use of frequency counts assisted in identifying factors contributing to the diagnostic process specific to the sample. Hence, the results for research questions three through five reported percentages based upon parental responses on the self-administered questionnaires. The questions analyzed were as follows.

RQS 3-5: Parents answered questions relating to their perspectives towards the diagnosis.

- RQ3A-H: What differences exist between URM and Caucasian parents and their perception of the causes, treatments, and prognoses for their child's ASD diagnosis?
- RQ4: What parental concerns exist for parents of children diagnosed with ASD regarding their child's symptoms and behaviors?
- RQ5: Are there common themes amongst ethnic groups in relationship to symptoms and behaviors revealed by children diagnosed with ASD?

The results revealed that the majority of all parents agreed with the statement that their health professionals were able to meet their child's needs, 63.3% for Caucasians and 43.3% for URMs. However, 18% of the URM parents disagreed versus 9.3% for the Caucasian parents. The remaining responses indicated "somewhat agree" with the statement, 27.3% for Caucasian parents and 38% for URM parents.

The majority of parents agreed or strongly agreed with the following question; Do parents agree that the services their child receives from doctors and other health care providers are able to meet their needs? For Caucasian parents, 63.3% agreed, and 46.7% of URM parents agreed. Additionally, 18.7% of the URM parents disagreed versus 10% for the Caucasian parents.

The majority of all parents agreed with the question; Do Parents agree the condition is likely to be life long rather than temporary? For Caucasian parents, 70% agreed and 66% of the URM parents agreed. In addition, the majority of all parents agreed with the question; Do parents agree the problems related to their child's condition can be prevented or decreased with treatment? For both groups 33.3% agreed. For the response "somewhat agreed", 48.7% of Caucasian parents and 39.3% for URM parents. However, 25.3% of the URM parents disagreed versus 17.3% for the Caucasian parents.

The majority of all parents disagreed with the question; do parents agree they have the power to change their child's condition? For Caucasian parents 60.7% disagreed, and 50.7% disagreed for URM. The majority of all parents also disagreed with the question; Do parents get upset when they think about their child's condition? For Caucasian parents 48% and 50% for URM.

For the question; Do parents agree their child's condition is genetic or hereditary?, the majority of the Caucasian parents agreed. Yet, more than half of URM parents somewhat agreed or disagreed. For Caucasian parents 36% agreed, 34% somewhat agreed, and 26.7% disagreed. For URM parents 26% agreed, 32% somewhat agreed and 32% disagreed. Lastly, the majority of the parents disagreed with the question. Do parents agree their child's condition was caused by something the child was exposed to in

utero, that is, before they was born? For Caucasian parents 60.7% disagreed and 43.3% disagreed for URM.

For research questions 4 and 5, parents answered questions relating to the symptoms and behaviors their child had during the time of their diagnosis, and at the time of the interviews. Frequency counts allowed for comparison of small variations and differences in parental reports regarding their child's symptoms and behaviors.

Question addressing RQ4: What symptoms and behaviors caused you concern at the time of diagnosis?

Question addressing RQ5: What symptoms does your child currently display?

Response frequency counts indicated more symptom concerns at the time of diagnosis by URM parents (Figure 22). Concerns were in the areas of: Vital functions: sleeping, eating, activity level, wandering, tantrums; Gross motor skills such as walking; Talked later than most children; Lost previously developed speech; Understanding adults; Fine motor skills; Learning; such as letters or numbers. For symptoms displayed currently by the child, URM reported higher rates of challenges with attention span. Both groups equally reported concerns with emotions, concentration, and behavior. Caucasian parents reported more hand flapping while URM reported more swaying back and forth by their children. Parents of URM reported their children had challenges initiating play and were fascinated with objects more often than the Caucasian group. Caucasian parents reported their children had more frequent mood swings.

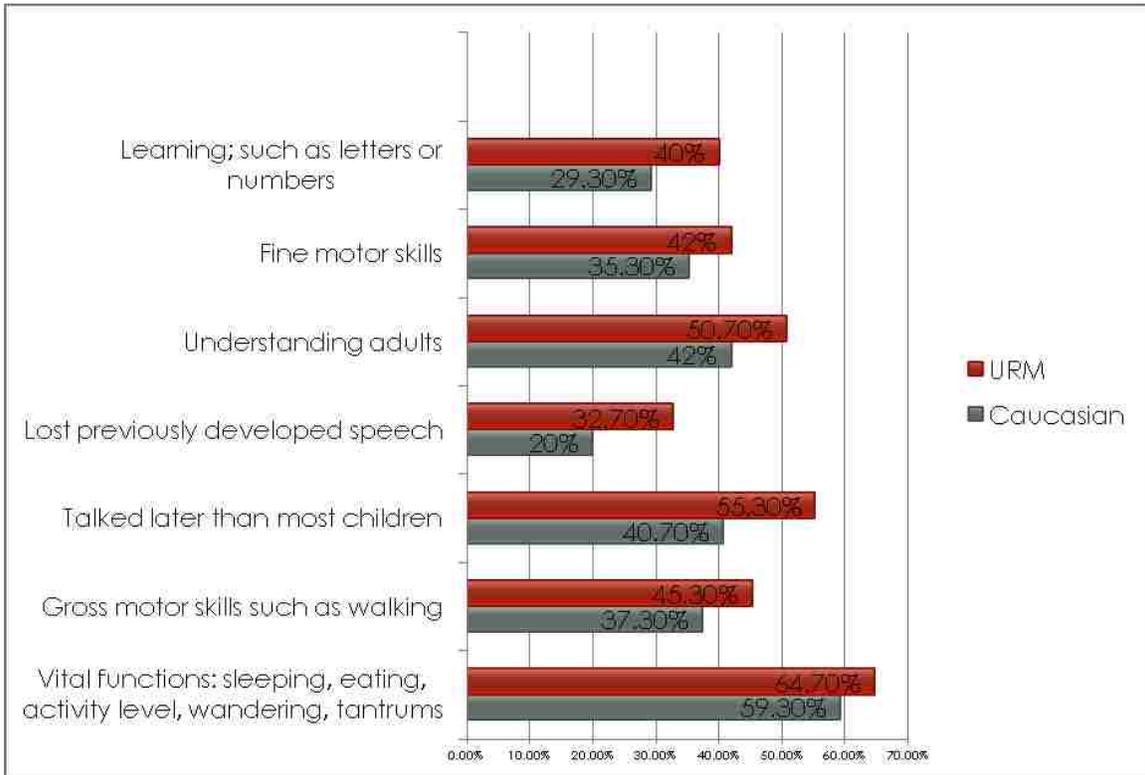


Figure 22. Symptoms during time of Diagnosis

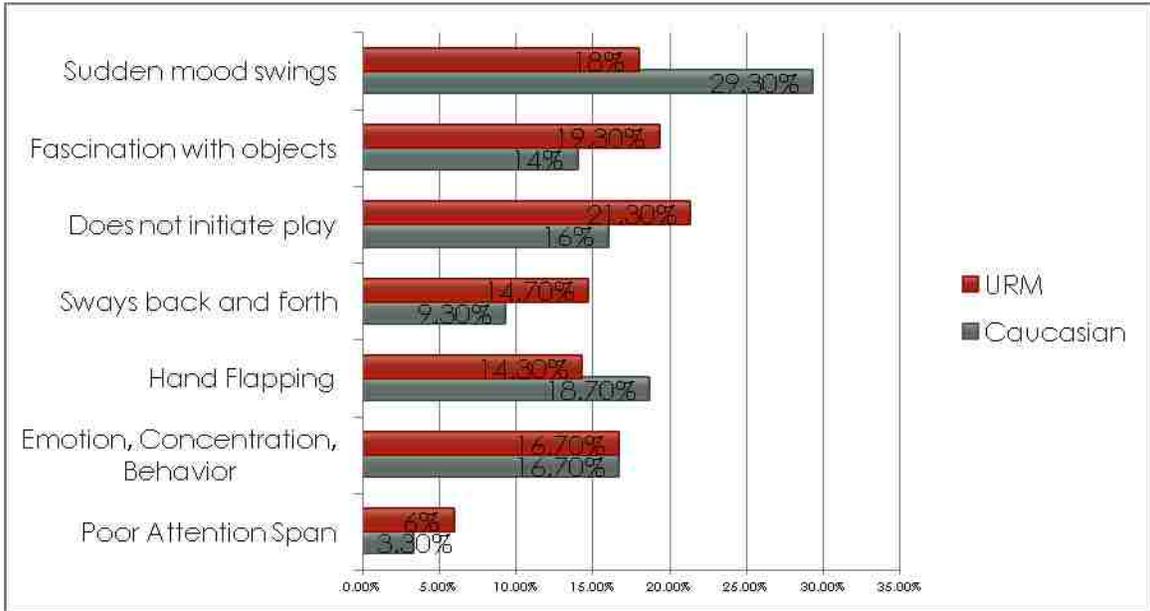


Figure 23. Parental Report of Child's Behavior

Summary of Findings

The study results did not reveal significant differences in child's age at the time of diagnosis, child's age at the time of parental of concern, or child's age when the parent sought out a medical professional. In this study, the majority of parents had greater than a High School education. This, this finding may have superseded race as a determinant. While this inference is plausible, it requires further investigation. Specifically, when addressing parental perceptions, a significant difference between parental education level and their seeking of a medical professional was noted. Findings revealed similarities in parental concerns regarding their child's symptoms and behaviors. However, URM parents reported a higher rate of concern and severity of symptoms. This observation leaves us asking the question, "why"? Perhaps personal factors, including parental culture, play a role in how the child was meeting expectations of cultural norms.

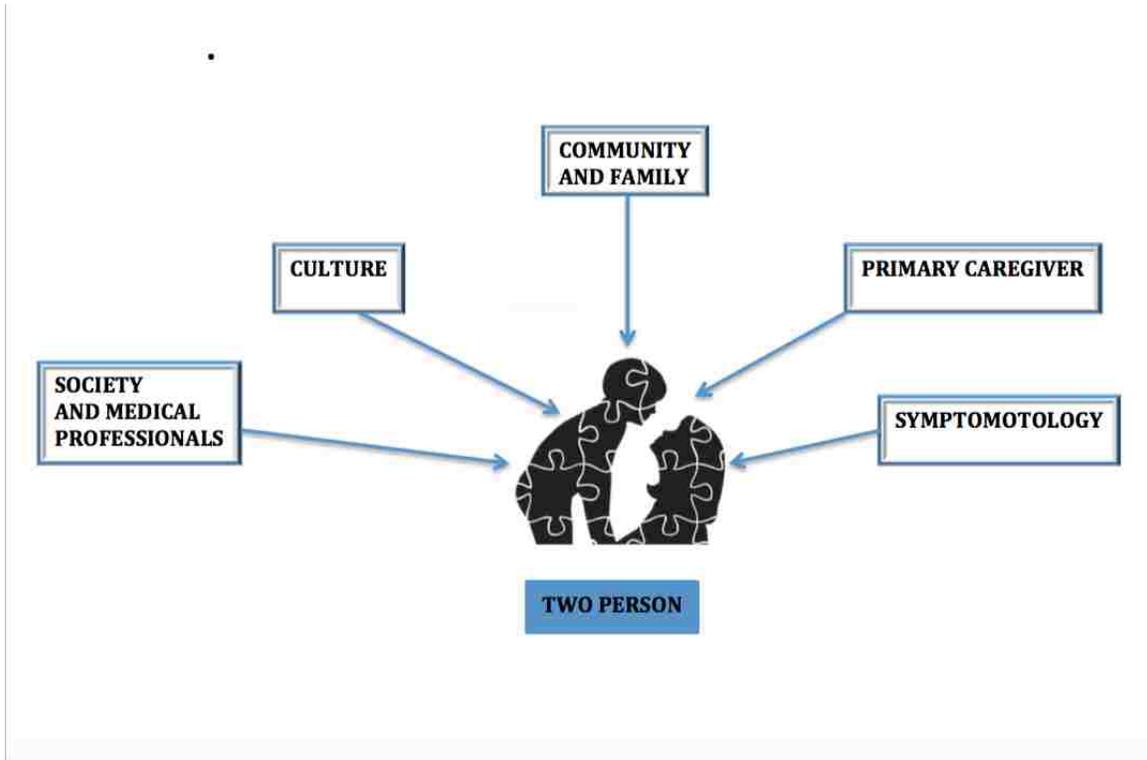
CHAPTER V

DISCUSSION

This study attempted to dissect "personal factors", associated with both the parent and child, which could uniquely influence the diagnostic process of ASD. Prior researchers marginalized investigations of personal factors such as race or socioeconomic factors. Hence, findings lacked the rigor required to address this multidimensional issue. Only two known studies investigated the correlation of parental concern with race and ethnicity. Therefore, this study

provides an important addition to the literature. The findings provide integral considerations to the issues surrounding the diagnostic process for ASD.

The Biopsychosocial model helped to organize and further explore the findings beyond prior research efforts to inform the disparities in the ASD diagnosis. To address this study's results, a revised model emerged to address the various components analyzed with the variables and research questions. Figure 24 illustrates the model and its components. The findings highlighted the significance of the personal factors of the child and parent on the diagnostic process of ASD. An application of the model allowed for the analysis based on the surrounding attributes of society and medical professionals, culture, community and family, primary caregiver, and symptomatology. Two-person refers to the caregiver child relationship. Factors relating to Two- Person are primary in determining a timely and accurate diagnosis of ASD. Therefore, that attribute is central to all of the other components.



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Figure 24. Theoretical Model. Following data analysis, the researcher developed the theoretical model based on the Biopsychosocial model. The model reflects the application of the theory identifying primary areas addressed through the Biopsychosocial model for determining an ASD diagnosis.

Overview of the Findings Based on the Model

Society and Medical Professionals:

While there were not significant findings, descriptive data revealed an overall gap in timing of diagnosis from age of concern, speaking to a doctor and receiving a diagnosis amongst all subjects. The gap ranged from initial concerns around the age of two years yet diagnosis after five years of age. Additionally, there were a large percentage of parents reporting that doctors did not perform a developmental screening or refer the child to a specialist.

Culture:

There were minor differences between the two groups. Yet, the data focused on race rather than culture. Culture, and differences between Caucasian and URM families, did not appear in the data.

Community and family:

Of the sample families, 18% of URM parents reported not having their child's needs met as compared to 10% of the Caucasian group. This information may indicate variations in healthcare and educational services provisions to URM children as compared to Caucasian children.

Primary Caregiver:

Parents revealed similar concerns regarding the diagnosis and experiences

with their child. Yet URM parents reported concerns at a higher rate. With both groups presenting similarities in demographics, this is an issue requiring further examination.

Symptomatology:

The children did not have vast differences in symptoms. Yet overall, URM parents expressed more concern regarding symptoms and behaviors displayed by their child during the diagnostic process and after.

Connection to the Literature

The Biopsychosocial model addresses biological, psychological, cognitive and social risk factors that contribute to a specific illness/condition and thus provides an in depth view. Therefore, the theoretical model provides an opportunity to analyze differentials based upon the various contributions from this study in comparison to the literature. Perhaps the model can further support identification of variations amongst racial and ethnic groups regarding the ASD diagnosis.

Under-Represented Minority (URM) children have disproportional occurrences of documented Autism diagnosis when compared to white children (Mandell, et al., 2009; Liptak, et.al, 2008). Overall, the results did not reveal any significant differences regarding the diagnosis ASD between Caucasians and URM groups. This is a difference in the data revealed from surveys analyzed in this study and more recent research. The literature previously revealed that Caucasian children displayed a likelihood of an Autism diagnosis around 30% more than African American children and almost 50% more than Hispanic individuals (Center for Disease Control, 2014).

While this is not a component of the present findings, results that are more promising emerged from the data.

Society and Medical Professionals

Current literature indicates that a misinterpretation of the parents' concerns leads to late diagnosis, misdiagnosis, and inappropriate treatment planning for service delivery.

(Angell & Solomon, 2014). Developmental screening presents challenges especially with language barriers (Zuckerman et al., 2013). Furthermore, many PCP's report not offering screenings in Spanish and express limitations their ability to assess risk for ASD. Hence, misdiagnoses ensue due to inefficient screening processes and lack of referrals.

The literature identifies frequent diagnosing, of African American children, with a variety of conditions other than Autism (Mandell, et. al., 2007). Furthermore, misdiagnosis, across racial groups occurs. Medical professionals often misinterpret undetected ASD as ADHD, conduct-related disorders, adjustment disorders, and cognitive disorders. Specific to African-American children, they are twice as likely to receive a diagnosis of conduct disorder (15.7% vs. 6.7%). Again, lack of proper screening of the ASD diagnosis may be a cause of misdiagnosis. Pediatric medical professionals self-report to routinely screen for developmental delays yet fail to routinely screen for Autism Spectrum Disorder. (Dosreis, Weiner, Johnson, & Newschaffer, 2006). While misdiagnoses did not emerge in the present study's data, similar findings reveal that almost half of the parents reported an absence of a developmental test when they initially expressed concerns regarding their child's development.

Based on prior research, nearly two thirds of physicians are unfamiliar with Autism screens and express a lack of sufficient time to screen for Autism (Dosreis, et al., 2006, p. S91). The issue of knowledge of the professional, and time, appear to be evident and a continued problem. Prior research states that almost half refer patients to a specialist, leaving the other half absent of such a crucial step (Dosreis, et al., 2006, p. S91). The findings in the present study align with such data as almost 30% of the medical professionals did not refer the child to a specialist.

Investigators indicate a person's SES proves to correlate to if a physician screens for Autism (Gibson, 2007). Children with more educated parents/mothers are more likely to be diagnosed at an earlier age (Fountain, King, & Bearman, 2011; Mandell, et al, 2009). Younger maternal ages, and lower maternal education attainment, show significant association to older ages of Autism diagnosis (Shattuck, et al., 2009). Hence, this is a connection to the findings in this dissertation.

One major difference to prior studies was the lack of variations in the SES of the subjects. Therefore, the higher SES of most of the sample subjects in this study may be indicative of the lack of differences in age of concern between groups. To this end, one's SES may be more of a factor contributing to the detection of the ASD diagnosis rather race. There was a slight correlation made between the educational level of the parent and age the sought out a medical professional. Hence, parental educational level may be a crucial component in the diagnostic process for ASD. Therefore, this warrants increased efforts for parental education regarding ASD signs and symptoms.

Further research regarding indirect affects on SES provides additional insight in the matter. Through requiring assistance with rendering care to their children, working and single mothers reduce contact with the child. Therefore, there are reduced opportunities to possibly detect symptoms (Ennis-Cole, Durodoye, & Harris, 2013). Furthermore, Tek & Landa (2012) revealed the absence of individuals with lower economic status from research. This may inform the lack of variation in the subjects for this dissertation study. As Tek & Landa indicated, there was an absence of those from lower economic status.

The gap in the age of diagnosis between the highest and lowest SES children remains (Fountain, et al., 2011). Thus, additional research is needed to gain a more generalized view of the sample population. In the present study, the parental educational and poverty levels, may relate to existing parental knowledge decreasing the chances of such misdiagnoses. The findings further support previous revelations regarding the impact of SES on the detection of the ASD diagnosis.

Culture

The data did not reveal enough information relating to culture. Variables acknowledged factors in relation to race. Yet, one cannot assume race as a direct correlation to one's culture. Culture has varying influences such as social norms, ethnicity, region one lives, religion, beliefs, and practices. This was absent from the data. Yet, such analysis could provide critical information addressing this matter.

Community and Family

In relation to access and services received by the family, results provide additional factors to explore. Most of the sample expressed having access to healthcare, educational services, and family healthcare coverage. However, the URM groups reported not having their child's needs met at higher rates as compared to the Caucasian group. This information may indicate variations in healthcare and educational services provisions to URM communities and families. Hence, this could be the reason why more URM did not believe treatment interventions could help improve their child's condition. As stated by King, Hurd, Hajek & Jones (2009), one's perceived needs and perception regarding the healthcare system are potential barriers.

Primary Caregiver

In relation to parental perception, the literature reveals that African-American and Hispanic children's parents have an age of concern that is 1.56 to 1.94 months later than the white non-Hispanic subjects (Rosenberg, Landa, Law, Stuart, & Law (2011). Disparity in age of diagnosis is revealed for African Americans, Hispanic, and other non-White ethnicities showing a lower confidence interval for those groups to predict the presence of an Autism diagnosis (Blacks 0.79, Hispanics 0.76, Other 0.65) (Mandell et al., 2009). The findings in this dissertation study did not reveal a difference in the age of concern, or age parents sought out a medical professional,

between Caucasian and URM parents. Yet, the results provide very insightful information requiring further investigation. As previously stated, SES may have a critical influence in the detection of the ASD diagnosis. The SES, in relation to poverty and education level, may supersede the impact of one's race.

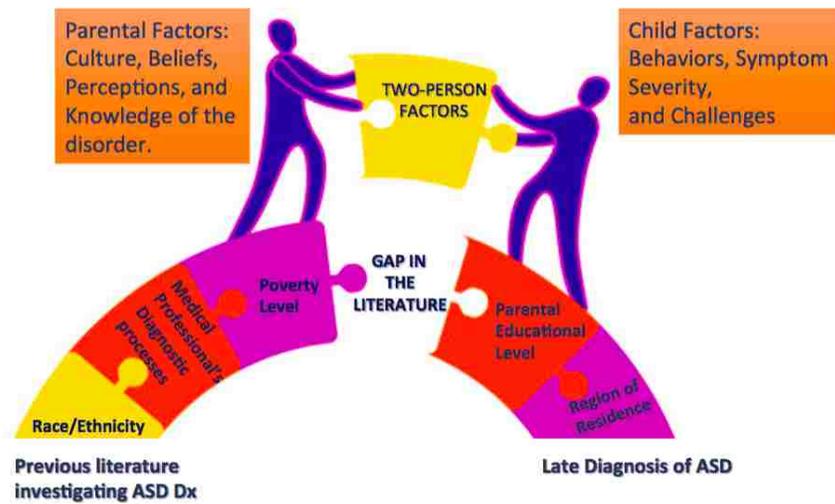
Symptomatology

Research indicates that children from URM groups are more likely to have lower communication scores presenting with delayed or atypical language (Tek & Landa, 2013). Furthermore, children from URM groups tended to have more frequent emotional outbursts (Becerra et al., 2014). The present findings revealed minor differences in the symptoms by URM children and Caucasian children. What is surprising is that despite the balancing of the subject groups, and vast similarities, URM parents reported more concerns regarding severity of symptoms during the diagnostic process and current symptomatology. Perhaps prior findings are in line with the literature that described more observable symptoms for the URM, similar to the language and emotional outbursts, which influence social norms. However, this may also be an indication that parents of URM may view symptoms as more severe and have greater concern regarding how others interpret the behaviors.

CHAPTER VI

CONCLUSION

The findings address a gap in the literature. While race, ethnicity, diagnostic processes, poverty level, parental education, and region of residence all contributed to the disparities in diagnosis of ASD, the Two-Person factor provides further insight (Figure 25).



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Figure 25. Schematic of gap in the literature related to findings

This study posed significant challenges. While previous literature acknowledged possible indicators related to disparity in diagnoses of ASD, few attempted to explore such theories. This study attempted to dissect the arbitrary “personal factors” which could uniquely influence the diagnostic process of ASD. With researchers marginalized investigations of individual factors such as race or socioeconomic factors, prior findings lacked the rigor required to address this multidimensional issue. Only two known studies investigated the correlation of parental concern with race and ethnicity. Hence, this study was the first of its kind to attempt to address the various components correlated to the diagnosis of ASD by placing the personal factors of the parent and child at the center of the investigation. The theoretical model acknowledges the multifaceted contributions to a timely and accurate diagnosis of ASD.

The conclusions are crucial and implicate a need for healthcare professionals to expand their ideas and theories surrounding the diagnostic process of ASD. While the disparity in diagnosis between racial groups ignited this study’s overarching inquiry, the findings supersede this concern. The gap between age of concern and age of diagnosis is staggering. This gap is persistent amongst all racial groups. In conclusion, no single factor addresses the persistent late age of diagnosis amongst. Awareness of this conclusion may be the first step in reducing the gap between age of concern and age of diagnosis.

The findings integrate, and reveal, the various assumptions indicated in the literature. The results acknowledge a continued concern regarding timing of diagnosis for

the ASD diagnosis overall. The primary implication fill the existing gap in the literature as follows. The more personal factors of the parent and child results in a higher age of concern, seeking of a medical professional, and age of diagnosis (Figure 26). Personal factors include the components of the theoretical model; Society and Medical Professionals, Culture, Community and Family, Primary Caregiver, and Symptomatology. Healthcare professionals involved in the diagnostic process as well as for further research agendas should consider the proposed “model for diagnostic process of ASD”.

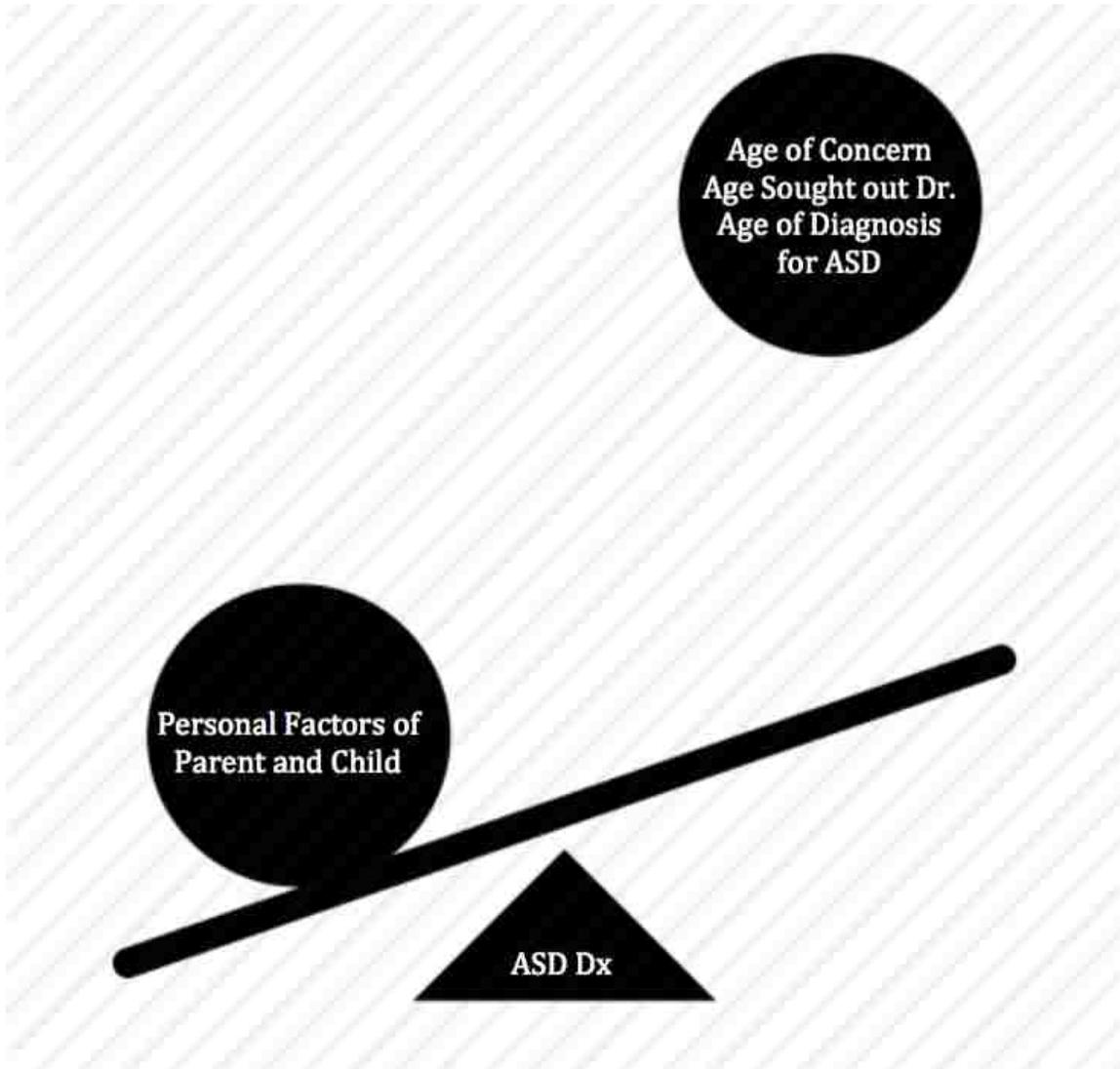
Future Directions

Additional research is crucial. Future studies should attempt to enhance recruitment efforts including individuals from various SES. The lack of individuals and families from lower SES groups continues to influence research studies producing homogeneity amongst the subjects. Hence, identifying specific group factors is compromised.

Researchers should also consider the ethnicities and cultures of the population sample rather solely race. This study explored data based on race. Sharing of a societal classification, primarily based on appearance, ignores the social norms and influences of a group. Traditions, beliefs, and habits of a culture or ethnic group could greatly affect parental perception and acknowledgement of symptomatology. Furthermore, these factors could have bearing over the diagnostic healthcare professionals’ perceptions and acknowledgement of symptoms.

The Survey of Pathways to Diagnosis and Services, 2017 will soon reveal additional data for further studies. It would be integral to assess that data to perform a longitudinal

analysis. Additionally, investigations should consider applying the theoretical model and The model for diagnostic process of ASD (Figure 26). The emerged models could lead to the development of an assessment tool to better address ethnicity and cultural influences in the diagnosis of ASD. The findings indicate a lack of culturally competent approaches in addressing parental concern regarding the symptoms of ASD. This researcher desires to further explore the ASD diagnostic process through application of the models introduced. However, the conclusions indicated a need for more qualitative research methods. To start, a focus group of parents from various cultures and SES may inform this issue and provide fruitful findings to better inform.



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Figure 26. The model for diagnostic process of ASD represents the contributing factors towards receipt of a timely ASD diagnosis.

Limitations

While the results are influential in this vast issue, limitations are present. The questions required participants to recall the history of their child's diagnosis. Therefore, recall bias was an implication. Sampling bias occurred secondary to the subjects being primarily from two regions, lacking variations in educational levels, and overall revealing of higher SES status. There were obvious challenges with recruitment of URM subjects, which perhaps limited the sample to those with higher educational levels, and knowledge of the condition.

Additional limitations correlate to differences of this study compared to prior literature. Prior national studies included examination of both health and educational records. With this current study relying solely on parental report, it may lack an accurate diagnostic rate retrieved as compared to parental report. (Center for Disease Control, 2014). Perhaps variations in the timeliness and accuracy of the ASD diagnosis relate more to education and poverty level. The Biopsychosocial Theoretical Model can inform the development of a tool to further assess the influence of ethnicity and culture. Lastly, the data is not generalizable secondary to the limitations and bias relating the sample demographics.

It is important to acknowledge that the gap in diagnosis between the various races may be closing perhaps due to early intervention and increased access to care.

Practitioners involved in the diagnoses of ASD must be aware that there remains a possible lag between the time parents have concern and receipt of an official diagnosis.

Delayed diagnosis may prevent timeliness of intervention services.

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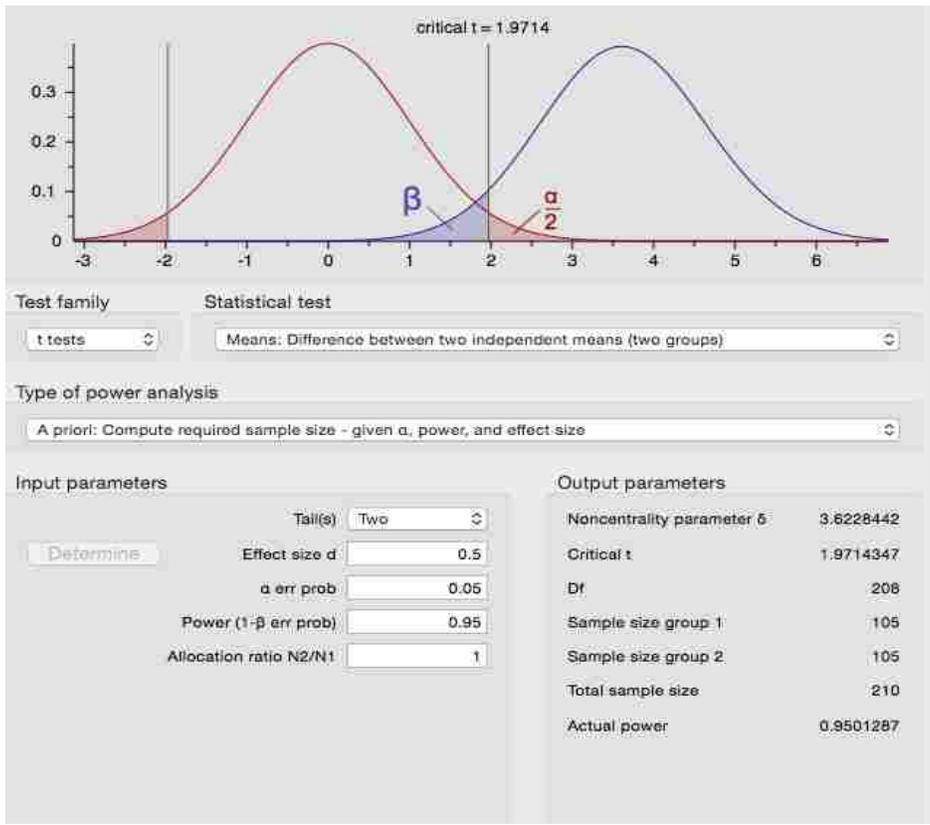
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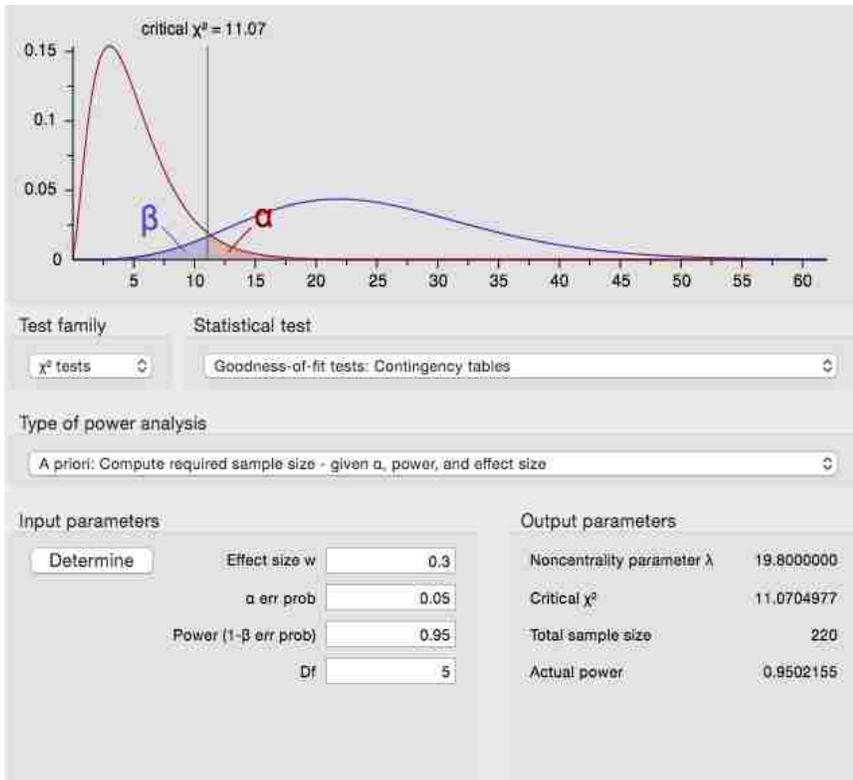
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APPENDIX A

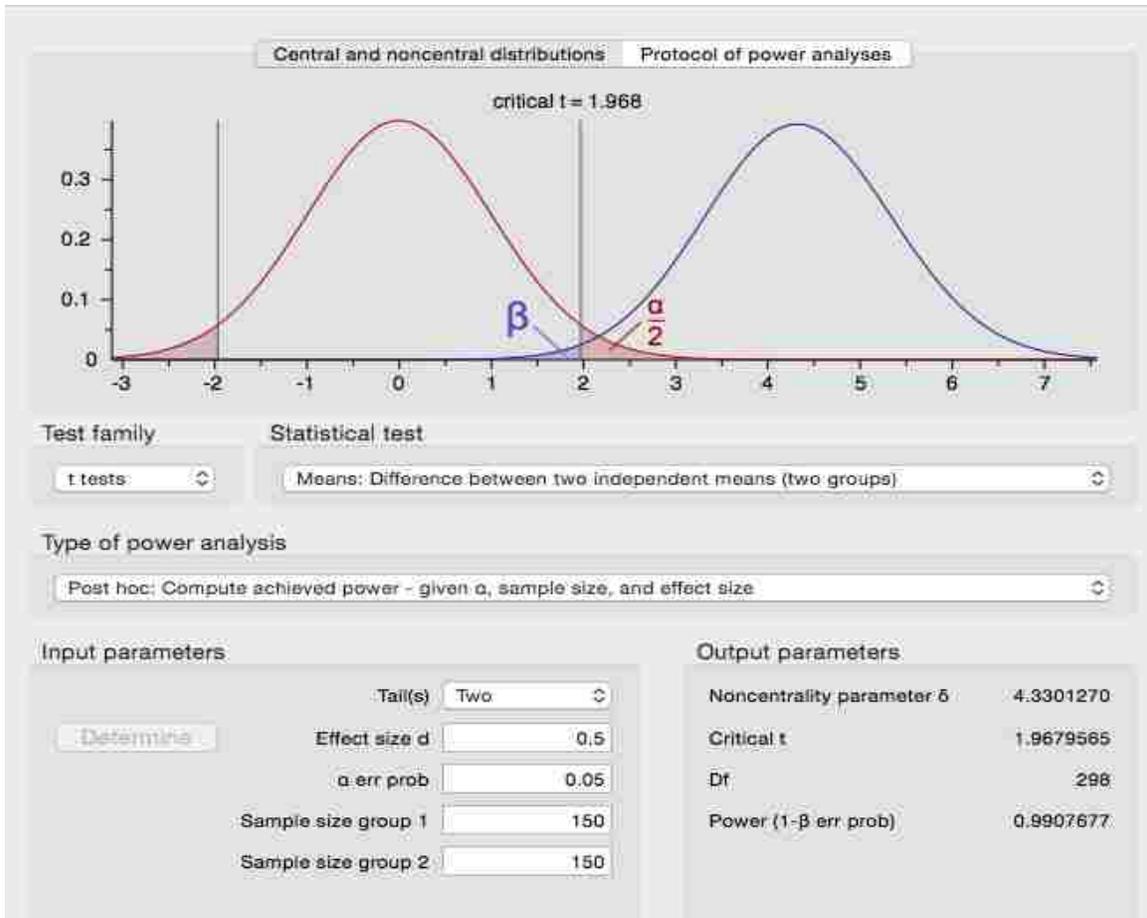
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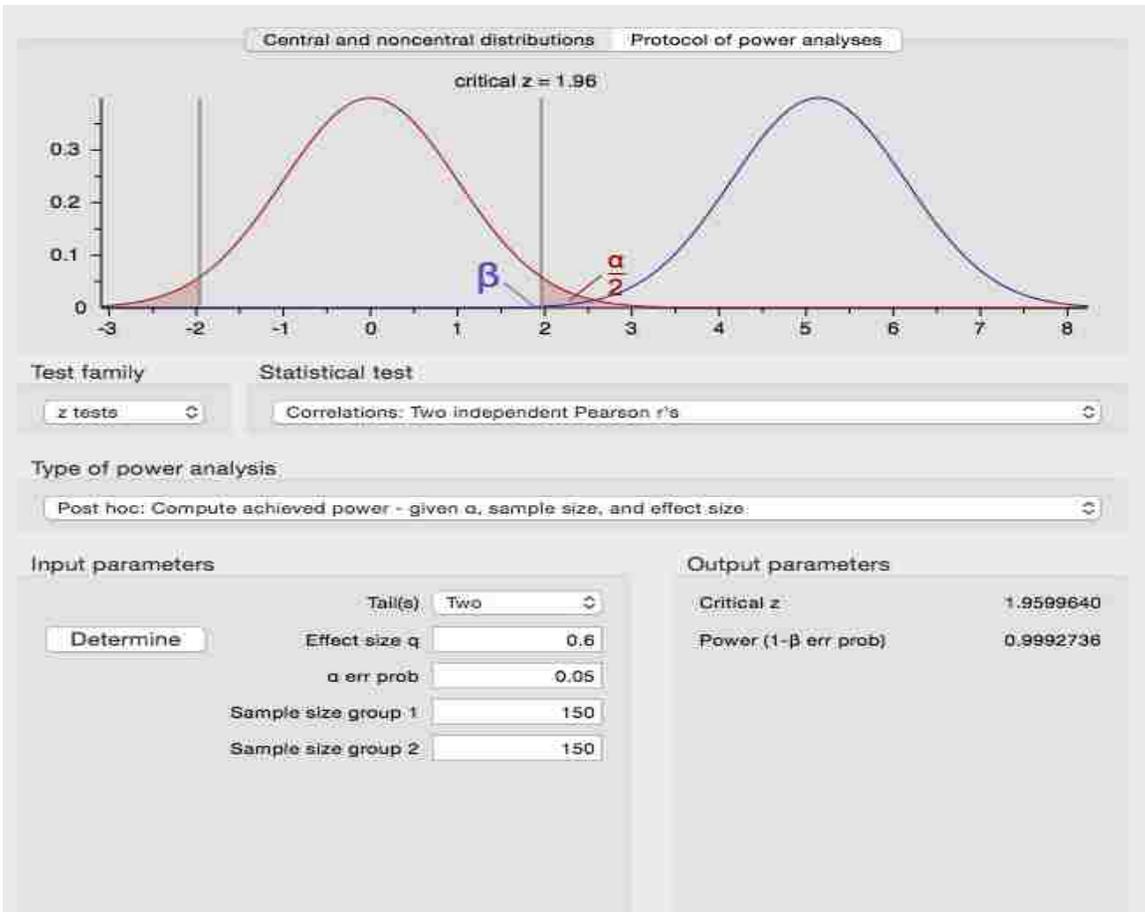




APPENDIX B

G*POWER POST-HOC ANALYSIS





APPENDIX C

APPROVAL TO ACCESS DATA FROM CAHMI



Your Data... My Story

www.childhealthdata.org

Data Resource Center for Child & Adolescent Health

A project of the Child and Adolescent Health Assessment Program



REQUEST FOR DATA RESOURCE CENTER INDICATOR DATA SET

Date: 10/29/15

Name: Varleisha D. Gibbs Title: OTD, OTR/L, Assoc. Prof.

E-mail address:

Daytime Phone:

Fax #:

Organization Name: Wesley College

Location (State, Country): DE, USA

Type:

Academic Research

Non-Academic policy research

Government - Federal

Government - State:

Health care provider

Health plan

Advocacy

Student

Private Vendor

Other

Select the data set(s) you are requesting:

National Survey of Children's Health (NSCH)

2003

2007

03 & 07 merged

Please note that only variables that were identical between 2003 and 2007 are included in this dataset.

2011-2012

Survey of Pathways to Diagnosis and Services (Pathways)

2011

National Survey of Children with Special Health Care Needs (NS-CSHCN)

2001 (Merged Interview File)

2005/06 (Merged Interview File)

2009/10 (Merged Interview File)

National Health Interview Survey (NHIS)

2012 (Child Complementary and Alternative Medicine Supplement)

Format preference:

SPSS

SAS

STATA

APPENDIX D

Seton Hall University Institutional Review Board (IRB) Approval



OFFICE OF INSTITUTIONAL
REVIEW BOARD

SETON HALL UNIVERSITY

September 28, 2016



Dear Ms. Gibbs,

The Seton Hall University Institutional Review Board has reviewed the information you have submitted addressing the concerns for your proposal entitled "Exploring Disparities in Underrepresented Minority Groups of Children Diagnosed with Autism Spectrum Disorders Using the Biopsychosocial Theoretical Model." Your research protocol is hereby accepted as revised and is categorized as exempt.

Please note that, where applicable, subjects must sign and must be given a copy of the Seton Hall University current stamped Letter of Solicitation or Consent Form before the subjects' participation. All data, as well as the investigator's copies of the signed Consent Forms, must be retained by the principal investigator for a period of at least three years following the termination of the project.

Should you wish to make changes to the IRB approved procedures, the following materials must be submitted for IRB review and be approved by the IRB prior to being instituted:

- Description of proposed revisions;
- *If applicable*, any new or revised materials, such as recruitment fliers, letters to subjects, or consent documents; and
- *If applicable*, updated letters of approval from cooperating institutions and IRBs.

At the present time, there is no need for further action on your part with the IRB.

In harmony with federal regulations, none of the investigators or research staff involved in the study took part in the final decision.

Sincerely,

Mary F. Ruzicka, Ph.D.
Professor
Director, Institutional Review Board

cc: Dr. Genevieve Pinto Zipp

Presidents Hall • 400 South Orange Avenue • South Orange, New Jersey 07079-2641 • Tel: 973.313.6314 • Fax: 973.275.2361

A H O M E F O R T H E M I N D , T H E H E A R T A N D T H E S P I R I T