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Margaret Gopaul

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Parents and Teachers' Perceptions and Clinical Diagnosis of Autism Among White and Non-White Groups

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Walden University

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Margaret Gopaul

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Walden University
2016

Abstract

Parents and Teachers' Perceptions and Clinical Diagnosis of Autism Among White and

Non-White Groups

by

Margaret T. Gopaul

MS, Walden University, 2014

MA, Liberty University, 2013

BS, Liberty University, 2012

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Clinical Psychology

Walden University

August 2016

Abstract

The pervasiveness of autism has significantly increased over the past 2 decades with the 2014 Center for Disease Control and Prevention report indicating 1 in 68 children are diagnosed with Autism Spectrum Disorder (ASD). Early intervention is recommended as the most effective treatment approach. Nevertheless, previous research has indicated that White children are diagnosed with ASD about 1.5 years earlier than are Non-White children. A current gap remains in literature regarding ASD and different racial groups, and evidence has been inconclusive regarding disparities in identifying and diagnosing ASD. To fill this gap, this study investigated the relationship between child race, parents and teachers' perceptions, and diagnosis of ASD among White and Non-White groups. The theoretical framework was the critical race theory. Archival data from the Psychological and School Services of Eastern Carolina included 48 preschool children from White (18) and Non-White (30) groups. The data's variables of race, perceptions, and diagnosis were analyzed using multivariate analysis of variance. Results indicated a higher rate of diagnosis of ASD among the White group compared to the Non-White group. Yet, teachers' perceptions of ASD were higher for the Non-White group, while parents' perceptions of ASD were lower for the Non-White group. This finding confirms the nuances of ASD among racial groups which could promote efforts to better educate parents and teachers on developmental milestones, explore families' unique beliefs, and emphasize the importance of accurate early detection. Also, considerations of culturally sensitive screening, diagnostic measures, protocols, and practices may be embraced to safeguard that children, regardless of race, receive timely and competent care.

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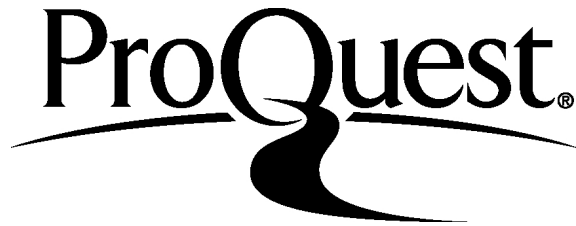
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Dedication

First and foremost, my dissertation is dedicated to God, whose manifold grace provided sustained health and wisdom that has brought me to this significant milestone. Mom (Yvonne) and Dad (Reuben), I dedicate this dissertation to you both for your steadfast prayers, counsel, and loving support throughout my life. Dad, your words “make hay while the sun shines” and mom your prudent counsel to “seek God first” has kept me disciplined, committed, and humbled in my academic journey. Last, but certainly not least, I dedicate this body of work to Rev. Martinelli and Rev. Thompson, who have both served as the wind beneath my wings during those ‘windless’ days. Rev. Martinelli, your gifted humor, prayers, and the nugget of wisdom from your dearly departed dad “don’t look left or right, just run your own race” has kept me focused on this finish line with “four quarters of fury.” Rev. Thompson, your timely text messages, and prayers were the most powerful catalyst that kept me inspired on days of health challenges. I have held to the scripture you shared, Philippians 4:13 “I can do all things through Christ who strengthens me.” So here I am, in your words “Dr. Maggie Gopaul, reporting for duty.”

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Table of Contents

List of Tables	v
List of Figures	vi
Chapter 1: Introduction to the Study.....	1
Background	2
Problem Statement	7
Purpose of the Study	9
Research Question and Hypothesis.....	10
Research Question	10
Hypothesis.....	10
Theoretical Framework.....	10
Nature of the Study	12
Definitions of Variables and Terms	14
Assumptions.....	17
Scope and Delimitations	17
Limitations	18
Significance.....	19
Summary	20
Chapter 2: Literature Review	23
Introduction.....	23
Literature Search Strategies	26
Theoretical Foundation	27

Literature Review Related to Key Variables	31
Historical Growth of the Term Autism.....	31
History of the Diagnostic Criteria for ASD	33
Complex Representation of ASD.....	36
Race, Ethnicity, and Sociodemographic Factors	37
Perception of Signs and Symptoms of ASD	40
DSM-5 Clinical Diagnostic Criteria of ASD	43
Diagnostic Procedure of ASD.....	47
Studies Related to Research Question	51
Summary and Conclusions	52
Chapter 3: Research Method.....	59
Introduction.....	59
Research Design and Rationale	60
Methodology.....	61
Population	61
Sampling and Sampling Procedures	62
Archival Data	64
Instrumentation and Operationalization of Constructs	65
Data Analysis Plan.....	72
Research Question	73
Hypothesis.....	73
Statistical Test.....	73

Threats to Validity	74
External Validity.....	74
Internal Validity	75
Construct Validity.....	75
Ethical Procedures	76
Summary	79
Chapter 4: Results.....	81
Introduction.....	81
Data Collection	81
Data Collection Time Frame, Recruitment and Response Rates	81
Data Cleaning and Screening.....	83
Possible Discrepancies in Data Collection	83
Sample’s Descriptive and Demographic Characteristics.....	84
Sample’s Generalizability.....	87
Results	88
Descriptive Statistics of Sample	88
Statistical Assumptions.....	92
Statistical Analysis.....	96
Summary.....	103
Chapter 5: Discussion, Conclusions, and Recommendations.....	106
Introduction.....	106
Nature of the Study.....	106

Key Findings.....	107
Interpretation of the Findings.....	109
Theoretical Framework Analysis and Interpretation	114
Limitations of the Study.....	115
Recommendations for Further Research.....	116
Methodological Expansions.....	116
Advancing Research	117
Implications.....	118
Positive Social Change	118
Conclusion	121
References.....	124
Appendix A: D5 Diagnostic Criteria for Autism Spectrum Disorder, 299.00	
(F84.0).....	142
Appendix B: Modules of a Comprehensive ASD Evaluation	146
Appendix C: Data Use Letter.....	147
Appendix D: Approved Data Use Agreement	149

List of Tables

Table 1. Demographics for Overall Sample ($N = 48$).....	86
Table 2. Race Between-Subjects Factors.....	88
Table 3. Group Between-Subjects Factors.....	88
Table 4. Descriptive Statistics for Diagnosis and Reported Perception of ASD.....	91
Table 5. Tests of Normality Diagnostic and Perception Measures of ASD.....	94
Table 6. Box's Test of Equality of Covariance Matrices ^a	95
Table 7. Levene's Test of Equality of Error Variances ^a for Diagnosis and Reported Perception of ASD.....	96
Table 8. Multivariate Tests ^a	98
Table 9. Univariate Statistics for Diagnosis and Reported Perception of ASD.....	101

List of Figures

Figure 1. Sample's placement prior to testing by PSSEC. 87

Chapter 1: Introduction to the Study

Autism spectrum disorder (ASD) has been identified as a major disability due to its severe lifelong impact on individuals and families (American Psychiatric Association, 2013). Reports have documented that autism disorders are evident across all racial and ethnic groups (The Centers for Disease Control and Prevention [CDC], 2014), and early intervention (evidence-based treatment) is recommended as the most effective treatment approach (Durkin et al., 2010). However, before early intervention can be initiated, symptoms of a developmental delay must be competently identified and evaluated to attain an accurate diagnosis, especially among various racial groups (Ennis-Cole, Durodoye, & Harris, 2013). Researchers have reported that White American children were, on average, diagnosed with autism about 1.5 years earlier than Non-White American children (Morrier, Hess, & Heflin, 2008).

Further, in 2013, the United States experienced a record influx of approximately 41.3 million immigrants, including 17.4 million children living with at least one immigrant parent (Zong & Batalova, 2015). Therefore, the rise in immigration, along with the gap in literature related to ASD and different racial groups (Jarquin, Wiggins, Schieve, & Van Naarden-Braun, 2011; Khowaja, Hazzard, & Robins, 2014; Thomas, Zahorodny, Peng, & Kim, 2012) give primacy to the necessity of this study. Additionally, this study may potentially precipitate positive social change by advancing both professional and public awareness of ASD among different racial and ethnic groups. Specifically, the study may motivate the consideration of more culturally sensitive screening, diagnostic measures, and programs to better educate families on childhood

developmental milestones. The overall study's outcome could lessen racial disparity in American's health care system.

In this chapter, I present a preparatory primer to the study's topic of ASD among White and Non-White children. Specifically, major sections of this chapter include a brief background of the study's topic, empirical consensus of the current problem, the study's purpose, research questions, hypothesis, theoretical framework, nature, definitions, assumptions, delimitations, limitations, and significance.

Background

Literature on the study's topic of ASD was ubiquitous and included various major themes. The history of the term autism confirmed how researchers in this discipline have influenced and added to the knowledge of ASD over the last century. In 1911, Swiss psychiatrist Eugen Bleuler coined the term autism when describing schizophrenia symptoms associated with incoherent thought patterns or a split mind (Bleuler, 1950). Later, studies in the 1920s identified the term autism when examining childhood schizophrenia (Künkel, 1920). However, the perception of autism continued to evolve when Ssucharewa framed autism in a contemporary context, which distinguished autism from childhood schizophrenia (Davis, White, & Ollendick, 2014). Further, in 1943, Kanner adopted and enhanced Bleuler's concept of autism by demonstrating that the withdrawal seen in autism was congenital, unlike schizophrenia, which demonstrated a clear distinction between schizophrenia and autism (Davis et al., 2014; Wing, 1997). However, although there have been numerous changes over the last 80 years to the lists

of the symptoms defining autism, a few essential characteristics of autism have remained unchanged (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004).

Another major theme in the literature was the historical changes involved in the diagnostic criteria of ASD. For example, in 1952, the Diagnostic and Statistical Manual (DSM-I) did not list separate criteria but used the diagnostic term Schizophrenic reaction, childhood type to classify autism (American Psychiatric Association, 1952). Similarly, in 1968, autism was not specified in the DSM-II, but the word was noted under the classification of 295.8 Schizophrenia, childhood type (American Psychiatric Association, 1968). It was not until 1980 that the American Psychiatric Association formally included autistic disorder as a diagnosis via the DSM-III publication (Volkmar, Reichow, & McPartland, 2012) with all six criteria required for the diagnosis (Davis et al., 2014). These six criteria specified that symptoms should start before age 2 ½, with determined absence of social responses, clear language development deficiencies, unusual speech patterns, peculiar interplay with the environment, and an absence of schizophrenia symptoms (American Psychiatric Association, 1980).

Since the DSM-III definition was interpreted as restrictive to the diagnosis of autism, in 1987, the DSM-III-R broadened the diagnostic criteria for autistic disorder to include at least eight of 16 items (American Psychiatric Association, 1987). The DSM-III-R specified two items that should be from the diminished social interactions category: one item from the diminished imaginative play and communication (verbal and nonverbal) category and one item from restrictive activities and interest as listed.

Furthermore, symptoms should present before 3 years old, if not it should be specified that onset occurred after 3 years of age (American Psychiatric Association, 1987).

Additionally, in 1994, the DSM-IV criteria for autism were further broadened (American Psychiatric Association, 1994). The DSM-IV added Asperger's disorder and pervasive developmental disorder-not otherwise specified (PPD-NOS), and it kept the age of onset as 3 years of age (American Psychiatric Association, 2000). Finally, in 2013, the DSM 5 publication declared the submission of the term ASD, with earlier classified disorders (Asperger's disorder, autistic disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), childhood disintegrative disorder and Rett's syndrome) placed under the single diagnosis of ASD (American Psychiatric Association, 2013). Also, similar to the DSM-III and DSM-IV, the DSM 5 maintained the requirement that specified symptoms must be recognizable in the early infancy and developmental period. However, what distinguished the DSM 5 from its predecessors is its recognition that symptoms "may not become fully manifested until social demands exceed limited capacities, or may be masked by learned strategies in later life" (American Psychiatric Association, 2013, p. 50).

Another emergent theme presented in the literature related to ethnicity and sociodemographic factors in the presentation of ASD. For instance, Becerra et al. (2014) postulated that there was a higher risk of ASD among children born to mothers who were born outside of the United States. These mothers were identified as Filipino, Black, African American, Vietnamese, Hispanic, and from South and Central American descent. However, Becerra et al. recommended further investigations that considered migration as

well as identifying and diagnosing ASD in such children. Overall, in this up-and-coming area of research, the findings remained inconclusive, and the recommendation for further studies were suggested by various researchers (Becerra et al., 2014; Blacher, Cohen, & Azad, 2014; Tek & Landa, 2012).

Similarly, several studies reported that minority children of Asian, Hispanic, and African-American descent were less likely to receive early diagnosis compared to Caucasian children (Blacher et al., 2014; Mandell et al., 2009; Tek & Landa, 2012). However, evidence for the considerable delay in diagnosis of ASD among minority children remains categorically inconclusive (Burkett, Morris, Manning-Courtney, Anthony, & Shambley-Ebron, 2015; Palmer, Walker, Mandell, Bayles, & Miller, 2010; Tek & Landa, 2012).

Over the past century, researchers have added to the wealth of knowledge within this discipline pertaining to ASD (Bleuler, 1950; Dyches et al., 2004; Eisenberg, & Kanner, 1956; Grebelskaya-Albatz, 1934; Künkel 1920; Parnas, 2011; Volkmar et al., 2012; Wing, 1997). For instance, a definite distinction between ASD and childhood schizophrenia has been established (Davis et al., 2014; Dyches et al., 2004). Thus, based on the evolution of the term autism, researchers such as Kanner were able to adopt and build on their predecessor's work. Hence, Bleuler's concept of autism demonstrated that the withdrawal displayed in autism was congenital, unlike schizophrenia. This discovery offered a clear distinction between the withdrawal that occurred in schizophrenia and autism (Davis et al., 2014; Wing, 1997). Therefore, it can be accurately surmised that ASD is not childhood schizophrenia (Davis et al., 2014; Dyches et al., 2004). Moreover,

though the diagnostic criteria defining autism has experienced a metamorphosis over the last 80 years, a few essential characteristics of autism have remained the same (Dyches et al., 2004). Thus, the delays in language and group interaction skills as well as restricted or unusual behavioral ranges are symptoms that have withstood the test of time.

Furthermore, as stated by Tek and Landa (2012), little is known as to whether or not the early expression of ASD symptoms vary in children from ethnic minority groups compared to nonminority groups. Hence, Blacher et al. (2014) expressed the need for further empirical studies to examine culture within various groups that can add to the limited understanding about the nuances of ASD.

Based on the present study's comprehensive literature review and limitations and gaps related to ASD, particularly ASD and different racial and ethnic groups were evident (Jarquin et al., 2011; Thomas et al., 2012). Literature has demonstrated that a large body of evidence exists that identified racial and ethnic disparities in the diagnosis and treatment of numerous health conditions (Institute of Medicine, 2002). However, evidence has been inconclusive regarding disparities in identifying and diagnosing ASD (Mandell et al., 2009). Some studies have reported higher incidents of delayed and missed diagnoses of ASD among underserved ethnic and racial minority groups (Jarquin et al., 2011; Thomas et al., 2012) while other studies produced mixed results (CDC, 2006).

Subsequently, research findings have underscored the need for additional ASD research in diverse racial populations to inform clinical practice and increase public awareness (Blacher et al., 2014; Becerra et al., 2014). For instance, Tek and Landa

(2012) sought to understand the presentation of early ASD symptoms and other developmental disorders between minority and nonminority children. However, the researchers suggested future research was needed to examine specific group differences that may exist in symptoms presentation of ASD within various minority groups. Additionally, Blacher et al. (2014) examined whether or not there was a difference between Anglo and Latino mothers' reports of ASD and any differences in experts' classification. However, they concluded that the modest findings suggested cultural differences that would need to be further explored. Furthermore, they indicated that additional studies in this area may reveal a deeper understanding of ASD in Latino children, whereby "actual symptoms of ASD may be in the eye of the beholder" (Blacher et al., 2014, p. 1655). Therefore, the present study specifically fills the gap in the literature by offering additional data and increases knowledge about different minority groups and ASD that will serve to increase knowledge in the discipline.

Subsequently, it is evident based on the comprehensive literature review of this study that this research is much needed to lessen the literature gap related to ASD, particularly ASD and racial and ethnic groups (Jarquin et al., 2011; Thomas et al., 2012). This study is also needed to address the scholarly consensus that has underscored the need for ASD research in diverse racial populations to better inform clinical practice and increase public awareness (Becerra et al., 2014; Blacher et al., 2014).

Problem Statement

The pervasiveness of autism has significantly increased in the United States over the past 2 decades, with current data indicating about 1 in 68 children being diagnosed

with ASD (CDC, 2014). ASD is identified as a major disability due to its severe lifelong impact on individuals and families with manifested symptoms of uncharacteristic development of socialization and communication along with restricted, repetitive interests and behaviors presenting in early childhood (American Psychiatric Association, 2013). Reports have documented that ASDs are evident within all racial and ethnic groups (CDC, 2014), and early intervention (evidence-based treatment) is recommended as the most effective approach to ASD care (Durkin et al., 2010).

However, before early intervention can be initiated, symptoms of a developmental delay must be competently identified and evaluated to obtain an accurate diagnosis (Ennis-Cole et al., 2013). For example, minority parents may fail to report subtle cues associated with ASD, such as perceiving delays in social skills and language as a phase that will be outgrown (Ennis-Cole et al., 2013). Researchers have also reported that White American children were diagnosed with ASD about 1.5 years earlier than Non-White American children (Morrier et al., 2008).

Although there is a plethora of evidence identifying racial and ethnic disparities in the diagnosis and treatment of numerous health conditions (Institute of Medicine, 2002), evidence has been inconclusive regarding disparities in identifying and diagnosing autism (Mandell et al., 2009). Notably, some current studies have reported higher delayed and missed diagnoses of autism among underserved ethnic and racial minorities (Jarquin et al., 2011; Thomas et al., 2012), while other studies produced mixed results (CDC, 2006). Subsequently, recent research findings have underscored and confirmed the current need

for ASD research in diverse racial populations to inform clinical practice and increase public awareness (Becerra et al., 2014; Blacher et al., 2014).

Therefore, in this study, I attempt to address the gap in the current literature that necessitates further research focused on ASD among diverse racial populations. This additional research could potentially contribute to more culturally sensitive ASD screening and assessment measures, with an emphasis on educating providers, clinicians, educators, and parents. Hence, this study will provide empirical findings that could better inform professionals and equip parents to identify early warning signs of ASD to safeguard that children, regardless of their race, receive timely and competent care.

Purpose of the Study

The purpose of this quantitative study is to investigate the relationship between child's race and reported perception of ASD, and clinical diagnosis of ASD among White and Non-White groups. Race is the independent variable, and the reported perception of ASD and clinician's diagnosis of ASD are the dependent variables. The perception of ASD is measured using data collected from the Adaptive Behavior Assessment System (ABAS-II), Child Behavior Checklist (CBCL), and Caregiver-Teacher Report Form (C-TRF; Achenbach & Rescorla, 2001; Harrison & Oakland, 2003). The clinician's diagnosis of ASD is measured using data collected from Childhood Autism Rating Scale-Second Edition (CARS-2) and the Psychoeducational Profile-Third Edition (PEP-3) instruments (Schopler, Lansing, Reichler, & Marcus, 2004; Schopler, Van Bourgondien, Wellman, & Love, 2010).

Research Question and Hypothesis

Research Question

Will the reported perceptions of ASD as measured by ABAS-II, CBCL, and C-TRF in White and Non-White groups differ from clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based on child's race?

Hypothesis

H_01 : There will be no differences between reported perceptions of ASD measured by ABAS-II, CBCL, and C-TRF in White and Non-White groups compared to clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based child's race

H_a1 : There will be differences between reported perceptions of ASD as measured by ABAS-II, CBCL, and C-TRF in White and Non-White groups compared to clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based on child's race

Theoretical Framework

The theoretical base for this study was Rimland's organic theory of autism (Rimland, 1964), which is essentially the conceptual framework of the treatment and education of autistic and related communication handicapped children (TEACCH) model (Mesibov, 1996). The TEACCH model originated in 1964 with a child research project by Schopler and Reichler (1971), which was later pioneered by Mesibov, Shea, and Schopler in the 1970s (as cited in Virues-Ortega, Julio, & Pastor-Barriuso, 2013). Since the TEACCH model's conceptual framework is based on behavioral, developmental, and

ecological theoretical perspectives that directly correlate with an organic theory of autism, this model was ideal to inform this study (Erba, 2000).

The TEACCH model views ASD as a lifetime condition and treats ASD as a culture as opposed to trying to cure ASD (Erba, 2000). The basic beliefs of TEACCH focus on individualization, and it does not differentiate between individuals with learning disabilities and those at a higher skill level (Virues-Ortega et al., 2013). The major theoretical propositions of the TEACCH model will be discussed in more depth in Chapter 2, found under the Theoretical Foundation section.

In this study, I consider the autistic child to be an individual with unique needs based on various factors, such as race, culture, and sociocultural influences similar to the research-based analysis of TEACCH. For instance, in a study by Erba (2000), the TEACCH program was compared to other programs, such as Floor Time, the Lifestyle Education for Activity Program (LEAP), and the Discrete Trial Training (DTT) program. The findings indicated that in contrast to the other programs, TEACCH embraced a wide selection of diagnostic tools, techniques, and services to find the best fit for each child in his or her family unit and culture. Hence, TEACCH reviewed each child for inclusion based on a review of each individual case. Therefore, the research question of whether or not parents and teachers' reported perceptions of ASD differs with the clinician's diagnosis of autism based on the race will build upon TEACCH's concept of inclusion involving individualized diagnosis and treatment (Erba, 2000).

Another theoretical basis for this study is critical race theory (CRT). CRT was developed in the 1970s by Freeman, Bell, and Delgado, for the purposes of reforming the

association of power, racism, and race (as cited in Graham, Brown-Jeffy, Aronson, & Stephens, 2011). Since CRT incorporates “transdisciplinary methodologies that draw on theory, experiential knowledge, and critical consciousness” to identify and contest the source of racism, it was beneficial to apply to this present study (Ford & Airhihenbuwa, 2010, p. 31). For instance, Ford and Airhihenbuwa (2010) contended that CRT can be seen as “a transdisciplinary approach” that lends itself as valuable to research about disparities in the area of health. Therefore, CRT contested the views that “race consciousness” can be equated with “racism” and “colorblindness,” which parallels to displaying no racism (Ford, & Airhihenbuwa, 2010, p. 31). Hence, according to CRT, colorblindness can be correctly defined as an “attitude and a school of thought,” that propose that “nonracial factors (e.g., income)” can essentially explain racial phenomena (Ford, & Airhihenbuwa, 2010, p. 31). The major theoretical propositions of the CRT will be discussed further in Chapter 2, found under the Theoretical Foundation section.

CRT is applicable to this study for it relates to the race factor being examined. Specifically, CRT addresses the research question of whether race may influence the perception and diagnosis of ASD among White and Non-White children which may be based on nonracial factors such as family income (Ford, & Airhihenbuwa, 2010). Therefore, CRT can be used as an existing theory upon which this present study can build.

Nature of the Study

A quantitative correlation design was used to analyze data from an archived database containing pediatric ASD intake and diagnostic data that will allow for

generalizing from that sample to a population. Additionally, the design allows for the study of associations between various variables along with their interrelations, which will fulfill this study's goal.

This study consists of two dependent variables, namely, reported perception of ASD (measured by ABAS-II, CBCL, and C-TRF) and clinician's diagnosis of ASD (measured by PEP-3 and CARS-2) in White and Non-White groups. The independent variable is race of the child: White, African American, Latino, or Other.

The population sample for this study was obtained from archival data collected (2008-2016) by the Psychological and School Services of Eastern Carolina (PSSEC). The data were collected from preschool children ages 2 to 5 years old who were referred by the Child Find Project in North Carolina to PSSEC for psychological evaluations. The data were analyzed using the multivariate analysis of variance (MANOVA) statistical test that involves two or more dependent variables (continuous) and one or more independent variable (categorical; Warne, 2014). Since this study consists of two dependent variables (perceptions of ASD and diagnosis of ASD) with continuous data and one independent variable (race) with categorical data, the MANOVA was selected to test the null and alternative hypotheses. Hence, the MANOVA statistical analysis was apt to examine if differences exist or not between reported perceptions of ASD in White and Non-White groups compared to clinician's diagnosis of ASD in White and Non-White groups based on child's race. Additionally, MANOVA considers the intercorrelations among dependent variables, which were pertinent to testing this study's hypothesis.

Definitions of Variables and Terms

Adaptive Behavior Assessment System (ABAS-II): An instrument that assesses norm-based adaptive behavior skills in individuals (birth to age 89 years) to determine individuals' level of independent functioning and social interactions within their community and cultural environment (Harrison & Oakland, 2003). In this study, the instrument was completed by either the child's teacher/daycare provider or parent/caregiver, and data were used to determine the reported perception of ASD.

Asperger's disorder (AS): A diagnostic classification assigned by the DSM-IV, which includes social interaction and nonverbal communication deficits, along with repetitive and fixed interests and behaviors (American Psychiatric Association, 1994).

Autism Diagnostic Observation Schedule (ADOS): A play-based tool that integrates a semistructured interaction between the child and examiner to evaluate the child's ASD symptomology such as play, restrictive and repetitive behaviors, social interaction; and communication (Lord et al., 2012).

Autism spectrum disorder (ASD): A diagnostic term introduced by the DSM 5, which in contrast to the DSM-IV, presents only two broad domains, namely challenges in social communication and interaction and restricted, repetitive patterns of behavior and interests rated by severity (American Psychiatric Association, 2013).

Autistic disorder: A diagnostic classification formally included in 1980 by the DSM-III associated with the absence of social responses, clear language development deficiencies, unusual speech patterns, peculiar interplay with environment, and absence of schizophrenia symptoms (American Psychiatric Association, 1980).

Caregiver-Teacher Report Form for Ages 1.5-5 (C-TRF): An empirically based assessment created to gather information on specific emotional and behavioral difficulties among preschoolers (ages 1½-5 years; Achenbach & Rescorla, 2001). In this study, the instrument was completed by either the child's caregiver or teacher, and data were used to determine the reported perception of ASD.

Child Behavior Checklist for Ages 1.5-5 (CBCL/1.5-5): An empirically based assessment created to gather information on specific emotional and behavioral difficulties among preschoolers (ages 1½-5 years; Achenbach & Rescorla, 2001). In this study, the instrument was completed by the child's parent, and data were used to determine the reported perception of ASD.

Childhood Autism Rating Scale-Second Edition (CARS-2): A standardized instrument developed by Schopler et al. (2010) to identify behavioral symptoms of ASD among children ages 2 and older, which is used to determine clinical diagnosis in this study.

Ethnicity: Typically refers to a common group of individuals sharing the same national, linguistic, religious, or cultural background (Betancourt & Lopez, 1993).

Perception: In the context of this study, it depicts the awareness of the parent, caregiver, teacher, or daycare provider in recognizing ASD symptoms in a particular child. The reported perception of ASD symptoms were measured using the ABAS-II (completed by either the child's teacher/daycare provider or parent/caregiver), C-TRF (completed by either caregiver or teacher), and CBCL (completed by parent).

Pervasive developmental disorders (PDD): The DSM-IV umbrella under which autistic disorder, Asperger's disorder, Rett's disorder, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified (PDD-NOS) are housed (American Psychiatric Association, 2000).

Pervasive developmental disorder-not otherwise specified (PDD-NOS): A diagnostic classification listed in the DSM-IV and DSM-IV-TR, which is used when impairments in social interaction, communication, or fixed behaviors are present. However, criteria are unmet for a specific pervasive developmental disorder (American Psychiatric Association, 2000).

Psychoeducational Profile-Third Edition (PEP-3): A standardized instrument used to evaluate behaviors and skills of children (6 months to 7 years) with ASD and communication deficits and was used to determine clinical diagnosis in this study (Schopler et al., 2004).

Race: Refers to a socially created system used to classify individuals based on biological characteristics as demonstrated by their physical appearance (Rowe, 2002).

Schizophrenia, childhood type: The classification used by the DSM-II to refer to the presentation of schizophrenic symptoms before adolescence associated with withdrawn and autistic behavior; significant immaturity, and reduced development (American Psychiatric Association, 1968).

Sociodemographic: Refers to factors such as an individual's age, gender, education level, marital status, employment status, income level, and reported social class (Otero-López & Villardefrancos, 2014).

Assumptions

This study consisted of the several assumptions. The first assumption is that the data collection was conducted in a standardized manner across the sampled population. Second, it was assumed that information collected on the intake measures were reported with full disclosure and honesty by parents, caregivers, daycare providers, and teachers. These assumptions were needed in context of this study since the data were previously collected and the aforementioned areas could not be validated.

Scope and Delimitations

A delimitation is using only archival data collected by the PSSEC site. PSSEC has limited access to data on full assessments of children with ASD, which subsequently could narrow the scope of this study. Next, the sampling frame is the lists of children referred to the PSSEC that would comprise the sample selection of children ages 2 to 5 years old. Hence, there was an exclusion of children younger than 2 years old and older than 5 years old since I sought only children 2 to 5 years old. Also, I did not implement a mix-methods approach whereby qualitative data could have been used along with the archival data, and thus broadened the scope of this study. However, incorporating the use of qualitative data was not used because the population (children ages 2-5 years old) is considered a vulnerable group that is challenging to access. I also did not possess the specialized training required to conduct assessments of children with ASD.

Theories excluded from the study, namely theory of mind (ToM) were not significantly related to the study (Carruthers, 1996). However, the investigation of the social construct theory that relates to the study was excluded. The social construct theory

postulates that there is subjectivity between what is considered normal and abnormal. Hence, ASD cannot be seen as an objective diagnosis but rather a social construct (Hacking, 1999). Finally, although correlational design typically facilitates a greater degree to which research findings can be generalized to individuals or situations outside the research setting, the use of secondary data may limit the study's generalizability (Frankfort-Nachmias, & Nachmias, 2008).

Limitations

One limitation of the study involves the use of a correlational design that presents a threat to internal validity in the sense that this design is unable to produce cause-and-effect relationships (Kaplan, 2004). For instance, if the study findings proved a correlation between two variables, this did not automatically prove causation. Therefore, this study could face ambiguous temporal precedence whereby it could potentially be challenged to establish definitely which variable ensued first or which variable caused the other variable (Shadish, Cook, & Campbell, 2002).

Another limitation involves the originally collected data from PSSEC, which does not include complete assessments such as information from multidisciplinary sources. Hence, the data were limited in its access to clinical measures, such as sensorimotor skills and speech development. Next, there is the potential threat to validity as the measurement instrument intake forms, used in the original data collection, were created in the form of questionnaires, which would limit the study from exploring questions in-depth (Gillham, 2008). Therefore, details, such as individual's racial beliefs or

acculturation levels, may be difficult to examine when using these instruments (Gillham, 2008).

Finally, the study faced the limitation of its inability to identify confounding variables due to the confines of the data that were measured. There are no known biases that could influence this study's outcomes. Reasonable measures to address the aforementioned limitations involved noting said limitations within the study's discussion of findings, whereby they can be used as recommendations for further research.

Significance

The original contribution of this study's findings is its role of adding to the limited scientific knowledge on the issue of ASD among minority groups. Therefore, by looking at this issue through the lens of various racial groups, this study uniquely addresses an underresearched area of ASD. By expanding knowledge in this discipline, the study could serve as a catalyst to motivate and potentially advance multicultural competency within the professional practice related to ASD. For instance, when conducting screenings, evaluations, or simply referrals for ASD, physicians, mental health professionals, and teachers may become more mindful to holistically consider the child's and family's unique beliefs based on child's race. Therefore, having diverse cultural data on ASD could practically enable mental health professionals to be more informed, sensitive, and effective in collaborating with parents of children who may have ASD (Kalyanpur, Harry, & Skrtic, 2000; Valicenti-McDermott, Hottinger, Seijo, & Shulman, 2012).

Furthermore, examining the relationship of the child's race and reported perception of ASD and the diagnosis of ASD will provide much-needed data to advance and promote public awareness among parents, teachers, daycare providers, healthcare providers, and society at large. Therefore, this increased awareness could potentially lead to the implementation of culturally sensitive screening and diagnostic measures, protocols, and practices for both White and Non-White families. For example, programs may be created to enable more accurate referrals, accessibility to screening, and education about childhood developmental milestones.

In summation, this study could result in positive social change. The implications for positive social change include advancing knowledge in the discipline and promoting culturally competent practice and awareness about ASD among racial groups to safeguard that children, regardless of race, receive timely and competent care.

Summary

A transitory introduction of this study's topic was established in this chapter presenting the background of ASD, the identification of the research problem, purpose, question and hypothesis, theoretical framework, nature, assumptions, delimitations, limitations, and significance. Literature on the study's topic of ASD was found to be numerous with various major themes being evident such as the evolution of the term autism to ASD and changes in diagnostic criteria starting with the DSM-1 to the DSM 5. However, albeit the diagnostic criteria changes, the DSM 5, similar to the DSM-III and DSM-IV, maintained the requirement that specified symptoms must be identifiable in early infancy and developmental period (American Psychiatric Association, 2013).

Nevertheless, contrastingly, the DSM 5 engaged the possibility that symptoms may become fully evident later in life due to increased social requirement or inability to disguise deficits (American Psychiatric Association, 2013).

Additionally, regarding the role race, ethnicity, and sociodemographic factors play in the presentation of ASD, empirically findings remained inconclusive, and recommendation for further studies were suggested by various researchers (Becerra et al., 2014; Blacher et al., 2014; Tek & Landa, 2012). Further, several studies reported that minority children of Asian, Hispanic, and African American decent were less likely to receive early diagnosis compared to Caucasian children (Blacher et al., 2014; Mandell et al., 2002, 2009; Tek & Landa, 2012). Conversely, evidence for the considerable delay in the diagnosis of ASD among minority children remains inconclusive (Burkett et al., 2015; Palmer et al., 2010; Tek & Landa, 2012).

Subsequently, the study is driven by the problem of considerable delay in diagnosis of ASD among minority children, along with the rise in America's immigration and the gap in literature related to ASD among different racial groups. Hence, in this quantitative study, I sought to correlate the relationship between the child's race and reported perception of ASD and clinical diagnosis of ASD among White and Non-White children in an attempt to address the aforementioned problems and need. In summation, I endeavored to report beneficial empirical outcome evidence that could advance knowledge in the discipline, improve practice, and promote public and professional awareness on ASD to safeguard that children, regardless of their race, receive timely and competent care.

In the ensuing chapter, I present an exhaustive literature review, including the specific literature search strategies used and further details on the theoretical foundation relating to this present study. In addition, studies related to the perception and diagnosis of ASD among racial groups are synthesized and presented to demonstrate what is recognized, what remains to be studied, and what is debatable in relation to the study's key variables and research question.

Chapter 2: Literature Review

Introduction

The pervasiveness of ASD has significantly increased in the United States over the past 2 decades with about 1 in 68 children currently being diagnosed with ASD (CDC, 2014). Autism is deemed a major disability due to its severe lifelong impact on individuals and families. Symptoms include delays in the development of socialization and communication along with restricted, repetitive interests and behaviors presenting in early childhood (American Psychiatric Association, 2013). Reports have documented that autism spectrum disorders are evident across all racial and ethnic groups (CDC, 2014), and early intervention (evidence-based treatment) is recommended as the most effective approach to ASD care (Durkin et al., 2010). However, before early intervention can be initiated, it is crucial that symptoms of a developmental delay be competently identified and examined to achieve a correct diagnosis, especially among all racial and cultural groups (Ennis-Cole et al., 2013). For example, minority parents may fail to report subtle cues associated with autism, such as perceiving delays in social skills and language as a phase that will be outgrown (Ennis-Cole et al., 2013). Researchers have also reported that White American children were diagnosed with ASD about 1.5 years earlier than Non-White American children (Morrier et al., 2008).

Unfortunately, while there is a large body of evidence identifying racial and ethnic disparities in the diagnosis and treatment of numerous health conditions (Institute of Medicine, 2002), evidence has been inconclusive regarding disparities in identifying and diagnosing ASD (Mandell et al., 2009). Notably, some studies have reported higher

rates of delayed and missed diagnoses of ASD among underserved ethnic and racial minorities (Jarquin et al., 2011; Thomas et al., 2012), while other studies produced mixed results (CDC, 2006).

As a result, several researchers in the field of ASD have highlighted the need for further investigations among diverse racial populations (Becerra et al., 2014; Blacher et al., 2014; Tek & Landa, 2012; Valicenti-McDermott et al., 2012). The reason for this need is based on researchers' summation that little is known about the nuances of ASD symptoms and perception among different groups along with the impact this may have on early detection rates (Becerra et al., 2014; Blacher, et al., 2014; Valicenti-McDermott et al., 2012). For instance, Tek and Landa (2012) conducted a treatment study that examined ethnic differences in the demonstration of early symptoms of ASD among children as reported by parents and professionals. The study's sample consisted of 84 children with ASD along with parents (Tek & Landa, 2012). They "compared 19 minority to 65 Caucasian children and their parents on variables obtained from the Mullen Scales of Early Learning, Autism Diagnostic Observation Schedule, and Communication and Symbolic Behavior Scales Caregiver Questionnaire" (Tek & Landa, 2012, p. 1967). The purpose of this study was to better understand group differences of "very early ASD symptoms and other developmental features between minority and non-minority children" (Tek & Landa, 2012, p. 1968). However, the study's findings suggested, "future research is needed to examine a variety of minority groups to investigate group-specific differences in the symptom presentation of autism" (Tek & Landa, 2012, p. 1972).

Additionally, Blacher et al. (2014) sought to examine whether or not there was a difference between Anglo and Latino mothers' reports of ASD and any differences in experts' classification. However, they concluded that the "modest findings reported here suggest cultural differences that may need to be investigated further" (Blacher et al., 2014, p. 1655). Additionally, they indicated that further study in this area may unveil "more nuanced understanding" of ASD in Latino children," whereby "actual symptoms of ASD may be in the eye of the beholder" (Blacher et al., 2014, p. 1655).

Evidently, current literature echoes a resounding plea from emerging researchers that underscores the need for additional ASD research among diverse racial populations to better inform clinical practice and increase public awareness (Becerra et al., 2014; Blacher et al., 2014; Tek & Landa, 2012). Further, in 2013, the United States experienced an all-time high influx of approximately 41.3 million immigrants with 17.4 million children living with at least one immigrant parent (Zong & Batalova, 2015). This rise in immigration presents urgency for researchers to consider the influence of race and culture on the etiology of ASD (Khowaja et al., 2014). Therefore, my attempts to add to this limited database could potentially contribute to more culturally-sensitive screening and assessments, with an emphasis on educating clinicians, health educators, and parents. Hence, this study could contribute to closing the gap on cultural disparity in America's mental health care by better informing professionals and empowering parents to identify early warning signs of ASD to safeguard that minority children receive effective services as nonminority children.

The purpose of this correlational study was to answer the question of whether or not the reported perception of ASD and clinician's diagnosis of ASD differs based on the race of the child. The reported perception of ASD and the diagnosis of ASD among White and Non-White children ages 2 to 5 years old were examined based on data collected from schools and daycare centers in rural North Carolina. Therefore, by answering this research question, the study contributes valuable data to help fill the gap in the existing literature regarding ASD among White and Non-White children.

In this chapter, I present a comprehensive literature review related to key variables of the study's topic of ASD among White and Non-White children. Specifically, major sections of this chapter include a brief introduction of the problem and a concise synopsis of current literature that justifies the relevance of the problem and the purpose of this present study. The literature search strategy as well as the theoretical foundations and research-based analysis of how the theories were previously used in similar studies along with its relatedness to this study's research questions are presented. Finally, I summarize what is known as well as unknown in the discipline related to ASD and describe how this present study fills one gap in the literature and adds to the database in this discipline.

Literature Search Strategies

The strategies used for this literature search included the following tools: Google Scholar, via Yale University, Walden University, and Liberty University, and online databases, namely, PsycINFO, PsycARTICLES, JAMA, ProQuest Central, PSYCline, and Academic Search Complete/Premier (EBSCO). Searches were also conducted using

journal websites, namely APA and Affiliated Journals and Psychology Journals-Elsevier, along with available electronic doctoral dissertations. Textbooks on the topic of ASD were made use of along with editorials, reviews, case reports, and conference presentations of research in the area of ASD.

Search terms and combinations of search terms included *autism*, *autism spectrum*, *Asperger's syndrome*, *autism prevalence*, *theory of mind*, *autism and ethnicity*, *autism and race*, *minority and autism*, *autism and culture*, *cross-culture*, *disparity*, and *autism*. Additional terms searched were *etiology*, *early diagnosis*, *autistic symptoms*, *ASD classification*, *ASD criteria*, *ASD diagnostic methods*, *ASD early indicators*, *identification*, *parental perceptions*, *caregiver perception*, *parents' first concerns*, *diagnostic criteria*, *DSM-1*, *II*, *III*, *IV*, *5*, *sensitivity*, and *specificity*. Next, searches included *Psychoeducational Profile*, *CARS*, *ABAS*, *CBCL*, *TRF*, and *caregiver-teacher report*. Final searches included *autism theory*, *TEACCH*, and *critical race theory*. Searches were limited to peer-reviewed literature published in the English language, and the dates were initially limited from 2010 to 2015 but were later expanded to include seminal peer-reviewed literature on the history of ASD.

Theoretical Foundation

The theoretical base for this study was Rimland's organic theory of autism (Rimland, 1964), which is essentially the conceptual framework of the TEACCH model (Mesibov, 1996). The TEACCH model originated in 1964 with a child research project by Schopler and Reichler (1971), which was later pioneered by Mesibov, Shea, and Schopler in the 1970s (as cited in Virues-Ortega et al., 2013). Since the TEACCH

model's conceptual framework is based on behavioral, developmental, and ecological theoretical perspectives that directly correlate with an organic theory of autism, this model was ideal to inform this study (Erba, 2000).

The TEACCH model views ASD as a lifetime condition and treats ASD as a culture as opposed to trying to cure ASD (Erba, 2000). The basic beliefs of TEACCH focus on individualization, whereby it does not differentiate between individuals with learning disabilities and those with much greater skill levels (Virues-Ortega et al., 2013). Further, this model uses assessments to create programs that meet the individual's needs, strengths, developing skill areas, and interest with the goal of fostering independence. For example, since TEACCH's procedure is embedded in behavior therapy and more recently cognitive elements, it suggests that typical ASD behaviors may originate from core problems in perception and understanding (Erba, 2000). Therefore, TEACCH works on the underlying reasons, such as the individual's lack of insight as to what to expect, or the next step and sensory issues (under- or over-stimulation), as opposed to working on the behavior directly. Finally, the TEACCH model strives to work in partnership with parents and families.

In terms of this current study that looks at the autistic child as an individual with unique needs based on various factors, such as race, culture, and sociocultural influences, research-based analysis of TEACCH has demonstrated similar application. For instance, in a study by Erba (2000), the TEACCH program was compared to other programs, such as Floor Time, the LEAP, and the DTT program. The findings indicated that in contrast to the other programs, TEACCH embraced a wide selection of diagnostic tools,

techniques, and services to find the best fit for each child in his or her family unit and culture. Hence, TEACCH reviewed each child for inclusion based on a review of each individual case.

Subsequently, Rimland's (1964) organic theory of autism that serves as the conceptual framework of TEACCH was selected based on its multifaceted (behavioral, developmental, and ecological) theoretical perspective that this current study can build upon (Mesibov, 1996). Furthermore, TEACCH is a model that is recognized for its international certification and established efficacy with individuals from various economic and cultural upbringing that relates to this present study (Callahan, Mehta, Magee, & Wie, 2010; Li, & Kimble, 2015). Therefore, the research question of whether or not parents' and teachers' perception of ASD differs with the clinician's diagnosis of autism based on the race and culture will build upon TEACCH's concept of inclusion involving individualized diagnosis and treatment (Erba, 2000).

Another theoretical base for this study is CRT, which was developed in the 1970s by Freeman et al., who wanted to reform the association of power, racism, and race (Graham et al., 2011). Since CRT incorporates "transdisciplinary methodologies that draw on theory, experiential knowledge, and critical consciousness" to identify and contest the source of racism, it would be beneficial to apply to this present study (Ford & Airhihenbuwa, 2010, p. 31). For instance, Ford and Airhihenbuwa (2010) contended that CRT can be seen as "a transdisciplinary approach" that lends itself as valuable to researches of disparities in the area of health. Therefore, CRT contests the views that "race consciousness" can be equated to "racism" and "colorblindness" which would

mean displaying no racism (Ford & Airhihenbuwa, 2010, p. 31). Hence, according to CRT, colorblindness can be correctly defined as an “attitude and a school of thought,” which proposes that “nonracial factors (e.g., income)” can essentially explain racial phenomena (Ford & Airhihenbuwa, 2010, p. 31).

Research-based analysis of CRT theory has similarly been applied in previous studies comparable to this present study. For instance, Ford and Airhihenbuwa (2010) examined HIV testing among African Americans, and public health used a similar concept of race consciousness. According to Ford and Airhihenbuwa, “public health’s tradition of championing social justice issues suggests that Critical Race Theory can provide powerful new tools for targeting racial and ethnic health inequities” (p. 34).

Subsequently, CRT was selected for it is built on philosophies of social justice and race equity that can help develop solutions towards bridging the gap in health care and encouraging more research of health disparities (Ford & Airhihenbuwa, 2010). Hence, CRT relates to this present study because it relates to the race factor being examined. Specifically, CRT addresses the research question of whether race may influence the perception and diagnosis of ASD among White and Non-White children, which may be based on nonracial factors such as family income (Ford & Airhihenbuwa, 2010). Therefore, CRT can be used as an existing theory upon which this present study can build.

Literature Review Related to Key Variables

Historical Growth of the Term Autism

In 1911, Swiss psychiatrist Bleuler coined the term *autism* to identify behaviors such as self-centered thinking styles and the departure into fantasy often seen in schizophrenic individuals (Bleuler, 1950). Later, in 1913, Kraepelin used this concept to describe *dementia praecox*, seen as prodromal schizophrenia that was more of an evolving disease as opposed to a congenital illness (Parnas, 2011). Subsequently, in the 1920s, the term autism was commonly used when examining childhood schizophrenia (Künkel 1920).

However, when using the term autism within a contemporary context, Davis et al. (2014) indicated that the pediatric neurologist from Russia, Ssucharewa, should be recognized for his contribution. Ssucharewa described the term autism as “a condition marked by profound social isolation” that paved the way for research to distinguish autism from childhood schizophrenia (Davis et al., 2014, p. 3). For instance, Grebelskaya-Albatz (1934) studied the subgroups of childhood schizophrenia and concluded that there were two groups. The first group consisted of children with average intelligence (schizoid psychopaths), and the second group was seen as those with greater thought and developmental challenges (Grebelskaya-Albatz, 1934).

Later, in 1943, Kanner was accredited not so much for defining autism as depicting it in the lives of 11 children who were observed as having a deep preference for sameness and being alone and being of high intelligence (Davis et al., 2014). Hence, Kanner used the term “early infantile autism” to describe behaviors witnessed in some

children (as cited in Wing, 1997, p. 13). These patterns of behaviors observed by Kanner included the child's social detachment, developmental delays, and routines that were fixed and repetitive (as cited in Wing, 1997). Therefore, the common characteristics of autism as solidified by Kanner included "preference for aloneness, intolerance of change (sameness), fascination with objects, impairments in the use of language, and restricted interests" (as cited in Davis et al., 2014, p. 4). Kanner also postulated from his case studies that social exchanges were a trigger for anxiety, and these children had a low tolerance for loud noises (as cited in Davis et al., 2014). Subsequently, Kanner was able to adopt and build on Bleuler's concept of autism by demonstrating that the withdrawal seen in autism was congenital, unlike schizophrenia, which offered a clear distinction between schizophrenia and autism (as cited in Davis et al., 2014; Wing, 1997).

The following year, 1944, Asperger wrote a paper that was different from Kanner's original paper. Asperger looked at the behaviors of children that were older than Kanner's group of teenagers (Wing, 1997). Wing (1997) noted that Asperger found that there were overlaps with his findings and that of Kanner's paper. It was proposed that due to the intensely thorough work done by both Kanner and Asperger in their papers, their works stood out among others in this field and continue to spark the interest of many scholars today (Wing, 1997).

However, in spite of Kanner's valuable contribution to the modern day definition of ASD, some flawed inferences were identified from his case series sample (Davis et al., 2014). First, there was the inference that since children appeared intelligent, they were not intellectually disabled, and Kanner presented no reported IQ results to validate this

conclusion (Davis et al., 2014). Second, Kanner's remarked that his sample consisted of parents that were well-educated professionals and that remark left room for an ascertainment bias towards parents who were not well-educated professionals and their access to resources (Davis et al., 2014).

Additionally, Dyches et al. (2004) offered information on the growth of the term autism. For example, Dyches et al. identified Kanner in the field of pediatric psychiatry and Asperger in pediatrics as recommending the novel diagnostic classification founded on Bleuler's insight of autism which is separate from mental delays and other forms of psychiatric illnesses (Dyches et al., 2004). Hence, Kanner's autism is now viewed as a separate disorder distinct from the wider spectrum of autistic disorders, such as "Asperser's disorder, Rett syndrome, Childhood disintegrative disorder, and pervasive developmental disorder—not otherwise specified" (Dyches et al., 2004, p. 211). It was noted that even though there have been frequent changes over the last 80 years to the lists of the symptoms defining autism yet a few essential characteristics of autism have remained unchanged (Dyches et al., 2004). For example, the delays in language and group interaction skills as well as restricted or unusual behavioral ranges are symptoms that have passed the test of time (Dyches et al., 2004).

History of the Diagnostic Criteria for ASD

Volkmar et al. (2012) clarified that the original papers of both Kanner and Asperger failed to unequivocally present diagnostic criteria for autism. In 1952, the Diagnostic and Statistical Manual of Mental Disorders (DSM) did not list a separate criteria but used the classification "Schizophrenic reaction, childhood type" to categorize

autism (American Psychiatric Association, 1952, p. 20). Likewise, in 1968, autism was not specified in the DSM-II, but the word was noted under the classification of “295.8 Schizophrenia, childhood type” (American Psychiatric Association, 1968, p. 32).

However, Eisenberg and Kanner (1956) were identified as the pioneers to offer criteria for autism followed by Wing (1981) who tallied critical features of Asperger’s syndrome. It was not until 1980 that the American Psychiatric Association formally included autistic disorder as a diagnosis via the DSM-III publication (Volkmar et al., 2012). Notably, this inclusion of the diagnosis of infantile autism into the DSM-III was momentous and it required that all six criteria be met based on history and clinical assessment (Davis et al., 2014). These criteria specified that symptoms should start before age 2 ½, with determined absence of social responses, clear language development deficiencies, unusual speech patterns, peculiar interplay with the environment, and an absence of schizophrenia symptoms (American Psychiatric Association, 1980). However, the requirement of all six criteria was seen as a narrow definition which served to restrict the diagnosis of autism (Volkmar et al., 2012).

Subsequently, in 1987, the DSM-III-R addressed this issue by broadening the diagnostic criteria for autistic disorder to include at least eight of 16 items (American Psychiatric Association, 1987). The DSM-III-R specified that two items should be from diminished social interactions category, one item from the diminished ability to have imaginative play and communication (verbal and nonverbal) category and one item from restrictive activities and interest as listed (American Psychiatric Association, 1987).

Moreover, symptoms should present before 3-year-old, if not it should be specified as occurring after 3 years of age (American Psychiatric Association, 1987).

Additionally, in 1994, the DSM-IV further broadened the criteria for autism (American Psychiatric Association, 1994). This broadening was propelled by research findings from Wing, and Gould (1979) and Wing (1981) that introduced the concept of the autism spectrum with a range from mild to severe (Davis et al., 2014). Furthermore, the DSM-IV added Asperger's disorder, pervasive developmental disorder-not otherwise specified (PPD-NOS) and it kept the age of onset as 3-years of age (American Psychiatric Association, 2000). The DSM-IV and its revision DSM-IV-TR's diagnostic criteria for autism disorder presented three domains, namely, clear deficiency in social interactions, language developmental delays repetitive behavior and/or restricted areas of interest (American Psychiatric Association, 1994; American Psychiatric Association, 2000). In the social domain, two symptoms were necessary, while one symptom each was required in the communication and repetitive behavior domain (Frith, 2004). However, there was no requirement of language delay needed for the diagnosis of Asperger's disorder (American Psychiatric Association, 2000).

In 2013, the publication of the DSM 5 marked the official submission of the term ASD, which according to Davis et al. (2014) exemplified the movement started much earlier in 1977 by Folstein and Rutter (1977). Evidently, when compared to the DSM-IV (American Psychiatric Association, 2000), the DSM 5 contrastingly presented only two broad domains, namely (a) "deficits in social communication and social interaction across multiple context" and (b) "restricted, repetitive patterns of behavior, interests or

activities” (American Psychiatric Association, 2013, p. 50). Also, the DSM 5 does not merely identify the lack or existence of a symptom, but it prompts the specification of severity in each domain (Davis et al., 2014; Gibb, Aldridge, Chandler, Witzlsperger, & Smith, 2012). However, akin to the DSM-III and DSM-IV, the DSM 5 maintained the requirement that the specified symptoms must be recognizable in early infancy and developmental period (American Psychiatric Association, 2013). Nevertheless, the DSM 5 engaged the possibility that symptoms “may not become fully manifested until social demands exceed limited capacities, or may be masked by learned strategies in later life” (American Psychiatric Association, 2013, p. 50).

Complex Representation of ASD

A meta-analysis by Chaste and Leboyer (2012) of several significant findings of epidemiological and genetic studies has demonstrated that ASD is an extremely multifaceted disorder. Hence, these studies revealed that ASD was the consequence of both genetic and environmental influences (Chaste & Leboyer, 2012). Further, Chaste and Leboyer indicated that developments and growth on the genetic roots, such as certain alleles that may play a role in autism have provided valuable pieces that may help solve the ASD puzzle. Nevertheless, it was found that most findings of Chaste and Leboyer’s meta-analysis noted that there are still several pieces of the ASD puzzle to be added, such as the role that environmental and cultural factors may have on autism. Hence, they suggested that research funding should be focused in the area of looking at the “role of common variants and the relationship between genotype and phenotype” when attempting to solve the ASD puzzle (Chaste & Leboyer, 2012, p. 289).

Likewise, Erba (2000) addressed the intricacy representative in dealing with the disorder of autism. For example, she identified that several theories linked to child development, cognitive, social, behavioral, affective, and neurobiological, have been utilized in an endeavor to better understanding the enigmatic impairment and capabilities of autistic individuals. However, Rogers (1996) showed that receiving early intervention was beneficial to the level of functionality in children with ASD (Rogers, 1996). Similarly, Erba's study similarly found that children before the age of 5 years revealed better responses to ASD interventions compared to children after the age of 5 years. Hence, Erba sought to provide related information that will help with early interventions by comparing four intervention programs. The programs compared in Erba's study were namely, "Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), discrete trial training, floor time and learning experiences and alternative program for preschoolers and their parents (LEAP)" (p. 82).

Race, Ethnicity, and Sociodemographic Factors

In examining ASD in terms of race and ethnicity, a population-based study conducted by Becerra et al. (2014) looked at children born from 1998 to 2009 who had a diagnosis of ASD. The study further linked these children to birth certificate records from 1995 to 2006 in Los Angeles, California. This comparison allowed them to look at the birth certificate information of the child's maternal race or ethnicity and birth weight. The purpose of the study was to examine the effects of the mother's ethnicity or race on pediatric ASD among Hispanics, Asians, and African American in America, which were

areas of limited research. Hence, the study looked at whether or not the risk of having ASD varied based on the mother ethnicity or race (Becerra et al., 2014).

Becerra et al. (2014) found a higher risk of ASD among children born to “black, Central/South American, Filipino, and Vietnamese, as well as among US-born Hispanic and African American/black mothers, compared with US-born whites” (p. e63). Also, African American, Hispanic and South or Central American mothers who were born in America had offspring that were at a greater risk of demonstrating limited language and higher emotional dysregulation compared to American-born White mothers (Becerra et al., 2014). Hence, the study concluded that maternal race and ethnicity were linked to the child’s diagnosis of ASD. However, further study was recommended to assess maternal factors associated to origin of birth and migration that may influence the identification and diagnosis of ASD in the offspring (Becerra et al., 2014).

Furthermore, Blacher et al. (2014) assessed children (28 Anglo and 55 Latino) suspected of ASD to better understand why there were higher rates of Hispanic children with ASD and whether they were being under-diagnosed and under-identified compared to Anglo children. Therefore, the study used the “Autism Diagnostic Observation Schedule (ADOS) and the mother Intake Form” to examine whether Latino and Anglo mothers reported different symptoms and if those children varied in the clinical diagnosis (Blacher et al., 2014, p. 1648). Findings indicated that Hispanic mother reported fewer ASD symptoms compared to the Anglo mothers (Blacher et al., 2014). However, Hispanic children diagnosed with ASD using the “ADOS received greater Autism severity scores than compared to Anglo children” (Blacher, et al., 2014, p. 1648).

Nevertheless, the study reported modest cultural differences with the suggestion that further research would be needed that may result in a better understanding of ASD in Latino children (Blacher et al., 2014).

Additionally, Khowaja et al. (2014) offered a different view by examining the sociodemographic obstacles to early detection of ASD. The study used 11,845 participants whose parents completed the Modified Checklist for Autism in Toddlers (M-CHAT or revision, M-CHAT-R) during a visit to the doctor's office. The study used sociodemographic predictors (maternal education and race) to study the variances in ASD participants' "screening, diagnostic evaluation rates and outcomes" as well as explanations for refusal to participate (Khowaja et al., 2014, p. 1573). The findings indicated that participants (mothers) who were from minority groups and had lesser education demonstrated overstated preliminary lesser involvement as well as lesser follow-up, with positive screening rates compared to non-minority. There were barriers such as incorrect phone numbers in contacting these families (Khowaja et al., 2014). On the other hand, there was a greater likelihood of families with higher educational attainment and Caucasians to decline participation in the evaluation (Khowaja et al., 2014). The study's findings recommended further research and public education about childhood development to reduce stigma, promote awareness, reduce stigma, and unify ASD screening.

Mandell et al. (2009) examined the ethnic disparities in recognizing ASD among 2568 children aged 8 years. They used a cross-sectional study to identify ASD by "population surveillance" (Mandell et al., 2009, p. 494). Clinicians were then used to

observe and score the data to access what cases met criteria (Mandell et al., 2009). The goal was to determine if those who met criteria based on the surveillance for ASD had any records (medical or school) of being diagnosed with ASD (Mandell et al., 2009).

The study reported noteworthy racial or ethnic disparities. For example, the diagnosis of an intellectual disability was found to dissuade mental health professionals from any further assessment of developmental delay among minority groups. Some of the influences linked to the disparity were identified as a mixture of the families' and mental health professionals' knowledge, behaviors and beliefs. Based on the study's finding, it was noted that further studies to examine ways to aid with the timely identification of pediatric ASD were recommended. They also suggested further studies to promote awareness and professional education and public awareness related to the heterogeneous presentation of ASD (Mandell et al., 2009)

Perception of Signs and Symptoms of ASD

Early detection of ASD, as timely as 14 months of age, has been documented as being vital in obtaining diagnosis, intervention, and services (Blacher et al., 2014; Landa, Holman, & Garrett-Mayer, 2007; Mandell et al., 2009; Tek & Landa, 2012). However, studies have reported that minority children, namely those of Asian, Hispanic, and African American descent were less likely to receive early ASD diagnosis compared to Caucasian children (Blacher et al., 2014; Mandell et al., 2002; Tek & Landa, 2012). However, evidence exploring the reasons for the considerable delay in diagnosis of ASD among minority children remains inconclusive (Burkett et al., 2015; Palmer et al., 2010; Tek & Landa, 2012).

Tek and Landa (2012) conducted a treatment study for children with ASD, which compared 65 Caucasian parents and child dyads to 19 minority parents and child dyads based on variables obtained from assessments and questionnaire. The study's findings indicated that children from lower SES backgrounds were at risk for delayed intervention services, and early detection was most likely in highly educated families possibly due to better accessibilities to resources. Notably, irrespective of ethnicity most of the parents and child dyads sample in the study was from a high SES background (Tek & Landa, 2012).

However, even though the two groups (minority and non-minority) were from the comparable SES groups they varied in terms of clinically presented symptoms of ASD (Tek & Landa, 2012). On the standardized tests, the scores for minority children with ASD revealed greater uncharacteristic language and communication scores compared to non-minority children. It was postulated that parental cultural difference in perception of what is considered typical and atypical developmentally in their children could be an influencing factor, but more specific research was suggested (Mandell & Novak, 2005). They proposed that minority parents may ignore early symptoms of ASD. For example, delayed milestones or unusual behaviors may be perceived within their cultural context as normal or inconsequential (Tek & Landa, 2012).

Subsequently, parent and caregiver interpretation of ASD symptoms may be based on cultural beliefs and values as seen in a study by Zhang, Wheeler, and Richey (2006). For instance, they found that behaviors such as, replicating parental behaviors, making direct eye contact, and pointing to show shared interest were deemed disrespectful

in the Asian culture. Likewise, among the Hispanic or Latino culture researchers have found that parents reported characteristically different understanding of developmental milestones and when skillsets should be accomplished (Blacher et al., 2014; Gannotti, Handwerke, Groce, & Cruz, 2001). Specifically Garcia, Perez, and Ortiz (2000) conducted a qualitative study to examine Mexican American mothers' beliefs about disabilities. They found that mothers expected their child's milestone for language acquisition or their understanding of language to not be until 3-years-old. Hence, culturally, the Mexican mothers in the study did not recognize that their child had a communication disorder (Garcia et al., 2000).

Similarly, Daley (2004) and Daley and Sigman (2002) found that Indian parents were more likely to perceive social difficulties in children compared to American parents. They postulated that the differences may be due to cultural values, whereby India culture places higher values on social conformity compared to the American culture, but more research was recommended in this area (Coonrod & Stone, 2004; Daley, 2004).

Further, Burkett et al. (2015) resolved that the presentation of ASD as well as how the symptoms are interpreted may vary based on culture groups. Likewise, other researchers contended that heterogeneity of ASD symptom presentation may be influenced by cultural standards (Grinker, Yeargin-Allsopp, & Boyle, 2011; Lord & Bishop, 2010; Mandell, Ittenbach, Levy, & Pinto-Martin, 2007; Tek & Landa, 2012). On the other hand, several researchers upheld that there was ambiguity regarding differences in symptoms demonstrated in African American children, with a call for further investigation (Cuccaro et al., 2007; Valicenti-McDermott et al., 2012).

Additionally, several studies have supported the notion that the clinical phenotype of ASD does not vary by race; however, there is evidence to support the supposition that occurrence of ASD varies across racial groups (Grinker et al., 2011; Mandell et al., 2009; Valicenti- McDermott et al., 2012; Yeargin-Allsopp et al., 2003). For instance, Burkett et al. (2015) reported extended delays in diagnosing African American compared to Caucasian children with ASD. Further, the researchers contended that the family beliefs and perception of ASD symptoms among African American remains significantly unexamined. This lack of investigation exists in spite of researchers' reports that ASD diagnosis may be differentially assigned due to cultural misinterpretation and family's interpretation (Burkett et al., 2015)

Moreover, Burkett et al. (2015) suggested that caregivers and service providers may vary in their perception of ASD symptoms which may influence the diagnosis of ASD in children from minority and non-minority groups. Likewise, Reijneveld, Harland, Brugman, Verhulst, and Verloove-Vanhorick (2005) found that the communication deficiencies connected with ASD could be perceived as a deficiency in using English as a first language among minority groups. Moreover, ASD related symptoms of social deficits in minority groups could be perceived as challenges associated to the acculturation process into the American culture and norms (Reijneveld et al., 2005).

DSM-5 Clinical Diagnostic Criteria of ASD

The use of a complete diagnostic system, such as the DSM 5 (APA, 2013) is essential to lessen unregulated diagnostic guidelines and preserve diagnostic consistency for clinicians' subjective judgments, and methods may vary based on competency,

experience and orientation (Gibbs et al., 2012; Williams, Higgins, & Brayne, 2006). Hence, having universal diagnostic criteria that presents a gradation of symptoms that specify the requirement for a diagnosis or what denotes a differential diagnosis is vital. The DSM 5 diagnostic criteria with the updated classifications related with ASD are listed in Appendix A.

The DSM 5 diagnostic criteria of ASD redefined autism in comparison to its predecessor, the DSM-IV-TR, which consisted of five PDDs (American Psychiatric Association, 2000; American Psychiatric Association, 2013). The DSM-IV-TR PPDs were namely Autistic disorder, Asperger's disorder, Rett's disorder, Childhood disintegrative disorder and PDD-NOS. However, the Autistic disorder, Asperger's disorder and PDD-NOS found in the DSM-IV-TR was subsumed by the single broad diagnosis of Autism spectrum disorder found in the DSM 5 (American Psychiatric Association, 2013; Huerta, Bishop, Duncan, Hus, & Lord, 2012).

Further, the DSM-5 also subsumed the social-related elements of autism under the social communication impairment and repetitive/restricted behaviors, and it not only reformed the taxonomic structure of the autism spectrum, but reformed the diagnostic paradigm of ASD itself (McPartland, Reichow, & Volkmar, 2013). Therefore, the added category called "restricted repetitive behaviors" (RRB) include sensory deviations, which is not found in the DSM-IV-TR criteria (McPartland et al., 2013, p. 370).

Klin, Lang, Cicchetti, and Volkmar (2000) and Lord, Petkova, and Hus (2011) contended that venerable criticism of the reliability and robustness of DSM-IV-TR diagnostic subtypes prompted the current changes in the DSM 5. Hence, McPartland et

al. (2012) proposed that by condensing the ASD diagnosis into the autism spectrum it will enhance the efficacy for the diagnostic rubric. For instance, the diagnostic rubric will be better correlated with the present psychometric standards. Therefore, the DSM 5 allowed for a more reliable and valid tool to distinguish ASD from typical development as well as other developmental disorders. Additionally, the DSM 5 provided a means to better differentiate ASD from psychiatric disorders, while demonstrating the sameness among ASDs which is now grouped into a single diagnostic classification (McPartland et al., 2012).

Subsequently, McPartland et al. (2012) examined the impact of the changes in the DSM-5 diagnostic criteria for ASD in terms of sensitivity and specificity. The study reanalyzed 977 subjects evaluated in the DSM-IV trial (657 diagnosed as having ASD, and 276 diagnosed with non-autistic disorder). They created an algorithm using individual items so that the symptom set will parallel to the DSM-5 diagnostic criteria for ASD which was administered by 125 clinicians at 21 international sites. The results indicated that “60.6% (95% confidence interval: 57–64%) of cases with a clinical diagnosis of an ASD met revised DSM-5 diagnostic criteria for ASD” and “specificity was high, with 94.9%” accuracy in exclusion of individuals from the spectrum (McPartland et al., 2012, p. 368). Hence, they concluded that the DSM 5 criteria significantly reformed the structure of the autism spectrum with greater specificity (McPartland et al., 2012). Similarly, other research findings (Frazier et al., 2012; Mattila et al., 2011; Mazefsky, McPartland, Gastgeb, & Minshew, 2013) have concurred that the DSM 5 demonstrated high specificity within its criteria.

However, those who were cognitively competent, as well as individuals with ASDs (other than Autistic disorder) were estimated to be less likely obtain a diagnosis on the autism spectrum (McPartland et al., 2012). Likewise, numerous reports (Gibbs et al. 2012; Matson, Belva, Horovitz, Kozlowski, & Bamburg, 2012; Matson, Kozlowski, Hattier, Horovitz, & Sipes, 2012; Worley & Matson, 2012) indicated that 60 % or less individual diagnosis with ASD using the DSM-IV (American Psychiatric Association 2000) would meet the DSM-5 criteria which emphasized over restrictiveness concerns. Additionally, when using the DSM 5 researchers (Mattila et al., 2011; Mazefsky et al., 2013; McPartland et al., 2012) found low levels of sensitivity among those diagnosed with Asperger's disorder or PDD-NOS, those with average cognitive function and well developed verbal abilities. Therefore, it was postulated that these more rigorous diagnostic criteria of the DSM 5 could have consequences in terms of public health involving various service entitlements (McPartland et al., 2012). Also, new changes to the DSM 5 criteria could affect the compatibility of both historical and future research.

On the other hand, Rutter (2012) contended that the DSM 5 criteria facilitate the benefit of consistent diagnostic categorization of ASD among studies regardless of heterogeneity of symptom presentation. Further, studies indicated that the DSM 5 offered more sensitivity of ASD diagnosis with the inclusions of traditionally underrepresented groups (girls, women, adults and minority groups, both racial and ethnic) (Mandy, Charman, Puura, & Skuse, 2014; Rai et al., 2012).

Specifically, Mandy et al., (2014) attempted to examine the generalizability of the DSM 5 to countries beyond North America and United Kingdom (UK) based on the view

that ASD has become a more worldwide diagnosis. The DSM 5 model was used with Finnish and UK participants with ASD. The “confirmatory factor analysis tested the DSM-5 model in Finland and compared the fit of this model between Finnish and UK participants (autism spectrum disorder, $n = 488$; broader autism phenotype, $n = 220$)” (Mandy et al., 2014, p. 45). The DSM-5 model was found to be culturally applicable to both the Finnish and UK participants with ASD. However, for the wider autism phenotype participants, the model use was better suited in the UK compared to Finland, where it was seen as a poor fit. The compatibility of the model among the aforementioned countries indicated that cross-cultural inconsistency may be highest for milder autistic symptoms (Mandy et al., 2014).

Diagnostic Procedure of ASD

The recommended diagnostic approach of ASD based on the American Psychological Association and the American Academy of Pediatrics is comprised of steps that may at times require repeated surveillance (Filipek et al., 2000). The approach should begin with the initial pediatric appointment, and a formal screen should be conducted if issues are identified during surveillance evaluation (Filipek et al., 2000; Huerta & Lord, 2012). A formal diagnostic assessment should be conducted if additional caregivers’ concerns are identified (Filipek et al., 2000; Huerta & Lord, 2012). Nevertheless, Braiden, Bothwell, and Duffy (2010) indicated that the educational programs appeared to be the first identifier of ASD symptoms, and the study reported that the likelihood of minority children being underdiagnosed was significant.

According to Huerta and Lord (2012), best practice diagnostic method should incorporate a multidisciplinary approach with an emphasis on numerous domains of functioning being assessed during a diagnostic evaluation. Additionally, a comprehensive evaluation should include information collected from multiple sources. These sources may include various methods, such as observational evaluations to evaluate the child's current level of functioning. This assessment can be conducted by a competent clinician in a context that allows for the child's social or communicative behavior, play, or peer interaction to be observed. Furthermore, parent interviews can be used to collect valuable information of the child's current functioning. Information collected from caregivers offered a broader context to aid in understanding the child's daily behavior in a broad array of situations, family's values, child's history, and contextual influences. Subsequently, Huerta and Lord purported that both the interview from parents along with the assessment of the child should be seen vital elements of the diagnostic evaluation. See Appendix B for a further outline of the modules of a comprehensive ASD evaluation. Finally, it is emphasized that the different components of an ASD evaluation should be conducted by competent and experienced clinicians trained in standardized testing of children particularly in ASD assessment (Huerta & Lord, 2012).

Literature relating to ASD suggested copious selections of diagnostic instruments used in the evaluation process, which could make selecting the best practice instruments challenging (Huerta & Lord, 2012; Stone, Coonrod, & Ousley, 2000). However, a guide for selecting the best diagnostic tools would help to find instruments that can measure

social functioning in a developmental context while considering unpredictability of behavior across different domains (National Research Council Committee on Educational Interventions for Children with Autism, 2001). According to the CDC (2015), when making a diagnosis of ASD more than one sources of information is recommended along with one or more diagnostic instruments. Examples of screening instruments referenced by the CDC include Communication and Symbolic Behavior Scales (CSBS), Ages and Stages Questionnaire (ASQ), and Parents' Evaluation of Developmental Status (PEDS). Some of the most frequently used instruments to diagnosis ASD in research studies have been identified as the Autism Diagnostic Observation Schedule (ADOS) (CDC, 2015; Lord et al., 2012; Lord, Rutter, DiLavore, & Risi, 1999). The ADOS-2 is a play-based tool that integrates a semi-structured interaction between the child and examiner to evaluate the child's ASD symptomology such as play, restrictive and repetitive behaviors, social interaction and communication (Lord et al., 2012).

Next, is the Autism Diagnostic Interview–Revised (ADI-R) instrument (Rutter, Le Couteur, & Lord, 2003; CDC, 2015) which is a semi structured interview used with parents or caregivers of patients ages 3 through adulthood that are being assessed for ASD. The ADI-R has demonstrated strong test retest and interrater reliabilities (>.9), as well as validity (Kim & Lord, 2012; Kim, Thurm, Shumway, & Lord, 2013). Therefore, the ADI-R is often used for diagnostic and treatment planning with patients ages 2 into adulthood (Rutter et al., 2003).

Additional diagnostic tools include the Childhood Autism Rating Scale (CARS-2) which is a questionnaire used to identify behavioral symptoms of ASD among children

ages 2 and older (CDC, 2015; Perry, Condillac, Freeman, Dunn-Geier, & Belair, 2005). Chakraborty, Thomas, Bhatia, Nimgaonkar, and Deshpand (2015) evaluated the Indian Scale for Assessment of Autism (ISAA), the CARS, and the Developmental Disability-Children Global Assessment Scale (DD-CGAS) and found that the overall ISAA scores were considerably correlated with CARS scores. Hence, the CARS demonstrated cultural validity (Chakraborty et al., 2015; Zhang et al., 2006). Further, the CARS was reported as being reliable for distinguishing between mental retardation and severe autism as well as mild, moderate or severe autism among children (Chakraborty et al., 2015; Chlebowski, Green, Barton, & Fein, 2010; Schopler, Reichler, DeVellis, Daly, 1980). In summation, the evaluation of several researchers have concurred that both the CARS and CARS-2 have demonstrated reliability and validity (Breibord & Croudace, 2013; Magyar & Pandolfi, 2007; Reszka, Boyd, McBee, Hume, & Odom, 2014) along with diagnostic accuracy (Falkmer, Anderson, Falkmer, & Horlin, 2013).

Another instrument to diagnosis ASD is the Psychoeducational Profile-Third Edition (PEP-3) (Schopler et al., 2004). A study conducted by Fu, Chen, Tseng, Chiang, and Hsieh (2012) tested the inter-respondent reliability, internal consistency, and convergent and divergent validity of PEP-3 in children with ASD. The study found that the “Cronbach’s alpha of the PEP3-CR subtests, ranging from 0.83 to 0.85, indicated sufficient internal consistency” (Fu et al., 2012, p. 115). Further, the intra class correlation coefficient (ICC) demonstrated moderate inter-respondent reliability with the PEP-3 being found reliable and valid to evaluate ASD symptoms and adaptive functioning.

Studies Related to Research Question

There were some studies that related in part to the research question of what extent reported perception of ASD symptoms differs with the clinician's diagnosis of ASD based on the race of the child. For instance, Tek and Landa (2012) compared 65 Caucasian parent and child dyads to 19 minority parent and child dyads based on variables obtained from assessments and questionnaires. The researchers found that although the two groups (minority and non-minority) were from comparable SES groups the clinically presented symptoms of ASD differed. It was hypothesized that parental cultural difference in how they perceived what is considered typical and atypical developmentally in their children could be an influencing factor, but more specific research was suggested (Mandell & Novak 2005; Tek & Landa, 2012). The study proposed that minority parents may overlook certain signs of ASD based on their cultural background. Hence, uncharacteristic behaviors or delayed milestones may not be seen as problematic as different cultural meanings may be attributed to the behaviors or milestone delays.

Additionally, Zhang et al. (2006) revealed that parental and caregivers' perception of ASD symptoms may differ, whereby behaviors such as replicating parental behaviors, making direct eye contact and pointing to show shared interest were deemed disrespectful in the Asian culture. Likewise, among the Hispanic or Latino culture researchers have found that parents reported characteristically different perception of developmental milestones and when skillsets should be accomplished (Blacher et al., 2014; Gannotti et al., 2001; Garcia et al., 2000). Garcia et al. found that the mothers' perceived milestone

for language acquisition or understanding language as being not until age 3. Therefore, in context of the Mexican mothers' cultural view, they did not perceive that their child had a communication disorder. Likewise, Daley (2004) and Daley and Sigman (2002) found that Indian parents were more likely to perceive social difficulties in children compared to American parents due to cultural values.

Additionally, several studies have supported the view that the clinical phenotype of ASD does not vary by race; however there is evidence to support that the occurrence varies across racial groups (Grinker et al. 2011; Mandell et al. 2009; Valicenti-McDermott et al. 2012; Yeargin-Allsopp et al., 2003). For instance, Burkett et al. (2015) reported extended delays in diagnosing African American compared to Caucasian children with ASD. Hence, Burkett et al. underlined that research among African American families in terms of their beliefs and interpretations of ASD symptoms is limited. This lack of research in this area is evident even with some researchers reporting that ASD diagnosis may be differentially assigned due to cultural misinterpretation and family's interpretation.

Summary and Conclusions

Literature on the topic of ASD was found to be numerous with various major themes being evident. The history of the term autism validated how researchers in this discipline have influenced and added to the knowledge of ASD over time starting with the Swiss psychiatrist Bleuler, who in 1911 coined the term autism to identify behaviors (Bleuler, 1950). Later studies in the 1920s identified the term autism when examining childhood schizophrenia (Künkel 1920). However, the perception of autism continued to

evolve with a distinction of autism being made from childhood schizophrenia which started with a pediatric neurologist from Russia, Ssucharewa, who saw autism in a contemporary context (Davis et al., 2014). Hence, in 1943, Kanner adopted and built on Bleuler's concept of autism by demonstrating that the withdrawal seen in autism was congenital, unlike schizophrenia, which offered a clear distinction between schizophrenia and autism (Davis et al., 2014; Wing, 1997). It was noted that even though there have been frequent changes over the last 80 years to the lists of the symptoms defining autism yet a few essential characteristics of autism have remained unchanged (Dyches et al., 2004).

Another major theme in literature was the historical changes involved in the diagnostic criteria of ASD. For example, in 1952, the DSM-I did not list separate criteria but used Schizophrenic reaction, childhood type to classify autism (American Psychiatric Association, 1952). Similarly, in 1968, autism was not specified in the DSM-II, but the word was noted under the classification of "295.8 Schizophrenia, childhood type" (American Psychiatric Association, 1968, p.32). It was not until 1980 that the American Psychiatric Association formally included autistic disorder as a diagnosis via the DSM-III publication (Volkmar et al., 2012) with all six criteria required for the diagnosis (Davis et al., 2014). The DSM-III definition was seen as restrictive to the diagnosis of autism so in 1987, the DSM-III-R broadened the diagnostic criteria for autistic disorder to include at least eight of 16 items (American Psychiatric Association, 1987). Additionally, in 1994, the DSM-IV further broadened the criteria for autism (American Psychiatric Association, 1994). Finally, in 2013, the publication of the DSM 5 marked the official submission of

the term ASD (American Psychiatric Association, 2013). Also, similar to the DSM-III and DSM-IV, the DSM 5 maintained the requirement that the specified symptoms must be recognizable in early infancy and developmental period (American Psychiatric Association, 2013). Nevertheless, the DSM 5 engaged the possibility that symptoms “may not become fully manifested until social demands exceed limited capacities, or may be masked by learned strategies in later life” (American Psychiatric Association, 2013, p. 50).

Further literature on the topic of ASD revealed that researchers have concurred that based on significant findings of epidemiological and genetic studies ASD is an extremely multifaceted disorder (Chaste & Leboyer, 2012). Likewise, Erba (2000) examined the intricacy of ASD and found several theories linked to child development, cognitive, social, behavioral, affective, and neurobiological have been utilized in an endeavor to better understanding the enigmatic impairment and capabilities of autistic individuals. Therefore, researchers suggested that research funding should be focused on common variants and the correlation between genotype and phenotype when attempting to solve the ASD puzzle (Chaste & Leboyer, 2012).

Another growing theme found in the literature was the question as to what role does race, ethnicity and sociodemographic factors play in the presentation of ASD. For instance, Becerra et al. (2014) discovered that there was a higher risk of autism among children born to mothers who were born outside of America. These mothers were identified as being Filipino, Black, African American, Vietnamese, Hispanic, South and Central American compared to American born whites. However, Becerra et al.

recommended further investigations to assess factors associated to migration, as well as identifying and diagnosing of autism in such children. Overall, in this budding area of research, the findings remained inconclusive and the recommendation for further studies were suggested by various researchers (Becerra et al., 2014; Blacher et al., 2014; Tek & Landa, 2012).

In the same vein, several studies reported that minority children of Asian, Hispanic, and African American decent were less likely to receive early diagnosis compared to Caucasian children (Blacher et al., 2014; Mandell et al., 2002, 2009; Tek & Landa, 2012). However, evidence for the considerable delay in diagnosis of ASD among minority children remains inconclusive (Burkett et al., 2015; Palmer et al., 2010; Tek & Landa, 2012).

Over the past century, researchers have added to the wealth of knowledge within this discipline pertaining to ASD (Bleuler, 1950; Dyches et al., 2004; Eisenberg, & Kanner, 1956; Grebelskaya-Albatz, 1934; Künkel 1920; Parnas, 2011; Volkmar et al., 2012; Wing, 1997). For instance, in the discipline related to the topic of study, it is known that ASD is not childhood schizophrenia (Davis et al., 2014; Dyches et al., 2004). Based on the evolution of the term autism researchers such as Kanner were able to adopt and build on their predecessor's work. Hence, Bleuler's concept of autism demonstrated that the withdrawal displayed in autism was congenital, unlike schizophrenia, which offered a clear distinction between the withdrawal that occurred in schizophrenia and autism (Davis et al., 2014; Wing, 1997). Therefore, in the discipline related to the topic of study, it is known that ASD is not childhood schizophrenia (Davis et al., 2014; Dyches

et al., 2004). Also, it what is known of ASD is that in spite of the frequent changes over the last 80 years to the lists of the symptoms defining autism, a few essential characteristics of autism have remained unchanged (Dyches et al., 2004). For example, the delays in language and group interaction skills as well as restricted or unusual behavioral ranges are symptoms that have passed the test of time.

Additionally, regardless of the many changes in the different DSM publications, the DSM-III and DSM-IV, the DSM 5 maintained the requirement that the specified symptoms must be recognizable in early infancy and developmental period (American Psychiatric Association, 2013). However, what is currently known about ASD is that according to the DSM 5 there is the possibility that symptoms may not only be seen in early childhood, but it may become fully expressed later in life. For instance, when social pressures surpass an individual's restricted abilities or when individuals learn to adapt to limitations by using avoidance and learned strategies.

In addition, studies such as a meta-analysis by Chaste and Leboyer (2012) of several significant findings of epidemiological and genetic studies have validated that autism is an extremely complex disorder. Hence, Chaste and Leboyer's meta-analysis confirmed that most findings noted that there are still several pieces of the ASD puzzle to be solved, such as the role that environmental and cultural factors may have on ASD. Therefore, little is known regarding ASD and what part common variants play as well as the association between genotype and phenotype when endeavoring to solve the ASD puzzle.

Furthermore, as stated by Tek and Landa (2012), not much is known as to whether or not the early expression of ASD symptoms vary in children from ethnic minority groups compared to non-minority groups. Hence, Balcher et al. (2014) called for further empirical researches to examine cultural differences among different culture groups which can add to the limited understanding of the nuances of ASD.

Based on my comprehensive literature review, limitations and gaps related to ASD, particularly ASD and different racial and ethnic groups were evident (Jarquin et al., 2011; Thomas et al., 2012). My literature review has demonstrated that a large body of evidence exists for identifying racial and ethnic disparities in the diagnosis and treatment of numerous health conditions (Institute of Medicine, 2002). However, evidence has been inconclusive regarding disparities in identifying and diagnosing ASD (Mandell et al., 2009). Some studies have reported higher delayed and missed diagnoses of ASD among underserved ethnic and racial minorities (Jarquin et al., 2011; Thomas et al., 2012) while other studies produced mixed results (CDC, 2006). Subsequently, research findings have underscored the need for ASD research in diverse racial populations to inform clinical practice and increase public awareness (Becerra et al., 2014; Blacher et al., 2014). For instance, Tek and Landa (2012) sought to understand group differences of early ASD symptoms and other developmental disorders between minority and non-minority children. However, the study suggested, future research was needed to examine a various minority groups in order to examine specific group differences that may exist in the symptom presentation of ASD. Therefore, I specifically

filled the gap in the literature by offering additional research data on different minority groups and ASD which serves to increase knowledge in the discipline.

Additionally, Blacher et al.'s (2014) study sought to examine whether or not there was a difference between Anglo and Latino mothers' reports of ASD and any differences in experts' classification. However, the researchers concluded that the modest findings suggested cultural differences which would need to be explored further. Additionally, the study indicated that further study in this area may unveil a deeper understanding of ASD in Latino children, whereby "actual symptoms of ASD may be in the eye of the beholder" (Blacher et al., 2014, p. 1655).

Subsequently, I justifiably filled this gap in the literature by further examining parents, caregivers and teachers reported perception of ASD symptoms compared to the diagnosis of ASD among White and Non-White children. Also, the findings of my study serves to increase knowledge in the discipline and heighten awareness amongst professionals to consider families' cultural beliefs and assumptions held about their child's developmental milestones and educational growth. Therefore, by adding to this limited database my study contributes to more culturally sensitive screening and assessments tools, with an emphasis on educating clinicians, health educators, and parents.

In the ensuing chapter I present the specific methodological structure used for this study. In addition, the population, sampling, sampling procedure, data collection, instrumentation and operationalization of constructs, threats to validity and ethical procedures are discussed in depth

Chapter 3: Research Method

Introduction

The purpose of this correlation study was to examine the reported perception of ASD, and the diagnosis of ASD among White and Non-White children ages 2 to 5 years old based on data collected from schools and daycares in rural North Carolina. Hence, I examined if the reported perceptions of ASD measured by ABAS-II, CBCL, and C-TRF in White and Non-White groups differed from clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based on the child's race. Therefore, having compared parents and/or teachers' perceptions of ASD to the clinician's diagnosis among different races groups, the study contributed valuable data and filled the gap in the existing literature regarding ASD among White and Non-White children.

In this chapter, I present a detailed description of the methodology used in this study that facilitated further replication by other researchers. The major sections describe the sampling and sampling procedures along with all procedures for recruitment, participation, and data collection connected with the main study from which this study's data set was derived. Next, the four instruments and the operationalization constructs including the developers, appropriateness to this study, and their reliability and validity are described. Additionally, the threats to validity such as the external, internal, and construct validity are presented. Finally, I describe ethical procedures and concerns related to this study.

Research Design and Rationale

The research question was crafted to examine whether reported perceptions of ASD measured by ABAS-II, CBCL, and C-TRF in White and Non-White groups differed from the clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based on the child's race. Hence, there were two dependent variables and one independent variable. One dependent variable could be found in the first hypothesis and the other in the second hypothesis. Therefore, the first dependent variable was the reported perception of ASD, which was measured based on data collected from intake forms completed by teachers, day-care workers, and parents. The second dependent variable was the clinical diagnosis of ASD from the clinician. In each hypothesis, the independent variable of race remained the same.

In the study, I employed a quantitative approach using a general nonexperimental design to analyze data from an archived database containing pediatric ASD intake and diagnostic data. Specifically, I used a correlation design that involved the examination of the relationship between variables (reported perception of ASD, clinical diagnosis of ASD, and race) and looked at their interrelations. Therefore, since I examined if there were any relationships between reported perceptions and diagnoses of ASD based on the two groups (White and Non-White), this design was appropriate for my goal. For instance, using a correlative design facilitated testing the null hypothesis and the alternative hypothesis. In brief, the null hypothesis stated there would be no differences between reported perceptions of ASD in White and Non-White groups compared to the clinician's diagnosis of ASD based on the child's race. However, the alternative

hypothesis stated that there would be differences between the reported perceptions of ASD in White and Non-White groups compared to the clinician's diagnosis of ASD based on the child's race.

The use of the correlational design in this study facilitated lesser time constraints and the ability to examine variables that were not easily generated in a laboratory (Jackson, 2012). Specifically, since this correlational design involved archival data, it was less expensive than other study methods. Additionally, the choice of the quantitative approach using a correlative design involved less cost and time in the data analysis since suitable and efficient computer software was used.

Further, the design choice was consistent with research designs needed to advance knowledge in this area of research (Tek & Landa, 2012). For instance, as aforementioned, correlation designs that are nonexperimental allow researchers to look at variables that cannot be controlled and manipulated. Thus, the process enabled me to examine questions off-limits to experimental researchers (Kaplan, 2004; Tek & Landa, 2012).

Methodology

Population

The target population was preschool children in Duplin County, North Carolina (NC). Specifically, this study's target population consisted of preschool children referred by the Child Find Project in NC to PSSEC between 2008 and 2016. The target population's approximate size was estimated as 75, based on sample size calculations.

Sampling and Sampling Procedures

Since I used secondary data, I employed a probability sampling (random) strategy to attain representativeness and generalization (Frankfort-Nachmias & Nachmias, 2008). Explicitly, I used a stratified random sampling whereby the population was separated by strata and then samples were randomly chosen from each stratum (Levy & Lemeshow, 2008). The stratified sampling strategy was appropriate for this study's broad goal of increasing reliability and validity, whereby broad inferences could be made to the population (Frankfort-Nachmias & Nachmias, 2008). For example, participants were allotted to homogenous subgroups based on race before the sampling, whereby each strata were equally exclusive with no population omitted. Further, simple random sampling was used with each stratum to increase representativeness and lessen sampling error (Jackson, 2012). Additionally, since this sampling strategy facilitated the choice of any given sampling unit separate from any previous sampling units, systematic bias from the study's sampling process was reduced (Frankfort-Nachmias & Nachmias, 2008). Thus, this sampling strategy was suitable for the study's research question and variable based on ASD among children (White and Non-White) ages 2 to 5 years old, which was not easily accessible data to obtain. Hence, data collection was conducted practically from the aforementioned randomly provided list amassed by secondary source that was then stratified by race (Pyrzczak, 2008).

One sampling strategy that was not appropriate was the convenience sampling strategy (Frankfort-Nachmias & Nachmias, 2008). Typically, researchers who implemented this sampling strategy would simply select participants who were within

proximity and easily accessible, which would lead to sampling bias or a lack representativeness as well as limited generalization (Frankfort-Nachmias & Nachmias, 2008).

The population sample for this study was obtained from archival data collected (2008-2016) by PSSEC. Specifically, the procedural steps for how the sample was drawn involved various steps. First, all participants were initially referred to the Duplin County, NC preschool via the Child Find Project and Head Start program. Referrals were accepted from physicians, teachers, parents, and other professionals, as well as from anonymous sources. Second, after the referrals were received by the NC Pre-K coordinator, participants completed a Division of Child Development and Early Education (DCDEE) process. Third, the parent(s) or legal guardian(s) were contacted for permission to conduct evaluations and ASD testing. Fourth, the participants were then referred to PSSEC where the parent(s) or legal guardian(s) completed final paperwork, which consented for the evaluations to be conducted. The consenting forms stipulated that participants could refuse to participate or withdraw from the no cost evaluation at any point during the process.

The study's sampling frame was the group of children who had an actual chance of being selected for the study's sample (Gall, Borg, & Gall, 2003). Therefore, specifically, the sampling frame was the lists of children referred to the PSSEC that comprised the sampled selection of children ages 2 to 5 years old. Concurrently, only children on that list had an actual chance of being selected. There was an exclusion of children younger than 2 years old and older than 5 years old because I sought only

children in that age range. Moreover, I only used selected data collected from those participants who fully consented and completed both the Pediatric Autism intakes and diagnostic forms. All races and ethnicities of children were included for the study examining both White and Non-White groups.

The power analysis to determine the study's sample size included a confidence level of 95% with a confidence interval (margin of error) of +/-5 points. The G*Power 3.1 software program was used, which justified the power level, alpha level, and effect size (Faul, Erdfelder, Buchner, & Lang, 2009). A one tail with an alpha level of $\alpha = .05$ and a medium effect size ($r = .30$) indicated that the sample size required to obtain adequate power level (.80) was 64 participants.

Archival Data

As aforementioned, procedures for recruitment involved various steps. First, all participants were initially referred to the Duplin County, NC preschool via the Child Find Project and Head Start program. Referrals were accepted from physicians, teachers, parents, and other professionals, as well as from anonymous sources. Second, after the referrals were received by the NC Pre-K coordinator, participants completed a DCDEE process. Third, the parent(s) or legal guardian(s) were contacted to obtain permission to conduct evaluations and ASD testing. Fourth, the participants were then referred to PSSEC.

During a meeting with PSSEC's licensed school psychologist, the parent(s) or legal guardian(s) completed final paperwork consenting for the evaluations to be conducted. The consenting form allowed for participants to refuse or withdraw from the

free-of-cost evaluation at any point during the process. There have been no reported drop-outs or refusal of participation after consent was granted to PSSEC.

The data collection for the main dataset involved PSSEC's licensed school psychologist grouping the participants into three areas for testing. The first group included the participants from Head Start or in daycare centers who were excused from their scheduled day to be evaluated. The second area involved the home participants who came to the school to be evaluated by PSSEC's licensed school psychologist. Third, involved individuals who were homebound due to severe disabilities that required a team present to conduct the evaluation at the child's place of residence. None of the participants in the main dataset met the criteria that required an evaluation at their residence.

Notably, the PSSEC's licensed school psychologist has sole legal rights to all equipment and protocols used in the process of the evaluation. Therefore, the procedure for gaining access to the data set involved a contractual agreement between the data provider (PSSEC) and data recipient (researcher), which permitted limited data set use for research activities only.

The data set agreement with PSSEC was limited to the de-identified demographic information and scores (protocols) for measures administered. The agreement excluded the reports from PSSEC's evaluations, which is owned exclusively by the NC school system. A detailed copy of the Data Use Agreement contract is located in Appendix D.

Instrumentation and Operationalization of Constructs

Childhood Autism Rating Scale-Second Edition (CARS-2). The CARS-2 is a

standardized instrument developed by Schopler et al. (2010) to identify behavioral symptoms of ASD among children ages 2 and older. The CARS-2 is also used to differentiate children with ASD symptoms from those with developmental disabilities, which makes it appropriate for the current study (Schopler et al., 2010). Three forms are included in the CARS-2. First, is the Standard Version (CARS2-ST) that is used with children below ages 6 and those with communication deficits or estimated IQ 79 or lower. Second, is the High-Functioning Version (CARS2-HF, ages 6 and up with above 80 estimated IQ). Third, is the Questionnaire for Parents or Caregivers (CARS2-QPC, Unscaled scale) that accumulates data to be used in the ratings by the CARS2-ST and CARS2-HF.

The CARS2-ST and CARS2-HF forms each include a 15-item rating scale that uses a 4-point rating scale. Each item is rated based on intensity, frequency, peculiarity, and duration. Both forms each consist of the following functional areas: (1) Relating to People, (2) Imitation (ST), (3) Social-Emotional Understanding (HF), (4) Emotional Response (ST), (5) Emotional Expression and Regulation of Emotions (HF), (6) Body Use, (7) Object Use (ST), (8) Object Use in Play (HF), (9) Adaptation to Change (ST), (10) Adaptation to Change/Restricted Interests (HF), (11) Visual Response, (12) Listening Response, (13) Taste, Smell, and Touch Response and Use, (14) Fear or Nervousness (ST), (15) Fear or Anxiety (HF), (16) Verbal Communication, (17) Nonverbal Communication, (18) Activity Level (ST), (19) Thinking/Cognitive Integration Skills (HF), (20) Level and Consistency of Intellectual Response, and (21) General Impressions.

Examples of two items from the “Imitation” category are “Appropriate imitation. The child can imitate sounds, words, and movements that are appropriate for his or her skill set” (scored as 1; Perry et al., 2005, p. 629). Next, is “mildly abnormal imitation. The child imitates simple behaviors” (scored as 2), and in between these two descriptions are scored as 1.5 (Perry et al., 2005, p. 629). The 15 items are given the following scores: “1 = normal for child’s age; 2 = mildly abnormal; 3 = moderately abnormal, 4 = severely abnormal” and “midpoint scores of 1.5, 2.5, and 3.5 are also used” (Perry et al., 2005, p. 629). The overall scores range from 15 to 60, with a score of 30 as the cutoff for an autism diagnosis (Perry et al., 2005). Additionally, the CARS2-QPC consists of questions for parents or caregivers regarding the child’s development milestones, communication, emotional and social skills, abnormal sensory interests, repetitive routines, play, and behaviors.

The CARS-2 was normed using an ASD sample of 1,034 and numerous researchers (Breidbord & Croudace, 2013; Chlebowski et al., 2010; Magyar & Pandolfi, 2007; Reszka et al., 2014) have concurred its reliability and validity in providing objective and measurable scores grounded on direct behavioral observation. Specifically, the CARS2-ST, that was used in this study’s data collection demonstrated high internal consistency (alpha = .93) (Vaughan, 2011). The CARS2-HF’s also showed a high internal consistency (alpha = .96). The CARS2-ST and CARS2-HF inter-rater reliability reported an average inter-rater reliability of .51 and, 73, respectively. Further, the CARS-2 test-retest consistency indicated .88 (Vaughan, 2011). Therefore, overall, the CARS-2 was reported as being reliable for distinguishing between mental retardation

and severe autism as well as mild, moderate or severe autism among children (Chlebowski et al., 2010; Vaughan, 2011).

The CAR-2's validity indicated an overall discrimination index value of .93 (Vaughan, 2011). The sensitivity indicated a value of .81 and the specificity indicated a value of .87. Additionally, the CAR2-HF was found to have a comparatively strong relationship with the ADOS which is deemed the gold standard for ASD instruments (Vaughan). In summation, the CARS-2 was ranked among the top three instruments esteemed for their diagnostic accuracy (Falkmer, Anderson, Falkmer, & Horlin, 2013).

Psychoeducational Profile-Third Edition (PEP-3). The PEP-3 was developed by Schopler et al. (2004) as a revision to the over 20-year-old instrument that has been used to evaluate behaviors and skills of children (6 months to 7 years) with ASD and communication deficits. Further, the PEP-3 can be used in educational settings to assess children (3 to 5 years-old) with disabilities as well as yielding valuable data for Individualized Education Programs (IEPs) for older students (Schopler et al., 2004).

The appropriateness of the PEP-3 in relation to this current study is its ability to provide a profile graph that maps irregular and peculiar development, emergent skills, and ASD behavioral traits among children that provide relevant data. Also, the revised PEP-3 has an added caregiver report (used prior to assessments) to gauge and compare the child's developmental level to those of average children. Improvements demonstrated by the PEP-3 include identifying areas of teachable skills and the child's unique learning strengths. Also, The PEP-3 is the only test that offers normative data collected from

large national samples (2002 to 2003) comparing both ASD and non-ASD children (ages 2 to 7 ½ years).

A study conducted by Fu et al. (2012) tested the inter-respondent reliability, internal consistency, and convergent and divergent validity of PEP-3 in children with ASD. The study reported that the “Cronbach’s alpha of the PEP3-CR subtests, ranging from 0.83 to 0.85, indicated sufficient internal consistency” (Fu et al., 2012, p. 115). Further, the intra-class correlation coefficient (ICC) demonstrated moderate inter-respondent reliability with the PEP-3 and was found reliable and valid in evaluating ASD symptoms and adaptive functioning.

Adaptive Behavior Assessment System (ABAS-II). The ABAS-II was developed by Harrison and Oakland (2003) as a revision to its predecessor. The ABAS-II assesses norm-based adaptive behavior skills in individuals (birth to age 89 years) to determine individuals’ level of independent functioning and social interactions within their community and cultural environment (Harrison & Oakland, 2003). In addition, the ABAS-II’s inclusion of the Infant/Preschool forms that offer conceptual, social, and practical domain scores make it an appropriate instrument for the current study. Also, there are five ABAS-II forms distinctively assigned for different age ranges and raters. Two forms are designated for use by teachers/daycare providers (ages 2 to 5 and 5 to 21), two forms for parents/primary caregiver (ages 0 to 5 and 5 to 21), and one form for adults (ages 19 to 89).

The ABAS-II measures 10 skills, namely, “communication; community use; functional academics; home living; health and safety; leisure; self-care; self-direction and

social” (Harrison & Oakland, 2003, p. 1). Examples of the two items for the communication domains are “cries or fusses when upset” and “raises voice to get attention” (Harrison & Oakland, 2003, p. 2). Each of the items uses the response scale “0 (is not able to perform the task), 1 (never or almost never perform the tasks), 2 (perform the task sometimes), 3 (always or almost always performs the task)” (Harrison & Oakland, 2003, p. 2). Also, there is a column to indicate if the response was guessed.

The “domain composite scores” and the “General Adaptive Composite” (GAC) both “have a mean of 100 and a standard deviation of 15,” while the “skill area standard scores have a mean of 10 and a standard deviation of 3” (Harrison & Oakland, 2003, p. 367). The internal consistency reliability scores were high, ranging “from .97 to .99 for GAC;” “.91 to .98 for the adaptive domains and .80 to .97 for the 10 individual skills areas” (Harrison & Oakland, 2003, p. 369). The test-retest reliability coefficient was .90 (excellent), and the inter-rater reliability were good, “between .82 and .91 for adaptive domains, and .70 to .82 for the skills areas” (Harrison & Oakland, 2003, p. 369). The validity of the ABAS-III is established on the American Association of Intellectual and Developmental Disabilities criteria and the construct and convergent validity indicate it is applicable to its designed theoretical basis.

Child Behavior Checklist for Ages 1.5-5 (CBCL/1.5-5) and Caregiver-Teacher Report Form for Ages 1.5-5 (C-TRF). Achenbach and Rescorla (2001) under the overall Achenbach System of Empirically Based Assessment (ASEBA) developed the preschool forms CBCL/1.5-5 and C-TRF/1.5-5 to gather information on specific emotional and behavioral difficulties among preschoolers (ages 1½ to 5 years).

Empirically based syndromes scored from both the CBCL/1½-5 and C-TRF produces patterns of difficulties resultant from both instruments' factor analysis. The CBCL/1½-5 and C-TRF have similar internalizing, externalizing, as well as total stress problems scales and a problems scale. However, the CBCL/1½-5 has an added sleep problem syndrome scale. The following syndrome scales are used to score: a) Emotionally Reactive, b) Anxious/Depressed, c) Somatic Complaints, d) Withdrawn, Attention Problems, e) Aggressive Behavior, and f) Sleep Problems. The following DSM-oriented scales are also used in scoring: a) Affective Problems, b) Anxiety Problems, c) Pervasive Developmental Problems, d) Attention Deficit/Hyperactivity Problems, e) Stress Problems, f) Autism Spectrum Problems, and g) Oppositional Defiant Problems. In addition, the measure obtains qualitative data beyond the 99 items using open-ended questions that allows for descriptions of main concerns/problems, mental and physical disabilities and strengths of the child (Achenbach & Rescorla, 2001).

The CBCL/1½-5 and C-TRF are widely used and researched measures which have demonstrated empirical cross-cultural (over 27,000 CBCLs and C-TRFs from 24 societies) normative data (Aebi, Metzke, & Steinhausen, 2010; Dulcan, 2010; Ivanova et al., 2007). In addition to the aforementioned efficacy of the CBCL/1½-5 and C-TRF, the multicultural options and scoring make these instruments appropriate and beneficial for this study. The CBCL/1½-5 measure was normed on a national (United States.) sample of 700 children, and the scales are derived from ratings of 1,728 children (Achenbach & Rescorla, 2001). The C-TRF measure was normed on 1,192 children, and the scales are derived from ratings of 1,113 children.

Developers of the CBCL/1½-5 and C-TRF along with other researchers conducted extensive research that established the construct criterion validity of these instruments (Achenbach & Rescorla, 2001; Ha, Kim, Song, Kwak, & Eom, 2011; Ivanova et al., 2010; Muratori et al., 2011). Additionally, both instruments demonstrated average reliability whereby the test-retest was 0.85 and the cross-informant agreement was 0.61 (Achenbach & Rescorla, 2001).

Data Analysis Plan

The International Business Machines' (IBM) Statistical Package for the Social Sciences (SPSS) Version 21.0 software was used to conduct the data analysis for this study (Green & Salkind, 2014). Before conducting statistical analyses, the data was cleaned whereby it was screened to guarantee the data were reliable, valid and usable for the study's purpose. The first screen used SPSS to check for missing data in order to guarantee that there were enough data points to run the analyses and avert any bias issues. Next, a boxplot was used in SPSS to identify outliers (individual variables and model) that could potentially move the mean from the median and thereby impact the findings of this study. Further, the distribution of the data (normality) in terms of certain variables was assessed to examine the shape, kurtosis (flatness of distribution) and skewness. This normality was gauged using SPSS that examined the boxplot to look at the shape of distribution. Finally, the linearity, homoscedasticity and multicollinearity were examined using the SPSS software (Green & Salkind, 2014).

Research Question

Will the reported perceptions of ASD measured by ABAS-II, CBCL and C-TRF in White and Non-White groups differ from clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based on child's race?

Hypothesis

H₀1: There will be no differences between reported perceptions of ASD measured by ABAS-II, CBCL and C-TRF in White and Non-White groups compared to clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based on child's race

H_a1: There will be differences between reported perceptions of ASD measured by ABAS-II, CBCL and C-TRF in White and Non-White groups compared to clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based on child's race

Statistical Test

MANOVA statistical test involves two or more dependent variables (continuous) and one or more independent variable (categorical) (Warne, 2014). Therefore, since this study consisted of two dependent variables (perceptions of ASD and diagnosis of ASD) with continuous data and one independent variable (race) with categorical data, the MANOVA was used to test the null and alternative hypotheses. Hence, the MANOVA statistical analysis was appropriate to examine whether differences existed between reported perceptions of ASD in White and Non-White groups compared to clinician's diagnosis of ASD in White and Non-White groups based on the child's race.

Additionally, MANOVA considered the inter-correlations among dependent variables which were pertinent to testing this study's hypothesis.

There was no inclusion of potential confounding variables such as low socioeconomic status (SES) for the study could not control for this variable. This point was discussed further in the limitation section of this study. Further, the results of this study were interpreted using certain key parameter estimates. These estimates required frequency data that were nominal (categorical) with categories mutually exclusive (Jackson, 2012). Also, the expected counts were required to be greater than 5 and none less than 1. Additionally, the results' interpretation called for a confidence level of 95% with a confidence interval (margin of error) of +/-5 points.

Threats to Validity

External Validity

External validity denotes the generalizability of a study's outcomes across numerous research settings or situations (Frankfort-Nachmias & Nachmias, 2008). I used a correlational design which typically facilitates a greater degree to which research findings can be generalized to individuals or situations outside the research setting (Creswell, 2013; Frankfort-Nachmias & Nachmias, 2008). Hence, this study resulted in a lesser degree of threats to external validity. For instance, no pretest was conducted which could have potentially influenced the participants' responsiveness or sensitivity to the experimental variable (Creswell, 2013). Therefore, there were no threats to a reactive or interaction effect of testing for this study. Also, there were no threats of multiple treatment interferences (no multiple treatments were given to the same subjects), nor

reactive effects of experimental arrangements for effects were from a nonexperimental setting which could have been easily generalized.

Internal Validity

The internal validity of a study involves the degree to which its design can produce a causal inference (Creswell, 2013; Frankfort-Nachmias & Nachmias, 2008). In this study, I used a correlation design which presented a threat to internal validity in the sense that this design was unable to produce cause-and-effect relationships (Kaplan, 2004). For instance, a proven correlation between two variables would not automatically prove causation. However, correlational designs are likely to have a greater degree of external validity (generalized to a greater population) which benefited this study's validity (Kaplan, 2004). Furthermore, in spite of the aforementioned threats to internal validity, the study's instrumentations demonstrated validity for there were no changes in the instruments or scorers which would have influenced changes in the outcomes.

Construct Validity

Frankfort-Nachmias and Nachmias (2008) proposed that the construct validity can be protected by connecting the measuring instrument to an overall theoretical framework. This study was not exposed to threats to construct validity, such as hypothesis guessing by participants, bias in experimental design and researcher expectations (secondary data was used) (MacKenzie, 2003). However, there was the initial threat to the construct validity whereby the study's outcome was defined too narrowly, but after review of the original data collection, this was addressed for the site conducted evaluations on a broad range of pediatric disorders. During this study, I was faced with the inability to identify

confounding variables due to the confines of the data that was measured. The aforementioned was addressed by identifying that this limitation will be an area for further studies to be performed.

Ethical Procedures

Agreement to gain access to the PSSEC data set was initially received by way of a data agreement letter (See Appendix C). Additionally, a formal data use agreement form was signed to permit usage of dataset from PSSEC. The agreement was limited to the de-identified demographic information and scores (protocols) for measures administered. The contract excluded the reports from PSSEC's evaluations, which are owned exclusively by the NC school system. A detailed copy of the data use agreement contract is located in Appendix D.

This study did not involve any interactions or observations of human subjects. The institutional permission which included an Institutional Review Board (IRB) application was obtained to ensure that the ethical principles of beneficence, justice and respect for persons were upheld in this study. The IRB approval number for this study is 04-12-16-0414952.

In this study, I used a secondary data set and therefore, there were no ethical concerns related to recruitment materials and processes, as well as, data collection. In the collection of the original data, the collector of the data, PSSEC, ensured that participants were treated fairly and that families were neither marginalized nor disempowered. Families in the collection of the original data were fully consented and informed about the benefits and risk involved in their participation. Confidentiality and limits to

confidentiality were discussed and guaranteed in the original collecting of this data set. Further, participants were informed of their right to refuse or withdraw from the evaluations process at any time provided in the Handbook on Parents' Rights. There were no reported withdrawals by participants or any adverse events that occurred during the original collection of this data set.

Data were confidential as stated in the consenting form used by PSSEC in the initial data collection and the Parent/Guardian Consent for Evaluation form provided to participants. There have been no reported breaches of confidentiality or concerns pertaining to this data set. The data shared for this study were de-identified and therefore anonymous to the researcher.

At PSSEC, there were strict measures to preserve the confidentiality of the data. The procedure involved no access to data, except for authorized PSSEC's Office Coordinator, who holds a Masters' level counseling degree and the licensed school psychologist. The data were securely stored in a locked, water and fireproof filing cabinet at PSSEC's office.

The data dissemination was limited to only the NC School System that solely obtained the final report. The parents and physicians were not recipients of this report or data. The PSSEC's licensed school psychologist, the Office Coordinator who holds a Masters' level counseling degree, and the researcher (limited access), were the only sources with access to this data set.

In compliance with the NC state, the data for children in special education are held until the participant reaches ages 21, plus an additional 4 years. In the case of

children who were not in special education, the data are held until graduation from high school, which typically occurs at ages 18, plus an additional 4 years.

Hard copies of de-identified data received from PSSEC are securely locked in a locked filing cabinet, and I am the only person with access to that secure cabinet. The raw data was then coded into SPSS for statistical analysis using my personally secured (administrator password-protected) computer equipped with Norton antivirus software, along with Malwarebytes anti-malware and anti-spyware protection. After analysis, statistical data were then securely stored on a stand-alone external hard drive with access restricted by administrator password-protection. Also, write permission was disabled to prevent formatting so that data will remain safe. Antivirus protection, along with Malwarebytes anti-malware and anti-spyware protection runs on a daily basis and updates are being applied to maintain the security of the data set. Lastly, the data are kept for five years as stipulated by Walden University, and copies are stored in two different locations for safe keeping (Walden University, 2014). After the five year period, the dataset will be securely shredded and disposed of, while stored electronic copies will be professionally erased from drives.

There were no other ethical issues in this study. For instances, I used secondary data so it eliminated the ethical risk of conducting the study at researcher's place of employment, power differentials and the use of incentives. Finally, there were no conflicts of interest within the study.

Summary

In this chapter, I presented justification for the research design and rationale for the researcher's use of a quantitative approach with a nonexperimental design to analyze data from an archived database. Specifically, the rationale for the use of a comparative design that involved comparing and contrasting two samples of study subjects on one or more variables conducted at a single point of time was discussed. Subsequently, it was agreed that a comparative design in this study facilitated testing the hypotheses of whether or not White and Non-White groups of children significantly differed or not in the reported perception of autism. Moreover, I compared and contrasted White and Non-White children and examined whether they significantly differed or not in clinician's diagnosis of ASD. Additionally, the methodology including the target population (preschool children, Duplin County, NC) sampling strategy (stratified random sampling), procedures, sampling frame and power analysis were used to determine sample size and discussed in sufficient depth to ensure that this study was replicable. Next, the data collection procedures of the archival data along with each published instrument (CARS-2, PEP-3, ABAS-II, CBCL/1.5-5 and C-TRF/1.5-5) were presented. Further, the study's threats to external, internal (i.e. inability to produce cause-and-effect relationships) and construct validity were examined and how these threats were addressed were presented. Finally, ethical procedures including agreements to access data set (i.e. de-identified) treatment of human participants (beneficence, justice, and respect) and treatment of data (confidentially maintained and protected) were examined and addressed. In the

subsequent chapter, I discuss the analysis of the data set, the study's findings and a summary of the answers to the research question.

Chapter 4: Results

Introduction

The purpose of this study was to investigate the relationship between child's race and reported perception of ASD, and clinical diagnosis of ASD among White and Non-White groups. Race was the independent variable, and the reported perception of ASD and clinician's diagnosis of ASD were the dependent variables. In the study I asked if the reported perceptions of ASD, as measured by ABAS-II, CBCL, and C-TRF, in White and Non-White groups differed from the clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based on the child's race. The main hypothesis stated that there would differences between reported perceptions of ASD as measured by ABAS-II, CBCL, and C-TRF in White and Non-White groups compared to clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based on child's race. In this chapter, data collection details such as the time frame for data collection and baseline descriptive and demographic characteristics of the sample are provided. Next, the results, including reported descriptive statistics characterizing the sample, evaluation of statistical assumptions, and reported statistical analysis in relation to research question and hypothesis are presented. Finally, a summation addressing the study's answers to the research question are presented.

Data Collection

Data Collection Time Frame, Recruitment and Response Rates

The time frame for data collection was from the period January 2008 to January 2016. All participants were initially referred to the Duplin County, NC preschool via the

Child Find Project and Head Start program. Referrals were accepted from physicians, teachers, parents, and other professionals, as well as from anonymous sources. Second, after the referrals were received by the NC Pre-K coordinator, participants completed a DCDEE process. Third, the parent(s) or legal guardian(s) were contacted to obtain permission to conduct evaluations and ASD testing. Fourth, the participants were then referred to PSSEC where they met with a licensed school psychologist and the parent(s) or legal guardian(s) completed final paperwork consenting for the evaluations to be conducted. The consent form allowed participants to refuse or withdraw from the free-of-cost evaluation at any point during the process. There was a high reported response rate and there were no reported drop-outs or refusals of participation after consent was granted to PSSEC.

Specifically, the data collection for the main dataset involved PSSEC's licensed school psychologist grouping the participants into three areas for testing. The first area included the participants from Head Start or in daycare centers who were excused from their scheduled day to be evaluated. The second area involved the home participants who came to the school to be evaluated by PSSEC's licensed school psychologist. Third, involved individuals who were homebound due to severe disabilities that required a team present to conduct evaluation at the child's place of residence. None of the participants in the main dataset met the criteria that required evaluating at their residence.

Notably, the PSSEC's licensed school psychologist has sole legal rights to all equipment and protocols used in the process of the evaluation. Therefore, the procedure for gaining access to the data set involved a contractual agreement between the data

provider (PSSEC) and the data recipient (researcher), which permits limited data set use for research activities only. The data set agreement with PSSEC was limited to the de-identified demographic information and scores (protocols) for measures administered. The agreement excluded the reports from PSSEC's evaluations, which is owned exclusively by the NC school system. A detailed copy of the Data Use Agreement contract is located in Appendix D.

Data Cleaning and Screening

SPSS Version 21.0 software was used to conduct the data analysis for this study. Before conducting statistical analyses, the data were cleaned, whereby they were screened to guarantee the data were reliable, valid, and usable for the study's purpose. The first screen using SPSS checked for missing data to guarantee there were enough data points to run the analyses and avert any bias issues. Next, a boxplot was used in SPSS to identify outliers (individual variables and model), which could potentially move the mean from the median and thereby impact the findings of this study. Further, the distribution of the data (normality) in terms of certain variables was assessed looking at the shape, kurtosis (flatness of distribution), and skewness. This was gauged using SPSS to examine the histogram or boxplot to look at the shape of distribution. Finally, the linearity, homoscedasticity, and multicollinearity were examined using the SPSS software.

Possible Discrepancies in Data Collection

Since I used secondary data, there were no discrepancies in data collection from the plan presented in Chapter 3.

Sample's Descriptive and Demographic Characteristics

As described in Chapter 3, the sample for this study was obtained from archival data collected from January 2008 to January 2016 by PSSEC. The reported baseline of the sample was all preschool children ages 2 to 5 years who were referred by the Child Find Project in NC to PSSEC for psychological evaluations. The archival sample totaled 48 participants, which consisted of males (72.9%) and females (21.1%) with an average age of 43 months. Of the sample, ($N = 48$), 18 (37.5%) were White, 17 (35.4%) were Black, 11 (22.9%) were Latino, and two (4.2%) were Other. Based on total sample size of 48 participants, 18 (37.5%) were from the White group, and 30 (62.5%) were from the Non-White group. The sample's eligibility for services included No Placement Services, five (10.4%), Autism Services, 29 (60.4%), Developmental Disability Services, 12 (25.0%) and Other Services, two (4.2%).

As mentioned in Chapter 3, the data collection for the main dataset involved PSSEC's licensed school psychologist grouping the participants into three areas for testing. The first area included the participants from Head Start/School (27.1%) and daycare centers (10.4%) who were excused from their scheduled day to be evaluated. The second area involved the home participants (62.5%) who came to the school to be evaluated by PSSEC's licensed school psychologist. The third, involved individuals who were homebound due to severe disabilities that required a team present to conduct evaluation at the child's place of residence. None of the participants in the main dataset met the criteria that required evaluating at their residence. Table 1 represents the reported

baseline descriptive and demographic characteristics of this study's sample. Placement prior to testing is also visually represented in Figure 1.

Table 1

Demographics for Overall Sample (N = 48)

Variable	<i>n</i>	%
Sex		
Male	35	72.9
Female	13	21.1
Age in months		
Mean	42.98	62.5
Race		
White	18	37.5
Black	17	35.4
Latino	11	22.9
Other	2	4.2
Groups		
White	18	37.5
Non-White	30	62.5
Eligibility for services		
No placement	5	10.4
Autism	29	60.4
Developmental disability	12	25.0
Other	2	4.2
Placement prior to testing		
Home	5	10.4
Daycare	13	27.1
School		

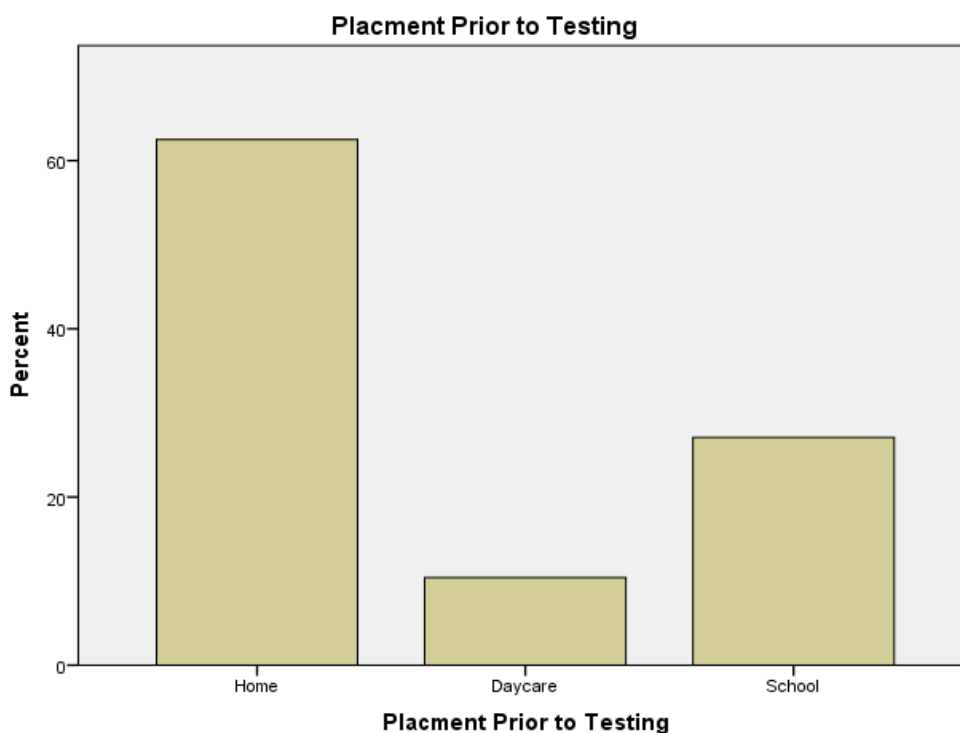


Figure 1. Sample's placement prior to testing by PSSEC.

Sample's Generalizability

The representative sample was drawn without bias from the population of interest for all participants who were initially referred to the Duplin County, NC preschool via the Child Find Project and Head Start program. Referrals were equally accepted from all physicians, teachers, parents, and other professionals, as well as from anonymous sources. All participants then completed the DCDEE process and parent(s) or legal guardian(s) were contacted to obtain permission to conduct evaluations and ASD testing before participants were referred to PSSEC. Therefore, the sample is a fairly unbiased indication of the population it represents.

Further, I used a stratified random sampling whereby the population was separated by strata and then samples randomly chosen from each stratum. The stratified sampling strategy helped to achieve my broad goal of increasing reliability and validity, whereby broad inferences can be made to the population.

Results

Descriptive Statistics of Sample

Data were collected on race (White, Black, Latino, Other). Of the total sample ($N = 48$), 18 (37.5%) were White, 17 (35.4%) were Black, 11 (22.9%) were Latino, and two (4.1%) were Other as illustrated in Table 2.

Table 2

<i>Race Between-Subjects Factors</i>		
Race	<i>n</i>	%
White	18	37.5
Black	17	35.4
Latino	11	22.9
Other	2	4.1

Of the total sample ($N = 48$), 18 (37.5%) were from the White group, and 30 (62.5%) were from the Non-White group as illustrated in Table 3.

Table 3

<i>Group Between-Subjects Factors</i>		
Group	<i>n</i>	%
White	18	37.5
Non-White	30	62.5

In addition, data from diagnostic measures were collected from the PEP-3 Composite Score-Communication, PEP-3 Composite Score-Motor, PEP-3 Composite Score-Maladaptive, and CARS-2-Overall Severity Group. Data from the perception measures were collected from the ABAS-II Parent-General Adaptive Composite, ABAS-II Parent-General Conceptual Composite, ABAS-II Parent-General Social Composite, ABAS-II Parent-General Practical Composite, ABAS-II Teacher-General Adaptive Composite, ABAS-II Teacher-General Conceptual Composite, ABAS-II Teacher-General Social Composite, ABAS-II Teacher-General Practical Composite, CBCL-Total Problems, and C-TRF-Total Problems scores. Table 4 illustrates the means and standard deviations for each diagnostic and reported perception measure of ASD

The PEP-3 Composite Score-in Communication for those in the White group was $M = 64.78$, $SD = 27.23$, and those in the Non-White group was $M = 45.40$, $SD = 23.61$. The PEP-3 Composite Score-Motor for those in the White group was $M = 59.33$, $SD = 26.93$, and those in the Non-White group was $M = 51.33$, $SD = 29.36$. The PEP-3 Composite Score-Maladaptive for those in the White group was $M = 57.38$, $SD = 32.54$, and those in the Non-White group $M = 35.90$, $SD = 33.36$. The CARS-2-Overall Severity Group score for those in the White group was $M = 28.80$, $SD = 8.89$, and those in the Non-White group was $M = 33.33$, $SD = 9.35$.

The ABAS-II Parent-General Adaptive Composite score for those in the White group was $M = 6.30$, $SD = 14.00$, and those in the Non-White group was $M = 3.76$, $SD = 9.63$. However, the ABAS-II Teacher-General Adaptive Composite score for those in the

White group was $M = 2.11$, $SD = 3.74$, and those in the Non-White group was $M = 3.74$, $SD = 6.31$.

The ABAS-II Parent-General Conceptual Composite score for those in the White group was $M = 9.83$, $SD = 15.57$, and those in the Non-White group was $M = 2.78$, $SD = 5.01$. However, the ABAS-II Teacher-General Conceptual Composite score for those in the White group was $M = 3.23$, $SD = 7.24$, and those in the Non-White group was $M = 3.74$, $SD = 5.62$.

The ABAS-II Parent-General Social Composite score for those in the White group was $M = 8.85$, $SD = 16.46$, and those in the Non-White group was $M = 6.11$, $SD = 11.44$. However, the ABAS-II Teacher-General Social Composite score for those in the White group was $M = 2.08$, $SD = 3.31$, and those in the Non-White group was $M = 3.48$, $SD = 6.84$.

The ABAS-II Parent-General Practical Composite score for those in the White group was $M = 5.13$, $SD = 12.75$, and those in the Non-White group was $M = 3.53$, $SD = 8.82$. However, the ABAS-II Teacher-General Practical Composite score for those in the White group was $M = 3.96$, $SD = 12.73$, and those in the Non-White group was $M = 6.17$, $SD = 14.74$.

The CBCL-Total Problems score for those in the White group was $M = 67.44$, $SD = 38.05$ and those in the Non-White group was $M = 62.40$, $SD = 38.40$. However, the C-TRF-Total Problems score for those in the White group was $M = 21.78$, $SD = 40.03$ and those in the Non-White group was $M = 35.33$, $SD = 43.41$. See Table 4 for further illustration.

Table 4

Descriptive Statistics for Diagnosis and Reported Perception of ASD

Measures	Group	Mean	Std. Deviation	<i>n</i>
PEP-3-Communication	White	64.78	27.234	18
	Non-White	45.40	23.617	30
	Total	52.67	26.501	48
PEP-3-Motor	White	59.333	26.9313	18
	Non-White	51.330	29.3663	30
	Total	54.331	28.4566	48
PEP-3-Maladaptive	White	57.83	32.547	18
	Non-White	35.90	33.363	30
	Total	44.13	34.425	48
CARS-2	White	28.806	8.8901	18
	Non-White	33.337	9.3575	30
	Total	31.638	9.3557	48
ABAS-II Parent-Adaptive	White	6.3044	14.00571	18
	Non-White	3.7686	9.63356	30
	Total	4.7196	11.39095	48
ABAS-II Parent-Conceptual	White	9.8383	15.75989	18
	Non-White	2.7833	5.01345	30
	Total	5.4289	10.82866	48
ABAS-II Parent-Social	White	8.8539	16.46335	18
	Non-White	6.1126	11.44899	30
	Total	7.1406	13.44299	48
ABAS-II Parent-Practical	White	5.1322	12.75369	18
	Non-White	3.5360	8.82690	30
	Total	4.1346	10.36908	48
ABAS-II Teacher-Adaptive	White	2.1166	4.72171	18
	Non-White	3.7429	6.31298	30
	Total	3.1331	5.76955	48
ABAS-II Teacher-Conceptual	White	3.233	7.2490	18
	Non-White	3.740	5.6276	30
	Total	3.550	6.2136	48
ABAS-II Teacher-Social	White	2.083	3.3108	18
	Non-White	3.480	6.8451	30
	Total	2.956	5.7743	48
ABAS-II Teacher-Practical	White	3.9610	12.73871	18
	Non-White	6.1763	14.74453	30
	Total	5.3456	13.92878	48

Table continues

Measures	Group	Mean	Std. Deviation	<i>n</i>
CBCL-Total Problems	White	67.44	38.055	18
	Non-White	62.40	39.138	30
	Total	64.29	38.406	48
C-TRF-Total Problems	White	21.78	40.036	18
	Non-White	35.33	43.416	30
	Total	30.25	42.270	48

Statistical Assumptions

Statistical analyses were performed to ensure the data met the assumptions of the MANOVA analysis. Nine assumptions of the MANOVA were evaluated as follows:

- Assumption 1, the data consisted of two dependent variables (perceptions of ASD and diagnosis of ASD) measured at the interval level (continuous data).
- Assumption 2, the data consisted of one independent variable (race) with two categorical independent groups (White groups and Non-White groups).
- Assumption 3, the data were randomly sampled from the population of interest.
- Assumption 4, the data met the independence of observations. There was no relationship between the groups of the observations in each group. For instance, no participant was placed in more than one group, so there were different participants in each group.
- Assumption 5, found that there were 18 participants in the White group, and 30 participants in the Non-White group, which were more than the number of dependent variables. Hence, there was an adequate sample size for analysis.

- Assumption 6 used an SPSS boxplot to identify outliers which can potentially move the mean from the median and thereby impact the findings of this study. There were no univariate or multivariate outliers.
- Assumption 7, the assumption of multivariate normality was tested $\alpha = .05$ level of significance using the Shapiro-Wilks test. Given that $p = .020$ for the diagnosis of ASD dependent variable (total of $p = .002$ for PEP-3 Composite Score-Communication, $p = .010$ for PEP-3 Composite Score-Motor, $p = < .001$ for PEP-3 Composite Score-Maladaptive, and $p = .070$ CARS-2-Overall Severity Group) the assumption of normality was been met and this level of dependent variable was normally distributed. However, for the perception of ASD dependent variable, the total of $p = < .001$, indicating that this level of dependent variable was not normally distributed. Nevertheless, the violation of this assumption was deemed inconsequential since the MANOVA is considered quite robust against violations of multivariate normality (Green & Salkind, 2014; Lindman, 1974). The means and standard deviations for each diagnostic and perception measure are illustrated in Table 5.

Table 5

Tests of Normality Diagnostic and Perception Measures of ASD

Measurements of ASD	Kolmogorov-Smirnov			Shapiro-Wilk		
	Stat.	df	p	Stat.	df	p
PEP-3-Communication	.130	48	.040	.915	48	.002
PEP-3-Motor	.134	48	.031	.934	48	.010
PEP-3-Maladaptive	.155	48	.005	.863	48	.000
CARS-2-Overall Severity Group	.096	48	.200 ^a	.956	48	.070
ABAS-II Parent-Adaptive	.365	48	.000	.442	48	.000
ABAS-II Parent-Conceptual	.344	48	.000	.530	48	.000
ABAS-II Parent-Social	.322	48	.000	.570	48	.000
ABAS-II Parent-General Practical	.348	48	.000	.401	48	.000
ABAS-II Teacher-General Adaptive	.478	48	.000	.460	48	.000
ABAS-II Teacher-General Conceptual	.472	48	.000	.504	48	.000
ABAS-II Teacher-General Social	.466	48	.000	.423	48	.000
ABAS-II Teacher-General Practical	.477	48	.000	.366	48	.000
CBCL-Total Problems	.245	48	.000	.771	48	.000
C-TRF-Total Problems	.422	48	.000	.631	48	.000

Note. ^aThis is a lower bound of the true significance. ^aLilliefors Significance Correction.

- Assumption 8, the homogeneity of equality of covariance matrices was checked by conducting the SPSS's Box's test of equality of covariance matrices using $p < .001$ as a criterion. The level of significance (p -value) for the test was below .001. *Box's M* (482.28) was significant, ($p = < .001$) indicating there were significant differences between the covariance matrices, so this assumption was not met. Therefore, Wilk's Lambda was not an appropriate test to use in this study. Instead, the Pillai's Trace test was used to interpret the multivariate F for it is considered a statistical test that is extremely robust and powerful of the four statistics (Green & Salkind, 2014). Also, the Pillai's trace test is not highly

connected to assumptions about the data's normality of the distribution. See exact statistic represented in Table 6.

Table 6

Box's Test of Equality of Covariance Matrices^a

Box's M	482.276
<i>F</i>	2.893
df1	105
df2	4078.218
Sig.	.000

Note. ^aDesign: Intercept + Group. Tests the null hypothesis that the observed covariance matrices of the dependent variables are equal across groups.

- Assumption 9, the homogeneity of variance was evaluated, and the equality of variances for each dependent variable was met. The Levene's test of equality of error variances test indicated that the both dependent variables were non-significant (Diagnosis of ASD, $p = .29$ and Perception of ASD, $p = .66$) and in both case $p > .05$. See Table 7 for individual illustration of each dependent variable.

Table 7

Levene's Test of Equality of Error Variances^a for Diagnosis and Reported Perception of ASD

Variable	<i>F</i>	<i>df1</i>	<i>df2</i>	<i>p</i>
PEP-3-Communication	1.026	1	46	.316
PEP-3-Motor	.434	1	46	.514
PEP-3-Maladaptive	.020	1	46	.887
CARS-2-Overall Severity Group	.005	1	46	.947
ABAS-II Parent-General Adaptive	1.089	1	46	.302
ABAS-II Parent-General Conceptual	17.881	1	46	.000
ABAS-II Parent-General Social	1.536	1	46	.222
ABAS-II Parent-General Practical	.535	1	46	.468
ABAS-II Teacher-General Adaptive	3.532	1	46	.067
ABAS-II Teacher-General Conceptual	.023	1	46	.881
ABAS-II Teacher-General Social	2.322	1	46	.134
ABAS-II Teacher-General Practical	.677	1	46	.415
CBCL-Total Problems	.681	1	46	.414
C-TRF-Total Problems	3.348	1	46	.074

Note. ^aDesign: Intercept + Group Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

Statistical Analysis

The purpose of this study was to investigate the relationship between child's race and reported perception of ASD, and clinical diagnosis of ASD among White and Non-White groups. Race was the independent variable, and the reported perception of ASD and clinician's diagnosis of ASD were the dependent variables. I asked, will the reported perceptions of ASD as measured by ABAS-II, CBCL, and C-TRF in White and Non-White groups differ from clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based on child's race?

Hypothesis. The null hypothesis stated, there will be no differences between reported perceptions of ASD measured by ABAS-II, CBCL, and C-TRF in White and Non-White groups compared to clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based child's race. Conducting a MANOVA using the Pillai's trace test, the study applied the criterion of alpha level of .05 to examine the p -value linked with the F statistic and the hypothesis. The null hypothesis that the specified predictor (race) has no effect on either of reported perception of ASD and diagnosis of ASD was evaluated with regard to this p -value. Therefore, for the specified alpha level of .05, if the p -value was less than alpha, then the null hypothesis would be rejected. The statistical analysis using Pillai's trace indicated there was a significant effect of race on reported perception of ASD and diagnosis of ASD, $V = 0.59$, $F(14, 33) = 3.36$, $p = .002$. Therefore, since the p -value was less than alpha, the main hypothesis was accepted that stated there will be differences between reported perceptions of ASD as measured by ABAS-II, CBCL, and C-TRF in White and Non-White groups compared to clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based on child's race. Table 8 illustrates the Pillai's trace examination of the p -value linked with the F statistic and the hypothesis that resulted in the study's findings.

Table 8

Multivariate Tests^a

Effect	Value	<i>F</i>	Ho. df	Error df	<i>p</i>	Partial Eta Squared	
Intercept	Pillai's Trace	.994	410.360 ^b	14.000	33.000	.000	.994
Group	Pillai's Trace	.588	3.361 ^b	14.000	33.000	.002	.588

Note. ^aDesign: Intercept + Group. ^bExact statistic. ^cComputed using alpha = .05

Specifically, the reported perceptions of ASD measured by the *ABAS-II* Parent-General Adaptive Composite score for those in the White group ($M = 6.30$, $SD = 14.00$) was higher than the *ABAS-II* Parent-General Adaptive Composite score for those in the Non-White group ($M = 3.76$, $SD = 9.63$). This difference indicated that parents in the White group reported more ASD adaptive symptoms in their children compared to parents in the Non-White group. However, the *ABAS-II* Teacher-General Adaptive Composite score for those in the White group ($M = 2.11$, $SD = 3.74$) was slightly lower than the *ABAS-II* Teacher-General Adaptive Composite score for those in the Non-White group ($M = 3.74$, $SD = 6.31$). This difference indicated that teachers reported slightly more adaptive ASD symptoms for children in the Non-White group compared to the children in the White group.

Likewise, the *ABAS-II* Parent-General Conceptual Composite score for those in the White group ($M = 9.83$, $SD = 15.57$) was higher than the *ABAS-II* Parent-General Conceptual Composite score for those in the Non-White group ($M = 2.78$, $SD = 5.01$). This difference indicated that parents in the White group reported more ASD conceptual

symptoms in their children compared to parents in the Non-White group. However, the ABAS-II Teacher-General Conceptual Composite score for those in the White group ($M = 3.23$, $SD = 7.24$) was slightly lower than the ABAS-II Teacher-General Conceptual Composite score for those in the Non-White group ($M = 3.74$, $SD = 5.62$). This difference indicated that teachers reported slightly more conceptual ASD symptoms for children in the Non-White group compared to the children in the White group.

Also, the ABAS-II Parent-General Social Composite score for those in the White group ($M = 8.85$, $SD = 16.46$) was higher than the ABAS-II Parent-General Social Composite score for those in the Non-White group ($M = 6.11$, $SD = 11.44$). This difference indicated that parents in the White group reported more ASD social symptoms in their children compared to parents in the Non-White group. However, the ABAS-II Teacher-General Social Composite score for those in the White group ($M = 2.08$, $SD = 3.31$) was lower than the ABAS-II Teacher-General Social Composite score for those in the Non-White group ($M = 3.48$, $SD = 6.84$). This difference indicated that teachers reported more social ASD symptoms for children in the Non-White group compared to the children in the White group.

Continuing the pattern, the ABAS-II Parent-General Practical Composite score for those in the White group ($M = 5.13$, $SD = 12.75$) was higher than the ABAS-II Parent-General Practical Composite score for those in the Non-White group ($M = 3.53$, $SD = 8.82$). This difference indicated that parents in the White group reported more ASD practical symptoms in their children compared to parents in the Non-White group. However, the ABAS-II Teacher-General Practical Composite score for those in the White

group ($M = 3.96$, $SD = 12.73$) was lower than the ABAS-II Teacher-General Practical Composite score for those in the Non-White group ($M = 6.17$, $SD = 14.74$). This difference indicated that teachers reported more practical ASD symptoms for children in the Non-White group compared to the children in the White group.

Additionally, The CBCL-Total Problems score for those in the White group ($M = 67.44$, $SD = 38.05$) was higher than those in the Non-White group ($M = 62.40$, $SD = 38.40$). This difference indicated that parents in the White group reported more behavioral ASD symptoms in their children compared to parents in the Non-White group. However, the C-TRF-Total Problems score for those in the White group was ($M = 21.78$, $SD = 40.03$) was higher than those in the Non-White group ($M = 35.33$, $SD = 43.41$). This difference indicated that teachers reported more behavioral ASD symptoms for children in the Non-White group compared to the children in the White group.

In looking at the diagnosis of ASD measured by the PEP-3, the Composite Score-in Communication for those in the White group ($M = 64.78$, $SD = 27.23$) was higher than the score in the Non-White group ($M = 45.40$, $SD = 23.61$). This difference between groups indicated that in the domain of communication skills, more children in the White group met criteria for ASD compared to children in the Non-White group.

The PEP-3 Composite Score-Motor for those in the White group ($M = 59.33$, $SD = 26.93$) slightly higher than those in the Non-White group was ($M = 51.33$, $SD = 29.36$). This difference between groups indicated that in the domain of motor skills, slightly more children in the White group met criteria for ASD compared to children in the Non-White group.

The PEP-3 Composite Score-Maladaptive for those in the White group ($M = 57.38$, $SD = 32.54$) was higher than those in the Non-White group ($M = 35.90$, $SD = 33.36$). This difference between groups indicated that in the domain of maladaptive behaviors, more children in the White group met criteria for ASD compared to children in the Non-White group.

On the other hand, the CARS-2-Overall Severity Group score for those in the White group ($M = 28.80$, $SD = 8.89$) was lower than those in the Non-White group was ($M = 33.33$, $SD = 9.35$). This difference between groups indicated that more children in the Non-White group met symptoms severity criteria for ASD compared to children in the White group. See univariate statistics for diagnosis and reported perception of ASD represented in Table 9.

Table 9

Univariate Statistics for Diagnosis and Reported Perception of ASD

Measures	Group	Mean	Std. Deviation	<i>n</i>
PEP-3-Communication	White	64.78	27.234	18
	Non-White	45.40	23.617	30
	Total	52.67	26.501	48
PEP-3-Motor	White	59.333	26.9313	18
	Non-White	51.330	29.3663	30
	Total	54.331	28.4566	48
PEP-3-Maladaptive	White	57.83	32.547	18
	Non-White	35.90	33.363	30
	Total	44.13	34.425	48
CARS-2	White	28.806	8.8901	18
	Non-White	33.337	9.3575	30
	Total	31.638	9.3557	48
ABAS-II Parent-Adaptive	White	6.3044	14.00571	18
	Non-White	3.7686	9.63356	30
	Total	4.7196	11.39095	48

Table continues

Measures	Group	Mean	Std. Deviation	<i>n</i>
ABAS-II Parent-Conceptual	White	9.8383	15.75989	18
	Non-White	2.7833	5.01345	30
	Total	5.4289	10.82866	48
ABAS-II Parent-Social	White	8.8539	16.46335	18
	Non-White	6.1126	11.44899	30
	Total	7.1406	13.44299	48
ABAS-II Parent-Practical	White	5.1322	12.75369	18
	Non-White	3.5360	8.82690	30
	Total	4.1346	10.36908	48
ABAS-II Teacher-Adaptive	White	2.1166	4.72171	18
	Non-White	3.7429	6.31298	30
	Total	3.1331	5.76955	48
ABAS-II Teacher-Conceptual	White	3.233	7.2490	18
	Non-White	3.740	5.6276	30
	Total	3.550	6.2136	48
ABAS-II Teacher-Social	White	2.083	3.3108	18
	Non-White	3.480	6.8451	30
	Total	2.956	5.7743	48
ABAS-II Teacher-Practical	White	3.9610	12.73871	18
	Non-White	6.1763	14.74453	30
	Total	5.3456	13.92878	48
CBCL-Total Problems	White	67.44	38.055	18
	Non-White	62.40	39.138	30
	Total	64.29	38.406	48
C-TRF-Total Problems	White	21.78	40.036	18
	Non-White	35.33	43.416	30
	Total	30.25	42.270	48

Research Question. In terms of answering the research question, the study's findings indicated that the reported perceptions of ASD measured by ABAS-II, CBCL, and C-TRF in White and Non-White groups did indicate significant differences from clinician's diagnosis of ASD measured by the PEP-3 and CARS-2 in White and Non-White groups based on the child's race. The main revealed difference was the overall higher clinically diagnosed of ASD (measured by the PEP-3 and CARS-2) among the

White group ($M = 52.88$) as compared to the Non-White group ($M = 41.49$). This was in contrast to the teachers' higher reported perception of ASD (measured by the ABAS-II, and the C-TRF) among children from the Non-White group compared to children from the White group.

More precisely, in examining the diagnostic measures independently, the findings answered the research question by specifically revealing that based on the PEP-3, more children in the White group were clinically diagnosed with ASD compared to children in the Non-White group. This was in contrast to the higher teachers' reported perception of ASD symptoms among Non-White groups measured by the ABAS-II, and the C-TRF. However, based on the CARS-2 measure, more children in the Non-White group were clinically diagnosed with ASD compared to children in the White group. This was in contrast to the higher parental reported perception of ASD symptoms among the White group measured by the ABAS-II, and the CBCL.

Hence, the study's findings revealed that the parents' reported perceptions of ASD measured by the ABAS-II, and the CBCL indicated that parents within the White group reported more ASD symptoms in their children over parents in the Non-White group. Conversely, teachers' reported perceptions of ASD measured by the ABAS-II, and the C-TRF indicated that teachers reported more ASD symptoms for children in the Non-White group over children in the White group.

Summary

This study's statistical analyses were reported with minimal caution secondary the violation to some of the MANOVA's assumptions. For instance, the reported perception

of ASD dependent variable, the total of $p = < .001$ indicated that this level of dependent variable was not normally distributed. Nevertheless, the violation of this assumption was deemed inconsequential since the MANOVA is considered quite robust against violations of multivariate normality (Green & Salkind, 2014; Lindman, 1974). Also, the level of significance (p -value) for the test was below .001. *Box's M* (482.28) was significant, ($p = < .001$) indicating there were significant differences between the covariance matrices, so this assumption was not met. However, the study fittingly used the Pillai's trace test to interpret the multivariate F for it is considered a statistical test that is more robust and powerful of the four statistics (Green & Salkind, 2014). Also, the Pillai's trace test is not highly connected to assumptions about the data's normality of the distribution.

In relation to the study's hypothesis, the analysis of the data demonstrated that there were differences between the reported perceptions of ASD as measured by ABAS-II, CBCL, and C-TRF in White and Non-White groups compared to clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based on child's race. The Pillai's trace indicated a significant effect of race on reported perception of ASD and diagnosis of ASD, $V = 0.59$, $F(14, 33) = 3.36$, $p = .002$ which validated the acceptance of the main hypothesis. Hence, the research question of whether the reported perceptions of ASD measured by ABAS-II, CBCL, and C-TRF in White and Non-White groups revealed a significant difference from clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based on the child's race was answered. Overall, there was a higher clinically diagnosed of ASD among the White group as compared to the Non-White group which differed from the teachers' higher

reported perception of ASD among the Non-White group compared the White group. Specifically, an individual examination of the diagnostic measures revealed that the PEP-3 indicated more clinical ASD diagnoses among the White group compared to the Non-White group which differed from the higher teachers' reported perception of ASD symptoms among the Non-White group. However, the CARS-2 measure indicated more clinical ASD diagnoses among the Non-White group compared to the White group which differed from the higher parental reported perception of ASD symptoms among the White group.

Hence, the study's findings revealed that parents within the White group reported more ASD symptoms in their children over parents in the Non-White group. On the other hand, teachers reported more ASD symptoms for children in the Non-White group over children in the White group. This emerging pattern of difference in relation to the reported perception of ASD between parents and teachers of children from White and Non-White groups confirmed and highlighted the nuances of ASD symptoms and perception among different groups identified in literature (Becerra et al., 2014; Blacher, et al., 2014; Valicenti-McDermott et al., 2012). This current study's additional findings will be further addressed in Chapter 5. Also, in Chapter 5, the study's overall findings will be compared to the literature, conclusions, and implications will be drawn, and a series of recommendations will be suggested.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

Based on the identified gap in empirical literature established in Chapter 2 regarding ASD among different racial groups, this study was conducted to investigate the relationship between children's race and reported perception of ASD and the clinical diagnosis of ASD among White and Non-White groups. Therefore, I examined if the reported perceptions of ASD measured by ABAS-II, CBCL, and C-TRF in White and Non-White groups differ from the clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based on child's race. Subsequently, by comparing parents and/or teachers' perceptions of ASD to the clinician's diagnosis among different races groups, I sought to contribute valuable data to help fill the gap in the existing literature regarding ASD among White and Non-White groups.

Nature of the Study

This study consisted of two dependent variables, namely, reported perception of ASD (measured by ABAS-II, CBCL, and C-TRF) and clinician's diagnosis of ASD (measured by PEP-3 and CARS-2) in White and Non-White groups. The independent variable was race of the child: White, African American, Latino, or Other classified into White and Non-White groups.

The population sample was obtained from archival data collected (2008-2016) by the PSSEC based on preschool children ages 2 to 5 years who were referred by the Child Find Project in NC to PSSEC for psychological evaluations. The data were analyzed using the MANOVA statistical test that consisted of two dependent variables

(perceptions of ASD and diagnosis of ASD) with continuous data and one independent variable (race) with categorical data. Hence, the MANOVA statistical analysis aptly examined if differences existed or not between reported perceptions of ASD in White and Non-White groups compared to the clinician's diagnosis of ASD in White and Non-White groups based on child's race. Additionally, MANOVA considered the intercorrelations among dependent variables, which were pertinent to testing this study's hypothesis.

Key Findings

The statistical analysis using Pillai's trace indicated that there was a significant effect of race on reported perception of ASD and diagnosis of ASD. This finding validated the acceptance of the main hypothesis by confirming differences between the reported perceptions of ASD as measured by ABAS-II, CBCL, and C-TRF in White and Non-White groups compared to the clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based on child's race. The key identified difference was the overall higher clinically diagnosis of ASD (measured by the PEP-3 and CARS-2) among the White group ($M = 52.88$) as compared to the Non-White group ($M = 41.49$). This was in contrast to the teachers' higher reported perception of ASD (measured by the ABAS-II and the C-TRF) among children from the Non-White group compared to children from the White group.

In examining the diagnostic measures independently based on the PEP-3, more children in the White group were clinically diagnosed with ASD compared to children in the Non-White group. This was in contrast to the higher teachers' reported perception of

ASD symptoms among Non-White groups measured by the ABAS-II and the C-TRF. However, based on the CARS-2, more children in the Non-White group were clinically diagnosed with ASD compared to children in the White group. This was in contrast to the higher parental reported perception of ASD symptoms among the White group measured by the ABAS-II and the CBCL. Hence, the ABAS-II and CBCL measures indicated that parents within the White group reported more ASD symptoms in their children over parents in the Non-White group. Conversely, the ABAS-II and C-TRF indicated that teachers reported more ASD symptoms for children in the Non-White group over children in the White group.

The ABAS-II Parent-General Adaptive Composite score for those in the White group ($M = 6.30$, $SD = 14.00$) was higher than the ABAS-II Parent-General Adaptive Composite score for those in the Non-White group ($M = 3.76$, $SD = 9.63$). The ABAS-II Parent-General Conceptual Composite score for those in the White group ($M = 9.83$, $SD = 15.57$) was higher than the ABAS-II Parent-General Conceptual Composite score for those in the Non-White group ($M = 2.78$, $SD = 5.01$). The ABAS-II Parent-General Social Composite score for those in the White group ($M = 8.85$, $SD = 16.46$) was higher than the ABAS-II Parent-General Social Composite score for those in the Non-White group ($M = 6.11$, $SD = 11.44$). The ABAS-II Parent-General Practical Composite score for those in the White group ($M = 5.13$, $SD = 12.75$) was higher than the ABAS-II Parent-General Practical Composite score for those in the Non-White group ($M = 3.53$, $SD = 8.82$). Finally, the CBCL-Total Problems score for those in the White group ($M =$

67.44, $SD = 38.05$) was higher than those in the Non-White group ($M = 62.40$, $SD = 38.40$).

In contrast, the ABAS-II Teacher-General Adaptive Composite score for those in the White group ($M = 2.11$, $SD = 3.74$) was slightly lower than the ABAS-II Teacher-General Adaptive Composite score for those in the Non-White group ($M = 3.74$, $SD = 6.31$). The ABAS-II Teacher-General Conceptual Composite score for those in the White group ($M = 3.23$, $SD = 7.24$) was slightly lower than the ABAS-II Teacher-General Conceptual Composite score for those in the Non-White group ($M = 3.74$, $SD = 5.62$). The ABAS-II Teacher-General Social Composite score for those in the White group ($M = 2.08$, $SD = 3.31$) was lower than the ABAS-II Teacher-General Social Composite score for those in the Non-White group ($M = 3.48$, $SD = 6.84$). The ABAS-II Teacher-General Practical Composite score for those in the White group ($M = 3.96$, $SD = 12.73$) was lower than the ABAS-II Teacher-General Practical Composite score for those in the Non-White group ($M = 6.17$, $SD = 14.74$). Finally, the C-TRF-Total Problems score for those in the White group was ($M = 21.78$, $SD = 40.03$) was lower than those in the Non-White group ($M = 35.33$, $SD = 43.41$).

Interpretation of the Findings

Pillai's trace indicated a significant effect of race on the reported perception of ASD and diagnosis of ASD, which validated the acceptance of the study's hypothesis. This means that the research question of whether the reported perceptions of ASD measured by ABAS-II, CBCL, and C-TRF in White and Non-White groups indicated a

significant difference from the clinician's diagnosis of ASD measured by PEP-3 and CARS-2 in White and Non-White groups based on the child's race was answered.

The findings specifically indicated an overall higher clinical rate of diagnosis of ASD (measured by the PEP-3 and CARS-2) among the White group ($M = 52.88$) as compared to the Non-White group ($M = 41.49$). This differed from the teachers' higher reported perception of ASD (measured by the ABAS-II and the C-TRF) among children from the Non-White group compared to children from the White group. Therefore, diagnostically more behaviors, skills, and communication deficits were identified in children from the White group. However, teachers reported children in the Non-White group as having more deficits in emotional and behavioral functioning, independent functioning, and social interactions within their community and cultural environment. This finding extended knowledge in the discipline based on what has been found in the peer-reviewed literature as presented in Chapter 2. For instance, several researchers in the field of ASD have highlighted the need for further investigations among diverse racial populations (Becerra et al., 2014; Blacher et al., 2014; Tek & Landa, 2012; Valicenti-McDermott et al., 2012). The reason for this need was based on researchers' summation that little was known about the nuances of ASD symptoms and perception among different groups along with the impact this may have on early detection rates (Becerra et al., 2014; Blacher et al., 2014; Valicenti-McDermott et al., 2012). Additionally, several studies have supported the view that the clinical phenotype of ASD does not vary by race. However, this study's findings disconfirmed that view and added to the empirical

evidence to support that the occurrence varied across racial groups (Grinker et al., 2011; Mandell et al., 2009; Valicenti-McDermott et al., 2012; Yeargin-Allsopp et al., 2003).

In addition, a further comparison of this study's findings, with similar studies, as discussed in Chapter 2, revealed a confirmation of previous empirical literature. For example, this study's findings revealed that parents within the White group reported more ASD symptoms in their children than parents in the Non-White group, and there was a higher clinical rate of diagnosis of ASD among the White group ($M = 52.88$) as compared to the Non-White group ($M = 41.49$). However, teachers reported more ASD symptoms for children in the Non-White group than children in the White group. This finding aligned with previous studies that reported minority children, namely those of Asian, Hispanic, and African American descent, were less likely to receive early ASD diagnosis compared to Caucasian children (Blacher et al., 2014; Mandell et al., 2002; Tek & Landa, 2012). Nevertheless, this study's finding corroborated previous studies' (Burkett et al., 2015; Palmer et al., 2010; Tek & Landa, 2012) indication that the reasons for the delay in the diagnosis of ASD among minority children remain inconclusive.

Furthermore, results revealed a higher reported perception of ASD among parents from the White group over the Non-White group, along with lower reported perception of ASD among teachers related to the White group over the Non-White group. This pattern of difference in relation to the reported perception of ASD between parents and teachers of children from White and Non-White groups confirmed and highlighted gradations of ASD symptoms and perceptions among different groups identified in previous empirical literature (Becerra et al., 2014; Blacher, et al., 2014; Valicenti-McDermott et al., 2012).

Hence, Blacher et al.'s (2014) study called for further research to unveil a deeper understanding of ASD in Latino children, whereby "actual symptoms of ASD may be in the eye of the beholder" (p. 1655).

Additionally, Tek and Landa (2012) proposed that minority parents may ignore early symptoms of ASD, whereby delayed milestones or unusual behaviors were perceived within their racial or cultural context as normal or inconsequential (Tek & Landa, 2012). Subsequently, parent and caregiver interpretations of ASD symptoms were based on racial or cultural beliefs and values as seen in a study by Zhang et al. (2006). Likewise, this study corroborated that variation of interpretation of ASD symptoms exists among White and Non-White groups. Specifically, ABAS-II Parent-General Adaptive Composite scores indicated that parents from the White group perceived higher deficits in their children compared to parents from the Non-White group. However, the ABAS-II Teacher-General Adaptive Composite score indicated that teachers perceived slightly lower deficits for children in the White group and higher deficits for children in the Non-White group. Again, based on the ABAS-II Parent-General Conceptual Composite score, parents in the White group reported more communication, functional preacademics, and self-direction deficits in their children compared to parents' reports from the Non-White group. However, based on the ABAS-II Teacher-General Conceptual Composite score, teachers reported less communication, functional preacademics, and self-direction deficits in the children from the White group compared to the Non-White group. This pattern of differences between parents' perception of ASD symptoms among White groups (higher reports of ASD symptoms)

and Non-White groups (lower reports of ASD symptoms) were consistent across the ABAS-II Parent-General Social Composite score, and the ABAS-II Parent-General Practical Composite score. Additionally, a similar difference was evident in CBCL-Total Problems score, whereby the parents from the White group perceived higher behavior problems in their children compared to those in the Non-White group. However, the C-TRF-Total Problems score from teachers indicated quite the opposite. Teachers perceived more behavioral problems in children from the Non-White group compared to the White group.

Therefore, the aforementioned pattern of differences between parents' perception of ASD symptoms among White and Non-White groups echoed the empirical literature, which reported higher rates of delayed and missed diagnoses of ASD among underserved ethnic and racial minorities (Jarquin et al., 2011; Thomas et al., 2012). For instance, studies have found that behaviors such as replicating parental behaviors, making direct eye contact, and pointing to show shared interest were deemed disrespectful in the Asian culture (Jarquin et al., 2011). Likewise, among the Hispanic/Latino culture, researchers have found that parents reported characteristically different understandings of developmental milestones and the timing of when skillsets should be accomplished (Blacher et al., 2014; Gannotti et al., 2001). Specifically, Garcia et al. (2000) conducted a qualitative study to examine Mexican American mothers' beliefs about disabilities. They found that mothers expected their child's milestone for language acquisition or the understanding of language to not be until 3 years old. Hence, culturally, Mexican

mothers in Garcia et al.'s study failed to recognize that their children had a communication disorder.

Theoretical Framework Analysis and Interpretation

This study's findings are interpreted within the context of the organic theory of autism, which is essentially the conceptual framework of the TEACCH model, along with the CRT built on philosophies of social justice and race equity (Mesibov, 1996). The beliefs of TEACCH, which focused on individualization and its established efficacy with individuals from various economic and cultural upbringings (Callahan et al., 2010; Li & Kimble, 2015) were foundational to this study's findings. For instance, the emphasis on individualization and its multifaceted (behavioral, developmental, and ecological) perspective spoke to the identified difference reported, such as the overall higher clinical rate of diagnosis of ASD among the White group as compared to the Non-White group. Furthermore, it laid a foundation that demonstrated the difference of teachers' higher reported perceptions of ASD among children from the Non-White group, in spite of the lower diagnosis of ASD among the Non-White group.

Additionally, Ford and Airhihenbuwa (2010) identified CRT as "a powerful new tool for targeting racial and ethnic health inequities" that encompassed this study's finding (p. 34). Subsequently, CRT asserts the foundation of the racial phenomena that was used to inform the study's findings of a higher clinical rate of diagnosis of ASD among the White group while teachers' indicted higher reported perception of ASD among children from the Non-White group. Moreover, CRT is built on philosophies of social justice and race equity that served an underpinning role when examining the

study's revealed difference between parents' perception of ASD symptoms among White and Non-White groups. This difference corroborated previously researchers' reported higher rates of delayed and missed diagnoses of ASD among underserved ethnic and racial minorities (Jarquin et al., 2011; Thomas et al., 2012).

Limitations of the Study

The execution of the study confirmed some limitations that aligned with previous limitations discussed in Chapter 1 of this study. The use of secondary data limited the study's generalizability. Specifically, since the secondary data provider, PSSEC, had limited access to data on full assessments of children with ASD, the scope of this study and generalizability were limited. For instance, the data were limited in their access to clinical measures, such as sensorimotor skills and speech development. Consequently, the study was unable to identify confounding variables due to the restraints of the data set. Subsequently, one of the main limitations of using secondary data involved the lack of control over participants and instrument selection.

Moreover, there were some limitations to the study's validity because the measurement instrument intake forms used in the original data collection were created in the form of questionnaires, which limited me from exploring questions in-depth. Therefore, details such as individual's racial beliefs or acculturation levels were unable to be examined when using these instruments. Furthermore, since the study used data that were collected during the period from 2008 to 2016, one instrument has since been revised. Subsequently, the ABAS-II was used in the secondary data collection as opposed to the currently revised ABAS-III (Harrison & Oakland, 2015).

Finally, the study's estimated a sample size of 64 participations using a one tail with an alpha level of $\alpha = .05$, and a medium effect size ($r = .30$), in order to obtain adequate power level (.80). However, the data set consisted of 48 participants who met the study's inclusion criteria. Nevertheless, in spite of this somewhat limited statistical power, as indicated in Chapter 4, the findings of this study are believed to be reliable and statistically significant.

Recommendations for Further Research

Methodological Expansions

Based on the limitations of this study, it would be beneficial to have further studies implement a mix-methods approach, whereby qualitative data could be used in conjunction with the secondary data which would add to this study's findings. Therefore, further studies that included more in-depth open-ended questions regarding parents and teacher's racial beliefs or acculturation levels, would help to identify confounding and covariates that may influence the perception and diagnosis of ASD across diverse racial and cultural groups.

Also, this study's target population was limited to preschool children in Duplin County, NC that were referred by the Child Find Project in NC to PSSEC. Therefore, future studies which included a broader target population would increase generalizability and provide more empirical data about the nuances of various racial and cultural perceptions of ASD.

Additionally, since secondary data analysis was conducted, there was no control over what had been done during the initial data collection process. For instance, the data

collected by the PSSEC site was limited by the site's inability to access data on a full assessment of children with ASD, which was narrowing the scope of this study.

Therefore, further studies that incorporate full assessments containing information from multidisciplinary sources would improve on this study's findings. Next, the use of currently updated instruments would counter the challenges faced in my use of secondary data in this study.

Also, further studies that control for covariates is recommended along with the collection of additional information from parents such as cultural beliefs and dominant language used at home. Lastly, additional studies which included a sample size greater than 64 ($n > 64$) would enhance this study's finding by adding more statistical power to the existing consistent and statistically significant findings.

Advancing Research

The study's findings indicated that the reported perceptions of ASD in White and Non-White groups demonstrated a significant difference from clinician's diagnosis of ASD in White and Non-White groups based on the child's race. The main difference was reported as an overall higher clinical diagnosed of ASD among the White group compared to the Non-White group. This finding was in contrast to the teachers' higher reported perception of ASD among children from the Non-White group compared to children from the White group. However, this finding was consistent with Blacher et al. (2014) conclusion that "actual symptoms of ASD may be in the eye of the beholder" (p. 1655). Hence, this empirical validation reinforced the need for future studies to examine other factors that would contribute to the disparity in the recognition of ASD among

different racial groups. Also, these findings add to the scholarly literature which has advocated for additional ASD research in diverse racial populations that would inform clinical practice and increase public awareness (Becerra et al., 2014; Blacher et al., 2014).

Further, the study's findings indicated that parents within the White group reported more ASD symptoms in their children than parents in the Non-White group, while teachers reported more ASD symptoms for children in the Non-White group than children in the White group. These findings revealed the differences in the way ASD symptoms were perceived and were consistent with the reported higher delayed and missed diagnoses of ASD among underserved ethnic and racial minorities (Jarquin et al., 2011; Thomas et al., 2012). Further, within the literature review in Chapter 2, I discussed Tek and Landa's (2012) hypothesis that minority parents may have overlooked certain signs of ASD based on their cultural background. Hence, it is speculated that uncharacteristic behaviors or delayed milestones may not be considered as problematic due to the belief that different cultural meanings are attributed to these behaviors. Therefore, this study's findings helped to highlight the need for further studies which examine the perception and diagnosis of ASD among different groups, along with the impact this may have on early detection rates and intervention (Becerra et al., 2014; Blacher et al., 2014; Valicenti-McDermott et al., 2012).

Implications

Positive Social Change

Individual /Family/ Organizational/Societal level. The study's findings provided robust data which highlight the overall difference in provider's higher diagnosis

of ASD among White children in contrast to the lower perception of ASD symptoms reported by teachers of Non-White children. Also, parents within the White group reported more ASD symptoms in their children than parents in the Non-White group. On the other hand, teachers reported more ASD symptoms for children in the Non-White group than children in the White group. This disparity which involved how the actual symptoms of ASD among White and Non-White groups were perceived was evident across context, ranging from the family, school/daycare, and clinical settings.

Therefore, this study's findings confirmed and highlighted the nuances of ASD symptoms and the perception among different racial groups previously identified in literature. It also served to advance and promote public awareness among parents, teachers, daycare providers, healthcare providers, and society at large. Consequently, this increased awareness could potentially lead to the implementation of culturally sensitive screening and diagnostic measures, protocols, and practices for both White and Non-White families. More specifically, programs could be created to enable more accurate referrals, accessibility to screening, and education about childhood developmental milestones.

For instance, workshops and forums could be created to educate parents and teachers on the developmental milestones, solicit discussions of their unique beliefs and perceptions of ASD symptoms, educate on the symptoms of ASD, and emphasize the value of accurate early detection. Ultimately, knowledge from this study may make for more accurate diagnosis, which in turn would lead to earlier intervention, to the benefit of the child, families and society which embodies positive social change.

Empirical implications. The empirical contribution of this study's findings has added to the limited scientific knowledge on the issue of ASD among minority groups. Therefore, by looking at this issue through the lens of various racial groups, I was able to uniquely address an under-researched area of ASD. By expanding knowledge in this discipline, the study's findings served as a catalyst to motivate and potentially advance multicultural competency within the professional practice related to ASD. For instance, when conducting screenings, evaluations, or simply referrals for ASD, physicians, mental health professionals and teachers may become more mindful to holistically consider the child's and family's unique beliefs, based on the child's race. Therefore, having the added diverse cultural data on ASD can practically enable mental health professionals to be more informed, sensitive, and effective in collaborating with parents of children who may have ASD (Kalyanpur et al., 2000; Valicenti-McDermott et al., 2012).

Recommendations for practice. The study's overall difference in the provider's higher rate of diagnosis of ASD among White groups in contrast to the lower reported perception of ASD symptoms among Non-White groups highlighted the ambiguities that still exist regarding ASD. In relation to ASD and different racial groups, it is recommended that providers implement increased efforts to become better aware of racial and cultural beliefs, parental perceptions of child's development and other nuances which can be integrated into a more informed and comprehensive assessment. For example, providers may interview and collaborate with parents as a means of better informing their clinical judgment. Next, if providers' and professionals (teachers/day-care providers) increase examination and awareness of assumptions entrenched in their practice that

influences their diagnosis and perception of ASD, it would be beneficial in addressing the diagnosis disparity of ASD between White and Non-White groups.

Conclusion

A plethora of empirical data confirmed the existence of ASD among all racial groups and emphasized the significance of early intervention. Therefore, my purpose for this study was driven by the scholarly findings which indicated delayed identification and diagnosis of ASD among minority children, the increased immigrants in American and insufficient literature related to ASD among different racial groups. Through the use of a quantitative approach, I investigated the relationship between race and reported perception of ASD, and clinical diagnosis of ASD among White and Non-White children. The framework of TEACCH and CRT served as this study's theoretical foundations. Using MANOVA, Pillai's trace indicated a significant effect of race on reported perception and diagnosis of ASD. The main difference was the overall higher diagnosed of ASD among the White group compared to the Non-White group. Contrastingly, teachers' reported perception of ASD was higher for the Non-White group, while parents reported perception of ASD was lower for the Non-White group. This finding was consistent with Blacher et al. (2014) conclusion that "actual symptoms of ASD may be in the eye of the beholder" (p. 1655). Hence, this empirical validation advanced the need for future studies to examine other factors that may contribute to the disparity in the recognition of ASD among different racial groups. Also, this finding added to the scholarly consensus which has recognized the need for ASD research in diverse racial populations in order to better inform clinical practice and increase public awareness

(Becerra et al., 2014; Blacher et al., 2014).

Further, the study's findings indicated that parents within the White group report more ASD symptoms in their children in comparison to parents in the Non-White group, while teachers report more ASD symptoms for children in the Non-White group over children in the White group. These findings also revealed the differences in the way ASD symptoms were perceived and were consistent with the reported higher delayed and missed diagnoses of ASD among underserved ethnic and racial minorities (Jarquin et al., 2011; Thomas et al., 2012). Further, the literature review in Chapter 2 addressed Tek and Landa's (2012) hypothesis that minority parents may overlook certain signs of ASD based on their cultural background. Hence, uncharacteristic behaviors or delayed milestones were considered problematic for different cultural meanings were attributed to the behaviors or milestone delays. Therefore, this study's findings help to highlight the need for further studies in order to examine the perception and diagnosis of ASD among different groups, along with the impact this may have on early detection rates and intervention (Becerra et al., 2014; Blacher et al., 2014; Valicenti-McDermott et al., 2012).

Therefore, based on my comprehensive literature review, it was evident that there were limitations, and gaps related to ASD, particularly ASD and different racial and groups (Jarquin et al., 2011; Thomas et al., 2012). Markedly, the present study specifically filled the gap in the literature by offering additional data and increased knowledge about different minority groups and ASD which serves to increase knowledge in the discipline. In summation, these findings emphasize the need for professional and

public awareness to enhance the identification of early warning signs of ASD across racial groups and effect positive social change. This positive social change would involve lessening disparity among racial groups, while safeguarding that children, regardless of race, receive timely and competent care.

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Appendix A: D5 Diagnostic Criteria for Autism Spectrum Disorder, 299.00 (F84.0)

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):
1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
 2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
 3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:

Severity is based on social communication impairments and restricted repetitive patterns of behavior (see Table 2).

- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):
1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 1).

- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor

(Coding note: Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioral disorder

(**Coding note:** Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition) (**Coding note:** Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

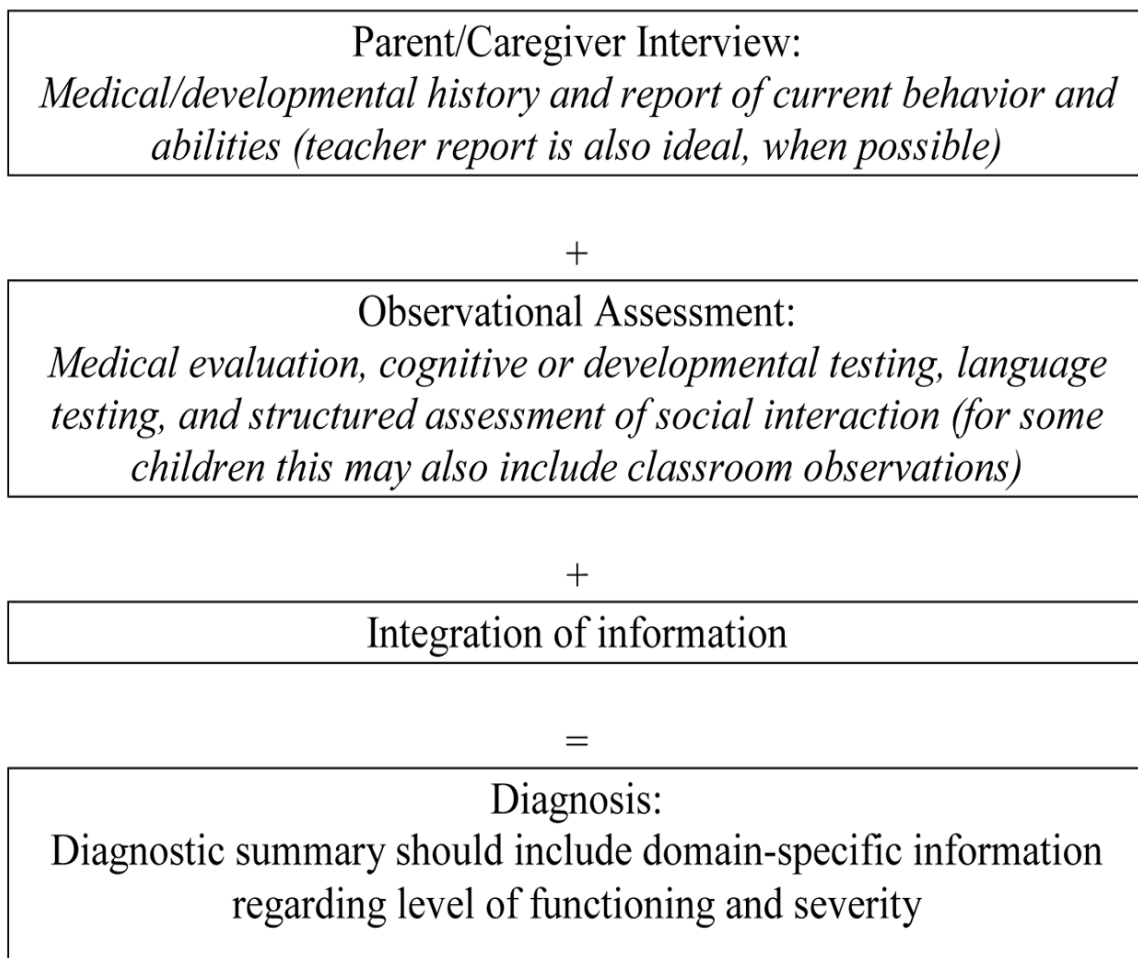
Table 1

Severity levels for autism spectrum disorder

Severity Level	Social Communication	Restricted, Repetitive Behaviors
Level 3: Requiring very substantial support	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interferes with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2: Requiring substantial support	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 1: Requiring support	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper

	interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and unsuccessful.	independence.
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Appendix B: Modules of a Comprehensive ASD Evaluation



Appendix C: Data Use Letter



Psychological and School Services
of Eastern Carolina, PLLC

Parliament Place, Suite 7
300 East Arlington Boulevard
Greenville, NC, 27858

phone: 252.227.3247
fax: 252.321.8740
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www.passec.com

March 4th, 2016

Margaret Gopaul, Ph.D.Candidate
4 Murphy Drive
Rocky Hill, CT 06067

Dear Ms. Gopaul,

Subject: Archival Data

Enclosed are scores from 59 children referred for psychological testing to rule out an Autism Spectrum Disorder. All identifying information has been removed. The data was placed in a format which can be viewed by dissertation students who may not have credentialing access to the protocols. I grant permission to use this data set for a dissertation conducted by the clinical psychology student, Margaret Gopaul. All other intentions are not approved without prior knowledge and consent.

The archival dates back to the 2008-2009 school year to current school year. The children were referred via Federal guidelines associated with Project Child Find (PCF). While referrals can be made by parents, medical doctors, daycare providers, preschool teachers, and other individuals associated with the child, ultimately, parents must provide consent for an evaluation. The main goal of PCF is locating and identify toddlers who may have a disability and or may be in need of exceptional children services. The public school system is responsible for assessing children once they turn 2 years 10 months. Prior to that time, a local public agency, Children's Developmental Services Agency (CDSA), conducts the evaluation. The CDSA does not always complete a formal battery or thorough battery and further assessment by the school system may be necessary to meet Department of Instruction (DPI) guidelines. This is why many of the subjects will only have a formal Autism assessment completed and why others may have a comprehensive battery completed. I only evaluated in areas requested by the Individualized Educational Program (IEP) Team.

Federal guidelines are interpreted at the state level, so there may be differences between states. I enclosed both a North Carolina's PCF handout and a copy of North Carolina's Department of Instruction, *Policies Governing Services for Children with Disabilities*. See pages 6 and 64 for the definition and evaluation procedures, respectively, for procedures specific to eligibility as Autistic.

Please feel free to contact me if you have any questions or need further information.

Regards,



Kelly C. Moynahan, MA, CAS, LPA, HSP-PA
School Psychologist II
Licensed Psychological Associate
Health Service Provider – Psychological Associate

Encl.: Data for subjects, PCF pamphlet, NC, DPI policy manual

CC: Dr. Steve Little, Ph.D. (Student's Chair)

Appendix D: Approved Data Use Agreement

DATA USE AGREEMENT

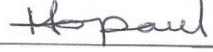
This Data Use Agreement ("Agreement"), effective as of 03/04/16 ("Effective Date"), is entered into by and between Margaret Gopaul, Ph.D. Candidate ("Data Recipient") and Psychological and School Services of Eastern Carolina, PLLC ("Data Provider"). The purpose of this Agreement is to provide Data Recipient with access to a Limited Data Set ("LOS") for use in research in accord with laws and regulations of the governing bodies associated with the Data Provider, Data Recipient, and Data Recipient's educational program. In the case of a discrepancy among laws, the agreement shall follow whichever law is more strict.

- I. Definitions. Due to the study's affiliation with Laureate, a USA-based company, unless otherwise specified in this Agreement, all capitalized terms used in this Agreement not otherwise defined have the meaning established for purposes of the USA "HIPAA Regulations" and/or "FERPA Regulations" codified in the United States Code of Federal Regulations, as amended from time to time.
2. Preparation of the LDS. Data Provider shall prepare and furnish to Data Recipient a LDS in accord with any applicable laws and regulations of the governing bodies associated with the Data Provider, Data Recipient, and Data Recipient's educational program.
3. Data Fields in the LDS. No direct identifiers such as names may be included in the Limited Data Set (LDS). In preparing the LDS, Data Provider shall include the data fields specified as follows, which are the minimum necessary to accomplish the research: List all data points that partner site will be providing (Example: gender, SAT scores, and high school GPA for every student in ABC program)
 - DOB, DOT, sex, race, school/home/daycare placement, and if the IEP team found the child as eligible for receiving services as Autistic.
 - Scores on the following measures: CARS2 (parent and teacher if child was in a school or daycare setting), CBCL, TRF (if child is in a school or daycare), PEP-3, ABAS-II (parent and teacher if child was in a school or daycare setting).
 - All children were special education referrals with a request for Autism Spectrum assessment in a rural North Carolina County.
4. Responsibilities of Data Recipient. Data Recipient agrees to:
 - a. Use or disclose the LOS only as permitted by this Agreement or as required by law;

- b. Use appropriate safeguards to prevent use or disclosure of the LDS other than as permitted by this Agreement or required by law;
 - c. Report to Data Provider any use or disclosure of the LDS of which it becomes aware that is not permitted by this Agreement or required by law;
 - d. Require any of its subcontractors or agents that receive or have access to the LDS to agree to the same restrictions and conditions on the use and/or disclosure of the LDS that apply to Data Recipient under this Agreement; and
 - e. Not use the information in the LDS to identify or contact the individuals who are data subjects.
5. Permitted Uses and Disclosures of the LDS. Data Recipient may use and/or disclose the LDS for its Research activities only.
6. Term and Termination.
- a. Term. The term of this Agreement shall commence as of the Effective Date and shall continue for so long as Data Recipient retains the LDS, unless sooner terminated as set forth in this Agreement.
 - b. Termination by Data Recipient. Data Recipient may terminate this agreement at any time by notifying the Data Provider and returning or destroying the LDS.
 - c. Termination by Data Provider. Data Provider may terminate this agreement at any time by providing thirty (30) days prior written notice to Data Recipient.
 - d. For Breach. Data Provider shall provide written notice to Data Recipient within ten (10) days of any determination that Data Recipient has breached a material term of this Agreement. Data Provider shall afford Data Recipient an opportunity to cure said alleged material breach upon mutually agreeable terms. Failure to agree on mutually agreeable terms for cure within thirty (30) days shall be grounds for the immediate termination of this Agreement by Data Provider.
 - e. Effect of Termination. Sections 1, 4, 5, 6(e) and 7 of this Agreement shall survive any termination of this Agreement under subsections c or d.
7. Miscellaneous.
- a. Change in Law. The parties agree to negotiate in good faith to amend this Agreement to comport with changes in federal law that materially alter either or both parties' obligations under this Agreement. Provided however, that if the parties are unable to agree to mutually acceptable amendment(s) by the compliance date of the change in applicable law or regulations, either Party may terminate this Agreement as provided in section 6.
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- b. Construction of Terms. The terms of this Agreement shall be construed to give effect to applicable federal interpretative guidance regarding the HIPAA Regulations.
- c. No Third Party Beneficiaries. Nothing in this Agreement shall confer upon any person other than the parties and their respective successors or assigns, any rights, remedies, obligations, or liabilities whatsoever.
- d. Counterparts. This Agreement may be executed in one or more counterparts, each of which shall be deemed an original, but all of which together shall constitute one and the same instrument.
- e. Headings. The headings and other captions in this Agreement are for convenience and reference only and shall not be used in interpreting, construing or enforcing any of the provisions of this Agreement.

IN WITNESS WHEREOF, each of the undersigned has caused this Agreement to be duly executed in its name and on its behalf.

DATA PROVIDER**DATA RECIPIENT**Date: 03/04/16Date: 03/04/16Signed: Signed: Name: Kelly C. Moynahan, LPAName: Margaret Gopaul, Ph.D. CandidateTitle: Licensed Psychological Associate
Licensed School Psychologist IITitle: Walden Clinical Psychology Student