ANXIETY SYMPTOMS IN CHILDREN WITH AUTISM SPECTRUM DISORDER AND IMPLICATIONS FOR FAMILY LIFE

BY

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ABSTRACT

Individuals with autism spectrum disorder (ASD) commonly experience comorbid anxiety disorders and anxiety symptoms. Recent research suggests that anxiety, while commonly co-occurring with ASD, is a distinct disorder and may exacerbate negative social, emotional, and behavioral outcomes for ASD individuals. This project examined differences in parent-reported symptoms of ASD and anxiety disorders in children with ASD aged 5-12, and the role of these symptoms in child and family functioning. Parents completed a survey in which they answered questions about the frequency of their child's symptoms, skills and behaviors, as well as their own experience of parenting and quality of family life. ASD core symptoms and anxiety symptoms were both related to child functioning and family outcomes, suggesting that children with ASD who experience co-occurring anxiety may experience greater difficulties than those they experience due to ASD core symptoms alone. ASD and anxiety were also demonstrated to uniquely predict the frequency of challenging behaviors, which subsequently were associated with more difficult parent experience and family life.

INTRODUCTION

Autism Spectrum Disorder (ASD) is a lifelong neurological disorder defined by persistent impairment in communication and social interaction and characterized by repetitive behaviors and restricted interests (American Psychiatric Association, 2013). Most recent statistics estimate that 1 in 59 individuals is diagnosed with ASD, with boys receiving an ASD diagnosis at about four times the rate of girls (Baio, Wiggins, & Christianson, 2018). Presentation and severity of symptoms across the autism spectrum vary significantly and result in a range of functional implications including deficits in social interactions and relationships, academic underachievement, hyper- and hypo-sensitivity to sensory stimuli, disrupted sleep patterns, self-harm and other challenging behaviors. Individuals with ASD also frequently receive comorbid diagnoses of other psychological disorders, such as depression, Attention-Deficit/Hyperactivity Disorder (ADHD), and Obsessive Compulsive Disorder (OCD) (Matson & Cervantes, 2014; Matson & Nebel-Schwalm, 2007; Williams, Matson, Beighley, Rieske, & Adams, 2014).

Anxiety disorders and anxiety symptoms represent some of the most common co-occurring psychological conditions experienced within the ASD population. While all humans experience some level of fear and worry throughout daily life (and appropriate levels of fear can be functional for survival), anxiety disorders are diagnosed when worry becomes "excessive", meaning greater in intensity than is typical, and "persisting," generally meaning lasting longer than six months (American Psychiatric Association, 2013). People with anxiety disorders experience stress or fear that is disproportionate to the realistic risk of the stimulus that provokes the emotional reaction and may experience impaired functioning in their school, work, family, and social routines as a result.

Specific disorders include Generalized Anxiety Disorder (GAD), Social Anxiety Disorder, Separation Anxiety Disorder, Panic Disorder, Selective Mutism, and Specific Phobias. OCD and Post-Traumatic Disorder (PTSD), previously categorized with Anxiety Disorders in the DSM-IV, are categorized independently in the DSM-5 (American Psychiatric Association, 2013).

GAD is considered to be a chronic condition, with high rates of symptomology persisting across the lifespan, and is frequently comorbid with other specific anxiety disorders and depressive disorders. (Tyrer & Baldwin, 2006). Symptoms of anxiety manifest in different ways, and anxiety disorders are broadly comprised of cognitive symptoms, behavioral symptoms, and physical symptoms. For those with GAD, excessive and uncontrollable worry persist across situations and environments, and can lead to significant occupational impairment throughout daily routines. GAD has also been linked to long term physical health outcomes, including gastrointestinal disorders, respiratory disorders, and heart disease (Carroll, Phillips, Gale, & Batty, 2011; Tully, Cosh, & Baune, 2013).

Presentation of Anxiety in ASD Populations

Estimates of anxiety rates within the ASD population vary greatly, ranging from 22% to 84% (Vasa & Mazurek, 2015). A recent meta-analysis found anxiety rates among children and youth with ASD to be around 40% experiencing at least one type of anxiety (van Steensel, Bögels, & Perrin, 2011). In contrast, an estimated 15% to 20% of typically developing children and adolescents will experience an anxiety disorder (Beesdo, Knappe, & Pine, 2009). A full understanding of the prevalence and effects of anxiety disorders in ASD populations has been hindered by insufficient understanding

and agreement among professionals regarding how to define and assess anxiety disorders comorbid with ASD. Subsequently, anxious symptoms and anxiety disorders often go undiagnosed and untreated in individuals with ASD.

Though comorbid diagnoses are common in ASD populations, it is not always clear how to differentiate ASD-related symptoms from separate disorders. One initial obstacle to identification of mental health problems in autistic populations is *diagnostic overshadowing*, the tendency to attribute any co-occurring psychological symptoms or conditions to a disabled individual's primary diagnosis, or to consider any co-occurring symptoms less important than the disability itself (Ambler, Eidels, & Gregory, 2015; Mason & Scior, 2004). When an autism diagnosis becomes the primary concern for parents, educators, and medical professionals, other underlying medical or psychological conditions often go unnoticed or unaddressed. Behavioral signs of underlying anxiety, such as aggression, may be attributed to ASD, especially in autistic individuals with lower communicative abilities (White, Oswald, Ollendick, & Scahill, 2009). In autistic populations, attribution of all symptoms and behaviors to the autism diagnosis prevents a full understanding of co-occurring psychopathologies, like anxiety, that may underlie those symptoms.

Another hindrance to the study of anxiety in ASD populations is the problem of defining the pathology itself. While symptoms and behaviors associated with anxiety are also commonly associated with ASD, anxiety is not currently included in the diagnostic criteria for ASD. Much conversation has centered around the issue of comorbidity or core symptomology – whether anxious symptoms are merely a byproduct of the core symptoms of autism or whether they represent an independently classifiable

psychopathology that simply happens to frequently coincide with ASD (Halim, Richdale, & Uljarević, 2018; Kerns & Kendall, 2012; Mazefsky & Herrington, 2014; Scahill, 2012; Wood & Gadow, 2010). This task is made additionally difficult by differences in symptom manifestation in ASD and non-ASD groups given differences in communicative ability, information processing, and behavioral responses to anxiety.

Kerns and Kendall (2012) argue that there is evidence to support anxiety as a separate and co-occurring condition, with impairing symptoms and implications that can be distinguished from autism alone. They emphasize that, while there are overlapping symptoms between anxiety and ASD, there are distinct risks for individuals with co-occurring anxiety and ASD above and beyond the risk factors of either disorder independently. These include greater symptom severity and functional disability, longer recovery time from illness, and greater service utilization. Therefore, for the purposes of intervention, is it important to recognize the autonomy of each diagnosis and the potential consequences of their co-occurrence. Kerns and colleagues (2014) proposed the notion of atypical presentations of anxiety symptoms in youth with ASD, arguing that those individuals experience typical symptoms of anxiety (consistent with the DSM-5) as well as atypical symptoms that deviate from DSM-5 definitions but are still functionally impairing. Examples of atypical anxiety noted by the researchers include functionally ambiguous rituals (e.g., excessive anticipatory worry about minor changes in routine, rule-breaking, or losing access to special interests), compulsions (e.g., verbal rituals, insistence on turning off light switches, insistence on keeping sleeves rolled down) and specific unusual fears (e.g., fear of coughing, balloons, the happy birthday song). In an examination of typical and atypical symptoms in a sample of youth with ASD, Kerns and

colleagues (2014) found evidence for typical anxiety disorders as well as prevalent occurrence of atypical anxiety symptoms, with 31% of subjects displaying both typical and atypical anxiety. The researchers propose that there may be two phenomenologically distinct mechanisms of anxiety in ASD populations – one consistent with anxiety disorders as they occur in typically developing populations, and another more centrally related to core ASD symptoms. Nevertheless, they maintain that there is separate and convincing evidence for the prevalence of anxiety disorders as distinct from ASD in this population.

To say that anxiety and ASD are distinct disorders does not negate the clear relationship between the two. In fact, better understanding the bidirectional relationship between the two diagnoses and their related symptoms and risk factors could be valuable in informing clinical intervention. Some researchers suggest that core symptoms of ASD may lead to anxiety; for example, White and collegues (2014) suggest that social deficits may subsequently contribute to anxiety, especially social anxiety. On the other hand, Wood and Gadow (2010) theorize that anxiety acts as a moderator of ASD core symptom severity; specifically, the experiences of anxiety may exacerbate deficits in social communication and repetitive behaviors. Duvekot, Ende, Verhulst, and Greaves-Lord, (2017) examined the proposed bidirectional relation between ASD and anxiety, exploring timing of core ASD symptom expression and symptoms of anxiety in children with ASD. In line with Wood and Gadow's (2010) theoretical proposal, Duvekot and colleagues (2017) found evidence that earlier anxiety appeared to affect later impairment associated with core symptoms of ASD, such as social communication. They did not find support for the reverse direction in the relationship.

The attempt to further our understanding of the timing and mechanisms of the anxiety-ASD relationship merit further investigation, especially considering the implications for individuals who experience both. Duvekot and colleagues (2017) in particular underscore the important clinical implications for recognizing and addressing early symptoms of anxiety in youth with ASD. Whether or not anxiety should be classified as a separate and co-occurring disorder in ASD populations, prevailing understanding of anxiety symptoms and their clinical relevance influences the ways in which parents, teachers, and clinicians address those symptoms. Weisbrot, Gadow, DeVincent, and Pomeroy (2005) argue that dual diagnoses are worthy of clinical consideration because anxiety and related symptoms present unique concerns in ASD populations. They emphasize that further efforts to understand symptom presentation and underlying mechanisms of anxiety and related symptoms as they differ in ASD populations is crucial to treating them more effectively. Scahill (2012) also noted that anxiety disorders are mixed in presentation even in typical populations, and that too much focus on terminology and drawing boundaries to separate diagnoses detracts from the practical necessities of improving measurement, and ultimately treatment, of anxiety symptoms in ASD individuals.

Anxiety and ASD: Child and Family Outcomes

Why is it important to expand understanding of anxiety as a distinct phenomenon commonly experienced by ASD individuals? Anxiety and its symptoms have serious functional implications for ASD youth across many environments. Comorbid anxiety disorders in ASD youth have been associated with more frequent self-injury, depression, aggression, and parental stress (Kerns et al., 2015). In the classroom environment, co-

occurring anxiety has been noted to predict greater anger and more frequent aggressive behaviors in students with ASD (Ambler et al., 2015). Anxiety may also play a role in academic underachievement and difficulties with social adjustment noted in ASD populations (Bush, Cohen, Eisenhower, & Blacher, 2017; Factor, Ryan, Farley, Ollendick, & Scarpa, 2017).

It is also important to consider how anxiety may affect functioning and wellbeing for ASD individuals in their home environment, and how symptoms may also affect family members and overall quality of family life. In qualitative work on family life and routines in families of children with ASD, parents reported feeling that ASD dominated the focus and attention of the family, interfering with other tasks and general wellbeing (DeGrace, 2004). Children with ASD often require more prompting with daily tasks and are less flexible with changes to routines, requiring families to center their schedules and activities around the needs of their ASD child.

Another consequence of ASD within the family environment is heightened caregiver stress. Parents of ASD children have been shown to experience greater stress as a function of their child's ASD severity and the frequency of challenging behaviors (Reed, Howse, Ho, & Osborne, 2017). Reed and colleagues also found that parents under high stress were more likely to resort to negative parenting behaviors, such as counterproductive stricter disciplinary style, which in turn could increase the likelihood of behavior problems. Parents of ASD children have also been shown to be at greater risk for anxiety and depression, with severe behavioral challenges particularly increasing chances of parent mental health issues (Machado Junior, Celestino, Serra, Caron, & Pondé, 2014). While these studies do not specifically address the effects of anxiety on

parental stress, given the link between anxiety and problem behaviors, it is likely that anxiety in ASD children may increase the effect of such behaviors on parental stress level. It is imperative to better understand the factors that may contribute to this cycle, so that family support services and therapies can address those factors more directly.

Furthermore, anxiety may play a role in ASD individuals' participation in leisure activities within their home and in the community. Some work has examined differential participation in leisure and community activities in families with an ASD child or children. According to a study by Simpson, Keen, Adams, Alston-Knox, and Roberts (2018), children with ASD are less involved in school, home, and community activities, and participate in a narrower range of leisure activities overall as compared to their typically developing peers. Caregivers surveyed for this study reported desires to increase the range of activities their ASD child would be willing or able to participate in. In another study, Lam, Wong, Leung, Ho, and Au-Yeung (2010) examined parents' willingness to participate in community activities, comparing parents of ASD and non-ASD preschoolers. In parents of ASD preschoolers, willingness to participate was influenced by assessment of the importance of the activity, the difficulty of participating, and the emotions experienced during the activity; non-ASD parents' willingness was not influenced by these factors.

The role of anxiety in ASD's impact on home and family life merits an increased focus in research efforts. It has been established in typical populations that anxiety affects and is affected by parenting behaviors and parental stress. Furthermore, there are established links between ASD and difficulties in family life and functioning. More explicit exploration is needed to understand the distinct role anxiety may play in the

effects of ASD on family life and an individual's functioning in their home and community. Furthermore, differentiating the impact of co-occurring conditions, such as anxiety, from that of core ASD symptoms will allow for the development of more targeted and efficient treatment plans, services, and supports for families.

With these needs in mind, this project was designed to directly explore the influence of anxiety in children with ASD within their home environment and on the overall quality of family life. The goals of this study are to:

1. Differentiate the presence of ASD core symptoms and anxiety symptoms.
2. Compare the effects of ASD and anxiety on parent-rated child functioning across home, school, and community environments.
3. Compare the effects of ASD and anxiety on parent experience and quality of family life.

Hypotheses

Anxiety Prevalence

1. Within the sample of children with ASD, significantly more children will meet the clinical threshold for anxiety based on screening criteria than will be reported to have a diagnosed anxiety disorder.

The Relationship Between Anxiety and ASD Core Symptoms

2. Higher frequency of core ASD symptoms will be related to higher frequency of anxiety symptoms.

The Role of Anxiety in Child and Family Wellbeing

3. More frequent ASD symptoms will be associated with more difficult parental experience and lower quality of family life.

4. More frequent anxiety symptoms will be associated with more difficult parental experience and lower quality of family life.
5. Anxiety will uniquely predict more difficult parental experience and lower quality of family life above and beyond core ASD symptoms alone.
6. Parents will report greater interference in child's home, school and community functioning due to anxiety symptoms than they will for core ASD symptoms.

The Role of Challenging Behaviors

7. Challenging behaviors will be uniquely related to anxiety symptoms above and beyond core ASD symptoms alone.
8. Challenging behaviors will partially explain the relation between anxiety symptoms and parent experience, quality of family life.

Secondary Hypotheses

9. Lower functional communication skills will predict higher anxiety.
10. The relations between sub-categories of anxiety and child/family outcomes will be explored.
    - 10a. Which subtypes of anxiety are most common?
    - 10b. Do different types of anxiety impact parental experience and family life more strongly?
    - 10c. Are there differences in home, school, and community functioning between anxiety subtypes?

Additional Covariates

Age	Adaptive Behavior	Cognitive Skills
Gender	Medical/Physical Disabilities	

METHOD

Participants

The sample was comprised of 103 parents who answered questions about their child, aged 5 through 12 with a diagnosis of ASD. Only one parent participated per child, meaning data were collected on 103 unique children. Parent participants were recruited through local schools and community programs in North Carolina that serve children on the autism spectrum, as well as through online postings in social media pages and internet communities of parents who have children with ASD. The mean age of the children was 106.38 months, or 8.9 years (*SD* = 25.86, range = 60-155 months). Twenty-three of the children were female (22.3%) and 80 were male (77.7%). This ratio is representative of the gender distribution in the diagnosed ASD population, usually approximated to be 4 boys to 1 girl (Baio et al., 2018).

Of the respondents, 100 were mothers (97.1%), 2 were fathers (1.9%) and 1 was a custodial grandparent. The majority of the children were White (77.7%), with 9 parents identifying their child as Black/African American (8.74%), 9 parents identifying their child as Hispanic/Latino (8.74%), and 6 parents identifying their child as Asian (5.83%). Parents also reported on the highest education level achieved by either parent as an indicator of family socioeconomic status (SES). Eleven parents reported having completed a doctorate degree (10.7%), 27 a master's degree (26.2%), and 32 a bachelor's degree (31.1%). Nineteen parents held an associate's degree (18.4%), 7 reported receiving some college credit without a degree (6.8%), 6 completed high school or received a GED (5.8%) and 1 parent completed some high school without a degree (1.0%).

Measures

Basic Demographic Information

Parents were asked a series of basic demographic questions (Appendix A). Information gathered included their child's birthdate, family's city/town of residence, child's race/ethnicity, parent's educational background, and number and ages of siblings living in the child's home. Parents were also asked if their child had any mental health diagnoses given by a licensed professional, to confirm their ASD diagnosis and collect information about any diagnosed comorbid disorders. They were asked to describe any of their child's co-occurring medical conditions or physical disabilities. Finally, parents were asked to specify the type of educational program in which their child was enrolled (e.g., mainstream classroom, specialized educational classroom in a mainstream school, specialized school placement, or homeschool).

Child & Adolescent Symptom Inventory-5 (CASI-5)

The Child and Adolescent Symptom Inventory-5 (CASI-5) is a DSM-5 based behavior rating scale for emotional and behavioral disorders for youth ages 5-18. The inventory includes items for both parents and teachers to rate the child's symptoms. Items were rated on a scale ranging from 1 (Never) to 4 (Very Often). Each section of symptom-specific questions was followed by the question "How often do the behaviors in [this category] interfere with youth's ability to do schoolwork or get along with others?"

As previously discussed, assessment of anxiety in ASD individuals is hindered by lack of adequate measuring tools and heavy reliance on verbal skills. A panel of professionals was assembled to assess the usefulness of a variety of measures in assessing anxiety in ASD populations (Lecavalier et al., 2014). Of the reviewed measures, the

CASI-4R was found to be clinically relevant, reliable and valid when compared to other indices of anxiety, and to be useful in ASD/DD populations with low reliance on verbal skills. Of the measures evaluated, the CASI-4R was recommended to be most appropriate. The CASI-5 is the most recent revision of the CASI-4R. It has some slight revisions but includes all previous items from the CASI-4R. This measure was chosen for assessing a variety of participants with and without verbal skills, in order to investigate the presentation of anxiety beyond high-functioning or verbal individuals.

Symptom frequency was scored in two ways for each participant – one method to assess Symptom Severity and one to assess the Symptom Count Cutoff. For most scale items, CASI-5 guidelines score "0" for responses of "Never" and "Sometimes" and a "1" for responses of "Often and Very Often" There are exceptions for specific diagnostic categories in which symptoms are scores "0" for Never and "1" for any other response (see Appendix A for specific scoring criteria for each subscale). A clinical threshold for number of symptoms is listed for each disorder category. For the purpose of comparing symptom count to clinical thresholds, each participant's symptom responses were scored "0" or "1" according to the guidelines, symptom count was also totaled.

Responses were separately given a Symptom Severity score, with each response receiving its own point value (Never = 1, Sometimes = 2, Often = 3, Very Often = 4) and averaged to develop an overall frequency score. These scores were used in analyses exploring the relation between symptoms and outcomes, to capture greater variability in participants' experiences of symptoms, subclinical symptom severity, and subsequent effects on daily functioning. Symptom Severity average scores have a possible range of

1 to 4, with 1 indicating no occurrence of any symptoms in the category and 4 representing the highest possible frequency of symptoms.

For the purpose of this study, the summative question asked after each subcategory was changed to "How often do the behaviors in [this category] interfere with the child's ability to function in the [school/home/community] environment?" This allowed the exploration of how symptoms impact child functioning within each specific environment. Answers to this question are answered on the same scale (Never = 1, Sometimes = 2, Often = 3, Very Often = 4) and result in an average range from 1 to 4, with 1 representing the least interference with functioning and 4 representing the most possible interference with functioning.

Autism symptoms. There are 16 items on the CASI-5 inventory that address symptoms of Autism Spectrum Disorder and Asperger's Disorder (the items correspond with the DSM-IV criterion for Autistic Disorder and Asperger's Disorder; see Appendix B). For the purposes of this study, all items were scored together to assess overall frequency of ASD symptoms.

Anxiety symptoms. There are 31 items of the CASI-5 inventory that specifically address symptoms of anxiety (Appendix C). These items are divided into subcategories including Generalized Anxiety (6 items), Social Anxiety (4 items), Separation Anxiety (8 items), Specific Phobia (1 item), Panic Disorder (1 item), Obsessions (1item) and Compulsions (1 item). Scores were computed for each participant on each subcategory, as well as for Total Anxiety as a cumulative score. Although OCD is now grouped separately from Anxiety Disorders in the DSM-5, the items were included because of close association with anxiety subtypes and their inclusion in the CASI-5 measure.

Due to a mistake made while entering survey items into Qualtrics, 4 items from the Separation Anxiety subscale were erroneously omitted, and therefore no data were collected for those items (see Appendix C for included and omitted items). The research team determined that the 4 included items were adequately representative of the category and thus included these data in this project's analyses. However, the omission means that the data collected may not fully capture Separation Anxiety symptoms as well as the full scale would have which may affect some analyses (for example, comparison of symptom count to the clinical cutoff).

Autism Family Experience Questionnaire (AFEQ)

The Autism Family Experience Questionnaire (Leadbitter et al., 2018) is a survey-based assessment of experiences and quality of life within families of young children with autism (Appendix D). This measure was developed through a series of focus groups with parents of ASD children to reflect their priorities surrounding their child's intervention and quality of family life. The complete survey consists of 48 items, both positively and negatively worded, with responses on a scale ranging from 1 (always) to 5 (never) as well as an option to select "Not Applicable."

Items on the complete AFEQ measure are organized into four subdomains – Parent Experience; Family Life; Child Development, Understanding, and Social Relationships; and Child Symptoms. For the purpose of this study only the first two subscales – Parent Experience (13 items) and Family Life (9 items) – were included. Eight items from the third subscale were used to measure functional communication (see below). The remaining items were omitted because of overlap with already measured variables.

Responses were averaged for each subscale. Responses of N/A were scored "0" and were not included in the scale average for each participant. Therefore, the possible range of scores for each subscale ranged from 1 to 5, with 1 representing the lowest quality outcome and 5 representing the highest quality outcome.

Functional Communication

To assess the child's ability to communicate basic needs throughout their daily routines, eight items were taken from the AFEQ's Child Development subscale that directly address communication (Appendix E). Items asked how often children could communicate basic needs and wants, and responses ranged from 1 (Never) to 5 (Always). Parents were specifically asked to respond based on their child's communication abilities using either verbal communication or any communication alternative (e.g., sign language, typing) to account for children who communicate effectively in ways that are not captured by assessments of verbal ability. An overall average score was computed for each individual, ranging from 1 (lowest functional communication skills) to 5 (highest functional communication skills).

Challenging Behaviors

To assess the frequency of problem behaviors that may be exacerbated by autism severity and anxiety, and which may contribute to family outcomes, parents were asked about the frequency of specific challenging behaviors in which their child engages (Appendix F). These behaviors were taken from a list of common challenging behaviors in Autism Speaks' "Challenging Behaviors Tool Kit" (*Challenging Behaviors Tool Kit*, 2012). Listed behaviors included physical and verbal aggression, self-injury, property destruction, elopement, meltdowns, PICA, incontinence, and eating or digestive

difficulties. Possible responses ranged from 1 (Never) to 4 (Very Often). An overall average score was computed for each individual, ranging from 1 (no occurrence of challenging behaviors) to 4 (most frequent occurrence of challenging behaviors).

Adaptive Behavior

The survey included five items to assess the child's level of independence within daily routines. These questions were not designed to be exhaustive, but rather to get a general idea of how independently the child functions within daily routines (e.g., dressing, toileting, eating). Parents were asked to describe "the child's ability to do the following tasks without help or supervision from a caregiver." Responses ranged from 1 (Never) to 5 (Always). Questions were adapted from the domains addressed in the Vineland-II Adaptive Behavior Scales (Sparrow & Cicchetti, 1989). An overall average score was computed for each individual, ranging from 1 (lowest adaptive behavior skills) to 5 (highest adaptive behavior skills).

Cognitive Skills

Parents answered six Likert-scale items that asked about their child's cognitive skills, relative to other children their age, in 7 domains (reading, writing, math, art, music, puzzles, and computer skills). These items were designed to assess basic academic level, as well as the presence of any particular cognitive strengths or splinter skills, areas in which individuals with ASD show particular giftedness despite deficits in other areas (Clark, 2016). Parents were asked to rate their child's ability level, relative to other children in each category, with responses ranging from 1 (Well Below Average) to 5 (Well Above Average). An overall average score was computed for each individual,

ranging from 1 (very low relative cognitive skills) to 5 (very high relative cognitive skills).

Procedure

The parent survey was accessible online using Qualtrics software. The survey was estimated to take participants 10-15 minutes to complete, although there was no time limit imposed on participants and they could pause and return to the survey as they liked. Brief information explaining the study was shared on social media platforms such as Facebook and Twitter, particularly on message boards or within groups geared towards parents of children with ASD. A link to the survey was provided through which parents could access the survey director. Parents were encouraged to share the survey with other parents of ASD children who may have been interested in participating. The research team also contacted local schools and programs that directly serve children with ASD. Organizations which were willing to participate displayed flyers, distributed handouts, and shared information about the study in electronic newsletter distributions.

Once parents accessed the survey through the given hyperlink, they were presented with a page of information about the study and a description of their rights as research participants (Appendix A). They were asked to indicate that they agreed to participate by selecting an "Agree" button. Participants could only continue on to the rest of the survey once they had selected "Agree." When participants completed the survey, their data were recorded. Participants who did not complete the survey were assumed to have chosen to discontinue their participation. Surveys that were not complete when data collection was terminated were not recorded.

RESULTS

Prevalence of Comorbid Diagnoses

Parents reported on coexisting diagnoses that their child had received from a licensed psychological or medical professional. Only those who were confirmed to have an ASD diagnosis were included in this study. A majority of the children were reported to have a coexisting diagnosis of ADD/ADHD (52.4%). The second most frequent category of comorbid diagnoses was Anxiety Disorders, with 34.0% of children having a diagnosis and 5.8% of children having a specific diagnosis of OCD. There were 18% of children reported to have a diagnosis of an Intellectual or Learning Disability, 9.7% were diagnosed with Depression, and 5.8% were diagnosed with Oppositional Defiance Disorder or Conduct Disorder.

Symptom Category Descriptives and Symptom Count Cutoffs

CASI-5 items were scored according to the guidelines to determine responses that reached the measure's Symptom Count Cutoff thresholds. The cutoff scores for each symptom category are included in Appendix A. Table 1 displays the mean scores for each symptom category, as well as the percentage of the sample that reached the Symptom Count Cutoff within each category.

It is important to note that the CASI-5 is a screening tool usually used by clinicians as one part of the diagnostic process, and that reaching the Symptom Count Cutoff alone does not indicate that a diagnosis would be given. A clinician or other professional evaluating an individual's case would consider the level of impairment caused by each category of symptoms, make a detailed assessment of each symptom, and would rule out any diagnoses that better explain the symptom's occurrence before giving

Table 1

ASD and Anxiety Subtypes: Means, standard deviations, ranges, and Symptom Count Cutoffs

Symptom Category	Symptom Severity *M*	Symptom Severity *SD*	Symptom Severity Range	% Meeting Symptom Count Cutoff
1. Autism Spectrum Disorder	2.61	0.52	1.38 – 3.69	
2. General Anxiety	2.34	0.66	1.17 – 4.00	37.9
3. Social Anxiety	2.19	0.82	1.00 – 4.00	26.7
4. Separation Anxiety	1.77	0.71	1.00 – 4.00	8.9/17.7[†]
5. Specific Phobia	2.19	0.86	1.00 – 4.00	81.6
6. Panic Disorder	1.50	0.73	1.00 – 4.00	37.9
7. Obsessive Compulsive Disorder	1.90	0.85	1.00 – 4.00	63.1

[†] Because 4 items from the Separation Anxiety subscale were omitted, the Symptom Count Cutoff for this subscale was considered in two ways. The first value represents the percentage of participants who reached the clinical cutoff ($\geq$3 symptoms) in their responses to the 4 included items alone. The second value indicates the percentage of participants who would be predicted to reach the clinical cutoff if their responses on the 4 omitted items had indicated equal or greater symptom severity as on the 4 included items (e.g., if those who reported $\geq$2 of the 4 included items could be predicted to have report $\geq$4 of the 8 total items.)

a diagnosis. However, the Cutoff scores do provide an indication of a level of symptom prevalence would merit further clinical consideration.

For Generalized Anxiety symptoms, 37.9% children met the cutoff for clinical concern. This proportion is in line with the estimated percentage of children with ASD who receive any anxiety disorder diagnosis, around 40% (Vasa & Mazurek, 2015).

Clinical levels of Social Anxiety were observed in 26.7% of the sample, while fewer met the threshold for Separation Anxiety (17.9%).

A large majority of the children also met the symptom cutoff for Specific Phobias. Text responses provided by parents in response to this item ranged from more common fears (e.g., loud noises, crowds, bugs, doctor's office) to more unique ones (e.g., elevators, holiday colors, global warming, being in a car on a highway). Some specific phobias named by parents also reflected obsessions and compulsions (e.g., slats in window blinds turned the wrong way, all light switches not off/on, rule-breaking). Many of these responses paralleled the atypical anxiety symptoms as defined by Kerns and colleagues (2014). A majority of the children also met the clinical cutoff for Obsessive Compulsive symptoms (63.1%). This may be a further reflection of such atypical anxiety symptoms, and may also suggest that parents' interpretation of the Obsession/Compulsion items as alluding to the rigid adherence to routines and rituals that is characteristic of ASD.

Within the entire sample, 89.3% met criteria for at least one anxiety subcategory Symptom Count Cutoff (excluding OCD, given the updated DSM-5 criteria). A significantly larger proportion of the children met diagnostic criteria for 1 or more anxiety subcategories based on the clinical cutoff than the proportion that received a diagnosis from a clinician ($\chi^2 = 25.39$, $p < .001$), confirming the hypothesis that more children would exhibit clinical levels of symptoms than would have a given diagnosis (Hypothesis 1). There were 55.5% of children that met criteria for two or more subcategories, and 33.0% that met the cutoff for 3 or more subcategories. While these may be overestimates of the percent of children who would realistically receive a clinical

diagnosis, these numbers affirm the fact that anxiety is prevalent within the sample and is a significant concern to ASD populations. Of the children in the sample who were reported to have an Anxiety Disorder diagnosis, 100% met clinical cutoff criteria for at least one category on the screening measure.

Sample Demographics

Means on symptom categories, family outcomes, and related variables were compared between gender groups to understand if any significant gender differences were present in our sample. Group means between males and females did not vary on any of these variables. Therefore, gender differences were not explored further.

Correlations were computed to determine which variables were significantly related to age, given the notable age range of the sample. Age was negatively related to ASD symptom severity (r = -.33, p = .001) and negatively related to Social Anxiety symptom severity (r = -.27, p = .007). Older children were reported to have less severe symptoms, particularly Social Anxiety symptoms, than younger children. This may reflect the natural progression of these symptoms as children age (for example, older children becoming less shy and more comfortable engaging with peers) or may also be due to the implementation therapies designed to reduce the presentation of these symptoms, especially those related to ASD. Age was not significantly related to any other symptom categories.

Age was also significantly associated with related child skills and behavior variables. Older children had higher parent-reported functional communication skills (r = .23, p = .02) and adaptive behavior skills (r = .37, p < .001). Age was significantly negatively associated with challenging behavior (r = -.27, p = .007), demonstrating that

challenging behaviors tend to decrease as children get older. Age was not significantly related to cognitive skills, which is to be expected given that the questions used to measure cognitive skills were asked in relation to the child's peers. In other words, children's relative cognitive standing within their age group, as assessed by their parents, did not significantly change with age.

Finally, correlations were calculated to determine associations with family outcomes. Age was not significantly related to the AFEQ Parent Experience subscale. It was, however, positively related to the AFEQ Family Life subscale (r = .30, p = .002), suggesting that navigating life as a family unit becomes easier as children get older. Because age was significantly associated with a number of variables, and given the significant developmental changes that occur within the sample age range, all further analyses were conducted with age a control variable.

Next, group differences were explored among children of difference race and ethnicity groups on psychological symptoms, child skills and behavior, and family outcomes scores. Because of the small sample sizes within different minority groups for this sample, independent samples t-tests were conducted between white vs. minority groups. White children scored significantly higher on functional communication than minority children, $t(101) = -2.01$, p = .047, suggesting that, on average, white children exhibited greater communication skills than minority children in the sample. No other significant group differences were found.

Correlations were also computed between parental education level (as a representation of SES) and psychological symptoms, child skills and behavior, and family outcomes. Interestingly, ASD symptoms were positively correlated with parental

education, suggesting that in families with better resources, parents perceive ASD symptoms to be less frequent or pervasive. No other variables of interest were significantly correlated with parent education.

Another variable that was proposed as a possible covariate was the presence of a co-occurring medical condition or physical disability. Parents answered "yes" or "no" to whether their child had any such condition, and if they answered "yes" they were then prompted to specify the condition. There were 21% of parents who reported that their child had a co-occurring medical or physical disability. Reported conditions included epilepsy, PANDAS/PANS, hearing impairment, asthma, and a range of other conditions. Independent groups t-tests comparing those who reported a co-occurring medical or physical condition and those who did not did not find any significant differences in psychological symptoms, child skills and behavior scores, or family outcomes scores. While these conditions are surely related to child and family life, the degree to which they were captured within these data was not significantly related to any variables of interest, and therefore the role of physical and medical conditions was not explored further.

Associations Between ASD Symptoms and Anxiety Symptoms

A correlation matrix was then created to assess initial associations between subcategories of psychological symptoms. It was hypothesized that greater levels of ASD symptoms would be positively correlated with anxiety symptoms. However, because no specific hypotheses were made about relations with specific anxiety subtypes, and because initial analysis was exploratory in nature, two-tailed tests were used to examine these associations.

Table 2 shows the correlations between ASD symptoms and symptoms of each individual anxiety subtype. ASD symptoms were weakly to moderately correlated with the subtypes of Generalized Anxiety, Social Anxiety, Separation Anxiety, and OCD, but not with Specific Phobia or Panic Disorder. This confirmed the hypothesis that more frequent core ASD symptoms would be associated with more frequent anxiety symptoms overall (Hypothesis 2), although it was not true for every anxiety subtype.

Table 2

Correlations Between ASD Symptoms and Anxiety Subtype Symptoms

Variable	1	2	3	4	5	6
1. Autism Spectrum Disorder						
2. Generalized Anxiety	.20*					
3. Social Anxiety	.25*	.29**				
4. Separation Anxiety	.21*	.56**	.31**			
5. Specific Phobia	-.03	.42**	.22*	.47**		
6. Panic Disorder	.07	.44**	.07	.43**	.52**	
7. Obsessive Compulsive Disorder	.18*	.45**	.26**	.29**	.28**	.28**

* indicates $p < .05$. ** indicates $p < .01$, two-tailed.
All correlations are partial correlations controlling for age.

Generalized Anxiety was significantly positively correlated with each of the other Anxiety subcategories. Most anxiety subcategory scores were also significantly correlated, with the exception of Panic Disorder and Social Anxiety. Given the significant association between anxiety subcategories, a Total Anxiety score was

calculated by averaging each participant's score across all anxiety subcategories to be used in further analyses.

Child Outcomes by ASD and Anxiety

After answering questions about their child's symptom severity, parents rated the degree to which specific symptom categories interfered with their child's ability to function in their school, home, and community environments. A 2-way within-subjects ANOVA was conducted to understand any differences in the level of functional impairment that parents reported by symptom category and across environments. Average levels of impairment could range from 1 to 4. For ASD symptoms, average impairment at school was 2.97 (*SD* = .81), at home was 2.55 (*SD* = 2.55), and in community settings was 2.95 (*SD* = .85). For Generalized Anxiety, average impairment at school was 2.70 (*SD* = .86), at home was 2.59 (*SD* = .85), and in community settings was 2.70 (*SD* = .86). Finally, for Total Anxiety, the mean level of impairment at school was 2.03 (*SD* = .64), at home was 1.9 (*SD* = .58), and in community settings was 2.07 (*SD* = .64). Mean responses by symptom category and environment type are displayed in Figure 1.

Mauchly's Test of Sphericity indicated that the assumption of sphericity had not been violated for the test of the main effect of symptom type, $\chi^2(2) = 2.10$, $p = .35$, or of the main effect of environment, $\chi^2(2) = 24.80$, $p = .09$. However, the assumption of sphericity was violated for the interaction test $\chi^2(2) = 34.9$, $p < .001$. Therefore, Greenhouse-Geiser corrected *F*-values were used for the interaction significance test. The 2-way ANOVA generated significant main effects for symptom type, $F(2, 202) = 133.96$,

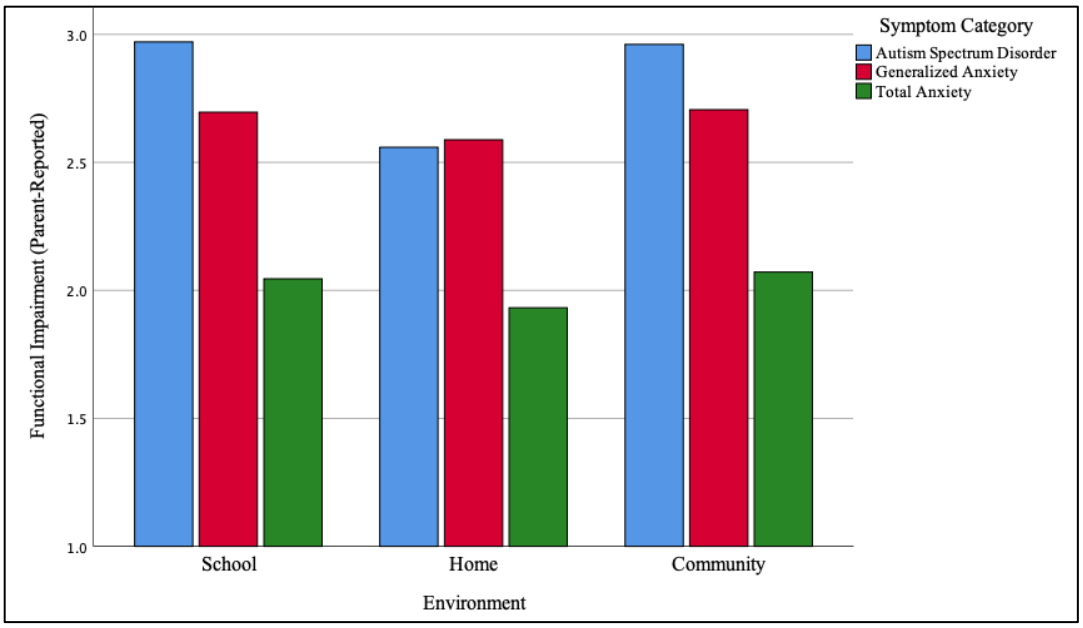

Figure 1. Functional Impairment by Symptom Subcategory and Environment.

$p < .001$, and environment, $F(2, 202) = 10.38$, $p < .001$. There was also a statistically significant interaction effect between the symptom type and environment on impairment level, $F(3.5, 350.4) = 8.20$, $p < .001$. Specifically, parents reported less severe impairment in their child's functioning due to ASD symptoms at home than they did for school and community environments, while reported impairment for Generalized Anxiety Symptoms and Total Anxiety symptoms did not differ significantly across environments.

Bonferroni post-hoc comparisons were conducted for symptom-group differences within each environment. Post-hoc comparisons for the school and community environments were significant for each pairwise comparison. Level of impairment due to ASD symptoms was significantly greater than impairment reported due to Generalized Anxiety and Total Anxiety symptoms, and impairment due to General Anxiety was significantly greater than impairment reported due to Total Anxiety symptoms at school and in the community. In the home environment, reported impairment due to ASD and

General Anxiety symptoms did not differ significantly, but both were significantly greater than impairment due to Total Anxiety symptoms. These results are contrary to Hypothesis 6, which predicted more impairment would be reported due to anxiety symptoms than to core ASD symptoms across environments.

Autism Family Experience Questionnaire Subscales

Parents completed two subscales of the Autism Family Experience Questionnaire (AFEQ) – the Parent Experience subscale and the Family Life subscale (Appendix D). The possible range for scores on each subscale was 1-6, with 1 being the poorest quality outcome and 6 being the highest quality outcome possible. The mean score on the Parent Experience subscale was 3.85 (*SD* = .47), with a range from 2.69 to 5.08. The mean score on the Family Life subscale was 4.06 (*SD* = .39), range 3.22-5.11. Scores on both subscales were distributed normally.

Reliability analyses were also conducted to assess the internal consistency of each subscale. Parent Experience subscale, consisting of 13 items, was shown to have good reliability (α = .741). The Family Life subscale, consisting of 9 items, showed much poorer reliability (α = .424). An inter-item correlation matrix was created to examine which individual items demonstrated the least consistency with the rest of the items in the scale. Ultimately, two items on the scale – "I feel guilty about not giving other members of the family enough attention" and "My child has fussy habits that make it difficult to go away for a break" – were removed from the scale. For the modified 7-item scale, Chronbach's alpha was .67. This modified Family Life scale was used for subsequent analyses. The mean for responses on the modified Family Life subscale was 4.24 (*SD* = .53), range 3.0-5.43.

Associations Between ASD, Anxiety, and Family Outcomes

Using the scores for ASD symptom frequency, Generalized Anxiety symptom frequency, and Total Anxiety symptom frequency, correlations were then conducted to assess the relations between symptom categories and family outcomes, holding age constant. It was hypothesized that more frequent ASD symptoms and more frequent anxiety symptoms would both predict more difficult Parental Experience and lower quality of Family Life (Hypotheses 3 and 4). Because these hypotheses were explicitly directional, one-tailed tests were used in these analyses.

Associations between ASD, Generalized Anxiety, and Total Anxiety are displayed in Table 3. The two AFEQ subscales, Parent Experience and Family Life, were significantly correlated ($r = .44$, $p < .001$). The hypotheses were mostly confirmed. More frequent ASD symptoms predicted lower scores on both Parent Experience and

Table 3

Correlations Between ASD, Anxiety Symptoms, and Family Outcomes

Variable	1	2	3	4
1. Autism Spectrum Disorder				
2. Generalized Anxiety	**.20***			
3. Total Anxiety	**.20***	**.76****		
4. AFEQ Parent Experience	**-.34****	**-.26****	-.11	
5. AFEQ Family Life	**-.37****	**-.25****	**-.26****	**.44****

* indicates $p < .05$. ** indicates $p < .01$, one-tailed.
All correlations are partial correlations with age as a control variable.

Family Life subscales. Higher Generalized Anxiety scores were also significantly correlated with lower scores on both subscales. Total Anxiety scores were significantly negatively correlated with responses on the Family Life subscale, but not with responses on the Parent Experience subscale.

While both AFEQ subscales were significantly related to Generalized Anxiety, only the Parenting Experience subscale was correlated with Total Anxiety symptoms. Further analyses were warranted to understand the role of specific anxiety subcategories in predicting family outcomes, due to the differential associations with each subscale (Hypotheses 10b). In addition to Generalized Anxiety, the Family Life subscale was significantly related to Panic Disorder symptoms (r = -.24, p = .02) and to Obsessive Compulsive symptoms (r = -.27, p = .01). Family Life was not significantly related with Social Anxiety, Separation Anxiety, or Specific Phobia symptoms. Responses on the Parent Experience subscale were not related to any other anxiety subcategory except for Generalized Anxiety, suggesting that the significant relation between Total Anxiety and Parent Experience was driven by the strength of its relation to Generalized Anxiety.

Because the hypothesis that ASD and anxiety were both demonstrably related to family outcomes was supported, multiple regression analyses were employed to assess the unique and relative predictive power of each symptom category. While Generalized Anxiety, Panic Disorder, and OCD were all individually related to Family Life, it was determined that Generalized Anxiety was the subcategory that was most well-captured within the CASI-5 measure. Furthermore, as previously discussed, OCD is now no longer included in the category of Anxiety Disorders. While further analysis Panic

Disorder and OCD is warranted, for the purpose of answering the central hypotheses of this study, the decision was made to focus on Generalized Anxiety symptoms.

Table 4 shows the multiple regression analysis predicting AFEQ Parent Experience responses with the variables age, ASD symptom frequency, and General Anxiety symptom frequency. The model explained 15.5% of variance in AFEQ Parent Experience responses, with both ASD Symptoms and General Anxiety symptoms contributing unique predictive power. This partially confirms the hypothesis that anxiety explains variability in the outcome of Parent Experience above and beyond ASD symptomology (Hypothesis 5). Age did not remain a significant predictor in the model.

A second multiple regression analysis was computed with the same predictor variables and with AFEQ Family Life subscale as the dependent variable. The results of this analysis are displayed in Table 5. For Family Life, only ASD remained a significant predictor when entered simultaneously with age and Generalized Anxiety. In contrast to

Table 4

Multiple Regression Predicting Parent Experience with Age, ASD, and Generalized Anxiety

Predictor	*b*	*beta*	Fit
(Intercept)	4.04		R^2 = .155**
Age	-0.00	-0.04	
Autism Spectrum Disorder	**-0.26****	-0.31	
Generalized Anxiety	**-0.13***	-0.21	

Note. A significant *b*-weight indicates the beta-weight and semi-partial correlation are also significant. *b* represents unstandardized regression weights. *beta* indicates the standardized regression weights. * indicates $p < .05$. ** indicates $p < .01$.

Table 5

Multiple Regression Predicting Family Life with Age, ASD, and Generalized Anxiety

Predictor	*b*	*beta*	Fit
(Intercept)	4.05		R^2 = .236**
Age	0.00*	0.19	
Autism Spectrum Disorder	-0.34**	-0.33	
Generalized Anxiety	-0.14	-0.18	

Note. A significant *b*-weight indicates the beta-weight and semi-partial correlation are also significant. *b* represents unstandardized regression weights. *beta* indicates the standardized regression weights. * indicates $p < .05$. ** indicates $p < .01$.

the previous model, age remained a significant predictor. Overall, the model explained 23.6% of variance in AFEQ Family Life scores.

The Role of Child Skills and Behavior in Family Outcomes

Data were collected on variables representing the child's skills and daily behaviors – functional communication skills, cognitive skills, adaptive behavior, and challenging behavior – that were considered to be potentially related to family outcomes and simultaneously relevant to developmental trajectories in ASD populations. Table 6 shows partial correlations between these variables, ASD and anxiety symptoms, and family outcomes, with age held constant.

ASD symptoms were significantly related to all four variables, with more severe ASD symptomology predicting higher rates of challenging behavior, and lower adaptive behavior skills, functional communication, and cognitive skills. Generalized Anxiety symptoms were also significantly positively correlated with the frequency of challenging

Table 6

Correlations Between ASD, Anxiety, Family Outcomes, and Potential Covariates

	ASD Symptoms	Generalized Anxiety Symptoms	Total Anxiety Symptoms	AFEQ Parent Experience	AFEQ Family Life
1. Adaptive Behavior	**-.63****	.04	.01	**.23***	**.21***
2. Functional Communication	**-.65****	**.23***	**.20***	**.24***	**.29****
3. Cognitive Skills	**-.48****	.15	**.20***	.19	.15
4. Challenging Behavior	**.43****	**.48****	**.42****	**-.45****	**-.50****

* indicates $p < .05$. ** indicates $p < .01$, two-tailed.
All correlations are partial correlations with age as a control variable.

behaviors, and with functional communication, which was contrary to the hypotheses that was made (Hypothesis 9). While it was proposed that lower functional communication might predict higher anxiety levels, the opposite pattern was observed. Generalized Anxiety was not significantly related to adaptive behavior skills or to cognitive skills. Total anxiety, however, was significantly positively related to cognitive skills in addition to functional communication.

As would be expected, adaptive behavior was positively related to the quality of family outcomes, suggesting that parenting and family life are easier when children can more independently navigate their daily care and routines. Likewise, family outcomes were positively related to functional communication, affirming that parenting experience and family life tend to be better when children can better communicate their needs and wants.

When all child skills and behavior variables were entered into a simultaneous model (Table 7), however, only challenging behavior remained a significant predictor of AFEQ Parent Experience. While the other child skills and behavior variables were correlated with Parent Experience scores, challenging behavior was clearly the strongest predictor of the quality of the parent's experience in this sample.

Table 7

Multiple Regression Predicting Parent Experience with Child Skills and Behavior

Predictor	*b*	*beta*	Fit
(Intercept)	4.61		R^2 = .221**
Age	-0.00	-0.13	
Cognitive Skills	0.05	0.12	
Functional Communication	0.04	0.07	
Adaptive Behavior Skills	-0.01	-0.03	
Challenging Behavior	-0.41**	-0.44	

Note. A significant *b*-weight indicates the beta-weight and semi-partial correlation are also significant. *b* represents unstandardized regression weights. *beta* indicates the standardized regression weights. * indicates $p < .05$. ** indicates $p < .01$.

A similar pattern of findings resulted from a multiple regression analysis predicting AFEQ Family Life from the same variables (Table 8). Cognitive skills, adaptive behavior, and functional communication, while directly correlated with Family Life, were no longer significant predictors when entered into a regression model alongside challenging behavior. For both Parent Experience and Family Life outcomes,

challenging behavior appears to be a strong and unique predictor above and beyond the other variables.

Table 8

Multiple Regression Predicting Family Life with Child Skills and Behavior

Predictor	*b*	*beta*	Fit
(Intercept)	4.57		R^2 = .342**
Age	0.00	0.15	
Cognitive Skills	-0.02	-0.04	
Functional Communication	0.13	0.24	
Adaptive Behavior Skills	-0.04	-0.09	
Challenging Behavior	-0.49**	-0.47	

Note. A significant *b*-weight indicates the beta-weight and semi-partial correlation are also significant. *b* represents unstandardized regression weights. *beta* indicates the standardized regression weights. * indicates $p < .05$. ** indicates $p < .01$.

ASD and Anxiety as Predictors of Challenging Behaviors

The hypothesis that anxiety would predict family outcomes above and beyond ASD symptoms was only partially supported, with ASD proving to be a stronger predictor of parent responses on both AFEQ subscales. When considering child skills and behavior, however, challenging behavior stood out clearly as a factor in both family outcomes. Therefore, it is necessary to try and understand the connection between ASD and anxiety symptoms and these challenging behaviors and how they might be jointly associated with family outcomes.

First, a multiple regression analysis was completed to predict the frequency of challenging behavior with the predictor variables age, ASD symptoms and Generalized Anxiety. Table 9 displays the results of this regression analysis. Age remained a significant predictor, and Generalized Anxiety Symptoms and ASD remained significant predictors of challenging behaviors above and beyond age. In predicting challenging behaviors, Generalized Anxiety (β = 4.15) appears to be a slightly stronger predictor than ASD (β = 3.20). Overall, the model explained 38.2% of the variance in challenging behaviors. This suggests that ASD and Generalized Anxiety symptomology are both significantly related to the occurrence of challenging behaviors, and clearly confirmed the hypothesis that challenging behavior was uniquely related to anxiety above and beyond its association with ASD (Hypothesis 7).

Table 9

Multiple Regression Predicting Challenging Behavior with ASD and Generalized Anxiety

Predictor	*b*	*beta*	Fit
(Intercept)	0.71		R^2 = .382**
Age	-0.00*	-0.19	
ASD	0.30**	0.32	
Generalized Anxiety	0.31**	0.41	

Note. A significant *b*-weight indicates the beta-weight and semi-partial correlation are also significant. *b* represents unstandardized regression weights. *beta* indicates the standardized regression weights. * indicates $p < .05$. ** indicates $p < .01$.

Finally, it was necessary to understand these relations together in the context of family outcomes. A hierarchical regression was conducted. Step 1 in the model repeated

the previously run multiple regression predicting Parent Experience with the variables age, ASD symptoms, and Generalized Anxiety symptoms (Table 4). Step 2 added challenging behavior as an additional predictor. Table 10 displays the results of this hierarchical regression.

In Step 2 of this model, Generalized Anxiety became a nonsignificant predictor, while ASD and challenging behavior both predicted unique variance in Parent Experience. ASD and challenging behavior appeared to be relatively similar in the strength of their predictive power, with standardized beta weights of -.24 and -0.25, respectively.

Table 10

Hierarchical Regression Predicting Parent Experience with ASD, Generalized Anxiety, and Challenging Behavior

	Predictor	*b*	*beta*	Fit	Difference
Step 1	(Intercept)	4.04		R^2 = .155**	
	Age	-0.00	-0.04		
	Autism Spectrum Disorder	-0.26**	-0.31		
	Generalized Anxiety	-0.13*	-0.21		
Step 2	(Intercept)	4.20		R^2 = .195**	ΔR^2 = .041*
	Age	-0.00	-0.09		
	Autism Spectrum Disorder	-0.20*	-0.24		
	Generalized Anxiety	-0.07	-0.11		
	Challenging Behavior	-0.22*	-0.25		

Note. A significant *b*-weight indicates the beta-weight and semi-partial correlation are also significant. *b* represents unstandardized regression weights. *beta* indicates the standardized regression weights. * indicates $p < .05$. ** indicates $p < .01$.

A second hierarchical regression was then conducted with the same variables, predicting Family Life as an outcome. Although Generalized Anxiety was shown to be insignificant as a predictor in this analysis previously, it was still included in each step given its significant relation to challenging behavior. These results can be found in Table 11.

Table 11

Hierarchical Regression Predicting Family Life with ASD, Generalized Anxiety, and Challenging Behavior

	Predictor	*b*	*beta*	Fit	Difference
Step 1	(Intercept)	4.05		R^2 = .236**	
	Age	0.00*	0.19		
	Autism Spectrum Disorder	-0.34**	-0.33		
	Generalized Anxiety	-0.14	-0.18		
Step 2	(Intercept)	4.37			
	Age	0.00	0.11	R^2 = .338**	ΔR^2 = .102**
	Autism Spectrum Disorder	-0.21*	-0.20		
	Generalized Anxiety	-0.01	-0.01		
	Challenging Behavior	-0.44**	-0.41		

Note. A significant *b*-weight indicates the beta-weight and semi-partial correlation are also significant. *b* represents unstandardized regression weights. *beta* indicates the standardized regression weights. * indicates $p < .05$. ** indicates $p < .01$.

In Step 2 of this model, age and Generalized Anxiety became nonsignificant predictors, while ASD and challenging behavior remained significant. With challenging behavior added as a predictor, the model explained significantly more variance (ΔR^2 = .102, $p < .01$) in Family Life than the model in Step 1. In predicting Family Life outcomes, challenging behavior appeared to be a stronger predictor than ASD with standardized beta weights of -.41 compared to ASD (β = -.20).

The Mediating Role of Challenging Behaviors

Because challenging behavior was uniquely related to ASD symptoms, anxiety, and family outcomes above the other related child variables, it was appropriate to test the hypothesis that challenging behavior works as a mediator of the relationship between anxiety and family outcomes (Hypothesis 8). Figure 2 shows the results of a mediation analysis testing the role of challenging behaviors as a mediator in the relation between Generalized Anxiety symptoms and responses on the AFEQ Parent Experience subscale. A Sobel test of significance confirmed this to be a significant mediation, $z = -2.71$, $p = 0.006$. After accounting for the mediational path, the direct association between Generalized Anxiety and Parent Experience was no longer significant.

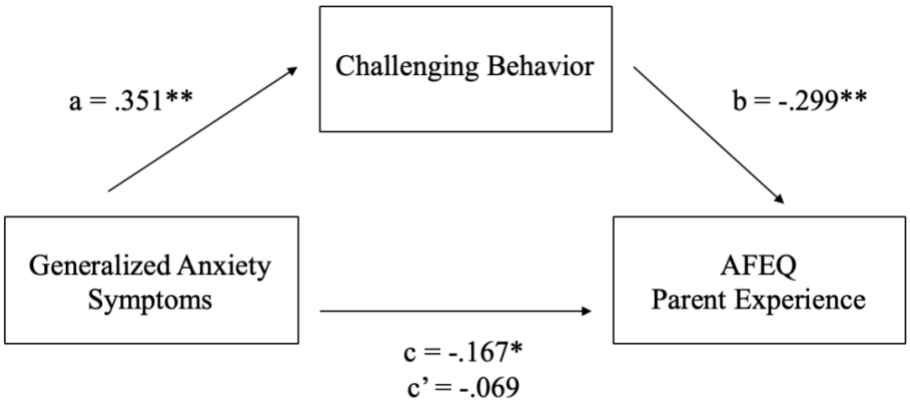

Figure 2. Analysis of Challenging Behavior as a mediator of the association between Generalized Anxiety Symptoms and AFEQ Parent Experience. Path coefficients are unstandardized regression weights.

Figure 3 shows the mediation model for challenging behavior on the relations between Generalized Anxiety and the AFEQ Family Life subscale. This mediation also proved to be significant as confirmed by a Sobel test, $z = -3.68$, $p < 0.001$. Once again,

when the mediation effect was accounted for, the direct path between Generalized Anxiety and Family Life was no longer significant.

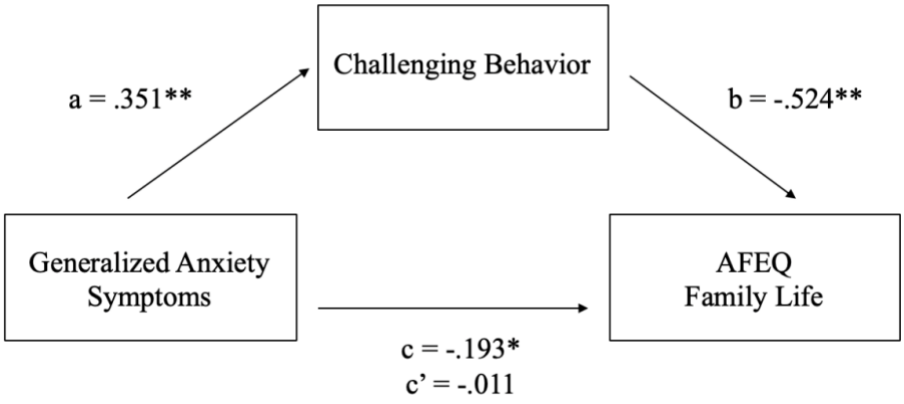

Figure 3. Analysis of Challenging Behavior as a mediator of the association between Generalized Anxiety Symptoms and AFEQ Family Life. Path coefficients are unstandardized regression weights.

The hypotheses regarding challenging behavior's role as a mediator were made specifically about the relationships between anxiety and family outcomes. However, because previous analyses demonstrated ASD symptoms to be a strong unique predictor of family outcomes when anxiety was held constant, and also related to challenging behavior, another mediation analysis was conducted to test whether challenging behavior also mediated this relationship. Figure 4 shows the mediation model with challenging behavior as a mediator of the relation between ASD symptoms and Parent Experience. The Sobel test confirmed this mediation as significant, $z = -2.44$, $p = .01$. In contrast to the previous anxiety models, the direct relationship between ASD and Parent Experience remained significant after the mediation.

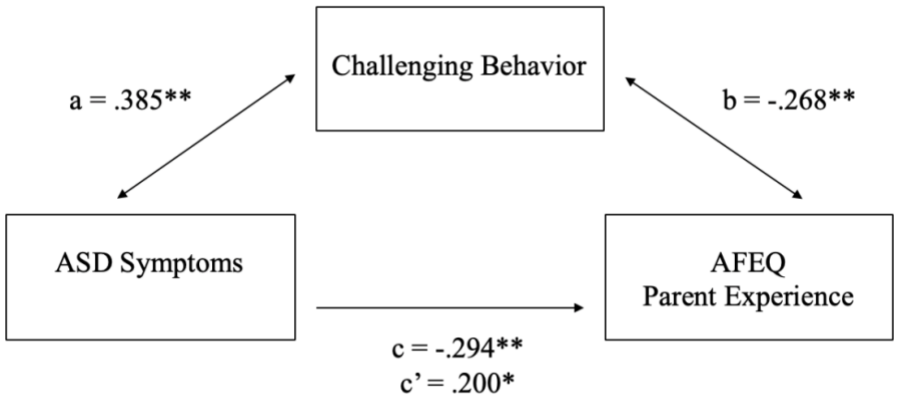

Figure 4. Analysis of Challenging Behavior as a mediator of the association between ASD Symptoms and AFEQ Parent Experience. Path coefficients are unstandardized regression weights.

A final mediation analysis was conducted to test challenging behavior as a mediator of the relationship between ASD symptoms and Family Life (Figure 5). A Sobel test found this mediation to be significant, $z = -3.10$, $p = .002$. Once again, the direct association between ASD and Family Life remained significant after the mediation, suggesting that ASD symptoms maintain a direct effect on Family Life in addition to the effect accounted for by challenging behaviors.

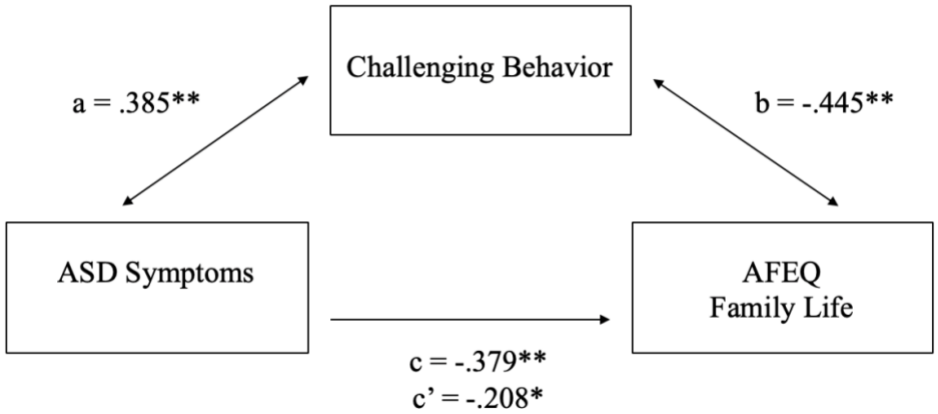

Figure 5. Analysis of Challenging Behavior as a mediator of the association between ASD Symptoms and AFEQ Family Life. Path coefficients are unstandardized regression weights.

These mediational models confirm the hypothesis that challenging behaviors is an important factor in understanding the relations between ASD and anxiety symptoms and family outcomes. For anxiety, challenging behaviors appear to explain the majority of the effects on parent experience and family life, suggesting that anxiety's role in family outcomes is largely indirect. ASD also appears to have an indirect effect on family outcomes through its relation with challenging behaviors, though it retains a direct effect independent of challenging behaviors.

DISCUSSION

Co-Occurrence of Anxiety Symptoms in Children with ASD

An initial purpose of this study was to capture the distinct occurrence of core symptoms associated with ASD and with anxiety. Estimates of the prevalence of anxiety in ASD populations have varied widely, and there has been ambiguity in the literature regarding the etiology of anxiety as a symptom of ASD versus a commonly co-occurring but independent condition. In this sample, ASD and Generalized Anxiety were associated but relatively weakly so, which supports the notion that the two categories of symptoms are related but distinct phenomena. Thus, anxiety maybe be recognized as a concern for individuals with ASD, but it merits distinctive attention as a focus of research and treatment. Likewise, anxiety subtypes were mostly related to each other but not perfectly associated, suggesting related mechanisms even within the anxiety category that operate somewhat differently. It may be necessary to examine the symptomology of specific subtypes and their roles in order to identify and manage symptoms effectively.

The percentage of children in the sample that had an official Anxiety Disorder diagnoses was higher than expected, and was in line with estimates of anxiety prevalence reported in previous literature. Given the young age range of the sample, it was expected that a smaller proportion of the sample would have received an anxiety diagnosis in addition to their ASD diagnosis. This may reflect increasing attention to the co-occurrence of anxiety in ASD populations in recent years and therefore a potential increase in diagnoses. If this is the case, it may indicate a higher likelihood that children with ASD are receiving more appropriate and targeted care for those comorbid symptoms.

It was hypothesized that the proportion of the sample whose reported symptoms met or exceeded clinical cutoffs would be higher than the proportion that already had a clinical diagnosis. The proportion of the sample whose reported symptoms met the clinical cutoff for GAD alone (37.9%) was similar to the percentage with an anxiety disorder diagnosis (34%), while the proportion of the sample who met the cutoff for one or more anxiety category (89.3%) or even two or more categories (55.3%) was much higher.

As previously discussed, the clinical cutoff thresholds of the CASI-5 are likely less stringent than the clinical criteria that would be required for a diagnosis. Therefore, the reported proportions of the sample reaching clinical thresholds may overestimate the number of individuals that warrant or would receive a clinical diagnosis. Particularly in the case of Specific Phobia and Obsessive-Compulsive Symptoms, the high parent response rates may reflect similarities to symptoms of ASD and the failure of the screening measure to account for additional diagnostic criteria (e.g., the required level of impairment caused by the symptoms).

Nevertheless, with almost 90% of the children in the sample exhibiting symptoms that may indicate clinical levels of anxiety, it is absolutely clear that anxiety is a critical issue in the psychological health and daily function of children with ASD. Anxiety disorders and the role of subclinical anxiety symptoms should be a priority for researchers and therapists who work with this population, and deliberate attempts should be made to address the presence of anxiety within treatments and services for these children.

Child and Family Functioning

A second purpose of this study was to evaluate the interference in child functioning associated with ASD and anxiety symptoms across school, home, and community environments. The hypothesis that parents would report more interference to child functioning due to anxiety symptoms as compared to core ASD symptoms was not confirmed. In actuality, parents reported more interference in their child's ability to succeed due to core ASD symptoms across environments. Interestingly, parents reported lower impairment due to ASD symptoms in the home environment than they did at school in the community, a difference that was not observed for reported impairment due GAD and Total Anxiety symptoms. This may mean that ASD symptoms interfere with child functioning in ways that parents feel are more disruptive in public places or when other individuals are present, but that parents feel better equipped to handle these behaviors at home or privately.

Although parents reported slightly less impairment due to anxiety as compared to core ASD symptoms, parents still reported significant difficulties in their child's ability to succeed across environments due to those anxiety-related. Given that the entire sample is diagnosed with ASD and that anxiety was not a criterion used in recruiting participants, the comparable impairment to functioning that parent reported to be a result of anxiety symptoms is notable. This affirms the notion that anxiety symptoms are a significant and impairing factor for the success of children with ASD across environments, and is a co-occurring condition that should be acknowledged and addressed in each environment.

The third and central purpose of this study was to explore the unique roles of ASD and anxiety in predicting family outcomes. It was hypothesized that more frequent

ASD and anxiety symptoms would both independently predict more difficult parenting experience and lower quality of family life, which was confirmed. Generalized Anxiety in particular proved to be predictive of both aspects of home life, and Panic Disorder and Obsessive Compulsive symptoms were significantly associated with family life.

Furthermore, it was predicted that anxiety would explain difficulties with parenting and family life above and beyond ASD symptoms. This hypothesis was partially confirmed, with anxiety predicting unique variability in Parent Experience but not in Family Life outcomes, once variance due to ASD symptoms and age was accounted for. While ASD appeared to be a stronger predictor of family outcomes, anxiety appears to also play some role in family functioning, particularly in a parent's feelings of confidence and attitudes toward their role in guiding their child's success. Therefore, when children experience impairment from both core ASD symptoms and from anxiety symptoms simultaneously, daily difficulties may be exacerbated for both child and family.

Some interesting conclusions can be derived from the difference in results between the two AFEQ subscales (Parent Experience and Family Life). It is important to consider the content of the items in each scale in order to contextualize these results. The Parent Experience subscale consists of items which asks parent to reflect directly on their own feelings and attitudes about their ability to make decisions and contribute positively to their child's development. In contrast, the items on the Family Life subscale ask parents to reflect on more logistical and practical issues, involving the family as a unit and not just the parent. Age also remained a unique predictor for Family Life outcomes alongside ASD, but it became a nonsignificant predictor for Parenting Experience. This

may indicate that the Family Life scale captured some of the chaos in daily routines that is to be expected when parenting young children (and that is alleviated as children get older) that the Parenting Experience scale did not.

One reason co-occurring anxiety symptoms were shown to be uniquely related to the parenting experience may be that parents receive less explicit training on recognizing and effectively addressing anxiety (as compared to the guidance they receive in addressing child issues more directly related to their child's ASD). Parents of children with ASD receive information about parenting their child from a wide range of sources – pediatricians, therapists, educators, ASD-specific community service providers, etc. Knowledge and training distributed to parents through these routes could be supplemented with specific information about identifying signs that their child is dealing with co-occurring anxiety and specific tools with which to address those symptoms. This may be one way to counteract the detrimental role co-occurring anxiety symptoms appears to have in parents' perception of their ability to parent effectively.

The Crucial Role of Challenging Behavior

Challenging behavior emerged as a crucial factor in understanding the experience of families with children on the autism spectrum. Challenging behavior was strongly related to both AFEQ subscales, suggesting that challenging behavior is detrimental to the parenting experience and quality of family life beyond other factors such as the child's cognitive abilities and independence in daily routines. Furthermore, ASD symptoms and Generalized Anxiety both predicted challenging behavior frequency and were similar in predictive strength even when overlapping variance was accounted for.

Given these associations, it is clear that anxiety is an important factor in child and family life, though its effects may be more indirect than the effect of ASD symptoms.

The mediation models further elucidate the differences in ASD and anxiety as predictors of family outcomes. After accounting for the indirect effect, via challenging behaviors, ASD symptoms maintained a direct effect on family outcomes. Meanwhile, anxiety became nonsignificant as a predictor when the mediational role of challenging behaviors was accounted for. Therefore, while ASD symptoms may have an indirect effect on family outcomes through their relation with challenging behaviors, they maintain a direct effect on family outcomes as well. On the other hand, anxiety's association with family outcomes appears to be largely indirect, and almost fully accounted for by its relation with challenging behaviors. This may explain the weaker predictive power of anxiety for the two family measures, but indicates that anxiety is an important factor to consider if seeking to understand child and family functioning. If children are experiencing ASD symptoms as well as anxiety, they may encounter greater barriers to optimal functioning than they would due to ASD symptoms alone.

The confirmed role of anxiety in challenging behavior specifically holds important implications for the development of services and supports for children with ASD and their families. Challenging behaviors are frequent targets of behavior therapy for children with autism, and if they are driven by anxiety this should be taken into account when developing effective interventions. If therapists and teachers can identify difficult behaviors that are related to anxiety, treatment plans may be more sensitive and effective than if difficult behaviors are simply attributed to noncompliance or disinterest on the part of the child. Furthermore, parents of children with ASD could benefit from

additional awareness of and education regarding the potential role of anxiety in their child's functioning and development. Parents may have more patience with difficult behaviors and find more effective ways to help their children manage those behaviors, when they can identify and understand the role of anxiety as an underlying cause.

Contrary to the relation that was hypothesized, children in the sample who had better functional communication skills also tended to have higher parent-reported anxiety. This is consistent with previous literature that has noted patterns of higher anxiety in children with higher IQ and verbal ability. While this may represent a real positive association between cognitive ability and the occurrence of anxiety, this observed pattern may also be a function of persistent difficulties in capturing anxiety in children with poorer communicative abilities. For example, if children are better able to communicate, parents may be more aware of their child's anxious thoughts and feelings. As a consequence, parents may report more frequent symptoms of anxiety.

Conclusions and Future Directions

This project confirmed the significant incidence of anxiety symptoms in children with ASD, and focused primarily on the role of these symptoms in the child's family life and their parent's experience. Anxiety was confirmed to be a frequently occurring condition for children with ASD, and was shown to be related to significant daily impairment. This is evidence that anxiety should be more directly examined as a potential contributor to the difficulties commonly associated with ASD. Challenging behavior was identified as a particularly important factor that negatively impacts daily child and family functioning, and anxiety was affirmed as a salient and significant factor that may drive the frequency and severity of these challenging behaviors. Therefore,

underlying anxiety must be accounted for in any effective treatment plan and supports employed across environments.

Parent- and family- related outcomes are only one area of functioning that must be considered in relation to anxiety in children with ASD. Anxiety symptoms may also play a role in a child's success at school, community participation, occupational skills. More research is also needed to determine how anxiety can be addressed within these environments to optimize child success. Better understanding of anxiety's prevalence and significant within this population is needed to inform the training of teachers, behavior therapists, and other service professionals.

Furthermore, anxiety could hold other implications for the mental and physical wellbeing of ASD individuals across the lifespan. As previously discussed, anxiety has been linked to poor health outcomes including cardiac disease and respiratory illness, as well as increased risk for other mental health disorders, substance use, and suicidality. It is imperative that researchers and health providers work to understand the presentation of anxiety within ASD populations so that it does not go unaddressed.

One noteworthy limitation to this study was the reliance on parent reports of the child's symptoms and behaviors. This allowed for the inclusion of a variety of children in the sample, For example, children were included who may not have been able to participate in direct assessment due to limitations of verbal communication. However, it does mean that our conclusions are subject to the bias of each parent's interpretation of their child's behaviors. This methodology did not allow for clinical analysis of reported symptoms and whether or not they truly represented underlying psychopathology. It also cannot be assumed that parent reports of their child's experience would be consistent

with the child's perspective. The conclusions of this project could be strengthened by further research that employs varied methodology (e.g., behavioral observations, physiological measures, child-report when possible). Furthermore, the data in this study were collected at one time point and represent the parent's best assessment of child and family variables at this point in time. It would be interesting to monitor child symptomology, child functioning, and family functioning on a longitudinal, even day-to-day, basis. This would allow for more direct analysis of the interactions of psychological and behavioral factors and their concurrent role in child and family functioning.

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APPENDIX A

Parent Consent Form and Demographic Information

You are invited to participate in a research study on children with Autism Spectrum Disorder (ASD), their mental health and daily routines, and the experience of their parents and family. You are qualified to participate in this study if you are the parent of a child that has an ASD diagnosis and is between the ages of 5 and 12. Your participation in this survey is completely voluntary. You may choose not to take part in the research or exit the survey at any time without penalty. You may choose not to answer any particular question that you do not wish to answer for any reason.

The purpose of this study is to learn more about the relationship between ASD and mental health, and how co-occurring symptoms may affect child and family functioning. For this study we will ask you to complete a survey with questions about your child's experiences, daily routines, behaviors and skills. You will also be asked questions about your experience as a parent and as a family. The survey should take approximately 10-15 minutes to complete. You will not receive any direct benefits from participating in this study. However, your responses may help us learn more about the experience of children with ASD and may help improve services and supports for children and their families in the future.

The risks involved in participating in this study are no more than those encountered in day-to-day life. There is a possibility that you may find some of the questions to be sensitive or personal. You may choose to skip any questions or discontinue the survey if you begin to feel uncomfortable. All your responses will be kept anonymous and will not be shared with anyone outside the research team.

Your survey answers will be collected and stored via Qualtrics and will be password protected. Qualtrics does not collect identifying information such as your name, email address, or IP address. No one outside the research team will be able to access your responses.

CONTACT

If you have questions at any time about the study or the procedures, you may contact the research team.

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This study has been reviewed and approved by the IRB (#00023306). If you have questions about your rights as a research subject, contact the Wake Forest University Office of Research and Sponsored Programs, 336-758-5888.

Please select your choice below. You may print a copy of this consent form for your records. Clicking on the "Agree" button indicates that

- You have read the above information
- You voluntarily agree to participate
- You are 18 years of age or older
- You are a current resident of the United States

Please fill out the following questions regarding your child who is aged 5-12 and has an ASD diagnosis.

1. What is your child's age, in months and years? Months _____ Years _____

2. What is your child's gender?
   - ☐ Male
   - ☐ Female

3. In what town/city and state does your family currently live?
   _____

4. What is your relationship to the child?
   - ☐ Mother
   - ☐ Father
   - ☐ Other (please specify) _____

5. What is your child's race/ethnicity? (choose any that apply)
   - ☐ American Indian or Alaska Native
   - ☐ Asian
   - ☐ Native Hawaiian or Other Pacific Islander
   - ☐ Black or African American
   - ☐ White
   - ☐ Hispanic or Latino/a
   - ☐ Other _____

6. What is the highest level of education completed by any parent/caregiver?
   - ☐ Some high school no diploma
   - ☐ High school diploma or GED
   - ☐ Some college credit, no degree
   - ☐ Associate degree
   - ☐ Bachelor's Degree
   - ☐ Master's Degree
   - ☐ Doctorate degree

7. Please list any siblings, and their ages, that live in the household. Do not include names (for example, "brother, age 7; sister, age 3")
   _____

8. Please select any of the following diagnoses that your child has received from a doctor, psychologist, or other licensed mental health provider:
   - ☐ Autism Spectrum Disorder (ASD)
   - ☐ ADD/ADHD
   - ☐ Depression
   - ☐ Anxiety Disorder
   - ☐ Obsessive Compulsive Disorder
   - ☐ Intellectual/Learning Disability
   - ☐ Oppositional Defiance Disorder/Conduct Disorder
   - ☐ Other: _____

9. Does your child have any co-occurring physical disability or medical condition (e.g., cerebral palsy, epilepsy, PANDAS/PANS)?
   - ☐ No
   - ☐ Yes
     If yes, please list. _____

10. Please choose the option that best describes your child's educational placement.
    - ☐ Mainstream classroom
    - ☐ Special education classroom in a mainstream school
    - ☐ Specialized school placement for autism or other special needs
    - ☐ Homeschool
    - ☐ Other (Please Describe): _____

11. What, if any, types of therapy does your child receive (e.g., Applied Behavior Analysis, Floortime, Cognitive Behavior Therapy)? For each type of therapy, please estimate the number of hours per week your child receives.
    _____

12. What extracurricular activities does your child participate in outside the home? Please estimate the number of hours per week your child spends participating in each.
    _____
    __

13. How did you find out about this research study? _____

APPENDIX B

Child and Adolescent Symptom Inventory 5 (CASI-5)

Autistic Disorder/Asperger's Disorder

Please choose the rating that most describes your child's behavior.

My child….	**Never**	**Sometimes**	**Often**	**Very Often**
Has an unusual way of relating to others (avoids eye contact, odd facial expressions or gestures, etc)				
Does not play easily with other children				
Not interested in making friends				
Is unaware or takes no interest in other people's feelings				
Has a significant problem with language				
Has difficulty making socially appropriate conversation				
Talks in an unusual way (repeats what others say, confuses words like "you" and "I, uses odd words or phrases, etc.)				
Is unable to "pretend" or "make believe" while playing				
Shows excessive preoccupation with one topic				
Gets very upset over small changes in routine or surroundings				
Makes repetitive movements (flapping arms, etc.)				
Has a particular fascination for parts of objects				
Is overly sensitive to sounds, smells, or the way things feel				
Does not seem to feel pain or react to extreme heat or cold				
Seems unaware of how to communicate with other people (talks like a professor, doesn't consider the interests of the listener, difficulty taking turns in conversations)				
Has difficulty understanding humor, words with double meanings, etc. when interacting with others				
How often do these behaviors interfere with the child's ability to function in the school environment?				
How often do these behaviors interfere with the child's ability to function in the home environment?				
How often do these behaviors interfere with the child's ability to function in the community (e.g. restaurants, public events)?				

APPENDIX C

Child and Adolescent Symptom Inventory 5 (CASI-5)

Generalized Anxiety Disorder

Please choose the rating that most describes your child's behavior.

My Child…	**Never**	**Sometimes**	**Often**	**Very Often**
Is overconcerned about abilities in school or social activities				
Has difficulty controlling worries				
Acts restless or on edge				
Is irritable for most of the day				
Is extremely tense or unable to relax				
Has difficulty falling asleep or staying asleep				
How often do these behaviors interfere with the child's ability to function in the school environment?				
How often do these behaviors interfere with the child's ability to function in the home environment?				
How often do these behaviors interfered with the child's ability to function in the community (e.g. restaurants, public events)?				

Symptom Count Cutoff Scoring: Items scored "0" for the responses "Never" and "Sometimes" and "1" for the responses "Often" and "Very Often". Child meets Symptom Count Cutoff for $\geq$1 response on the first two items, and $\geq$3 total on all items.

Specific Phobia

Please choose the rating that most describes your child's behavior.

My Child…	**Never**	**Sometimes**	**Often**	**Very Often**
Is overly fearful of or tries to avoid specific objects or situations (please describe).				
How often do these behaviors interfere with the child's ability to function in the school environment?				
How often do these behaviors interfere with the child's ability to function in the home environment?				
How often do these behaviors interfere with the child's ability to function in the community (e.g. restaurants, public events)?				

Symptom Count Cutoff Scoring: Items scored "0" for the responses "Never" and "1" for the responses "Sometime", "Often", and "Very Often". Child meets Symptom Count Cutoff for 1 symptom.

Panic Disorder

Please choose the rating that most describes your child's behavior.

My Child…	**Never**	**Sometimes**	**Often**	**Very Often**
Complains about heart pounding, shortness of breath, feeling dizzy, trembling, or fear of dying				
How often do these behaviors interfere with the child's ability to function in the school environment?				
How often do these behaviors interfere with the child's ability to function in the home environment?				
How often do these behaviors interfere with the child's ability to function in the community (e.g. restaurants, public events)?				

Symptom Count Cutoff Scoring: Items scored "0" for the responses "Never" and and "1" for the responses "Sometime", "Often", and "Very Often". Child meets Symptom Count Cutoff for 1 symptom.

Obsessions and Compulsions

Please choose the rating that most describes your child's behavior.

My Child…	**Never**	**Sometimes**	**Often**	**Very Often**
Cannot get distressing thoughts out of his/her mind (worries about germs, doing things perfectly, etc.)				
Feels they must perform unusual habits (hand washing, checking locks, repeating things a set number of times)				
How often do these behaviors interfere with the child's ability to function in the school environment?				
How often do these behaviors interfere with the child's ability to function in the home environment?				
How often do these behaviors interfere with the child's ability to function in the community (e.g. restaurants, public events)?				

Symptom Count Cutoff Scoring: Items scored "0" for the responses "Never" and and "1" for the responses "Sometime", "Often", and "Very Often". Child meets Symptom Count

Cutoff for Obsessions for 1 symptom, and Symptom Count Cutoff for Compulsions for 1 symptom.

Social Anxiety

Please choose the rating that most describes your child's behavior.

My Child…	**Never**	**Sometimes**	**Often**	**Very Often**
Tries to avoid contact with strangers, abnormally shy				
Is more anxious in social situations than other youth of same age				
Is excessively shy with peers				
When put in uncomfortable situation, child cries, freezes, or withdraws from interacting				
How often do these behaviors interfere with the child's ability to function in the school environment?				
How often do these behaviors interfere with the child's ability to function in the home environment?				
How often do these behaviors interfere with the child's ability to function in the community (e.g. restaurants, public events)?				

Symptom Count Cutoff Scoring: Items scored "0" for the responses "Never" and "Sometimes" and "1" for the responses "Often" and "Very Often". Child meets Symptom Count Cutoff for $\geq$2 symptoms of the first, third, and fourth items.

Separation Anxiety

Please choose the rating that most describes your child's behavior.

	Never	**Sometimes**	**Often**	**Very Often**
Gets very upset when he/she expects to be separated from home or parents				
Worries that parents will be hurt or leave home and not come back				
Worries that some disaster (getting lost, kidnapped, etc.) will separate him/her from parents				
Tries to avoid going to school to stay home with parents				
Worries about being left at home alone or with a sitter†				
Afraid to go to sleep unless next to a parent†				

Has nightmares about being separated from parent†				
Complains about feeling sick when he/she expects to be separated from home or parents†				
How often do these behaviors interfere with the child's ability to function in the school environment?				
How often do these behaviors interfere with the child's ability to function in the home environment?				
How often do these behaviors interfere with the child's ability to function in the community (e.g. restaurants, public events)?				

Symptom Count Cutoff Scoring: Items scored "0" for the responses "Never" and "Sometimes" and "1" for the responses "Often" and "Very Often". Child meets Symptom Count Cutoff for $\geq$3 symptoms.

† Items erroneously omitted from survey; no data collected.

APPENDIX D

Autism Family Experiences Questionnaire (AFEQ)

Parent Experience Subscale

Please choose the statement that best describes your experience as a parent to your child.

	N/A	Never	Rarely	Sometimes	Often	Always
1. I lack confidence in knowing how to help my child						
2. I feel listened to by professionals						
3. Working with therapists or professionals helps me feel confident						
4. I am confident that I understand my child's level of development						
5. I feel I know how to help my child's progress						
6. I feel I'm getting it wrong						
7. I have realistic milestones for my child's development						
8. I doubt my ability to help my child's development						
9. I feel frustrated at not knowing how to help my child						
10. Professionals don't understand my family's needs						
11. I have coping mechanisms to help my child						
12. It's a continual battle to get the right help for my child						
13. My child is getting the right help						

Family Life Subscale

Please choose the statement that best describes your family experience.

	N/A	Never	Rarely	Sometime	Often	Always
1. Family life is a battle						
2. I feel guilty about not giving other members of the family enough attention						
3. My child is flexible in adapting to the demands of family life						
4. Family life is calm						
5. I know how to cope with my child when going on an outing in a public place (e.g. a restaurant)						
6. I feel confident to go out to family events with my child						
7. I feel comfortable making routines at home more manageable for my child						
8. I feel comfortable having visitors to our home						
9. My child has fussy habits that make it difficult to go away for a break						

APPENDIX E

Parent Questionnaire – Child Skills and Behavior

Functional Communication Skills

If your child uses an alternative method of communication other than verbal speech (e.g., American Sign Language, picture exchange, typing, and iPad application such as Proloquo2Go), please describe: _____

Please choose the statements that best describe your child's ability to communicate. For the purpose of these questions, "communication" can be verbal (speaking) or non-verbal (e.g., typing, PECS, an iPad).

My child ….	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**
Can spontaneously begin communication with me					
Can spontaneously begin communication with other members of the family					
Can spontaneously request his/her needs appropriately					
Gets frustrated at not being understood					
Can let me know when he/she is hurting					
Can describe when he/she doesn't feel well					
Can tell me when he/she is uncomfortable or overwhelmed in a situation					
Can describe or share their worried thoughts					

Frequency of Challenging Behaviors

Please choose the statement that reflects how often your child experiences or exhibits the following behaviors.

	Never	**Sometimes**	**Often**	**Very Often**
Physical aggression towards other people (e.g. pulling others' hair, biting)				
Verbal aggression towards others (e.g. cursing at or threatening others)				
Self-Injury (e.g. biting self, banging head)				
Property Destruction (e.g. throwing or breaking items)				
Elopement (e.g. running from parent or caregiver)				
Inappropriate Sexual Behavior (e.g. touching self or others inappropriately)				
Meltdown or Tantrum (e.g. emotional outburst, loss of control)				
PICA (eating non-food items)				
Incontinence (urinating or having bowel movement outside of the bathroom)				
Eating Abnormalities or **Digestion Problems** (e.g. refusing to eat, stomach distress with no apparent cause)				

Adaptive Behavior

Please choose the statement that best describes your child's ability to do the following tasks **without** direct help or supervision from a caregiver.

My child…	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**
Can use the bathroom independently					
Can get dressed/undressed independently					
Can complete simple hygiene tasks (e.g. washing face, brushing teeth) independently					
Can prepare and eat a snack or meal independently					
Can play with other children his/her age independently					
Can complete simple household tasks independently (cleaning a room, wiping up a spill)					

Cognitive Skills

Please rate your child's abilities in each category, compared to other children his or her age.

	Well Below Average	**Below Average**	**Average**	**Above Average**	**Above Average**
Reading					
Writing					
Math					
Memory					
Art					
Music					
Puzzles					
Computer Skills					

CURRICULUM VITAE

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Education

Wake Forest University
M.A. Psychology, expected graduation May 2019
GPA: 4.00

University of North Carolina - Chapel Hill
B.S. with Highest Honors in Psychology, May 2013
Minors: Social and Economic Justice, Hispanic Studies
Cumulative GPA: 3.52, Psychology GPA: 3.82

Danish Institute for Study Abroad
Child Development and Diversity, Children with Special Needs, Fall 2011

Honors and Funding

Gordon A. Melson Outstanding Master's Student Award Nominee (2018) *Wake Forest University*
Graduate Assistantship, Tuition Waiver, & Stipend - $49,828 (2018) *Wake Forest University*
Graduate Assistantship, Tuition Waiver, & Stipend - $49,028 (2017) *Wake Forest University*
Alumni Travel Award - $300 (2018) *Wake Forest University*
Psi Chi International Honors Society in Psychology (2013)
Buckley Public Service Scholar (2013) *UNC-Chapel Hill*
Dean's List (2009-2012) *UNC-Chapel Hill*

Research Experience

Graduate Researcher *(2017-present)* Wake Forest University, Winston-Salem, NC

Advisor: Dr. Deborah Best
First Year Project: *Teacher and Parent Reports of On-Task Behavior – Inhibition and Implications in Preschoolers*
Major Area Paper: *Anxiety and Autism – Assessment, Treatment, and Functional Implications*
Thesis: *Anxiety Symptoms in Children with ASD and Implications for Family Wellbeing*

- Developed independent project proposal in collaboration with a local school program to examine relationships between adverse childhood experiences (ACEs), parent and teacher relationships, and school adjustment

- Collected, scored, and analyzed data for a project examining executive function, on-task behavior, and school readiness in preschoolers
- Completed thesis project that explored the ways in which co-occurring anxiety symptoms and ASD impact child, parent, and family wellbeing

Undergraduate Research Assistant *(2010-2013)* Children's Memory Lab
UNC-Chapel Hill, NC
Advisors: Dr. Peter Ornstein, Dr. Jennifer Coffman
Honors Thesis: *Home Environment, Teacher Language, and Literacy Development Across the First Grade Year*
- Coded, scored, and organized data for multiple projects examining children's memory development
- Conducted one-on-one memory and achievement assessments with first-grade participants
- Developed independent research project examining links between home literacy, environment, teacher memory-relevant language, and child literacy development

Professional Presentations

Buchanan, K., & Best, D.L. (2019, February). *How cultural contexts impact the diagnosis and treatment of autism.* Paper presented at the annual meeting of the Society for Cross-Cultural Research, Jacksonville, FL.

Capobianco, N., **Buchanan, K**., & Best, D.L., (2019, March). *Understanding school readiness: The interacting roles of behavioral regulation and teacher-child relationship quality.* Poster presented at the biannual meeting of the Society for Research in Child Development, Baltimore, MD.

Professional Experience

Graduate Intern, *(2017 - present),* Amos Cottage – Wake Forest Baptist Health
Winston-Salem, NC
- Serve as developmental evaluator for WFU Baptist Hospital NICU Follow-Up Clinic and Child Developmental Services Agency (CDSA)
- Administer the *Bayley-III Scales of Infant and Toddler* Development and the *Developmental Assessment of Young Children (DAYC-2)* to assess developmental delays in at-risk children from birth to 3 years of age
- Integrate developmental evaluation results, medical background, parental report, and clinical observation to determine eligibility for the NC Infant-Toddler Program
- Collaborate with Early Intervention service team and parents/caregivers to identify priorities, determine goals, and develop strategies to optimally support child's development

Attendant, *(2013-2017)*, VA Department of Medical Assistance Services
Charlottesville, VA

- Provided in-home and community support for program participants with autism and their families
- Supported participants in developing skills for independent living, community participation, and leisure time

Instructor, *(2013 - 2016),* Virginia Institute of Autism
Charlottesville, VA

- Provided 1-on-1 educational and therapeutic services to students on the autism spectrum
- Attended regular trainings in current applied behavioral analysis methods and workplace skills
- Executed behavior support plans to manage and reduce problem behaviors
- Created and implemented educational programming based on individualized education plans (IEPs)

Activity Director, Counselor *(2012-14),* Camp Lakey Gap
Black Mountain, NC

- Developed and led daily structured events for children and adults on the autism spectrum
- Assisted with camper care during daily activities and overnight
- Oversaw first-year counselors in small group to provide practical and moral support

Additional Activities & Service

Student Volunteer *(2011-2013),* TEACCH Autism Program
Chapel Hill, NC

- Worked with children on the autism spectrum aged 2-5 in a variety of structured social groups
- Assisted lead teachers in organization and execution of structured and unstructured activities to encourage appropriate peer interaction and communication skills

Pediatric Therapy Volunteer *(2010-2012),* UNC Hospitals
Chapel Hill, NC

- Collaborated with music therapists, physical therapists, counselors, and other hospital staff to serve pediatric patients in residence
- Utilized music, art, and play in a therapeutic setting to promote positive expression and attitude