ACCURACY OF THE AUTISM SPECTRUM SCREENING QUESTIONNAIRE – GIRL IN IDENTIFYING FEMALES WITH AUTISM SPECTRUM DISORDER

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by

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Keywords: autism spectrum disorder, females, screening tools, questionnaire

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ABSTRACT

Females with autism spectrum disorder (ASD) is an emerging research topic in the field of special education. Identification of ASD begins with the use of screening tools. This study utilized the Autism Spectrum Screening Questionnaire – Revised Extended Version (ASSQ-REV) to (1) evaluate the accuracy of the Autism Spectrum Screening Questionnaire (ASSQ) in identifying males and females with ASD and (2) evaluate the accuracy of the Autism Spectrum Screening Questionnaire – GIRL (ASSQ-GIRL) questions in distinguishing between the female and male phenotypes of ASD. Two hypotheses were proposed: (1) males will more accurately be identified than females as having ASD using the ASSQ and (2) the ASSQ-GIRL will identify the female phenotype of ASD at a greater rate than the male phenotype of ASD. Heterogenous convenience sampling was utilized to recruit 49 participants. Responses were analyzed through quantitative analysis using the McNemar's test. Results showed no statistically significant difference for both hypotheses thus disproving both proposed hypotheses. Further research should focus on the inclusion of characteristics of females with ASD into ASD screening tools. This research has the potential to lead to earlier ages of diagnosis for females with ASD thus resulting in increased access to needed interventions and supports.

Keywords: autism spectrum disorder, females, screening tools, questionnaire

PREFACE

This research sparked from an unexpected course change while completing my master's degree. I had intended to complete a practicum to earn licensure as a special education teacher but decided against this at the last minute. I again changed my mind and ended up completing that practicum, but that change lead me to a class titled, "Introduction to Autism Spectrum Disorder." I soon discovered a love for understanding the characteristics of autism and how they are identified. I ended up going on to complete a graduate certificate in autism spectrum disorders (ASD) becoming a Certified Autism Specialist. My experiences as a first and second grade teacher combined with my knowledge of ASD led me to pursue a dissertation focused on females with ASD. My hope is to see this research used as a basis for modifying ASD screening tools to better identify females with ASD.

DEDICATION

This dissertation is dedicated to my parents, Michelle and David Castonguay. Thank you for always believing in me and continually pushing me to be my best. I would not have made it this far without you both.

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CHAPTER 1

A quick internet search on rates of females to males with autism spectrum disorder (ASD) shows the disproportionality in the rates of clinical diagnosis (Loomes et al., 2017; Maenner et al., 2023; McCrossin, 2022; Nag et al., 2018; Posserud et al., 2021; Ratto et al., 2018; Zhang et al., 2020). Research has begun to highlight differences in characteristics between the sexes for individuals with ASD (Backer van Ommeren et al., 2016; Burton et al., 2020; Cridland et al, 2013; Dean et al., 2014; de Giambattista et al., 2021; Harrop et al., 2018; Locke et al., 2018; Reindal et al., 2020). Presently, females are diagnosed with ASD at a rate of 1:3.8 compared to males (Maenner et al., 2023). Females with an average or above average intelligence quotient (IQ) are more likely to be unidentified or misidentified compared to male counterparts (Ratto et al., 2018). This underrepresentation of females with ASD is leading to later age of diagnosis and intervention for females with ASD. Studies have shown a later age of diagnosis and intervention for females leads to higher rates of depression, anxiety, and suicidal ideations (Arwert & Sizoo, 2020; Cridland et al., 2013; Salazar et al., 2015; South et al., 2020).

ASD is often associated with comorbid diagnoses including psychiatric disorders and medical conditions (Rujeedawa & Zaman, 2022). Common comorbid conditions include intellectual disability (ID), attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), anxiety, depression, seizures, and hypertension (Rujeedawa & Zaman, 2022). The extent of the characteristics of the comorbid diagnosis can sometimes overshadow ASD characteristics leading to a misdiagnosis or missed diagnosis (Rujeedawa & Zaman, 2022). Females are more likely than males to be given a diagnosis of an associated comorbidity instead of ASD (Rujeedawa & Zaman, 2022).

Early intervention is key to helping navigate ASD and behaviors related to ASD (Maksimović et al., 2023). Research has shown that early intervention has a positive effect on autistic behaviors in young children (Maksimović et al., 2023). Studies have determined early intervention is often more successful in managing autistic behaviors than interventions started after age four (Maksimović et al., 2023). Maksimović et al. (2023) discerned noticeable differences in treatment effectiveness between children aged three and four. Thus, the younger intervention begins, the greater the positive effect it has on behaviors (Maksimović et al., 2023). Early intervention cannot begin until a developmental concern is present (Maksimović et al., 2023).

A first step in getting females with ASD necessary support is to identify them using an effective screening tool (Kopp & Gillberg, 2011). Males are ten times more likely than females to be referred for an ASD evaluation (Estrin et al., 2021). On average, females receive a diagnosis of ASD one year later than males (Bonney et al., 2021). The Office of Autism Research Coordination National Institutes of Health (2019) reports the average age of ASD diagnosis for males is 4.8 years of age while the average age of ASD diagnosis for females is 5.4 years of age. It is hypothesized this is due to ASD screening tools focusing on the male phenotype of ASD which has been dominant in ASD research (Estrin et al., 2021; Loomes et al., 2017). Often, females present with ASD characteristics differently than males and current diagnostic tools are not as sensitive to these characteristics (Posserud et al., 2021). Some research has been done to develop a screening tool that is effective in identifying females with ASD at an age like that of males with ASD (Bonney et al., 2021).

Another reason females are underdiagnosed with ASD compared to males might be the lack of inclusion of females in studies (Estrin et al., 2021). Historically, ASD has been referred

to as a boy's disorder and the rates of diagnosis support this claim (Estrin et al., 2021). It is challenging to determine if certain screening tools are identifying females at rates like males because of the small norming samples (Estrin et al., 2021). Some researchers hypothesize ASD may have a genetic component thus resulting in more males having ASD than females (Rivet & Matson, 2011). Rett's Disorder, which is no longer a recognized diagnosis and falls into the category of ASD, is the only disorder related to ASD that has shown to have higher rates of diagnosis for females than males (Rivet & Matson, 2011). Rett's Disorder has an identified genetic component which supports theories that ASD may have a genetic tie (Rivet & Matson, 2011).

This study aspires to add to this field of research. This study utilized a homogenous sampling of children with a diagnosis of ASD (Jager et al., 2017). Parents or legal guardians of participants completed the Autism Spectrum Screening Questionnaire (ASSQ) and Autism Spectrum Screening Questionnaire- GIRL (ASSQ-GIRL) using the Autism Spectrum Screening Questionnaire- Revised Extended Version (ASSQ-REV) created by Kopp and Gillberg (2011). A cutoff score was determined to see how many individuals would surpass the threshold on the ASSQ and ASSQ-GIRL to be referred for further ASD evaluations (Ehlers et al., 1999). It was hypothesized that all male participants would surpass the cutoff score on the ASSQ, and all female participants would surpass the cutoff score on the ASSQ-GIRL as these individuals already hold a diagnosis of ASD. It was also hypothesized that more males would surpass the cutoff score on the ASSQ than females and more females would surpass the ASSQ-GIRL scores than males due to the nature of the questions. The information gleaned from this study will add to the literature relating to the use of ASD screening tools for females.

Existing Research

The earliest account of what is now known as ASD dates to 1747 to a man named Hugh Blair (Wolff, 2004). Blair displayed deficits in his social relationships including abnormal gaze, abnormal use of language including echolalia, repetitive odd mannerisms, and lacking in common sense (Wolff, 2004). He did not have a formal diagnosis other than severe retardation (Wolff, 2004). The next recorded instance of an individual with ASD-like behaviors was published in 1809 (Wolff, 2004). A seven-year-old child was delayed in his ability to walk and talk, observed to play alone and not engage with other students, and had obsessive interests (Wolff, 2004). A boy named Victor was discovered in the woods in 1798 (Wolff, 2004). A French doctor, Jean Itard, began observing and working with Victor (Wolff, 2004). Itard worked with Victor for over five years, but Victor never spoke other than single syllable imitations (Wolff, 2004). Itard is credited with formulating teaching methods that are presently used with individuals with ASD and intellectual disabilities (Wolff, 2004).

Other syndromes identified throughout the years are thought to have been commensurate with ASD (Wolff, 2004). Dementia infantilis, dementia praecocissima, and primitive catatonia of idiocy are noted to have similar characteristics as present-day ASD (Wolff, 2004). Grunya Efimovna Sukhareva is credited with describing six boys as presenting with features that align to what we now refer to as high-functioning autism in 1926 (Posar & Visconti, 2017). Sukhareva is also acknowledged as the first female to study and publish articles relating to autism (Posar & Visconti, 2017). Sukhareva's work highlighted the inclusion of sensory abnormalities as a characteristic of persons with autism (Posar & Visconti, 2017). Sukhareva's study noted key characteristic differences between children with autism and children diagnosed with schizophrenia (Al Ghazi, 2018). Her research showed how restrictive and repetitive behaviors,

social contact, and fixated interests differed between individuals with autism and individuals with schizophrenia (Al Ghazi, 2018).

Leo Kanner published a study in 1943 that described his experience working with children who presently would be diagnosed with autism (Kanner, 1943). Kanner included eight boys and three girls in his study (Kanner, 1943). Participants were thoroughly described and input from family members were also included in these descriptions (Kanner, 1943). Kanner characterized his patients as favoring solitude and rigidity in routines (Kanner, 1943). The individuals were noted to be clumsy and have gross motor deficiencies (Kanner, 1943). Kanner also noted that the parents of these children were not cordial; instead, they were closed-off in their engagements with others (Kanner, 1943). Kanner hypothesized that the children were biologically predisposed to these anti-social behaviors based on what he observed in the parents (Kanner, 1943). Kanner noted that some of the children were highly intelligent, obtaining high levels of reading skills, while others were deemed mentally slow and sent to psychiatric facilities (Kanner, 1943).

Hans Asperger, an Austrian physician, described what is now referred to as high-functioning autism (HFA), as a syndrome that occurred from birth and showed progression in terms of social interactions throughout lifespan development (Barahona-Corrêa & Filipe, 2016). HFA is an informal term referencing individuals with an IQ of at least 70 (Riccioni et al., 2021). Asperger's description further supported Sukhareva's statements that these behaviors differed from those of individuals with schizophrenia as these individuals did not show improvement in social behaviors as they matured (Barahona-Corrêa & Filipe, 2016). Asperger described his patients as having unusual interests, fascination with art, unique physical appearances, including thin features and an appearance of nobility (Asperger, 1944; Barahona-Corrêa & Filipe, 2016).

Asperger stated that his patients were different from Kanner's as they had a normal development in the first three years of life, had higher levels of cognitive and language skills, and tried to interact with peers, but had a flaw in their social abilities (Barahona-Corrêa & Filipe, 2015).

Leo Eisenberg and Kanner published a paper in 1958 titled "Early Infantile Autism" (Eisenberg & Kanner, 1958). The authors studied 11 children who met the criteria for early infantile autism (Eisenberg & Kanner, 1958). The criteria for early infantile autism included extreme levels of detachment from human relationships which did not occur overtime, but rather enveloped the child from an early age (Eisenberg & Kanner, 1958). Parents described the children as being self-isolating and lacking in language use (Eisenberg & Kanner, 1958).

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is considered a handbook for diagnosing and classifying mental disorders (Khoury et al., 2014). The intent of the DSM is to provide common language for physicians and researchers when it comes to understanding mental disorders (Khoury et al., 2014). The DSM was written to create a systematic classification of mental disorders including characteristics and criteria for diagnosis (Khoury et al., 2014). There have been five versions and two revisions published since 1952 (Khoury et al., 2014). The current edition of the DSM, DSM-5, was published May 18, 2013, by the American Psychiatric Association (Khoury et al., 2014).

Autism was first included in the DSM-III in 1980 under the condition pervasive developmental disorder (PDD) (Volkmar & Reichow, 2013). The definition of PDD was based on descriptions of infantile autism and late-onset autism as they had been researched up to that point (Volkmar & Reichow, 2013). The DSM-III-R published in 1987 added a subcategory to PDD titled pervasive developmental disorder not otherwise specified (PDD-NOS) (Volkmar & Reichow, 2013). Greater criteria were developed with symptom definitions referencing social,

communication, and opposition to change (Volkmar & Reichow, 2013). Afterwards, it was found that this definition of PDD-NOS over diagnosed individuals with higher cognitive abilities and underdiagnosed individuals with an IQ at the lower end of the range (Volkmar & Reichow, 2013).

The DSM-IV was published in 1994 and included an in-depth review of data related to autism creating a more detailed definition, incorporating a balance of sensitivity and specificity, and showed improved reliability amongst different raters (Volkmar & Reichow, 2013). The DSM-IV added three new disorders under the category of PDD-NOS: childhood disintegrative disorder, Asperger's disorder, and Rett's disorder (Volkmar & Reichow, 2013). The definition of Asperger's disorder was vague and caused it to be used erratically for diagnosis (Volkmar & Reichow, 2013).

A committee on neurodevelopmental disorders was established prior to the creation of the DSM-V (Volkmar & Reichow, 2013). The term autism spectrum disorder (ASD) was used to encompass multiple disorders in the DSM-V, a major change from previous versions of the DSM (Volkmar & Reichow, 2013). ASD now included the previous disorders of Rett's disorder, Asperger's disorder, childhood disintegrative disorder, Kanner's syndrome, and PDD-NOS (Volkmar & Reichow, 2013). Social (pragmatic) communication disorder was added as a possible diagnosis for when ASD criteria is not met (Volkmar & Reichow, 2013). Diagnostic criteria were strengthened, having gone from needing to meet two out of four criteria to three out of three criteria (Volkmar & Reichow, 2013).

The DSM-V defines ASD as meeting two criteria: (1) "persistent impairment in reciprocal social communication and social interaction (American Psychiatric Association [APA], 2013)" and (2) "restricted and repetitive patterns of behavior (APA, 2013, p. 50)". Initial

concerns were raised regarding this new definition (Mayes et al., 2013). Only 27% of children diagnosed with PDD-NOS were found to meet the DSM-V for ASD (Mayes et al., 2013). The rate of true negatives increased from 97% in the DSM-IV to 100% in the DSM-V definitions (Mayes et al., 2013). The DSM-V-TR was published in March 2022 (Hess, 2022). A major revision was not made to the definition of ASD, but an advantageous change was made by rephrasing ‘as manifested by the following’ to ‘as manifested by all of the following’ (Hess, 2022). This eliminated uncertainty as to whether any or all the criteria had to be met for a diagnosis of ASD (Hess, 2022). Another change included switching the term behavioral disorder to behavioral problem (Hess, 2022). This change allows practitioners to provide additional information related to behavior even if it does not rise to the level of an additional disorder (Hess, 2022).

Significance of Study

Kopp and Gillberg (2011) have begun the work towards modifying ASD screening tools to include the female phenotype of ASD. Kopp and Gillberg (2011) were sparked by an interest pertaining to differences between the sexes in social relationships. The researchers set out to find a well-studied and research-based ASD screening tool from which they could develop a new screening tool (Kopp & Gillberg, 2011). Kopp and Gillberg (2011) settled on the ASSQ, which was originally developed to screen for Aspergers syndrome, but has been modified and studied to screen for ASD (Zirakashvili et al., 2022). Its high levels of validity and reliability led Kopp and Gillberg (2011) to use the ASSQ as the starting point for their study.

Kopp and Gillberg (2011) created focus-groups consisting of parents of females with ASD and held in-depth conversations with clinicians to determine what aspects of the female phenotype of ASD were not already included in the ASSQ. They then took this information and

created 18 new questions specific to the female phenotype of ASD and titled them ASSQ-GIRL (Kopp & Gillberg, 2011). The researchers then combined the existing 27 ASSQ questions with the 18 developed ASSQ-GIRL questions and created the ASSQ-REV (Kopp & Gillberg, 2011). Kopp and Gillberg (2011) were the only ones who have published a study based on their ASSQ-REV. The ASSQ-REV showed good ability to determine between females with ASD and neurotypical females but did not show a difference in overall scores between males and females with ASD (Kopp & Gillberg, 2011). Some of the ASSQ-GIRL questions did distinguish well between males and females with ASD, while others did not (Kopp & Gillberg, 2011).

The present study intended to replicate the Kopp and Gillberg (2011), but with modifications. The focus of this study was to (1) evaluate the accuracy of the ASSQ in identifying males and females with ASD and (2) evaluate the accuracy of the ASSQ-GIRL questions in distinguishing between the female and male phenotypes of ASD (Kopp & Gillberg, 2011). Kopp and Gillberg (2011) appear to be heading in the right direction for modifying ASD screening tools to better identify females who may have ASD (Kopp & Gillberg, 2011). Currently, females are identified with ASD at a rate of 1:3.8 compared to males (Maenner et al., 2023). Kopp and Gillberg (2011) have started the process towards proportioning the identification rates of ASD in males and females. This study planned to quantify data relating to the ASSQ and ASSQ-GIRL (Kopp & Gillberg, 2011).

Delimitations

A few limitations were brought forth during this study. Non-probability sampling was used for this study. Non-probability sampling is selective in choosing participants whereas probability sampling ensures every individual in the population has an equal chance of being

chosen for the study (Elfil & Negida, 2017). The non-probability sampling method of convenience sampling was selected for a few reasons: (1) females with ASD are located throughout the country and it is not possible to identify every female with ASD residing within the United States due to confidentiality laws, (2) participants in this study are homogeneous as they share the common characteristics of having a child between the ages of 6-17 diagnosed with ASD and reside in the United States (Jager et al., 2017), and (3) participants were recruited via word of mouth and online platforms to generate a greater number of participants. Thus, the results of this study serve as a suggestion rather than a generalization to the population being sampled (Chetty, 2016).

Data collected were analyzed using non-parametric tests which are described in more detail in successive chapters. Non-parametric tests do not make assumptions about the underlying population whereas parametric tests do make these assumptions (Sullivan & Artino, 2013). "Nonparametric tests are less powerful than parametric tests and usually require a larger sample size (n value) to have the same power as parametric tests to find a difference between groups when a difference actually exists (Sullivan & Artino, 2013, p. 541)." Non-parametric tests were used because of the selected sampling method and stated research questions. The use of non-parametric statistical analysis contributes to these results being suggestions rather than generalizations to the population (Chetty, 2016).

Probability samples are necessary to generalize findings to a population (Kukull & Ganguli, 2012). Probability sampling synonymizes the term population with all people or cases that fit stated criteria (Kukull & Ganguli, 2012). Probability sampling achieves a participant group that is considered representative of the entire population (Kukull & Ganguli, 2012). Non-probability sampling cannot be equated with representing the entire population as it is selective

in the participants chosen to be included in the study (Kukull & Ganguli, 2012). Selection bias can occur in non-probability sampling (Kukull & Ganguli, 2012). A study that uses probability sampling can generalize findings to the population because the population is wholly represented in the study (Kukull & Ganguli, 2012). A study, such as this study, which uses non-probability sampling can only provide suggestions based on findings as the entire population is not wholly represented in the participant group (Kukull & Ganguli, 2012).

A standardized questionnaire was utilized in this study. Responses to the questionnaire were statistically analyzed allowing for the researcher to draw conclusions to the research questions. Participants were limited in choosing a response on a five-point Likert scale ranging from "no, not at all" to "yes, all the time" (Sullivan & Artino, 2013). The Likert scale does allow for ambiguity in responses and can be interpreted differently by participants (Sullivan & Artino, 2013). A more in-depth analysis of questions using an interview or focus group would provide additional data on the participants' views relating to the accuracy of the questionnaire in identifying characteristics of ASD that are presented in their child (Chetty, 2016).

Interpretation of the perceived distance between a low-end and high-end response on a Likert scale can lead to skewing of data (Bishop & Herron, 2015). This study utilized a scale of five points with only points one and five labeled (Kopp & Gillberg, 2011). Point one is labeled "no, not at all" and point five is labeled "yes, all the time," but the three medial points do not have descriptive labels (Kopp & Gillberg, 2011). Some individuals may interpret point three as "neutral" while others may view it as a lesser version of "yes, all the time," but a stronger version of "no, not at all." The Likert scale leaves room for ambiguity in interpreting the responses (Bishop & Herron, 2015). Some respondents may choose only "no, not at all" and "yes, all the time" as responses creating an anchor effect (Bishop & Herron, 2015). An anchor

effect occurs when participants choose the more extreme responses over medial responses (Bishop & Herron, 2015). Responses can change the interpretation of the scale and skew data toward one extreme (Bishop & Herron, 2015).

Definition of Terms

Autism Spectrum Disorder (ASD) – a neurological and developmental disorder characterized by deficits in social communication and interaction and restricted or repetitive behaviors (American Psychiatric Association [APA], 2022). Deficits in social communication and interaction include social-emotional reciprocity, nonverbal communication behaviors used for social interactions, and deficits in acquiring, upholding, and perception of social relationships (APA, 2022). Social-emotional reciprocity relates to the ability to have a back-and-forth conversation or engagement with another person (APA, 2022). Nonverbal communicative behaviors include body language, physical movements and gestures, eye contact, and facial expressions (APA, 2022). Lack of interaction with peers, playing alongside rather than with peers, and an inability to adjust language and movements to different social contexts are elements of developing, maintaining, and understanding relationships (APA, 2022). Examples of restricted or repetitive behaviors include repeating phrases stated by others, repeated involuntary body movements, strict adherence to routine, extreme fascination with a specific topic, and sensory abnormalities (APA, 2022). An individual must display deficits in all three social communication and interaction categories and two of the four repetitive or restrictive behaviors to receive a diagnosis of ASD (APA, 2022).

Female phenotype of ASD – characterized by camouflaging social behaviors, low self-esteem, immaturity, hyper- or hypo-sensitive to sensory elements, and shyness or hesitation in social situations (Backer van Ommeren et al., 2016; Burton et al., 2020; Cridland et al., 2013; Dean et al., 2014; de Giambattista et al., 2021; Locke et al., 2018; Stroth et al., 2022).

Formal diagnosis – a diagnosis of ASD from a pediatric neurologist, developmental or behavioral pediatrician, or a child psychiatrist (Boston Medical Center).

Legal guardian – an individual who has "custody of the children and the authority to make decisions concerning the child(ren)'s protection, education, care, discipline, etc. (*What does it mean to be a legal guardian; where can I find information?*, n.d.)."

Male phenotype of ASD – characterized by physical repetitive behaviors, intense interest in uncommon or non-age-appropriate themes, speech abnormalities including stereotyped use of words and phrases, and hyperactivity (de Giambattista et al., 2021; Stroth et al., 2022).

Parent – "one that begets or brings forth offspring (Parent, n.d.)."

Universal – any individual that meets the population characteristics can be administered a screening tool (Thabtah & Peebles, 2019).

Screening tools – identify individuals that need further assessment to determine whether they meet diagnostic criteria for a diagnosis (Thabtah & Peebles, 2019). Screening tools are intended to be short but comprehensive pictures of an individual's characteristics (Thabtah & Peebles, 2019).

Sensitivity – opposite of specificity; the ability of a screening tool to correctly identify individuals with a condition (Swift et al., 2020). Sensitivity is important because it

measures the accuracy of the screening tool in precisely determining if an individual shows signs of having a potential disorder (Swift et al., 2020). Sensitivity is also referred to as a true positive (Swift et al., 2020).

Sex – the biological attributes assigned at birth and identified using the terminology male or female (Torgrimson & Minson, 2005).

Specificity – opposite of sensitivity; specificity is the ability of a test to correctly identify individuals without a condition (Swift et al., 2020). Specificity is referred to as a true negative (Swift et al., 2020).

True negative – the screening tool identifies the individual as not having a condition and the individual does not have the condition (Swift et al., 2020).

True positive – the screening tool identifies the individual as having a condition and the individual does in fact have the condition.

Conclusion

Disorders like ASD have been in the literature for over 250 years (Wolff, 2004). The DSM-V definition of ASD changed the way an individual qualifies for a diagnosis (APA, 2013; APA, 2022). Screening tools have been adapting to the DSM changes in definition and adjusting their criteria accordingly (Thabtah & Peebles, 2019). Research shows the female to male ratio for diagnosis of ASD is 1:3.8 (Maenner et al., 2023). Hypotheses as to this disparity include a genetic component to ASD that favors males, lack of female subjects to include in studies, and differences in ASD characteristics between males and females (Backer van Ommeren et al., 2016; Burton et al., 2020; Cridland et al, 2013; Dean et al., 2014; de Giambattista et al., 2021; Estrin et al., 2021; Harrop et al., 2018; Locke et al., 2018; Reindal et al., 2020; Rivet & Matson, 2011). The present study focuses on the hypothesis that differences between the male and female

phenotype of ASD are not always captured on existing screening tools (Thabtah & Peebles, 2019). Data from this will add to the research by determining the accuracy of the ASSQ-GIRL in identifying females with ASD (Kopp & Gillberg, 2011).

CHAPTER 2

Recent research has begun to uncover differences in characteristics between the sexes for individuals with autism spectrum disorder (ASD) (Backer van Ommeren et al., 2016; Burton et al., 2020; Cridland et al, 2013; Dean et al., 2014; de Giambattista et al., 2021; Harrop et al., 2018; Locke et al., 2018; Reindal et al., 2020). Quantitative, qualitative, and mixed methods studies have highlighted the contrast between attributes of ASD in male and female individuals. Researchers have begun to focus on the underrepresentation of females with ASD in the literature. Newer studies are including more females with ASD in comparison groups to males with ASD. Studies have shown that the traits of ASD exemplified in females can differ from those in males. Studies prevail showing overlap in ASD characteristics, but current research is showing the differences that exist between the sexes.

One goal of this literature review was to analyze the ASD characteristics portrayed in females with ASD. Specifically, the intent was to yield insight into the distinction of external and internal ASD traits between males and females with ASD. This study focused on research that defined the term “sex” as the sex assignment given to an individual at birth and identified using the terminology “male” or “female” (Torgrimson & Minson, 2005). Research focused on studies that compared ASD characteristics in males and females. Studies were analyzed for differences between males and females with ASD.

Researchers took information regarding differing characteristics of ASD between males and females and shifted to analyzing the effectiveness of existing screening tools for ASD. The intent was to determine whether these screeners were identifying females with ASD at rates comparable to identifying males with ASD (Dworzynski et al., 2012; Evans et al., 2018; Frazier et al., 2013; Kirkovski et al., 2013; Kreiser & White, 2013; Lundström et al., 2019; Morales-

Hidalgo et al., 2018; Ratto et al., 2018; Werling, 2016). Screening tools that have been studied include the Autism Diagnostic Interview- Revised (ADI-R) (Ratto et al., 2018), Autism Diagnostic Observation Schedule (ADOS or ADOS-2) (Morales-Hidalgo et al., 2018; Ratto et al., 2018), Autism Spectrum Screening Questionnaire – Revised Extended Version (ASSQ-REV) (Kopp & Gillberg, 2011), Autism-Tics, Attention-Deficit/Hyperactivity Disorder (ADHD), and Comorbidities (A-TAC) (Lundström et al., 2019), Childhood Autism Spectrum Test (CAST) (Dworzynski et al., 2012), Social Communication Questionnaire (SCQ) (Evans et al., 2018), Social Responsiveness Scale (SRS) (Ratto et al., 2018), and Vineland Adaptive Behavior Scales, Second Edition, Survey Interview (Vineland-II) (Ratto et al., 2018). Explanations of methodology and results of the studies are discussed in the literature review and analysis of the literature.

Review of the Literature

Comparison of Autism Spectrum Disorder Characteristics Between Males and Females

Research is beginning to highlight the differences between the male and female phenotype of ASD. Cridland et al. (2013) conducted a qualitative study to highlight experiences of girls with ASD during adolescence. The purpose of the study was to gain an understanding of experiences for girls with ASD and their families. The homogenous sample consisted of five females with ASD aged 12-17 and their mothers. The researchers used semi-structured interviews to guide the interpretative phenomenological analysis to provide explanations of participants' views and personal meanings on issues related to being a female with ASD. The researchers conducted interviews with the participants centered around open-ended questions relating to experiences of being an adolescent girl with an ASD or being a parent of an adolescent girl with ASD. The interviews lasted 60 minutes, on average, and were recorded to be

transcribed and analyzed following completion of the interview. Analysis of the interviews determined seven key themes: diagnostic issues, being surrounded by boys, experiences of high school, complexity of adolescent female relationships, puberty and its related issues, sexual relationships and concerns, and the impact of having an adolescent daughter with ASD. The researchers concluded that many of the social behaviors discussed by participants are in line with the literature that shows girls are better able to mask or camouflage their social difficulties. This is the first study to investigate the experiences of adolescent girls with ASD from the individuals themselves and their mothers. The researchers state a further need to replicate this study using male and female adolescents with ASD to determine the differences in experiences among the sexes. The goal of the study was not to generalize the findings to all females with ASD, but to provide context and analysis of their experiences highlighting the need for further research.

Research into social-emotional needs of females with ASD is bringing forth the importance of early identification of females with ASD. Dean et al. (2014) completed a secondary analysis of data from two previous studies to determine rates of social acceptance and rejection among male and female students with and without ASD. The purpose of the study was to determine differences based on gender for social relationships of girls and boys with ASD. There were a total of 100 participants in the analysis categorized into four groups: 25 females without ASD, 25 females with ASD, 25 males without ASD, and 25 males with ASD. Data analyzed included the Friendship Survey. The Friendship Surveys were evaluated using six variables: social acceptance, social preference, social connections, social salience, reciprocal friendship, and rejection. All variables were separated by gender and statistical analysis was applied to determine differences in rates between males and females with and without ASD. Results

showed that social challenges related to ASD were equally present in both male and female participates with ASD. Females showed no differences than males in their abilities at camouflaging their social differences. Participants, with and without ASD, were observed to socialize primarily with their same-sex peers. Females and males with ASD were found to be less accepted by peers, have fewer friends, and have less social standing than females and males without ASD. Girls with ASD were found to be overlooked by neurotypical peers whereas boys were excluded from socialization with neurotypical peers. Girls with ASD were found to be seeking acceptance into peer groups more than boys with ASD. This analysis was one of the first that included many females with high-functioning ASD. These data support emerging research that characteristics of ASD differ based on gender. Further studies including females with high-functioning ASD are needed to determine distinct differences between boys and girls with ASD and their social characteristics.

Research highlighting social-emotional needs of females with ASD has begun to uncover how these needs differ from males with ASD. Backer van Ommeren et al. (2016) carried out a quantitative study to compare reciprocal behavior differences between males and females with ASD and typically developing (TD) males and females. The study consisted of 146 participants with ASD (32 girls, 114 boys) and 79 TD participants (24 girls, 55 boys). The researchers used standardized assessments to measure reciprocal interaction between a child and a researcher, receptive vocabulary achievement and verbal ability, and severity of ASD symptoms in a natural setting. Results showed children with ASD had limitations in reciprocal behavior compared to TD children. Females with ASD had higher reciprocal behavior scores than males with ASD. Females with ASD had subtle differences in reciprocal behavior compared to TD females.

Results indicate that females with ASD may be more likely to participate in social interactions that include shared goals than males with ASD. This study highlighted the differences in reciprocal behavior differences between males and females with ASD. This study was limited in its sample as participants were not matched in age and IQ. Further research needs to include matched samples to explore the reciprocal behavior differences between males and females with ASD.

Restrictive and repetitive behaviors are a key characteristic of identifying ASD (APA, 2022). Research has begun to show that these behaviors are often more socially accepted in females than in males which is why this characteristic can be easily overlooked in females (Harrop et al., 2018). Harrop et al. (2018) conducted a quantitative study to determine whether circumscribed interests in females with ASD were more closely aligned with interests reported in neurotypical females than those reported for males with ASD. The study consisted of 87 participants in four categories: 27 males with ASD, 27 females with ASD, 16 neurotypical males, and 17 neurotypical females. The researchers used formal assessments to determine cognitive abilities, restrictive and repetitive behaviors, and circumscribed interests. The researchers used eye-tracking studies to determine which images females and males with and without ASD spent the most time viewing, which images were viewed most often, and how much detail was inspected in each image. Results showed the neurotypical children spent more time than children with ASD referring to the screen. Males with ASD were found to be more detailed oriented than both females with ASD and neurotypical females. There were no differences found between males with ASD and neurotypical males. Females and males from all groups attended to images typically associated with their biological sex. Findings suggest that males and females with ASD tend to have circumscribed interests like their neurotypical peers of

the same sex. This study focused on using a paradigm of typical sex differences. Further research using eye-tracking studies to determine circumscribed interests between males and females with ASD and their neurotypical peers need to include gendered arrays to see whether the effects of circumscribed interest or gender are stronger.

The DSM-V definition of ASD guides the diagnosis of ASD (APA, 2022). de Giambattista et al. (2021) conducted a mixed methods study to highlight key differences in the diagnostic criteria of males and females with ASD. The study included 54 females and 55 males with an ASD diagnosis. The researchers examined the rates of identification for females and males on each section of the DSM-V definition of ASD. More males than females were identified in the following categories: abnormal speech approach, failure of normal back-and-forth conversation, abnormalities in eye contact and body language, deficits in understanding and use of gestures, a total lack of facial expressions and nonverbal communication, deficits in developing, maintaining, and understanding relationships, extreme distress at small changes and/or difficulties with transitions, rigid thinking patterns and greeting rituals, highly restricted and fixated interests that are abnormal in intensity or focus, adverse response to specific sounds or textures, and visual fascination with lights or movement. More females than males were identified in the following categories: poorly integrated nonverbal and verbal communication, echolalia/idiosyncratic phrases, need to take the same routine or eat food every day, apparent indifference to pain/temperature, and excessive smelling or touching of objects. Results showed there are subtle, yet key differences in the exhibition of characteristics of ASD between females and males. The categories that highlighted more females need to be incorporated into more screening tools to better determine whether a female has ASD.

Another characteristic of ASD is impairments in social communication (APA, 2022). Locke et al. (2018) completed a quantitative social network analysis to determine whether children with ASD tend to socialize more with same sex or opposite sex peers. The intent of the study was to help educators understand whether peer models for children with ASD need to be of the same or opposite sex. The researchers drew data from three studies that utilized the Friendship Survey. Surveys were coded to analyze individual centrality, social network centrality, and cluster centrality. Results showed male children with ASD had higher social connectivity, but their social connectivity was lower than a comparable female when the male was friends with a female. Males with ASD had better social network salience when they had more friends of the same sex. Female children with ASD had received greater friendship nominations from friends of both sexes than males with ASD. The researchers suggest that females with ASD may befriend children of both sexes more than males with ASD due to their ability to camouflage characteristics of ASD. This study focused on peer relationships between males and females with ASD and their friends based on sex. Further studies need to continue to examine friendship differences between the sexes, but also consider social hierarchy when analyzing those friendships.

Further research has examined the social communication skills of females with ASD compared to males with ASD (Burton et al., 2020). Burton et al. (2020) carried out a quantitative study to analyze the social communication skills of girls with high-functioning autism spectrum disorder (HFASD). The study included 37 female participants aged seven years, five months to 15 years, two months. Eighteen participants were females with HFASD, and 19 participants were typically developing (TD) females. The researchers used four assessments related to pragmatic

language, language fundamentals, and receptive and expressive language. Two assessments were conducted with the participants and two assessments were conducted with the parents of the participants. Data showed significantly lower scores in the areas of social communication for girls with HFASD than TD girls. Girls with HFASD earned significantly lower scores on the Vineland Adaptive Behavior Scales- Second Edition compared to TD girls. No significant differences were found between the groups on language fundamentals. There is a common belief that girls with HFASD are better able than boys with HFASD to mask their social communication difficulties compared to TD girls and boys. This study highlights the need to include multiple sources of information when evaluating social communication needs of females with HFASD as the data show they typically have impaired social communication skills compared to TD females.

Research has also examined whether factors not included in the DSM-V manual definition of ASD have any influence on an eventual diagnosis of ASD. Reindal et al. (2020) conducted a quantitative study to determine whether an older age of first walking (AOW) is related to an individual receiving a diagnosis of ASD. Four hundred ninety participants with suspected ASD were included in the study. The researchers utilized validated assessments to measure rates of autistic symptoms to determine a diagnosis of ASD for 376 participants. Independent sample t-tests and Pearson's Chi square were used to compare age of first walking to severity of ASD symptoms. Data concluded the average AOW was later for children diagnosed with ASD than their neurotypical peers. Females with ASD had a more significant delay in their average AOW compared to neurotypical females than males with ASD had compared to neurotypical males. The researchers suggest that females with a delayed AOW are more likely to receive an ASD diagnosis than males with a delayed AOW based on collected

data. This study highlights the need for future research to make further correlations between AOW and ASD diagnosis. The underlying mechanisms as to why females with ASD typically have a delayed AOW should also be part of the research.

Implications of Characteristics of Autism Spectrum Disorder in Females on Screening Tools

Identification of ASD in children often begins with a screening tool. These tools are designed to alert practitioners to signs of ASD (Dworzynski et al., 2012; Evans et al., 2018; Frazier et al., 2013; Kirkovski et al., 2013; Kreiser & White, 2013; Lundström et al., 2019; Morales-Hidalgo et al., 2018; Ratto et al., 2018; Werling, 2016). A universal screening tool is designed to be used with all individuals meeting specified criteria (Thabtah & Peebles, 2019). ASD screening tools present characteristics of ASD in a variety of formats and are most often completed by parents and legal guardians (Thabtah & Peebles, 2019). An individual whose score falls above or below a criterion, depending on the screening tool used, is then referred for further evaluations related to ASD. Screening tools are highly researched and validated before being put into use (Thabtah & Peebles, 2019). Numerous screening tools exist for ASD, but each comes with their own limitations (Thabtah & Peebles, 2019).

Various screening tools were developed prior to 2013 before the DSM-V created the diagnosis of ASD (APA, 2013; Thabtah & Peebles, 2019). Asperger syndrome was challenging to distinguish from other developmental disorders when it was an included diagnosis in the DSM (APA, 2013; Thabtah & Peebles, 2019). The following screening tools were widely used and researched when screening for Asperger syndrome: Asperger Syndrome Diagnostic Scale (ASDS), Gilliam Asperger's Disorder Scale (GADS), Krug Asperger Disorder Index (KADI), and the Australian Scale for Asperger Syndrome (ASAS) (Thabtah & Peebles, 2019). These

tools all had a focus on social behaviors and communication (Thabtah & Peebles, 2019). They were all used to predict an individual's likelihood of having Asperger syndrome (Thabtah & Peebles, 2019). They can still provide important information related to ASD, but are no longer commonly used in the ASD screening process (Thabtah & Peebles, 2019).

One of the first created screening tools for ASD is the Quantitative Checklist for Autism in Toddlers (Q-CHAT) (Thabtah & Peebles, 2019). Q-CHAT was validated for use with children aged 18 to 24 months and was to be completed by a child's parents (Thabtah & Peebles, 2019). Studies showed Q-CHAT had a relatively low level of sensitivity at only 38% (Thabtah & Peebles, 2019). Q-CHAT was then altered to the Modified Checklist for Autism in Toddlers (M-CHAT) (Thabtah & Peebles, 2019). The M-CHAT contained over 20 questions completed using a rating scale (Thabtah & Peebles, 2019). There was an additional modification made creating the Modified Checklist for Autism in Toddlers, Revised (M-CHAT-R/F) which included a two-part screening method (Thabtah & Peebles, 2019). This process was found to be time-consuming, thus a shortened version of the M-CHAT-R/F was created using only 10 questions (10-Q-CHAT) (Thabtah & Peebles, 2019). This made the tool more user-friendly and time efficient thus causing it to gain popularity (Thabtah & Peebles, 2019). The 10-Q-CHAT is utilized worldwide and is available in multiple languages (Thabtah & Peebles, 2019). The 10-Q-CHAT has a sensitivity of 91% (Thabtah & Peebles, 2019).

Another screening tool that has been around for many years is the Child Behavior Checklist (CBCL) (Thabtah & Peebles, 2019). The CBCL was created in 1991 by Tomas Achenbach with the intention of screening children aged 1.5-18 for possible behavior disorders (Thabtah & Peebles, 2019). One hundred questions are rated on a Likert scale on the preschool version (ages 1.5-5) and 118 questions are completed on the school age version (ages 6-18)

(Thabtah & Peebles, 2019). The CBCL assesses both internal and external behaviors creating two sub scores that are added together for an overall score (Thabtah & Peebles, 2019). The higher the overall score, the greater the risk of a behavior disorder (Thabtah & Peebles, 2019). A study using the CBCL with a Brazilian sample population resulted in high sensitivity and specificity levels for the CBCL (Thabtah & Peebles, 2019).

The Autism Screening Instrument for Educational Planning – 3rd Version (ASIEP-3) is a five-part screening tool validated for use with individuals aged 0-13 (Thabtah & Peebles, 2019). Part one is an Autism Behavior Checklist (ABC) which measures a child's communication and language skills (Thabtah & Peebles, 2019). Part two requires collecting a sample of the child's vocal behaviors (Thabtah & Peebles, 2019). Part three is an interaction assessment where the child's spontaneous social skills and language abilities are assessed (Thabtah & Peebles, 2019). Part four is an educational assessment that determines a child's academic abilities (Thabtah & Peebles, 2019). Part five calculates the child's rate of learning (Thabtah & Peebles, 2019). The ASIEP-3 is a time-consuming screening tool typically lasting 90-120 minutes (Thabtah & Peebles, 2019).

The Autism Behavior Checklist (ABC) uses a rating scale questionnaire format to measure behaviors in five categories: sensory, communication and language skills, body language, social behaviors, and behaviors related to object use (Thabtah & Peebles, 2019). ABC is most often used for children ages 12-14 and is completed by a parent or teacher (Thabtah & Peebles, 2019). Studies have shown the ABC has a sensitivity rate of 77% and specificity rate of 91% (Thabtah & Peebles, 2019). ABC is commonly used to distinguish between autistic behaviors and behaviors associated with obsessive-compulsive disorders (OCD) (Thabtah & Peebles, 2019).

The Autism Spectrum Quotient (AQ) is intended for use with adults (Thabtah & Peebles, 2019). An individual answers the questions selecting definitely agree, slightly agree, slightly disagree, and definitely disagree (Thabtah & Peebles, 2019). The categorical score is converted to a numerical score ranging from 0-50 (Thabtah & Peebles, 2019). The cut-off score is 32 with a score greater than 32 being referred for further ASD evaluation (Thabtah & Peebles, 2019). The AQ can be used with ages 4-15 and completed by an adult in 20-30 minutes (Thabtah & Peebles, 2019). A shortened version of the AQ with 10 questions (AQ-10) uses a similar rating scale and has a cutoff score of six (Thabtah & Peebles, 2019). The AQ-10 can be used as a precursor to complete the AQ or can be a standalone screening tool (Thabtah & Peebles, 2019). The AQ has a sensitivity of 77% and specificity of 74% (Thabtah & Peebles, 2019).

The Childhood Autism Rating Scale (CARS) is intended to identify symptoms of ASD and rate their severity (Thabtah & Peebles, 2019). CARS was validated for use with children aged six and under, while the revised version, CARS-2, can be used with individuals aged 6-13 (Thabtah & Peebles, 2019). This questionnaire assesses hypo- and hyper-sensitivities, social behaviors, communication skills, and intellectual abilities (Thabtah & Peebles, 2019). CARS-2 can also determine whether an individual has a low, mild, or high level of ASD (Thabtah & Peebles, 2019). An individual must be trained to administer and score the CARS and CARS-2 (Thabtah & Peebles, 2019). CARS-2 had an 81% sensitivity and an 87% specificity (Thabtah & Peebles, 2019).

The Childhood Asperger Syndrome Test (CAST) was developed for use with children ages 5-11 to screen for signs of Asperger Syndrome (Thabtah & Peebles, 2019). Asperger Syndrome is no longer a diagnosis that can be given to children since the DSM-V definition of ASD was developed (American Psychiatric Association, 2013). The CAST still provides useful

information for screening for ASD (Thabtah & Peebles, 2019). This questionnaire includes 37 questions to be answered by parents or legal guardians (Thabtah & Peebles, 2019). The CAST utilizes a rating system where children who score higher than 15 are referred for further ASD evaluation (Thabtah & Peebles, 2019). The CAST has been shown to have a sensitivity of 100% and specificity of 97%.

The Developmental Behavior Checklist-Early Screen (DBD-ES) is one of the weaker rated screening tools for ASD (Thabtah & Peebles, 2019). Completion of the DBD-ES takes six-months and includes observing a child's behavior and emotional regulation skills (Thabtah & Peebles, 2019). There are multiple versions of the DBD-ES designed for ages 4-18 and 18-48 months of age (Thabtah & Peebles, 2019). Observations are converted to a rating scale by asking basic questions related to observed behaviors (Thabtah & Peebles, 2019). The DBD-ES has a sensitivity of 83% and specificity of 48% thus showing it is not a reliable screening tool for ASD (Thabtah & Peebles, 2019).

The Developmental Behavior Checklist-Autism Screening Algorithm (DBC-ASA) is a modified version of the DBD-ES (Thabtah & Peebles, 2019). Its goal is to distinguish between ASD and other developmental disorders for children aged 4-18 (Thabtah & Peebles, 2019). A parent or legal guardian completes the 29 questions relating to social and communication behaviors (Thabtah & Peebles, 2019). The sensitivity and specificity levels for the DBC-ASA are not explicitly reported, but it is noted that optimum levels were achieved for both (Thabtah & Peebles, 2019).

The Early Screening for Autistic Traits (ESAT) is intended for use with children suspected of having a developmental problem (Thabtah & Peebles, 2019). The ESAT was designed to distinguish behaviors related to ASD from other developmental disorders (Thabtah

& Peebles, 2019). The ESAT utilizes questions related to a child's social and communication skills (Thabtah & Peebles, 2019). ESAT can be completed in 10-15 minutes making it a desirable screening tool due to its time efficiency (Thabtah & Peebles, 2019). Studies utilizing the ESAT have shown it does not distinguish well between true and false positives of ASD (Thabtah & Peebles, 2019). The levels of sensitivity and specificity have not been determined due to the small number of studies that have used the ESAT (Thabtah & Peebles, 2019). Further research using the ESAT has the screening tool of choice is needed to determine whether it is a reliable screening tool for ASD (Thabtah & Peebles, 2019).

The Communication and Symbolic Behavior Scales Developmental Profile (CSBS-DP) screens children for possible challenges related to symbolic and expressive language (Thabtah & Peebles, 2019). Challenges with language are a key component of ASD; while this tool was not designed specifically for ASD, it can help to screen for behaviors related to ASD (Thabtah & Peebles, 2019). It can be used with children aged six months through six years (Thabtah & Peebles, 2019). It is a multi-step questionnaire that is completed by parents or legal guardians in 15-20 minutes (Thabtah & Peebles, 2019). Sensitivity and specificity have not been reported for the CSBS-DP (Thabtah & Peebles, 2019).

The Infant Toddler Check List (ICT) is one portion of the CSBS-DP (Thabtah & Peebles, 2019). This section of the CSBS-DP was designed to identify language delays even before a child begins to speak (Thabtah & Peebles, 2019). It is not specified for use as an ASD screening tool, but rather can be used to predict possible language delays for children aged 6-24 months (Thabtah & Peebles, 2019). The ICT uses a rating scale and can be completed in 5-10 minutes making it an efficient tool to use if language difficulties are suspected (Thabtah & Peebles, 2019). The ITC has a sensitivity of 78% and specificity of 84% (Thabtah & Peebles, 2019). The

ITC is a useful tool for discovering language delays early in a child's development (Thabtah & Peebles, 2019).

The First Year Inventory (FYI) was developed as research had shown the first year of life is the most critical stage of neurological development (Thabtah & Peebles, 2019). It is used to screen for neurobiological disorders related to social skills and sensory regulation (Thabtah & Peebles, 2019). It includes 63 questions using a Likert scale completed by an adult that closely observes the child (Thabtah & Peebles, 2019). There are no reported levels of sensitivity and specificity for the FYI (Thabtah & Peebles, 2019). The FYI continues to undergo studies and modifications to increase its efficacy in determining ASD versus other developmental disorders (Thabtah & Peebles, 2019).

Fine and gross motor skills are assessed when completing screenings for ASD as they can be a component of ASD behaviors (Thabtah & Peebles, 2019). The Movement Assessment Battery for Children (MABC-2) is norm-based for use with children aged 3-17 (Thabtah & Peebles, 2019). The assessment has three parts and are given based on a child's age (Thabtah & Peebles, 2019). A range of motor skills are assessed including a child's ball skills, dynamic and static skills, and self-care skills (Thabtah & Peebles, 2019). Each item is scored on a rating scale and an overall score is acquired (Thabtah & Peebles, 2019). A child who scores above 95 is at high-risk of having motor difficulties and is referred for further evaluation (Thabtah & Peebles, 2019). A score between 85-94 places a child at moderate risk for motor difficulties and is often referred for further evaluation (Thabtah & Peebles, 2019). A score below 85 indicates little to no risk for motor difficulties and further evaluation is not recommended (Thabtah & Peebles, 2019). The MABC-2 has a high level of specificity at 88%, but a low level of sensitivity at 41% thus making it an uncompelling screening tool (Thabtah & Peebles, 2019).

The Parents Evaluation of Developmental Status (PEDS) was created in 1996 by Frances Page Glascoe, a Professor of Pediatrics at Vanderbilt University (Thabtah & Peebles, 2019). The PEDS was designed to target parent concerns regarding a child's development or lack thereof (Thabtah & Peebles, 2019). PEDS is a 10-question questionnaire for use with children aged 3-19 (Thabtah & Peebles, 2019). The following are assessed on the PEDS: cognitive behavior skills, expressive and receptive language, fine and gross motor skills, social/emotional behaviors, self-care skills, and academic abilities (Thabtah & Peebles, 2019). The PEDS can be administered and scored by a parent giving the individual an immediate result as to whether a child may require further evaluations (Thabtah & Peebles, 2019). It is recommended that parents consult with a professional before seeking further evaluation (Thabtah & Peebles, 2019). The PEDS has a 79% sensitivity rate and 80% specificity rate (Thabtah & Peebles, 2019). This is a good starting point for parents with concerns about their child's development progress (Thabtah & Peebles, 2019).

The Pervasive Developmental Disorders Screening Test-Second Edition (PDDST-II) was created in 2004 as a revision to the PDDST developed in 1993 (Thabtah & Peebles, 2019). PDD is no longer a diagnosis given to children as it falls under ASD in the DSM-V definition (American Psychiatric Association, 2013). The PDDST-II is designed for use with children 18-48 months and has three parts: (1) determine a child's behaviors in their primary setting, (2) assess developmental milestones, and (3) distinguish between ASD and other developmental disorders (Thabtah & Peebles, 2019). The PDDST-II has shown variability in its rates of sensitivity and specificity ranging from 49%-92% (Thabtah & Peebles, 2019). The PDDST-II is not a frequently used screening tool for ASD due to its low levels of reliability and lack of refinement for the most up-to-date definition of ASD (Thabtah & Peebles, 2019).

The Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R) is a screening tool designed for use with adults over age 18 (Thabtah & Peebles, 2019). Dr. Ariella Riva Ritvo developed the RAADS-R in 2011 after noticing a need for screening tools to help diagnosis ASD in adults (Thabtah & Peebles, 2019). The RAADS-R consists of 80 questions completed by the individual in 20 minutes (Thabtah & Peebles, 2019). The RAADS-R has shown high levels of sensitivity and specificity at 97% and 100% respectively (Thabtah & Peebles, 2019). This tool is helpful in determining a diagnosis of ASD in adults who may not have met the criteria for ASD in childhood or developed ASD-like behaviors as an adult (Thabtah & Peebles, 2019).

The Screening Tool for Autism in Toddlers and Young Children (STAT) is designed for use with children aged 24-36 months suspected of having ASD (Thabtah & Peebles, 2019). The STAT can be utilized by a variety of professionals who work with children with ASD (Thabtah & Peebles, 2019). The STAT measures social behaviors including requesting items, imitating behaviors, cooperative play, and reacting to behaviors of others (Thabtah & Peebles, 2019). The STAT includes 12 items and can be completed in 20 minutes (Thabtah & Peebles, 2019). The STAT has been shown to have a 95% accuracy for sensitivity and 73% accuracy for specificity (Thabtah & Peebles, 2019). The STAT is a beneficial screening tool when determining levels of social interaction (Thabtah & Peebles, 2019).

The Social Communication Questionnaire (SCQ) is used to evaluate social and communication behaviors related to ASD (Thabtah & Peebles, 2019). The SCQ is available in two editions: lifetime and current (Thabtah & Peebles, 2019). The SCQ Lifetime has parents and legal guardians complete questions regarding the child’s development throughout their lifetime (Thabtah & Peebles, 2019). The SCQ Current considers behaviors from only the past three months (Thabtah & Peebles, 2019). Results of the SCQ have been used to develop Individual

Education Plans (IEPs), intervention programs, and treatment plans (Thabtah & Peebles, 2019). The SCQ has shown high levels of sensitivity and specificity at 96% and 80% respectively (Thabtah & Peebles, 2019). The SCQ is one of the more commonly used screening tools for ASD (Thabtah & Peebles, 2019).

The Social Responsiveness Scale (SRS) is a 65-question questionnaire completed by family members of an individual aged 4-18 to evaluate social interactions and behavior challenges (Thabtah & Peebles, 2019). The SRS-2 is an updated version of the SRS released in 2012 (Thabtah & Peebles, 2019). It includes questions relating to the following categories: social awareness, social motivation, social cognition, restricted interests, and social communication (Thabtah & Peebles, 2019). The SRS-2 can determine if a child may have ASD and the severity level of ASD (Thabtah & Peebles, 2019). Several studies have concluded the overall sensitivity of the SRS-2 to be 78% and the specificity to be 94% (Thabtah & Peebles, 2019).

The Autism Spectrum Screening Questionnaire (ASSQ) forms the basis for this dissertation study. The ASSQ was developed by Ehlers, Gillberg, and Wing in 1993 (Zirakashvili et al., 2022). It was designed to screen for Asperger syndrome but has since been validated to screen for ASD (Zirakashvili et al., 2022). It is one of the most used ASD screening tools (Zirakashvili et al., 2022). The ASSQ includes 27 questions completed by a parent or teacher of a child aged 7-16 rated on a scale from 0-2 (yes, somewhat, no) and determines whether an individual has characteristics of ASD (Thabtah & Peebles, 2019). The ASSQ has an overall accuracy of 90% with a 91% sensitivity and 86% specificity (Thabtah & Peebles, 2019). The ASSQ-REV is a revision of the ASSQ.

The ASSQ-REV was created by Kopp & Gillberg in 2011 (Kopp & Gillberg, 2011). The intent of the revision was to include questions specific to the female phenotype of ASD (Kopp &

Gillberg, 2011). The goal of the ASSQ-REV is to identify females with ASD at rates closer to those of males with ASD (Kopp & Gillberg, 2011). An additional 18 questions specific to the female phenotype of ASD were added to the original 27 questions on the ASSQ (Kopp & Gillberg, 2011). There have not been enough studies utilizing the ASSQ-REV to determine levels of sensitivity and specificity (Kopp & Gillberg, 2011). This study used the ASSQ-REV as the primary assessment for collecting data (Kopp & Gillberg, 2011).

Analysis of certain ASD screening tools has led to an under identification of females being identified for further evaluations (Dworzynski et al., 2012). Dworzynski et al. (2012) carried out a quantitative study to compare results of the Childhood Autism Spectrum Test (CAST) between males and females. The researchers examined the CAST results for two groups: girls and boys aged 10-12 meeting diagnostic criteria for ASD and girls and boys aged 10-12 failing to meet diagnostic criteria for ASD despite high scores on the CAST. Results indicated females meeting the diagnostic criteria for ASD had significantly more problems (i.e., low intellectual level, behavioral difficulties) than males meeting the diagnostic criteria for ASD. The researchers hypothesize girls are less likely than boys to meet ASD diagnostic criteria when exhibiting the same level of autistic traits. This may be due to gender bias in ASD assessment or reflection of females' ability to camouflage behaviors. Further research is needed to determine whether ASD assessment tools are accurately measuring the characteristics of females with ASD.

One challenge in creating accurate screening tools to identify females with ASD is the current rate at which females are identified with ASD compared to males. Presently, males are prominent in studies related to ASD as more males are identified with ASD than females.

Morales-Hidalgo et al. (2018) conducted a quantitative study of Spanish speaking school-aged children to determine rates and severity of ASD within the population. A sample of 5,582 children were screened for the study, with a total of 557 children participating in the study. The researchers used a two-part procedure to collect data: first, participants were screened for ASD and second, all participants were assessed by trained clinicians to determine whether they met the criteria for a positive ASD diagnosis. Results showed significant gender differences in all categories (risk symptoms, subclinical diagnosis, and clinical diagnosis) with males exhibiting higher prevalence of characteristics than females. Preschool girls with ASD presented with lower communication problems and severity scores on the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) than preschool boys with ASD. Primary aged girls with ASD had less communication problems than primary aged boys with ASD as assessed by the ADOS-2. The researchers' data confirmed that parents and teachers expressed fewer concerns for girls than boys with regards to concerns for ASD at the preschool and primary age. This study was strong in determining rates of ASD among children for the identified nationality and geographic locations. The study was lacking in the inclusion of females with ASD. Further research needs to include greater sample sizes of females with ASD to draw accurate conclusions when making comparisons between the sexes.

Additional studies highlight the male dominance in ASD identification. Stroth et al. (2022) analyzed whether existing screening tools were accurately identifying females with ASD. The researchers used data from existing completed ADOS screeners for 1057 participants diagnosed with ASD, 18.1% who are female, and 1230 participants not diagnosed with ASD, 17.9% who are female. A random forest algorithm combined with t-tests were used to analyze

the data. Stroth et al. concluded while there were some phenotypic differences between males and females evidenced in the ADOS, their results do not show a need for new diagnostic tools to be created to identify females with ASD. The researchers determined that the ADOS was as effective in identifying females with ASD as it was for males with ASD. They do state that different categories held different weights for the overall classification, but the outcome for a diagnosis remained the same between the sexes.

Additional biological factors are being analyzed in different studies to highlight the differences between the male and female phenotype of ASD. Werling (2016) carried out a literature review to analyze why rates of ASD are higher in males than in females. Werling focused on biological differences between the sexes when reviewing the literature. Werling used data from qualitative and quantitative studies to derive three main conclusions: autism prevalence is male-biased, there is evidence for a female protective effect in ASD and proposed biological risk and protective factors for ASD. Werling makes these judgements based on data collected from studies conducted in the fields of ASD research and biology research. Werling claims rates of ASD are higher for males than females due to a bias in diagnostic criteria that caters towards male characteristics of ASD. Werling found that biological studies concluded that females have a greater genetic predisposition to female protective effect than males. Werling's study highlights the need for further research into biological differences between males and females with ASD. This study also brings forth the need to continue to review ASD diagnostic processes and evaluate whether the process is taking into consideration the unique characteristics of females with ASD.

Other studies have supported claims made by Werling (2016). Ratto et al. (2018) carried out a quantitative study to compare characteristics of ASD between males and females. The

purpose of the study was to use standardized measures to determine sex differences within the population of individuals with an ASD. A matched sample of 228 children (114 females, 114 males) was created ensuring no statistical difference in age or IQ between matched participants. The researchers used the Autism Diagnostic Observation Schedule (ADOS or ADOS-2), Autism Diagnostic Interview- Revised (ADI-R), the Social Responsiveness Scale (SRS) completed by parents, and the Vineland Adaptive Behavior Scales, Second Edition, Survey Interview (Vineland-II) to collect data on characteristics of ASD observed in the participants. Pearson chi square analyses were used to determine the sex differences in rates of ASD on the ADOS and ADI-R, and *t* tests were used to assess differences in sex using the ADOS Comparison Score. Results showed there were no significant sex differences in the ADOS Comparison Score, consistent with the researchers' hypothesis. There were no significant differences in males and females for meeting the diagnostic criteria for ASD using the ADI-R. No significant sex differences were found in play skills or conversation skills on the ADOS. Item-level analysis of the ADOS evidenced females scored lower than males on the expressive interests' section concluding that females demonstrated fewer restricted or repetitive behaviors than males. Findings concluded that females showed lower rates of hyperactivity than males, and females scored higher in identifying and sharing emotions with others than males. The Vineland-II revealed significant differences on all five domains of the SRS with females having significantly stronger autistic traits: females had lower scores on daily living skills than males, social skills were more impaired in females, and females with ASD were more impaired compared to typically developing females than males with ASD compared to typically developing males. Item analyses of the ADOS and results of the Vineland-II in this study demonstrate the need for further research explicitly studying distinct characteristics of ASD and how they are observed in

males and females. The researchers suggest conducting further studies comparing males and females with ASD based on a DSM-V criteria diagnosis rather than a diagnosis from the ADOS or other standardized measure. This would account for a broader sampling of females with an ASD that have not been identified using standardized measures.

The female phenotype of ASD is a relatively new topic of study in the realm of ASD, thus inclusion of criteria related to the female phenotype of ASD is still being investigated. Lundström et al. (2019) conducted a quantitative study statistically comparing standardized raw scores on the Autism-Tics, Attention-Deficit/Hyperactivity Disorder (ADHD), and Comorbidities (A-TAC) rating scale between males and females diagnosed with ASD. The researchers used parent-interviews to complete the A-TAC rating scale for 308 boys and 122 girls diagnosed with ASD participating in a Child and Adolescent Twin Study in Sweden. Results indicated males had a higher raw score on the A-TAC than females. Conversion of female raw scores to z-scores showed female scores deviated farther from the mean score for females than male scores deviated for the mean score for males. Females also had higher standardized mean values than males for the categories of ADHD, learning disabilities, and Oppositional Defiance Disorder (ODD). Results suggest that females must demonstrate more extreme behaviors than males to meet the same cutoff criteria for consideration of an ASD diagnostic evaluation. Further research needs to consider whether rating scales are accurately identifying female characteristics of ASD and whether sex-specific cutoff scores should be developed.

Screening tools may not be accurately identifying females because the female phenotype of ASD is not wholly included in screening questions. Frazier et al. (2013) conducted a quantitative study to determine differences in characteristics of Autism in males and females.

Participant data were drawn from the Simons Simplex Collection, a resource of the Simons Foundation Autism Research Initiative. Data were analyzed from 2,418 individuals (304 female and 2,114 male). The researchers used data drawn from formal assessments to analyze core autism symptoms, cognitive and motor functioning, and adaptive behavior and associated problems. Differences in the characteristics were estimated using independent sample t-tests or Chi-square statistics. Results showed females with autism had lower levels of restricted interests, lower cognitive abilities, weaker adaptive skills, greater externalizing problems, and greater social communication impairments than males with autism. IQ reduction showed greater social impairments and reduced adaptive behavior in females with autism. No statistically significant difference was found in the diagnostic assessments indicating these instruments captured autism characteristics equivalently in males and females. The researchers state that evaluators need to be aware of differences between males and females with autism and how those characteristics will be portrayed using diagnostic assessments. Future studies are needed to look specifically at behavior examples and specific cognitive processes are needed to further understand sex differences in autism.

Females tend to have to display more extreme behaviors than males just to be identified at the same level of behavior. Lundström et al. (2019) conducted a quantitative study statistically comparing standardized raw scores on the Autism-Tics, Attention-Deficit/Hyperactivity Disorder (ADHD), and Comorbidities (A-TAC) rating scale between males and females diagnosed with ASD. The researchers used parent-interviews to complete the A-TAC rating scale for 308 boys and 122 girls diagnosed with ASD participating in a Child and Adolescent Twin Study in Sweden. Results indicated males had a higher raw score on the A-TAC than females. Conversion of female raw scores to z-scores showed female scores deviated farther from the mean score for

females than male scores deviated for the mean score for males. Females also had higher standardized mean values than males for the categories of ADHD, learning disabilities, and Oppositional Defiance Disorder (ODD). Results suggest that females must demonstrate more extreme behaviors than males to meet the same cutoff criteria for consideration of an ASD diagnostic evaluation. Further research needs to consider whether rating scales are accurately identifying female characteristics of ASD and whether sex-specific cutoff scores should be developed.

Qualitative and quantitative studies are both beginning to highlight discrepancies between the female phenotype of ASD and screening tools being used to alert practitioners to these characteristics. Kirkovski et al. (2013) completed a qualitative review of the literature related to the profile of females with an ASD. The authors reviewed 113 papers found in the Medline and Psych-Info databases. The researchers analyzed the literature to draw conclusions around topics related to ASD and gender. The authors used qualitative methods to create a discussion of results drawn from the literature. Analysis of the literature revealed five key themes: clinical and diagnostic features, comorbid psychopathology, cognition and neuropsychological profiles, etiology, and brain development. Females tend to not display characteristics of ASD that are required in a diagnosis. Females with ASD are observed to have comorbid diagnoses at the same rates as males with ASD. Females with ASD tend to have lower cognitive abilities than males with ASD. Findings have suggested that females need to have greater genetic abnormalities to display ASD characteristics than males. Much of the current literature focuses on males with ASD. Future research needs to explore gender differences across the autism spectrum using greater numbers of females with ASD in studies. This will lead to a better understanding of characteristics of ASD in females for researchers, practitioners, and the public.

ASD screening tools are often under scrutiny for their abilities to distinguish between socio-cultural behaviors and behaviors related to ASD. Kreiser & White (2013) examined socio-cultural factors that may influence the rates of ASD diagnosis in males and females. The researchers analyzed existing literature to determine if differences in societal and cultural expectations of males and females influence the rates of ASD diagnosis. Kreiser & White (2013) contend under identification of females with ASD without co-occurring intellectual impairment is likely due to subtle gender differences in symptom presentation. Females are less likely than males to engage in stereotypical and repetitive behaviors and experience greater internalizing problems than males. These differences between the male and female ASD phenotype may contribute to bias in assessment and diagnostic tools. Further analysis of assessment and diagnostic tools for ASD is needed to determine whether they are biased towards a male phenotype.

Socio-cultural factors must be considered in the identification of ASD as social-communication deficits are a key component of the definition of ASD. Evans et al. (2018) completed a quantitative study using a population-based sample of children in South Carolina ages 8-10. The purpose of the study was to review performances of girls and boys on the Social Communication Questionnaire (SCQ). The population sample produced 3,520 eligible children, with a total of 272 of those children completing the direct assessment. The researchers used the SCQ Lifetime Form to screen for ASD in the full sample. Two hundred seventy-two participants completed a direct assessment which included a primary caregiver interview, Autism Diagnostic Observation Schedule, and assessments related to social and cognitive functioning. A bifactor model was used to analyze the SCQ data. Results showed that boys were more likely to fall into the “at-risk” or “subthreshold” categories for ASD than girls. Boys were rated higher than girls

for all symptoms counts on the SCQ. Girls with ASD have higher SCQ scores than typically developing girls but have greater social communication problems. Girls with ASD were found to have greater social communication problems than boys with ASD. Findings coincide with the sentiment that girls need to exhibit more severe difficulties to receive an ASD diagnosis. The study utilized an unpublished structured interview format to assess the population. The researchers state that this assessment was chosen due to a bias towards males in ASD definitions and diagnoses that correlates to well-validated, published assessments. The study promotes broader research specifically around social-communication and interaction behaviors in girls ages 4-5.

ASD screening tools continue to be designed and redeveloped as research persists to highlight key characteristics of ASD (Thabtah & Peebles, 2019). An area for continued research and advancement is the inclusion of female characteristics of ASD in screening tools (Thabtah & Peebles, 2019). Tools need to be developed to better identify females with possible ASD at younger ages to get them earlier interventions (Ratto et al., 2018). Access to early interventions will help mitigate behaviors related to ASD, yet these interventions cannot be provided unless females are identified on screening tools and referred for evaluations at a younger age (Ratto et al., 2018).

Analysis of the Autism Spectrum Screening Questionnaire – Revised Extended Version

Presently, only one study exists that utilized the ASSQ-REV as the screening tool being measured. Kopp & Gillberg (2011) completed a quantitative study to determine the effectiveness of the ASSQ-REV in identifying females with ASD. The researchers took the existing Autism Spectrum Screening Questionnaire (ASSQ) and used focus groups and experts in ASD to develop an additional 18 questions specific to the female phenotype of ASD (ASSQ-GIRL)

creating the ASSQ-REV. Participants included 71 clinic females (females with ASD, ADHD, or other neuropsychiatric disorders), 62 clinic males (males with ASD, ADHD, or other neuropsychiatric disorders), and 58 community females (neurotypical females). The SPSS 14.0 and SAS 9.2 were used for statistical analysis of the ASSQ-REV scores. Results showed no statistically significant differences in mean scores between clinic females and males. Opposingly, there were statistically significant differences between community females and females with ASD on all but two items on the ASSQ-REV. This study shows that the ASSQ-REV was able to capture differences between neurotypical females and females with ASD. Further research is required to determine the effectiveness of the ASSQ-GIRL questions in identifying the female phenotype of ASD compared to the male phenotype of ASD.

Analysis of the Literature

Comparison of Autism Spectrum Disorder Characteristics Between Males and Females

Three main themes emerged from the literature relating to characteristics of ASD between males and females: internalizing characteristics, diagnostic definitions and assessments that are missing or overlooking key intrinsic traits displayed by females with ASD, and biological differences (Backer van Ommeren et al., 2016; Burton et al., 2020; Cridland et al, 2013; Dean et al., 2014; Harrop et al., 2018; Locke et al., 2018; Reindal et al., 2020). Internalizing characteristics focuses on behaviors directed towards oneself. Diagnostic definitions and assessments relate to receiving a formal diagnosis of ASD. Biological differences acknowledge the physical, chemical, and genetic composition of one’s body. These identified themes serve as a basis for further research.

Internalizing characteristics are behaviors directed inwardly towards oneself including depression, social-withdrawal, obsessive-compulsive behaviors, and selective mutism (Gresham

et al., 2004). Arwert and Sizoo (2020) found adult females with ASD reported higher rates of depression, greater number of suicide attempts, and higher rates of suicidal ideation than adult males with ASD. Greenlee et al. (2020) study results showed that females with ASD reported higher rates of depression and anxiety than males with ASD. South et al. (2020) identified a theme claiming relentless distress is related to poor mental health for women with autistic traits. Research is beginning to show that females with ASD possess higher levels of internalizing characteristics than males with ASD.

Biological differences between males and females with ASD is a topic emerging in the literature. Kirkovski et al. (2013) findings suggest females need to have greater genetic abnormalities to display ASD characteristics than males. Werling (2016) found that biological studies concluded that females have a greater genetic predisposition to female protective effect than males. Additional research needs to focus on the biological foundation of ASD and its relation to characteristics displayed in females.

Implications of Characteristics of Autism Spectrum Disorder in Females on Screening Tools

Diagnostic definitions and assessments that are missing or overlooking key intrinsic traits displayed by females with ASD were mentioned in many of the studies. Dean et al. (2014) presented data that support emerging research that characteristics of ASD differ based on gender. Evans et al. (2018) had findings that coincide with the sentiment that girls need to exhibit more severe difficulties to receive an ASD diagnosis. Frazier et al. (2013) stated evaluators need to be aware of differences between males and females with autism and how those characteristics will be portrayed using diagnostic assessments. Kirkovski et al. (2013) concluded females tend to not display characteristics of ASD that are required in a diagnosis. Werling (2016) claims rates of

ASD are higher for males than females due to a bias in diagnostic criteria that caters towards male characteristics of ASD. Research is highlighting the differences in ASD traits displayed between females and males with ASD. At times, characteristics displayed by females are often unnoticed or underemphasized in diagnostic definitions and assessments for ASD.

Analysis of the Autism Spectrum Screening Questionnaire – Revised Extended Version

A study conducted by Kopp & Gillberg (2011) concluded the ASSQ-REV discriminated well between cases of diagnosed ASD and non-diagnosed individuals. A theme that emerges from this study is how certain questions meant to identify the female phenotype of ASD did identify females eventually diagnosed with ASD more often than neurotypical females. Thus, remains the question as to whether the ASSQ-REV is effectively identifying females at-risk for being identified with an ASD.

Purpose for the Study

The purpose of this study stems from the research conducted by Kopp & Gillberg (2011). Kopp & Gillberg (2011) took the Autism Spectrum Screening Questionnaire (ASSQ) and developed an additional 18 questions specific to the female phenotype of ASD, which they titled ASSQ-GIRL, and created the ASSQ-REV. Kopp & Gillberg (2011) were able to conclude that the ASSQ-REV differentiated well between neurotypical females and females with ASD. Their study did not show statistically significant differences between males and females on the ASSQ-GIRL questions. This study will take the ASSQ-REV and analyze the ASSQ-GIRL questions to determine the accuracy of the questions to capture the female phenotype of ASD compared to the male phenotype of ASD.

The goals of this study are to (1) evaluate the accuracy of the ASSQ in identifying males and females with ASD and (2) evaluate the accuracy of the ASSQ-GIRL questions in

distinguishing between the female and male phenotypes of ASD. Literature has shown that females are significantly under-identified with ASD compared to males (Loomes et al., 2017; McCrossin, 2022; Nag et al., 2018; Posserud et al., 2021; Ratto et al., 2018; Zhang et al., 2020). This may stem from screening tools based on the male phenotype of ASD. Research is needed to determine if the ASSQ-GIRL has the potential to equalize the rates of ASD identification between males and females.

Research into females with ASD continues to be prominent in the field of special education. More research is needed to examine the tools that are being used to screen females for further assessments to determine if they qualify for a diagnosis of ASD. Screening tools are the first step in an ASD diagnostic process. Rates of ASD in females will continue to be lower than rates of ASD in males if females continue to not be accurately identified by screening tools. This study plans to add relevant data and information regarding the ASSQ-REV to the field to continue to adapt and modify existing screening tools to better identify the female phenotype of ASD.

Conclusion

Research is beginning to bring forth the differences in characteristics and display of ASD between males and females (Backer van Ommeren et al., 2016; Burton et al., 2020; Cridland et al, 2013; Dean et al., 2014; Harrop et al., 2018; Locke et al., 2018; Reindal et al., 2020). Analysis of the literature showed females with ASD tend to have more internalized behaviors and traits than males with ASD. Females with ASD are often overlooked due to underrepresentation of their common ASD traits in screening and diagnostic measures (Dworzynski et al., 2012; Evans et al., 2018; Frazier et al., 2013; Kirkovski et al., 2013; Kreiser & White, 2013; Lundström et al., 2019; Morales-Hidalgo et al., 2018; Ratto et al., 2018; Werling, 2016). Research is continuing to

inquire into the biological differences between the sexes and presentation of ASD. Females with ASD is an emerging topic in the literature.

Further research needs to focus on identifying characteristics of ASD presented in females. Subsequently, the inclusion of these ASD traits in screening and diagnostic assessments needs to be made to accurately identify females with ASD. Females with ASD tend to be underrepresented in studies of ASD because they are identified with ASD at rates much lower than males (Ratto et al., 2018). Comparison of characteristics of ASD between the sexes shows that females with ASD exhibit symptoms and behaviors that often differ from males with ASD (Backer van Ommeren et al., 2016; Burton et al., 2020; Cridland et al, 2013; Dean et al., 2014; Harrop et al., 2018; Locke et al., 2018; Reindal et al., 2020). Accurate identification of ASD in females will come with additional research into differences in ASD characteristics between the sexes and modifications to assessments that are used to diagnose ASD.

Research has begun to highlight the differing characteristics of ASD between males and females (Backer van Ommeren et al., 2016; Burton et al., 2020; Cridland et al, 2013; Dean et al., 2014; de Giambattista et al., 2021; Harrop et al., 2018; Locke et al., 2018; Reindal et al., 2020). This research prompted an analysis of the effectiveness of screening tools for ASD in identifying females at-risk for a diagnosis of ASD (Dworzynski et al., 2012; Evans et al., 2018; Frazier et al., 2013; Kirkovski et al., 2013; Kreiser & White, 2013; Lundström et al., 2019; Morales-Hidalgo et al., 2018; Ratto et al., 2018; Stroth et al., 2022; Werling, 2016). Researchers then expanded upon a commonly used screening tool for ASD, the Autism Spectrum Screening Questionnaire (ASSQ) developing a revised edition intending to better identify the female phenotype of ASD (Kopp & Gillberg, 2011). Only one peer-reviewed study exists measuring the validity of the ASSQ-REV in identifying females at-risk for a diagnosis of ASD (Kopp &

Gillberg, 2011). Thus, a gap in the literature exists in determining whether the ASSQ-GIRL is effective in identifying females at-risk for a diagnosis of ASD.

CHAPTER 3

The female to male ratio for a diagnosis of ASD is 1:3.8 (Maenner et al., 2023). An estimated 75 million people worldwide have ASD (Centers for Disease Control and Prevention, 2022). This means approximately 18.75 million females worldwide have ASD (Centers for Disease Control and Prevention, 2022). About one in 36 children in the United States is diagnosed with ASD (Centers for Disease Control and Prevention, 2022). Thus, roughly 1.68 million children living in the United States are diagnosed with ASD (Centers for Disease Control and Prevention, 2022). An estimated 400,000 of those children are female (Centers for Disease Control and Prevention, 2022; Nag et al., 2018; Ratto et al., 2018; Zhang et al., 2020).

This study utilized a homogeneous convenience sample to obtain participants. Homogenous convenience sampling has an advantage over heterogenous sampling as it allows for a greater level of generalizability as there are fewer differences in the population and subpopulations (Jager et al., 2017). Heterogenous samples include participants from diverse backgrounds without matching participants based on specified characteristics (Jager et al., 2017). Homogenous sampling includes specific constraints and are tied to a target population (Jager et al., 2017). A homogenous sample offers a narrower, but more specific generalization of findings as it is tied to a specific population or characteristic (Jager et al., 2017). The more homogenous a sampled population is, the more likely it is that findings can be generalized to the population (Jager et al., 2017). Homogenous convenience sampling more closely mimics probability sampling than heterogenous sampling as it narrows the focus of findings to the specified population (Jager et al., 2017).

Participants shared two characteristics: (1) a parent or legal guardian of an individual aged 6-17 with a formal diagnosis of ASD and (2) reside in the United States. These two criteria were

chosen for this study based on validated data. The Autism Spectrum Screening Questionnaire (ASSQ) is validated for use with individuals aged 6-17 thus leading to the first inclusion criteria (Ehlers, Gillberg, & Wing, 1999). The Centers for Disease Control and Prevention estimates 1 in 36 children is diagnosed with ASD (Centers for Disease Control and Prevention, 2022). Ample data exist on the number of individuals diagnosed with ASD in the United States. The researcher is a resident of the United States. These factors contributed to the inclusion of the second criteria to participate in this study.

Participants were provided with an informed consent form. They were given the option to select “yes” or “no” regarding their participation in the study. Participants who selected “no” were prompted to exit the study. A homogenous convenience sampling method was used to recruit participants, thus there is no Internal Review Board (IRB), or site permission required. Participants were able to read information about the study, including risks, before deciding to give consent and complete the study.

Risks of the study included breach of confidentiality, psychological discomfort, and coercion. Breach of confidentiality was possible since an online platform was utilized to collect participant data. This was minimized by removing personally identifying demographic questions from the survey and using an online form (Google Forms) with built-in data protection services. Psychological discomfort was possible as the questions could bring forth negative thoughts or feelings relating to the participants’ child. This risk was lessened by allowing participants to discontinue the study at any point without ramifications and by providing participants with information about the study before being asked to complete the questionnaire. Coercion was possible as convenience sampling was utilized, and participants may have felt obligated to participate due to the nature of their relationship with the person from whom they learned about

the study. This was minimized by allowing participants to read and agree to the informed consent before participating anonymously in the study.

This study utilized elements of the ASSQ which is standardized for youth ages 6-17 (Adachi et al., 2018; Ehlers et al., 1999; Kopp & Gillberg, 2011). This study focused on females and males aged 6-17 with ASD living in the United States. Sample size is a representation of individuals from a population (Qualtrics, 2020). Sample size allows researchers to generalize findings to a population using statistical analysis (Qualtrics, 2020). McNemar's test is the statistical analysis used for this study. McNemar's test does not have a minimum sample size requirement. A minimum of one participant per group was required to conduct a statistical analysis. The participants had to complete both the ASSQ and ASSQ-GIRL, which was ensured by having both questionnaires included in the one survey link. This maintained the number of participants per participant group remained the same for both the ASSQ and ASSQ-GIRL.

Quantitative methodology uses probability or non-probability sampling to gather participants for research studies (Elfil & Negida, 2017). This study employed the non-probability sampling method of convenience sampling (Elfil & Negida, 2017). Convenience sampling includes participants to which the researchers have easy access (Elfil & Negida, 2017). Data were collected from parents and/or legal guardians of individuals in two different participant groups. Group 1 consisted of parents/guardians of females aged 6-17 living in the United States with a formal diagnosis of ASD. A formal diagnosis of ASD can be made by a pediatric neurologist, developmental or behavioral pediatrician, or a child psychiatrist (Boston Medical Center). Group 2 contained parents/guardians of males aged 6-17 living in the United States with a formal diagnosis of ASD. Matching age groups, disability category, and country of residence allowed for generalizations to this population. Each participant was assigned a random number

upon completion of the questionnaire to report findings while maintaining participant confidentiality.

Parents and/or legal guardians of the individuals within each group were provided with a quick-response (QR) code and online link to a modified version of the ASSQ-REV (see Appendix A) (Kopp & Gillberg, 2011). Parents and/or legal guardians were provided a copy of the informed consent which included the purpose of the study, expected duration of participation, statement that research voluntary and consent can be withdrawn at any time, risks, and benefits of participation in the study, and confidentiality (Manti & Licari, 2018). Participant data were only included in analysis if a signed informed consent form was provided. This was necessary to comply with regulations surrounding the use of human participants in research studies (Manti & Licari, 2018).

Four demographic questions were removed from the ASSQ-REV: “name of child,” “date of birth,” “name of rater,” and “date of rating” (Kopp & Gillberg, 2011). These changes were necessary to ensure the confidentiality of the participants. Four demographic questions replaced the eliminated questions to determine into which participant group their child would qualify: (1) how old is your child? (2) does your child have a formal diagnosis of autism spectrum disorder (ASD) (formal diagnosis is defined as a diagnosis of ASD from a pediatric neurologist, developmental or behavioral pediatrician, or a child psychiatrist (Boston Medical Center))? (3) select the sex of your child: female or male, and (4) do you and your child currently reside in the United States? Privacy was protected by not recording child or parent names, collecting forms in a secure online location, and not asking for personally identifying information including student grade, student identification number, and student school of attendance.

Two open-ended questions were removed from the end of the ASSQ-REV as they do not affect the scoring of the questionnaire: “write down the behaviors or difficulties that most concern you at present” and “list this child’s greatest strengths or qualities” (Kopp & Gillberg, 2011). The intent of this study was to make statistical comparisons of the data. The two questions removed from the questionnaire do not factor into the overall scoring of the ASSQ-REV. Written responses cannot be quantified to include in a final score thus it was necessary to remove these questions to remain focused on the quantitative nature of the study. The ASSQ-REV modified version used for this study did not alter the rating scale, wording of directions, or wording of questions from the ASSQ-REV created by Kopp & Gillberg (2011).

The research questions for this study were (1) what is the accuracy of the ASSQ in identifying males and females with ASD and (2) what is the accuracy of the ASSQ-GIRL questions in distinguishing between the female and male phenotypes of ASD (Kopp & Gillberg, 2011)? The hypothesis tied to the first research question states males will more accurately be identified than females as having ASD using the ASSQ. The hypothesis tied to the second research question states the ASSQ-GIRL will identify the female phenotype of ASD at a greater rate than the male phenotype of ASD. Accuracy rates were determined by taking the total number of participants diagnosed with ASD and comparing the rate of individuals that met the threshold for further ASD testing using the ASSQ and ASSQ-GIRL (Kopp & Gillberg, 2011). All participants in the study had a child with an ASD diagnosis, thus the accuracy rates for the completed ASSQ and ASSQ-GIRL questionnaires in this study should be 100 percent.

The female phenotype of ASD is characterized by camouflaging social behaviors, low self-esteem, immaturity, hyper- or hypo-sensitive to sensory elements, and shyness or hesitation in social situations (Backer van Ommeren et al., 2016; Burton et al., 2020; Cridland et al., 2013;

Dean et al., 2014; de Giambattista et al., 2021; Locke et al., 2018; Stroth et al., 2022). Female phenotype of ASD is operationalized by the following set of items from the ASSQ-REV titled ASSQ-GIRL (Kopp & Gillberg, 2011):

- Copies you (can be in a very discrete way)
- Episodes of eating problems
- No time perception
- Too much sympathy
- Extremely interested in pop/rock bands, soap operas, or catastrophes involving large numbers of people
- Avoids demands
- Very determined
- Difficulties with choosing; always avoids choosing
- Difficulties with self-care
- Carefree or over meticulous with regard to physical appearance and dress
- Naïve
- Comes too close to other people
- Interacts mostly with younger children
- Engages in dangerous activities
- Exaggeratedly fanciful
- Talks without content
- Writes long stories (which can be in stark contrast to level of talk)
- Acts or lives different parts (TV stars, videos, animals)

The hypotheses for this study examine differences in the questions specific to the female phenotype of ASD as they relate to differences between the sexes. Sex is defined as the biological attributes assigned at birth and identified using the terminology “male” or “female” (Torgrimson & Minson, 2005). ASD is characterized by restrictive and repetitive interests and behaviors, difficulties with social interaction, sensory sensitivities, motor and/or speech difficulties (Burton et al., 2020; Dean et al., 2014; Harrop et al., 2018; Locke et al., 2018; Reindal et al., 2020). ASD is operationalized by the inclusion of all questions on the ASSQ-REV.

Data Collection

Data was collected from the ASSQ-REV online form provided to families of participants in the two participant groups. The following steps were required of the parent or guardian to complete all parts of the data collection procedure:

1. Read this informed consent form (approximate time to complete: 10 minutes).
2. Sign and date this consent form (approximate time to complete: 5 minutes).
3. Select a response for the four demographic questions on the ASSQ-REV (approximate time to complete: 5 minutes).
4. Read each statement on the ASSQ-REV and select a response ranging from “no, not at all” to “yes, all the time” that best describes your child (approximate time to complete: 20 minutes).
5. Submit the completed survey (approximate time to complete: 2 minutes).

Data Analysis

Participants were divided into two categories based on collected demographic information. Group 1 was parents and/or legal guardians of females aged 6-17 with a formal

diagnosis of ASD. Group 2 was parents and/or legal guardians of males aged 6-17 with a formal diagnosis of ASD. Parents and/or legal guardians were the individuals who provided the information for this quantitative study, but the data were reported for children aged 6-17.

This study proposed two hypothesizes: (1) the ASSQ positively identified males with ASD at a rate higher than identifying females with ASD and (2) the ASSQ-GIRL positively identifies females with ASD at rates higher than positively identifying males with ASD. The dependent variable (females or males with ASD) is categorical, and the dichotomous trait (ASSQ or ASSQ-GIRL scores) is applied at two different points on the same population thus McNemar's test is an appropriate statistical measure for the hypotheses (McNemar's test, 2022).

Hypotheses Testing

McNemar's Test is, "a non-parametric (distribution-free) test [that] assesses if a statistically significant change in proportions has occurred on a dichotomous trait at two time points on the same population (McNemar's test, 2022)." McNemar's test is calculated using a 2x2 contingency table that represents paired categorical data (McNemar's test, 2022). The table is comprised of four cells and each cell represents a combination of the two dual outcomes being compared (McNemar's test, 2022). Cell A represents the number of cases where both observations are concordant, or are in the same category (McNemar's test, 2022). Cell D represents the number of cases where both observations are discordant, or both are in different categories (McNemar's test, 2022). Cells B and C represent the number of cases where the first observation is in one category, and the second observation is in the other category (McNemar's test, 2022).

In this study, cell A represented a positive or above the cutoff score on both the ASSQ and ASSQ-GIRL in this study. Cell B represented a positive or above the cutoff score on the

ASSQ-GIRL and a negative or below the cutoff score on the ASSQ. Cell C represented a positive or above the cutoff score on the ASSQ and a negative or below the cutoff score on the ASSQ-GIRL. Cell D represented a negative or below the cutoff score on both the ASSQ and ASSQ-GIRL.

McNemar's test statistic is calculated using the formula $x^2 = \frac{(b-c)^2}{b+c}$ (McNemar's test, 2022). This test statistic follows a chi-square distribution with 1 degree of freedom (McNemar's test, 2022). The calculated 2x2 contingency values are compared with the critical value from the chi-square distribution to determine statistical significance (McNemar's test, 2022). McNemar's Test is used when data can pass the following three assumptions: (1) the dependent variable has two categories, and the independent variable has two categories; (2) each participant is only in one of two participant groups; and (3) participants are a random sample from the population (University of Sheffield).

The dependent variable for this study (ASSQ or ASSQ-GIRL) has two categories (at-risk or not at-risk), and the independent variable has two categories (females with ASD and males with ASD) thus assumption one is met (University of Sheffield). Females with ASD will comprise one participant group while males with ASD will comprise another participant group and participants cannot be in multiple groups at the same time hence assumption two is met (University of Sheffield). The participants in this study were selected using non-probability sampling meaning each object does not always have an equal chance of being chosen (Glen, 2022). Each participant did not have an equal chance of being chosen for the study. Therefore, even with the use of non-probability sampling, the participants still meet the standard for random sampling satisfying the requirement of assumption three (University of Sheffield).

Ehlers et al. (1999) published a study where they determined a cutoff score to be used with the ASSQ when deciding whether an individual is at-risk for ASD. The ASSQ consists of 27 questions, rated 0-2, for a maximum total of 54 points (Ehlers et al., 1999). The researchers concluded 19 is the ideal cutoff score on the ASSQ for an individual to be at-risk for ASD when completed by parents (Ehlers et al., 1999). 19 of 54 points is a percentage of 35.19 meaning a total percentage of points greater than 35.19 refers the individual for further ASD evaluations (Ehlers et al., 1999).

Kopp & Gillberg (2011) did not determine a cutoff score for the ASSQ-REV. A cutoff score was needed to analyze hypothesis one. The 27 ASSQ questions included in the ASSQ-REV were converted to a five-point scale (Kopp & Gillberg, 2011). The maximum score for these questions totaled 108 points (Kopp & Gillberg, 2011). Thirty-eight became the cutoff score for the ASSQ questions embedded within the ASSQ-REV in this study in keeping with the proportionality of 35.19% of points being the cutoff (Ehlers, et al., 1999; Kopp & Gillberg, 2011). The 18 ASSQ-GIRL questions included in the ASSQ-REV were completed on a five-point scale (Kopp & Gillberg, 2011). No data exists that supports a specific cutoff score for the ASSQ-GIRL questions (Kopp & Gillberg, 2011). The maximum score for these questions totaled 72 points (Kopp & Gillberg, 2011). Twenty-five became the cutoff score for the ASSQ-GIRL questions within the ASSQ-REV (Ehlers, et al., 1999; Kopp & Gillberg, 2011). The ASSQ-REV scores are analyzed in two sections (ASSQ and ASSQ-GIRL) to strengthen the results of the study by using existing research to determine a cutoff score (Ehlers, et al., 1999; Kopp & Gillberg, 2011).

Limitations

The present study is limited due to its sampling method. Non-probability sampling does not guarantee that every individual within the population has an equal chance of being selected for the study (Elfil & Negida, 2017). Non-probability sampling is less likely to be illustrative of the population compared to probability sampling (Elfil & Negida, 2017). Non-probability sampling was utilized for the following reasons: (1) females with ASD are located throughout the country and it is not possible to identify every female with ASD residing within the United States due to confidentiality laws, (2) participants in this study are homogeneous as they share the common characteristics of having a child between the ages of 6-17 diagnosed with ASD and reside in the United States (Jager et al., 2017), and (3) participants were recruited via word of mouth and online platforms to generate a greater number of participants.

The present study is limited in its analysis of hypothesis two using McNemar's test. Kopp & Gillberg (2011) did not determine a cutoff score for the ASSQ-GIRL questions. A cutoff score was needed to analyze data collected related to hypothesis two. A cutoff score was created using information obtained from the creation of the cutoff score for the ASSQ, which has been well reviewed and validated for use as an ASD screening tool (Ehlers et al., 1999). The calculated cutoff score for the ASSQ-GIRL questions was not chosen arbitrarily, but was calculated using information from the validated ASSQ (Ehlers & Gillberg, 2011; Ehlers et al., 1999). There are no data to support the use of 25 as a cutoff score for the ASSQ-GIRL questions outside of this study. The present study intended to add to the research around the ASSQ-GIRL questions by calculating and analyzing a cutoff score to determine its accuracy in predicting a future diagnosis of ASD.

Summary

McNemar's test allowed the data collected to be analyzed relating to the two hypotheses. Hypothesis one evaluates the accuracy of the ASSQ in identifying males and females with ASD. Hypothetically, all completed questionnaires should surpass the cutoff score of 38 as all responses to questions were based on individuals holding a diagnosis of ASD (Ehlers & Gillberg, 2011). McNemar's test will also show whether the ASSQ-GIRL questions are accurate in distinguishing between the female and male phenotypes of ASD (Kopp & Gillberg, 2011). Hypothesis two evaluates the accuracy of the ASSQ-GIRL questions in distinguishing between the female and male phenotypes of ASD. Theoretically, more females than males should meet the cutoff score of 25 on the ASSQ-GIRL questions as the questions were designed to identify the female phenotype of ASD (Ehlers & Gillberg, 2011; Ehlers et al., 1999; Kopp & Gillberg, 2011). Statistical analysis and findings for the present study are discussed in chapter four.

CHAPTER 4

Results

A total of 59 individuals completed the ASSQ-REV questionnaire. Individuals were assigned a number to represent their responses in the data analysis with numbers ranging from 1-59. This was done to protect participant confidentiality. Results from 49 participants were included in the data analysis. Responses from participants 11, 15, 54, and 59 were excluded due to responding "no" to the demographic question, "does your child have a formal diagnosis of ASD?" which was an inclusion criterion. Responses from participants 10, 17, 26, 31, and 41 were excluded due to responding "no" to the demographic question, "do you and your child currently reside in the United States?" which was an inclusion criterion. Responses from participant 50 were excluded due to stating the age of the child was 5 which does not meet the inclusion criteria of being a parent or legal guardian of a child aged 6-17 with a formal diagnosis of ASD. Thus, data collected from 49 respondents or 83% of total respondents was included in data analysis. Informed consent was obtained for all participants. Participant demographic information and questionnaire totals are included in table 1 on page 90.

Group 1 (parents and/or legal guardians of females aged 6-17 with a formal diagnosis of ASD) included 35 participants. The participant breakdown by child's age was as follows: three aged six, two aged seven, five aged eight, three aged nine, three aged 10, three aged 11, six aged 12, five aged 13, one aged 14, one aged 15, two aged 16, and one aged 17. Group 2 (parents and/or legal guardians of males aged 6-17 with a formal diagnosis of ASD) included 14 participants. The participant breakdown by child's age was as follows: two aged six, zero aged seven, zero aged eight, two aged nine, one aged 10, three aged 11, one aged 12, one aged 13, one

aged 14, one aged 15, two aged, 16, and zero aged 17. Participant breakdown by child's age is included in table 2 on page 92.

Findings

McNemar's test was utilized to draw conclusions related to hypotheses one and two. A 2x2 contingency table utilizing McNemar's test is included in table 3 on page 93. Hypothesis one stated males will more accurately be identified than females as having ASD using the ASSQ. The results of McNemar's test for group 2 resulted in two discordant pairs. Discordant pairs mean the participant was ASSQ- and ASSQ-GIRL+ or ASSQ+ and ASSQ-GIRL- for the purpose of this study (InfluentialPoints.com). The two-tailed P-value equals 0.4795 meaning this difference is not considered to be statistically significant (*McNemar's test to analyze a matched case-control study*). This P value was calculated using McNemar's test with continuity correction (*McNemar's test to analyze a matched case-control study*). The Chi-Square equals 0.500 with 1 degree of freedom (*McNemar's test to analyze a matched case-control study*). The odds ratio could not be calculated because one of the discordant values was zero (*McNemar's test to analyze a matched case-control study*). Thus, the data did not show males to be more accurately identified than females as having ASD using the ASSQ disproving hypothesis one.

Hypothesis two stated the ASSQ-GIRL will identify the female phenotype of ASD at a greater rate than the male phenotype of ASD. The results of McNemar's test for group 1 resulted in seven discordant pairs. Discordant pairs mean the participant was ASSQ- and ASSQ-GIRL+ or ASSQ+ and ASSQ-GIRL- for the purpose of this study (InfluentialPoints.com). The two-tailed P-value equals 0.4497 meaning this difference is not considered to be statistically significant (*McNemar's test to analyze a matched case-control study*). This P value was calculated using McNemar's test with continuity correction (*McNemar's test to analyze a*

matched case-control study). The Chi-Square equals 0.571 with 1 degree of freedom (*McNemar's test to analyze a matched case-control study*). The odds ratio is 2.500 with a 95% confidence interval (*McNemar's test to analyze a matched case-control study*). Thus, the data did not show the ASSQ-GIRL identifying the female phenotype of ASD at a greater rate than the male phenotype of ASD disproving hypothesis two.

The research questions for this study were (1) what is the accuracy of the ASSQ in identifying males and females with ASD and (2) what is the accuracy of the ASSQ-GIRL questions in distinguishing between the female and male phenotypes of ASD (Kopp & Gillberg, 2011)? All participants in the study had a child with an ASD diagnosis, thus the accuracy rates for the completed ASSQ and ASSQ-GIRL questionnaires in this study should be 100 percent. The accuracy of the ASSQ in identifying males and females with ASD was 50% for males and 60% for females. The accuracy of the ASSQ-GIRL in distinguishing between the male and female phenotypes of ASD was 64% for males and 69% for females.

The measures of central tendency were calculated for each participant group on each questionnaire. These measures of central tendency were calculated for the ASSQ. The mean or average score for group 1 was 43.69 points (Little, 2014). The mean for group 2 was 47.5 points (Little, 2014). The median or midpoint of the range of values for group 1 was 44 points (Little, 2014). The median for group 2 was 43.5 points (Little, 2014). The modes or values that appear most often in the sample for group 1 were 27, 28, 36, 48, 49, and 70 points, each appearing two times in the data (Little, 2014). All values in the data appear just one time in group 2 (Little, 2014). The range or distance between the highest score and lowest score for group 1 was 66 points. The range for group 2 was 68 points.

The measures of central tendency were calculated for each participant group on each questionnaire. These measures of central tendency were calculated for the ASSQ-GIRL. The mean score for group 1 was 32.71 points (Little, 2014). The mean score for group 2 was 27.93 points (Little, 2014). The median score for group 1 was 31 points (Little, 2014). The median score for group 2 was 30.5 points (Little, 2014). The mode for group 1 was 21 points, appearing four times (Little, 2014). All values in the data appear just one time in group 2 (Little, 2014). The range for group 1 was 54 points (Little, 2014). The range for group 2 was 47 points (Little, 2014).

The mean score for males on the ASSQ was 47.5 points and for females was 43.69. There was not a statistically significant difference found using McNemar's test. The average score for males was higher than females on the ASSQ. The mean score for males on the ASSQ-GIRL was 27.93 points and for females was 32.71. Again, no statistically significant difference was found using McNemar's test. The average score for females was higher than males on the ASSQ-GIRL. This could mean there is potential for the ASSQ-GIRL questions to better identify the female phenotype of ASD with revisions including utilizing modern research to rewrite and clarify the questions. Statistical analysis conducted shows that the data collected in this study refutes the two proposed hypotheses.

CHAPTER 5

Summary

The results of this study disproved both proposed hypotheses. McNemar's test was used to calculate the P-value for analysis of data from group 1 and for group 2. The data did not show males to be more accurately identified than females as having ASD using the ASSQ disproving hypothesis one. The data did not show the ASSQ-GIRL identifying the female phenotype of ASD at a greater rate than the male phenotype of ASD disproving hypothesis two. The results of this study align with the results obtained by Kopp and Gillberg in their 2011 study (Kopp & Gillberg, 2011). Kopp and Gillberg concluded no overall differences between genders for males and females aged 6-16 with ASD between the ASSQ and ASSQ-GIRL (Kopp & Gillberg, 2011). This study concluded no statistically significant differences between the identification of males and females on the ASSQ and ASSQ-GIRL.

The ASSQ-GIRL was created by Kopp and Gillberg in 2011 (Kopp & Gillberg, 2011). Thirteen years of new research exist that better describe the differences in characteristics between males and females. Kopp and Gillberg (2011) utilized data available at the time to create the ASSQ-GIRL. This study showed new information about the female phenotype of ASD might not have been known when the ASSQ-GIRL was created (Kopp & Gillberg, 2011). This new information not being included in the ASSQ-GIRL could have a part in the ASSQ-GIRL not identifying the female phenotype of ASD at higher rates than the male phenotype of ASD.

Kopp and Gillberg (2011) have opened the door to modifying existing screening tools for ASD to better identify the female phenotype of ASD. Current focus groups, interviews, and observations are needed to better define the female phenotype of ASD in screening questions. Kopp and Gillberg's (2011) questions did not show a greater identification of the female

phenotype of ASD as hypothesized. Modern research combined with additional knowledge on the characteristics of the female phenotype of ASD need to be used to create questions that will better screen for the female phenotype of ASD.

There is a possibility that participant bias may have influenced the results. All participants were parents or legal guardians of a child with a formal diagnosis of ASD (Boston Medical Center). Thus, it can be assumed that these participants have more knowledge and exposure to the field of ASD than a parent or legal guardian who is presently undergoing the diagnostic process for ASD. This increased knowledge could have led to skewing of the data as participants may have rated known characteristics of ASD on the questionnaire higher than areas known to not have as great an impact on an ASD diagnosis. It is possible that participants have completed a similar questionnaire and are familiar with the scoring process thus influencing how they chose their responses. A recommendation to combat this bias would be to include a control group of participants whose child does not have a formal diagnosis of ASD to compare ratings between responses.

There was evidence of extreme response styles in the completed questionnaires (Liu et al., 2017). Extreme response styles often occur in surveys that utilize a Likert-type scale (Liu et al., 2017). This means these respondents tended to choose the responses at the extreme ends of the rating scale (Lin et al., 2017). This coincides with research that American participants tend to select the extreme endpoints of the response scales (Lin et al., 2017). The lowest score one could have on the ASSQ or ASSQ-GIRL was 0 (Kopp & Gillberg, 2011). One respondent had an ASSQ score of 10 and four respondents had an ASSQ-GIRL score of eight or less. The highest score one could have on the ASSQ was 108 and on the ASSQ-GIRL was 72 (Kopp & Gillberg, 2011). Two respondents had a score of 79 or greater on the ASSQ and four respondents had a

score of 50 or greater on the ASSQ-GIRL. This shows there may have been extreme response styles utilized by the participants.

Opposingly, there appeared to be evidence of non-extreme or neutral response styles (Liu et al., 2017). Non-extreme respondents tend to select the very middle or neutral response to questions (Liu et al., 2017). Selecting neutral for all responses on the ASSQ would give a score of 54 and a score of 36 on the ASSQ-GIRL. One participant had a score of 54 on the ASSQ. This participant had responses ranging from 0-4 with 19% of responses at 2 or neutral. Two respondents had a score of 36 on the ASSQ-GIRL. One participant had responses ranging from 0-4 with 22% of responses at 2 or neutral. The other participant had responses ranging from 0-4 with 11% of responses at 2 or neutral. These scores could be a result of both extreme end scores and/or from selecting only neutral scores. The data show these scores resulted from participants giving scores across the Likert-scale which averaged to neutral, rather than giving all neutral scores.

Research from the past few years has shown a steady decrease in the ratio of females to males with ASD. Presently, the ratio stands at 1:3.8 (Maenner et al., 2023). Some researchers have estimated that the ratio may be closer to 1:3 (Loomes et al., 2017). This study assumes that the ratio of females to males with ASD will continue to decrease ergo accuracy rates of autism screening tools should increase for females. Males predominately compose the participants in ASD research (Napolitano et al., 2022). There needs to be a greater inclusion of females with ASD in research studies to increase the accuracy rates of ASD screening tools for females. Modifying ASD screening tools to include known characteristics of ASD in females is one step towards equalizing the rates of male and female participants in ASD research.

Implications

Research has shown that females are typically diagnosed with ASD at a later age than males which leads to increased rates of anxiety, depression, and suicidal ideation (Arwert & Sizoo, 2020; Bonney et al., 2021; Cridland et al., 2013; Office of Autism Research Coordination National Institutes of Health, 2019; Salazar et al., 2015; South et al., 2020). The results of this study are a step in the right direction towards helping to equalize the age of diagnosis thus decreasing rates of anxiety, depression, and suicidal ideation. More research into how females with ASD are identified on ASD screening tools will lead to information that can be used to modify these screening tools to better include characteristics of the female phenotype of ASD.

This study set forth to bring attention to the lack of inclusion of female characteristics in ASD in screening tools. Research exists to show a true difference in ways males and females display characteristics of ASD (Backer van Ommeren et al., 2016; Burton et al., 2020; Cridland et al., 2013; Dean et al., 2014; de Giambattista et al., 2021; Locke et al., 2018; Stroth et al., 2022). Research also shows that these characteristics are not always included in screening and diagnostic tools for ASD. This study set out to fill part of that void by showing a need for the inclusion of female characteristics of ASD in screening tools.

This study provides evidence for a need to use multiple screening and diagnostic tools when assessing a child for ASD. All participants in the study had a formal diagnosis of ASD, yet only 50% of males and 60% of females met the cutoff score on the ASSQ to be referred for further evaluations. Often, families are presented with one screening tool for ASD at a pediatrician's well visit and unless concerns are expressed, may never see another screening tool for ASD (Johnson et al., 2007). This highlights the importance of a comprehensive evaluation for ASD (Johnson et al., 2007).

Comprehensive evaluations for ASD begin with screening and surveillance (Johnson et al., 2007). Screening captures an individual's behaviors at a moment in time while surveillance represents an ongoing picture of a child's development (Johnson et al., 2007). It is recommended that screening and surveillance be used in conjunction with one another to develop a more complete picture of a child's abilities (Johnson et al., 2007). Using just screening tools can miss developmental moments that occur for a child (Johnson et al., 2007). Using just surveillance may not be enough to provide concrete data or make comparisons between age-appropriate norms and a child's development (Johnson et al., 2007). Screening and surveillance need to be an ongoing process throughout the child's early years of development to highlight potential signs of ASD (Johnson et al., 2007).

Pediatricians need to be well versed in developmental milestones and understand how differences in achieving these milestones may be presented for an individual who has ASD (Johnson et al., 2007). Pediatricians are often the ones to provide families with information related to ASD including the clinical definition and explaining the screening and diagnostic process (Johnson et al., 2007). Also, they need to have knowledge of community resources available for families of individuals with ASD to provide guidance to parents (Johnson et al., 2007). It is vital that pediatricians understand signs of ASD in child development (Johnson et al., 2007). It is also important that parents take their child to the pediatrician, or another medical professional, should they have concerns for their child's development.

A comprehensive evaluation for ASD typically includes multiple assessments (Johnson et al., 2007). It is often recommended to begin laboratory work to determine if there is a known etiology cause or a coexisting medical condition (Johnson et al., 2007). A family history including health, development, and behaviors for at least three generations is recommended

(Johnson et al., 2007). A physical examination of the child is included along with a developmental or psychometric evaluation to determine the child's current level of functioning (Johnson et al., 2007). Analysis of these components is done to determine if the child meets the DSM-V-TR of ASD (Johnson et al., 2007).

Relying on only one screening or diagnostic measure would not give a complete picture of a child's development (Johnson et al., 2007). This study only included one screening tool to draw conclusions based on the stated hypotheses. This study was able to show a need for multiple screening and diagnostic tools to be used in a comprehensive evaluation for ASD. This study included participants who all had a diagnosis of ASD, yet only 50% of males and 60% of females met the cutoff score on the ASSQ to be referred for further evaluations. This shows how reliability and validity of screening tools included in a comprehensive exam are also of utmost importance (Johnson et al., 2007). No one tool is going to provide enough information to conclude an ASD diagnosis. This study shows the importance of using multiple tools to create a wholistic picture of a child when determining if criteria are met for an ASD diagnosis.

Recommendations for further research

This study promotes a need for a reevaluation of existing screening tools for ASD. It suggests there is a demand for ongoing refinement or development of more precise tools to increase the accuracy rates of ASD diagnosis. Practitioners need to be aware of potential gender-related differences in the performance of screening tools and consider additional or supplementary assessments or tools when evaluating females for ASD. Further research should explore whether gender-specific diagnostic criteria or tools are necessary to capture the female phenotype of ASD. Research should focus on refining existing screening tools, incorporating current knowledge, and ensuring they are more sensitive to the differing ways ASD may present

between the genders. Future studies should attempt to include more females in samples to improve the generalizability of results.

The results of this study show a need for further research into screening tools used in the ASD diagnostic process. Specifically, screening tools need to be analyzed for their inclusion of criteria relating to the female phenotype of ASD (Backer van Ommeren et al., 2016; Burton et al., 2020; Cridland et al., 2013; Dean et al., 2014; de Giambattista et al., 2021; Locke et al., 2018; Stroth et al., 2022). Much research has gone into studying and creating a definition for the female phenotype of ASD, but there has been little application of this material. Kopp and Gillberg (2011) began the process towards including characteristics of the female phenotype of ASD into screening tools. Much more research on the differing characteristics between males and females with ASD has emerged in the 12 years since Kopp and Gillberg's 2011 study (Kopp & Gillberg, 2011). There have been no other studies conducted based on Kopp and Gillberg's findings from 2011. There is little research focusing on modifying existing screening tools to include criteria of the female phenotype of ASD.

Since more information on the female phenotype of ASD has been presented in the literature, a logical next step is to apply this information in screening and diagnostic tools. The most common ASD screening tools include the Ages and Stages Questionnaire (ASQ), Communication and Symbolic Behavior Scales (CSBS), Parents Evaluation of Developmental Status (PEDS), Modified Checklist for Autism in Toddlers (MCHAT), and the Screening Tool for Autism in Toddlers and Young Children (STAT) (Centers for Disease Control and Prevention, 2022). The most recent edition of the ASQ, known as the ASQ-3, was published in 2009 (Squires & Bricker, 2019). The CSBS was published in 2002 (Wetherby & Prizant, 2021).

The most recent edition of the MCHAT, known as the M-CHAT-R/F was published in 2009 (Robins, 2023). The STAT was published in 2000 (Stone et al., 2004).

There is sufficient evidence to show that these screening tools have been highly studied and found to be reliable and valid, yet the publication dates show that the emerging research on the female phenotype of ASD is not being included in these screening tools. There needs to be a shift in modernizing these screening tools. The research exists on what to include in these screening tools to better identify females with ASD, but the work has yet to be done to modify these tools to meet this need. This is an area of ASD research that needs to be further explored and publicized.

The PEDS-R is a 2023 update to the PEDS published in 2013. This is the only one of the aforementioned screening tools to have an update beyond 2009. The PEDS-R handbook does not mention any inclusion of criteria specific to females or the female phenotype of ASD (Glascoe et al., 2023). An emphasis is placed on improvements in criteria related to mental health, social-emotional and behavioral problems, and developmental delays or disorders (Glascoe et al., 2023). It is possible that some of these improvements are related to research around the female phenotype of ASD, but that is not explicitly stated. The handbook specifically states that updates have been made based on responses collected from low income and Spanish-speaking parents. There is a section of the handbook relating to cultural sensitivity and working with unique populations, but the focus of this section is on translation of the PEDS-R to different languages (Glascoe et al., 2023). A recommendation for further research is to examine the questions in the PEDS-R to see if they fit criteria related to the female phenotype of ASD and to examine the accuracy rates between males and females on this screening tool.

This study takes a key step towards beginning the process of modifying ASD screening tools to include characteristics specific to the female phenotype of ASD. This study looked specifically at the ASSQ and ASSQ-GIRL. The methodology utilized in this study could be applied to many different screening tools. One individual who completed the questionnaire could not be included in the final analysis because the age of the child was five years of age, thus younger than the specified criteria. This shows an interest in participants of younger ages which could be done using other screening tools. Further research could examine results of the ASSQ-GIRL compared to other existing screening tools such as the ASQ-3, M-CHAT-R/F, STAT, or PEDS-R. The same hypotheses could be applied to compare results of accurate identification of ASD. A control group of parents or legal guardians whose child does not have a formal diagnosis of ASD could be used to strengthen these studies.

Kopp and Gillberg (2011) created the ASSQ-GIRL with research that existed at the time. Nevertheless, the research surrounding females with ASD has progressed and expanded since 2011. Substantially more data and information now exist on the characteristics, behaviors, and qualities of females with ASD. These new data need to be turned into a screening questionnaire to better meet the needs of females. A recommendation for further research would include analyzing the most common characteristics of females with ASD and creating questions to include in screening tools to target these characteristics. This would be a multifaceted project with a need for frequent testing and modification of the created questions to determine their validity and reliability. Questions from the ASSQ-GIRL could be used as a starting point and updated based on current information.

This study was limited to include participants from the United States to allow for suggestions to be made about the population. Five questionnaires were completed by individuals

living outside of the United States. Participant screening, using demographic questions, was completed before analysis of data to ensure all participants met the stated criteria (University of Maryland, Baltimore County). There appears to be interest in the topic of how females are screened for ASD outside of the United States. Future studies could focus on different countries or include participants from multiple countries to make suggestions to different populations.

Four individuals who completed the study stated their child did not have a formal diagnosis of ASD, thus disqualifying them from the study (Boston Medical Center). One reason these individuals may have completed the study is due to their child having an educational diagnosis of ASD rather than a medical or formal diagnosis of ASD (CAR Autism Roadmap, 2020). An individual who meets the DSM-V-TR criteria for an ASD diagnosis and receives the diagnosis from a pediatric neurologist, developmental or behavioral pediatrician, or a child psychiatrist, receives a medical or formal diagnosis of ASD (Boston Medical Center). By contrast, an educational diagnosis of ASD is made by a team of educational professionals and parents or legal guardians who determine the child meets the state's definition of ASD and needs specialized education services (CAR Autism Roadmap, 2020).

A student with a formal diagnosis of ASD may not qualify for an educational diagnosis and vice versa (CAR Autism Roadmap, 2020). A medical diagnosis centers on meeting the criteria in the DSM-V-TR as evidenced through multiple diagnostic tools (Boston Medical Center). An educational diagnosis emphasizes the impact a disability has on the child's learning (CAR Autism Roadmap, 2020). It is more common for an individual to have a medical diagnosis of ASD and not qualify for an educational diagnosis than the other way around (CAR Autism Roadmap, 2020). It is possible for education personnel to qualify a student under the educational disability category of ASD without a medical diagnosis of ASD (CAR Autism Roadmap, 2020).

An educational diagnosis of ASD can be made given the student meets the state's definition of ASD and the disability has negatively impacted the student's learning (CAR Autism Roadmap, 2020). Note that the educational definition of ASD does differ from state to state (CAR Autism Roadmap, 2020). Further studies could differentiate between the two diagnoses using a demographic question to group participants based on medical or educational diagnosis. Results could then be compared across the separate groups.

Conclusions

Inclusion of the female phenotype in ASD screening tools remains an under-researched topic in the field of autism research. Perhaps this is due to an emphasis being placed on learning the characteristics of ASD specific to ASD. This is a need, but now there is a need to apply what has been learned to the screening process. There exist data that show a bias towards males in ASD screening tools (Estrin et al., 2021; Loomes et al, 2017; Posserud et al., 2021). The research exists to help combat this bias, but it has yet to be put into practice. Further research needs to focus on taking the information learned about the female phenotype of ASD and applying it to ASD screening tools that will be used. This study is one part of beginning that next step of research.

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TABLES

Table 1

Participant Demographic Information and Questionnaire Totals

Participant	Sex	Age	Formal diagnosis	Resides in USA	ASSQ score	Yes/No met ASSQ cutoff score	ASSQ-GIRL score	Yes/No met ASSQ-GIRL cutoff score
1	M	12	Y	Y	34	N	7	N
2	M	9	Y	Y	12	N	4	N
3	M	6	Y	Y	40	Y	42	Y
4	F	10	Y	Y	20	N	16	N
5	F	13	Y	Y	44	Y	15	N
6	F	9	Y	Y	51	Y	40	Y
7	F	6	Y	Y	55	Y	50	Y
8	F	13	Y	Y	76	Y	48	Y
9	F	16	Y	Y	48	Y	28	Y
12	F	8	Y	Y	57	Y	31	Y
13	F	12	Y	Y	26	N	35	Y
14	F	12	Y	Y	70	Y	57	Y
16	M	10	Y	Y	80	Y	46	Y
18	F	9	Y	Y	49	Y	29	Y
19	F	12	Y	Y	23	N	19	N
20	F	8	Y	Y	62	Y	49	Y
21	F	14	Y	Y	24	N	21	N
22	F	15	Y	Y	63	Y	36	Y
23	F	6	Y	Y	36	N	30	Y
24	M	11	Y	Y	58	Y	48	Y
25	F	8	Y	Y	39	Y	32	Y
27	F	16	Y	Y	37	N	31	Y

Table 1 Continued

Participant	Sex	Age	Formal diagnosis	Resides in USA	ASSQ score	Yes/No met ASSQ cutoff score	ASSQ-GIRL score	Yes/No met ASSQ-GIRL cutoff score
28	F	11	Y	Y	54	Y	39	Y
29	F	11	Y	Y	43	Y	29	Y
30	F	9	Y	Y	60	Y	34	Y
32	F	13	Y	Y	67	Y	55	Y
33	F	6	Y	Y	27	N	23	N
34	F	13	Y	Y	42	Y	44	Y
35	F	7	Y	Y	30	N	33	Y
36	F	11	Y	Y	28	N	21	N
37	F	12	Y	Y	48	Y	38	Y
38	M	15	Y	Y	62	Y	33	Y
39	M	16	Y	Y	66	Y	36	Y
40	M	9	Y	Y	33	N	28	Y
42	F	8	Y	Y	27	N	23	N
43	M	6	Y	Y	21	N	11	N
44	M	16	Y	Y	79	Y	51	Y
45	F	8	Y	Y	65	Y	60	Y
46	M	14	Y	Y	32	N	25	Y
47	F	17	Y	Y	10	N	6	N
48	F	13	Y	Y	70	Y	44	Y
49	M	11	Y	Y	65	Y	35	Y
51	F	12	Y	Y	36	N	22	N
52	F	10	Y	Y	49	Y	21	N
53	F	12	Y	Y	15	N	21	N
55	M	11	Y	Y	36	N	17	N
56	F	10	Y	Y	50	Y	35	Y

Table 1 Continued

Participant	Sex	Age	Formal diagnosis	Resides in USA	ASSQ score	Yes/No met ASSQ cutoff score	ASSQ-GIRL score	Yes/No met ASSQ-GIRL cutoff score
57	M	13	Y	Y	37	N	8	N
58	F	7	Y	Y	28	N	30	Y

Note. The following abbreviations are used in table 1: Y = yes, N = no, M = male, and F = female. Data for participants 10, 11, 15, 17, 26, 31, 41, 50, 54, and 59 were removed from the table as they did not meet the inclusion criteria and were not included in data analysis.

Table 2

Participant Breakdown by Child's Age

Child's age	Group 1	Group 2
6	3	2
7	2	0
8	5	0
9	3	2
10	3	1
11	3	3
12	6	1
13	5	1
14	1	1
15	1	1
16	2	2
17	1	0
Total	35	14

Table 3

Screening Results per Questionnaire by Participant Group Using McNemar's Test

	Group 1				Group 2		
	ASSQ+	ASSQ-			ASSQ+	ASSQ-	
ASSQ-GIRL+	19	5	24	ASSQ-GIRL+	7	2	9
ASSQ-GIRL-	2	9	11	ASSQ-GIRL-	0	5	5
	21	14	35		7	7	14

Note. ASSQ+ represents a score of 38 or greater equating to a positive screening result on the Autism Spectrum Screening Questionnaire (ASSQ). ASSQ- represents a score of 37 or less equating to a negative screening result on the Autism Spectrum Screening Questionnaire (ASSQ). ASSQ-GIRL+ represents a score of 25 or greater equating to a positive screening result on the Autism Spectrum Screening Questionnaire – GIRL (ASSQ-GIRL). ASSQ-GIRL- represents a score of 24 or less equating to a negative screening result on the Autism Spectrum Screening Questionnaire – GIRL (ASSQ-GIRL).

APPENDIX A: STUDY MATERIALS

Slippery Rock University of Pennsylvania

TO: Dr.Ashlea Rineer-Hershey
Special Education

FROM: _____
James Preston, D.Ed., Vice-Chairperson
Institutional Review Board (IRB)

DATE: December 13, 2023

RE: Protocol Approved

Protocol #: 2024-022-88-B
Protocol Title: Accuracy of the Autism Spectrum Screening Questionnaire - GIRL in Identifying Females with Autism Spectrum Disorder

The Institutional Review Board (IRB) of Slippery Rock University has received and reviewed the requested modification(s) to the above-referenced protocol utilizing the expedited review process. The IRB has approved the protocol effective December 13, 2023.

You may begin your project as of December 13, 2023. Your approved protocol will expire on December 12, 2024. You will need to submit a Progress/Final Report at least 7 days prior to the expiration date.

Enclosed are copies of the approved consent and assent forms to be copied for participants to sign. (if applicable)

If you complete the study within the next year, please notify the IRB with a Final Report. The Final Report form and instructions can be found on the IRB website.

Please contact the IRB Office by phone at (724)738-4846 or via email at irb@sru.edu should your protocol change in any way.

PARTICIPANTS NEEDED

FOR A STUDY ON CHARACTERISTICS OF AUTISM

The purpose of this study is to evaluate the accuracy of the Autism Spectrum Screening Questionnaire – GIRL (ASSQ-GIRL) in identifying females with autism spectrum disorder (ASD).

- Parent and/or legal guardian of females and males aged 6-17 with a diagnosis of autism spectrum disorder (ASD)
- Must reside in the United States
- Reads English and/or Spanish

Participants will be asked to complete an informed consent form and a modified version of the ASSQ-REV which will take about 15-20 minutes.

To complete the survey

SCAN ME

Survey link: https://forms.gle/Nbatk6r9LCN3PejB7

Contact for more information: Sydney Castonguay at **shc1004@sru.edu**
Dissertation study conducted under the direction of Dr. Ashlea Rineer-Hersey
a.rineer-Hershey@sru.edu

(ASSQ) – Rev (2011)

How old is your child?	6 7 8 9 10 11 12 13 14 15 16 17	
Does your child have a formal diagnosis of autism spectrum disorder (ASD) (formal diagnosis is defined as a diagnosis of ASD from a pediatric neurologist, developmental or behavioral pediatrician, or a child psychiatrist[1])?	Yes	No
Select the sex of your child:	Male	Female
Do you and your child currently reside in the United States?	Yes	No

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

	No, not at all (0)	**(1)**	**(2)**	**(3)**	**Yes, all the time (4)**
1. Is old fashioned or precocious	◯	◯	◯	◯	◯
2. Is regarded as an 'eccentric professor' by the other children	◯	◯	◯	◯	◯
3. Lives somewhat in a world of his/her own with restricted idiosyncratic intellectual interests	◯	◯	◯	◯	◯
4. Accumulates facts on certain subjects (good rote memory) but does not really understand the meaning	◯	◯	◯	◯	◯
5. Has a literal understanding of ambiguous and metamorphic language	◯	◯	◯	◯	◯
6. Has a deviant style of communication with a formal, fussy, 'old	◯	◯	◯	◯	◯

[1] From Boston Medical Center (n.d.). *Diagnosis*. https://www.bmc.org/pediatrics-special-kids-help/autism/diagnosis

fashioned' or 'robot like' language					
7. Invents idiosyncratic words and expressions	◯	◯	◯	◯	◯
8. Has a different voice or speech	◯	◯	◯	◯	◯
9. Expresses sounds involuntarily; clears throat, grunts, smacks, cries**,** or screams	◯	◯	◯	◯	◯
10. Is surprisingly good at some things and surprisingly poor at others	◯	◯	◯	◯	◯
11. Uses language freely but fails to make adjustments to fit social contexts or the needs of different listeners	◯	◯	◯	◯	◯
12. Lacks empathy	◯	◯	◯	◯	◯
13. Makes naïve and embarrassing remarks	◯	◯	◯	◯	◯
14. Has a deviant style of gaze	◯	◯	◯	◯	◯
15. Wishes to be sociable but fails to make relationships with peers	◯	◯	◯	◯	◯
16. Can be with other children but only on his/her terms	◯	◯	◯	◯	◯
17. Lacks best friend	◯	◯	◯	◯	◯
18. Lacks common sense	◯	◯	◯	◯	◯
19. Is poor at games: no idea of cooperating in a team, scores 'own goals'	◯	◯	◯	◯	◯
20. Has clumsy, ill-coordinated, ungainly, awkward movements or gestures	◯	◯	◯	◯	◯
21. Has involuntary face or body movements	◯	◯	◯	◯	◯
22. Has difficulty in completing simple daily activities because of	◯	◯	◯	◯	◯

compulsory repetition of certain actions or thoughts					
23. Has special routines: insists on no change	◯	◯	◯	◯	◯
24. Shows idiosyncratic attachment to objects	◯	◯	◯	◯	◯
25. Is bullied by other children	◯	◯	◯	◯	◯
26. Has markedly unusual facial expressions	◯	◯	◯	◯	◯
27. Has markedly unusual posture	◯	◯	◯	◯	◯
28. Copies you (can be in a very discrete way)	◯	◯	◯	◯	◯
29. Episodes of eating problems	◯	◯	◯	◯	◯
30. No time perception	◯	◯	◯	◯	◯
31. Too much sympathy	◯	◯	◯	◯	◯
32. Extremely interested in pop/rock bands, soap operas or catastrophes involving large numbers of people	◯	◯	◯	◯	◯
33. Avoids demands	◯	◯	◯	◯	◯
34. Very determined	◯	◯	◯	◯	◯
35. Difficulties with choosing: always avoids choosing	◯	◯	◯	◯	◯
36. Difficulties with self-care	◯	◯	◯	◯	◯
37. Carefree or over meticulous with regard to physical appearance and dress	◯	◯	◯	◯	◯
38. Naïve	◯	◯	◯	◯	◯
39. Comes too close to other people	◯	◯	◯	◯	◯
40. Interacts mostly with younger children	◯	◯	◯	◯	◯
41. Engages in dangerous activity	◯	◯	◯	◯	◯
42. Exaggeratedly fanciful	◯	◯	◯	◯	◯
43. Talks without content	◯	◯	◯	◯	◯

44. Writes long stories (which can be in stark contrast to level of talk)	◯	◯	◯	◯	◯
45. Acts or lives different parts (TV stars, videos, animals)	◯	◯	◯	◯	◯

[2]

[2] From "The Autism Spectrum Screening Questionnaire (ASSQ)-Revised Extended Version (ASSQ-REV): An instrument for better capturing the autism phenotype in girls? A preliminary study involving 191 clinical cases and community controls" by S. Kopp & C. Gillberg, 2011, *Research in Developmental Disabilities*, *32*(6), pg. 2875.

Study Information

TITLE OF STUDY

Accuracy of the Autism Spectrum Screening Questionnaire - GIRL (ASSQ-GIRL) in Identifying Females with Autism Spectrum Disorder

PRINCIPAL INVESTIGATOR

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CO-INVESTIGATOR

Sydney Castonguay, CAS, MSE

Doctoral Student, Department of Special Education

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PURPOSE OF STUDY

You are being asked to participate in a research study. Before you decide to participate in this study, it is important that you understand why the research is being done and what it will involve. Please read the following information carefully. Please ask the researchers if there is anything that is not clear or if you need more information.

The purpose of this study is to (1) evaluate the accuracy of the ASSQ in identifying females with autism spectrum disorder (ASD) and (2) evaluate the accuracy of the ASSQ-GIRL questions in distinguishing between the female and male phenotypes of ASD. Research is needed to determine if the ASSQ-REV has the potential to equalize the rates of ASD identification between males and females. Individual question analysis is necessary to determine if the female phenotype of ASD is being assessed in the ASSQ-REV.

Research into females with ASD continues to be prominent in the field of special education. More research is needed to examine the tools that are being used to screen females for further assessments to determine if they qualify for a diagnosis of ASD. Screening tools are the first step in an ASD diagnostic process. Rates of ASD in females will continue to be lower than rates of ASD in males if females continue to not be accurately identified by screening tools. This study aims to add relevant data and information regarding the ASSQ-REV to the field to continue to adapt and modify existing screening tools to better identify the female phenotype of ASD.

STUDY PROCEDURES

1. Read this informed
consent form (approximate time to complete: 10 minutes).

2. Sign and date this
consent form (approximate time to complete: 5 minutes).

3. Select a response for the four demographic questions on the ASSQ-REV (approximate time to complete: 5
minutes).

4. Read each statement on
the ASSQ-REV and select a response ranging from “no, not at all” to “yes, all the time” that best describes your child (approximate time to complete: 30
minutes).

5. Submit the completed
survey (approximate time to complete: 2 minutes).

RISKS

Breach of Confidentiality: It is possible that response forms
could be breached via online software and platforms. However, the chance of a breach of confidentiality is decreased by not collecting identifying information on students such as name, school, school ID, date of birth, and parent name. For additional information on the Google
Forms security statement, please view this link: https://policies.google.com/privacy

Psychological: It is possible that completing the ASSQ-REV
will cause some emotional distress as it is addressing behaviors related to ASD. There is a chance that you may feel uncomfortable sharing information about a child's behaviors. Some of the questions may cause negative feelings to arise as comparisons are made between neurodivergent and neurotypical individuals. There is mention of bullying within the questions. However, the chance of psychological discomfort is minimized using a rating scale, stating the purpose of the study, and allowing for you to withdraw from the study at any time.

You may decline to answer any or all questions and you
may terminate your involvement at any time you choose.

BENEFITS

There will be no direct benefit to you for your participation in this study. However, we hope that the information in this study may benefit you by reviewing characteristics of autism spectrum disorder thus helping to promote supports for families and students.

CONFIDENTIALITY

For the purpose of this study, demographic information is included to identify appropriate participant groups. Every effort will be made by the researcher to preserve your confidentiality including the following:

-Assigning code numbers for all participants that will be used on all research notes and documents.

-Completed questionnaires and inform consent forms will be stored in a secure online database.

-Research staff are trained in the IRB-approved methods for managing and storing research data.

Participant data will be kept confidential except in cases where the researcher is legally obligated to report specific incidents. These incidents include, but may not be limited to, incidents of abuse and suicide risk.

CONTACT INFORMATION

If you have any questions at any time about this study, or you experience adverse effects as the result of participating in this study, you may contact the researcher whose contact information is provided on the first page. If you have questions regarding your rights as a research participant, or if problems arise which you do not feel you can discuss with the Primary Investigator, please contact the Institutional Review Board at 724.738.4846.

VOLUNTARY PARTICIPATION

Your participation in this study is voluntary. It is up to you to decide whether or not to take part in this study. If you decide to take part in this study, you will be asked to sign a consent form. After you sign the consent form, you are still free to withdraw at any time and without giving a reason. Withdrawing from the study will not affect the relationship(s) you have, if any, with the researcher(s). If you withdraw from the study before data collection is completed, your data will be returned to you or destroyed.

CONSENT TO PARTICIPATE IN RESEARCH

I have read and understand the provided information and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without cost. I understand that I will be given a copy of this consent form upon request. By selecting yes, I voluntarily agree to take part in this study.

I have reviewed the study information presented above. By selecting yes, I voluntarily agree to take part in this study. *

- ○ Yes
- ○ No

APPENDIX B: SIGNATORY PAGE FOR DISSERTATION

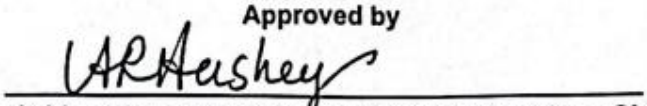
Signatory Page for Dissertation

Slippery Rock University of Pennsylvania
Department of Special Education

A Dissertation Written By
Sydney H. Castonguay

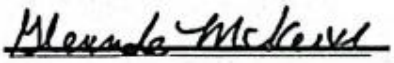
Bachelor of Science in Elementary Education, Westfield State University, May 2017
Master of Science in Special Education, University of Kansas, August 2020
Doctorate of Education in Special Education, Slippery Rock University of Pennsylvania, May 2024

Approved by



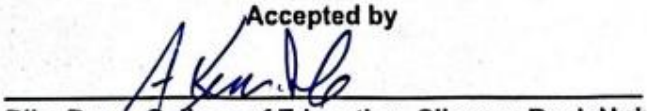
Dr. Ashlea Rineer-Hershey, Dissertation Committee Chair
03/22/2024

Dr. Richard Busi, Committee Member
03/22/2024



Dr. Glennda McKeithan, Committee Member
03/22/2024

Accepted by



Dr. Keith Dils, Dean, College of Education, Slippery Rock University of Pennsylvania
03/09/2024