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Females With Autism Traits: A Retrospective Look at Developmental Trajectories

Greer Caroline Willman Finster

A thesis submitted to the faculty of  
Brigham Young University  
in partial fulfillment of the requirements for the degree of  
Educational Specialist

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## ABSTRACT

### Females With Autism Traits: A Retrospective Look at Developmental Trajectories

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It is becoming more apparent in recent years that many females with autism spectrum disorder (autism) have not been identified, sometimes until adulthood. Most of what is known about early signs of autism is based on predominantly male symptomatic presentations or data gathered from females with autism who are severely affected by autism and co-morbid conditions such as intellectual developmental disorder. One of the issues contributing to the underdiagnosis of females is that the presentation of symptoms or traits and developmental histories of females with autism may not be the same as those of males. There is a gap in the research literature regarding the early presentations of autism in females, particularly for females with age-appropriate language and cognitive abilities. We interviewed parents of adolescent and adult females with significant autism symptoms or traits (but without intellectual developmental disorder). Interviews asked about developmental histories and parent recollections of differences they may have noticed in their daughters' early years. We also interviewed a group of parents whose daughters were not showing significant signs of autism but had similar social isolation and anxiety. Interpretative phenomenological analysis methods were used to analyze conversations with parents as a way to determine what seemed most salient to them about their daughters' early years without being influenced by symptom checklists. We found communication differences, restricted or repetitive interest and social communication differences to be recurring themes in the reports from parents interviewed. Learning about what early development in females with autism might look like can help us to reformulate our identification and assessment procedures for young children, particularly females who show developmental differences that have not previously been associated with autism.

Keywords: autism spectrum disorder, females with autism, development, early identification

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## DESCRIPTION OF THESIS STRUCTURE AND CONTENT

This thesis, *Females with Autism Traits: A Retrospective Look at Developmental Trajectories* is presented in a hybrid format. This hybrid format combines traditional thesis requirements with a journal publication format.

The preliminary pages of the thesis reflect requirements for submission to the university. The thesis report is presented as a journal article and conforms to length and style requirements for submitting research reports to education journals.

The extended literature review is included in Appendix A. Appendix B contains Institutional Review Board approval, recruitment, and consent forms. Appendix C and D contain the outlines of interviews used to gather data for the study.

This thesis format contains two reference lists. The first reference list contains references included in the journal-ready article. The second list includes all citations used in the Appendix entitled “Review of the Literature.”

## **Introduction**

Autism spectrum disorder (autism) describes an individual with social and communicative impairments or traits, with possible restrictive and repetitive behaviors, sensory issues, and/or stereotypical behavior present. These impairments can include but are not limited to deficits in verbal communication, social interactions, maintaining or understanding relationships, and emotional awareness. People with autism may also display behaviors that are repetitive or overly focused on one specific area of interest, which can be socially isolating (American Psychiatric Association [APA], 2022).

### **Females With Autism**

Because autism is often characterized with gender identity issues in this manuscript, the terms “males” and “females” will refer to males and females as assigned at birth. The terminology of “autistic” and “individual with autism” will be used interchangeably to honor differing preferences among self-advocates. According to ongoing United States Centers for Disease Control and Prevention (CDC) prevalence studies, the current male-to-female ratio for children with autism is 4.2 to 1, determined by a study of children aged 8 years. The current prevalence of autism is 1 in every 44 children in the population sample (Maenner et al., 2021). One recent study challenges the 4.2:1 ratio, suggesting that it is actually closer to 3:1 (Loomes et al., 2017). That systematic review and meta-analysis concluded that the disproportion of males to females may be affected by difficulties identifying some females with autism, likely due to diagnostic bias among professionals arising from a variety of origins.

Autism has formerly been thought of as a primarily male disorder which only affected females at the lowest end of intellectual functioning (Kopp & Gillberg, 1992). According to Volkmar et al. (1993), females who have traditionally been identified with autism have been

more severely affected and commonly have other disorders that would make them more likely to be identified as they needed significant supports from early childhood. This makes research on autistic females somewhat biased, suggesting a need to control for IQ when seeking to learn more about a broader range of females with autism. Females without any obvious cognitive problems are diagnosed with autism much later than their male peers (Giarelli et al., 2010), so it is possible that our prior assumptions about autistic females have not included a possibly substantial population of females with autism but not intellectual developmental disorder (IDD).

The early signs and diagnostic criteria traditionally associated with autism are based on the “male-prototype” or male phenotypes (Kopp & Gillberg, 1992, p. 97). One study supported the idea that even in the presence of similar *severity* of autistic traits that females are less likely to be diagnosed than a male peer. This is especially true when females do not manifest with additional intellectual and behavioral problems (Dworzynski et al., 2012).

Another factor that may explain missed diagnoses of females with autism is their ability to hide social problems when compared with males. In a recent study, teachers reported that males with autism had more apparent social problems when compared to females with autism. Because of the need for observation for identification and diagnosis, this makes the identification process for females more difficult when compared to their male counterparts (Sedgewick et al., 2015). Females were reported as having more emotional problems, which was viewed by teachers as fitting within neurotypical female behavior, also making it even more difficult to identify females with autism (Mandy et al., 2012). Also well documented is the ability of females with autism to camouflage their autistic traits, making symptoms and presentation less evident to non-specialists (Ratto et al., 2018). When females with autism across the entire spectrum are

found, researchers can learn more about their symptom development, trajectory, and presentation, which will help with earlier identification (Mandy et al., 2012).

In recent prevalence studies in the United States, two trends have been clearly identified. First, the ratio of males to females diagnosed with autism has changed from 4.5 to 1 (10-12 years ago) to 4.0:1 recently (Baio et al., 2018), then reversing back to 4.2:1 (Maenner et al., 2021). The second trend is that now the proportions for females with autism and ID closely equals that of males with ID, following many years of reporting that females with autism were more likely to have ID than their male counterparts. There is also a trend towards more equivalent identification of children in ethnic minority groups being identified earlier, although still not as early as White children by age 8 (Baio et al., 2018; Maenner et al., 2021).

### **Developmental Profile of Females With Autism**

Gender differences within autism have been somewhat absent in research until very recently, and there have been very limited studies exploring the differences in behaviors among those with autism by gender (Bölte et al., 2011; Giarelli et al., 2010). Despite few studies on the topic, researchers have found clear cognitive differences in autism according to sex assigned at birth, in terms of executive functioning and expected stereotypical behaviors (Bölte et al., 2011).

Given the lack of differentiation in research between males and females with autism, there are likely to be very subtle differences in frequency and severity of symptoms that can often be overlooked. Autistic females often display more difficulties in communication and sleep when compared to their male peers, as one example. They also may have higher anxiety and depression rates compared to their male counterparts. Autistic males often show more of the more obvious stereotypical and socially isolating behaviors such as more restricted, repetitive behaviors (RRBs) than their female peers (Hartley & Sikora, 2009).

Females with autism may be less likely to be identified as having RRBs when compared with males (McFayden et al., 2019) but it is possible that bias on the part of the observer may be obscuring this trait rather than a lack of RRBs (APA, 2022). Females with autism are more likely to have appropriate socially acceptable interests when compared to males (Kopp & Gillberg, 1992; Wolff & McGuire, 1995). Bölte et al. (2011) found that females scored higher in tasks that were designed to show impairment in executive functioning while males scored higher in their attention to details. This may help lead to the belief that autistic males present more stereotypical behavior such as repetitive and ritualistic patterns of behavior (Carter et al., 2007).

### **Gender Identity and Sexuality**

Baron-Cohen et al. theorized that the “extreme male brain theory of autism,” may suggest that autism is an extreme of the “normal male profile,” in which systemizing is seen more often than the empathizing behavior commonly seen in females (2003, p. 248). Females with autism also report irregular and often difficult menstrual cycles, polycystic ovary syndrome, severe acne, and epilepsy, among other medical issues in their genetic legacy (Ingudomnukul et al., 2007). Other researchers also found that females with autism may be more likely to be described as tomboys, or less feminine while growing up and report no sexual preferences (George & Stokes, 2018; Schottle et al., 2017).

Females with autism are more likely to self-identify as having gender identity issues compared to neurotypical peers. Researchers in the Netherlands found that 7.8% of the children referred to a clinic for gender dysphoria (GD) were identified as autistic, which is much higher than expected according to prevalence rates of autism in the general population (van der Miesen et al., 2018).

## **Speech and Language Development**

Speech and language development is one of the most important domains of a child's early childhood. Through speech and language, a child can communicate their thoughts and needs to those around them. Children with autism can have impairments in their language that will often lead to receptive vocabulary deficits (Horvath et al., 2018). Speech delays are reported to be the symptom that parents of autistic children will typically first prompt them to seek help for (Chawarska et al., 2007). Neurotypical children often use social or context clues to help them understand the meaning of a new word. Autistic children may be able to see patterns and regularities in vocabulary at a faster rate than their typical peers but this higher level of language understand often will center on tasks or areas of high interest (Foti et al., 2015; Mayo & Eigsti, 2012; Obeid et al., 2015).

## **Restricted and Repetitive Interests**

Females with autism are less likely to have traditionally identified restricted behaviors when compared with males (McFayden et al., 2019). Females may actually have *more* restricted interests than males, but they are more likely to have socially acceptable interests when compared to males (Kopp & Gillberg, 1992; Wolff & McGuire, 1995). This helps autistic females to blend in more with their peers and makes them less likely to be identified by teachers or parents.

## **Social Skills, Communication, and Play**

Neurotypical females are more likely to make long-term friendships and be involved in more verbal social interactions than males. Most of the time males are more interested in physical play compared to females who are more interested in imaginative play (Sedgewick et al., 2015).



Social skills and communication of autistic females is a little less clear. Most research focuses on males with autism in this area, and there is little research on social skills in general. Autistic females may be able to recognize the importance of non-verbal communication such as gestures and eye gaze (Barbu et al., 2011) for example, which is not as common in males in autistic populations. Females with autism often experience increased social and communication impairments during adolescence (as opposed to toddlerhood) when compared to males (Kirkovski et al., 2013; Koenig & Tsatsanis, 2005; McLennan et al., 1993). This can lead to more social isolation, which can be very damaging at a time when social inclusion is important for development and transition to adulthood. When provided with particular social skills training for females with autism, females showed more confidence and felt more comfortable with their skills (Hull et al., 2017).

### **Age of Diagnosis**

One study suggested that parents of females who were eventually diagnosed with autism, on average, showed a longer time between “first concerns” and diagnosis when compared to males (Begeer et al., 2013). The CDC provides data on prevalence ratios and the rate of intellectual disabilities between male and females, but the report does not yet break down the age of diagnosis by gender (Baio et al., 2018; Maenner et al., 2021).

### **Dangers of Late or Missed Diagnosis**

Because females with autism often go undiagnosed (without appropriate supports) until later in life, they may have high rates of anorexia nervosa, bullying, social isolation and suicidal ideation and behaviors (Postorino et al., 2017). There are also extensive reports of camouflaging to fit into gender expectations and roles (Ratto et al., 2018). The act of camouflaging requires intense cognitive effort, causing mental stress on the female who is attempting to hide their

autistic traits, often leading to anxiety and depression (Lai et al., 2017). The act of camouflaging not only adds immeasurable stress on the autistic female but can also make it more difficult to provide accurate support and intervention (Gould, 2017). Some females with autism adopt camouflaging behavior in order to face the social demands of life such as peer interaction. This can make it more difficult to identify them for research and appropriate clinical services (Mandy et al., 2012).

Autistic females have a significantly higher prevalence of suicidal thoughts and behaviors, including death by suicide, compared to their neurotypical peers. In a clinical cohort study, autistic individuals were asked to complete a self-report questionnaire regarding their lifetime experiences of depression, suicidal ideation and suicide attempts or plans. Females with diagnosed autism and a history of depression reported suicidal ideation in 89% of the sample compared to 62% of females without autism and history of depression (Cassidy et al., 2015). A longitudinal study found that individuals with autism were eight times more likely to die by suicide than neurotypical peers. In this study, females with autism had a suicide rate 13 times higher than in the general population (Hirvikoski et al., 2019). Another study looked at the suicide rates in Utah over 20 years, comparing over 22,472 age and gender matches to examine the suicide rate. It found that 0.03% of the typical population of females died by suicide compared to 0.17% of females with an autism diagnosis (Kirby et al., 2019).

### **Barriers to Identification**

Females diagnosed with autism have better skills in some areas that can benefit them, obscuring their symptomatic presentation in comparison to their male peers, which may account for later diagnosis. Females may have superior fine motor skills, have a higher rate of internalizing problems and a lower rate of externalizing behaviors than expected in the autistic

male population (Halpern, 1995; Zahn-Waxler & Shirtcliff, 2008). Autistic females are less likely to focus on faces during conversation than their typical peers (Ketelaars et al., 2016), but adult females with autism seem to be more interested in social interaction compared to males with ASD (Kirkovski et al., 2013) and are less readily diagnosed (Begeer et al., 2013).

Gender bias against females, criteria based on male phenotypes, extreme male brain theory, lack of intellectual developmental disorder and language delays all lead to difficulties identifying females with autism. These factors, combined with seemingly appropriate social interactions (camouflaging) are reasons why clinicians may not consider autism in their differential diagnoses or educational classification decision-making.

### **Statement of the Problem**

Although the CDC's public awareness campaign, *Learn the Signs, Act Early* focuses on parent education regarding early signs of autism (CDC, 2021), most current research on autism does not highlight the early development of females with autism through the eyes of their parents. Differences in autism traits between the genders are strongly suspected but have been difficult to discover in the current body of autism research literature as a whole, primarily because of some ascertainment bias towards males and females with comorbid intellectual disabilities and other co-morbid conditions along with autism. Focus on the male-centric phenotype and/or severely affected female traits can lead to problems in early identification of females with autism without intellectual developmental disorder, who likely have different or “nuanced” manifestations or traits and may not receive a diagnosis until much later in life. Among all measures and instruments used in comprehensive diagnostic assessments, only a very small number even have separate normative data for males and females (Constantino & Gruber, 2012). All of these factors can lead to an underdiagnosis of females with autism.

## **Statement of Purpose**

We looked for patterns in retrospective parent-reported developmental histories to identify some possible early identifying signs and symptoms in females that may have been noticed at the time, but not associated with autism. We anticipate our results will identify possible early signs in females with autism or autistic like traits. This is an exploratory first step towards improving screening and assessment methods and measures for autism in females.

## **Research Questions or Research Hypotheses**

This study addresses the following research questions or research hypotheses:

1. What are the signs of language or communication differences that are evident in retrospective accounts of developmental histories of females with autism traits?
2. What are the signs of restricted or repetitive interests of behaviors that are evident in retrospective accounts of the developmental histories of females with autism traits?
3. What are the signs of social communication differences that are evident in the retrospective accounts of developmental histories of females with autism traits?

## **Methods**

### **Setting**

This research was approved by the university's Institutional Review Board. Our data come from a larger study that specifically looked at social difficulties among females aged 14 years and older, conducted at a large private university in the western United States. Female participants in this larger study were recruited using flyers with the question, "Do social situations leave you exhausted?" that were posted on local university campuses. The larger study included online questionnaires to qualify participants to move forward to an extensive in-person assessment on campus. Measures specific to this study (subsequent to the original recruitment)

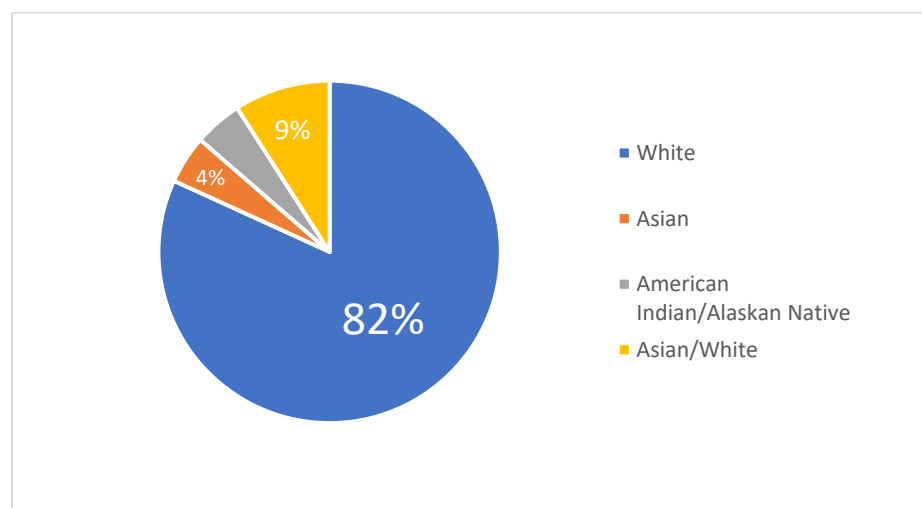
were all conducted online (using Zoom) or by phone. Participants were provided informed, written consent for data collection which included video and audio recordings as they volunteered to be interviewed.

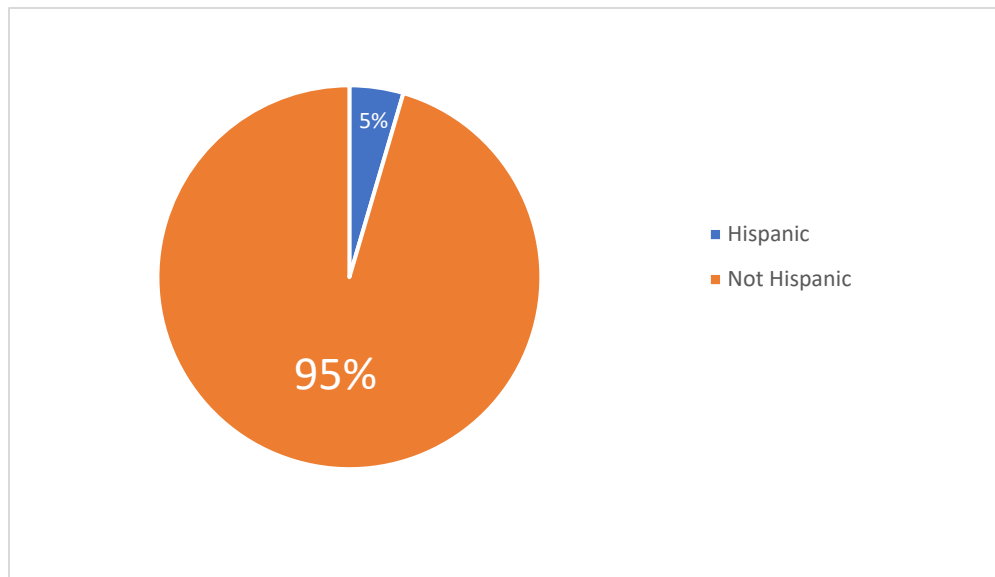
## Participants

The study recruited 49 sets of parents from the prior study who were contacted with the consent of the female participants (daughters), then consented to be interviewed. Many of these parents know their daughter has been diagnosed with autism. Some may not have been aware of their daughter's diagnosis, or their daughter may have some significant social anxiety or other diagnosis that currently creates social difficulties for her. Adult female participants self-selected into the larger study based on the recruitment flyer, typically with the daughter initiating contact with the study. These individuals ranged in age from 18 to 64 years of age. Of the 49 possible sets of parents, 30 parents agreed to interviews on their daughter's early development. All parents were contacted but some did not respond or expressed that they were not interested in the interview. Figures 1 and 2 show the race and ethnicity of the sample.

**Figure 1**

*Participants Race (Daughters)*



**Figure 2***Participant Ethnicity (Daughters)***Measures**

Autism traits and other characteristics were measured as part of the larger study inclusionary criteria. Traits were measured in terms of presence/absence and severity across measures. Other characteristics relevant to characteristic profiles, such as cognitive and language abilities were also measured. Only measures relevant to the current study are included here.

***Wechsler Abbreviated Scales of Intelligence, Second Edition (WASI-II)***

The WASI-II provided a quick and reliable measurement of verbal, nonverbal and combined cognitive functions for female participants in the larger study. The two-subtest version was used, consisting of Vocabulary and Matrix Reasoning subtests to generate a brief IQ score. The test is normed for individuals between 6 and 90 years of age. The normative sample size contained 2,300 examinees that were stratified using the most recent census data from 2008 (Wechsler, 2011).

### ***Broad Autism Phenotype Questionnaire (BAPQ)***

The BAPQ is a set of questions that examines personality and language characteristics often found in individuals with autism, but perhaps not enough to meet full diagnostic criteria. The questionnaire has >70% sensitivity and >70% specificity (Hurley et al., 2007). To qualify for participation in the larger study, the results of the BAPQ for female participants (daughters) needed to meet a threshold of likely social impairment, namely a score of 3.0 or higher on the BAPQ. Research on the BAPQ has indicated two possible cutoff scores to establish the significant level of broader autism phenotype traits based on Sasson et al. (2013): a “low” cutoff score of 3.17, which was recommended for females; and a more conservative “high” score of 3.55 which was recommended for males as indicating some autistic traits. In the larger study, further measures were completed if this initial criterion was met. Parents completed the BAPQ for their adolescent daughters who participated in this study. Adult female participants in the larger study completed the BAPQ for themselves.

### ***Social Responsiveness Scales, Second Edition (SRS-2)***

The SRS-2 examines the presence and severity of social impairments related to autism and similar disorders. It is not necessarily diagnostic, however. This test was normed for individuals ages 2 years, 6 months through adulthood. The questionnaire was standardized with over 2,000 individuals following the most recent census proportions for diversity (Constantino & Gruber, 2012). Adult participants completed the SRS-2 Self-Report regarding their own social abilities. There is no gender-specific normative sample for this version of the SRS-2, although gendered norms are available in the School-Age version (Constantino & Gruber, 2012).

### ***Social Communication Questionnaire - Lifetime (SCQ-L)***

Parents completed a questionnaire on their daughter's social behaviors with a focus on behaviors between the ages of 4 and 5 or at any time (phrased as "Has your child ever \_\_\_\_?"). The SCQ (Rutter, Bailey, et al., 2003) was developed from the questions on the Autism Diagnostic Interview, Revised (ADI-R; Lord et al., 2000). The SCQ-L is considered to be an at-risk screening measure, with positive results indicating the need for comprehensive evaluation of autism. It is often used in research as a measure of autism symptoms or traits along with other measures.

### ***Autism Spectrum Quotient (AQ)***

The AQ is a 50-item self-report questionnaire completed by participants (daughters) in the larger study. The questionnaire covers communication, social skills, attention switching, attention to detail and imagination (Baron-Cohen et al., 2003). The AQ is a screening measure for more extensive autism evaluation and is often used in research to establish autism symptoms along with other measures. Female cutoff scores are available for the AQ with males with ASD having a score of 35.1 and women an average mean of 38.1, with a cutoff score generally listed as 26. See Table 1.

### ***Autism Diagnostic Observation Schedule, Second Edition (ADOS-2, Module 4)***

The ADOS-2 is an in-person social interaction assessment often considered a gold-standard of autism diagnostic instruments. It is not normed separately for males and females. It is used in research and clinical settings to identify autism traits along with other measures (Falkmer et al., 2013). Scores recommended for reporting are the Calibrated Severity Scores (CSS), or Comparison Scores, based on a normative sample by age and Module. Module 4 was administered in the study, as it is appropriate for adolescents and adults with fluent language



skills (Lord et al., 2012). As the ADOS-2 does not have scoring options by gender, the ADOS-2 CSS scores are reported by prior diagnostic history but are not divided into groups by CSS scores, see Table 2.

**Table 1**

*Demographics of the Sample (Daughters), n=22*

	Mean	Standard Deviation	Score Range Indicating Significant Autism Traits
Broad Autism Phenotype Questionnaire (BAPQ)	3.90	0.45	3.17 = cutoff for females <sup>1</sup>
Autism Spectrum Questionnaire (AQ)	26.07	4.11	29+ considered clinically significant autism traits
Social Responsiveness Scales-Second Ed.	87.72	21.56	Severe = 76 or higher <sup>2</sup>
Autism Diagnostic Observation Schedule, Second Edition	3.23	2.04	<u>Level of Evidence</u> 1-2=Minimal to no 3-4=Low 5-7=Moderate 8-10=High
Age of First Concern (Parent) in years	8.44	5.56	Range = 2 -18 year
Age of First Concern (Others) <sup>3</sup> in years	9.2	6.10	Range = 3 -18 years
Age at Participation	23.13	5.48	Range = 18 -41 years
Intelligence Quotient (Full Scale IQ)	110.90	11.25	Range = 83-133

<sup>1</sup>Sasson et al., 2013

<sup>2</sup> Hus, V., & Lord, C. (2014).

<sup>3</sup> Others included but are not limited to extended family, teachers, and family friends.

**Table 2***ADOS Calibrated Severity Scores (CSS) Compared Across Participants<sup>1</sup>*

<i>n</i> , % of sample	Parent Reported diagnosis	ADOS-2 CSS Minimal-to-None	ADOS-2 CSS Moderate	ADOS-2 CSS High	ADOS – 2 CSS Not Reported
Formal (Prior) Diagnosis	8 (36)	4 (18)	--	1(5)	3(14)
No Formal <sup>2</sup> Diagnosis Reported	14 (63%)	3(14)	2(9)	1(5)	8(36) <sup>3</sup>

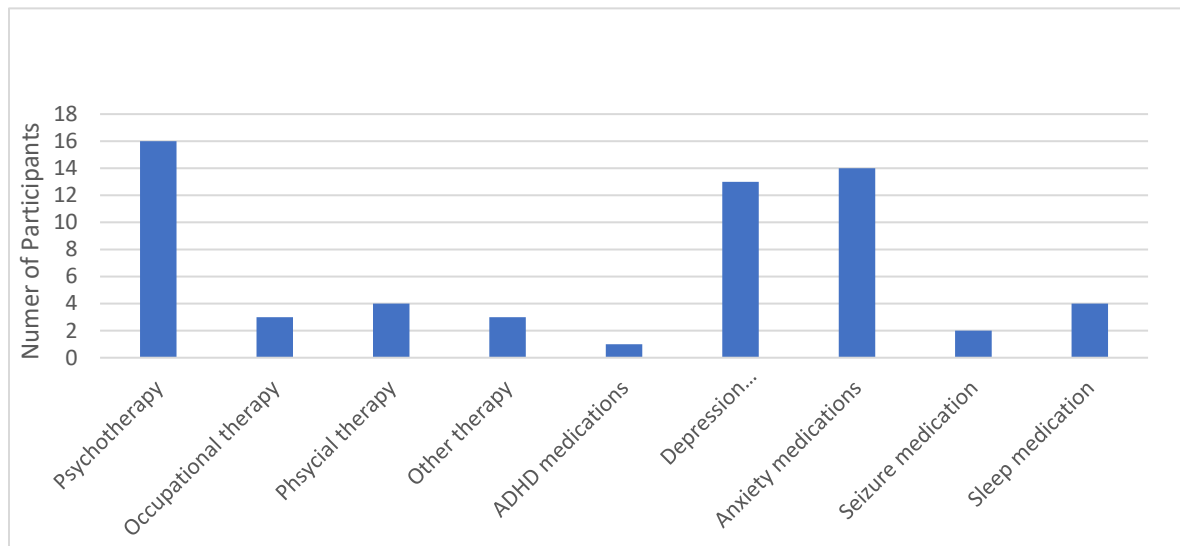
<sup>1</sup>Also known as the ADOS-2 Comparison Score<sup>2</sup>Formal Diagnoses were self-reported by parents on a digital questionnaire, so both categories may be underreported or overreported and may not have matched diagnostic status reported by daughters.<sup>3</sup>Some missing scores were individuals from a local autism specialty clinic that referred women with autism diagnoses for research participation.***Developmental and Treatment History***

Questions about developmental milestones were developed specifically for this study, based on typical clinical intake questionnaires for comprehensive evaluations of children (e.g., the Structured Developmental History from the Behavior Assessment System for Children, BASC-2). The history was completed by the parents of participants as part of a larger online survey. The questions included basic demographic information, then progressed to developmental history. Pregnancy and newborn health, current health and age of diagnosis were asked. Developmental milestones and age of first concerns were queried. Speech and language, social, emotional and behavioral development were included, and an educational history was

gathered. Along with existing or prior mental health or other diagnoses, data were also gathered about treatment history. See Figure 3.

**Figure 3**

*Treatment History*



***Follow-Up Interviews With Parents***

Questions in the follow-up interview were developed in a semi-structured interview format, based on introductory questions from the Autism Diagnostic Interview, Revised (ADI-R; Rutter, LeCouteur, et al., 2003). Interviews were completed by researchers and recorded so that they could be transcribed for analysis. Parents were asked several questions about their daughter's early development. Questions included the following:

- Tell us about the early years of development for your daughter, primarily before she entered kindergarten.
- What do you remember about developmental milestones or anything that stands out to you about her development in those early years?

Possible probes were given to the interviewers as well, including the following:

- When did you become first concerned about the early development of your child?
- What did that look like?
- What delays, if any, did you notice in your daughter's early development? (if necessary, further prompt) Walking, talking, toilet training, play?
- What did you notice in your daughter's behaviors growing up that may have been different from other children, or different from your expectations?
- Were there any behaviors that others would consider inappropriate for that situation?
- What other concerns did you notice in your daughter's early development?
- Is there anything else you would want us to be aware of in your daughter's history?

Additional questions were included regarding reading comprehension that were part of a related study and are not included here because we did not include those data in our research questions.

## **Procedures**

### **Online Data Collection**

#### ***Inclusionary Criteria***

Participants of the larger study were asked to complete questionnaires online regarding their experiences in social situations and questionnaires designed to determine the level of autism traits. Participants were selected for further study if they had enough autism symptoms to meet at least a low threshold cutoff score on the BAPQ. With participant permission, basic early developmental information was collected from parents using a developmental questionnaire delivered by Qualtrics.

### ***Exclusionary Criteria***

Adolescent participants also gave assent along with parental consent for participation, with the parent initiating contact. We did not include them in our sample here because parents were interviewed about developmental milestones by research assistants (while their daughters completed in-person evaluation) before interviews for this study began.

### ***Autism Trait Data Collection***

**In-Person.** Autism, social, cognitive, and language measures were conducted in person with the daughters as part of the larger study to further characterize the daughters' autism symptom levels and other characteristics (e.g., IQ). Information about any prior autism diagnoses, including age of diagnosis, was also gathered by parent or self-report.

**Interview Preparation.** Following main study participation by the daughters, and the electronic questionnaires completed by parents, follow-up requests for interviews were made to parents. These interviews were designed to elicit the memories that were most salient, relevant, and present in their minds as they reflected on the early development of their daughter.

To prepare for the interviews, we referred to the answers given in the developmental questionnaire for a preview of areas of concern. Interview questions themselves were open ended and broad rather than specific (see Follow-Up Interviews with Parents section above). Answers to the broad questions were likely to include the observations or concerns already reported, but we wanted a sense of what was most important to the parents by asking them the open-ended questions first.

One of the investigators with extensive autism expertise reviewed all of the parents' Qualtrics responses to indicate priorities for follow up during interviews. These priorities were

not framed as questions posed to the parents, however, unless the topic was not mentioned spontaneously in the interview.

### ***Parent Interviews***

Interviews were conducted using a designated HIPAA-compliant Zoom teleconferencing platform. If parents (interviews were conducted with one or both parents), were not comfortable with video recording, audio only (camera off) was offered as an option with the interviewer available on video. Interviewees were a combination of father and mother or both parents together. Interview recordings were uploaded from the researcher's computer to a highly confidential Box account and Microsoft OneDrive (as backup) for transcription and analysis.

**Interview Procedures.** The interviews were in-depth semi-structured interviews which allow for probing as needed, as described in the Measures section. This approach was chosen as it allows the researchers to actively listen to the participants, reflect and ask follow-up questions for more information (Tracy, 2020). Data collection by interview was chosen as the study was designed to be a retrospective look at childhood development which cannot be observed (Tracy, 2020).

Interview length ranged from 30 minutes to approximately 1 hour. Parents and one or two researchers were included. Daughters were specifically not included. This was done to help keep communication open and to create a lower stress environment for the parents. All participants in the interview were encouraged to share as much as they felt comfortable with. Parents gave written and oral consent to engage in the interview.

**Transcription.** Interview recordings were transcribed by research assistants and faculty support personnel who were not affiliated with other study procedures (i.e., they had never met the participants). Transcripts were then verified by research assistants by replaying the video or

audio recordings and checking the accuracy of the transcription. At all stages, access to the videos were protected to maximize confidentiality. Videos were not identified in filenames, but the names of the parent participants and daughters were occasionally mentioned in the videos.

## **Research Design**

This study is a qualitative, retrospective investigation of early signs of developmental differences in females later diagnosed with autism in the hopes of identifying early signs of autism. Due to gaps in the literature regarding early developmental signs of autism in females without intellectual developmental disorder, we considered interpretative phenomenological analysis (IPA). This method was chosen as it helps to provide a more detailed look into an individual's personal experience and then creates a full picture based on the interviews. This method was also chosen due to its lack of formal assumptions or hypotheses. The data were gathered through in-depth interviews of parents, and then analyzed as described below.

### ***Trustworthiness in Qualitative Inquiry***

Tracy (2020) highlighted eight criteria for researchers to consider for quality qualitative inquiry. They are as follows: (a) worthy topic; (b) rich rigor; (c) sincerity; (d) credibility; (e) resonance; (f) significant contribution; (g) ethical; (h) meaningful coherence.

**Worthy Topic.** Tracy (2020) raises the idea that a worthy topic one that is theoretically relevant, has practical application or the opportunity for social transformation. Researchers are also encouraged to think about the interesting in their study and how it may add to the field. Due to the suspected underdiagnosis rate and late diagnoses of females with autism (Loomes et al., 2017) and the lifelong impacts lack of supports and understanding can have in a woman's life, this is believed to be a worthy topic.

**Rich Rigor.** Rich rigor is the idea that the research is collected is sufficient and appropriate for the task and has been collected and analyzed with appropriate research practice. One important piece of this is the informational power or how rich the information provided is. There are five specific criteria that should be considered to determine if a study has sufficient information power. These characteristics are (a) study aim, (b) sample specificity, (c) use of established theory, (d) quality of dialogue, and (e) analysis strategy (Malterud et al., 2016).

***Study Aim.*** If a study has a broad aim, then a larger interview sample size is needed. The study aim for this study is narrow, as we are seeking to learn more about the early developmental history of females with autism traits.

***Sample Specificity.*** In this study, parents of females with autism or autism traits are closely connected with their daughter's early development and childhoods. This specificity is important, related to how closely participants have experienced the phenomena that is being researched. In the literature review, the prevalence of missed and late diagnoses in females reduces the availability of specificity regarding existing diagnoses, which was replaced by the recruitment phrasing of exhaustion in social settings as a key indicator of a socially significant autistic trait.

***Established Theory, Quality of Dialogue and Analysis Strategy.*** Researchers must determine if they will apply established theory to their study or not. Small studies can be rigorous if they uncover new learning. Due to the lack of research in this area any findings from this study could be considered new learning. Because autism is a low-incidence condition and the subset of females has traditionally been both lower than males and under-represented (Loomes et al., 2017; Maenner et al., 2021), IPA has been shown to be a good option when exploring the issues of gender and autism, as used by Mo et al. (2022) and Viswanathan et al.



(2022) in their IPA and autism studies. An interview that contains strong dialogue between the participants and interviewer requires few participants according to Malterud et al. (2016). In our study, the length of interviews, the open dialog, preview of developmental reporting and training of interviewers produced strong dialog.

**Sincerity (Statement of Positionality).** This marker encourages researchers to have an honest awareness of their own identity and to approach the data in a way that shows respect for the participants and research stake holders. In my work with the special education community, I have seen females with nuanced autism traits often overlooked because they did not match the textbook definition. I have worked as a high school special education teacher and seen females identified as autistic as late as 11<sup>th</sup> grade. My purpose in this research is to better serve these girls and women who often are overlooked by highlighting their differences so that we can do better as society for them.

**Credibility.** Credibility is achieved when the researcher provides a high level of detail about the process and activities of the research (Tracy, 2020). In this research, credibility means a dependable trustworthiness in the researcher and full transparency in methods.

**Resonance.** Resonance is the transferability or generalization of research. In this study, we intend to provide exploratory results in hope of generalization, as these results may aid in the earlier identification of autism traits in young females. We recognize that experience across cultures, races, and languages needs to be broadened for meaningful generalization.

**Significant Contribution.** Significant contribution refers to how the findings transform or on the other hand, complicate the body of knowledge and the impact it has on practice (Tracy, 2020). The goal of this study is study is to contribute to the body of knowledge of early development for individuals with autism, specifically females. Because of historical bias toward

male presentations of autism, differentiation of early signs is expected to contribute to the scientific literature moving forward.

**Ethical Procedures.** This study was reviewed in detail and approved by the university IRB committee to protect the rights of all participants, including data protection. Scientific review of the study was provided by the thesis committee.

**Meaningful Coherence.** Researchers worked to ensure the stated purpose, created plans with the purpose in mind, used methods and practices that are approved and interconnected current research with possible results. Studying the early development females with subsequent autism traits to determine if there are any connects between the individual's experiences and later life provides the interconnectedness intended by this characteristic.

### ***Data Analysis in Qualitative Inquiry***

Interviews were transcribed verbatim from the video interviews. Transcriptions of the 22 interviews were randomly selected to serve as our randomized sample. This sample was selected at random from the 30 parent interviews that were available at the time. Due to the use of the IPA method it was important to have between 2 and 25 samples (Alase, 2017). The analysis was completed using within-case and cross-case coding to establish themes and trends within the interview. All interviews were randomly assigned to individuals within a trained research group and no member of the group ever reviewed the same transcript twice. Transcriptions of the interviews were analyzed for saturation on any ideas or events that presented as recurring themes among the interviews. Transcriptionists completed memos following each transcription regarding coding and analyzing data at the same time to work on establishing patterns. Memos used in this study and others were reviewed by team members as part of the weekly review. See Table 3 for the steps of IPA.

**Table 3***Interpretative Phenomenological Analysis --Adaptive Six Steps\**

<b><i>Step</i></b>	<b><i>Process</i></b>
<b><i>1</i></b>	Read and re-read transcript to get to know the data.
<b><i>2</i></b>	Make initial notes (codes) to systematically capture participants' experience.
<b><i>3</i></b>	Develop emerging categories for each case.
<b><i>3b</i></b>	Attend to reflexivity.
<b><i>4</i></b>	Search for connections across categories for each case.
<b><i>5</i></b>	Move to the next case.
<b><i>6</i></b>	Look for patterns across case. Look for overarching themes across cases.
<b><i>6b</i></b>	Attend to reflexivity.

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\*Taken from Goldspink & Engward, 2018; Smith, 2019

The goal of this study was to better understand the early development of females with autism and how their early experiences may differ from those of male with autism. The research team gathered over zoom and discussed what to look for in the transcripts regarding coding. This included a seminar by an autism specialist on autism, specifically looking at autism traits as themes to help establish typical and atypical development and responses. The first round of data review involved each individual on the research team reading and re-reading the transcriptions. In the second cycle of analyzing research team members took initial notes on their transcripts with their first thoughts and ideas while reading. The research team was encouraged to keep the research questions in mind but also permitted to pull other quotes.

- What recollections of language or communication differences were reported in the daughters' early development?

- What recollections of restricted or repetitive interests were reported in the daughters' early development?
- What recollections of social communication or social interaction differences were reported in the daughters' early development?

First thoughts in analysis were recorded on a set worksheet . For Step 3, all researchers turned in their worksheets for the development of categories of information gathered. This data was then reviewed with the expert on IPA to help consolidate the results into *a priori* codes. The researchers then monitored themselves for reflexivity to check that no prior beliefs were infringing on the *a priori* codes.

In step 4, each member of the research team worked with different transcriptions than they had access to while completing *a priori* coding to prevent in sample biases. These results were compiled and consolidated into topics before being sent to an expert in autism for her review.

Data was organized into these themed codes which allowed the research team to create a deeper understanding of the data across many interviews and personal experiences.

## **Themes**

From the *themes coding* a second reading of the transcripts was completed with each researcher reading new transcripts. The researchers were provided a new to track their quotes in. This worksheet included the themes and an area to gather quote that agreed or disagreed with the set theme for that page. These quotes were then gathered and reviewed by the head researcher and reflections were made of reflexivity. The data were then reviewed by an autism expert, developmental expert, and early childhood education expert to determine what themes may be

seen through the many responses. These themes led to another data review of the transcripts to look specifically for the themes listed below.

- Rapid language development
- Speech services
- High levels of vocabulary
- Lack of restricted or repetitive interests
- Not being able to generalize in social settings
- Over or under emotional responding
- Health issues

## **Results**

Many strong themes emerged from the analysis of the transcribed interviews. Some of these themes were in line with expectations based on previously completed research but many new areas appeared as common connections between the daughters in the study, based on the recollections of their parents.

### **Across Group Themes**

#### ***Early Reading***

Parents often noted that their daughters presented as early readers (de-identified participant numbers are listed in parentheses following each quote). One parent stated,

She, she learned quickly and easily. She, . . . was able to read the Magic Tree House chapter books. I don't know if you know what those are, they're about a second-grade level, when she was five. She comprehended easily. . . at age four she was spelling, she was doing decoding, spelling things out...(1)

While parents noted that their daughters were early readers, many questioned how well their daughters understood the text.

### ***Voracious Reading***

Some parents described their daughters as constantly reading to a point where families had to restrict books. One parent stated in reference to her daughter, age 8 at the time, “She sat in the little kid wagon with a book and read a book the whole time at the zoo. Never got out of the wagon,” (13).

Parents also noted that their daughter’s love of reading contributed to sleeping issues. “She would read all the time. In fact, we have, there was [sic] sleep issues when she’d just sit there and read for hours,” (3).

### ***Memory***

Three parents reported advanced levels of memorization, specifically referring to books their daughters liked to read. Parents reported that their daughters could memorize entire books and could directly quote the text to them.

Some parents also noticed that their daughters quickly memorized things like directions, numbers, or ABCs, “And so she knew all her ABCs by then and could recognize them by the time she was 18 months old,” (8).

### ***Lack of Social Awareness***

One area that parents noticed was a lack of social awareness, extending to lack of safety awareness in their daughters. This looked different for every daughter, but according to the parents it could look like monopolizing conversations, speaking in a very loud voice during conversations or (according to parents) being just a bit too brave. One parent reported “We’ve tried to warn her. . . the internet is a scary place for her though, because she gets in chat groups

and just wants to socialize, but some, yeah, she has run into really some pretty bad people...” (13).

Another parent highlighted that this lack of social awareness continued into high school and needed to be pointed out.

I feel like she’s sometimes a little unaware of social norms and is a little immature about it. Like she wants to hold her friend’s hands in public and her senior year were like ‘[daughter’s name], stop holding [friend’s name]’s hand. She’s like ‘She likes it!’ I said ‘No she doesn’t! You’re not—When we see her, we see that she’s uncomfortable with that. Stop doing that.’ ‘We’re just friends!’ ‘I know you’re just friends, but other people think you’re not just friends. You’re making her uncomfortable.’ And she wouldn’t get that.” (10)

### ***Low Social Language Engagement***

Parents noted that their daughters often did not seem interested in social language engagement but would often pick and choose who they engaged with at home. Many parents could not comment about the school or social settings but just what they saw at home.

I figured that [name] just wasn’t that interested in talking and that turned out to be true, she just really wasn’t that interested. It was about 4 ½ when I realized that my neighbor’s 3-year-old was talking to me and saying, “I am going to my birthday and I am going to have this, and I am going to have this” and my daughter was just over there pushing buttons. (2)

Other parents noted that their daughters may need an hour or two alone after school before they came and talked to their families about their days.

### ***Restrictive and Repetitive Behaviors***

Some parents noted that their daughters demonstrated restrictive and repetitive behaviors but not necessarily similar to males with autism. Many of the restricted and repetitive behaviors that parents reported related to reading or organization. Many of the girls preferred to re-read the same book many times and would rarely branch out to new books or series. Regarding restricted play, one mother described her daughter's lack of variety in sorting Legos.

So, I would get down on the floor and would sort with her and I'd say, "Do you want a red one," she would start lining up all the red one and I would say "Oh, I have a red one," and she would take it from me and put it down. And then I'd say, "Do you wanna do the purples?" and she knew what purple was...but she wasn't, didn't care. She only sorted the red ones all day! (2)

Another parent experienced her daughter's repetitive behavior in watching an educational show, "But they use words and then they teach them and [name] loves it, but she watches the same one over and over" (15).

### ***Camouflaging and Recovery***

Camouflaging is not a symptom of autism but can be a learned coping strategy used by females with autism to better fit in with peers or social contexts. Some parents reported seeing their daughters "holding it together" around their friends to act and behave in an expected way only to be unable to do it at home. One parent stated,

No, she, when she's with friends, she pulls it together and I think what it is for [daughter] is her energy comes...I don't know, her recharging comes from being alone. And so, she needs her down alone time. And then she can recharge and be good and social and happy at school and with friend. (5)



Another parent stated that when with friends and peers “she just pulls it together for them, when she needs to, basically,” (10). This parent’s experience mirrors other parent reports that their daughters were able to camouflage when needed.

### ***Sensory Issues***

Parents reported a variety of sensory issues, many of which appeared in early childhood. Some of the families remembered issues regarding tags on clothing, socks being wrinkled (thus unwearable) and the need for shirts to hit a specific place on one’s arm. Other parents also reported sensory sensitivities towards food and specific textures in food. For one, “Her underwear wouldn’t be quite right so she would have to try to fiddle with her underwear. She had . . . pretty severe issues with food,” (13).

### ***Rigidity and “Epic” Meltdowns***

Parents noted that their daughter was very rigid in what to expect or how things should go and when it did not go that way, the daughters would have meltdowns as described by the parents. One mother noted that she once saw her daughter spending hours trying to get the Velcro straight on a doll’s shirt and when she was unsuccessful she had a meltdown. The mother noted that this meltdown was most likely due to her daughter’s lack of language skills to ask for help.

Many parents reported that meltdowns could happen at any time when their daughter was younger and could, according to one parent, be “epic.” Many parents reported that their daughter’s meltdowns lasted 2-4 hours and that often the parents could not calm their daughters.

Then she’d calm down and, and we’d ask later, you know, “What was that all about?” and it would be something like, a kid looked at her. Or something, you

know. It would be something, that's what she would say. [meltdowns lasted for] 2 or 3 hours, (14).

## **Thematic Summaries**

### ***Communication Differences***

Parents noted high levels of epic meltdowns over things events seemed incredibly minor from the parents' viewpoints. These meltdowns highlight the possibility of communication differences when communicating frustration to those around them. They may also illustrate the effects of sensory sensitivities that are not readily identified.

### ***Restricted or Repetitive Interests or Behaviors***

Parent reports of excessive interest in reading has not previously been highlighted in autism literature as a restricted interest, but this was frequently mentioned by parents in the study. This could mean that many teachers and parents do not notice the behavior due to the social acceptability of high volume reading in society. It is also possible that we gathered more information about reading because of some of the interview guiding questions specifically asked about reading and comprehension, but not generally about frequency or intensity of reading interest.

### ***Social Communication Differences***

Using an IPA approach, we found that parents noticed low social language engagement at home, but this finding should be interpreted with caution. Many parents noted that their daughters had some social language engagement that was seen outside the house, but within the family, they did not see high levels of it within the house.

We also found that lack of social awareness was seen by some families. They explained that often their daughters spoke too loudly or monopolized the conversation by not showing

appropriate turn taking. The lack of social awareness can also be very dangerous as some parents talked about their daughters not understanding to discriminate between people who are safe to talk to compared to those who are unsafe.

### ***Shame***

One theme that was seen across many of the transcripts was shame. While this was not a specific theme we as the research team was searching for it is important to note. As parents reflected on their daughter early development researchers would often hear comments like “how did we not notice that (2)” or “yeah, that was a bit different than her sisters,” (13). A few parents commented that they wish they would have gotten their daughters help sooner but they did not know how to help them.

### **Insights Gained**

To our knowledge, this study is the first of its kind to retrospectively look at the experiences of females with autism and their early childhood development. Our goal was to look at establishing potential clues for practitioners to look for in practice and assessment processes.

One finding that was somewhat novel was consideration of intense (voracious) reading as a restricted and repetitive interest (APA, 2022). Differences in restricted and repetitive behaviors in females are beginning to be mentioned in the literature as something that may be more age appropriate like animals or celebrities. The nature of the interest did not raise any concerns, but the intensity of the interest was noticed and recalled by parents. Reading has not been explored much as a possible restricted interest that has been noticed but not interpreted as a restricted interest, despite the intensity and repeated patterns. By itself, it may not be significant, but in the presence of other autism traits, it may be important to note.

Other findings were more typical and in line with established traits, but with subtle differences. Although it is typical to read of parents enduring long meltdowns over trivial things, there was some hint at social context for meltdowns that is less common in the established male-biased literature. Sensory sensitivities were also not surprising, but again, the context associated with parent reports was not always within examples commonly given in the literature, other than sensitivity to clothing. Feeding problems noted have potential for life-threatening eating disorders in later years.

Finally, the ‘recovery’ or withdrawal after extensive camouflaging was notable to parents, even at young ages when camouflaging is not yet identified or perhaps even suspected. The natural imitation of peers in early development may look like camouflaging, but parents also commented on the need to recover afterwards, with this type of exhaustion not usually considered as common in neurotypical girls. It is frequently described in the first-person literature by females with late diagnoses of autism in particular (Bargiela et al., 2016).

## **Discussion**

### **Limitations**

The study has limiting factors that may affect generalization of results to other samples. The participants and their families were recruited from one geographical location with limited diversity as part of a larger study. In the larger study, women were recruited by flyer, asking if social situations left them exhausted. The recruiting strategy was designed to capture some women who may not yet have been identified as having autism, but the nonspecific recruitment flyer resulted in participants with uncertain status regarding autism. Results will need to be interpreted in a dimensional manner rather than a categorical manner given the lack of female-specific normative data in many autism measures.

The use of a retrospective data collection may be subject to variability in recollection, but the design was also intentional in terms of collecting memories of characteristics in early childhood that stand out in memory as being noticeable and different. One area of note is that some parent participants stated that they could not remember their daughter's early development with 100% accuracy due to same-gender siblings within a year or two of age.

Limitations also included the logistical barriers in contacting parents of a relatively small sample of women who participated in a study of autism and/or social anxiety in females. Qualitative case studies are limited by the lived experience of participants, which may not represent the population (in this case, the population of all women with autism, including women who may not have formal diagnoses). Nevertheless, the study results are expected to lay the groundwork for more extensive investigations of developmental trajectories in the future.

Within a retrospective design, there is always the possibility of a limitation in the recall of parents. The interview process is designed to provide probes and prompts to memory, but details may be forgotten or recalled through a biased lens because of subsequent experiences. The retrospective design also has the advantage of hindsight, in knowing the eventual outcome of events that occurred early in childhood. Bias and assumptions on the part of researchers are acknowledged in the trustworthiness section.

### **Implications for Future Research**

Our findings are limited in scope and information produced as an early exploratory study to inform future research. Additional studies may consider examining a closer timeframe between females in early childhood and interviewing (e.g., interviewing parents when their daughters are elementary school age). They should also consider a larger, more diverse sample size to represent the current makeup of the United States across cultures and peoples. While there

were common threads in many of the parents' experiences, there is not enough data to establish a reliable or representative phenotype at this point. As one example, the availability of books in early childhood may not be equal across the lived experience of many, so our findings regarding reading may differ across populations. Rather, there are suggestions of future aspects of early development to investigate in females later identified with autistic traits. Future studies could also include a prospective longitudinal study following high risk females (such as siblings) from early childhood into adulthood to track and monitor their growth through the years. Overall, more research needs to be completed to help establish a more accurate profile or range of profiles typical of autistic females.

### **Implications for Practice**

Despite limitations, the study provides some early clues for practitioners to gain awareness of as they evaluate young children, male and female, for developmental differences. Experiences within this sample population can be compared with first-person accounts and emerging scientific literature as practitioners and researchers alike recalibrate to the more nuanced type of autism that has perhaps been missed in early childhood in the past, particularly in females. Many parents in the study reported shame over not knowing males and females with autism present differently and regret over not getting help sooner. It is possible that families may experience regret or difficulty wondering how they did not effectively “connect the dots” regarding some of the signs that were noticed with their daughter’s subsequent difficulties and identification of autism. Although understandable, reassurance that this type of information was not widely available to anyone, especially parents, in prior decades should be given.

This study highlights the need for more exploration of early developmental interviews with parents as part of a comprehensive diagnostic process. Parent interviews can help provide

practitioners with much needed early development information that parents may not have thought relevant until asked. By completing in-depth in-person interviews, practitioners are able to ask more follow-up questions and receive more stories that could provide a more robust picture of the individual in her early development. As part of their child find mandate (Individuals with Disabilities Education Act, 2004) schools can also alleviate some of the miscommunication or possible shame by providing psychoeducation to parents and teachers, explaining that females and males present with autism differently.

## **Conclusion**

Our study found that by parent report, there were differences in females later diagnosed with autism, or with significant autism traits compared to their typical peers. Through parent interview it was found that these females did show some communication differences, restrictive or repetitive behaviors and social communication differences when compared to typical peers.

A theme found regarding language and communication was epic meltdowns that would last at least two hours at a time, seemingly innocuous triggers or antecedents. Some signs of restrictive or repetitive interest were found, frequently centered around reading. This could mean that many teachers and parents do not notice the behavior due to the social acceptability of high volume reading in society. One interesting hypothesis regarding reading to consider is that reading as a restricted interest might be one explanation for lower comprehension skills that often occur in autism when the student ostensibly has good reading skills as measured in the early grades. It is also possible that we gathered more information about reading because of some of the interview guiding questions. We also found that parents noticed low social language engagement at home, but this finding should be interpreted with caution. Many parents noted that

their daughters had some social language engagement that was seen outside the house but they as the family did not see high levels of it within their families at home.

While this study produced interesting results, it is necessary to continue research on this subject. Females with autism are often overlooked in research and academia which has led to a lack of research and public education on this subject. This lack of public education makes it harder for parents, teachers, and community members to notice signs of autism in females and may lead to more emotional and social struggles for these women.



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## APPENDIX A

### Review of the Literature

Autism spectrum disorder (autism) describes an individual with social and communicative impairments or traits, with restrictive and repetitive behaviors, sensory issues, and/or stereotypical behavior present. These impairments can include but are not limited to deficits in verbal communication, social interactions, maintaining or understanding relationships, and emotional awareness. People with autism may also display behaviors that are repetitive or overly focused on one specific area of interest (American Psychiatric Association [APA], 2022).

In many cases, autism can be identified by the time an individual is two years old (Chawarska et al., 2007; Guthrie et al., 2013; Zwaigenbaum et al., 2014). This is possible because of knowledge of well-researched early signs and identifiers that have helped families as well as physicians recognize autism in its early stages. Some of the common signs and symptoms are intense repetitive behaviors, social impairments, extreme or obsessive interests and cognitive deficits (Maenner et al., 2021). These signs are not always present in each case of autism, but this overall pattern of symptoms can be identified in many of these cases. Without early identification, people with autism may not have access to early intervention, which can limit outcomes, including the possibility that individuals with autism may be less likely to become as independent as they would like to be (Maenner et al., 2021).

While there is no clearly identified cause of autism, many researchers agree that there is a strong genetic factor that makes some individuals more at risk for autism (Huguet et al., 2013). Also, children born to older parents have a higher risk of developing autism when compared to peers with younger parent ages (Durkin et al., 2008).

## Females and Autism

Because there are many individuals with autism who have gender identity issues (de Vries et al., 2010), in this manuscript, the terms “males” and “females” will refer to male and female gender as assigned at birth. The terminology “autistic” and “individual with autism” will be used interchangeably to honor the preferences of self-advocates. According to ongoing Centers for Disease Control (CDC) prevalence studies, the current male-to-female ratio for children with autism is 4.2:1, determined by a study of children aged 8 years. The current prevalence of autism is 1 in every 44 children in the population sample (Maenner et al., 2021). One recent study challenges the 4.2:1 ratio, suggesting that it is actually closer to 3:1 (Loomes et al. 2017; Maenner et al., 2021). The study’s hypothesis is that the disproportion of males to females may be affected by difficulties identifying females with autism, likely due to gender bias in standardized testing.

Autism has formerly been labeled as a primarily male disorder which only affected females at the lowest end of intellectual functioning (Kopp & Gillberg, 1992). According to Rutter et al. (1996), females who have traditionally been identified with autism are more severely affected and commonly have other disorders that would make them more likely to be identified, suggesting a need to control for IQ when looking to identify females with autism. Females without any clear cognitive problems are typically diagnosed with autism much later than their male peers (Giarelli et al., 2010), so it is possible that our prior assumptions about females with autism have not included a possibly substantial population of females with autism but not ID.

The early signs and diagnostic criteria traditionally associated with autism are based on the “male-prototype” or male phenotypes (Kopp & Gillberg, 1992, p. 97). One study supported the idea that even in the presence of similar *severity* of autistic traits that females are less likely

to be diagnosed than a male peer. This is especially true when females do not manifest with additional intellectual and behavioral problems (Dworzynski et al., 2012).

Another factor that may explain missed diagnoses of females with autism is their ability to hide social problems when compared with males. In a recent study, teachers reported that males with autism had more apparent social problems when compared to females with autism. This makes the identification process for females more difficult when compared to their male counterparts (Sedgewick et al., 2015). Females were reported as having more emotional problems, which was viewed by teachers as fitting within stereotypical female behavior, also making it even more difficult to identify females with autism (Mandy et al., 2012). Also, well-documented is the ability of with females with autism to camouflage their signs of autism, making symptoms and presentation less evident (Ratto et al., 2018). When females with autism across the entire spectrum *are found*, researchers can learn more about their symptom development, trajectory, and presentation, which will help with earlier identification (Mandy et al., 2012).

In recent prevalence studies in the United States, two trends have been clearly identified. First, the ratio of males to females diagnosed with autism has changed from 4.5 to 1 10-12 years ago to 4.0:1 recently (Baio et al., 2018), then reversing back to 4.2:1 (Maenner et al., 2021). The second new trend is that now the proportions for females with autism and intellectual developmental disorder (IDD) is now closely equal to that of males with IDD, following many years of reporting that females with autism were more likely to have IDD than their male counterparts. There is also a trend towards more equivalent identification of children in ethnic minority groups being identified earlier, although still not as early as White children at age 8 (Baio et al., 2018).

## **Developmental Profile of Females With Autism**

Gender differences within autism have been neglected in research until very recently, and there have been very limited studies that explore the differences in behaviors among those with autism by gender (Bölte et al., 2011; Giarelli et al., 2010). In spite of the fact that there are very few studies on the topic, researchers have found clear cognitive differences in autism according to sex assigned at birth, in terms of executive functioning and expected stereotypical behaviors (Bölte et al., 2011).

While there are noticeable differences between males and females with autism, there are also very subtle differences in frequency and severity of symptoms that can often be overlooked. Females with autism often display more difficulties in communication and sleep when compared to their male peers. They also are more likely to have higher anxiety and depression rates. Males with autism show more of the more obvious stereotypical signs like more restricted, repetitive behaviors (RRBs) than their female peers (Hartley & Sikora, 2009).

Females with autism may be less likely to be identified as having RRBs when compared with males (McFayden et al., 2019) but this may be bias on the part of the observer rather than a lack of RRBs. Females with autism are more likely to have appropriate socially acceptable interests when compared to males (Kopp & Gillberg, 1992; Wolff & McGuire, 1995). This helps females with autism blend in more with their peers and be less likely to be identified by teachers or staff. Although appropriate in nature, the intensity of the interest is beyond what is found in typical development.

Bölte et al. (2011) found that females scored higher in tasks that were designed to show impairment in executive functioning while males scored higher in their attention to details. This

may have led to the belief that males with autism present more stereotypical behavior such as repetitive and ritualistic patterns of behavior (Carter et al., 2007).

### **Gender Identity and Sexuality**

Baron-Cohen has theorized that the “extreme male brain theory of autism,” which may suggest that autism is an extreme of the “normal male profile” in which *systemizing* is seen more often than the empathizing behavior commonly seen in females (2003, p. 248). The androgen theory of autism believes that autism is partly explained by elevated levels of fetal testosterone (Ingudomnukul et al., 2007). There is a positive correlation between elevated fetal testosterone and traits that are commonly associated with autism. This implies that females with autism may not present with the same traits expected for their gender as their neurotypical female peers, which could help aid in the diagnosis. This theory also led to some hypotheses regarding possible protective effects from the XX chromosomal structure in females that would explain the lower prevalence of autism in females (Ingudomnukul et al., 2007).

There are other elements of being female with autism that have also been reported. Females with autism report irregular and often difficult menstrual cycles, polycystic ovary syndrome, severe acne, and epilepsy, among other medical issues in their genetic legacy (Ingudomnukul et al., 2007). Other researchers also found that females with autism may be more likely to be described tomboys while growing up and report no sexual preferences (Turner et al., 2017). When directly compared with typical peers, females with autism may be perceived as less feminine (George & Stokes., 2018).

Females with autism are more likely to describe themselves as having gender identity issues. Gender-dysphoria (GD) is a condition in which the individual experiences a continuous state of disappointment and conflict between their self-perceived and assigned gender.

Researchers in the Netherlands found that 7.8% of the children referred to a clinic for GD were identified as autistic, which is much higher than expected for autism in the general population. (van der Miesen et al., 2018)

### **Eating Disorders**

Individuals with autism are often described as picky eaters or selective eaters. They tend to accept only the same few foods and refuse to try new ones. This can be an issue that some children may outgrow while others may stick to their favorite foods for their whole life. This aversion to new foods can create unhealthy eating habits that have health implications across the lifespan. Children with autism receive less calcium, vitamin D and dairy from their food than their typical peers (Graf-Myles et al., 2013). Fear of new foods can lead to anorexia nervosa in adolescence, which is an eating disorder characterized by quick and rapid weight loss, an intense fear of weight gain and a distorted body image as children get older (APA, 2022). Many studies have shown a high correlation between elevated signs of autism and anorexia nervosa. It is estimated that 23% of females with a autism diagnosis have anorexia nervosa (Huke et al., 2013; Westwood & Tchanturia, 2017). Sadly, the treatment for anorexia nervosa becomes less effective in the presence of more elevated signs and symptoms of autism (Westwood & Tchanturia, 2017).

### **Speech and Language Development**

Speech and language development is one of the most important parts of a child's early childhood. Through speech and language, a child can communicate their thoughts and needs to those around them. Children with autism can have impairments in their language that will often lead to receptive vocabulary deficits (Horvath et al., 2018). Speech delays are reported to be the symptom that parents of children with autism will typically first seek help for (Chawarska et al., 2007). Typically developing children often use social or context clues to help them understand

the meaning of a new word. This is very difficult for children with autism. Children with autism may be able to see patterns and regularities in vocabulary at a faster rate than their typical peers but often will act on their knowledge (Foti et al., 2015; Mayo & Eigsti, 2012; Obeid et al., 2015).

Children usually learn speech and vocabulary from their parents. This is no different for children with autism or any other developmental disability. In language development, temporal response contingency, or the chance that you will get to speak again is used to help promote conversation turn-taking. Turn-taking is used in parent-child interactions as soon as the parent engages with the child in speech (Stern et al., 2017). Mothers of children with autism tend to be more likely to use a responsive strategy than mothers with typical children (Stern et al., 2017). The temporal response contingency is often used as an early intervention for students that have been identified as autism to help in their development. One study looked at pre-school age children with autism to determine their acquisition of verbs. The study found that children with autism were looking for patterns when being taught new words using video modeling (Horvath et al., 2018).

Children with autism can show atypical language development, which is when a child develops language skills in a very different manner than their typical peers (McDaniel et al., 2018). An atypical discrepancy between receptive and expressive language skills exhibited by some children with autism is one manifestation of different or delayed language development (e.g., Davidson et al., 2017; Hudry et al., 2010; Kim et al., 2014; Luyster et al., 2008). In children with autism between the ages of 13 and 25 months, visual attention (or the lack thereof) on the speaker was heavily correlated with receptive-expressive language skills discrepancies. Horvath also found that children with autism are more likely to look away (off-task gaze behavior) when others were talking with them, reducing their likelihood of learning the



nonverbal communication that accompanies and is an integral part of language acquisition (Horvath et al., 2018).

Children with autism on average have a smaller receptive-expressive vocabulary size discrepancy than their typically developing peers with the same expressive vocabulary (McDaniel et al., 2018). The children with autism tended to exhibit comprehension of fewer words than expected, relative to the number of words they said. Children with language delays without autism generally showed better receptive than expressive language abilities, thus the larger gap (e.g., Charman et al., 2003; Hudry et al., 2010; Hudry et al., 2014; Kover & Ellis Weismer, 2014; Luyster et al., 2008; Volden et al., 2011; Woynaroski et al., 2016). Children with autism struggle with word comprehension especially when the words are presented in a social situation.

### **Repetitive Interests**

One of the identifiers used for early identification of individuals with autism is repetitive or restricted interests. Males with autism may have an interest in cars, planes, rocks or so on, but this is not the same for females. Females with autism are also less likely to have traditionally identified restricted behaviors when compared with males (McFayden et al., 2019). Females may actually have more restricted interests than males, but they are more likely to have appropriate, socially acceptable interests when compared to males (Kopp & Gillberg, 1992; Wolff & McGuire, 1995). This helps females with autism to blend in more with their peers and makes them less likely to be identified by teachers or parents.

### **Social Skills, Communication, and Play**

Neurotypical females are more likely to make long-term friendships and be involved in more verbal social interactions than males. Most of the time males are more interested in

physical play compared to females who are more interested in imaginative play (Sedgewick et al., 2015).

Social skills and communication of females with autism is a little less clear. Most research focuses on males with autism in this area, and there is little research on social skills in general. One important thing to keep in mind according to Crombie (1988) is that social behaviors and expectations for what social competence looks like varies between the genders. Females begin to recognize the importance of non-verbal communication such as gestures and eye gaze (Barbu et al., 2011) for example, which is not as common in males in autism populations. Females with autism will often experience increased social and communication impairments during adolescence (as opposed to toddlerhood) when compared to males (Kirkovski et al., 2013; Koenig & Tsatsanis, 2005; McLennan et al., 1993). This can lead to more social isolation, which can be very damaging at a time when social inclusion is important for development and transition to adulthood.

Social skills instruction can be very valuable to individuals with autism. They do, however, need to be taught in a way that is applicable to their needs as a female. Many of the social skills training that are available are written towards the male symptomatic presentation. This does not mean that the females will not benefit from this training but could lead to a lower level of benefit for females compared to their male counterparts. When provided particular social skills training for females with autism, females showed more confidence and felt more comfortable with their skills (Hull et al., 2017).

### **Age of Diagnosis**

One study suggested that parents of females who were eventually diagnosed with autism, on average, showed a longer time between “first concerns” and diagnosis when compared to

males (Begeer et al., 2013). The CDC provides data on prevalence ratios and the rate of intellectual disabilities between male and females, but the report does not yet break down the age of diagnosis by gender (Baio et al., 2018; Maenner et al., 2021).

### **Dangers of Late or Missed Diagnosis**

Because females with autism often go undiagnosed until later in life, they may be left without proper support and are vulnerable to other comorbid conditions and issues associated with autism. These issues are high rates of anorexia nervosa, bullying, social isolation and suicidal ideation and behaviors (Postorino et al., 2017). Identification of females with autism is difficult due to their ability to camouflage for a period of time when they are in a social situation. Females with autism can camouflage in order to hide deficits in social communication to fit in socially. They also camouflage to fit into gender expectations and roles (Ratto et al., 2018). The act of camouflaging requires intense cognitive effort, which causes mental stress on the female who is attempting to hide their autistic traits or her authentic self, which can lead to anxiety and depression (Lai et al., 2017). The act of camouflaging not only adds immeasurable stress but can also make it more difficult to provide accurate support and intervention (Gould, 2017). Some autistic females adopt camouflaging behavior in order to face the social hardships of life in situations like peer interactions. This can make it more difficult to identify them for research and clinical services (Mandy et al., 2012).

In a clinical cohort study, individuals with autism were asked to complete a self-reported questionnaire regarding their lifetime experiences of depression, suicidal ideation and suicide attempts or plans. Females with diagnosed autism and a history of depression reported suicidal ideation (89%) compared to 62% of females without autism and history of depression (Cassidy et al., 2015).

Unfortunately, including the full range of severity of autism in females has proven to be elusive to researchers who are attempting to understand their experiences and critical issues that they are facing every day. Therefore, researchers have a hard time drawing conclusions to aid them in the identification of females with autism.

There are many mental health issues that are present for females with autism that can lead to a lower quality of life. One study examined the social connectedness and loneliness in individuals with autism and found that they were significantly less connected than their peers and displayed higher levels of loneliness. For females only, the indirect pathway from broader autism phenotype (BAP) traits to internalizing symptoms through social connectedness was also significant, which suggests that, for females with stronger autistic profiles, lower levels of social connectedness can lead to increased anxiety and depressive symptoms for reasons other than loneliness (Stice, 2019).

People with autism in general have a higher rate of suicide than their neurotypical peers. Females diagnosed with autism have a significantly higher prevalence of suicidal thoughts and behaviors, including death by suicide compared to their typical peers. A long-term study was conducted reviewing the diagnosis of autism or other developmental disabilities and the rate of suicides. The study found that individuals with autism were eight times more likely to die by suicide than typical peers. It found that females with autism had a suicide rate that is 13 times more likely than in the general population (Hirvikoski et al., 2019). Another study looked at the suicide rates in Utah over 20 years, comparing over 22,472 age and gender matches to examine the suicide rate. It found that 0.03% of the typical population of females died by suicide compared to 0.17% of females with an autism diagnosis (Kirby et al., 2019).

Females diagnosed with autism have more developed skills in some areas that can benefit them, which can obscure their symptomatic presentation in comparison to their male peers, accounting for later or missed diagnoses. Females may have superior fine motor skills, have a higher rate of internalizing problems and a lower rate of externalizing behaviors (Halpern, 1995; Zahn-Waxler & Shirtcliff, 2008). Females with autism are less likely to focus on faces during conversation than their typical peers (Ketelaars et al., 2016), but adult females with autism seem to be more interested in social interaction (Kirkovski et al., 2013) and are less readily diagnosed (Begeer et al., 2013). When comparing males and females with autism, females showed more psychological issues by self- and parent-report measures. This could also be attributed to higher reported issues with social problems and thought problems. Females also have a higher social pressure to be considered normal. This may lead to more psychological issues in females than males.

Gender bias against females, criteria based on male phenotypes, extreme male brain theory, lack of intellectual developmental disorder and gender issues all lead to difficulties identification of females with autism. This presents a problem due to the many stressors which females with autism face and the difficulties they encounter in receiving appropriate help for an individual with autism if they are not diagnosed. Females with autism have an increased risk of depression, anxiety, suicidal ideation and suicidal attempts or completions. Finding treatment help for these conditions may not be difficult, but if the providers are not aware that their patient has autism, much time and effort may be wasted in ineffective techniques. Even when techniques are adapted for autism, therapy results may take much longer (Anderberg et al., 2017). It is vital that researchers, practitioners, school psychologists, parents and other involved parties are aware

of these issues in order to better identify more females with autism spectrum disorder in a timely manner which will provide better opportunity for support throughout the lifespan.

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## APPENDIX B

**Institutional Review Board Documents****Memorandum**

To: Dr Lundwall

Department: BYU - FHSS - Psychology

From: Sandee Aina, MPA, HRPP Manager

Wayne Larsen, MAcc, IRB Administrator

Bob Ridge, PhD, IRB Chair

Date: March 17, 2020

IRB#: IRB2020-082

Title: Unseen, But in Plain Sight: Identifying Developmental Patterns of Females with Symptoms of Autism Spectrum Disorder

Brigham Young University IRB approved the research study referenced in the subject heading at the full-board level. The approval period is from 03/17/2020 to 03/04/2021. Please reference your assigned IRB identification number in any correspondence with the IRB. Continued approval is conditional upon your compliance with the following requirements:

1. A copy of the approved informed consent statement and associated recruiting documents (if applicable) can be accessed in iRIS. No other consent statement should be used. Each research subject must be provided with a copy or a way to access the consent statement.
2. Any modifications to the approved protocol must be submitted, reviewed, and approved by the IRB before modifications are incorporated in the study.
3. All recruiting tools must be submitted and approved by the IRB prior to use.
4. In addition, serious adverse events must be reported to the IRB immediately, with a written report by the PI within 24 hours of the PI's becoming aware of the event. Serious adverse events are (1) death of a research participant; or (2) serious injury to a research participant.
5. All other non-serious unanticipated problems should be reported to the IRB within 2 weeks of the first awareness of the problem by the PI. Prompt reporting is important, as unanticipated problems often require some modification of study procedures, protocols, and/or informed consent processes. Such modifications require the review and approval of the IRB.

Instruction to access approved documents, submit modifications, report complaints and adverse event can be found on the IRB websites under iRIS guidance:

[http://orca.byu.edu/irb/iRIS/story\\_html5.html](http://orca.byu.edu/irb/iRIS/story_html5.html).

A few months before the expiration date, you will receive a prompt from iRIS to renew this protocol. There will be two reminders. Please complete the form in a timely manner to ensure that there is no lapse in the study approval. Please refer to the [IRB website](#) for more information.

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### **Consent to Participate in a Research Study (Adult)**

**Study Title:** Developmental Patterns in Females with the Broader Autism Phenotype

**Principal Investigator:** Rebecca A. Lundwall, PhD, (phone: 801-422-5977)

#### **Introduction**

My name is Rebecca A. Lundwall, PhD. I am a professor at Brigham Young University. I am conducting a research study to collect information on your developmental experiences that might be related to the Broader Autism Phenotype. The Broader Autism Phenotype is not a disorder, but a name for a collection of symptoms that are thought to relate to autism.

#### **Procedures**

We want to ask you questions about your experiences growing up and how you feel about past and current social situations. For example, we will ask you about friendships; any teasing or bullying you might have experienced; sources of anxiety for you; and discomfort (e.g., confusion or fatigue) in social situations. We will also ask you about times you have sought help. There are 2 portions to this study. The first portion will be done online. The optional second portion will involve an approximately two-hour visit to campus.

#### **Online Portion**

There are eight questionnaires to be completed online. We estimate that this will take about 2 hours. You can take breaks between measures.

1. The Tennessee Self Concept Scale (TSCS-2) Short Form contains 20 items to give us a brief idea of what you think of yourself.
2. Depression, anxiety, and stress scale, short version (DASS-21) is a 21-item self-report instrument assessing the presence and severity of depression, anxiety, and stress symptoms.
3. The Gender Group Identification Scale. This scale asks you questions about how comfortable you feel with your gender group (other females). There are 7 questions.
4. A developmental history questionnaire that is unique to this study. This questionnaire will ask about milestones of development such as language and social interaction as well as physical symptoms such as gastrointestinal problems and food restriction, which some people have with broader autism phenotype symptoms. Because you might not remember very much about your early growing up, we would like to have your parent complete a copy of this questionnaire regarding your growing-up years. It takes most people about 30 minutes to complete.
5. The Broad Autism Phenotype Questionnaire. This is a 36-item questionnaire concernin symptoms sometimes seen in individuals who have relatives with autism.
6. The Social Responsiveness Scale. The SRS-2 assessment is a screening device. It can be completed in 15 to 20 minutes and identifies social impairment associated with ASDs. It is sensitive enough to detect subtle symptoms throughout the lifespan. We would also like your parent to complete a copy regarding your growing up years.

7. The Autism Spectrum Quotient (AQ). This is a 50-item self-report measure with four options per question. It assesses traits related to autism, such as social skills, attention, communication, and imagination.
8. The Camouflaging Autistic Traits Questionnaire (CAT-Q) is a 25-item self-report measure with seven options per question. It assesses social strategies used to compensate for autistic traits during social interactions

Notice that there are two forms we would like to have your parent complete (the SRS-2 and the Developmental History). We would like to get your permission to have your parent complete these forms because they concern time periods you might not remember well (when you were growing up). If this is acceptable to you, please provide your parents contact information as requested below. If this is not acceptable to you, please call our office at 801-422-5977 to discuss options. You may also email us at [social\\_study@byu.edu](mailto:social_study@byu.edu).

☐ I give consent for the research team to contact my parent (check if “yes”).

Parent’s Name:

---

Parent’s Email Address:

---

Parent’s Phone number:

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### **Face-to-Face Portion**

After you complete the online portion, you might be invited for a face-to-face interview. We will also have you watch some short videos of social interactions and answer some questions about the videos. Finally, we will follow up on some of your responses to the online questionnaire that we want to ask you more details about. At the end of the session, we will ask you a few questions about how you are doing overall and give you a personalized list of some resources in your area that might be helpful to you. The entire face-to-face session will take about two hours.

There are six measures for you to complete:

1. The Autism Diagnostic Observation Schedule-Second Edition (ADOS-2). The ADOS-2 consists of a series of activities. One of the research team will complete this standard autism assessment with you.
2. Follow up Developmental History measure. We will review your responses to this measure online and ask any clarifying questions that we need to.
3. The Awareness of Social Inference Test-Short Form (TASIT-S) - The TASIT-S uses short video clips to assess your social awareness.
4. The Wechsler Abbreviated Scale of Intelligence – second edition (WASI-II). We will administer the 2-scale version to determine your estimated IQ, just to make sure you are not having any cognitive difficulties.
5. Delis-Kaplan Executive Functioning System (D-KEFS). We will administer two subtests: trail making which assesses visual scanning and switching, and color-word interference which assesses inhibition and flexibility.
6. Suicidal Behavior Questionnaire – Revised (SBQ-R). The SBQ-R is a brief, 4-item self report measure of suicidal thoughts and behavior. We need to ask these questions to find out if you are OK.

There is one measure for your parent to complete (if you agree), and they can do this either by coming to your interview with you and being interviewed in a separate room, or by scheduling a telephone conversation with a member of our research team.

1. Follow-up Developmental History measure. We will review your parent's responses to the developmental measure and ask any clarifying questions that we need to about things that you may not remember (such as events early in your life).

If you do not want to be invited for the face-to-face portion, please check here:

☐ I do NOT want the research team to contact me for the face-to-face portion of the study (leave blank if it is OK to contact you).

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### **Risks**

Possible risks are likely small. Fatigue is possible and so we will encourage you to take breaks. Some of the questions about social relationships might be uncomfortable for some people. If that happens during the online portion, you may stop answering the questions and take a break. If that doesn't help, you may call us during business hours, so we can walk through some options with you. There will also be opportunities to stop for breaks during the face-to-face session if you feel tired.

### **Confidentiality**

We will not tell anyone outside the research team that you participated. We will also not tell anyone outside the research team that any particular answers were yours. However, if we feel something you say reflects the experiences of girls and women with the broader autism phenotype, we might quote a part of what you say without identifying you. This will be to help clinicians and researchers better understand the experiences of girls and women who have some symptoms of autism. If we do so, we will remove any names, places, or other identifying information to make it very difficult for anyone to identify you.

All paper documents will be stored in locked cabinets in locked offices on the BYU campus. All computer files will be encrypted and stored locally on password protected computers in locked offices. This includes a log linking your name to your ID number, which includes an extra level of encryption. We will keep the log for up to one year after data collection for all subjects is complete and then it will be destroyed. The purpose of keeping the log is in case we need to contact you for additional information. However, if you do not want us to, then you can just let us know and we will not contact you. We will also video tape portions of the face-to-face session so that we can accurately capture what you tell us. There is a separate consent form for the face-to-face portion of the study and for video recording. We will destroy the video one year after all data collection for this study is complete.

### **Benefits**

The ADOS-2 is the gold-standard in autism assessment and we will give you the score report so that you can take it to a provider who is experienced enough to help you. We will also give you a list of resources that might be helpful for you. In addition, we hope that your participation in this study will help us make things better for other girls and women who have symptoms on the Broader Autism Phenotype.



**Compensation**

You will be paid \$20 for completing the online questionnaires and, if invited to the face-to-face portion of this study, \$30 for completing that interview. In the event that you are unable to complete the face-to-face portion of the study or must stay longer than originally anticipated, you will be compensated based on your total time spent participating in the study.

**Questions about the Research**

You may ask questions about the study before, during, and after your participation. If the research team is not able to answer your questions, or if you have comments or complaints about the study, then please contact me (the primary investigator) by one of the methods below:

Rebecca A. Lundwall, PhD

Brigham Young University

1064 KMBL

Provo, UT 84602

[Rebecca\\_Lundwall@byu.edu](mailto:Rebecca_Lundwall@byu.edu)

801-422-5977

In addition, if you have questions about your rights as a study participant or want to submit comments or complaints about the study for university oversight, then you may contact the IRB Administrator:

IRB Administrator

Brigham Young University

A-285 ASB

Provo, UT 84602

[irb@byu.edu](mailto:irb@byu.edu) or (801) 422-1461

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## Participation

(Optional) Please check yes to indicate your permission to be referred to other studies conducted by Dr. Lundwall and her research team. If this is not acceptable, simply check “no.”

I give Dr. Lundwall permission to contact me for her other studies: yes \_\_\_\_\_ no \_\_\_\_\_

(Required to participate in the current study) You may choose to not to participate. You may also withdraw from the study at any time. Neither of these actions will cause you to lose any benefits to which you are otherwise entitled. By signing this consent form, you indicate your consent to take part in this study. You also indicate that you have been given a copy of this form for your records.

Name (please print) \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_

Researcher/Assistant Signature \_\_\_\_\_ Date \_\_\_\_\_

If yes to future contact,

Physical address \_\_\_\_\_

Email address \_\_\_\_\_

Cell phone number \_\_\_\_\_

Landline phone number \_\_\_\_\_

**Video Release Form**

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As part of this project, I will be making video recordings of your child during your participation. Please indicate what uses of this video you are willing to permit, by initialing next to the uses you agree to and signing at the end. This choice is completely up to you. I will only use the video in the ways that you agree to. In any use of the video, we will emphasize the importance of confidentiality.

☐ Video can be shown in small groups for training graduate clinicians.

☐ Video can be used for scientific publications (e.g., linked provide)

☐ Video can be shared with other researchers in a password protected database (e.g., Databrary).

☐ Video can be shown at scientific conferences or meetings.

☐ Video can be shown in classrooms to college students.

☐ Video can be shown in public presentations to non-scientific groups for training purposes.

I have read the above descriptions and give my express written consent for the use of the video as indicated by my initials above.

Child Name: \_\_\_\_\_

Parent Name (Printed) \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_

You have the right to rescind this permission at any time. Please notify me in writing or by email if you wish to do so: Please be aware that videos linked in a publication cannot always be removed from the Internet.

Rebecca A. (Becky) Lundwall, Ph.D.  
 Assistant Professor  
 Psychology Department and Neuroscience Center  
 1064 KMBL  
 Brigham Young University  
 Provo, UT 84602  
[Rebecca\\_Lundwall@byu.edu](mailto:Rebecca_Lundwall@byu.edu)

## APPENDIX C

**Parent Questionnaire (History and Early Development of Daughter)****Parent form:**RESPONDER INFORMATION

Your relationship to the participant: Mother Father Other: \_\_\_\_\_

Have you known the participant since her birth? Yes No. Since how old: \_\_\_\_\_

How many years have you lived with the participant? \_\_\_\_\_

Are you currently living with the participant? Yes No

*In subsequent questions, “the participant” will be referred to as “your daughter.”*

DEMOGRAPHICS

Your daughter’s birthdate: \_\_\_\_\_

Please select your daughter’s race:

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White

Please select your daughter's ethnicity:

- Hispanic or Latino.
- Not Hispanic or Latino

Your daughter's mother's educational background:

- Some high school
- High school diploma or GED
- Some college
- Associate's degree
- Bachelor's degree
- Advanced degree
- Other: \_\_\_\_\_

Your daughter's father's education background:

- Some high school
- High school diploma or GED
- Some college
- Associate's degree
- Bachelor's degree
- Advanced degree
- Other: \_\_\_\_\_

0-5 yrs. 5-10 yrs. 10-15 yrs.

The zipcode your daughter lived in for the \_\_\_\_\_

majority of time during these time periods:

PREGNANCY & NEWBORN PERIOD (for this daughter)

Describe:

Medical problems during pregnancy Yes No \_\_\_\_\_

(e.g., infections, diabetes)?

Did the mother take medications during Yes No \_\_\_\_\_

the pregnancy?

Any substance use during the pregnancy Yes No \_\_\_\_\_

(e.g., smoking, alcohol, drugs)?

Was the birth premature? Yes No \_\_\_\_\_

Problems with labor or delivery? Yes No \_\_\_\_\_

Problems during newborn period Yes No \_\_\_\_\_

(e.g., seizures, birth defects)

FIRST CONCERN

How old was your daughter when you first noticed that social Age: \_\_\_\_\_ N/A

interactions were more challenging for her than her peers?

How old was your daughter when others (e.g., teacher, pediatrician, Age: \_\_\_\_\_ N/A

neighbor) told you they had concerns about your daughter's social

development?

## HEALTH

Have you had concerns about your daughter's health? Has your daughter ever been formally diagnosed with a medical condition?

	Age of first concern	Age of diagnosis	Severity in childhood: 0 – None 1 – Mild 2 – Moderate 3 - Severe	Severity in adolescence: 0 – None 1 – Mild 2 – Moderate 3 - Severe	Current severity: 0 – None 1 – Mild 2 – Moderate 3 - Severe
Epilepsy/Seizures					
Migraines/Headaches					
Gastrointestinal problem:					
Genetic disorder/syndrome (e.g., Rett's):					
Neurological disorder:					
Head injury					
Chronic illness:					
Sleep problem problems falling asleep problems staying asleep waking up too early waking up too late					
Other:					
Other:					
Other:					

Have any of the diagnoses indicated above been determined by professionals to be inappropriate or inaccurate? If so, which:

---



Have you had concerns about your daughter's psychological functioning? Or has she received a formal psychological diagnosis?

	Age of first concern	Age of diagnosis	Severity in childhood: 0 – None 1 – Mild 2 – Moderate 3 - Severe	Severity in adolescence: 0 – None 1 – Mild 2 – Moderate 3 - Severe	Current severity: 0 – None 1 – Mild 2 – Moderate 3 - Severe
Attention-deficit/hyperactivity disorder					
Autism spectrum disorder Autism Asperger syndrome PDD-NOS					
Learning disorder dyslexia (reading) dyscalculia (math) dysgraphia (writing)					
Generalized anxiety disorder					
Social phobia					
Phobia					
Obsessive compulsive disorder					
Depression Suicidal ideation Suicide attempt					
Bipolar disorder					
Eating disorder restricted food intake binging purging excessive exercise					
Self-harm					
Other:					

Other:					
Other:					

Have any of the diagnoses indicated above been determined by professionals to be inappropriate or inaccurate? If so, which:

---

Has your daughter received any treatment for medical or psychological concerns?

Description	Age when treatment started	Treatment Duration	Ongoing (Y/N)
Therapy (e.g., psychotherapy, physical therapy, speech therapy, occupational therapy)			
Medication (e.g., antidepressant, stimulant, antipsychotic)			

PHYSICAL DEVELOPMENT

Were any of the following difficult or slow to develop for your daughter?

Describe:

Head/neck control (the ability to hold the head up and not let it fall/lag when pulled to sitting from lying on back; 0-6 mos.) Yes No \_\_\_\_\_

Roll from back to stomach (6-9 mos.) Yes No \_\_\_\_\_

Walking alone (12-18 mos.) Yes No \_\_\_\_\_

Bowel training (2-4 yrs.) Yes No \_\_\_\_\_

Bladder training (2-4 yrs.) Yes No \_\_\_\_\_

Tying shoes (4-6 yrs.) Yes No \_\_\_\_\_

Writing letters (3-5 yrs.) Yes No \_\_\_\_\_

Riding bike Yes No \_\_\_\_\_

Did your daughter walk on her toes more frequently than other children? Yes No

Do you think of your daughter as being more clumsy than her peers? Yes No

LANGUAGE DEVELOPMENT

When did your daughter develop these language skills?

Describe:

First word (12-18 mos.) Early Average Late \_\_\_\_\_

Spoke in sentences (2-3 yrs.) Early Average Late \_\_\_\_\_

Able to read single words (4-6 yrs.) Early Average Late \_\_\_\_\_

Able to read sentences fluently (6-8 yrs.) Early Average Late \_\_\_\_\_

EDUCATIONAL HISTORY

Behavior problems in school: Describe (age, contexts):

Hyperactivity Yes No \_\_\_\_\_

Inattention Yes No \_\_\_\_\_

Aggression to others Yes No \_\_\_\_\_

Disobedience to teacher Yes No \_\_\_\_\_

Special help in school:

Tutoring Yes No \_\_\_\_\_

Special education class Yes No \_\_\_\_\_

Resource class Yes No \_\_\_\_\_

504 plan Yes No \_\_\_\_\_

IEP plan Yes No \_\_\_\_\_

Held back a grade Yes No \_\_\_\_\_

Has your daughter ever been homeschooled? If so, for which grades:

\_\_\_\_\_

### SOCIAL DEVELOPMENT

Did your daughter: Describe (age, contexts):

Have problems making friends? Yes No \_\_\_\_\_

Have problems keeping friends? Yes No \_\_\_\_\_

Have a best friend? Yes No \_\_\_\_\_

Struggle to keep friends similar to her in age? Yes No \_\_\_\_\_

Get regularly asked to play or hang out by Yes No \_\_\_\_\_

friends?

Appropriately take turns with friends? Yes No \_\_\_\_\_

Maintain physical space boundaries? Yes No \_\_\_\_\_

Sometimes engage with a friend in an activity Yes No \_\_\_\_\_  
that was the friend's preference, even if she was  
not interested in the activity?

React appropriately to negative peer pressure? Yes No \_\_\_\_\_

Get teased or bullied more than peers? Yes No \_\_\_\_\_

"Read" the emotions of others appropriately? Yes No \_\_\_\_\_

Understand when others were joking? Yes No \_\_\_\_\_

Understand others' points of view? Yes No \_\_\_\_\_

React appropriately to others in distress? Yes No \_\_\_\_\_

Successfully negotiate conflict? Yes No \_\_\_\_\_

EMOTIONAL & BEHAVIORAL DEVELOPMENT

Would you describe your daughter as:

Describe (age, contexts):

Overactive Yes No \_\_\_\_\_

Has a hard time focusing or paying attention Yes No \_\_\_\_\_

Anxious/Worrier Yes No \_\_\_\_\_

Irritable , easily upset Yes No \_\_\_\_\_

Changes mood from happy to sad quickly Yes No \_\_\_\_\_

Easily frustrated Yes No \_\_\_\_\_

Has a hard time with transitions Yes No \_\_\_\_\_

Unpredictable Yes No \_\_\_\_\_

Emotionally overreactive Yes No \_\_\_\_\_

Able to solve problems on her own Yes No \_\_\_\_\_

Able to plan and organize tasks Yes No \_\_\_\_\_

SENSORY

How does your child respond to sensory experiences?

	<u>LESS SENSITIVE</u>		<u>AVERAGE</u>	<u>MORE SENSITIVE</u>	
	Alot	Somewhat		Somewhat	A lot
Light	A lot	Somewhat	Average	Somewhat	A lot
Loud noises	A lot	Somewhat	Average	Somewhat	A lot
Just certain noises	A lot	Somewhat	Average	Somewhat	A lot
Touch (e.g., hugs)	A lot	Somewhat	Average	Somewhat	A lot
Tastes	A lot	Somewhat	Average	Somewhat	A lot
Textures (food, clothing)	A lot	Somewhat	Average	Somewhat	A lot
Pain	A lot	Somewhat	Average	Somewhat	A lot
Temperature	A lot	Somewhat	Average	Somewhat	A lot

MAJOR STRESSORS

Has your daughter experienced any major life stressors?

Describe:

Divorce Yes No \_\_\_\_\_

Death of immediate family member Yes No \_\_\_\_\_

Natural disaster Yes No \_\_\_\_\_

Major accident Yes No \_\_\_\_\_

Major illness or operation Yes No \_\_\_\_\_

Abuse Yes No \_\_\_\_\_

Other: \_\_\_\_\_ Yes No \_\_\_\_\_

ADDITIONAL COMMENTS

Is there anything else you feel would be important for us to understand about your daughter's history or background?

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## APPENDIX D

*a priori* Code WorksheetsWorksheet for *a priori* codes. (Per Participant)

Participant #

<i>a priori</i> code 1: Language or communication differences	(Evidence of)
<ul style="list-style-type: none"> <li>▪ Quote:</li>   <li>▪ Quote:</li>   <li>▪ Quote:</li> </ul>	
<i>a priori</i> code 1: Language or communication differences	(Lack of Evidence of)
<ul style="list-style-type: none"> <li>▪ Quote:</li>   <li>▪ Quote:</li>   <li>▪ Quote:</li> </ul>	

<i>a priori</i> code 2: Restricted Interest	(Evidence of)
<ul style="list-style-type: none"><li>• Quote:</li> <li>▪ Quote:</li> <li>▪ Quote:</li></ul>	
<i>a priori</i> code 2: Restricted Interest	(Lack of Evidence of)
<ul style="list-style-type: none"><li>▪ Quote:</li> <li>▪ Quote:</li> <li>▪ Quote:</li></ul>	

<i>a priori</i> code 3: Repetitive Interest	(Evidence of)
<ul style="list-style-type: none"><li>▪ Quote:</li> <li>▪ Quote:</li> <li>▪ Quote:</li></ul>	
<i>a priori</i> code 3: Repetitive Interest	(Lack of Evidence of)
<ul style="list-style-type: none"><li>▪ Quote:</li> <li>▪ Quote:</li> <li>▪ Quote:</li></ul>	

<i>a priori</i> code 4: Social communication/social interaction difference (Evidence of)
<ul style="list-style-type: none"> <li>• Quote</li>   <li>▪ Quote:</li>   <li>▪ Quote:</li> </ul>
<i>a priori</i> code 4: Social communication/social interaction difference (Lack of Evidence of)
<ul style="list-style-type: none"> <li>▪ Quote:</li>   <li>▪ Quote:</li>   <li>▪ Quote:</li> </ul>

## APPENDIX E

**Themes Code Worksheets**

Worksheet themes

Participant #

Rapid Language Development
<ul style="list-style-type: none"> <li>▪ Quote:</li> <li>▪ Quote:</li> <li>▪ Quote:</li> </ul>
Speech Services
<ul style="list-style-type: none"> <li>▪ Quote:</li> <li>▪ Quote:</li> <li>▪ Quote:</li> </ul>
Formal Speech (talking only when needed or learning from a book)
<ul style="list-style-type: none"> <li>▪ Quote:</li> <li>▪ Quote:</li> <li>▪ Quote:</li> </ul>
Vocabulary
<ul style="list-style-type: none"> <li>▪ Quote:</li> <li>▪ Quote:</li> <li>▪ Quote:</li> </ul>
Lack of restricted or repetitive

<ul style="list-style-type: none"><li>▪ Quote:</li><li>▪ Quote:</li><li>▪ Quote:</li></ul>
No generalization in social settings
<ul style="list-style-type: none"><li>▪ Quote:</li><li>▪ Quote:</li><li>▪ Quote:</li></ul>
Overemotional or underemotional
<ul style="list-style-type: none"><li>▪ Quote:</li><li>▪ Quote:</li><li>▪ Quote:</li></ul>
Health issues
<ul style="list-style-type: none"><li>▪ Quote:</li><li>▪ Quote:</li><li>▪ Quote:</li></ul>