SUPPORTING SCHOOL-AGED GIRLS WITH AUTISM SPECTRUM DISORDER: A QUALITATIVE EXAMINATION OF INTERVENTION EXPERIENCE

By
Shuzi Meng

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The dissertation is approved by the following members of the Final Oral Committee:
Jennifer Asmus, Professor, School Psychology
S. Andrew Garbacz, Associate Professor, School Psychology
Katie Eklund, Associate Professor, School Psychology
Keisha Lindsay, Associate Professor, Gender and Women's Studies and Political Science
Lindsay McCary, Affiliate Faculty, School Psychology

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Abstract

There is currently an overall lack of literature investigating assessments and interventions for girls with autism spectrum disorder (ASD; Kirkovski et al., 2013). Females included in research investigating ASD across all age ranges represent only 15% of all participants (Watkins et al., 2014), and school-aged female participation is even fewer. Scattered coverage and inconsistent conclusions on why and how school-aged girls with an ASD diagnosis differ or may differ from their male peers in social-emotional functioning or intervention needs might consequently lead to a scarcity of literature or knowledge of the true impact on social skill intervention design and implementation for this population (Jamison et al., 2015). Researchers have shown that females diagnosed with ASD not only face a more complex social scene (Bussey & Bandura, 1999), but that they also bear more pressure to socialize in a neurotypically-normed manner compared to their male counterparts (Dean et al., 2017). The prolonged cognitive and social efforts to mask their symptoms have made females diagnosed with ASD more prone to emotional overbearing and anxiety (Cridland et al., 2014).

Although gender-specific social-emotional problems are empirically supported (Dean, 2013; Van Wijingaarden-Cremers et al., 2014), it is not clear whether the existing social skill interventions sufficiently support the social needs of school-aged girls’ who are diagnosed with ASD. To date, no study has attempted to investigate whether there is a necessity for gender-specific social skill intervention for school-aged girls diagnosed with ASD. The current study seeks to address this gap by qualitatively exploring whether existing social skill interventions designed for school-aged children diagnosed with ASD have provided girls diagnosed with ASD self-described benefits from these interventions. Additionally, this study aims to explore whether these intervention programs resulted in significant gender differences in the participants’ social functioning post intervention.

This study utilized a participatory approach to examine how social skill interventions are experienced and reflected by school-aged girls with ASD to inform future intervention development for this group. Data was collected from 18 participants from five categories (i.e., school-aged girls with ASD, adult women with ASD, caregivers/parents, school-based and community-based service providers). Each participant received a one-hour (30 minutes for girls on the spectrum) semi-structured interview following protocols designed based on Smith et al's 2009 guidelines on interpretative phenomenological analysis (IPA) interviews, modified per the community partner's advice on language, structure, and rapport building activities. Nineteen themes were formed and are discussed. The manifestation of autism traits and symptoms in girls remains a prominent factor of delayed and/or misdiagnosis of autism in girls. While later diagnosis certainly contributes to delayed access to social skills services for families, the diagnostic experience along with the quality of the feedback process when delivering the diagnosis were mentioned as the key reason for a deterred decision to seek services, social skill learning services included. Findings also indicated that access to social skill and social emotional learning services are delayed for females on the autism spectrum when compared to their male counterparts. Findings indicated that delayed access to services often leads to less treatment buy-in from parents and caregivers, the way services are delivered, and the treatment timeline.

Many families and participants on the autism spectrum described experiences of being categorized under non-autism labels in their school-based services. The mismatch between medical autism diagnosis and the label qualified them for an IEP but were described as often leading to mismatched, ineffective supports with social skill learning services often omitted. All stakeholders mentioned the benefits of an autism diagnosis being shared with schools regardless of the type of services girls on the spectrum received (e.g., academic, social emotional,

behavioral). Participants on the autism spectrum frequently reported negative social experiences associated with being placed in the regular educational classrooms including social isolation, social confusion, and need for masking. The key complaint was the lack of inclusiveness in these classrooms despite being physically placed in a regular education classroom. Participants on the autism spectrum also reported that good quality Tier 1 and Tier 2 support in social emotional teaching, sometimes to all children in the classroom, mitigated such difficulties; however, many mentioned the lack of continuity in maintaining good quality supports across different grades and classrooms, potentially due to fidelity issues in tiered system data collection.

Practitioners and caregivers reported that cognitive behavioral approaches have been the most effective help for their girls on the spectrum in terms of being able to navigate their comparatively more demanding social environment. All reported finding explicitly explaining social situations with repetition to be helpful. Participants on the autism spectrum reported positive experiences with mental health providers who are/were able/willing to explicitly explain social situations to them with repetition. With that said, practitioners and parents reported having to alter manualized interventions to meet specific social needs of girls on the autism spectrum, alluding to a more complicated and demanding social environment and social dynamic for girls on the autism spectrum. The “triple whammy” situation proposed in this study is supported by the participants accounts and was reported by all categories of stakeholders in this study.

Current barriers of equitable health care in the area of social skill development and social emotional functioning were reported by the participants, including professional development challenges for school-based providers, health care system barriers, as well as systemic ableism, racism, and sexism issues. Some solutions reported included building an inclusive social

environment in school classrooms, teaching inclusive skills to all children, increased cross-setting collaborations, interdisciplinary work, and strengthening family-school partnerships.

This study is one of the few research studies examining the topic of quality support for school-aged girls on the autism spectrum in their social skill and social emotional development. It is also to date the first study using a participatory approach and inviting participants from all stakeholder categories to share their perspectives of this topic. Though this study aimed at investigating then gender differences in receiving social skill and social emotional support for children on the autism spectrum, it revealed an even more dire need of support in this area for this population given such supports are still rare and highly dependent on individual providers. Implications and limitation of this study are also discussed, finally, future research on this topic and other future directions are outlined.

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Chapter 1

Literature Review

Introduction

Presently, the Centers for Disease Control and Prevention (CDC) estimates that approximately one in every 54 children in the U.S. is diagnosed with Autism Spectrum Disorder (ASD) (CDC, 2020). This amounts to approximately 1.85% of children being identified with the disorder as of 2016 in the United States (2020). All racial, ethnic and socioeconomic groups have reported the occurrence of ASD (Baio et al., 2018; Fombonne et al., 2001), and of specific importance to this paper, the rates of diagnosis are 4.3 times higher for males than for females (Centers for Disease Control and Prevention, 2020). ASD is a neurodevelopmental disorder and children diagnosed with ASD have a different scope of impairment in their social emotional development and display restricted and repetitive behaviors to different degrees (American Psychiatric Association, 2013). The Diagnostic and Statistical Manual of Mental Disorders – Fifth edition (DSM-5) defines social communication and social interaction deficits as current or historical failures in social-emotional reciprocity, understanding nonverbal communicative behaviors in social interactions, and deficits in developing, maintaining, and understanding relationships (2013). The restricted, repetitive patterns of behavior, interests, or activities are defined as stereotyped or repetitive motor movements, use of objects, or speech, inflexible adherences to sameness, routines, or ritualized patterns or verbal nonverbal behaviors, highly restricted fixated interests, and hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (2013).

Due to the spectrum nature of ASD, children with an ASD diagnosis can look very different from one another, as autism symptoms manifest differently for each individual. The

DSM-5 has included an ASD symptom severity system (Level 1= requiring support, Level 2= requiring substantial support, Level 3= requiring very substantial support) in order to detail the extent of impairment and the amount of support that an individual will require based on current challenges with social communication, social interaction, and restricted and repetitive behaviors. Though the symptoms are neurologically based and common among individuals diagnosed with ASD, the behavioral presentation of symptoms, extent of functional impairment, required levels of support, and disorder prognoses are diverse and vary significantly across individuals (American Psychiatric Association, 2013; Hyman et al., 2020). For example, those who do not display intellectual impairment or disability are often characterized as high functioning (Hiller, Young & Weber, 2014). According to the DSM-5, children diagnosed with ASD need different levels of support (American Psychiatric Association, 2013), and the term “high-functioning autism” has been replaced by “children diagnosed with ASD who require support (level 1)”. Children who need level 1 support (lowest level of support) have difficulties initiating social interactions and have clear records of unsuccessful or atypical response to social overtures of others. Additionally, though individuals diagnosed with ASD at level 1 are capable of verbal communications and speak in full sentences, the to- and-fro conversations of these individuals usually do not occur or have no social reciprocity. Children who need level 1 support also have inflexibility of behaviors in one or more areas, such as difficulties with disruptions to established routines, which can cause significant interferences with daily functioning (2013).

“Gender” In This Paper

Biological sex vs. Gender. While gender and biological sex were used as synonyms in most historic contexts, sociologists and feminist psychologists have long been pointing out that “gender” is separate from biological sex. Biological sex is specifically referring to physical features and reproductive characteristics a person displays from birth. Gender, however, is an interpretative category which enables individuals to make social decisions and make sense of the social structures they function in (Lazar, 2007). Another important function that gender serves is beyond the individual scope: “gender” organizes our society via social relations and social activities. It is perhaps fair to say that every social practice in our current society is likely gendered. Therefore, internal awareness of one’s gender is not necessarily aligned with how this person is being perceived by others in a social relationship.

Gender identities vs. gender expression. Gender identities are individuals’ internal sense of their own gender (Randal, 2016), whereas gender expression refers to how others perceive a person’s gender based on their stereotypical mannerisms, interests, and appearance (American Psychological Association, 2015). Furthermore, social consequences can be assigned to an individual solely based on biological sex or physical appearance and therefore constrain a person’s social experiences/actions, regardless of each person’s chosen gender identity (Lazar, 2007, p5.). Therefore, it is important to differentiate gender identity from gender expression.

In this paper. Biological sex at birth, gender identity, and gender expression all impact the way a person functions in their social environment (Lurye, Zosuls, & Ruble, 2008). A biologically female person who identifies as a girl or woman and who has feminine gender expression will receive different social attention and social pressure than a biological female person who identifies as a girl or woman but has masculine gender expression. A cisgender person (i.e., gender identity is aligned with biological sex assigned at birth) may not experience their social environment the same way as a transgender person (i.e., gender identity not aligned with biological sex assigned at birth). The interaction of sex, gender identity, and gender expression constitute, at least partially, social relationships and social practices (Edwards-Leeper & Spack, 2012; American Psychological Association, 2015).

Gender identity and gender expression have profound interactions with other aspects of a person’s identity (Warner, 2008), and it is therefore important to recognize that the exploration of individuals diagnosed with ASD’s social experience cannot be separated from their sex, gender identity, and gender expression. This paper will be exploring the social experiences of individuals diagnosed with ASD, and this paper will be focused on those who identify as a cisgender/transgender girl, with or without feminine expression, as long as the individual is being socially viewed as a girl and constructs social relationships with other girls predominantly. For example, an individual whose gender assigned at birth is a girl, uses she/her pronouns, and predominantly socializes with other girls would be included in this paper. Additionally, an individual whose gender assigned at birth was a boy, however, uses she/her pronouns, and predominantly socialize with other girls would also be included in this paper. On the other hand, an individual whose gender assigned at birth was a girl, however, uses he/his pronouns, and predominantly socializes with other boys would not be included in this paper.

This paper used girls or women and females as ways to differentiate between social identities (including gender identity and gender expression) and biological sex assigned at birth. Usage of any of these three terms aligned with previous literature and how researchers in these peer-reviewed articles have adopted the terms.

Gender Difference in Autism Spectrum Disorder

As indicated, the CDC has identified that the prevalence of ASD in boys is 4.3 times that of girls (CDC, 2020). Furthermore, girls diagnosed with ASD are only one tenth as likely to require Level 1 support (the group needing the least amount of support), compared to boys in the same group. This indicates that girls who obtain a diagnosis of ASD are more likely to display cognitive impairment than boys diagnosed with ASD (Fombonne, 2009, Rivet & Matson, 2011). Research to date on why prevalence differs by gender (Hiller, Young, & Weber, 2014; Lai et al., 2017) provides different hypotheses to explain this difference. This includes theorizing genetic differences such as the *multi-factorial multi-threshold model* which hypothesizes that the genetic liability for reaching a diagnosis is higher for females than for males (Reich, Cloninger, & Guze, 1975); meaning it is hypothesized that there are multiple genes and multiple environmental factors that interact in a complex way that ultimately led to ASD. This theory argues that the environmental risk factors threshold for females is higher than for males; the *multi-factorial sex/gender-differential liability model*, proposes that female-specific prenatal hormones are responsible for the lower amount of ASD diagnoses in females (Auyeung, Lombardo, & Baron-Cohen, 2013; Baron-Cohen et al., 2014); the greater genetic variability in males hypothesis, suggests that males have greater genetic variation than females do in the general population and thus receive ASD diagnosis more often and display less severe symptoms of ASD than females (Wing, 1981). Finally, the *genetic heterogeneity and sex-differential penetrance model* predicts that females are qualitatively different from males in terms of genetic etiological factors. This model proposes that the penetrance of autism risk genes might be less in females compared to males (Zhao, et al., 2007). Although all of the above models attempted to explain the gender differences in prevalence, not one model has absolute advantage over the others. The reason for gender differences in prevalence in ASD is yet to be explored.

Beyond the different hypothesized models to explain the differential rate of ASD diagnosis by gender, more recently, an increasing number of researchers have raised questions about the diagnostic criteria of ASD itself, indicating the presence of systemic biases towards females seeking an ASD diagnosis (Mandy & Lai, 2017). For example, Duvekot et al. (2017) reported that the current conceptualization of ASD lacked a comprehensive understanding of how autism symptoms manifest in females. Specifically, clinicians reported using the restricted and repetitive behaviors and interests domain (RRB) more often than using the social-communication domain when making an ASD diagnosis. This RRB focus may be problematic since clinicians might be hesitant in diagnosing a girl with ASD because they either do not see enough RRB or they do not qualify some of the RRBs as ASD related. Other research has hypothesized that the current measures have limited ability to capture what RRBs and interest look like in female clients (Frazier & Harden, 2017; Duvekot et al., 2017). This potential bias, it has been argued, may be leading to clinicians "missing" or not diagnosing girls with ASD (Sutherland, Hodge, Bruck, Costley, & Klieve, 2017) and therefore responsible for decreased diagnosis of girls with ASD.

Beyond the potential measurement and diagnostic errors, researchers also proposed that teachers and clinician's perspective of girls' social behaviors and interests may contribute to the prevalence rate differences (Hiller, Young & Weber, 2014; Dean, Harwood, & Kasari, 2017; Lai et al., 2017). The "*camouflage hypothesis*" proposes that girls diagnosed with ASD are in general less salient in their symptom manifestation (Dean et al., 2017). This hypothesis postulates that while boys diagnosed with ASD are "easy" to spot due to the fact that they more often socially isolate to the observers' eyes, whereas girls diagnosed with ASD are able to stay in close distance with their same-sex peers (Dean, Harwood, & Kasari, 2017), therefore, females do not stand out and are therefore less likely to receive an early referral for ASD. While social exclusion by their peers still exists for girls, the lack of apparent physical distance will most likely shield observers from quickly noticing the social challenges girls experience and who miss out on those who have the potential to be diagnosed with ASD (Dean et al., 2017).

Furthermore, girls diagnosed with ASD have been identified to be more capable of demonstrating compensatory behaviors such as an effort to mimic social behaviors of others that may serve to mask their social deficits (Lai et al., 2017). Other than social functioning differences in appearance, clinicians noted that gender differences are especially salient in the RRB domain (Mandy & Lai, 2017). School-aged children and adolescents are especially more likely to display this difference. Girls' specialized interests are more in line with traditionally feminine activities (e.g., celebrities and princesses), and therefore are less likely to be noticed by observers as "abnormal" or "atypical" and may reduce the possibility of girls being referred for further evaluation (Little et al., 2017). Meanwhile, boys' special interests can be out of the ordinary for a child (e.g., wheels of a car, train tracks), and more easily noticeable for referral and evaluation of ASD (CDC, 2020).

The possible biases in diagnostic framework, measurement tools, and observer's view creates opportunities for an explanation of why girls are not only less likely to be referred for ASD diagnosis but also less likely to receive an ASD diagnosis and therefore miss out on vital early support until much later in their lives, if ever (Hiller, Young & Weber, 2014; Van Wijingaarden-Cremers et al., 2014). While the average age of first diagnosis for ASD in the United States is 4.5 years, the median age is 5.7 years for girls (Centers for Disease Control and Prevention, 2012; Shattuck et al., 2009). Compared to boys on the autism spectrum, there is on average a 4.3-year delay in diagnosis (Begeer et al. 2013). This may mean a diagnosis is not provided for girls on the autism spectrum until they have entered adolescence (Cridland et al., 2014) or even adulthood (Begeer et al., 2013). Intervention effects are tremendously diminished by the time girls on the autism spectrum typically access these services. In response, many recent research papers have started to focus on symptom-presentation differences, hoping to shed light on this issue (Kirkovski, Enticott, & Fitzgerald, 2013). Due to the scope of this study, the focus of this section was on illustrating the distinct advantages and difficulties school-aged girls diagnosed with ASD face socially as a manifestation of their ASD symptoms.

Girls diagnosed with ASD: A “Triple Whammy” Situation in Socialization

To understand social emotional advantages and difficulties for school-aged girls diagnosed with ASD, two types of comparisons are necessary (Koenig & Tsatsanis, 2005): differences between a typically developing school-aged girl and a girl diagnosed with ASD symptoms; and gender differences within school-aged children diagnosed with ASD. Previous literature has indicated that girls diagnosed with ASD face a much more complicated social scene compared to same-aged peers from either comparable group (Bussey & Bandura, 1999). For example, compared to typically developing girls, girls with ASD have a harder time navigating group structure changes or multitasking (e.g., talking while walking) (Dean, 2013). Compared to boys with ASD, girls with ASD are more likely to be expected to do the aforementioned tasks as girls tend to socialize in groups more often than boys (2013). Their ASD-related mannerisms exacerbate the already more complicated social relationships between school-aged girls (Jamison & Schuttler, 2017). Acknowledging the interactions between the two identities (individual diagnosed with ASD symptoms and the female gender) is an important step towards identifying appropriate support for this group, such as designing an inclusive and effective social emotional intervention (Kreiser & White, 2014).

Gender difference in typically developing children’s social emotional development.

Gender differences in typically developing children’s social interactions and emotional development has been studied intensively in the field of social developmental psychology. Gender differences are seen in the size of play groups (Benenson, 1993; Underwood, 2007), attitudes towards emotions (Keubli, Butler, & Fivush, 1995), proximity to adults during play time (Omark, Omark, & Edelman), and ways of expressing aggressions (Hey et al., 2011;). Previous literature showed that typically developing girls tend to have more intimate peer groups, care more about group cohesion, and tend to engage in unstructured activities such as talking (Weinberger & Stein, 2008; Goodwin, 2006; Blatchford, Bains, & Pellegrini, 2003).

Gendered behaviors are commonly seen in typically developing school-aged children. For example, while both genders choose to socialize either in a group or in a dyad format, girls tend to participate in activities with more unstructured time and prefer talking, while boys tend to participate in structured activities (games) with rules and do not engage in as many social conversations (Blatchford, Baines, & Pellegrini, 2003; Dean, 2013). School-aged children with typically developing trajectories also differ by gender when it comes to group conversations. Girls tend to show more fluidity in these conversations than their male peers (Goodwin, 2006, Dean, 2013). Dean further observed that while both genders engage in talking and playing at the same time, girls tend to focus more on talking than playing whereas boys displayed the opposite preference (2013). More specifically, talking seems to serve the purpose of facilitating play for boys. However, talking and playing are more integrated for typically developing girls, and girls are better at multi-tasking socially than their male peers (Dean, 2013). Furthermore, Dean argues that girls tend to move between activities, from peer to peer, all while maintaining a fluent conversation (2013). These findings indicate the higher level of attention needed from girls to read social cues, comply with social rules, and maintain reciprocal play and conversation within a social peer group (2013). These findings suggest girls with ASD will enter a more complex and challenging social scene than boys with ASD. Yet to date, minimal research has focused on these differences or that the way boys and girls with or without ASD engage with their peers matters.

Gender identities also impact the ways school-aged children compete in games and tasks. This line of research highlights a heavier interest in securing social relationships with their same-gendered peers from typically developing girls (Gneezy & Rustichini, 2004). While both school-aged boys and girls can be competitive in a competition game, girls are more likely to seek out partners within same-sex peer groups while competing in a task, whereas boys tend to solely focus on the task (Gneezy & Rustichini, 2004; Weinberger & Stein, 2008). Gender and gender composition of the group also impact competitiveness when participating in a group game. While boys are more competitive than girls when both genders are in mono-gendered groups, such difference in competitiveness disappeared when the groups were altered, and each contained children with mixed genders (Weinberger & Stein, 2008; Geary et al., 2003). Weinberger and Stein further argued that girls are no less competitive than boys by nature; however, they perceived that competing within all-girl groups generally indicated a higher social cost rather than benefits. Girls seem to have a higher discomfort level when put in direct competition with their same gender peers. In other words, girls, when placed with same gendered peers, tend to have more concerns about disrupting their relationships with other girls than competing and winning in a game (2008). Comfort, competition and perceived social cost have been identified as important components of social connection for typically developing girsl but there has been a clear absence of focus on these areas when it relates to girls with ASD and how or if the interventions developed to improve social skills for males and especially females, consider or incorporate any of these critical elements.

Girls diagnosed with ASD VS. Typically Developing Girls. Social interactions between girls and their peers, while not necessarily more difficult than social interactions in all boy groups, are more focused on group cohesion, social communication, and the ability to engage in unstructured activities (Gneezy & Rustichini, 2004; Weinberger & Stein, 2008). All of those aforementioned group cohesion efforts are inherently challenging for children diagnosed with ASD, and potentially challenging for girls diagnosed with ASD as well. Existing literature has described a variety of social impairments seen in populations diagnosed with ASD (White, Keonig, & Scahill, 2007). The most frequently presented problems include reading social cues and conforming to social rules (e.g., having to and fro conversations; taking perspectives), difficulty understanding and expressing emotions and using verbal cues correctly (e.g., reading sarcasm and metaphor), and therefore leading to difficulties building and maintaining social relationships (Krasny et al., 2003; Kerbel & Grunwell 1998; Shaked & Yirmiya, 2004; Tager-Flusberg& Joseph, 2003). For school-aged children diagnosed with ASD, it is well documented that this population has a relatively more limited repertoire for play (Dean, 2013), fewer reciprocal friendships, lower social status in the classroom (Chamberlain, Kasari & Rotherman-Fuller, 2007), and therefore limited social experiences or opportunities to practice and develop social skills (Bauminger & Kasari, 2000; Bauminger & Shulman, 2003). In addition to the ASD symptoms discussed above, some research has found that girls diagnosed with ASD demonstrated a high sensitivity for social demands and other people’s opinions (Gaub & Carlson, 1997). Meaning that while girls diagnosed with ASD experienced more social challenges compared to their typically developed same-gendered peers, they might experience even more social stress compared to their male counterparts due to their heightened need for friends and higher vulnerability to peer exclusion. These conclusions are based on a very small number of studies and need additional focus and attention to clearly identify the costs and needs of social engagement for girls with ASD. This is needed not only to determine if female needs differ from male needs, but as importantly, how those different requirements will be incorporated into interventions is critical and in need of attention.

Girls diagnosed with ASD vs. boys diagnosed with ASD. Literature is inconsistent on whether or how girls diagnosed with ASD differ from their male peers in social emotional development. Researchers reached inconsistent results when examining social communication gender differences within the ASD population (Van Wijingaarden-Cremers et al., 2013). Some reported girls diagnosed with ASD as having more social difficulties and less ability to participate in social play and social imitative play than boys with ASD (Holtmann et al., 2007), others either found no gender differences in social behaviors or reported that girls diagnosed with ASD had more of an advantage with socialization than boys diagnosed with ASD, in areas such as imaginative play (Banach et al., 2009; Carter et al., 2007; Knickmeyer et al, 2008), some of this may be due to the limited number of girls included in these research papers in ASD (Watkins, et al., 2014). Additionally, researchers have argued that this is also potentially due to the fact that fewer higher functioning autistic females are diagnosed, and therefore excluded from research (Baird et al., 2011). Diagnoses for females were more likely if an individual displayed classic symptom, appeared to need more intensive support, or had lower intellectual abilities (Baird et al. 2011; Begeer et al., 2013). Late diagnoses are also seen more frequently in autistic girls with milder symptoms or higher intellectual abilities, this may also lead to less inclusion of this group of girls in many possible studies (Kopp & Gillberg; 1992; Siklos & Kerns 2007; Begger et al., 2013) as well as opportunity for early intervention. Therefore, some researchers suggested that the potentially biased diagnostic criterion may have excluded many high functioning girls from receiving an ASD diagnosis, and this would have otherwise boosted the social functioning level of all autistic girls as a group (Ehlers & Gillberg, 1993; Van Wijingaarden-Cremers et al., 2013). It is also possible that the comparisons will naturally have different results based on the method and approach of the study. For example, Holtmann et al.'s 2007 study used parental rating scales to measure social skill outcomes. Such rating scales may be subject to adult biases, such as parents' higher expectations for girls to show social competence in comparison to boys (Holtmann et al., 2007). Similar differences from parental ratings were also present in the 2007 study done by Carter and colleagues (2007). This study utilized more sensitive and objective measures such as the Autism Diagnostic Interview-Revised (ADI-R; Rutter et al., 2003) and Autism Diagnostic Observation Schedule, Second Edition (ADOS-II; Lord & Rutter, 2012) to measure gender differences in social emotional skill development. Disadvantages in social competence for girls were not seen in laboratory observation and measurements in comparison to parental ratings (Carter et al., 2007).

Multifaceted identities. Nonetheless, girls diagnosed with ASD face multi-faceted challenges and advantages during social activities. Their identity as a girl and as a child diagnosed with ASD might mean that their advantages and disadvantages are very unique and multi-dimensional. More recent studies have presented observation data, highlighting that many of the gender differences in socializations between typically developing boys and girls are also seen in those diagnosed with ASD (Dean, 2013). For example, a structured observation conducted by Dean showed that typically developing girls were inclined to engage in verbal social communication whereas typically developing boys preferred structured games (2013). For example, typically developing girls preferred talking whereas their male peers wanted to play boardgames and other games with rules (2013). Gender differences in preference of group play structure were also seen in children diagnosed with ASD, where girls diagnosed with ASD engaged in more group activities than dyad or solo play than boys diagnosed with ASD (Maccoby, 1998). Therefore, it appears that traditional differences in preference for gendered activities between typically developed boys and girls is also carried over to boys and girls diagnosed with ASD (Kopp & Gillberg, 1992). Girls diagnosed with ASD play more traditionally feminine (e.g., jumping rope) and gender-neutral activities (e.g., walking and talking), whereas boys diagnosed with ASD prefer traditional masculine activities (e.g., playing basketball, playing boardgames). However, boys with ASD are more likely to engage in these same activities in isolated and peculiar ways (e.g., playing alone; playing with only part of the toy; not playing with toys using their intended functions), whereas girls do not. This means that the gender differences in socialization will naturally make girls diagnosed with ASD less likely to be noticed by adult observers, if the observers were simply filling out a rating scale based on observations conducted from afar, as many of these social behaviors are easy to be subjected to subliminal gender biases from adult observers (e.g., clinicians, teachers, and parents). Specifically, it would appear that a girl diagnosed with ASD is likely to be standing close to their peer group, participating to a normal extent to an observer's eyes, and appear to enjoy activities similar to their same-gendered peers (Dean, Harwood, & Kasari, 2017; Dean et al., 2013; Lai et al., 2017).

Compared to their male counterparts, who often isolate themselves from others, do not participate in interactive play, and do not appear to enjoy the activities of their peer group, girls diagnosed with ASD face a more complex interaction between their ASD symptoms and the peer group dynamics they encounter. For example, while girl groups tend to have more fluid group dynamics and are generally more likely to multi-task (i.e., converse while playing), the nature of

ASD symptoms makes cutting in and out of social conversations and following the change of group dynamics very difficult for children diagnosed with ASD to understand and participate in social activities with peers (Dean, 2013). Despite the unique challenges girls diagnosed with ASD face, they have been found to try longer and harder to join their peer social groups compared to boys (Dean, 2013). While social groups of girls contain more frequent and fluid dynamic changes and conversation flows, girls diagnosed with ASD still displayed more effort to participate despite rejections and exclusion, compared to boys diagnosed with ASD. It is possible that this continued effort may have originated from a heightened desire to join the group (Dean, 2013; Attwood, 2007; Connellan et al., 2000). However, it is also possible that girls diagnosed with ASD were not able to read the group's alienating social cues (Dean, 2013). The research presented here highlights the unique challenges girls with ASD face in diagnosis and social interaction. However, it also suggests that males and females with ASD are quite different relative to social skill needs and expectations, yet often treatment is a one size fits all gender offering. A failure of this work to date then, is that there are limited to no studies that have focused on potentially different outcomes to treatment for social skills for males vs females with ASD.

Race, Ethnicity and Class

All racial, ethnic, and socioeconomic groups have reported the occurrence of ASD (Baio et al., 2018; Fombonne et al., 2001), yet the diagnostic data and access to service data indicated that there is significant disparity between different gender identities, racial, and ethnic groups (CDC, 2020). For example, a 2017 study reported that when comparing prevalence data by race and ethnicity, those who identify as Hispanic have a much lower prevalence rate reported compared to other groups such as non-Hispanic white, non-Hispanic black, or Asian Pacific

Islander (Durkin et al., 2017). Disparity in autism diagnostic and treatment services exists in many areas. The ADDM network's 2020 report presented disparities between gender groups, racial and ethnic groups, and geographic locations (Community Report from the ADDM Network, 2020). The ADDM provides prevalence data and other characteristics among children aged eight years (Baio et al., 2018), their surveillance data as of 2014 showed that African American and Hispanic Children are less likely to be identified with ASD than Caucasian-American children. Additionally, there is a general lack of data on Asian children or children from Indigenous communities (2020). The disparity between racial and ethnic groups could potentially be attributed to socioeconomic barriers, lack of or delayed access to evaluation, diagnoses, and services (2020). The same report also illustrated geographically based disparities in ASD prevalence rate. Within the U.S., states like Florida and Maryland have an ASD prevalence rate higher than 4% whereas in states like Ohio and Texas, less than 2% of the population has a diagnosis of ASD. Factors such as identification method, insurance coverage for ASD services, and distance to service centers can impact this variation between states (2020).

Summary. For girls diagnosed with ASD, their gender identity has been shown to result in having to function in more complex group dynamics compared to boys with ASD. These group dynamics place 1) higher demands on their abilities to read implicit social cues and social rules, maintain a longer and less structured conversation, while participating in unstructured activities more frequently (Dean, 2013). These abilities, however, are 2) already hindered due to their ASD symptoms (Kopp & Gillberg, 2011)). These interactions between gender and ASD symptoms, may often result in social challenges (2011), yet at the same time, their social challenges are 3) not as visible to adult observers compared with their boy counterparts, because of their more subtle nature. It is, indeed, a triple whammy situation. The implication here is that there appears to be reason for increased examination as to if the typical treatments and interventions, that often include majority males with ASD as participants are appropriate, effective, or sufficient to treat and improve social outcomes for girls with ASD.

Current Research on Recognizing Girls on the Spectrum

As a reaction to the need to better support this population, there is a rise in research interest studying how to best recognize, evaluate and support girls diagnosed with ASD (Begeer et al., 2012; Kopp et al., 2010; Lai et al., 2017; Kopp& Gillberg, 2001; Posserud et al., 2008). The following section will highlight current issues and findings in this area.

Evaluation & Assessment

There has been a consistent call from researchers for access to early interventions to achieve better outcomes and results for children diagnosed with ASD and their family, and early intervention depends on early detection (Wiggins et al., 2006; Dawson, 2008). It is also widely recognized that girls on the autism spectrum who require level 1 support may be overwhelmingly underdiagnosed (Baird et al., 2001). A 2014 study done by Begeer et al. (year) showed that while there is little to no gender difference in identification timing for children diagnosed with high-functioning autism (using DSM-IV criteria for ASD, this is equivalent to ASD requiring level 1 support according to DSM-V), girls were identified later than boys among children diagnosed with ASD who were at level 1 support. Using data from the National Survey of Children's Health as a community-based sample, and Centers for Disease Control and Prevention population data as a clinic-based sample, researchers estimated that there should have been approximately 39% more girls receiving an ASD diagnosis (Barnard-Brak et al., 2019). This outcome makes it clear that the symptoms and red flags often applied and used to identify, refer, and diagnose males with ASD is often a threshold not met by and may be inappropriate to use to identify, refer, and diagnose females with ASD.

Multiple areas have been identified in the existing literature as areas of caution when assessing girls diagnosed with ASD in order to prevent a false negative decision, such as possible adult gender biases in rating scales and reporting (e.g., not noticing gender-typical behaviors as RRBs), potential observational biases (e.g., observing from afar resulting in missing information), and likely screening and diagnostic tool biases (e.g., overlooking subtle gender differences in social communication) (Little et al., 2017; Dean, 2013; Conlon et al., 2019). Accordingly, current literature has identified some general implications and future directions on how to improve the process for girls relative to evaluating and diagnosing ASD. Kreiser and White suggested some ways to overcome adult observers' possible implicit gender biases (2014). Despite following evidence-based assessment and practice methods as a clinician during diagnostic sessions (Ozonoff et al., 2005), Kreiser and White suggested mindful questions to be asked when evaluating a child's social emotional functioning by obtaining historical information of functioning across multiple social contexts (2014). When investigating seemingly repetitive or restricted behaviors, they suggested that clinicians examine the intensity and quality of the behaviors and interest to avoid situations where these seemingly gender-appropriate behaviors are mistaken as typical (2014). For example, if a girl has an interest in playing with dolls, the clinician should pay further attention to how frequently this girl plays with the doll, and whether her interest in dolls is preventing her from engaging in other activities. Additionally, Conlon et al. directed attention to the possible difference in social communication skills between girls and boys diagnosed with ASD (with no intellectual impairment) (2019). They suggested closer attention to the symptom presentation differences in the two genders, as well as a more sensitive tool (e.g., a specific tool analyzing language used by boys and girls during a social narrative) (Conlon et al., 2019) would be useful to improve referral and identification.

Efforts to examine these recommendations have already begun. For example, Kopp & Gillberg (2011) launched an effort to develop a female-specific version of the Autism Spectrum Screening Questionnaire (ASSQ), a widely utilized screening tool in evaluating children diagnosed with ASD. The author reported effectiveness in the tool's ability to distinguish ASD presentations from non-ASD presentations, especially in the girl groups (Kopp & Gillberg, 2011). They further identified items that were highly predictive of girls diagnosed with ASD: "avoids demands", "determined", "carefree with regard to physical appearance and dress", and "interacts mostly with younger children" (2011). Though previous findings on the gender differences in assessment results are scarce, some researchers suggest that this could be explained by the fact that cases of boys with mild ASD symptoms are more available and included in these studies, and therefore the gender consistency in assessment finding should be treated with skepticism (Ehlers & Gillberg, 1993; Kopp & Gillberg, 2011).

The efforts to improve evaluating and diagnosing ASD for girls put forth by previous researchers has not yet led to a conclusive diagnostic tool just for girls. Previous studies are also unclear on whether such a gender specific tool is needed. Suggestions for practitioners are so far oriented around individual clinical judgement and are limited to general guidelines. However, the studies highlighted here make it clear there is more work to be done and a strong suggestion that more attention, detail, and refinement of evaluation of females is needed to increase early identification of ASD for young girls.

Intervention & Social Supports

Despite the rising amount of research on how to improve assessment and evaluation for girls diagnosed with ASD, intervention research on how to better support girls diagnosed with ASD and those who needed similar social support is scarce. Research on females diagnosed with ASD represent only 15% of all participants studied across published research (Watkins, Zimmermann, & Poling, 2014). Scattered coverage on why and how school-aged girls with an ASD diagnosis differ from their male counterparts in social-emotional development might have contributed to the scarcity of literature on social skill intervention design and implementation for this population. (Jamison, Schuttler, & Pak, 2015). Therefore, the next part of this literature review will focus on evaluating the existing social emotional interventions designed for school-aged children diagnosed with ASD published within the past 15 years (2004-2019). This is to determine how and if these interventions addressed gender-specific symptoms, if at all, within the school-aged autistic population.

Gender Difference in Social Emotional Intervention Effectiveness

Article Extraction

This section of the literature review includes a review of articles from the past 15 years (2004-2019). The following databases were used for the search: Cochrane Database of Systematic Reviews, Database of Abstracts of Review of Effects (DARE), BMJ Clinical Evidence, EBSCOhost, ERIC, and PsychINFO. The following keywords were used for searches: “Female” or “Girls” and; “social emotional” or “social skill” or “emotional development” and; “Intervention” or “training” or “skill teaching” or and “autism spectrum disorder” or and “applied behavioral analysis” or “ABA” or “behavior intervention” or and “ASD” or “PDD” or “autism” or “Asperger disorder” or and “gender” or “gender identity” or “inclusive” or “exclusive”.

Resulting Articles

A total of 162 articles were found using the above extraction process. All 162 articles were screened for inclusion based on the following criteria: 1) The article must have been published between 2004 and 2019; 2) The article must discuss an intervention for individuals with ASD (or equivalent disorders prior to the publication of DSM-V); and 3) The intervention discussed in the article must be targeting one or more aspects of the participant's social behavior challenges. Fifty-five articles were selected for inclusion based on these criteria. These 55 articles evaluated a total of 24 interventions. These articles included initial evaluation of a new intervention, follow-up studies of the specific intervention being adapted into different cultures or countries, and studies evaluating the effectiveness of the expended version of an existing intervention. Each intervention was broken down to identify the core treatment elements most commonly used across treatments (see Table 1). The core treatment elements used from most to least frequent were: didactic training and computer/virtual tools (six interventions), followed by the use of social stories (five interventions), peer mediated interventions (five interventions), role play (four interventions) and social modeling (three interventions). Those used in less than three interventions are listed in Table 1.

Twenty-two of the twenty-four interventions evaluated in these studies (total participants n = 713) indicated that there were **female** participants involved in the study. Nineteen of those twenty-two interventions indicated that participants in the study were **female and** had a diagnosis of **ASD** (n = 78). A total of three out of those nineteen interventions (i.e., *The Junior Detective Training Program*; the *Secret Agent Society program*; and the *Transporters program*) indicated that they ran at least one type of analysis measuring whether gender identity made a significant difference on the intervention's effectiveness (see Table 2 for detailed participant information fo these three interventions)). All three studies reported no significant differences between genders in the effectiveness of the interventions (see Table 2), and of these three studies, a total of 21 (out of 188) participants were school-aged girls with an ASD diagnosis (Beaumount & Sofronoff, 2008; Einfeld et al., 2018; Williams et al., 2012). An average of 11% of the participants in these three studies were females diagnosed with ASD. How sensitive each program was to gender differences with less than 15% female participants with ASD across each study is challenging to discern.

Five out of the 24 interventions evaluated in the studies identified did not include any females diagnosed with ASD as participants, and therefore no information about effectiveness of these interventions if implemented with school-aged girls diagnosed with ASD could be inferred. Eighteen out of the 24 interventions identified for review, though they included female participants diagnosed with ASD, did not provide any information or specifically analyze whether gender made a significant difference on the effectiveness of the intervention. The lack of analysis, in combination with the very small number of female participants, makes it hard to infer whether these girls diagnosed with ASD benefited equally from the interventions as did males and overall study findings suggest. Next, each intervention that did analyze gender differences was examined.

Four of the interventions provided information on if or how much school-aged girls diagnosed with ASD would benefit from the social emotional skill training designed. The *Junior Detective Training Program* incorporated multiple components of social skill training including training on emotion recognition, emotion regulation skills, modeling, role-plays, and group discussions (Beaumount & Sofronoff, 2008). This program targeted school-aged children with Asperger syndrome. The study's participants were 49 children aged between 7 and 12 years old (female participants total = 5, experimental group n=3, control group n=2), and it utilized pre and post parent and teacher reports (i.e., social ratings scale) to measure the participants' social skill level. The study authors concluded that the children in the experimental group had significant improvement in their emotion management strategies similar to the characters in the social stories, however not in specific areas such as facial expression and body-posture recognition measures (2008). This study did delineate treatment effects for the female participants and a Chi-square analysis indicated no significant differences between the two genders (2008). However, the small sample size of female participants (n = 5), and only 3/25 in the intervention group significantly limited three aspects of this study's conclusion: 1) since there were no descriptive data provided by the authors on how each of the five female participants performed post-intervention, it is hard to infer whether there was significant differences in outcomes when comparing girls from the control group and girls from the experimental group; 2) whether true gender differences could have been detected; and 3) whether the conclusion of no gender differences could be generalized.

The *Secret Agent Society* program (SAS) is a school-based intervention aiming to enhance social-emotional skills for children diagnosed with ASD. This program incorporated treatment elements such as virtual reality, didactic training, parent training, and peer-mediated interventions (Einfeld et al., 2018). In the evaluation study, 84 participants (75 males and 9 females) aged from 8.2 to 14.6 were recruited. All participants had a confirmed and recent (<12 month) diagnosis of ASD at the time of the study. All students experienced treatment-as-usual for a period, and the experimental group (female participant number not shown) received SAS programming during a second treatment phase. All participants received a 12-month follow up (2018). Due to participant retention issues, only 66/84 families were included in the follow-up assessment (x/66 were female). This study adopted multiple assessment methods to measure social skill levels pre and post-intervention. Rating scales (i.e., SSQ-P; SSQ-T) were given to parents and teachers to measure the participants' competence in several social emotional domains. This study also directly measured the children's knowledge of emotional strategies using two social stories (i.e., James and the Math Test; Dylan is Being Teased) examining the participants' knowledge of appropriate anxiety management strategies and appropriate anger management strategies (Attwood, 2004). Both stories used in this study focused on a boy character (2018). This study identified the SAS program as an effective social skill training program for children diagnosed with ASD in the school setting. Reports from the participants' parents and teachers suggested improvements in their emotional regulation and awareness, as well as social problem-solving ability. A regression analysis did not find gender to have any significant impact on the effectiveness of the SAS program on all post measures (2018). Though this study was able to recruit slightly more female participants, the sample size is still too small to generalize that this intervention would be effective when used with girls with ASD. Additionally, since this study did not include the full text of the social stories used in the intervention manual, it is hard to infer what was included in the social stories and whether the main characters, both boys, will have any school difficulties that can represent social challenges girls with ASD experience in school. Another limitation that should be noted is that the SSQ-P and SSQ-T are highly oriented around parents and teachers' perspectives on the child's social emotional competence. Such rating scale results may be subject to adult biases against girls (Holtmann et al.'s 2007), or it may overlook some of the masking behaviors that girls with ASD can display (Little et al., 2017).

The *Transporters* program is an emotion training program aiming to teach young children diagnosed with ASD emotion recognition skills (Williams et al., 2012). The treatment elements included in this program include video or virtual learning and didactic training (Changing Media Development, 2006). The study included 55 children aged between four to seven years old with an existing diagnosis of ASD. There was a total of seven girls included in this study, and it was not indicated how many of these girls were in the experimental group and how many were in the control group. This study used a variety of standardized testing tools (e.g., NEPSY-II; Vineland-II) to measure pre- and post-social skill competency of the participants. Additionally, this study also utilized emotion identification and emotion matching tasks, and situational and desire-based mindreading tasks to directly measure emotion recognition in facial expressions and contextual situations (2012). The evaluation of the *Transporters program* suggested limited evidence supporting the effectiveness of this program. Additionally, this study found no difference in different gender groups (2012). Similar to the previous two studies, this study also had a small sample size, which makes the generalization of this study's results difficult.

Other noteworthy studies excluded from the article review included an evaluation of whether females diagnosed with ASD responded differently than their male counterparts to The Program for the Education and Enrichment of Relational Skills (PEERS®), a social skills intervention (McVey et al., 2017). This study recruited females diagnosed with ASD ranging from adolescence to young adulthood. Though this study was not included in the previous literature review, due to the blend of adolescent and adult participants, it provides critical information to the current study. Utilizing both PEERS® and PEERS® for Young Adults, McVey et al. measured whether the social skills intervention had an impact on social behaviors among females diagnosed with ASD (2017). PEERS® is a well-validated social skill intervention designed for children diagnosed with ASD (Laugeson et al., 2012; Schohl et al., 2014). Both the original and the extended version for young adults incorporate elements such as social conversations, social stories, didactic teaching, and peer-mediated learning. With a total of 177 participants completing the study (88 in the control group and 89 in the experimental group), this evaluation used a pre- and post-intervention measure including assessment of social skills knowledge filled out by the participants (Test of Adolescent Social Skills Knowledge or TASSK), teacher rating scales and primary caregiver rating scales (Social Responsiveness Scale or SRS; the Social Skills Improvement System-Rating Scales or SSIS-RS; Quality of Socialization Questionnaire or QSQ),. This study found no gender difference in responding patterns to the PEERS® and PEERS® for Young Adults intervention program. However, as pointed out by the authors, this study only examined quantitative differences by gender, not qualitative differences when recruiting for participants. Although male and female participants had similar IQ scores, autism severity, or social behaviors prior to the interventions, the researchers indicated that there might have been qualitative differences in their ASD symptoms which were not measured prior to the study. Future studies on whether females diagnosed with ASD respond to social skill interventions like PEERS® qualitatively should be undertaken. This study recommended qualitative measures to garner more information in future studies such as self-reports of social interactive experience, third-party observations, and participant's view on the intervention which is quite rare to include. Additionally, analyzing which components of PEERS® may be specifically beneficial for females diagnosed with ASD is also worth exploring (2017).

Another intervention excluded from review as it only included females, is the *Girls Night Out* (GNO) program, a social emotional development program specifically designed for girls diagnosed with ASD who need level 1 support (Jamison & Schutter, 2017). GNO is designed to improve self-perception and self-confidence in adolescent girls diagnosed with ASD. GNO aims to achieve this goal by teaching socially valid behaviors (e.g., reciprocal conversations) based on adolescent female social norms and the needs of the ASD population. Based on social learning, cognitive behavioral, and behavior analysis theory, this intervention utilized treatment elements such as group discussion, didactic teaching, video modeling (e.g., video modeling on conversational skills), modeling (e.g., facilitators modeling social skills), role play (e.g., participants role play social scenarios), in-vivo training (e.g., during self-care tasks, facilitators would whisper specific feedback or praises to the participants), token economy, and peer-mediated components (e.g., peers modeling and coaching social skills) as part of the program's design (2017). An analysis on quantitative and qualitative data collected indicated that adolescent girls diagnosed with ASD responded well to this program and were highly satisfied with the program (2017). The participants were given self-report measures to evaluate their social-emotional health, improvements in overall social competence, and quality of life using the SSIS rating scale. During the preliminary phase of data analysis, this study conducted a one-tail t-test in a combined sample of 34 participants (all girls) to determine the effectiveness of the program. The study reported statistically significant improvements in these girls' overall social competence ($p=.011$, effect size $=.43$) and quality of life ($p=.016$, effect size $=.55$). However, the SSIS rating scale given to parents did not report significant changes in the participants' overall social competence. Additionally, the participants reported a decrease in their internalizing symptoms following intervention ($p=.003$; effect size$=.45$). A qualitative analysis indicated that the participants self-reported improvements in conversation and self-care skills (2017). The authors also indicated that there will be future work on improving the quality of data by utilizing a variety of assessment tools and data collection in specific skill domains (2017). The authors also suggested a population specific intervention approach with a structured curriculum and individualized goal setting component would also be forthcoming (2017). The authors concluded that their intervention was successful (2017). Due to the exclusion of male-gender participants in this study, it was not possible to compare whether this intervention would be more, less, or just as successful if implemented for same-aged boys with ASD as it was not designed for that purpose. However, it did demonstrate that when an intervention is designed and targeted only to girls diagnosed with ASD, it can be effective in improving social skills and social experiences for girls on the autism spectrum. This is one of the only interventions targeted and developed for girls, and our understanding of the needs of girls with ASD relative to intervention is lacking.

Summary. As a relatively new topic, supporting girls diagnosed with ASD in their social development faces a three-fold challenge. First, there is a lack of clarity on whether gender identity makes a significant impact on the effectiveness of social skill interventions designed based on a largely male-focused sample (McVey et al., 2017). Though there is substantial evidence indicating that girls diagnosed with ASD function in a different way and face different social challenges in different social scenes compared to their male counterparts (Mandy & Lai, 2017), there is limited to no evidence supporting the necessity of a gender-specific intervention. On the other hand, however, the limited number of studies which included girls diagnosed with ASD mostly or all relied on parent and teacher ratings scales to determine if there were changes in social competence post-intervention. The limited number of females diagnosed with ASD participating in the above studies, and the lack of direct and precise measurement of social skills pre and post-intervention, make the determination of the usefulness of these interventions for girls diagnosed with ASD subject to doubt relative to their ability to determine positive treatment effects for girls with ASD.

Second there is a lack of knowledge on whether gender identity matters for social skill generalization within the ASD population. The majority of studies reviewed in this paper did not include information on the retention of social skills for girls diagnosed with ASD. Of the studies that delineated the results for girls diagnosed with ASD, limited information was provided on the retention level of social skills for this population. Given the triple whammy situation described in this paper in an earlier section, social skills learned in a structured environment may generate different results for girls diagnosed with ASD compared to their boy counterparts. The difference in social context alone may alter how practically and how successfully girls diagnosed with ASD can generalize these social skills. However, with no to limited studies directly evaluating this, the answer to this issue remains uncertain but critical to determine. If girls are to benefit from treatments for social difficulties there is a need to understand and structure treatment to be beneficial, specifically not as an ancillary to treatment developed for boys.

The third challenge in this line of work is the lack of a framework in adapting and modifying social skill interventions for ASD populations with diverse gender identities. Girls diagnosed with ASD have become an increasingly focused area of interest for researchers and interventionists (McVey et al., 2017). Additionally, although the non-binary gender identities with an ASD diagnosis are beyond the scope of this paper, it should be noted that practitioners and researchers have started to notice an increase of ASD symptoms in the non-binary gendered communities as well (van der Miesen et al., 2017). It is fair to infer that social skill interventions designed based on male-oriented samples will need to be examined, modified, or adapted so that they can adjust to this demographic change and better support school-aged children with non-male gender identities. However, there is a paucity of research which has touched on this topic and in conjunction with the need to research and better understand the needs of girls with ASD relative to treatment.

Evaluating Social Skill Intervention Services

Common Procedural Elements of Social Skill Intervention Supports Provided in Schools and Communities

Existing literature does not seem to provide sufficient evidence on whether gender-based differences are present in the effectiveness of social interventions. Previous research also does not provide enough information on how experiences of social skill training and social skill intervention supports differ based on gender. It is thus difficult to infer where gender-based differences emerge in the intervention process; this includes intervention conceptualization, intervention design, intervention delivery, and support in generalization of skills.

To examine the timepoint at which gender-based differences emerge in the intervention process, one needs to first dissect procedural elements of intervention supports provided to children. This information can then be utilized to guide subsequent steps. Existing literature in intervention support has some shared themes in these procedural elements. These elements can be roughly categorized as the following: 1) Intervention elements (procedural and content-wise), 2) Implementation elements, and 3) Generalization considerations, and each of these categories will be described and outlined below.

Intervention Elements. Common programmatic elements in evidence-based social skills training interventions for ASD includes three general categories according to an article by Moody & Laugeson that reviewed social skills training progress in ASD across the lifespan (2020). *Program structure* included session format, teaching personnel, parent, and peer involvement, as well as group modality (i.e., small group or large group). *In-session elements* included teaching methods (e.g., didactic instruction), treatment core elements (e.g., modeling, role play, in-vivo) and reinforcement format (e.g., praise, rewards). *Generalization supports* include homework assignments and a support network outside of the intervention sessions. Authors have also outlined content elements in evidence-based social skills training interventions. There is universal content across lifespan such as emotion recognition, body boundaries, nonverbal communications, perspective-taking, problem-solving, accepting rejection and responding to bullying. Additionally, common content elements seen in interventions designed for children have been identified, such as sharing, turn-taking, knowledge of game rules, group play, basic manners etc. (Moody & Laugeson, 2020).

Implementation elements.

Selection. Although individual practices may vary when it comes to how practitioners select an intervention for their clients, there are several existing guiding documents to inform practitioners regarding best practices when it comes to providing evidence-based interventions for their clients and students. For example, the PRIME (Planning Realistic Implementation and Maintenance by Educators) project provided guided steps in selecting an evidence-based intervention for a school-aged child: 1) identify the issue of concern, collect baseline data, and develop goals, 2) searching for primary resource for intervention (e.g., What Works Clearinghouse; Intervention Central), 3) evaluating the benefits and disadvantages of intervention options with considerations of student characteristics, contextual factors, practicality and evidence of effectiveness, and 4) selection of intervention (Sanetti et al. 2014).

Instructions and content delivery. Different intervention programs have different instructions on how implementers can plan and deliver the intervention content. On the other hand, the same intervention program may be delivered very differently based on facilitators and instruction settings. For example, the PEERs intervention produced manuals for both a parent-assisted outpatient model (facilitated by mental health professionals) and a teacher-facilitated school-based model (Laugeson, 2014, Preface). The implementation facility (e.g., clinic setting or school-based) may also alter specific implementation steps. For example, school-based interventions may have to alter session duration, address varied level of training of the implementers, or sometimes experiences threats to implementation fidelity due to resources and time constraints (Locke et al., 2015). However, despite the above-listed challenges and differences, there are some common content delivery elements included in social skill interventions specific to the ASD population.

Implementation Planning. Implementation planning refers to the steps implementers take to prepare for intervention delivery. This may also contain the steps implementers take to identify potential barriers to ongoing implementation (Sanetti, et al., 2014). This may include preparing for personnel, physical facilities, and materials (Sanetti, et al., 2014; Laugeson, 2014, p7). The PRIME project also gave some general concrete steps implementers should take to prepare for content delivery: explain session purpose, identify student issues, review intervention steps, modify intervention steps if necessary, identify logistics of intervention, discuss resources needed if applicable, summarize the action plan, identify potential barriers to implementation, identify strategies to address barriers, summarize coping planning, and close the planning session (Sanetti, et al., 2014).

Content delivery. Specific techniques are recommended for content delivery when implementing social skill interventions to children diagnosed with ASD. For example, many social skill interventions designed for children diagnosed with ASD recommended using concrete rules and steps to facilitate teaching. This is because of the general inclination of autistic children to follow rules and to make sense of their social surroundings using concrete steps (Laugeson, 2014). Behavioral management (e.g., reinforcements, prevention of behaviors, and ABA techniques) and modeling (peer-mediated elements, social modeling, in-vivo modeling, video modeling, ABA techniques) are commonly recommended and integrated in many social interventions designed for this population as shown in Table 1.

Data tracking and progress monitoring. Effectiveness of the intervention can be reflected by data collected during and after the intervention delivery step (Sanetti, et al., 2014). Treatment fidelity data reflects the level of *adherence* to the intervention the design implementer was able to demonstrate, the *quality* of the intervention material delivery, and the level of learner *exposure* to the intervention (i.e., frequency and duration of the intervention sessions) (2014). Fidelity data can be collected via direct observation, review of permanent products (e.g., teaching materials), or via self-report of the implementer (2014). Fidelity data collection tools are sometimes provided by the intervention manual; however, implementers may need to create a fidelity tool by themselves.

Another important type of data is progress monitoring data, which tracks how learners who received the intervention progressed in the target skills being interviewed. This data is critical in reviewing intervention effectiveness, making future decisions about intervention implementation, and altering intervention goals if needed (PRIME, 2014). The PRIME guide provides some general suggestions on how to monitor progress. Some key parts outlined in the guide are 1) defining the issue of concern, 2) choosing an assessment measure, 3) collecting baseline data, 4) setting an intervention goal, and 5) administering the measure regularly. Intervention designers sometimes offer tools for progress monitoring specifically used in their intervention program. For example, the Girl's Night Out authors indicated that they used both quantitative (rating scales) and qualitative data (self-report interviews) to monitor progress. Other interventions such as PEERs used ratings scales, criterion-referenced tests, and questionnaires such as the Social Skills Improvement System (SSIS) constructed by Gresham & Elliot in 2008, Social Anxiety Scale (SAS) designed by La Greca and Lopez in 1998, Friendship Qualities Scale (FQS) designed by Bukowski et al. in 1994, Test of Adolescent Social Skills Knowledge (TASSK) (a written test testing criterion knowledge) (Laugeson, 2004), and Quality of Socialization Questionnaire (QSQ) (Laugeson, 2004)) adapted from Quality of Play Questionnaire published by Frankel & Mintz in 2011 (Frankel & Mintz, 2011)

Generalization Supports. The effectiveness of social skill interventions provided to children diagnosed with ASD has been well documented in previous literature (Cotugno, 2009; Radley et al., 2014). However, one of the more challenging parts of this line of work is the generalization of social skills across different or new settings for children diagnosed with ASD (Bellini et al., 2007; Yakubova & Taber-Doughty, 2013). Stokes and Osnes (1989) outlined twelve types of generalization for consideration, however, there are three types of generalization efforts that are of particular interest relative to social skills training for children with ASD: 1) exploiting current functional contingencies of reinforcement; 2) Training diversely; and 3) engaging functional mediators of behavior, and each will be described and summarized below.

Exploiting current functional contingencies of reinforcement can be addressed through providing natural (positive) consequences of utilizing social skills (Radley et al., 2014). For example, *The Superheroes Social Skills* program (Jenson et al., 2011) promoted generalization of social skills via providing access to peer praise as a type of reinforcement. *Training diversely* involves providing diverse training materials so that the children diagnosed with ASD are provided with enough and various examples of behaviors to demonstrate across a variety of social situations. For example, the PEERS program provides didactic materials, behavioral examples and rehearsals, as well as a variety of peer activities across different social situations (e.g., starting and joining conversations, get-togethers, and handling arguments) to facilitate skill generalization. *Engaging functional mediators of behavior* can be realized through providing functional cues and monitoring/self-management of target social skills either through built-in fade-out content or through peer-mediated practices. For example, Wichnick-Gillis et al. designed a fade-out phase to assist children diagnosed with ASD to initiate un-scripted social activities to promote generalization of learned skills in multiple social settings (2019). Participants in this study were given an assigned number and a tablet. The participants were assigned randomized types of activities based on their pre-assigned number, and participants would receive cues from the tablet, from the instructors, and from peers to demonstrate relevant social skills earned from previous intervention sessions (Wichnick-Gillis et al., 2019).

Voices from Individuals with ASD

Lack of Participant Voices. Several of the existing studies reviewed throughout this literature review on social skill intervention services provided to individuals on the autism spectrum have evaluated intervention services through knowledge-based surveys for the participants, ratings scales and informant interviews collected from parents and service providers. However, there is an overall lack of focus on listening to the participants' own voice. The limited number of studies that utilized qualitative data from participants treated that data as supplemental or anecdotal evidence supporting the effectiveness of the intervention being evaluated (Jamison & Schuttler, 2017). While the field of autism research is starting to value the lived experience of individuals on the autism spectrum (Nicolaidis et al., 2019), more studies analyzing how individuals with ASD experience and reflect on the social skill support they receive(d) are needed, as they are close to non-existent. However, one reason research on this area may be limited relates to the accuracy of self-report for individuals with ASD.

Concerns and Benefits of Participants' Self Report. The accuracy of self-reports has been a concern in research, not limited to the autism community. General concerns of using self-reports in research includes the participants' desire to look socially acceptable and thus concealing their true thoughts or elevating positive aspects of oneself (Holtgraves, 2004). Specific concerns of the accuracy of self-reports in the autism community also exist. One area of concern is how well can individuals with ASD remember and reflect their experience that happened in the past. For example, a study comparing memory functioning between typically developing adults and adults on the autism spectrum argued that the latter group extracts less meaning from their narratives when reflecting on self-defining and everyday memories of events (Crane et al., 2010). Another study on memory functioning of adults with ASD reported that self-related memory may decline in adults with ASD overtime (Yamamoto & Masumoto, 2018).

Despite the above concerns, self-reports from individuals with ASD can provide valuable information for researchers and service providers. Past studies explored whether and to what extent self-reports from individuals with ASD differ from their informant's accounts. For example, studies on memory functioning of individuals with ASD suggested that though there are qualitative differences in self-related memories between adults with ASD and typically developing adults, adults with ASD are able to accurately differentiate between self-defining memories and everyday memories (Carne, 2009). Additionally, adults with ASD can perform recognition memory tasks as accurately as their typically developing counterparts (Yamamoto & Masumoto, 2018). Previous studies investigating diagnostic services for individuals with ASD revealed that there is a high level of convergence between self-reports and informant reports in the area of ASD symptoms severity (Sandercock et al., 2020). This means that although there might be some qualitative differences when recalling events from their past compared to their typically developing peers, individuals with ASD can still provide accurate and meaningful information about themselves.

In addition, individuals with ASD might be able to report events and experiences that are not visible to parents or their service providers. For example, participants from Sandercock et al's (2020) study reported less difficulties in everyday life skills, higher life satisfaction, and less unmet service needs than reports by their parents. Another study investigating mental health challenges experienced by individuals with ASD showed that individuals with ASD rated their experiences of depression and anxiety significantly higher than their parents (Moss et al., 2015).

Self-reports From Children with ASD. Previous studies provided empirical evidence that children on the autism spectrum are capable of reporting on their own behaviors with validity when controlled for attention functioning and intelligence quotient scores (Bakhtiari et al., 2021). Previous concerns of disagreement between self-report and parent-report on behavior, emotions, social difficulties, and mental health challenges thought to be unique to children with ASD were also seen in typically developed children of the same age (De Los Reyes & Kazdin, 2005). Disagreement between children with ASD and their parents is sometimes lower than their typically developed peers (Hurtig et al., 2009; Straitis & Lecavalier, 2014). Utilizing self-reports when understanding the experience of children with ASD in specific areas has its own unique advantages (Keith et al., 2018).

Self-reports From Adults with ASD on Their Past. Generating events from the past and in the future was considered a deficiency for adults with ASD. This was considered to be related to the lack of introspection abilities among individuals on the autism spectrum, reduction in autonoetic awareness (the conscious re-experiencing of a past event), and an elevated level of noetic awareness (an awareness of the knowledge but challenges in recalling learning that knowledge) (Bowler et al., 2007; Tanweer et al, 2010). However, a recent study conducted by Crane et al indicated that adults on the autism spectrum had a comparable level of generating events from their past when they were not asked to recall a highly specific event (Crane, 2013). In other words, when asked to generate past events in a relatively open format with less constraints from the interviewer (e.g., time constraints, verbalized format vs. written formats), adults on the autism spectrum generated past events with comparable quality to peers their age (2013).

Conclusion. It is supported by previous research that voices from both school-aged children and adults on the autism spectrum will inform researchers and service providers on unique experiences of social skill intervention supports. Both groups of participants might provide narratives that are unique and different from narratives provided by their parents or practicing professionals. Though there are some previous concerns on the accuracy and validity of self-reports provided by individuals with ASD, this may be partly because there are so few studies that have included the perspective of individuals with ASD. However, existing literature provides direction on how future research can optimize research design to elevate the accuracy and validity of self-reports for individuals with ASD in order to provide insight and reflection on their experience with intervention.

Methodology Utilized in Previous Research on Similar Topics

Using qualitative methods to illuminate the field with rich, contextual data is especially useful when studying communities that were previously overlooked by researchers (Biber, 2011). For example, Cridland and colleagues conducted semi-structured interviews to understand adolescent girls on the autism spectrum's experience with diagnostic services, emotional development, and mental wellness shed light on how this population experiences ASD similar to or different from boys their age (2014).

Qualitative Approach. Interpretative Phenomenological Analysis (IPA) was originally proposed by Smith in 1996 (Smith 1996; Smith et al., 1999). Researchers can use this method to collect and gather qualitative data, especially in areas where few other researchers have collected any data (Cridland et al., 2014). IPA proposes explorations of participants' views and personal meanings of an experience or an issue. IPA suggests a small and homogenous sample, typically three to four participants from each group from whom the researcher intends to learn. This is to ensure an in-depth investigation of the interested issue (Smith 1996; Smith et al., 1999). When using this method, researchers do not provide any objective accounts or explanations (Oliver, 1992). The participants provide their lived experience in a particular area or their opinions of a particular issue. Instead of being passively interviewed, IPA treats participants as the experts of their personal experiences. This approach also requires respects of the commonalities and diversities of personal experiences, and it recognizes that the data collected from the participants might be influenced by the interviewer's inevitable subjectiveness during data interpretation (Cridland et al., 2014).

Smith and colleagues laid out general guidelines for interview processes when using IPA, including instructions on sample size, session time, setting of the interview, interview structure, and devices used for the interview and data collection (Smith et al., 2009). IPA research studies should recruit as few as two participants and as many as twenty-five (2009). The interview duration is recommended to last between sixty and ninety minutes and should take place in settings that are deemed to be safe and comfortable for the participants (2009). The devices used for interview should reflect the participants'' informed consent and the researcher' needs for the study (e.g., pen and pencil, recording devices, and video recording devices, if needed) (2009). Smith et al. further suggested researchers use semi-structured or unstructured interviews when using IPA. They also stressed the importance of first building rapport between the interviewer and the participants to allow for participants to feel comfortable sharing their personal experiences (2009). It is further underscored that the interviewer and the interviewee should engage in a dialogue formatted interaction, and while researchers should prepare initial questions entering the interview, the questions can be modified or adjusted in light of the participants' responses. The interviewer should also enquire about any new areas of interest that may arise during the interview (2009).

Participatory Research Methodology Guidelines

Research collaborations between academia and members of the autism community have been advocated and encouraged in the recent decade. Academics and community members have come together to conduct research that benefits the autism community and promoted the ethics behind community-based participatory research. One such partnership is the *Academic Autism Spectrum Partnership in Research and Education* (AASPIRE). Founded in 2006, with members including academics, members of the autism community, family members, and health care professions, the AASPIRE put forth a set of principles developed over the years based on the principles of community-based participatory research (CBPR; Israel et al., 2003) to guide future research on autism (Nicolaidis et al., 2019). This set of principles was developed under equal partnership between researchers and the community. These principles are also gradually formed via a variety of large research projects over the years (Nicolaidis et al., 2019). There are seven general guidelines with specific instructions within each major guideline (see Table 3 for a copy of the guidelines from Nicolaidis et al., 2019).

Guideline 1: Transparency in Partnership Goal. This goal discusses the importance of being clear, realistic, and transparent about what the partnership between the researcher and the community member will look like. There are several types of partnership possible (e.g., equal partnership, authentic engagement, consultation), and one should choose a style that best suits the goal of the research.

Guideline 2: Definition of roles. This goal encourages researchers and community partners to clearly define each partner's role in the research process. This includes clear definition of roles, clear expectations for each partner, and an appropriate partner selection process.

Guideline 3 & 4: Communication, power sharing, and trust. Throughout the partnership, it is important to have effective communication, equal partnership, and maintain trust between the primary investigator and the community partners.

Guidelines 5, 6 & 7: Research dissemination, capacitation, and compensation. Before presenting the research results, the primary investigator should consult with community partners on how best to present findings in any published paper to minimize stigma or harm. One way to accomplish this goal is to have community partners review language use in any written reports or public presentations. Other ways include inviting community partners to research presentations, written publications, and acknowledging their partnership in the publication. The primary investigator should strive to provide community partners opportunities to be co-researchers and co-authors of future related projects if feasible. Additionally, the primary investigator should communicate honestly about the compensation of the study with the participants and the partners.

Summary of the Literature

The research presented above indicates a complicated socializing situation for school-aged girls diagnosed with ASD. Besides difficulties in receiving a prompt and accurate diagnosis of ASD and receiving appropriate support, this group faces a “triple whammy” situation where they are more likely to be required to function in a more complex group dynamic due to their gender identity, with a different set of social skills due to their ASD diagnoses, and at the same time less likely to be noticed by adults due to the subtlety of their social challenges (e.g., difficulties with cutting in and out of social conversations).

Despite the complicated social situation this group encounters, existing interventions designed for school-aged children diagnosed with ASD lack attention on whether girls diagnosed with ASD in particular would benefit from the published and evaluated intervention program, as the majority of the participants included remain males. Of the limited intervention evaluation studies that provided gender information, none indicated any significant gender differences in the effectiveness of their intervention. However, across studies, a limited number of female participants were included, studies lacked post-measure method varieties, and there was missing information regarding the generalization levels included, resulting in difficulties interpreting the conclusion of these studies and leaving room for doubt about their effectiveness for girls diagnosed with ASD in particular.

As a result, socially supporting girls diagnosed with ASD faces a threefold challenge: 1)lack of clarity on whether gender identity makes an impact on the social skill intervention effectiveness, 2) lack of information on whether school-aged girls and boys diagnosed with ASD differ in their social skill generalization level when given the same social skill intervention, and 3) limited effort in exploring a modification framework to better support girls diagnosed with

ASD. This constellation of information makes it clear that exploring gender differences in generalization levels post social skill interventions can inform research and practice aimed at better supporting school-aged girls diagnosed with ASD.

Current Proposed Study

The goal of this current study is to provide initial information and general directions on where researchers should start when evaluating social intervention supports received by school-aged girls. To achieve this goal, this study collected data from different stakeholders of this process (i.e., school-aged girls on the autism spectrum, adult woman diagnosed with ASD who received social skill services in elementary school, parents, school-based and community-based services providers) via qualitative interviews and quantitative surveys, under the guidance of community research partners. Specifically, this study aims to take initial steps addressing the first and second challenge outlined in the previous section faced by school-aged girls on the autism spectrum. Answers addressing these two challenges may further inform the third challenge in future studies. The specific research questions are summarized below:

1. What do ***school-aged girls*** with an ASD diagnosis, who are receiving level 1 support services, report as their favorite and most helpful support they receive at school relative to their social experience? Which social skill construct and core practice element(s) do they identify as most responsible for improving or being used as part of social skill interventions at school? What do they report as ongoing difficulties or barriers in their social environment that precludes them from learning, using, and/or generalizing social skills interventions?
2. What do ***adult women*** with an ASD diagnosis, who receives(d) level 1 support during school, report as the most impactful and effective support they received during their

schooling related to their social experience? Which social skill construct and core practice element did the support they identified incorporate? What experiences (positive and/or negative) did they report relative to the social-emotional interventions they received during school? What were the difficulties they reported in terms of their ability to apply and generalize the skills they were taught during school into everyday life?

3. What do ***parents of school-aged girls with an ASD diagnosis***, who are receiving level 1 support services, report as the most effective or impactful skill of the current or previous social skill intervention services their children receive at school or in the community? What type of support relative to social skills do parents report having to provide to their children in support of or in addition to interventions provided at school? What do parents report relative to generalization of social skills following the services received at school in both the home and community setting?
4. What do ***school-based service providers and community-based service providers*** report regarding their perception of the effectiveness of the social skill intervention services they provide to children on the autism spectrum? What are some of the common barriers of implementing social support for school-aged girls on the spectrum in their setting? What are some differences they experienced when providing such support to boys vs girls with ASD of similar age?
5. What ***do parents of adult women on the autism spectrum***, who are receiving or received level 1 support services, report as the most effective or impactful skill of the current or previous social skill intervention services their children received at school or in the community? What type of support relative to social skills do parents report having to provide to their children or in addition to interventions provided at school? What do

parents report relative to the generalization of social skills following the services received at school in both the home and community setting?

Table 1

Core Elements Included in the Interventions Evaluated

Core Elements	Used in No. of Interventions
Didactic training	6
Virtual/computer-based components	6
Social stories	5
Peer-mediated	5
Role plays	4
Social modeling	3
Parent education	2
ABA techniques	2
Video modeling	2
Music therapy	2
Non-directed play	1
In vivo component	1
Bio/neurofeedback	1

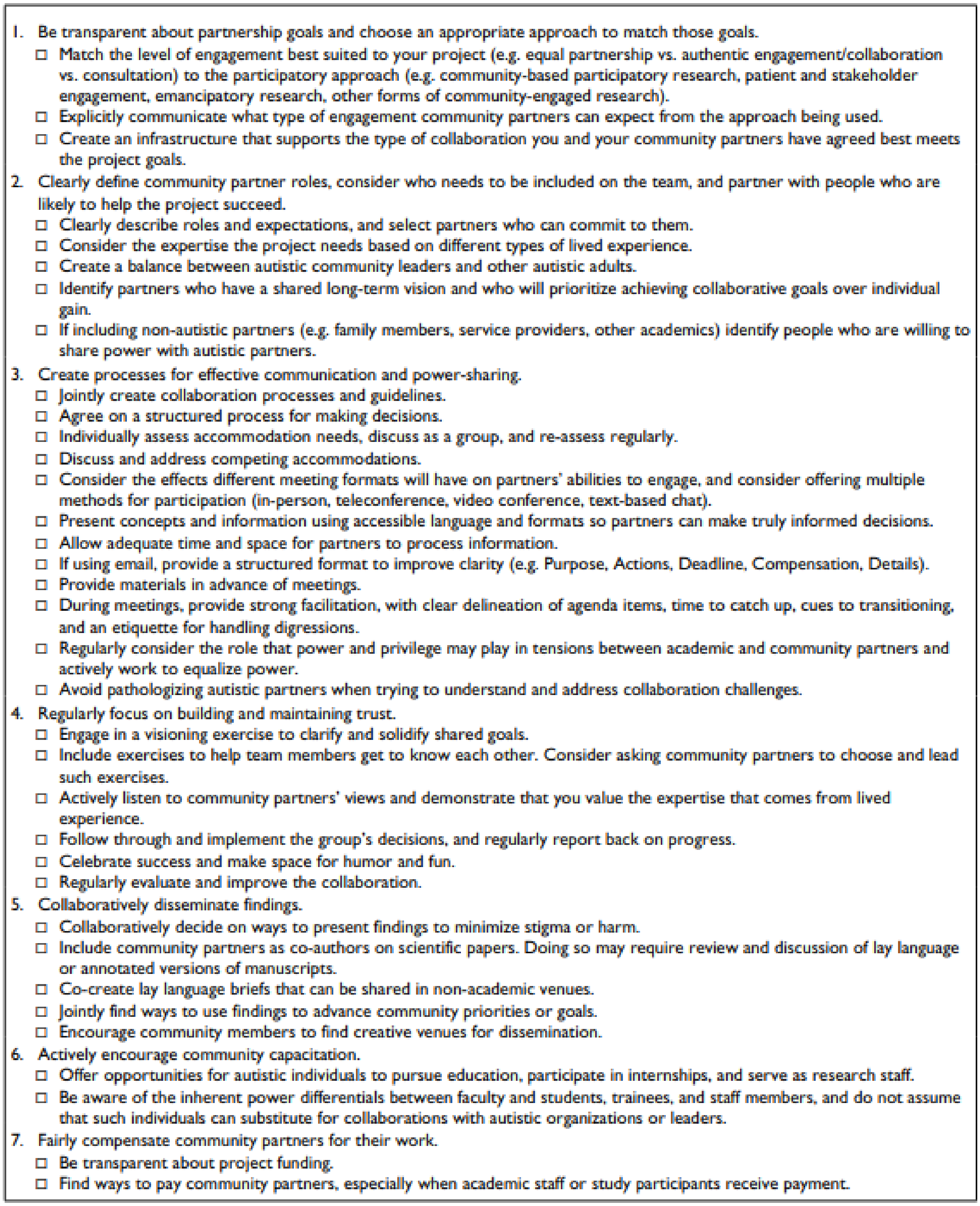
Table 2

Interventions that Evaluated Gender Identity's Impact on Effectiveness

Study	Intervention Evaluated	Participants	Type of Analysis	Results	Whether Gender Identity Matters
Beaumount & Sofronoff, 2008	The Junior Detective Training Program	Participants n=49 Male n=44 Female n=5 Age Range: 7.5–11.7 yrs	Chi Square	$\chi^2 < 1$	No
Einfeld et al., 2018	The Secret Agent Society Program	Participants n=84 Male n=75 Female n=9 Age Range: 8.2–14.6 yrs	Regression	$p>.01$	No
William, Gray, & Tonge, 2012	The Transporters Program	Participants n=55 Male n=48 Female n=7 Age Range: 4–7 yrs	Mixed-Design Regression	Not indicated	No

Table 3.

Guidelines for inclusion of autistic adults in research (Nicolaidis et al., 2019)



1. Be transparent about partnership goals and choose an appropriate approach to match those goals.
   - ☐ Match the level of engagement best suited to your project (e.g. equal partnership vs. authentic engagement/collaboration vs. consultation) to the participatory approach (e.g. community-based participatory research, patient and stakeholder engagement, emancipatory research, other forms of community-engaged research).
   - ☐ Explicitly communicate what type of engagement community partners can expect from the approach being used.
   - ☐ Create an infrastructure that supports the type of collaboration you and your community partners have agreed best meets the project goals.
2. Clearly define community partner roles, consider who needs to be included on the team, and partner with people who are likely to help the project succeed.
   - ☐ Clearly describe roles and expectations, and select partners who can commit to them.
   - ☐ Consider the expertise the project needs based on different types of lived experience.
   - ☐ Create a balance between autistic community leaders and other autistic adults.
   - ☐ Identify partners who have a shared long-term vision and who will prioritize achieving collaborative goals over individual gain.
   - ☐ If including non-autistic partners (e.g. family members, service providers, other academics) identify people who are willing to share power with autistic partners.
3. Create processes for effective communication and power-sharing.
   - ☐ Jointly create collaboration processes and guidelines.
   - ☐ Agree on a structured process for making decisions.
   - ☐ Individually assess accommodation needs, discuss as a group, and re-assess regularly.
   - ☐ Discuss and address competing accommodations.
   - ☐ Consider the effects different meeting formats will have on partners' abilities to engage, and consider offering multiple methods for participation (in-person, teleconference, video conference, text-based chat).
   - ☐ Present concepts and information using accessible language and formats so partners can make truly informed decisions.
   - ☐ Allow adequate time and space for partners to process information.
   - ☐ If using email, provide a structured format to improve clarity (e.g. Purpose, Actions, Deadline, Compensation, Details).
   - ☐ Provide materials in advance of meetings.
   - ☐ During meetings, provide strong facilitation, with clear delineation of agenda items, time to catch up, cues to transitioning, and an etiquette for handling digressions.
   - ☐ Regularly consider the role that power and privilege may play in tensions between academic and community partners and actively work to equalize power.
   - ☐ Avoid pathologizing autistic partners when trying to understand and address collaboration challenges.
4. Regularly focus on building and maintaining trust.
   - ☐ Engage in a visioning exercise to clarify and solidify shared goals.
   - ☐ Include exercises to help team members get to know each other. Consider asking community partners to choose and lead such exercises.
   - ☐ Actively listen to community partners' views and demonstrate that you value the expertise that comes from lived experience.
   - ☐ Follow through and implement the group's decisions, and regularly report back on progress.
   - ☐ Celebrate success and make space for humor and fun.
   - ☐ Regularly evaluate and improve the collaboration.
5. Collaboratively disseminate findings.
   - ☐ Collaboratively decide on ways to present findings to minimize stigma or harm.
   - ☐ Include community partners as co-authors on scientific papers. Doing so may require review and discussion of lay language or annotated versions of manuscripts.
   - ☐ Co-create lay language briefs that can be shared in non-academic venues.
   - ☐ Jointly find ways to use findings to advance community priorities or goals.
   - ☐ Encourage community members to find creative venues for dissemination.
6. Actively encourage community capacitation.
   - ☐ Offer opportunities for autistic individuals to pursue education, participate in internships, and serve as research staff.
   - ☐ Be aware of the inherent power differentials between faculty and students, trainees, and staff members, and do not assume that such individuals can substitute for collaborations with autistic organizations or leaders.
7. Fairly compensate community partners for their work.
   - ☐ Be transparent about project funding.
   - ☐ Find ways to pay community partners, especially when academic staff or study participants receive payment.

Chapter 2

Methods

This chapter describes the general procedure of the study: participatory research procedure, potential participants and recruitment plans, and data collection procedure. Specifically, recruitment materials and procedure, screening procedures, participatory research qualitative interview protocols, and quantitative surveys are provided and discussed.

Participatory Research Procedure

Community Partner

Following the guidelines proposed in the Nicolaidis et al. study (2019) and summarized in the literature review section, a community partner who identifies as an autistic woman (i.e., she considers autism as being part of her identity) was recruited. The community partner was not enrolled in the study as a participant. The following areas were made available to the community partner. The author and the community partner were in agreement of the materials being used in the study as well as the interpretation of the results before finalization: 1) materials used in recruitment of participants, 2) materials used in screening interviews, 3) interview protocol used in the qualitative interview, 4) data analysis results and interpretations, and 5) overall language use. Throughout the collaboration, the following action plan was followed:

Action Plan

Creating Partnership Plan. Due to the nature of this dissertation study, partnership with the community partner on this project took the form of consultation. To reach authentic consultation, the primary investigator and the community partner collaborated on an agreed plan on how this consultation relationship would proceed. A virtual conversation took place prior to the partnership establishment between this author and the community partner regarding expectations and supports the partner would need. Four consultation meetings took place via Zoom prior to the start of the study. Verbal and written formats of feedback were discussed and incorporated into the finalized study procedure.

Consultation Goals. Some primary needs for consultation are in the following areas:

Consultation on procedural elements. Consultation with the community partner took place throughout the research process. Once the partnership was established, this author introduced the research project thoroughly (e.g., goal of the study, methodology, data collection and analysis plan) to the community partner. The primary investigator consulted with the partner about whether she had any comments, suggestions, or need for further explanation and revision in each section of the study. Upon discussion, accommodations and revisions were added into the original study plan in the following areas:

Virtual Interview Accommodations: Autism researchers have a history of using telehealth technologies to conduct interviews, assessments, and interventions (Sutherland et al., 2018). Remote services could provide logistical convenience before the COVID-19 pandemic (2018) and now health benefits as well (Morning et al., 2020). However, it is not well researched whether virtual interviews should take exactly the same steps as an in-person interview with individuals diagnosed with ASD. Many community advocates have voiced the need for specific accommodations for individuals on the autism spectrum during virtual interactions, such as providing written instruction in addition to oral instructions (Zender, 2020). In this study, it was agreed that the study should provide accommodations for both caregivers and participants on the autism spectrum in terms of alternative formats of the interview (e.g., written format). The community partner had advised that given a higher possibility of caregivers of participants on the autism spectrum to be also on the spectrum themselves, accommodation options should be communicated with participants prior to the interview.

Review of instruments and materials. Another area that the primary investigator sought consultation from the community partner was related to the instruments and materials used in the study, especially for participants on the autism spectrum and their caregivers. Participants who are on the autism spectrum should be provided with accessible materials, an accessible consent process, multiple modes of participation, and using instruments validated for this population (Nicolaidis et al., 2019). The addition of the community partner as a consultant should translate into being able to reach recruitment and content output goals for this project. Therefore, advice, comments, and revisions from the community partner about the following topics were sought out:1) how to make the consent process (for adult participants) and assent process (for child participants) as accessible as possible; 2) the best way to communicate the qualitative interview procedures with the participants; 3) appropriate modes of participation (e.g., online, via-phone, in-person if possible); 4) qualitative interview protocols and quantitative instruments used in this study; 5) interpretation of codes developed and themes recognized during data analysis; and 6) any other topics that the community partners deems important to discuss.

Research Dissemination & Compensation

This resulting dissertation manuscript was reviewed by the community research partner and will be again before any publication. This is to ensure language use and results interpretations are free of stigmatizing language and inaccurate representations of the autism community. Upon publication, the community partner will be recognized for their contribution. Any future presentations of this study will include the partner as co-presenter and/or audience based on their preference. The partner will be offered to continue to be included in any future studies in this line of research as co-researchers, consultants, or participants based on the study and their preference. The community partner’s time was compensated in the format of free meals and gift cards.

Disagreement

It was verbally communicated with the community partner that all advice given would be treated with respect and transparency. If there was any disagreement between the primary investigator, the primary investigators dissertation chair, or dissertation committee members, and the community partner in any of the areas outlined in the consultation goals above, the primary investigator brought the suggested modifications to the dissertation committee for further advisement. Due to the nature of this dissertation study, the dissertation chair and committee held the final authority over any suggested changes to the proposed instruments, materials, procedures, and results. This decision was clearly communicated to the community partner both in advance, and again if any disagreements occur. Throughout the study, no unresolvable disagreement was present between the primary investigator and the community partner.

Proposed Changes

The community partner proposed changes mainly in the areas of instrument adjustment and interview activities. The community partner suggested pausing between sentences in the opening paragraph explaining the procedure of the interview (Appendix B1 and B2 – Step 2), as well as making the language more succinct and direct for individuals on the autism spectrum to understand. Additionally, the community partner stressed the importance of asking certain interview guidance questions to obtain richer information. For example, the interview guiding question “Did you receive any support from places other than school about social interactions” (Appendix B2) was not intended to be asked to all participants within the group. It was meant to be a guiding question only if participants do not mention enough social support. The community partner communicated that this question could prompt participants to think comprehensively what social support and social skill services could mean beyond what they typically consider as qualifying answers. The community partner proposed this change based on her knowledge and lived experience that many individuals on the autism spectrum seek support online for information or virtual groups for social support. It is also based on the tendencies of more literal thinking within the population per the community partner. Interview activities for the school-aged group was suggested to be included, such as sensory breaks for school-aged children and adult women. The community partner suggested the activity of asking to identify five senses the participant can feel in their environment (e.g., “Use all your senses, seeing, hearing, taste, touch, and smell to tell me about where you are right now.”) as an opening activity or a break activity. The community partner also advised suggesting this activity be presented to the child if discomfort was sensed or stated during the interview.

Beyond changes to the materials or the study procedure, the community partner also provided additional advice and input to prompt in-depth understanding of this population for a neurotypical researcher. The community partner suggested journal articles and Op-ed articles written by women on the autism spectrum regarding their lived experience. The community partner also prompted the interviewer to be mindful of how each individual conceptualized social skill support, and how that could mean different things for different individuals.

Participants

In order to understand the social skill intervention experiences of school-aged girls, participants were recruited from each of the following six subgroups: 1) School-aged (elementary or middle school) girls diagnosed with ASD between the ages of 6 and 12; 2) Adult women diagnosed with ASD between the ages of 18 and 35; 3) Parents of school-aged girls between the ages of 6 and 12, with the child having a diagnosis of ASD; 4) Parents of adult women who were diagnosed with ASD during their elementary or middle school-aged years (child had a diagnosis of ASD when they were between the ages of 6-12; could have been diagnosed earlier than 6 but must have had a diagnosis within the ages of 6-12 ; 5) School-based service providers serving in elementary or middle school settings; and 6) Community and/or hospital-based service providers who serve in the role of a psychologist or counselor working with school-aged children with ASD related to social skills interventions. For each group, a minimum of two participants were needed and the sample size was determined to not exceed four. This is consistent with small sample suggestions of IPA methodology (Smith 1996; Smith et al., 1999), which was the guiding focus of this proposed research.

Recruitment materials for all groups of participants were sent to local service providers and local academic medical centers. Flyers were also posted via university department-wide email lists, university disability service email lists, and social media groups. Recruitment period ranged from Feb. 2022 to May 2022. A link to an electronic consent form and screening survey was embedded in the recruitment email/post and a QR code with the link to the same electronic consent form and screening survey was embedded for phone scanning in the printed recruitment flyers (Appendix A). Within this link, there were two pages. Page one was the consent form, and page two was the screening survey. The consent form explained the purpose and the format of the study. It also explained that participation was entirely voluntary, and that any participant could decide to withdraw at any point of the study. The consent form also contained options to consent for oneself if a parent, and consent for their child if both were interested in participating in the study. It was explained in the form that if parents consented for their child to participate, the children’s assent would be obtained verbally at the beginning of the interview and the children could refuse to participate or withdraw at any time. A copy of the assent script used in the study is included in Appendix A2. Once the participants consent to be screened, they could access page two. A total of 21 participants responded and accessed the link to the consent forms. 19 participants consented and completed the screening survey (Appendix A4). Eighteen participants were identified as meeting the study criteria and were contacted to schedule the interview. All 18 participants interview data were collected and analyzed in this study.

Of the 18 participants, there were three pairs of school-aged girls and their mothers, four adult women on the autism spectrum, four school-based service providers, and four community-based service providers. Participants were given a copy of the demographic questionnaire prior to the interview (Appendix A3). Demographic data were otherwise collected via verbal inquiry or self-disclosure during the interview if the questionnaire was not completed. All participants identified as cis-gendered girls/women. One of the adult women on the autism spectrum identified as Asian. Two of the service providers identified as Hispanic. The rest of the participants identified as White. School-aged girls aged between 6 and 12. All participants were verbal. Two had both medical diagnosis of autism spectrum disorder and educational diagnosis of autism within the school system. One had a medical diagnosis of autism spectrum disorder, and at the time of this study, the parent prepared to seek educational diagnosis of ASD in the coming year. All three participants had an IEP or 504 plan. All three mothers of the school-aged girls participated in the study as well, all identified as White. Two of the three mothers worked in education. Of the four school-based providers, two were practicing school psychologists who worked in the public school district serving in traditional grade schools. One was previously a special education teacher, and one served as a special education teacher in a multilingual grade school. Of the four community-based providers, two were practicing clinical psychologists, one was a doctoral level clinician completing her pre-doctoral internship under the supervision of a clinical psychologist, and one was a practicing clinical social worker. See Table 4 for demographic characteristics.

Table 4.

Participant Demographic Data

	Code Name	Age Range	Education/Employment Status	Race
School-aged Girls (SG)	N=3			
	SG001(Boobear)	6-12	Attending traditional grade school/indicated experience of attending alternative community learning centers	White
	SG002	6-12	Attending traditional grade school	White
	SG003 (Flopsy)	6-12	Attending traditional grade school/indicated a relatively smaller rural school setting	White
Parents of SG (PSG)	N=3			
	PSG001	-	Profession related to or adjacent to the educational field	White
	PSG002	-	Profession unrelated to the educational field	White
	PSG003	-	Currently working as a paraprofessional in her child’s grade school.	White
Adult Women (AW)	N=4			
	AW001	18-35	Student-Post Secondary	White
	AW002	18-35	Student-Post Secondary	Asian
	AW003	18-35	Student-Post Secondary	White
	AW004	18-35	Working Professional	White

	Code Name	Years of Experience	Professional Role and Setting	
School-based Providers (SPC)	N=4			
	SPC001	5-10 years	School Psychologist – Public School	White
	SPC002	<5 years	School Psychologist – Public School	White
	SPC003	<5 years	Previous Special Education Teacher	White
	SPC004	>10 years	Special Education Teacher – Multilingual Grade School	Hispanic
Community-based Providers (HPC)	N=4			
	HPC001	5-10 Years	Clinical Psychologist	White
	HPC002	<5 Years	Doctoral Clinician – Clinical Counseling Service/Affiliation with a school psychologist	White
	HPC003	5-10 Years	Clinical Social Worker – Community mental health center	White
	HPC004	5-10 Years	Clinical Psychologist	Hispanic

Parent-Child Pairs

School-Aged Girls Diagnosed with ASD

Three school-aged participants previously diagnosed with ASD participated in the study. All three participants were cis-gender girls who used she/her pronouns, based on information provided by their parents. All girls were able to verbally express themselves. All girls were provided a chance to choose a pseudo name for themselves to be used in this study as part of a rapport building activity. SG001 and SG003 chose their own pseudo names. SG002 refused to do so and was named as the code name SG002. SG001 will be referred to as Boobear and SG003 will be referred to as Flopsy. They were aged between 6 and 12. Boobear (SG001) participated in a video interview. Flopsy (SG003) participated in a phone interview due to zoom fatigue, and

SG002 participated in the interview with her mother asking her questions and recorded in a written summary.

Parents

The three mothers of the above three school-aged girls participated in the study. Of the three participants, Boobear's mother reported that she had a degree in teacher education. Flopsy's mother reported she was currently employed at her daughter's school as a paraprofessional. SG002's mother reported no formal educational background or experience but that she has (as the other two mothers also reported) been an avid advocate for her daughter's education. All three parent-child pairs reside in the same state in the mid-west.

Adult Women Diagnosed with ASD

Four adult women previously diagnosed with ASD participated in the study. All used She/Her pronouns. Two of the participants currently identified as autistic, one identified as neurodiverse, and one indicated no preference. All women participated in verbal interviews with video on zoom. Of the four participants, three are currently attending undergraduate studies, and one of the participants is currently working. The three undergraduate participants in this study attended a university with a large campus population.

Parents

The current study was unable to recruit parents of adult women on the autism spectrum to participate. There was a total of three perspective participants who responded to the recruitment invites. Two parents declined consent. One parent failed to pass the screening process and was therefore excluded from the current study. Though the parent-of school-aged-girl participants and the school-aged girls were parent-daughter pairs, participating as parent-child pairs was not a requirement during this study's recruitment process. Therefore, the adult women on the autism spectrum participants all participated as individuals initially. Two of the parents of these adult women declined consent upon inquiry. One parent (not the parent of any adult women participants) responded to the recruitment material, however failed to pass the screening process (could not provide autism diagnosis paperwork).

School-based Service Providers

Four school-based service providers were interviewed. Of the four participants, two were school psychologists, working in different elementary schools. One participant was a former special education teacher in a self-contained classroom who provided school-based services in an elementary school. One participant was a current special education teacher who provided school-based services in a bilingual school (English and Spanish). All participants were working in the same state in the Midwest.

Community & Hospital Based Service Providers

Four community and hospital-based service providers were interviewed. Two of the participants work in academic medical centers, though in different institutions. They both provided diagnostic services, family-focused therapies, individual and group therapies to children with neurodevelopmental disabilities, and have served school-aged girls on the autism spectrum in both individual and group settings. It should be noted that the two participants used to work in the same academic medical center in the mid-west state and knew each other. The second participant came to know the study through word of mouth from the first participant. One of the participants is a licensed social worker who provides mental health services in the community. This participant previously served as the social worker of a therapeutic residential school, most of her clients were diagnosed with mental health disorders and neurodevelopmental disorders. One of the participants was a pre-doctoral intern clinician who provided diagnostic and intervention services to children with a variety of development and learning needs, and she had an affiliation with a local school district. She has provided individual therapies to school-aged girls on the autism spectrum.

Materials/Instruments

All materials and instruments used in this study are included in Appendix A to E. See Appendices A to E for samples of screening survey and interview protocols.

Interview protocols. Interview protocols were designed based on Smith et al's 2009 guidelines on how to utilize IPA in research. The interviews were semi-structured and lasted approximately 60 minutes (Smith et al., 2009), except for the three children, the interview time was designed to be between fifteen minutes and thirty minutes to accommodate their shorter attention span compared to adult participants (National Institution of Health, 2017). The interviews began with a rapport building activity, followed by a general open-ended question. These questions differed for each group of participants; however, they all served as a way to initiate conversations about the participants' general experience with social skill interventions provided to school-aged girls on the autism spectrum. The remainder of the proposed questions in the protocols served as guiding questions. All interview audios except for SG002 were recorded and transcribed. Some interviews generated video recordings when applicable and with consent. For the list of prepared guiding questions, see Appendix B to E.

Opening question. The primary investigator started the interview with an open-ended question such as "Tell me your experiences with social skill interventions (if a practitioner)" or "Tell me about the social activities you do at school (if school-aged children)" or "Tell me about your experiences with social interventions when you were in elementary school (if adult diagnosed with ASD)" or "Tell me about your experience with your child receiving social skill interventions (if parent)." These open-ended questions were adapted from the Cridland et al.'s 2014 study, that used an open-ended statement "what have been your experiences of being an adolescent girl with ASD/having an adolescent daughter with ASD." During the interviews, the primary investigator encouraged the participants to cover several aspects of the intervention process. For each aspect of the social skill intervention experience, the primary investigator asked one to two pre-prepared questions to direct the conversation. The primary investigator then followed the participant's lead and asked follow-up questions if applicable. Smith et al.'s 2009 guidelines in conducting interviews using IPA indicated that the researcher could follow up when the participant missed a targeted area of interest during the interview. However, this follow up should ideally be attempted one time (2009). In this study, if the participant did not cover a specific aspect of the social skill intervention experience as outlined in the research questions, the interviewer attempted to ask a follow-up question in that area one more time. If the participant chose to not discuss that area, the interviewer moved on.

Guiding *questions for participants diagnosed with ASD.* For participants diagnosed with ASD, the primary investigator asked questions that covered the following areas: 1) individual experiences with the social skill interventions they received during school-aged years; 2) experiences about the instructions/content they received during this time; 3) experiences about generalization supports regarding social skills application in multiple settings, and 4) experience about social experiences after learning about the social skills from the intervention sessions. For SG002, a copy of the interview protocol was given to her mother. The mother also had a virtual meeting with the interviewer and went over ways to ask questions and ways to follow up. Interview protocols for both school-aged girls diagnosed with ASD and parents of adult women diagnosed with ASD are included in Appendix B1 and B2.

Guiding questions for parents. For parents, interviews covered the following areas: 1) parent individual experiences of seeking social skill intervention services for their children; 2) parent experiences with aiding intervention implementation either as a parent or as a co-facilitator of an intervention; 3) parent experiences with providing generalization support outside of the intervention settings; and 4) parent perspectives about their children's socialization after receiving social skill interventions. Interview protocols for parents of both school-aged girls diagnosed with ASD and adult women diagnosed with ASD (though not used as indicated) are included in Appendix C1 and C2.

Guiding questions for school-based service providers. For school-based service providers, questions investigated the following aspects of their experiences: 1) experiences with identifying girls diagnosed with ASD who were in need of social skill interventions, 2) experiences selecting appropriate interventions for girls diagnosed with ASD, 3) experiences with intervention implementation for girls diagnosed with ASD, 4) experiences providing generalization supports for girls diagnosed with ASD, and 5) school-related barriers to providing interventions services to girls diagnosed with ASD. The interview protocol for school-based service providers is included in Appendix D.

Guiding questions for community-based service providers. Questions for community-based service providers followed these categories: 1) experiences with how they received referrals for intervention services for school-aged girls diagnosed with ASD, 2) experience with how they selected and implemented social skill interventions for girls diagnosed with ASD, 3) experiences with providing generalization supports for girls diagnosed with ASD, and 4) related barriers to intervention services for girls diagnosed with ASD. The interview protocol for community-based service providers is included in Appendix E.

Practice elements survey. One of the research goals of this study was to investigate the common practice elements present in the intervention services school-aged girls are/were receiving. A practice element is defined as “a discrete clinical technique or strategy used as part of a larger intervention plan” (Chorpita & Daleiden, 2009, p.569). The PracticeWise Evidence-based Services (PWEBS) database presents multiple frequently used practice elements used in interventions designed for individuals diagnosed with ASD. Some of these practice elements included cognitive behavior therapy (CBT), modeling, parent psychoeducation. As described in chapter 1, practice elements presented in social skill interventions vary in the interventions included in the literature. Although this paper summarized the common practice elements used in published interventions (as shown in Table 1), it is unclear if that data is representative of the practice elements included in the interventions frequently used in practice. Therefore, this information was obtained by extracting practice elements data from the participants’ interviews.

At the end of each interview, a survey containing a list of practice elements and their definitions was provided to all participants. Each practice element included one or two examples. This survey was constructed based on the PWEBS database’s description of practice elements (PWEBS). Participants were directed to check “yes” if they have experienced the practice element during their intervention experience or “no” if they did not experience the practice element. To make sure that the participants understood the example, this survey was conducted with the primary investigator present. If the participants had any questions about any particular practice element, the primary investigator was present to answer the questions. This survey was given to all participants with some adaptations for each category of participants. A copy of this survey is included in Appendix F.

Other surveys. In order to give more context to the qualitative data from the interviews, the following quantitative data was collected: 1) demographic data for each subgroup: this included age, race, ethnicity, residency area, employment, education (all participants)(Appendix A3); 2) diagnosis data: this included time of diagnosis, setting of diagnosis (school-based or clinic-based); and service provider (school-aged and women diagnosed with ASD); and 3) service history data: this included time period of the services received, type of services received, and settings where the services were/are received (for all groups but community providers). The diagnosis data and service history data were collected from the dialogues in the interviews and via reading the diagnostic reports provided by the families living with a child currently or previously diagnosed with ASD.

Participants Inclusion Criteria Screening

To determine whether individuals who responded to the flyers qualified for the study, a screening step was added for each category of participants to determine their eligibility. All participants who were on the autism spectrum were asked to provide documents confirming that they received a diagnosis of ASD (clinical or educational diagnosis). All such records were copied and saved on a secured drive. These records were only viewable by this researcher and would be permanently deleted from the secured drive after five years from the day of receiving the records. For school-aged girls diagnosed with ASD, parents were asked screening questions to determine whether their child could engage in a conversation with the interviewer about their social experience in school. The interviewer also asked parents whether their child would be able to engage in individual conversation with the interviewer, parent-facilitated conversation with the interviewer, or back and forth conversation between child and parent. Participants whose response was “no” to all types of conversations were thanked for their time. Participants whose response was “yes” to any of the above formats of conversations were included in the study. The researcher was then connected with the participant and scheduled an interview time. A copy of the screening questions is included in Appendix A. All three parent child pairs had the parent interview scheduled first. The three parent-participants then scheduled their children’s interview except for PSG002. PSG002 indicated after chatting with her child, SG002 assented to participating, however, preferred to only speak with her mother. It was then arranged that PSG002 would attend a virtual meeting with the interviewer to go through the interview protocol and the procedure of asking the interview questions. SG002’s mother then returned the written summary of her daughter’s answers. On the day of the interview scheduled for Flopsy (SG003), Flopsy indicated that she felt more comfortable speaking with the interviewer with her mother present and with the video turned off. The interview was then changed to a phone conversation. However, Flopsy independently answered the questions. Flopsy’s mother facilitated repeating her answer to the interviewer if her volume was lower or if there were enunciation difficulties.

Data Analysis Procedure

Data Analysis Method

Thematic analysis is a widely used qualitative analytic method (Braun & Clarke, 2006). This method is commonly used for identifying, analyzing and reporting patterns or themes within data collected via qualitative interviews (Braun & Clarke, 2006). Though there are no unified ways to utilize thematic analysis in research, there are some common steps researchers take. Braun and Clarke outlined six phases researchers can take when conducting thematic analysis (2006). See below for a detailed description of how these steps were followed in this study.

Reflection of positionality. Although the reflection of the researcher’s positionality was not outlined in Braun and Clarke’s guide on how to conduct thematic analysis, this researcher believed that it was vital in this research to do so. As an individual who identifies as a neurotypical Asian woman, this researcher wanted to ensure she was reflective on how her presentation, her thought process, and her neurotypicality would impact her interactions, her interpretations, and the power dynamic when engaging with the participants. As the primary investigator, I identify as a neurotypical cis-gender woman of East Asian descent. The primary researcher also identifies as a first-generation immigrant, having lived experience with both East Asian culture and the dominant American culture. The primary researcher has previous graduate level training in research and clinical work with children on the autism spectrum. The graduate coders had general level of graduate psychological research and clinical work training in school psychology, however not necessarily in-depth training in working with children on the autism spectrum. The above information was shared with the adult participants during the interview through conversations.

Data transcription. All audio transcripts were automatically transcribed by Zoom's transcription service. Each audio transcript was thoroughly read twice by two coders. Transcription errors were adjusted if they might impact the coder's comprehension of the text. Additional explanations were added if the audio was disrupted. The explanations were interpreted from available video recordings and were inferred based on contextual data. The two readers discussed any adjustments that needed further clarification. Adjustments of wording (i.e., adjustments of spelling, grammar, and adding omitted words) occurred for all transcripts. Interpretations (i.e., explanations and summary of inaudible texts by the interviewer) were needed for 2 of the 18 interviews conducted. A final version of all transcriptions was agreed on before the next step commenced.

Generating initial codes. Bruan and Clarke emphasized the importance of differentiating themes that are data-driven and themes that are theory-driven. Data-driven themes are themes seen in the data. Theory-driven themes are the ones that may inform the research question in a specific way (2006). In the context of the current study, themes are generated from both data-driven and theory-driven approaches. The primary investigator and four graduate students coded the transcripts independently. The primary investigator coded all 18 transcripts, and the four graduate students each coded four transcripts for the initial round of coding. All coders were directed to follow what Braun and Clarke outlined: 1) pay attention to as many potential themes/patterns as possible; 2) code extracts of data inclusively, which means keeping the contexts of the codes when extracting data; and 3) the same entry of data can be coded multiple times if it fits. For a general flow chart of the coding procedure in this step, see figure 1.

Coder Training. Four graduate students in school psychology were recruited as coders. The coders went through a training process including an introduction presentation session, a virtual coding training session, and a reliability training session. All coding results coded by the coders were reviewed by the primary investigator, who also served as the primary coder. Before the introduction presentation, a copy of the research proposal and a practical guide of how to conduct thematic analysis were sent to the coders as supplemental reading materials. During the introduction presentation, information regarding the purpose of the study, the structure and design of the study, as well as the data collection and analysis methodology were introduced and reviewed with the coders. A video recording of the primary coder using the coding software and performing an example coding session were shared with the coders. Coders were instructed to watch the video, perform a sample coding session independently, and each coder had a review session with the primary coder. All coders were sent transcripts to code after passing the reliability test (equal to or higher than 80% consistency with the primary coder's coding using the codes).

Initial Coding Round. After all coders were trained in thematic analysis and using the coding software NVIVO (QSR International, 2020), for each set of participants, all coders generated initial codes independently using both data-driven and theory-driven approaches. The independent coding used ensures that the coders were not impacted by one another in terms of their initial interpretation of qualitative data. It is especially important to avoid the power dynamics between the primary investigator and the graduate assistants so as not to impact initial interpretations. All coders then met as a group and discussed all codes generated. Duplicated (or similar in meaning) codes were pruned. Codes that were too general to make meaningful interpretations were dissolved (e.g., treatment). Codes that were specific to one transcript and could be interpreted within a broader code were incorporated as a sub-code (e.g., "school is boring" was incorporated as a sub-code of the code "negative experience or negative perceptions of school or schooling). After a master coding framework was generated, each coder was responsible for a category of participants (i.e., school-aged participants, adult women on the autism spectrum, parents of the school-aged girls, community-based providers, and school-based providers), and performed secondary coding.

Secondary Coding Round. During this round of coding, coders used the master coding framework to adjust the primary investigator's initial coding of all transcripts. The secondary coders checked individual transcripts in their category by file and by code. By file, coders checked whether all passages coded under a code were justified. By code, coders checked whether any code should be generated within a transcript that was not previously generated. All data was then coded and collated. Generally speaking, only minor changes took place during the secondary coding round, such as adjustment of certain sub codes. No major code changes occurred.

Searching for themes. Once data was coded and collated, coders sorted codes in their categories into potential themes using thematic maps. Thematic maps were provided in the guide by Braun and Clark as a visual tool used to organize codes into themes (2006). The primary investigator then met with each coder and discussed the themes generated. A general thematic map is also formed across all categories. Overarching themes and sub-themes were formed and recorded. The themes were then presented to the community research partner for verification and adjustment. For an example of a thematic map used in this study, see Figure 2.

Reviewing themes. A consultation meeting was held with the community partner. The community partner and the primary investigator reviewed and checked the themes. Any concerns or suggestions were incorporated. No major theme changes occurred during this process. The community partner provided general perspectives and insights of the analysis process. For example, the community partner cautioned the investigator that though there were shared experiences between different individuals on the autism spectrum, it was important to respect the diversity of this community. For example, it was possible that certain remarks made by the participants could be over-generalized unintentionally.

Defining and naming themes. Themes are operationally defined, and context and narratives were provided to describe and define the themes. Themes were reviewed to ensure they worked together as a whole. No one theme was to be so general that it would capture everything, and the themes were intended to complement each other so that the themes would together incapsulate what the study was trying to investigate, as suggested by Bruan and Clark (2006). Analyses of each theme will be presented in the next chapter.

Figure 1. Coding Process Flow Chart

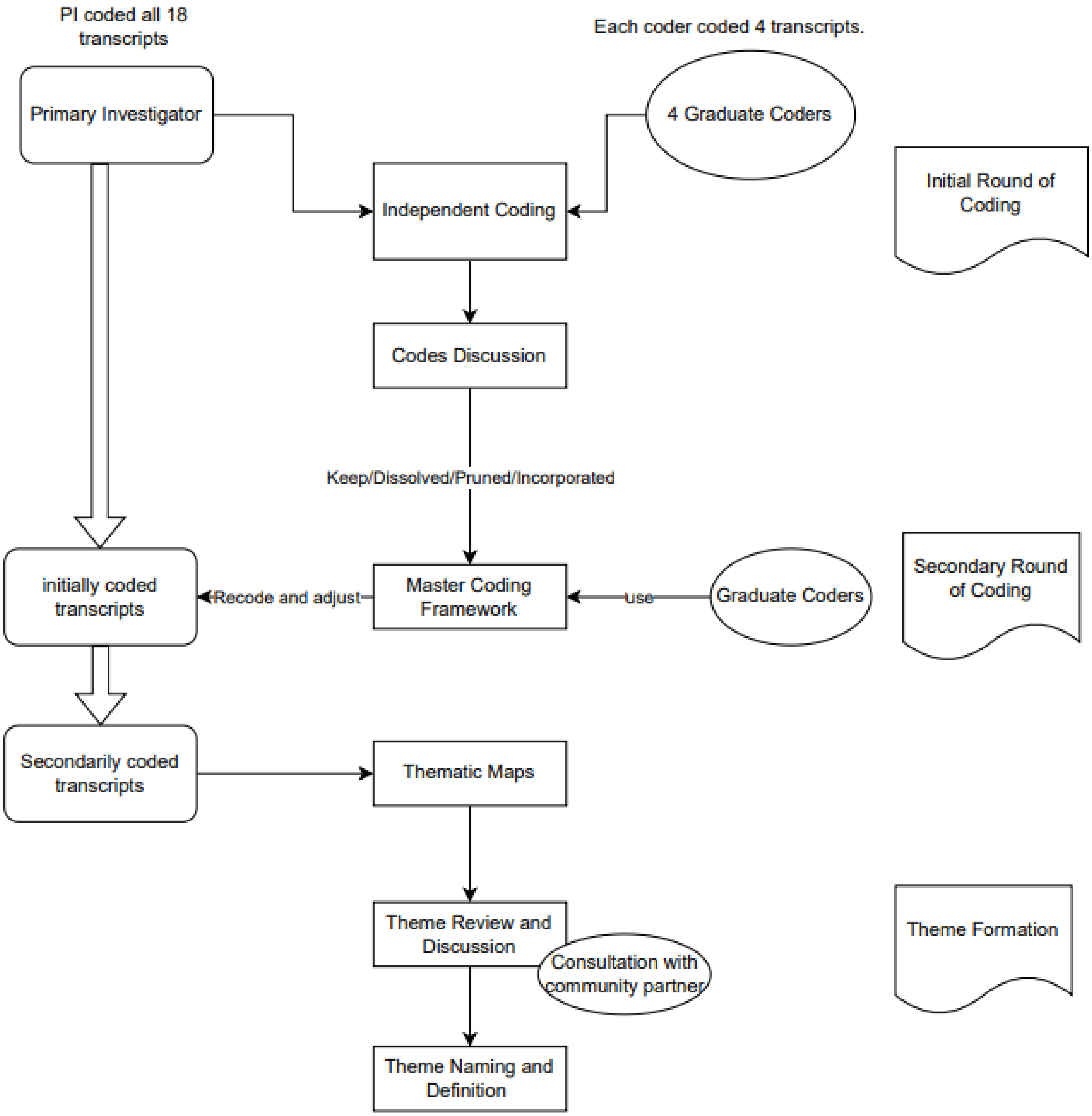
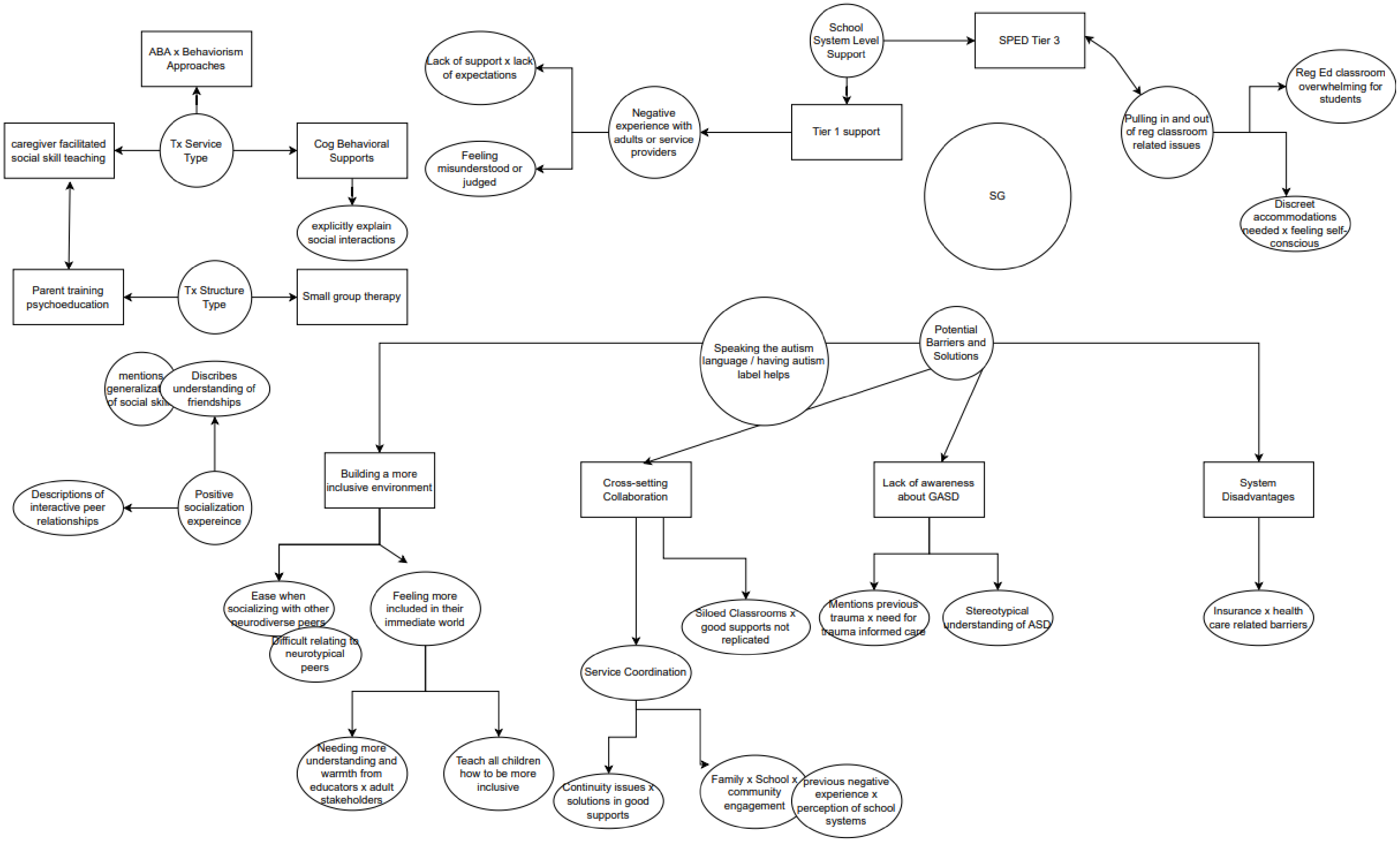


Figure 2. Thematic Map: School-aged Girls with ASD



Chapter 3

Results

Results are first organized and presented by research questions. Within each research question, findings are summarized by topics that emerged within the participant groups. All participants' names were replaced by abbreviated codes except for school-aged participants, whose pseudo names were chosen by themselves (except for SG002, who did not choose a name for herself). Community or hospital-based practitioners were named as HPC; School-based practitioners were named as SPC; Adult women on the autism spectrum were named as AW; School-aged girls on the autism spectrum were named as SG. Parents of school-aged girls on the autism spectrum were named as PSG. Among the parent-child pairs: PSG001 is Boobear (SG001)'s mother; PSG002 is SG002's mother; PSG003 is Flopsy (SG003)'s mother. It should be noted that later participant groups might have data corroborating topics shared by a previous group and are presented as such. Though the paragraphs might be more focused on information that is unique to that specific group, it does not diminish the importance of those similarly shared sentiment with other groups.

To examine the rich data in ways that emphasize similarities across different groups, this paper also identified 19 key themes that emerged across different groups of participants. Within each theme, selected passages are presented in quotations to illustrate respected themes. Brackets were added for clarification. Ellipses (…) indicate material omitted for conciseness. Themes are being categorized under bolded headings. All themes entail information extracted from interviews across all categories of participants (see Appendix G for a complete overview of themes organized by participant groups.) It should be noted that although this paper organizes the data this way, it is not to say this is the only way to examine the rich narratives provided by the participants.

Summary of Results Based by Research Questions

Research Question 1: Experiences of School Aged Girls

Schooling Experience and Peer Relationships

Interviews conducted with three participants who were school aged, provided the information for this research question. Some of these perspectives were provided with the assistance of their parents for clarification. All three participants reported neutral to negative social experiences of school and schooling, mostly related to the feelings of being socially excluded, being confused about social situations, and the need for masking efforts. One participant directly voiced feelings of embarrassment, anger, and anxiety when receiving unwanted attention from their teacher and misusing her accommodations from her IEP plan. Two other participants' parents (who are also participants of this study) reported such experiences. However, these were indirect reports. Negative peer relationships were also directly reported by two of the three participants, and indirectly by one participant's parent. Boobear (SG001) specifically reported positive peer relationships in a smaller educational setting, and reported supportive relationships with a peer who was able to understand her perspective and accommodate her special interests. Such sentiment was also shared by her parent (PSG001). Other parent-daughter pairs alluded to the same notion that positive peer relationships were mostly related to a smaller, more supportive educational environment and peers with good social skills. All three parent-child pairs reported directly or indirectly (reported by their parent that they have shared with them) that they connect well with others who are also on the autism spectrum or have similar support needs in their educational setting. Two of the three participants

(Boobear, Flopsy) reported wanting to build peer relationships with other school-aged girls, however also reported having anxiety around building such connections, especially during group settings.

Interactions with Service Providers

All participants (and corroborated by their parent participants) reported negative encounters with service providers in school who were characterized as not particularly good at building inclusive classroom environments or had poor understandings of the participants' IEP or 504 plans. They however reported positive experiences with school providers who were good at providing Tier 1 services to all peers in the classroom, and therefore made their IEP or 504 accommodations more socially desirable and created a higher sense of social cohesiveness between the participants and their peers in the classroom. Participants (mostly corroborated by their parents) reported positive experiences with providers who were able to explain social situations to them explicitly and with patience (mostly reflected as being able to repeat their explanations).

Research Question 2: Experiences of Adult Women with ASD

Delayed Access

All four participants of the adult women group reflected a general sense of delayed or denied access to an autism diagnosis due to what they characterized as their less obvious autism symptoms to providers. All four participants reported receiving an autism diagnosis later in their development or later than they wished for. As a result, they all reported delayed access to social skills support. Three of the four participants mentioned their gender as a possible reason to be overlooked for their autism symptoms. One of the four participants, AW002 mentioned her racial identity as a possible reason in addition to her gender identity. Three of the four participants spontaneously mentioned being impacted by essentially the “triple whammy” impact (AW001), AW003, AW004). For Example, AW001 mentioned that she was not initially given the autism diagnosis, and that her food sensitivities due to autism were dismissed as sensitivities of being a girl. She alluded that she was able to mask her social difficulties and adults in the educational settings did not notice her difficulties early on. One participant (AW002) alluded to this impact upon the interviewer mentioning this effect. This same participant also mentioned her racial identity (Asian American) as an added layer of stereotype (i.e., being quiet and not socially affluent) she experienced leading to her delayed access to obtaining diagnostic support.

Reflection on School Experience

Adult women on the autism spectrum shared similar experiences in their school years as their younger counterparts. This includes similar sentiment on negative social experiences as a result of poorly executed IEP support in the regular education classroom. They also reported a lack of continuity of high-quality support across grades and classrooms. Three of the four participants (AW001, AW002, and AW003) reported that as students, they were categorized under non-autism labels in their school-based services. They shared experiences of receiving mismatched IEP support, ineffective educational or social support, and remembering a general sense of discomfort with their special education support. Two participants (AW001 & AW003) explicitly mentioned wishing for individualized school support accommodating their autism experience. One participant (AW004) reported leaving regular educational setting and attending alternative schooling due to a high level of negative experience with schooling and peer relationships. In addition, the AW participants provided perspectives of their school experiences as adults, and shared reflections on their post-secondary experiences. One participant (AW002) who was overlooked for support in high school, reported an increased level of support once entering college. She reported further that this resulted from being able to build peer relationships with other neurodivergent peers. Two participants (AW001 & AW003) reported struggles adjusting to college due to a change in their established support network from high school. One participant (AW004) reported continued difficulties establishing an effective social support system.

Peer Relationship and Social Emotional Functioning

Three of the four participants (all except AW002) reported receiving social emotional services provided by psychological providers either in the school setting or in the community setting. One participant (AW002) reported an effort to join a social group in a post-secondary setting, however discontinued due to lack of resources the group received. Two participants (AW001 & AW003) explicitly reported benefiting from providers explicitly explaining social relationships and social situations to them. One participant (AW004) reported positive experiences with her provider due to the provider’s ability to respect her autism experiences. Specifically, AW004 reported that a teacher who provided group services in the alternative educational setting understood her difficulties with group social settings, and sensory overload related to autism. This teacher provided respected accommodations without questioning her.

Two of the four participants (AW001, AW003) explicitly mentioned their high masking effort, in an attempt to be more socially acceptable. For example, AW001 reporting refraining from flapping her hands unless she is in a private setting even though flapping her hands calms her. One participant (AW002) described trying to modify her language and alter her behavior to be more accepted by her family, which is similar to the concept of masking (i.e., AW002 shared that she tried to not talk as much in fear of saying offensive things around her family). The remaining participant did not report a high level of masking effort, however reported feeling the pressure to alter her behavior at times (i.e., AW004 shared feeling the need to be more like neurotypical peers growing up). All four participants reported difficulties socializing with neurotypical peers, reporting feeling not understood, being emotionally exhausted, or difficulties maintaining such relationships due to anxiety and depressive feelings resulting from other obstacles (e.g., difficulties with attention and organizations, difficulties maintaining academic excellence in post-secondary educational settings, work-related stress). Three of the four participants (all except AW004) reported long-term friendship (AW001 and AW003) or romantic relationships with peers either on the autism spectrum (AW002) or who are otherwise identified as neurodivergent. All four reported an easier time connecting with other neurodivergent peers.

Racism, Sexism, and Ableism

All participants in the AW group reported experiencing different levels of racism, sexism, or ableism. AW002, the participant who identified as Asian American, mentioned being overlooked when she was struggling to understand, build, and maintain social interactions, possibly due to her gender and her racial identity. She mentioned being viewed as academically competent but socially awkward. Being consistent with the stereotype of an Asian girl, she reported that she was not identified as needing social support while in school. Two of the four participants (AW001 & AW003) mentioned their autism experiences being viewed as “typical girl behavior” such as sensitivity to certain food items. Three of the four participants (all except AW002) mentioned experiencing ableism, specifically being viewed as less capable in their academic or professional activities. They reported this was reflected in experiences such as being placed in academic groups that were below one's ability or being recommended occupational paths that were below one's professional skills. Two of the four (AW002 & AW003) participants mentioned discrimination of their gender and ability on a system level, specifically reporting being placed in inappropriate academic settings due to ablism or neglecting their social needs due to gender stereotypes.

Research Question 3: Experiences of Parents of School-aged Girls with ASD

Diagnostic-Treatment Pipeline

Two of the three parent participants (PSG001 & PSG003) explicitly reported experiencing delayed diagnosis for their daughters. All three participants attributed the difficulties obtaining an autism diagnosis to their children's subtle autism symptoms, providers who were not observing close or long enough, or poor understanding of girls on the spectrum at the time. One of the three participants (PSG002) reported not realizing her child had such symptoms until her child started struggling in school. Two participants (PSG001 & PSG003) explicitly alluded to the "Tripple Whammy" effect in their effort seeking diagnosis of their children. For example, PSG003 reported being dismissed by service providers multiple times before obtaining a diagnosis due to the subtleness of her daughter's symptoms, describing how her daughter's appearance unintentionally made adult providers overlook her social difficulties, and that her daughter did not understand social cues and struggled with her same-gendered peers. The remaining participant (PSG002) alluded to this concept after being asked by the interviewer, reporting her daughter struggling socially in school however could not secure school services due to her high masking effort in school. Two of the three participants (PSG001 & PSG002) reflected that their child's diagnostic experiences along with the quality of the feedback process from the providers were the key reasons for feelings of hesitation accessing intervention services or confusions of the services available to them. One participant (PSG003) reported a positive feedback session with her child's provider who provided clear steps of how and where to access such services along with a social worker. She also mentioned the trust the provider built with her as a key factor of accessing intervention services immediately.

Intervention Services

All participants expressed a sense of delay in terms of accessing social emotional or social skills services, and all mentioned spending a period of time experimenting with what works for their daughters. One participant (PSG001) explicitly expressed apprehensive feelings towards applied behavioral analysis therapy. She also expressed that it is possible that the services she had access to in her area was not the best option for her child, or that the format of the ABA therapy may have changed since then. She expressed negative feelings of being excluded from the sessions and the intensity of the therapy (20-40 hours per week) being unsustainable. One participant (PSG002) reported that she specifically did not have her child attend ABA therapy due to her daughter's level of skills and age. When her daughter was diagnosed, she was school-aged, and she deemed ABA therapy to be no longer suitable based on her impression of ABA therapy being more directive and focused on basic skill teaching. One participant (PSG003) did not specifically mention feelings for ABA therapy as a format. Her child attended available community services which she described as using assorted techniques and a variety of therapy options. Two of the three participants (PSG001 & PSG003) explicitly reported that explaining social situations and social emotions to their children repeatedly to be helpful. One participant (PSG002) mentioned such practices throughout her interaction with her child, not limited to social situations.

School Services

Similar to adult women on the autism spectrum's experience, participants from this group expressed the importance of sharing medical and educational diagnoses with providers in either setting and deemed it as an important step in their experience to coordinate and facilitate services for their child. Two of the three participants (PSG002 & PSG003) mentioned a previous diagnostic label given to their children in school that were not in the autism category. All three participants acknowledged that it was important for their children's development that the appropriate autism category was eventually assigned. Two of the three participants (PSG001 & PSG002) reported receiving inadequate or insufficient services due to the mismatched label. They explained the services were not adequate due to others not fulling understanding the impact of autism symptoms on all areas of a child's life. One participant (PSG003) reported working as a paraprofessional and occasionally served as a substitute teacher in her child's school, therefore she was able to have close monitoring of her daughter's needs. She however intended to pursue the educational autism label as a next step. Two of the three participants (PSG001 & PSG003) reported choosing a smaller (i.e. small school in a rural setting) or an alternative school (i.e., community learning center) setting to have been beneficial for their children's access to services, higher quality of collaborations with parents, and an easier time voicing their needs and concerns. All participants reported frequent and intense interactions with the school team. All participants reported feelings of frustration and being misunderstood from these interactions. Two of the three participants (PSG001 & PSG002) reported a strong sense of helplessness when they failed to obtain appropriate school support due to what they reported as their children's masking effort in school resulting in elevated levels of behavioral challenges at home. All parents mentioned the impact of the general societal and zeitgeist issues impacting their children's wellbeing. Specifically, the school system, scarce resources in certain areas, difficulties interacting with the medical and health care system and COVID-19 lockdowns presented significant challenges for the parents.

Research Question 4a: Experiences of School-based Providers

Difficulties of Diagnosing ASD in Schools

All school providers reported feeling less confident giving a diagnosis of autism spectrum disorder to girls due to subtler symptoms compared to their boy counterparts and less exposure and training in autism diagnostic services. In addition, all school providers reported lack of general awareness and understanding of girls on the spectrum or insufficient training in this area. All school providers discussed that educational diagnostic criteria presented as a challenging factor for school providers to identify an ASD diagnosis to those who mask in school but were reported to have significant challenges at home. One participant (SPC001) shared that though school providers understood that special education services would likely reduce at-home challenges, limited resources in the school setting and the educational diagnostic standards often blocked them from doing so given the less obvious needs in school reported by teachers. Similar to what PSGs described, two of the four participants (SPC001 & SPC002) explicitly described the "Tripple Whammy" situation for school-aged girls on the spectrum, while one participant (SPC003) reported difficulties for school providers to differentiate between anxiety and autism symptoms without time and resources to closely observe and spend time with this population. Three of the four participants (SPC001, SPC002, SPC004), who are currently working in school settings, alluded to the benefits of interdisciplinary collaboration and consultation work with providers in other settings and with teachers, parents, and caregivers. Specifically, regarding diagnostic services, these three participants expressed appreciation of the autism diagnosis being shared across settings. However, three of the four participants (SPC001, SPC002, SPC004), expressed difficulties coordinating such collaborations, and reported observing parents facilitating most of these collaborations.

School-based Services

Three of the four participants (SPC001, SPC002, SPC004) reported difficulties with limited time, resources and training to deliver social skill services to the extent they would prefer. One participant (SPC003) mentioned relying on her other training and personal experience with special education to provide such services, as opposed to specialized training to provide services for individuals with ASD. All participants expressed a desire for better training and professional development support in this area. Three participants (SPC001, SPC002, SPC004), who worked in this profession during the COVID-19 pandemic, reported elevated levels of stress associated with feelings of burnout, high volume of special education evaluations, and lack of time and energy to provide social emotional support. All participants reported concerns that teacher burnout was a contributing cause of children with less overt challenges receiving inadequate support in the classroom, girls with ASD being one of those groups being impacted.

Three of the four participants (SPC001, SPC002, SPC004) explicitly stressed the importance of high-quality Tier 1 support to be beneficial for all children, especially for children with special education service incorporated in the regular education classroom and for children with more social difficulties. Two participants (SPC002 & SPC004) reported specific strategies they have used to facilitate the cohesiveness of the social environment in the classroom, and one participant (SPC001) reported that when classrooms had teachers who were more capable of building an inclusive social environment, there were fewer behavioral challenges from the students. Specifically, three of the four participants (all except SPC003) reflected that neurotypical children with better social emotional support tended to be more capable of forming high quality friendships or acquaintanceships with children on the spectrum, contributing to a more inclusive environment. Three of the four providers (all except SPC004) who work in a traditional public-school setting, reflected on the continuity issues with good Tier 1 support across different classrooms and grade levels. All participants reflected on the inevitable influence of the multi-tiered system of education on the social emotional and social skill services available and delivered to school-aged girls on the autism spectrum. Specifically, whether girls on the autism spectrum are receiving enough attention in their social difficulties when designing and maintaining Tier 1 support, whether Tier 2 support in social skills training are available given limited time and resources, and the true meaning of maintaining least restricted educational environment for this population (i.e., what inclusiveness means to this population and how to balance that with supporting friendships and solidarity between neurodiverse peers).

Research Question 4b: Experiences of Community-based Providers

Diagnostic-Treatment Services in the Community

Similar to the school providers and the examples the parent group described, community-based providers all described the “Tripple Whammy” situations faced by this population. In addition, all also reported that they had exposure to less research, clinical exposure and focus on this topic in their professional development, as reasons why it was harder to diagnosis girls with autism spectrum disorder in an accurate and timely fashion. All participants attributed the delayed access of services to the delayed timeline of receiving an autism diagnosis for this population. Providers agreed with parents in this study that the feedback part of the diagnostic process was key to accessing intervention services appropriately and without duplicated efforts of explaining the diagnosis to the families. Specifically, three of the four participants (all but HPC002) reported having to take extra time and effort to provide an in-depth explanation about why their child met autism diagnosis criteria and what that means for their child in their development at the beginning of providing intervention services (even though they were not serving as the diagnostic providers). They reported that this was less so the case for families with boys on the autism spectrum, indicating that often times when the girls are initially seen for intervention services, it is without a having an established ASD diagnosis and explanation.

Intervention Services

All community-based providers reported using assorted techniques to provide social skill services to girls on the autism spectrum. This included a variety of cognitive-behavioral techniques, role playing, modeling, parent training, as well as implementing manualized social skill interventions. All participants reported having to modify manualized interventions to better suit their clients' needs, however all participants expressed being unsure whether such modifications were needed due their individual clients' needs or if that was a shared necessity for girls with ASD. They all, however, reported feeling the need to provide more individualization and modification for girls on the spectrum, especially in teaching social relationship topics, though they reported having a limited number of girl clients. Two of the four participants (HPC001& HPC003) reported resistance of behavioral techniques and ABA therapy options from parents of girls on the spectrum. Specifically, they reflected that it was possibly the more mature age of these children, while one participant (HPC001) reflected on the reputation of ABA therapy in the autism community in recent years, and one participant (HPC003) reflected on whether ABA therapy is suited for every family's needs when given as a general recommendation. All participants mentioned that they found traditional talk therapy to be difficult for individuals on the autism spectrum and reported direct or indirect experiences providing cognitive-behavior therapy to girls on the spectrum, with repetition to be more effective. Two participants (HPC002 & HPC003) gave similar examples of role playing with their clients in specific social situations, also mentioning the need for repetition for their clients to teach appropriate interpretation and reactions in these social situations. One participant (HPC001) provided successful examples of engaging in such teaching in a group setting. One participant (HPC002) provided successful examples of teaching parents to engage in such practice at home.

System Issues

All four participants reflected on the system obstacles in place to adequately provide services to girls on the autism spectrum. Though these obstacles were generally true for most of the populations they served (e.g., children with different ability levels or development needs), all identified specific system issues that seemed more prominent when it came to school-aged girls on the autism spectrum. Specifically, all four participants pointed to the institutional sexism playing a part in recognizing and diagnosing autism for girls (though individual biases towards girls remains prominent as well). All four participants shared the obstacle od recognizing girls on the spectrum due to lack of professional training and development in this area, which could be traced back to their graduate level training, both in content and in awareness. All four participants acknowledged the impact of the health care system in their work with underprivileged groups, including this population. All participants mentioned the benefits of working with parents and providers in other settings, especially for this population. However, they acknowledged the difficulties of such interdisciplinary or cross-setting collaborations due to resources or logistical difficulties.

Summary of Results Organized by Themes

Diagnostic Issues and the Delay of Service

Participants mentioned the diagnostic process as a key factor impacting social skills services. The manifestation of autism traits and symptoms in girls remains a prominent factor of delayed and/or misdiagnosis of autism in girls. All providers observed difficulties recognizing and diagnosing autism in girls, sometimes despite advanced training in autism diagnostic services (i.e., HPC001 and HPC003). Parents and providers agreed that subtlety in symptom presentations played a key factor in difficulties recognizing autism in girls. Lack of awareness and professional training on what autism looks like in girls served as an additional barrier to assessing autism.

Theme 1: Autism Diagnosis for Girls is a Comparably a Complex and Difficult Process

Difficulties Obtaining an Autism Diagnosis. It is difficult for girls to obtain an autism diagnosis. Autism symptom presentation in girls, sometimes overlapped with stereotypical gender norms of girl behavior, lack of awareness and training in autism and girls, all were reported to contribute to delayed or wrong diagnosis in girls. All parents who participated in the study mentioned a challenging or a negative experience obtaining an ASD diagnosis for their children. All three parents reported seeing their children experiencing difficulties in various ways for a long time before knowing it was related to autism, or before they were able to receive validation from an autism diagnosis. Three of the four adult women on the autism spectrum also confirmed similar experiences in obtaining a diagnosis. Reasons shared by the participants included atypical autism symptoms compared to a stereotypical understanding of autism, comorbid or related neurodevelopmental disorders clouding the need for an autism diagnosis, subtler symptoms and less overt developmental impact leading to difficulties meeting the diagnostic criteria early on. One adult woman on the spectrum specifically pointed out reasons related to sexism and racism. Being an Asian American who was a girl with high academic abilities, chances of her being identified were missed due to others attributing her social difficulties to being shy and quiet, which fitted the stereotype of an Asian and a girl.

Difficulties Granting an Autism Diagnosis. Providers regardless of their work settings shared the sentiment that it was difficult to recognize autism in girls. All providers reported having less exposure to girls on the autism spectrum. All four providers based in community care and hospital settings acknowledged seeing less girls on the autism spectrum compared to boys. Five of the eight providers interviewed reported experiences where they spent extra time, resources, and thought when navigating whether a girl they were evaluating met the criteria of an autism diagnosis. Practitioners mentioned utilizing interdisciplinary effort, consulting with more experienced providers, ordering extensive accompanying evaluations beyond their typical practice trying to rule out other diagnoses.

> It’s tricky because it could look so different but also sometimes I think, because some of the girls that come in for diagnoses, or it’s a [client] I didn’t provide the diagnosis for and they are coming in for treatment, sometimes their social skills aren’t at first glance, as different as other girls, but once you start breaking down some of the conflicts that they are having in school really getting information from them, from parents, sometimes we are lucky from school staff, then I think that’s where the cracks start to show up. But, I feel like sometimes at first glance it’s really hard to see the differences. (HPC004)

There was also a significant lack of awareness and understanding in girls on the autism spectrum. Providers reported a common misunderstanding of the spectrum nature of autism. It seemed that the clinical society, similar to the general public, is not immune to stereotypical thinking of what autism “should” look like. Participants reported hearing or observing colleagues expressing thinking there are “classic indicators” of autism. Similar experiences were also reported by parents. Such stereotypical views of autism presentations often led to delayed or a missed diagnosis in girls.

> …the general idea of autism is like that non-verbal…difficulties being able to interact…and anything outside of the [stereotypical understanding of autism] is just “no it can’t be autism” …so that whole idea of a spectrum still not being accepted by the general idea of the public can be really, really invalidating for a lot of people with the diagnosis [who] are more functioning. (HPC 003, Community-based Provider)

> I mean she (Flopsy) is funny and warm, and gives you eye contact, but I could tell you from months she was born, that she was on the spectrum. No matter who I asked, no matter what practitioner, and they were all fabulous, we probably had 20 to 22 different practitioners…and I asked if they think she’s on the spectrum, they all said, oh she has such great eye contact, and oh, she is so warm and she is so social…they are saying, you are trying to fit too many things together, and they just don’t fit…[My daughter] was diagnosed at five, but even at five, she could have been diagnosed [so much earlier]…(PSG 003, Mother)

Some providers mentioned that they found themselves having to re-examine whether their therapy clients were wrongly diagnosed with another disorder or if their clients are on the autism spectrum in addition to their existing diagnoses. All providers mentioned treating girls on the autism spectrum who were misdiagnosed early on.

Theme 2: Diagnostic Process Impact the Timing and Willingness to Access Services, Social Skill Services Included.

While later diagnosis certainly contributed to delayed access to social skills services for families, the diagnostic experience along with the quality of the feedback process when delivering the diagnosis were mentioned as the key reason for a deterred decision to seek services, social skill learning services included. All three parents attributed their hesitation or motivation to seek appropriate services for their children to their experience with the diagnostic process. Parents mentioned not having enough time and space to process the information given to them. Two of the three parents mentioned that their children struggled to remain calm after the evaluation process, therefore the parents could not focus on the recommendations related support listed by the provider. Two of the three parents mentioned that they received a very long list of recommendations with little to no support on how to navigate obtaining these supports.

> I was alone at the appointment with her we had been there for hours, she was… [we were] completely toast. Honestly, it would have been so much better to have just gone home without any diagnosis, for them, just to say thank you for coming, we will write up our report and we will have a follow up appointment for you. So, she [the clinician] diagnosed her and then handed me a folder and said congratulations, she's autistic, here's your folder of directions. Go through the folder and read all of the things…it was literally just a folder that she handed me at the end of the appointment [and she was like] this is your to do list… [child name] was sitting in my lap crying and clawing at me…she didn't like new spaces. She was very unhappy, and I was emotionally spent and drained. The folder had a lot of information, [but the provider] didn't help to explain what autism was, or how they came to the diagnosis…I really wanted that piece. (PSG001, Mother)

One of the parents reported a positive diagnostic experience, where the feedback session was delivered separately from the evaluation session and navigation support was provided by a social worker who was knowledgeable and well versed in explaining the various types of support available in the community and how to prioritize these supports.

> It was a really really in depth look at every angle…I was very happy and then all the resources that come along with the [academic medical center] of like this, you know here, if you want to get this, call this number or here, we can help you with that if [you need it]. (PSG 003, Mother)

Theme 3: Delayed access to services impacts many aspects of the service delivery.

The access to social skill and social emotional learning services were delayed for girls on the autism spectrum compared to their boy counterparts. All providers based in the communities reported that the delayed access to services for girls impacted many aspects of service delivery. This included treatment buy-in from parents and caregivers, the way services were delivered, and the treatment timeline.

One logistical consequence of delayed access to service was the relatively older age of the girls' when first seen by the clinician for treatment setting compared to their other treatment clients. Some clinicians mentioned that they adopted a different approach where more self-identity development content had to be incorporated into the therapy session. A more mature starting age for girls on the autism spectrum also meant a higher likelihood of a more complex social scene they were experiencing, leading clinicians to start the treatment cycle with more thought and effort given to sorting out the treatment priority. A more mature starting age also meant less treatment buy-in for behavioral approaches, where parents deemed such approaches to be more fitting for younger children.

Related to the previous themes, subtlety in girls' autism traits, a difficult diagnostic process, and a rushed or overwhelming feedback session often meant that the subsequent clinician would need to spend part of the therapy sessions to answer diagnostic questions and clarify autism-related considerations, pushing back the therapy content planned for those sessions. This happened even when the clinician who provided the treatment was not necessarily the diagnostic clinician (or affiliated in anyway). All participants indicated that this was less the case for boys on the autism spectrum, who were more likely to show stereotypical autism traits of which the information is more easily available to the public.

School-based supports

Theme 4: Mislabeling in Schools, Lack of Effective Services and Non-existent Social Skill Services

Many families and participants on the autism spectrum described experiences of being categorized under non-autism labels in their school-based services. The mismatch between medical autism diagnosis and the label qualified them for an IEP, but frequently led to mismatched, ineffective supports with social skill learning services often omitted. A large part of the mis-labeling was attributed to the general diagnostic difficulties for girls on the autism spectrum. Similar to what was discussed in the last section, one main reason that participants discussed was related to gender norms and how that may impact initial referrals for an autism evaluation.

School-based recognition of autism, however, also was reported to present unique challenges. The mis-labeling was sometimes due to the unique criteria of an educational diagnosis of autism. Many parents and participants on the spectrum reported feeling overwhelmed and needing support in schools, however due to their masking, most of the difficulties they were experiencing were not apparent to others in the school environment. It was rather an extension of school difficulties, however manifested in the home environment for which they sought out needed services..

Another main reason for such a mislabeling was due to providers' reluctance for a label of autism, for reported fear of afflicting stigma on the student unnecessarily. Many participants on the spectrum reported being told that they would have access to similar supports despite the label. However, many participants on the spectrum found that to be not true. One of the many potential reasons was that school personnel did not have the ability, willingness, time or resources to provide support based on individual needs. It was rather easy to make the mistake of attributing difficulties related to autism to the student's subjective intention. Thus, many participants reported experiencing (or reported seeing) the blame being placed on students on the spectrum, consequently leading to further traumatic experiences of schools or schooling.

All participants on the spectrum and parents expressed dissatisfaction for such a mislabeling. All parents reported some level of contention with their school districts. Only one parent mentioned that she intentionally did not seek an autism label (educational diagnosis) due to circumstantial reasons, however, this parent planned to seek one in the coming school year (this parent’s child has a medical diagnosis of autism spectrum disorder). This participant also voiced that she recognizes the importance of an autism label for her daughter to access appropriate services. School providers reported not having enough time, resources or training to deliver social skill services to the extent they would like to provide. Many expressed being overwhelmed with special education evaluations, COVID-19 related difficulties, and lack of administrative support. Concerns for teacher burnout and logistical difficulties to provide professional development opportunities also contributed to missed opportunities for Tier 1 and Tier 2 support in social skill training.

All stakeholders mentioned the benefits of an autism diagnosis being shared with schools regardless of the type of services girls on the spectrum received (e.g., academic, social emotional, behavioral). Sometimes though, there were reports that the support seemed to not address any autism related difficulties, which had underlying impact on the effectiveness of such support. For example, one frequently overlooked difficulty expressed by the participants was the challenges in their math studies where making inferences is a necessary skill to understand the concept and complete the math problem. Once the autism label was shared with the school team, teachers intentionally spent extra time on explaining how to make inferences. This support was previously not provided due the fact that teachers were not making the connection between the students having autism and them having sudden difficulties in math which they thrived in before their current grade.

Theme 5: The Interaction of Autism and Gender in the Context of a Tiered System

Participants on the autism spectrum frequently reported negative social experiences when they were placed in the regular educational classroom, including social isolation, social confusion, and need for masking. The experience of pull-out services or having a para-professional by their side exacerbated their social anxiety and feelings of embarrassment. This was not, however, to say that being included in the regular education classrooms was the problem. Some participants had positive experiences in the regular education classroom where they felt accepted, included, and cherished for their strength. The key issue seemed to be the lack of inclusiveness in these classrooms despite being physically placed in a regular education classroom.

High quality Tier 1 support in social emotional teaching, sometimes to all children in the classroom, mitigated the aforementioned difficulties. Classroom teachers who were able to provide quality Tier 1 support in the classroom effectively reduced feelings of being different, embarrassment, and boosted the sense of community in the classroom for girls with autism. Additionally, parents, participants on the autism spectrum, and school providers all expressed similar sentiment of past practices where they found having peers with good Tier 1 support around to be very helpful in fostering an inclusive environment in schools or in the community.

Though good support was reported by participants, many reflected the continuity issues in such supports across different grades and classrooms. Sometimes, good support seemed to be highly teacher-dependent and was not effectively replicated in different classrooms or when students advance through grade levels. School providers reflected that this discontinuity of good support was potentially due to fidelity issues in tiered system data collection. When teachers were able to provide Ter 1 or Tier 2 support, it was not often fully documented in the tier data collection system. This resulted in difficulties replicating such support in another setting.

Burnout in school service providers, limited time and resources, and lack of understanding in the multi-tiered support system (MTSS) were also mentioned as barriers.

Girls on the autism spectrum moved through the tiered system in a unique way. Practitioners from both school and community settings observed the impact of their gender identity on how they were recognized, their behaviors interpreted, and their needs supported or neglected.

The “triple whammy” situation, as described in Chapter 1, was reflected by many participants. Girls on the autism spectrum faced a more demanding social environment as compared to their same-aged peers both due to their autism traits and their gender identity. Even for those who had early access to social skill services in pre-school, their social environment became overwhelmingly demanding as they grew older and entered elementary/middle school. Parents and providers found it hard to pinpoint the exact differences between girls and boys on the spectrum and between neurotypical girls and girls on the autism spectrum in terms of their social relationships and social difficulties, however all acknowledged observing qualitative differences. Parents and providers alike expressed concerns for girls on the spectrum specifically due to their susceptibility to toxic and harmful relationships, sexual abuse, and other trauma.

However, identification and support design for girls on the spectrum fell short. Referrals were more likely initiated due to more overt difficulties experienced in schools such as apparent behavioral challenges, differences in academic performance, or other externalizing issues such as inattention or hyperactivity. Participants reported experiencing less referrals that started with the question of autism in mind where social skill difficulties were the main issue. The participants on the autism spectrum in this study who were recognized earlier all had the above difficulties during their early school years. However, all adult participants reported not being effectively supported in their social skill development at school before or after they were identified.

Providers reported observing a general impact of gender norms on how girls on the autism spectrum were overlooked. Parents and adult women on the autism spectrum reported experiences of gender stereotypes leading to misunderstandings and ill-advised supports. To name some, emotional outbursts due to masking and lack of support of their difficulties were attributed to “girls being emotional” and ignored; specialized interests that were aligned with stereotypical girl interests were explained as such; food related sensitivities were neglected and blamed on “girls being too sensitive”.

Social Skill Services and Social Emotional Supports

Theme 6: Individualized Support with Assorted Approaches and Techniques

All participants reported experiencing/providing individualized support one way or another, either through caregiver facilitated support, through school, or via community-based supports. Providers frequently reported using assorted techniques and approaches to conduct intervention sessions with girls on the spectrum. Approaches included cognitive-behavioral therapy (e.g., recognizing thoughts, feelings, and behaviors), behavioral techniques (e.g., visual schedules, operant conditioning techniques), role-playing and modeling, psychoeducation for parents, mental health counselling, self-identity supports, and manualized social skill interventions (e.g., PEERS). All practitioners reported using assorted techniques mixed in each session slot, and all parents and participants reported experiencing these techniques in their support in some form. Community-based providers also mentioned having to modify manualized interventions to better suit their clients’ needs. Though they reported making modifications for all their clients, they found themselves having to pay more attention to the required changes for girls with autism.

Practitioners gave reasons for using assorted techniques and making modifications of manualized interventions in their session with girls on the spectrum and their family, one being the inherently different focus of a session for girls due to their goals and interests. Another reason for assorted technique usage and modifications was reported to be due to the fact that manualized interventions could not address girl-specific needs in social relationships.

As presented in the previous section discussing how delayed access to services could impact service delivery, delayed service also impacted treatment buy-in from parents and caregivers, specifically regarding techniques based on ABA principles. Using tangibles as positive reinforcement is less welcomed, self-identity support is needed more for girls, and there are also differences in social skill services buy-in between parents and their children. This resulted in more time allotted for self-identity exploration, psychoeducation for parents who had a less informed understanding of behavioral approaches (e.g., mixing behavioral approaches with discreet trial training in ABA therapies), as well as exploring goal setting that met the needs of the client and their caregivers.

Theme 7: Autism and Difficulties with Traditional Talk Therapy

Practitioners reported taking extra effort in facilitating their clients in reconstruction and reconceptualizing their clients' understanding of social experiences. Several practitioners had the sentiment that it was likely difficult for individuals on the autism spectrum to truly benefit from traditional talk therapy due to their difference in perspective-taking. Therefore, incorporating role-playing, modeling, and perspective-taking exercises were especially helpful for their clients. Parents and caregivers also reported using similar techniques. However, participants also expressed that this might be helpful for many individuals on the autism spectrum regardless of their gender identity.

Theme 8: Cognitive Behavioral Approaches with Explicit and Repetitive Explanation Seem to Work Well

Practitioners and caregivers reported that cognitive-behavioral approaches had been the most effective way they used to help girls on the spectrum to navigate their comparatively more demanding social environment. All found explicitly explaining social situations with repetition to be helpful. Participants on the autism spectrum reported positive experiences with mental health providers who were able/willing to explicitly explain social situations to them with repetition. Caregivers who had experience teaching or facilitating their child's social skills and social emotional development also reported using such techniques in their daily interactions.

Lived Experience

Theme 9: Social Experiences with Peers

Positive social experiences often stemmed from more understanding and warmth from peers or adults. Acts of kindness and inclusivity often led to positive peer relationships and trusting relationships. Shared interests also boosted lasting friendships. All participants on the autism spectrum reported reciprocal relationships with their peers at a given point of their social environment. Many reported positive peer support while navigating their environment.

Negative peer relationships were frequently reported as well. Social isolation, relational aggression, verbal and physical bullying were reported by all participants on the autism spectrum and the participating parents. Reasons for such negative peer experience were due to several reasons. For example, being different from the peer group, such as food sensitivity, different demeaners, or different schedules due to special education arrangements, all made the participants on the autism spectrum an easy target of peer aggression. Not understanding or operating under neurotypical social rules exacerbated peer aggression as well.

Negative peer experience with neurotypical peers is a shared sentiment. Some of the participants also expressed difficulties understanding or connecting with neurotypical peers due to different life experiences. They also expressed a relative ease connecting with other peers with neurodiverse identities. Feelings of being equal, being similar to one another, and shared topics contributed to such ease.

Theme 10: Yearning for connections with other girls, however struggling to establish such connections

Two of the three parent-daughter pairs reported the desire for these girls to make connections with other girls or engage in stereotypical girl activities (e.g., playing with dolls). They also reported when their children were able to establish a connection with other girls, especially with girls who were also on the autism spectrum, they felt happier. Adult women on the spectrum also expressed similar desires when they were younger.

In the meantime, participants expressed confusion and elevated levels of anxiety trying to build connections with other girls. Some reported that their children found the social rules of their girl peers difficult to understand and navigate. The same participant said her child later decided to explore social connections with boys her age, where social rules were more structured, based on games and activities, and easier for her to understand. Others reported that they were only able to build connections in a one-on-one setting and that socializing with a group of girl peers felt overwhelming.

Theme 11: Social Experiences with Service Providers (e.g., Educators, Practitioners, Support Staff)

All participants on the autism spectrum and parents of school-aged girls reported having negative interactions with adults in the school environment. For parent participants, these negative interactions ranged from disputes over special education evaluation, fidelity of support, to low quality of services and harmful practices.

For adult participants on the autism spectrum, past trauma, aggressive and abusive language, and behaviors from school educators were frequently mentioned. For school-aged girls on the autism spectrum, they reported that sometimes narratives were repeated by their parents, negative experiences were related to educators not understanding their needs related to autism, attributing behavioral difficulties to subjective intentions, breaking IEP or 504 plan agreements, and lack of skills to build a positive social environment in the classroom.

There were also many positive interactions with adults in the school buildings reported by the participants. Some shared qualities of these relationship were related to the skills and willingness to respect boundaries, not forcing compliance, good understandings of autism-related difficulties and needs, strong skills of recognizing and acknowledging individual strengths, and competence in building inclusive social environment in the classroom.

Theme 12: Negative Experience and Perceptions of Schools and Schooling

There was a shared negative experience and perception of schools and schooling among participants on the autism spectrum. In addition to the negative interactions with school personnel and negative peer interactions as discussed in the previous sections, a shared sentiment was the discomfort of being in a socially complex environment where social rules were not clear and social relationships were overwhelming to navigate. Only two participants mentioned a relatively positive experience and perceptions of school, and both reflected that a smaller school with a higher sense of community and belonging contributed to their positive experience.

Theme 13: High Masking Efforts

All adult women on the autism spectrum reported a high level of masking efforts, extending from their early development years till the present. Participants reported masking their self-stimulating behaviors in a way to regulate themselves, masking their anxiety and emotional reactions, and some mentioned spending more time in academic activities to mask their fear of other school-related activities. All adult women on the autism spectrum reflected that such masking efforts can be a conscious choice to avoid social isolation, discomfort, or to conceal social confusion.

It was also mentioned as a subconscious learned behavior that has been fused with their personal demeanor and hard to differentiate from how they truly wish to behave. The same participants reported feeling sad over their masking behaviors being fused with their true identities. It was also reported that masking led to elevated levels of anxiety, discomfort, and exhaustion for them.

Parents have also reported seeing their children displaying masking efforts in their social interactions with others, which was harder to recognize even by a parent.

> My husband said doody, she [Flopsy] laughed and I asked her if she was laughing at doody, she said yes. I asked if she knows what doody is, she goes, no. But she just pick[s] up on cues. My husband would say a joke, she will laugh at the exact moment. I asked him if she knows what the joke means, he will be like, “she does, she laughed.”. I will say to him, ask her though. She will be like “I don’t know”. She just knows how to mask, I mean I can tell you a hundred things [about her masking behavior]…(PSG003, Mother)

All participants who reported engaging in masking behaviors expressed that they felt encouraged to do so, either hearing explicit praise when they did so, or they were shaped by their environment being less hostile to them when they masked.

> Because you see other people doing it, and especially when I got older and I was masking you know, and people didn’t know as easily. So like my teachers, they didn’t really know that I had an issue until I said it, but it further made me want to continue to mask. I’m like well, these people, even my friends would be like that person is weird because they are

> doing that…I don’t care so much anymore just with strangers, but anybody that I know and have to interact with I really care. I don’t want to be perceived as different by you, and then you have negative feelings towards me or judge me and talk about me behind my back. (AW001)

Barriers and Solutions Proposed by the Participants

In this section, barriers in receiving quality social skill services and social emotional development supports identified by the participants are presented. Many participants also expressed their opinions on potential solutions to address the barriers. It should be noted that many of the barriers mentioned were already presented in the previous sections. Diagnostic difficulties for girls on the autism spectrum, delayed access to services, school-related barriers, and the aforementioned “triple whammy” situation discussed in the previous sections all were reported to contribute to systemic barriers. This section contains other specific barriers not already included.

Theme 14: Provider Professional Development Challenges

Regardless of the practice setting, providers from different stages of their career reported the need to address provider professional development challenges in the area of autism diagnostic and intervention services. Practitioners alike identified the lack of support starting in their graduate studies regarding training in autism topics. Several practitioners reflected anxious feelings towards their abilities to serve individuals and families seeking autism-related services compared to other categories of diagnoses in the early stages of their career. Some reflected that they had individually sought professional development opportunities outside of their generalist graduate programs. Training in autism services to those with minoritized gender identities was even more scarce. Practitioners shared the sentiment that they had very limited exposure to girls on the autism spectrum compared to boys or other types of clinical service provision.

Limited professional development opportunities focused on autism was also a prominent report in schools according to six service providers and two parents who worked or are working in schools as educators. Feelings of burnout, limited time and resources, lack of systematic training in recognizing and supporting children on the autism spectrum, high demand for teachers' time and attention, as well as school disruptions and backlogged caseload due to the Covid-19 pandemic all contributed to professional development difficulties in the schools.

Theme 15: The Covid-19 Aftermath

All three parents, two of the four community-based providers, and three of the four school-based providers explicitly mentioned difficulties and aftershock of the Covid-19 pandemic as a barrier to accessing quality social emotional services. All parents mentioned significant disruptions in their children's schooling or social emotional services due to the Covid-19 lockdowns, as well as disruptions in their children's social opportunities.

Two of the four community-based providers explicitly voiced concerns over collaboration difficulties with schools due to the high stress schools were experiencing post-lockdown. Three of the four providers mentioned highly stressed school workload due to backlogged evaluations, high incidents of social emotional and behavioral concerns, and need to provide backlogged Tier 2 services. All five providers expressed concerns post COVID about atypical developmental, social-emotional, and academic difficulties for all school children were experiencing, with even more significant implications for children on the autism spectrum.

Theme 16: Cross-setting Collaborations and Interdisciplinary Work

Adult participants across all categories voiced the need for more cross-setting collaborations between school, community-based services, families, and within the community. Positive experience with cross-setting collaborations and the ability to engage in interdisciplinary work in providing social skill services and social emotional development supports were reported as widely beneficial to families, schools, providers, and most importantly the child. Though such positive experiences should be extended to all children, specific benefits were discussed regarding girls on the autism spectrum. The unique challenges imposed by the "triple whammy" situation makes this collaboration for girls on the autism spectrum especially important.

Providers from both school settings and community settings expressed that such collaborations could lead to earlier detection of autism, as well as effective prevention and intervention work, especially for girls. For example, related to the reported phenomenon of girls masking in schools and later experiencing high levels of social emotional difficulties at home, good home-school collaborations and communication could detect such difficulties earlier. Another example is interdisciplinary collaborations between private service providers and school providers, the convenience of such information sharing would have the possibility of leading to earlier diagnosis with better accuracy, clarity and a "wrap-around" preventative/intervention effort for girls on the spectrum.

However, many providers and parents in this study reported that such collaborations are not easy to establish. Current barriers for such collaborations were attributed to logistic barriers, limited time and resources, and school provider burnout. Though most providers will spend extra time and effort trying to establish interdisciplinary work, successful collaborative effort mentioned in this study was often led by a caregiver or an advocate who was fluent with how the school and medical systems work, educated in autism-related issues, and highly vigilant.

Theme 17: Building Inclusive Social Environment

The need to build a more inclusive environment was explicitly or implicitly mentioned in the participants' accounts. Practitioners, parents, and adult women on the autism spectrum all expressed the desire for a society where stigma towards autism-related difficulties and differences were addressed and eliminated. Aside from de-stigmatizing autism, participants on the autism spectrum in particular expressed a desire for teachers to facilitate a more inclusive environment in schools, to include teaching other neurotypical peers how to be socially inclusive. This could include skills for neurotypical peers to understand that every person may operate in different ways, skills to include someone in their play or conversation, and skills to build positive friendships with others. While providers in this study already engage in such practices, it seems to be an individual-dependent practice.

Three of the four adult women on the autism spectrum reported different levels of reconciliation with their autism traits after learning more about neurodiversity concepts and self-identity development. Three of the four adult women on the autism spectrum reported feeling limited by both the stereotypes of autism and gender norms of women.

Theme 18: Health Care System Issues

All three parents mentioned disruptions or lack of access to support due to health care system issues. All reported disruptions in supports due to health insurance disruptions, lack of coverage, or lack of health care resources in remote areas. All three parents reported having to withdraw from services they trusted and enjoyed due to insurance changes. One of the parents raised the issues of scarce resources in rural areas, including quality therapy options. She also reported longer driving distances between the school and the services she chose for her daughter.

Providers expressed concern over the systemic barriers for children on the autism spectrum in general, with specific concerns for those with accompanying anxieties and complex behaviors. Specifically, providers expressed concerns for disruptions of services (social skill services and social emotional development support included) for those with a higher level of aggressive behaviors or complex behaviors. Providers reported that children on the autism spectrum can shift through the health care system across different facilities often, which in turn created unfriendly environment for someone who might already experience high level of stress and anxiety due to their autism experience. Providers expressed that this could especially become difficult for girls on the autism spectrum who have higher levels of emotional distress, and it had the potential to create a bad loop for them.

Theme 19: Ableism, Racism, and Sexism Issues

Ableism. Across different categories, participants expressed experiences or concerns regarding explicit, implicit, or structural discriminations based on their sex, race, or ability profiles. All four adult women on the autism spectrum either explicitly recounted an experience where they were discriminated against because of their neural-diverse mannerisms related to autism, or that they had acknowledged that this was an issue they have been concerned about which frequently leading them to engage in masking behaviors. One participant specifically mentioned that her difficulties or preferences in other areas of life were attributed to her autism profile and were treated as if these difficulties would disappear if she was able to "manage their autism symptoms." Two of the four adult women on the autism spectrum mentioned specific ableism experiences where they were either held to a lower expectation for their other abilities (e.g., academic, career-wise) due to their autism profile.

> There [was] an instance, one time, I was getting ready for cross country practice, and I've seen this one teacher about how I was planning on enlisting in the National Guard soon and what she did was, she had me like, going with her into the computer room and she started bringing up like on the computer like, low, lower level career options, and to look at in lieu of National Guard or something. That just made me feel like invalidated. I actually was so discouraged, I almost skipped practice that day. (AW004)

Sexism. Parents, providers, and adults on the autism spectrum alike mentioned issues related to implicit biases against girls/women impacting how services were provided or received.

Like previously discussed in the “triple whammy” situation, when girls on the autism spectrum do not exhibit overt difficulties or externalizing challenges, they are much more likely to fly under the radar for autism identification. Specifically due to implicit biases about how girls “should” carry themselves, multiple participants strongly suggested that school-aged girls on the autism spectrum are not identified as such even when they exhibit clear challenges. Gender stereotypes like “girls are more emotional”, “girls will likely talk about “girly” things”, and “girls will not be harmful even if they engage in aggressive behaviors” were all mentioned by participants as potential reasons blocking them from accessing appropriate diagnostic services or matching social emotional supports.

Racism. Of the four adult women on the autism spectrum, only one identified as a member of a racially minoritized group. This participant identified as an Asian American. Only this participant explicitly reported accounts of experiencing racial-related implicit biases against her. She recounted the experiences of being under-recognized for her social difficulties with her peers due to the combination of her excellence in academic abilities, and the racial stereotype that Asians are socially awkward but good at academic subjects. This participant reported that she did not receive quality services in terms of her social emotional development and social skill difficulties growing up, despite the tremendous difficulties she experienced in the school environment. This participant relied on the internet and media resources to understand her challenges and eventually, with peer support, sought out evaluation and obtained an autism diagnosis.

Four of the eight practitioners across community and school settings mentioned unprompted, explicit or structural racism as a barrier for girls and women on the autism spectrum with a minoritized racial identity to access equitable care. Specific narratives included:

minorized group members challenges being dismissed by the health care system more often, minoritized group members had less trust with the medical system, language and cultural barriers in medical literacy and so on. Practitioners reported putting in individual effort to accommodate families with minoritized racial and cultural backgrounds, however recognized that they were bounded by the health care system and their efforts were limited by their demanding workload to make significant and long-lasting change.

Chapter 4: Discussion

Summary of Findings

This study utilized a participatory approach to examine how social skills interventions are experienced and reflected by school-aged girls with ASD to inform future intervention development for this group. Data was collected from 18 participants from five categories (i.e., school-aged girls with ASD, adult women with ASD, caregivers/parents, school-based and community-based service providers). Each participant received a one-hour (30 minutes for girls on the spectrum) semi-structured interview following protocols designed based on Smith et al's 2009 guidelines on interpretative phenomenological analysis (IPA) interviews, modified per the community partner's advice on language, structure, and rapport building activities. Though interview questions were specifically designed to focus on the intervention experience of social skills teaching and social emotional development, the rich qualitative data collected from the participants painted a more holistic picture of not only social skills intervention experiences, but also the interconnected system factors that impacted this experience. A total of nineteen themes emerged across all the participants, covering broad categories of (a) Diagnostic Issues and the Delay of Services (three themes); (b) School Based Supports (two themes); (c) Social Skill Services and Social Emotional Supports (three themes); (d) Lived Experiences (five themes); and

(e) Barriers and Solutions Proposed by the Participants (six themes). Due to the fact that the process of providing support to the social development of school-aged girls on the autism spectrum can be so multifaceted, and that answers divided into siloed categories of participants may not paint a whole and just picture, the next section will organize the information based on responses received addressing the process from school-aged girls on the autism spectrum receiving the diagnosis to how they learned and generalized social emotional skills in their life, and later in their young adulthood. However, the information provided will include which specific research questions were answered and the sources of such information for the readers' convenience. The fifth research question was not able to be answered as recruitment for parents of adult women with autism were not able to be recruited. Based on the flow of the data, four natural categories for discussion are generated. The *first category* will focus on narratives generated from the adult participants of this study (i.e., caregivers/parents, providers, and adult women with ASD). These participants had either fully experienced social support during their school age, are currently supporting their children through this process, or have provided full range of such support to school-aged girls on the autism spectrum. Their shared insight can therefore shed light on this topic from a holistic point of view. This first category provides information to answer part or all of *research questions 1, 3, and 4* and includes information shared across all participants. The *second category* includes views from those who are on the autism spectrum and have lived experience of how autism interacts with their social development (school-aged girls with autism and adult women with autism). Information from this category provides valuable insight from the receiving end of such support. This category provides information to answer part or all of *research questions 1 and 2*. The *third category* explores the providers' (i.e., community-based [HPC] and school-based [SPC] providers) experience. This category provides information to answer *research question 4*. The *fourth category* includes shared insights and valuable future directions generated across all participants and does not address any of the research questions specifically. Instead, this category mostly includes information from the participants' own critical thinking and individual insights and opinions of the system they have lived and operated in and are the unintended, but valuable fruit, of the IPA methodology. To reiterate, here are the four research questions this study aimed to answer:

Research Question 1 (RQ1) investigated the experience of school-aged girls with an ASD diagnosis. What did they report as their favorite and most helpful support they receive at school relative to their social experience? Which social skill construct and core practice element(s) did they identify as most responsible for improving or being used as part of social skill interventions at school? What did they report as ongoing difficulties or barriers in their social environment that precludes them from learning, using, and/or generalizing social skills interventions?

Research Question 2 (RQ2) focused on the adult women with an ASD diagnosis. What did they report as the most impactful and effective support they received during their schooling related to their social experience? Which social skill construct and core practice element did the support they identified incorporate? What experiences (positive and/or negative) did they report relative to the social-emotional support they received during school? What were the difficulties they reported in terms of their ability to apply and generalize the skills they were taught during school into everyday life?

Research Question 3 (RQ3) focused on the experiences of parents of school-aged girls with an ASD diagnosis. What did they report as the most effective or impactful skill of the current or previous social skill intervention services their children received at school or in the community? What type of support relative to social skills did parents report having to provide to their children in support of or in addition to interventions provided at school? What did parents report relative to generalization of social skills following the services received at school in both the home and community setting?

Research Question 4 (RQ4) explored services providers' (school RQ4a and community based RQ4b) perception of the effectiveness of the social skill intervention services they provided to children on the autism spectrum? What were some of the common barriers of implementing social support for school-aged girls on the spectrum in their setting? What were some differences they experienced when providing such support to boys vs girls with ASD of similar age?

Below is a summary of findings and how they directly relate to answering the four research questions proposed at the outset of this investigation.

Parents, Providers, and Adult Women with ASD

The manifestation of autism traits and symptoms in girls being different than for boys remains a prominent factor of delayed and/or misdiagnosis of autism in girls and was reflected in all adult participants (i.e., parents, providers, and adult women on the autism spectrum) (RQ2, 3 and 4) responses, similar to what we see in the literature (Dean et al., 2017; Mandy & Lai, 2017). Participants (RQ2, 3, and 4) provided accounts of their different presentation of autism symptoms being misjudged as not related to autism and therefore were diagnosed much later in their life. Similarly, the lack of exposure to girls on the autism spectrum, limited training opportunities on this topic, stereotypical understanding of autism, and collaboration difficulties all contributed to the challenges providers (RQ 3, 4) reported they experienced in diagnostic services for girls, as can be seen in the literature (Little et al., 2017; Dean, 2013; Conlon et al., 2019; Austriaco et al., 2019; Harris et al., 2020). The access to social skill and social emotional learning services were reported to consequently delayed for girls on the autism spectrum compared to their boy counterparts. This is consistent with previous literature, where girls on the autism spectrum collectively access services at a later date (Shattuck et al., 2009; Begeer et al., 2013). In addition, the diagnostic experience, along with the quality of the feedback process, when delivering the diagnosis, were mentioned as other key reasons for a deferred decision to seek services (RQ 3), including and most importantly social skills learning services. The delayed access to services often led to less treatment buy-in from parents and caregivers, the way services were delivered, and the treatment timeline (RQ 3 and RQ4b).

Less prominent in the literature, many families and participants on the autism spectrum described experiences of being categorized under non-autism labels in their school-based services (RQ 2, 3, 4a). The mismatch between a medical autism diagnosis and the education label that qualifies students for an IEP often was reported to lead to mismatched, ineffective support with social skills learning services often omitted (RQ 2,3). Parents and practitioners (RQ 3, 4) reported several reasons for such mislabeling, some of which were supported in the literature. This included fear of afflicting the stigma of autism onto the child, unique criteria of an educational diagnosis of autism such as evidence of educational impact and overlooking home difficulties as an extension of school-related challenges. Though previous literature has discussed the stigma associated with autism labeling, either among students, teachers or parents of children on autism spectrum (Botha et al., 2019; Liao et al., 2019), few discussed whether fear of afflicting stigma impacted school-based providers' willingness to accurately label children under the autism category and should be further explored. Across all research questions, all stakeholders mentioned the benefits of an autism diagnosis being shared with schools regardless of the type of services girls on the spectrum received (e.g., academic, social emotional, behavioral). This was reported to boost educators' understanding of autism-related difficulties and reduced attribution biases, which was specifically discussed in previous literature (Kesterson, 2012).

School-aged Girls and Adult Women on the Autism Spectrum

The literature supports the finding that participants on the autism spectrum (RQ 1 & 2) frequently reported negative social experiences when placed in the general education classroom including social isolation, social confusion, and need for masking, being present without others fully recognizing their presence (e.g., Charter et al., 2005; Carter et al., 2008; Asmus & Brock, 2015; Hughes et al., 2013). The key complaint from participants was focused on the lack of inclusiveness in these classrooms despite being physically placed in a general education classroom. High quality Tier 1 and Tier 2 support in social emotional skill development, for all children in the classroom, was reported to mitigate such difficulties; however, many mentioned the challenges with continuity of good supports across different grades and within grades across classrooms, potentially due to fidelity issues in tiered system data collection. This takeaway is something with limited support in the literature, that strong supports in social emotional development are highly dependent on individual educators. Most of the current literature emphasizes school-wide or MTSS focused support. Clearly, based on the data from this study, school-wide support practices are being implemented inconsistently across teachers and grades, which impacts all students, but students on the autism spectrum in particular. Therefore, one suggestion from the findings of this study that bear more examination and consideration, are that additional time and resources for individual teachers who provide support to students with autism appears needed to improve consistency and to maintain gains across school years.

Although not an explicit research question, this study did corroborate the literature (Dean, 2013; Kopp & Gillberg, 2011) and found that girls on the autism spectrum do indeed face the aforementioned “triple whammy” situation in schools. As indicated in the review of literature, for girls diagnosed with ASD, their gender identity has been shown to result in having to function in more complex group dynamics compared to boys with ASD which place 1) higher demands on their abilities to read implicit social cues and social rules, maintain a longer and less structured conversation, while participating in unstructured activities more frequently (Dean, 2013). With these abilities already hindered due to their ASD symptoms (Kopp & Gillberg, 2011) the 2) resulting interactions between gender and ASD symptoms, often result in social challenges (2011), yet at the same time, their social challenges are 3) not as visible to adult observers compared with their boy counterparts, because of their more subtle nature. This same “triple whammy” effect was a commonly recognized issue among the participants of this study. Specifically, that girls on the autism spectrum (RQ 1 & 2) reported facing a more demanding social environment compared to their same-aged peers due to combined difficulties of being a girl and being on the spectrum. Delayed recognition of their autism diagnosis or even referral for evaluation of the possible diagnosis and resulting limited-service access were commonly shared by study participants who were on the autism spectrum. Implicit biases against the female gender were also reported to impact educators and service providers’ (RQ2, 3, 4) judgement and evaluation of social difficulties faced by these girls. This issue has had much less focus within the literature and will require additional investigation and support. Practitioners alluded to such difficulties as well. The situation was not reported to improve significantly even for those who had early access to quality social skills services and social emotional support. The “triple whammy" situation was reported to be especially hard to break out of if the child in question was of minoritized racial identities.

Community-based and School-based Providers

To determine an answer to Research Question 4, regarding reports from school-based service and community-based service providers, individualized support with assorted approaches and techniques in social skill services and mental health therapies remained a primary approach many practitioners reported using. Parents (RQ 3) and adult women on the autism spectrum (RQ 2) recalled similar structures too. Service providers (RQ 4) frequently reported the need to make modifications of manualized interventions for their sessions with girls on the spectrum and their family members. This was reported to be done in an effort to address girl-specific needs in social relationships and to address likely resistance from parents of certain behavioral approaches. There is limited focus on this topic in the literature, with the majority focused on early childhood intervention or ABA centered practices. Yet it is another important component to consider and better understand, when girls are diagnosed later and may need alternative approaches then those typically used to address more typical autism symptoms or when identification and diagnosis is obtained early, rather than delayed as with so many girls with autism. Practitioners and caregivers (RQ 3, 4) reported that cognitive-behavioral approaches were the most effective way they were able to assist girls on the spectrum to navigate their comparatively more demanding social environments. All found explicitly explaining social situations with repetition to be helpful. Participants on the autism spectrum (RQ 1 & 2) alluded to the effectiveness of this approach and reported positive experiences with mental health providers who were able/willing to explicitly explain social situations to them with repetition. Two types of providers identified in the data from this study reported doing so (reported having done so) when providing therapy services: 1) those who had prior knowledge that their clients were on the autism spectrum and could identify repetition as necessary, and 2) those with clinical skill expertise/experience who were able to recognize fairly quickly that repetitions were needed and would be successful with their clients, even when they did not have prior knowledge that their clients were on the autism spectrum (RQ2, 4b). This leaves out practitioners without extensive experience with this population or those who are freshly out of their training programs who do not have autism-related training. This also leaves out those experiencing social difficulties due to autism, who have not yet been diagnosed. In combination, this can mean many in need of social skill support from individual therapy are most likely not accessing ideal support.

Provider professional development challenges (RQ 4) in autism related services, and specifically social emotional teaching, were identified as a significant issue by school and clinic/hospital providers. The limited time and resources as well as feelings of burnout among educators and service providers remains a difficult issue to solve.

Across All Participants

Participants (RQ 1-4) also mentioned the COVID-19 aftermath to be especially challenging for families. The atypical social emotional development environment, disruptions in schooling, as well as high stress across society in general, contributed to a halt of social skills learning. Social emotional and behavioral concerns were reported to have spiked as a result. Although existing literature is starting to address COVID-19's impact across all individuals on the autism spectrum and are pointing out specific directions to focus on (Esteban et al., 2021; Harrop et al., 2021), it might be time to explore brief and cost-effective interventions families and providers can utilize to specifically address issues faced by girls on the autism spectrum to mitigate the aftermath of COVID-19 impacts. Though previous literature has alluded to the effectiveness of brief crises intervention techniques (Zhang et al., 2020), it remains valuable to explore the effectiveness for such techniques to be implemented among girls on the autism spectrum during crisis times.

System level issues and structural discriminations such as sexism, racism, and ableism were all reported to a various degree from participants as barriers to access quality care. These are issues that are not wholly addressed together within the literature but are more commonly studied in isolation as opposed to in tandem. Here again the “triple whammy” effect is present and impacting girls on the autism spectrum. Unfortunately, there is also not a single and straightforward answer to this problem. Until system level issues are able to be addressed, such discrimination will continue to unfairly impact members with minoritized identities.

Participants across all categories (RQ 1-4) identified cross-setting collaborations and interdisciplinary work to be widely beneficial to children on the autism spectrum, with specific benefits to girls on the spectrum. Such support can provide “wrap-around” services to girls on the autism spectrum facing the “triple whammy” situation, which has the potential to lead to early detection, appropriate labeling, continuous high-quality support, and healthy social emotional environments. However, many participants acknowledged that such collaborations were hard to establish due to logistical barriers, limited time, and resources. Building an inclusive social environment remains an urgent action to support girls on the autism spectrum and in need of additional research. Such actions can include addressing stigma towards autism-related difficulties, improving educators’ abilities to provide strength-based teaching, and facilitating social emotional teaching to all children to build better social skills to include others.

Supports in self-identify and self-advocacy were also raised as a high need for girls and women on the autism spectrum.

Impact of the Current Study

This present study is one of the few to investigate social skills and social emotional support provided to girls on the autism spectrum. The partnership between the primary investigator and a community partner who identifies as an autistic woman studying this topic is also one of the first. This partnership generated valuable impact at three levels. At the most foundational level, the community partner provided guidance on how best to word interview questions (e.g., direct vs. indirect), design rapport activities (e.g., sensory calming games instead of small talks), and shared with this author her social capital (i.e., participants had natural trust when hearing about this partnership) during the recruitment phase. At a metacognitive level, this partnership produced meaningful discussions regarding ways of interpreting the rich qualitative data from participants. Though this author had previous and current experience providing services to families and individuals on the autism spectrum, there are knowledge blind spots this author has. For example, the community partner pointed out the level of caution when interpreting adult women's experiences who are on the autism spectrum, where cultural background and individual differences may further diversify how they experience and interpret autism as they mature developmentally. The community partner also provided refreshing and significant future directions this line of study could focus on that may not have entered this author's consideration, such as how race/gender/class identities can specifically impact the presentation of autism symptoms (e.g., how self-stimulating behaviors can look differently based on culture and group identities). On a third level, this partnership yielded a human-level connection that is not limited to the existence of this study. Being able to observe the community partner’s line of logic and ways of expression has enriched this author’s academic experience to say the least. It has also humbled this author in ways that can impact her future interactions and future partnerships she might build with people who are neurodiverse.

This study also shed some light on how this process is perceived on the ground, based on the phenomenological experiences of practitioners, parents, girls and women on the autism spectrum. While addressing the important question of whether girls on the autism spectrum are receiving different support in their social skills and social emotional functioning compared to their boy counterparts, it poses the even more urgent question of whether girls on the autism spectrum are receiving any quality support in this area to begin with.

Though some of the issues highlighted in this paper are consistent with previous literature on experiences of school-aged children on the autism spectrum for all genders, it is important to stress that these issues have different phenomenological characteristics, as the research relied heavily on boys/males. This study demonstrated that it seems less obvious when, what, and how to identify, refer, and provide intervention for girls, in particular relative to referring, providing and receiving social skills and social emotional support. It was clear through discussions with current school-aged girls, and women who have completed their schooling, that the long-term developmental impact of these issues manifests differently for girls, and later young women. The findings of this study are testimonials of such a difference. Many participants in this study pointed to their gender identity as the reason for an additional layer of difficulties accessing needed services outside of their autism experience.

The dearth of literature on this topic is alarming given the increasing number of school-aged girls on the autism spectrum seeking to access and receive services in the social emotional area (Jamison & Schuttler, 2017). The arguably unintentional or inevitable exclusion of school-aged girls as participants in many evidence-based social skill and social emotional intervention studies is worrisome. Albeit it can be hard to recruit eligible participants in these studies who are school-aged girls on the autism spectrum, it should be acknowledged that this is an area of limitation when developing and testing social skills intervention manuals. It is also difficult to know to what extent individual practitioners are adapting the intervention manuals and accommodating individual differences to address their girl specific needs in this population. Similarly, while quality social emotional and social skills teaching are happening for this population in the school environment, the result of this study indicated that such quality support is highly individual-dependent and hard to replicate across grade levels or even different classrooms without documentation and most likely ongoing training and support to school personnel.

This poses two problems: 1) Without systematic investigation on what is best practice for school-aged girls on the autism spectrum when teaching and addressing social skills and social emotional needs, practitioners rely on their past experience and clinical competence to “learn on the job”. While this speaks to the resilience of providers and families and can be sufficient in some cases, families risk time and effort to find providers with the right experience and clinical competence for their children. Negative experiences with a provider can lead to detrimental mistrust and service avoidance down the road. While arguably every practitioner should have the clinical competence to adapt and learn from their individual clients and should have the capabilities to adapt intervention materials and to seek out consultation with other more experienced clinicians when necessary to meet their client’s needs (American Psychological Association, 2017), supporting girls on the autism spectrum appears to be different enough, even less training on this subpopulation is provided in graduate programs, and therefore less known by many school and community-based practitioners, that careful consideration for the need for specific guidelines to be generated appears warranted. 2) When clinicians adapt and make accommodations for girls on the spectrum, either in individual sessions or in the school environment, it is hard to know which of the practice elements in the intervention effectively produced a positive outcome. It may very well be likely that the same practice elements that have been effectively implemented with boys on the autism spectrum would still apply to girls. However, without sufficient documentation and empirical investigations it is not possible to determine the validity of these intervention components when utilized with girls.

Therefore, this study supports the significant need to further explore the aforementioned issues in their entirety. There is a need for a series of studies exploring and documenting how practitioners are providing social skill and social emotional support to girls on the autism spectrum and a careful and empirical evaluation of those changes and adaptations. It may well be that the field is at a tipping point to adapt existing social skills interventions and social emotional models specifically for school-aged girls on the autism spectrum. Some future directions for how this might look are discussed in the next sections.

Future Research

There are many remaining questions in this line of research. To further propose what could be done, it is worth exploring how other disciplines in psychological research have approached parallel difficulties. There is a rich body of literature building and examining cultural adaptation models of evidence-based practice in psychotherapy for ethnocultural groups (ECGs). At the root of the debate for this body of research is the issue of whether evidence-based practice (EBP) developed within a specific cultural and linguistic context could be generalized into other ECGs (Bernal et al., 2009). Researchers in this area first proposed some adaptation models based on the literature, and a model proposed by Lau in 2006 provided a road map to use data to decide whether and when an adaptation is warranted. Lau used dual approaches in which one prong of the model targets contextualizing content of the EBP so that the adapted intervention addresses the distinctive contextual factors related to the presenting problem in the community, and the second prong of the model enhances implementation of EBP strategies with low social validity (Lau, 2006). The ecological validity model proposed by Bernal et al. is another framework used to adapt EBPs for ECGs. In this framework, eight dimensions (language, persons, metaphors, content, concepts, goals, methods, and context) of interventions served as a guide for such an adaptation, where the content and the method of an intervention could be altered and adapted (Bernal et al., 1995; Rossello et al., 2008).

In the context of the current study, several questions need to be answered: 1) Would an investigation of the identified accommodations and adaptations that the individual practitioners made for school-aged girls on the autism spectrum change the proposed core components and procedures of an existing treatment model developed based on male participants? If so, then 2) Are there any universally shared similarities in proposed changes, and could there be a new intervention being formed in practice that is not currently known to research? If not, then 3) The adaptations made (either in content or in method) should be examined and reviewed to further benefit the rest of the field by providing best practice guidance in evidence-based adaptations of existing social skills and social emotional interventions provided to girls on the autism spectrum. To answer these questions, future studies could focus on specific manualized interventions and to examine how much of the practice elements are being altered for implementation for girls on the autism spectrum. Expert review of existing practices in social skills teaching and social emotional supports (that are not based on manualized interventions) can also form a framework that could be further tested via implementation and replication studies.

Other Future Directions

The present study alludes to the important ties between intervention services and the diagnostic process, especially the feedback session. A critical juncture many of these families noted was the point and manner in which the information about an autism diagnosis was delivered (e.g., at the end of a long day of testing vs a separate appointment) and the content and specificity with which next steps and supports was outlined (e.g., a packet of information for families to read and complete, vs specific contacts, support, and suggested road map of steps to follow explained) (Hennel, 2016; Mulligan et al., 2012; Carlsson et al., 2016; Mulligan et al., 2012). While not a specific research question, it is worth exploring and better communicating and teaching the best practice approach to deliver and organize a feedback session, regardless of how “classic” the autism-related symptoms might look to the practitioner. It is also important to further explore the best way to close the loop between the feedback session and the family’s first contact or outreach to seek treatment. Recent studies have revealed gaps and individual variations in autism diagnosis disclosure. A call for further exploration in the best practice in feedback sessions is warranted (Pattison et al., 2022). Results from the current study suggest that prioritized recommendations of both school and community providers, the type of support and specific techniques to provide social skills instruction and social emotional support are high on the list of needs. Further, exploration as to if a best practice approach provides a significant boost in the family’s willingness and efficiency in accessing appropriate support for girls on the autism spectrum is needed.

This study also revealed that one frequently used justification, not labeling a student to be on the autism spectrum in an educational setting, is worth considering relative to other labels (e.g., Other Health Impairment) which can provide similar supports with lower potential for stigma in the school setting. However, it appears to be inaccurate, at least for girls in this study. Participants often mentioned receiving mismatched and ineffective support when an autism diagnosis was absent leading to social skills services and social emotional support being non-existent or at the very least not meeting the students' needs. Families indicated that the outcome of mislabeling, and inadequate support and intervention resulted in being stigmatized by peers or even educators due to less understanding of autism-related behaviors, as they were absent from the shared mislabeled diagnosis. Therefore, it is worth exploring how and why mislabeling of autism takes place in the educational setting. Some possible reasons could be: different standards made in the department of public instruction of individual states; education and training resources for school-based practitioners in recognizing and supporting children on the autism spectrum; and school-family collaboration differences (Gardner et al., 2022; Pennington et al., 2014). Consequently, it would be worth exploring on a larger scale whether the results of the present study on this topic are generalized and the extent that generalization extends to other demographic groups.

Another unintended, yet interesting finding from the current study, was how generalization of social communication skills and social emotional functioning looked like in post-secondary educational and professional settings for adult women on the autism spectrum. The result of this study mirrors previous literature on this topic (Paskins, 2018). Social communication difficulties and lack of social emotional support is a persistent yet less discussed issue for young adults on the autism spectrum. For girls and women on the autism spectrum, who may have accessed such support later in their primary and secondary school years, the women interviewed in this study reported that they were also provided less support in college in comparison to their male counterparts. It appears worth exploring whether increased post-secondary social emotional and social skills support can mitigate the negative impacts of late access to such support.

Limitations

Participant Positionality

The participants in this study mostly resided in a state in the Midwest, with access to a nearby academic medical center. In addition, two of the three parent participants were either currently working in an educational setting or have had many past experiences with special education. It is therefore very likely that all participants in this study received a higher quality of diagnostic and treatment support compared to the rest of the country. However, it is worth noting that this study sent out recruitment information via social media, word of mouth, clinician recommendations, and university email lists. Only one participant responded through social media group posts. The author of this study encountered elevated levels of resentment towards the research community from social media groups. It is therefore possible that the participants in this study were a self-selected group that either had a slightly better experience with the clinical and research world, or that they only responded to this study because of an established trust with a clinician or with the institution they are in. It is also possible that some of the findings in this study are highly specific to how this Midwestern state creates and provides policies regarding autism services and health care access. Although the author has no intention to generalize the experience described in this study to all school-aged girls and adult women on the autism spectrum, their families, school and community-based providers, it is possible that participants in this study unintentionally generalized their experiences with some girls and women on the autism spectrum to all and reported as such.

Homogeneity Limitation

Whilst the participant pool in this study is considered homogeneous for a study utilizing the IPA method, there remain areas to be improved. For example, greater homogeneity within the autism spectrum could be improved for future studies (i.e., level of social and/or cognitive functioning); more specific descriptions of the type of experiences one needed to participate as a provider (e.g., years of experiences, number of clients served, type of services provided); and greater attention to the type of providers could be given for future studies (e.g., only teachers or only school psychologists for school-based providers). In addition, more consistency in the way in which answers to study questions were collected would be beneficial. With such a small sample to begin with, when variations in interview format (zoom, in person, written responses from one parent interviewing their child) occur, it becomes difficult to understand how to interpret different content and information accuracy.

Intersectionality

Intersectionality research aims to examine the heterogeneity across different intersections of social positions and their profound impact on a person’s health and social experiences (Bauer et al., 2021). Rooted in black feminist theory, it was raised by Kimberle Crenshaw, originally to better illuminate the experience of Black women in the US (Crenshaw, 1989). It has since been widely used in qualitative and more recently quantitative studies on how the intersectionality of social positions shape human experience (Bauer, 2014, 2021). Of the 18 participants in the current study, 15 identified as White, two identified as Latinx American, and one identified as

Asian American. There are limited discussions as to how minoritized racial and ethnic identities may impact their experiences providing, consuming, or seeking autism related services. It was therefore not clear how these participants' different social identities intersect and how that intersectionality between their racial and cultural identities, gender identities, and the participants' autism experience shaped their life and wellness. Furthermore, future research could incorporate studies adopting the intersectionality research methods to further examine how neurodiversity, as a social identity, could participate in the examination of intersectionality, and how neurodiversity as a social identity could formulate a person's experience in terms of their experience of social power within the context of physical health and mental wellness. In addition, though this study did not exclude any non-cisgender participants during the recruitment process, all participants on the autism spectrum who eventually participated in the study identified as cis-gender girls or women. Therefore, the experience of transgender girls or women on the spectrum is beyond the scope of this study and should be further explored.

Conclusion

The current study utilized the IPA methodology and participatory research methods to paint a snapshot of the experience of school-aged girls, the parents of those school-aged girls, the school-aged recollections of adult women with autism who were receiving or had received social skills and social emotional supports, and school and community-based providers. Various challenges from individual and systemic levels were discussed and presented, many of which were specific to the "triple whammy" situation girls on the autism spectrum face. In this "triple whammy", school-aged girls are disadvantaged both due to their autism experience and their female gender identity. In addition, they are also less likely to be recognized and acknowledged as an individual on the autism spectrum by adults in their life compared to their boy counterparts due to various reasons. The result of this study supports the proposed hypothesis of this “triple whammy” hypothesis, and further supports the urgency of a systematic examination of the social skills and social emotional interventions available and utilized for this population. In doing so, this study also stressed the importance of the partnership between researchers and community partners in recognizing the future steps of this line of research. This study also gave rise to the phrase “triple whammy” and corroboration for the underlying concept that girls on the autism spectrum. This study demonstrated how a community partner can greatly contribute to understanding and interpretation of the experiences of a population and enrich the lens of the researcher. Finally, this study identified several areas of need and potential avenues for education (e.g., classroom and school support staff as well as graduate training) on the nuances and needs for identification and intervention support needs for girls with autism as well as several future areas of research to explore to ensure that girls with autism are not left behind but allowed to find support, intervention, and understanding within their families, schools, and community to flourish and engage in a quality of life everyone deserves.

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Appendix A1. Consent Form

Consent Form

The Qualitative Experience of Social Skill Intervention Received by School-aged Girls with ASD

Please read the informed consent and provide your consent by clicking “Yes, I agree to participate in this study” at the bottom of the page.

Introduction

You are invited to participate in a research project to gather information about the qualitative experience of social skill interventions received during school-aged (6 years to 17 years) years among girls on the autism spectrum (aged between 6 years and 17 years old) and adult women with an ASD diagnosis (aged between 18 and 35 years old). This research project is also aimed at gathering information on the individual experience of parents/caregivers, and service providers who have provided or facilitated social skill interventions to girls with ASD between 6 and 17 years old. This research project is being conducted by researchers at the University of Wisconsin-Madison to fulfill the requirements for a dissertation for a doctoral degree in the School Psychology Program.

Purpose

The purpose of our research is to understand how school-aged girls with autism spectrum disorders are currently being supported in their social development from school, home, and their communities. The study also aims to understand how and if such support has changed and in what ways over the past decades.

Procedures

Following informed consent, potential participants will be screened for eligibility to be a part of this study. If eligible, participants will complete a virtual (over Zoom), semi-structured interview following a review of the key features of the informed consent form. The completion of the interview is anticipated to take about 60 minutes (for adults), and 30 minutes for (children/adolescents).

Interviews will be audio and video recorded and transcribed by transcription technology for data analysis purposes. De-identified transcriptions will be saved indefinitely for possible use in future research. Video and audio recordings will be kept confidentially for seven years on a secured drive, which are only accessible to the primary investigator (Dr. Jennifer Asmus), and the project coordinator (Shuzi Meng), and verified study team members. The recordings will then be permanently deleted after seven years.

Benefits

There are no direct benefits to you (or your child) for participation in our study. We hope to use the information from the survey findings to improve the understanding of how to better support the social skill development school-aged girls with ASD.

Right to Refuse or Withdraw

Your participation in this study is voluntary and you may refuse to participate or discontinue answering questions at any time without penalization.

Confidential Data Collection

Data collection will be entirely confidential. The transcriptions of the video and audio recordings of the interview will be coded and stored separately from the recordings and other identifiable information. All recordings will be kept confidential on a secured device. All recordings will be deleted in seven years after the project is finished.

Risks and Discomforts

By providing responses to open-ended questions, participants run the risk of identifying themselves or revealing personal or sensitive information. However, no personal sensitive, or identifiable information will be included in data analysis or published results.

PLEASE NOTE: The researcher will not break confidentiality unless we learn anything that leads us to understand children (under 18) are being harmed by others or if a participant indicates thoughts about harming themselves or others. In those cases, we will need to break confidentiality to report to the appropriate authorities so that we can help protect the safety of our participants.

Confidentiality of Records

All responses to measures will be confidential. Any published results will not contain personally identifiable information and your name will not be associated with any of the data.

Contact Information

You may ask any questions about the research at any time. If you have questions, concerns, or complaints, or think that participating in the research has hurt you, talk to the research team or contact the project coordinator, Shuzi Meng (smeng28@wisc.edu) or primary investigator, Dr. Jennifer Asmus (asmus@wisc.edu).

If you have any questions about your rights as a research participant or have complaints about the research study or study team, call the confidential research compliance line at 1-833-652-2506. Staff will work with you to address concerns about research participation and assist in resolving problems."

Acceptance

I have read the information provided above and I voluntarily agree to participate in this study. By checking "Yes, I agree to participate in this study" I am giving my consent to participate. If you wish to keep a copy of this form for your records, please print or save one now.

Thank you for participating!

Adult participants:

By choosing YES, you are indicating that you have read this form, understand any potential risks and benefits, and agree to participate in this study.

☐ Yes, I agree to participate in this study

☐ No, I do not agree to participate in this study

Parental Consent for participants under 18:

By choosing YES, you are indicating that you have read this form, understand any potential risks and benefits, and agree for your child to participant in this study:

☐ Yes, I agree for my child to participate in this study

☐ No, I do not agree for my child to participate in this study

Please click the following box and type your name to indicate your electronic signature:

☒ [Participant Name]

Appendix A2 Script Obtaining Child Assent

Hi [Child Name]

My name is Shuzi, and I’m here today to talk with you about school! We will talk about 30 minutes, but we will take two breaks! I’m recording our conversation, so I don’t forget what was said! Your [legal guardian role’s name] said it’s ok. Would you like to talk with me today? It’s ok if you don’t want to!

If you choose to talk to me, everything you say will stay between you and me, unless you tell me anything that makes me worry someone could be hurting you or that you want to harm yourself or others. If that happened, I would talk to another adult about it so we can keep you and others safe!

1) Do you have any questions about the study?

If yes, answer the questions, then go the next step.

If no, go to next step.

2) Will you be willing to participate in this study? You can say no! If you say yes, you are also free to stop participating at any time you’d like!

If verbally said yes, go to next step

If no, say: [Thank you for listening to me explain what the study is! That will be all for today!]

3) Ok! We will have two more breaks, and at each break I will ask you again. However, you are free to say you’d like to stop participating at any time you’d like, just let me know!

At each scheduled break:

[Do you wish to keep participating in this study?]

If yes, continue.

If no, say [thanks for answering my questions, that will be all for today!]

Appendix A3. Demographic Information Questionnaire

If you or your child are participating as someone who were diagnosed with autism spectrum disorder:

please indicate your age (or your child's age if filling out for your child): ____

A. 6-12
B. 13-17
C. 18-35
D. Not applicable

Please indicate your (or if filling out for your child, her) current employment/educational status:

A. Grade School
B. Post-secondary School
C. Alternative educational setting – please specify____
D. Graduate school
E. Full time employee
F. Other – please specify____

If you are participating as a school-based or a community-based service provider:

please indicate your years of service: _____

A. Less than five years
B. Five to ten years
C. More than ten years
D. Not applicable

Please indicate the setting of your service: ____

A. School
B. Community Mental Health Centers
C. Community Learning Centers
D. Academic Medical Center
E. Other clinical settings-please specify: _____
F. Other educational settings-please specific: ____

What best describes your race/ethnicity? _____

A. Asian
B. Black
C. Hispanic
D. Multi-racial
E. Pacific Islander
F. White
G. Other: _____:

Which state are you currently living in?_____
Where did you grow up?_____

Appendix A4. Screening Survey

Screening Survey for School-aged Girls on the Autism Spectrum (administered to their parents).

1. Are you a parent of an individual who is on the autism spectrum?
2. Can you provide a proof of an ASD diagnosis for your child? (e.g., a diagnostic report or an IEP/504 plan)
3. Does your child identify as a girl? (i.e., born as female and identifies as a girl, or born as male and identifies as a girl)
4. To your knowledge, does your child speak in sentences and can engage in an interactive conversation with another person for longer than 10 minutes (approximately 15-30 minutes)?

Screening Survey for Adult Women on the Autism Spectrum

1. Are you an individual who is on the autism spectrum?
2. Can you provide a proof of your ASD diagnosis? (e.g., a diagnostic report or an IEP/504 plan when you were in school)
3. Did you receive intervention services when you were in elementary school or when you were between 6 and 12 years old?
4. Do you identify as a woman? (i.e., born as female and identifies as a woman, or born as male and identifies as a woman)
5. Would you be willing to speak with an interviewer about your experiences with social skill support from when you were between 6-12 years old (approximately 60 minutes)?

Screening Survey for Parents of Girls on the Autism Spectrum

1. Are you a parent of a school-aged child (aged between 6-12) who is on the autism spectrum?
2. Is your child also participating in this study? If not, can you provide a proof of an ASD diagnosis? (e.g., a diagnostic report or an IEP/504 plan)
3. Does your child identify as a girl? (i.e., born as female and identifies as a girl, or born as male and identifies as a girl)
4. Would you be willing to speak with an interviewer about your experiences with providing, advocating, and facilitating social skill support for your child (approximately 60 minutes)?

Screening Survey for Parents of Adult Women on the Autism Spectrum

1. Are you a parent of an adult individual who is on the autism spectrum?
2. Is your child also participating in this study? If not, can you provide a proof of an ASD diagnosis? (e.g., a diagnostic report or an IEP/504 plan from when your child was in school)
3. Does your child identify as a woman? (i.e., born as female and identifies as a woman, or born as male and identifies as a woman).
4. Would you be willing to speak with an interviewer about your experiences with providing, advocating for, and facilitating social skill support for your child from when your child was between 6-12 years old (approximately 60 minutes)?

Appendix B1. Interview Protocol – School-aged Girls Diagnosed with ASD

Step 1: Inclusion Activity- A brief game to build rapport

Step 2: Explain goal of today’s interview

Today, I will ask you some questions about you. There is no right or wrong answers to the questions. I am just trying to understand your daily life better! If you are not sure what I am asking, please let me know and I can explain more. Do you have any questions about today’s activity?

Step 3: Interview

1. Tell me a little bit about your school! What do you do in school?
2. (If child does not mention any social activities to question 1) Do you play any games at school? Do you play with any children at your school? Do you plan with any adults at your school?
3. (if child does not mention any social activities with adults to question 2) Do you learn anything about the following topics: making friends, playing with friends, appropriate things to say with other children and so on…
4. How do you feel about learning these topics?
5. Further questions based on the child’s answers.

Step 4: Closure

Thank you so much for talking with me [child’s name]! I had so much fun today! Do you have any questions about what we covered today?
If yes, answer the child’s question.
If no, thank the child and conclude the interview.

Appendix B2. Interview Protocol – Adult Women on the Autism Spectrum

Step 1: Inclusion Activity- a introduction activity to build rapport

Step 2: Explain goal of today's interview

Today, I will ask you some questions about your experiences with receiving social skill services and support from when you were in elementary school. For example, if you attended any classes learning about social skills (e.g., how to organize a get-together), that would count! There are no right or wrong answers to these questions, and the purpose of this study is for me to better understand your experiences with these supports from when you were a school-aged girl. If you are not sure what I am asking, please feel free to ask me, and I will be more than happy to explain. Do you have any questions about what we are doing today?

Step 3: Interview

1. Tell me one thing you liked and disliked about your school experience!
2. Tell me about your social experiences from when you were in elementary school. This can be a long time ago, just tell me as much as you remember.
3. Did you receive any support from school about social interactions? For example, did you learn anything about the following topics: making friends, playing with friends, appropriate things to say with other children and so on…
4. Did you receive any support from places other than school about social interactions?
5. How did you feel about learning these topics? How do you feel now?
6. Did you feel those supports were helpful to you? How do you feel about that now?
7. Further questions based on the participant's answers to previous questions.

Step 4: Closure

Thank you so much for talking with me [name]! Do you have any questions about what we covered today?
If yes, answer the question.
If no, thank the participant and conclude the interview.

Appendix C. Interview Protocol – Parents of school-aged girls on the autism spectrum

Step 1: Inclusion Activity- a introduction activity to build rapport

Step 2: Explain goal of today's interview

Today, I will ask you some questions about your experiences about the social skill services and support your child has received or is currently receiving. For example, if your child attended any classes learning about social skills (e.g., how to organize a get-together), that would count! Other examples can be any type of social learning sessions between your child and another adult, such as a school psychologist, or a therapist outside of school. There are no right or wrong answers to these questions, and the purpose of this study is for me to better understand your experiences with these supports. If you are not sure what I am asking, please feel free to ask me, and I will be more than happy to explain. Do you have any questions about what we are doing today?

Step 3: Interview

1. Tell me about the social supports your child is receiving or has received.
2. Tell me about your observations about your child's social experiences.
3. Did your child receive any support from school about social interactions? For example, did your child learn anything about the following topics: making friends, playing with friends, appropriate things to say with other children and so on…
4. Does your child receive any support from places other than school about social interactions?
5. Tell me about your support for your child in this area.
6. Tell me about your feelings about these services.
7. Do you feel those supports are helpful to your child?
8. Further questions based on the participant's answers to previous questions.

Step 4: Closure

Thank you so much for talking with me [name]! Do you have any questions about what we covered today?
If yes, answer the question.
If no, thank the participant and conclude the interview.

Appendix D. Interview Protocol – School-based service providers

Step 1: Inclusion Activity- a introduction activity to build rapport

Step 2: Explain goal of today’s interview

Today, I will ask you some questions about your experiences with providing social skill services and support to school-aged girls on the autism spectrum. Some examples of the services I mentioned above can be social skill lessons, social skill support, peer-mediated interventions, play-based social learning session and so on. There are no right or wrong answers to these questions, and the purpose of this study is for me to better understand your experiences with these supports. If you are not sure what I am asking, please feel free to ask me, and I will be more than happy to explain. Do you have any questions about what we are doing today?

Step 3: Interview

1. What type of social skill support do you provide to school-aged girls on the autism spectrum?
2. Tell me about your experiences providing such supports. (ask follow-up questions about the intervention selection, intervention implementation, progress monitoring and data tracking, and providing generalization supports)
3. Is providing such support to girls any different from providing them to boys on the spectrum?
4. What are some common barriers you experienced providing such supports in school?
5. Ask any follow-up questions based on the participants’ answers to previous questions.

Step 4: Closure

Thank you so much for talking with me [name]! Do you have any questions about what we covered today?
If yes, answer the question.
If no, thank the participant and conclude the interview.

Appendix E. Interview Protocol - Community and hospital-based service providers

Step 1: Inclusion Activity- a introduction activity to build rapport

Step 2: Explain goal of today’s interview

Today, I will ask you some questions about your experiences with providing social skill services and support to school-aged girls on the autism spectrum. Some examples of the services I mentioned above can be social skill lessons, social skill support, peer-mediated interventions, play-based social learning session and so on. There are no right or wrong answers to these questions, and the purpose of this study is for me to better understand your experiences with these supports. If you are not sure what I am asking, please feel free to ask me, and I will be more than happy to explain. Do you have any questions about what we are doing today?

Step 3: Interview

1. What type of social skill support do you provide to school-aged girls on the autism spectrum?
2. Tell me about your experiences providing such supports. (ask follow-up questions about the intervention selection, intervention implementation, progress monitoring and data tracking, and providing generalization supports)
3. Is providing such support to girls any different from providing them to boys on the spectrum?
4. What are some common barriers you experienced providing such supports in your setting?
5. Ask any follow-up questions based on the participants’ answers to previous questions.

Step 4: Closure

Thank you so much for talking with me [name]! Do you have any questions about what we covered today?
If yes, answer the question.
If no, thank the participant and conclude the interview.

Appendix F. Practice Element Questionnaire

Practice Element	**For Example…**	**This was present**	**This was not present**
Didactic Teaching	A class on social interactions. Listening to a teacher talk about social topics.		
Modeling	Watching a video about a social conversation between two people. Sometimes there will be a scenario that is appropriate and another that is not.		
Peer-mediated	If there is(was) a same-aged child with you and you were practicing some of the social skills learned from the lesson!		
Play-based	If you were playing a board game while learning something in social interactions!		
Parent psychoeducation	If your parent is learning about how to support you. If you (the parent) are learning how to best support your child in social interactions. If you (service provider) are providing psychoeducation to a parent.		
Behavioral techniques	If your teacher gives you a reward if you did something cool! / If your child gets a reinforcer for an appropriate social interaction / if you provide reinforcers to children.		
In-vivo	If your teacher helps you during your social interactions with another person in the moment! / If you (parent/service provider) provide in-the-moment coaching about the child’s social interactions.		
Social Stories	A story about a social situation.		
Role play	If two people are role playing about a social situation.		

Appendix G. Themes Organized by Participant Group

Participant Group	**Category of Themes**	**Theme No.**	**Theme Name**
School-aged Girls on the Autism Spectrum (SG)	School Based Supports (4,5) Social Skill Services and Social Emotional Supports (6,8) Lived Experience (9, 10, 11, 12)	4,5,6,8,9,10,11,12	Theme 4: Mislabeling in Schools, Lack of Effective Services and Non-existent Social Skill Services Theme 5: The Interaction of Autism and Gender in the Context of a Tiered System Theme 6: Individualized Support with Assorted Approaches and Techniques Theme 8: Cognitive Behavioral Approaches with Explicit and Repetitive Explanation Seem to Work Well Theme 9: Social Experiences with Peers Theme 10: Yearning for Connections with Other Girls, However Struggling to Establish such Connections Theme 11” Social Experiences with Service Providers (e.g., Educators, Practitioner, Support Staff) Theme 12: Negative Experience and Perceptions of Schools and Schooling
Adult Women on the Autism Spectrum (AW)	Diagnostic Issues and the Delay of Services (1) School Based Supports (4,5) Social Skill Services and Social Emotional Supports (6,8) Lived Experience (9, 10, 11, 12, 13) Barriers and Solutions	1,4,5,6,8,9,10,11,12,13,16,17,19	Theme 1: Autism Diagnosis for Girls is a Comparably a Complex and Difficult Process Theme 4: Mislabeling in Schools, Lack of Effective Services and Non-existent Social Skill Services Theme 5: The Interaction of Autism and Gender in the Context of a Tiered System Theme 6: Individualized Support with Assorted Approaches and Techniques Theme 8: Cognitive Behavioral Approaches with Explicit and Repetitive Explanation Seem to Work Well Theme 9: Social Experiences with Peers Theme 10: Yearning for Connections with Other Girls, However Struggling to Establish such Connections Theme 11” Social Experiences with Service Providers (e.g., Educators, Practitioner, Support Staff) Theme 12: Negative Experience and Perceptions of Schools and Schooling Theme 13: High Masking Efforts

	Proposed by the Participants (16, 17, 19)		Theme 16: Cross-setting Collaborations and Interdisciplinary Work Theme 17: Building Inclusive Social Environment Theme 19: Ableism, Racism, and Sexism Issues
Parents of School-aged Girls on the Autism Spectrum (PSG)	Diagnostic Issues and the Delay of Services (1,2) School-based Supports (4,5) Social Skill Services and Social Emotional Supports (6,7,8) Lived Experience (9, 10, 11, 13) Barriers and Solutions Proposed by the Participants (14, 15, 16, 17, 18, 19)	1,2,4, 5,6,7, 8,9,10, 11,13,14, 15,16,17, 18,19	Theme 1: Autism Diagnosis for Girls is a Comparably a Complex and Difficult Process Theme 2: Diagnostic Process Impact the Timing and Willingness to Access Services, Social Skill Services Included. Theme 4: Mislabeling in Schools, Lack of Effective Services and Non-existent Social Skill Services Theme 5: The Interaction of Autism and Gender in the Context of a Tiered System Theme 6: Individualized Support with Assorted Approaches and Techniques Theme 7: Autism and Difficulties with Traditional Talk Therapy Theme 8: Cognitive Behavioral Approaches with Explicit and Repetitive Explanation Seem to Work Well Theme 9: Social Experiences with Peers Theme 10: Yearning for Connections with Other Girls, However Struggling to Establish such Connections Theme 11” Social Experiences with Service Providers (e.g., Educators, Practitioner, Support Staff) Theme 13: High Masking Efforts Theme 14: Provider Professional Development Challenges Theme 15: The Covid-19 Aftermath Theme 16: Cross-setting Collaborations and Interdisciplinary Work Theme 17: Building Inclusive Social Environment Theme 18: Health Care System Issues Theme 19: Ableism, Racism, and Sexism Issues
Community-Based Service Providers (HPC)	Diagnostic Issues and the Delay of Services (1,2,3)	1,3,4, 5,6,7, 8,14,15,	Theme 1: Autism Diagnosis for Girls is a Comparably a Complex and Difficult Process Theme 3: Delayed access to services impacts many aspects of the service delivery.

	School-based Supports (4,5) Social Skill Services and Social Emotional Supports (6,7,8) Barriers and Solutions Proposed by the Participants (14, 15, 16, 17, 18, 19)	16,17,18, 19	Theme 4: Mislabeling in Schools, Lack of Effective Services and Non-existent Social Skill Services Theme 5: The Interaction of Autism and Gender in the Context of a Tiered System Theme 6: Individualized Support with Assorted Approaches and Techniques Theme 7: Autism and Difficulties with Traditional Talk Therapy Theme 8: Cognitive Behavioral Approaches with Explicit and Repetitive Explanation Seem to Work Well Theme 14: Provider Professional Development Challenges Theme 15: The Covid-19 Aftermath Theme 16: Cross-setting Collaborations and Interdisciplinary Work Theme 17: Building Inclusive Social Environment Theme 18: Health Care System Issues Theme 19: Ableism, Racism, and Sexism Issues
School-based Service Providers (SPC)	Diagnostic Issues and the Delay of Services (1,2,3) School-based Supports (4,5) Social Skill Services and Social Emotional Supports (6,7,8) Barriers and Solutions Proposed by the Participants (14, 15, 16, 17, 18, 19)	1,3,4, 5,6,7, 8,14,15, 16,17,18, 19	Theme 1: Autism Diagnosis for Girls is a Comparably a Complex and Difficult Process Theme 3: Delayed access to services impacts many aspects of the service delivery. Theme 4: Mislabeling in Schools, Lack of Effective Services and Non-existent Social Skill Services Theme 5: The Interaction of Autism and Gender in the Context of a Tiered System Theme 6: Individualized Support with Assorted Approaches and Techniques Theme 7: Autism and Difficulties with Traditional Talk Therapy Theme 8: Cognitive Behavioral Approaches with Explicit and Repetitive Explanation Seem to Work Well Theme 14: Provider Professional Development Challenges Theme 15: The Covid-19 Aftermath Theme 16: Cross-setting Collaborations and Interdisciplinary Work Theme 17: Building Inclusive Social Environment Theme 18: Health Care System Issues Theme 19: Ableism, Racism, and Sexism Issues