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Anxiety in Children and Adolescents with Autism Spectrum Disorder: Behavioural Phenotypes and Environmental Factors

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A thesis submitted in partial fulfillment of the requirements for the Master of Arts degree in Education

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Abstract

Anxiety is the most prevalent comorbidity among children and adolescents with autism spectrum disorder (ASD). The phenotypical presentation of anxiety among children and adolescents with ASD is lacking within the literature. This study sought to differentiate behavioral phenotypes associated with anxiety in children with ASD from anxiety in typically-developing children. Participants (N = 262) completed a series of child and parent reports measuring anxiety, depressive symptoms, ASD symptom severity, emotional problems, parental stress, and socioeconomic factors. Three distinct cluster profiles were identified. Results demonstrated that depression is the strongest predictor of high anxiety among children and adolescents with ASD. Additionally, frequent peer problems result in reports of high anxiety and depressive symptoms in children and adolescents with ASD. Early intervention to develop and strengthen social and communication skills is critical to minimize peer problems and manage depression among children and adolescents with ASD who have anxiety.

Keywords

Autism spectrum disorder, anxiety, ASD-specific anxiety, depression, peer problems

Summary for Lay Audience

Children and adolescents with autism spectrum disorder (ASD) often experience difficulty with social communication and interaction, use of expression and language, and can become fixated on specific behaviors or interests. Anxiety is the most common mental health disorder among children and adolescents with ASD. A clear understanding of the outward, observable presentation of anxiety among children and adolescents with ASD is lacking within the academic community. The current study aimed to discriminate between the behavioral presentation of anxiety in ASD and anxiety experienced by children and teens without ASD. Additionally, this work sought to identify anxiety symptoms that explain the differences observed between those with and without anxiety. Two-hundred sixty-two children and adolescents, with and without ASD, completed questionnaires measuring anxiety, depression, ASD symptom severity, emotional issues, parental practices and stress, and socioeconomic factors. Measures were completed by participants and their parents for comparison. Three unique phenotypical clusters were identified. Results show that depressive symptoms, such as unhappiness and isolation, are the strongest indicator of high anxiety among children and adolescents with ASD. As well, frequent peer relationship problems led to reports of high anxiety and depressive symptoms in children and adolescents with ASD. Mental health professionals, such as registered psychotherapists or psychologists, should assess for and treat depressive symptoms in clients with ASD. Furthermore, early treatment among children and adolescents with ASD and anxiety should aim to develop and strengthen social and communication skills in order to reduce negative interactions with peers and manage depressive symptoms.

Co-Authorship Statement

Chapter 2 was adapted from the manuscript title “Anxiety in children and adolescents with autism spectrum disorder: Behavioral phenotypes and environmental factors” that is under review at the International Journal of Methods in Psychiatric Research. Although the current thesis was primarily conducted and written by the first author, Caitlin Leachman, other important contributions were made that required the inclusion of co-authors. Guidance and teaching on the use of self-organizing maps in data analysis was provided by Dr. Emily Nichols and Sarah Al-Saoud. Upon learning to conduct the data analysis plan, statistical analysis was completed by Caitlin Leachman under the supervision of Dr. Emma Duerden. Given the assistance provided by Dr. Nichols, Sarah Al-Saoud, and Dr. Duerden, each was included in authorship. Caitlin Leachman solely completed the entire literature review and all sections of the final thesis write-up. All appendices, tables, figures, and references were also created and formatted by Caitlin Leachman.

Acknowledgments

I would like to express my sincerest gratitude to Dr. Emma Duerden, who graciously guided me and provided relevant and critical feedback that refined the current work. Her continued support and encouragement will never be forgotten. I would also like to thank Dr. Emily Nichols and Sarah Al-Saoud for lending their extensive knowledge on statistical tools and analysis that allowed for the successful completion of this project. Furthermore, I would like to extend my appreciation to the Child Mind Institute for collecting and storing the data that was kindly made available for this project. Thank you to all of the wonderful families who offered up their own experiences with autism spectrum disorder, without which this work would not have been possible.

I would also like to thank my incredible parents, Greg and Brenda, for their unwavering support in my journey to pursue a master's degree in counselling psychology. They have kept me going through the most difficult of times, and always have my back. Their continued check-ins and texted pictures of my dogs back home, whom I miss dearly, have been the motivation I needed to keep going.

I would like to dedicate this project to my late nana, Dorothy, who taught me how to keep going in the face of adversity. I know that she is proud of what I have and will accomplish.

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Chapter 1

1 Introduction

Autism spectrum disorder (ASD) is characterized by impairments in social communication and interaction, as well as restricted and repetitive behaviors and interests (Duvekot et al., 2018). Anxiety is the most prevalent comorbidity in autistic children and adolescents, with up to 80% experiencing symptoms of anxiety (Lau et al., 2020; & Van Steensel & Heeman, 2017). Anxiety may include intense panic, avoidance of social situations and activities, disruptions in sleep, and various somatic symptoms (e.g., chest pain and shallow breathing)(American Psychiatric Association, 2013). In children and adolescents with ASD, the risk of being diagnosed with comorbid anxiety is two-times higher compared to typically-developing (TD) youth (Van Steensel et al., 2011). ASD-specific anxiety refers to anxiety symptoms that are present in those also diagnosed with ASD. Although interest in the biological underpinnings of ASD-specific anxiety has peaked recently, the overt behaviors associated with ASD-specific anxiety remain unclear (Andrews et al., 2022; Bal et al., 2018; Duvekot et al., 2018).

1.1 Autism Spectrum Disorder

ASD is a neurodevelopmental disorder associated with significant deficits in social communication and interactions, along with the presence of restricted behaviors (American Psychiatric Association, 2013). Impaired social communication may include difficulty sharing information, expressing thoughts and feelings, and working on joint ideas with others (Fuller & Kaiser, 2020). In autistic children and adolescents, disruption in social communication often extends to nonverbal communication skills, such as limited eye

contact, hand gestures, and body language. Social communication skills are essential to maintaining the attention of others, completing satisfying interactions, and regulating behavior and mood. Autistic children and adolescents who experience challenges with social communication may face greater difficulty than their TD counterparts in forming meaningful connections, gaining independence from family, and are far more likely to face bullying, harassment, and discrimination in their lifetime. Repetitive or restrictive behaviors often include repetitive motor movements, insistence on sameness and routine, fixated interests, and hyper or hyposensitivity to sensory input (Hyman et al., 2020). In order to receive a clinical diagnosis of ASD, an individual must display persistent deficits in social communication and interaction and at least two of the four types of restricted and repetitive behaviors listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013).

ASD is typically diagnosed between the ages of 18 and 24 months of age, though continued monitoring of developmental milestones and progression is encouraged by health care providers (Hyman et al., 2020). In many cases, ASD remains undiagnosed until adolescence or adulthood, which may be the result of limited access to diagnostic and treatment services and a lack of culturally appropriate diagnostic screening tools. Parents, primary care physicians, and educators are advised to monitor children and adolescents for early signs of ASD. Behavioral indicators of ASD may include poor or abnormal verbal and nonverbal communication (e.g., lack of facial expressions or body language), motor stereotypes (e.g., lining up toys or objects in a specific manner), repeating words or phrases over and over (echolalia), the absence of interest in peers or loved ones, strong attachment to objects, extreme distress in response to minute changes, and adverse

response to sounds, textures, smells, or visual stimuli. Approximately 1.7% of children in the United States are diagnosed with ASD (Fuller & Kaiser, 2020; Hyman et al., 2020).

However, the Centers for Disease Control and Prevention (CDC) suggests that the true prevalence is closer to 2.78% (Centers for Disease Control and Prevention, 2023).

Although the presence of ASD does not discriminate across racial, ethnic, cultural, and socioeconomic groups, it is more often diagnosed among middle to upper class families who have access to primary care and treatment resources. Furthermore, one female will be diagnosed with ASD for every four boys, indicating differences in overt expressions of symptomatic behavior (Duvekot et al., 2018). In addition, diagnostic rates for non-industrialized societies are non-existent in the literature. The prevalence rate of ASD continues to steadily increase over time, a phenomenon largely attributed to increased public awareness of early symptoms, the broadening of diagnostic criteria and a greater distinction between intellectual disabilities (IDs) and ASD, universal screening protocols, and wider availability of early intervention and education-based programs (Hyman et al., 2020).

1.2 Impacts of Autism Spectrum Disorder

While many autistic individuals lead a very full and accomplished life, there are significant financial, emotional, and social costs that create barriers to mental wellbeing, independence, and financial comfort. Medical costs are twice as high among those with ASD than TD youth and adults, as those with ASD make greater use of services and have high medication costs (Rogge & Janssen, 2019). With regard to costs for occupational, speech, physical, and family therapy costs, individuals and families may pay up to \$60,000 annually. The cost of special education makes up the largest proportion of

expenses for children with ASD, and costs an average of 70 to 175% more than education for TD children. Families can spend anywhere from \$10,000 to \$50,000 for specialized school programs, education assistance, and individualized education plans (IEPs).

Approximately 80% of adults with ASD are underemployed or unemployed, likely due to challenges with communication and discrimination in the hiring process. Production loss in adults accounts for over 30% of lifetime costs for adults with ASD, and decreases the likelihood of financial independence from family and government subsidies. Among autistic children, 57% of parents report having to reduce or cease work to care for their child. In 2015, the total financial cost for ASD community resources in the United States was \$268 billion (Fuller & Kaiser, 2020; Hyman et al., 2020). The individual lifetime cost of ASD was estimated between \$1.4 and \$2.4 million, but is significantly higher among those with multiple diagnoses (Rogge & Janssen, 2019).

The cost of informal care and lost productivity among caregivers varies depending on the family's income, social status, and, access to resources (Rogge & Janssen, 2019). Cost to families can also include loss of leisurely time that is spent caring for the child, which can lead to significant caregiver burnout and stress. Additionally, out-of-pocket expenses add up quickly, with parents reporting around \$200 per week on top of regular bills and fees. Should a child require inpatient services or group home care, a family may be required to pay up to \$90, 000 out-of-pocket for one year of residency. There are also serious emotional and social costs to managing ASD that are necessary to consider. Many youth with ASD may feel like an outsider or have difficulty forming connections with their peers. They may experience peer victimization as a result of their unique differences and may face discrimination from educators, employers, and family. Autistic individuals are

also at increased risk to developing various comorbid mental health and health disorders. For example, many individuals diagnosed with ASD are also diagnosed with anxiety, depression, obsessive-compulsive disorder (OCD), gastro-intestinal issues, sleep concerns, and epilepsy. It is clear that autistic people are faced with overwhelming financial and personal costs that impact the individual, the family, and society as a whole. These costs may be amplified in those with ASD-specific anxiety, resulting in incalculable financial, emotional, and social strain on the individual and their family.

1.3 Anxiety

Anxiety is both an affective and physiological response to the anticipation of a real or imagined threat (Penninx et al., 2021; White et al., 2014). Common symptoms of anxiety include excessive worry, restlessness, exhaustion, irritability, sleep disturbances, trouble concentrating, difficulty breathing, headaches, and stomach pain (American Psychiatric Association, 2013). Autistic children and adolescents with anxiety symptoms report a worse quality of life compared to TD children, with and without anxiety, in terms of emotional function, mood regulation, and ability to form meaningful social connections (Van Steensel et al., 2012). For example, one study explored the quality of life (QoL) in children with comorbid ASD and anxiety (Adams et al., 2019). Children who reported higher anxiety symptoms on the Anxiety Scale for Children with Autism Spectrum Disorder-Child Form (ASC-ASD-C) also indicated worse physical, emotional, social, and school functioning compared to their counterparts with lower anxiety symptomatology

(Adams et al., 2019). ASD-specific anxiety is also associated with family stress, non-suicidal self-injury (NSSI), and additional mood disorders (Frank et al., 2022).

Anxiety is commonly accompanied by depression, a serious mood disorder marked by persistent sadness and hopelessness, as well as a loss of interest in activities (American Psychiatric Association, 2013). Unfortunately, autistic children are at a significantly greater risk of engaging in NSSI and suicidal behaviors (e.g., planning suicide in detail) than their TD counterparts (Oliphant et al., 2020). This is accounted for by the high prevalence of anxiety and subsequent depression among this population. One study conducted with TD participants found that 5-15% of youth aged 11 to 19 reported a history of NSSI and suicide attempts. Among youth with ASD-specific anxiety, 63% under 18 reported wanting to end their own lives. Another study found that youth and adults with ASD-specific anxiety were up to eight times more likely to attempt suicide than TD individuals (Hirvikoski et al., 2020). Clearly, ASD-specific anxiety presents a serious safety risk among youth, yet it is a construct that is largely absent in the literature (Oliphant et al., 2020).

1.4 Anxiety in Children and Adolescents with ASD

Although there is limited information regarding the relationship between anxiety and ASD, there are several key assumptions that have been repeatedly demonstrated over time. The first is that anxiety is very common in autistic children and adolescents (Van Steensel & Heeman, 2017). It has been hypothesized that the social skill deficits experienced by children with ASD increase the child's risk of entering anxiety provoking situations, such as bullying by peers (Duvekot et al., 2018; & Lau et al., 2020). Among the most prevalent anxieties in children with ASD are specific phobias. However, the

phobias of children with ASD tend to be atypical and qualitatively distinct to the phobias of TD children (Van Steensel et al., 2011). For example, children with ASD were found to be petrified of bubbles, radio jingles, or the sound of a baby crying (Kerns et al., 2014). For reference, a typical phobia may include fear of the dark, needles, or spiders. It is presumed by researchers that anxiety severity in autistic children likely depends on age, gender, parental factors, socioeconomic status (SES), and which ASD symptom is most significant in that individual (Van Steensel et al., 2011). As the literature stands, it is not known as to whether ASD predisposes a child to experience anxiety, or if anxiety exacerbates ASD symptom severity (Duvekot et al., 2018).

1.5 Current Interest in the Literature

A considerable proportion of the existing literature on autistic children with anxiety symptoms is narrow, focused primarily on the prevalence of anxiety among the ASD population (Bellini, 2004; Den Houting et al., 2018; Kerns et al., 2014; & Van Steensel & Heeman, 2017). Despite the astoundingly high rates of anxiety in children and adolescents with ASD, there remains uncertainty regarding how anxiety differs between children and adolescents with and without ASD. It may be challenging to tease apart symptoms of anxiety from ASD symptomatology (Lecavalier et al., 2014). Further, many children and adolescents with ASD and co-occurring anxiety display low cognitive functioning. It is difficult to understand one's personal account of anxiety when they are verbally or cognitively unable to assess and relay their own unique experience. Additionally, youth with anxiety symptoms or disorders often present with symptoms from different diagnostic categories. For example, a child may insist that each meal they eat is the same, but also struggle to connect with peers socially. It is difficult to determine if these

symptoms are manifestations of ASD, generalized anxiety, or social anxiety disorder. Finally, nearly 40 different measures have been utilized to assess anxiety symptoms in autistic youth. However, most instruments have yet to be validated for use within the ASD population and are likely overlooking a range of anxiety symptoms exclusive to or heightened within the ASD community.

One study sought to explore the overt manifestations of anxiety in autistic children that differ significantly from anxiety that presents in TD children (Lecavalier et al., 2014). A panel of experts in ASD and comorbid mental health challenges was formed by Autism Speaks, a nonprofit agency dedicated to research, advocacy, information, innovation, and support for individuals and families diagnosed with ASD (Autism Speaks, n.d.; Lecavalier et al., 2014). Each panel member was tasked with conducting a full systematic review of measures used to assess anxiety in autistic children (Lecavalier et al., 2014). Examples of commonly used measures include the Child and Adolescent Symptom Inventory (CASI), the Pediatric Anxiety Rating Scale (PARS), and the Anxiety Disorders Interview Schedule (ADIS). Children with ASD and comorbid anxiety disorders were at greater risk for tantrums, social avoidance, non-compliance, repetitive behaviors, and NSSI when compared to TD youth. In turn, each of these findings was strongly correlated with high anxiety scores. Lecavalier and colleagues (2014) concluded that anxiety is very common in autistic children and it is therefore clinically necessary to target ASD-specific anxiety in therapeutic treatment. As well, existing measures of anxiety require extensive alterations in order to be used appropriately within the ASD population. Following the publication of this study, interest in ASD-specific anxiety began to rise within the academic community, and it became more apparent than before that the symptoms of

anxiety unique to youth with ASD must be isolated in order to provide appropriate diagnostic and treatment services.

In recent years, neurological research has become popular in this area of interest. Many studies have established a strong connection between amygdala function and the development of anxiety in children with ASD (Amaral & Corbett, 2003; Chen et al., 2021; Herrington et al., 2017). For example, Herrington and colleagues (2017) invited 53 children with ASD to undergo structural magnetic resonance imaging (MRI). Three subgroups were created to compare those with at least one anxiety disorder diagnosis, those without, and a TD control group. The group presenting with ASD and anxiety demonstrated significantly decreased right amygdala volume in relation to those with ASD and no anxiety and the TD group. In 2021, Chen and colleagues utilized functional MRI (fMRI) to compare amygdala threat responses in children with and without ASD. Autistic children and anxiety symptoms showed a significantly stronger amygdala and hippocampal response to images of threatening faces than did their TD peers. Each of these studies provides support for the working theory that ASD-specific anxiety is motivated by unique neurodevelopmental underpinnings.

Emotional regulation (ER) has also been assessed and studies found that anxiety may result in children with ASD who underutilize ER skills (Conner et al., 2020; & Jefferson & Erp, 2022). Mindfulness and identifying and naming emotions are examples of ER skills (Jefferson & Erp, 2022). Reduced capacity in ER skills can directly decrease emotional well-being, the quality of interactions and personal relationships, and create disruptions in the school environment. However, no study to date has accounted for the influence of environmental factors, such as parental stability and stress, accessibility, and

SES, on the development and maintenance of anxiety in autistic children and adolescents. Moreover, anxiety in children with ASD that is distinct from traditional anxiety has yet to be explored. Ultimately, such areas of focus require greater clarity so that new knowledge can be applied in therapeutic settings and to policy in the assessment of autistic children. The limited understanding of anxiety in children with ASD is perhaps most noticeable in that tools used to assess children with ASD have not been adapted to be appropriately utilized within that population. Therefore, the research to date is far from adequate to create positive change in the lives of autistic children and their families.

The understanding of anxiety in autistic children and adolescents is limited. The etiology and developmental factors that are related to anxiety in this population, as well as the behavioral phenotypes remain unexplored. However this information could inform treatment plans for autistic children and adolescents with anxiety. A point of agreement is that the majority of children with ASD have some form of anxiety, which does support a strong biological basis for anxiety in this population. Understanding the causal and maintenance factors behind anxiety in children and adolescents with ASD is especially critical, as anxiety in this population only further aggravates existing social and behavioral deficits (Kerns et al., 2014; & White et al., 2014). Children with ASD-specific anxiety demonstrate a reduced response to common behavioral and speech therapies, such as cognitive behavioral therapy (CBT), making social skill development significantly less likely in the child or adolescent. As a result, children and adolescents with ASD-specific anxiety are unlikely to integrate into society or form meaningful relationships as easily as TD youth and autistic children who do not experience anxiety.

1.6 The Present Study

In the current study, the presentation of anxiety in autistic children and adolescents was addressed. Children and their parents completed a series of questionnaires regarding ASD symptom severity, anxiety and depression symptoms, emotional problems, ADHD symptoms, parenting styles and stress, cognitive ability, and socioeconomic factors. Two aims were examined. First, the behavioral phenotypes that are characteristic of anxiety in children and adolescents with ASD were identified and differentiated from anxiety in TD youth. It was hypothesized that children and adolescents with ASD exhibit distinct anxiety profiles that are not solely explained by features of ASD symptomatology, but rather represent a unique clustering of anxiety-related characteristics within the ASD population. Lastly, the anxiety measures that account for the most significant differences between those with and without ASD were identified. It was predicted that social factors would be the strongest indicator of anxiety in children with ASD.

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Chapter 2

2 Introduction

Autism spectrum disorder (ASD) is characterized by impairments in social communication and interaction, as well as restricted and repetitive behaviors and interests (Duvekot et al., 2018). Studies have shown that up to 70% of children and adolescents with ASD have one comorbid psychopathology, while 40% have at least two (Den Houting et al., 2018). Anxiety symptoms are the most prevalent comorbidity in children and adolescents with ASD, with 30 to 80% experiencing symptoms (Lau et al., 2020; & Van Steensel & Heeman, 2017). Clinically severe anxiety may include uncontrollable panic, an inability or limited capacity to engage in social activities, disrupted sleep, difficulty concentrating, somatic symptoms (e.g., chest pain, nausea, trouble breathing), and avoiding triggering places and people (American Psychiatric Association, 2013). The likelihood of being diagnosed with anxiety while under the age of 18 is more than two-times higher in those with ASD, compared to typically developing (TD) children and adolescents (Van Steensel et al., 2011). ASD-specific anxiety refers to individuals diagnosed with ASD who also display atypical characteristics of anxiety, such as abnormal phobias or extreme rigidity (Andrews et al., 2022; Den Houting et al., 2019; & Lau et al., 2020). Although academic interest in the biological mechanisms and symptoms that underly anxiety in autistic children has peaked in recent years (Andrews et al., 2022; Ben-Itzhak et al., 2020; Chen et al., 2021; Kerns et al., 2016; Lau et al., 2020; & Spackman et al., 2022), the extent to which anxiety influences overt behaviors remains largely unknown.

The high prevalence of anxiety in children with ASD has encouraged the exploration into etiological and behavioural mechanisms (Chen et al., 2021; Lau et al., 2020; Kerns et al., 2014; Ung et al., 2013; & Wood & Gadow, 2010). Autistic children and adolescents with anxiety report worse emotional functioning, mood regulation, and ability to form meaningful social relationships than TD children both with and without anxiety (Van Steensel et al., 2012). One study identified a distinction between common anxiety characteristics in the general population and “autism-related” anxiety symptoms (Lau et al., 2020). A more recent imaging study examined children with ASD and no anxiety, ASD and typical anxiety, ASD-specific anxiety, and TD youth with and without anxiety (Andrews et al., 2022). Left and right amygdala volumes were compared at four time points between the ages of three and 13. Autistic children with typical anxiety showed significantly larger right amygdala volumes than TD children. In contrast, children with ASD-specific anxiety demonstrated significantly slower right amygdala growth and reduced volume than all other groups. These behavioral and biological differences highlight the unique developmental trajectory of ASD-specific anxieties.

Anxiety in children with ASD is also associated with family stress, mood disorders, and depression (Frank et al., 2022). In the general population, up to 88% of individuals diagnosed with an anxiety disorder have also met the criteria for a depressive disorder (Jacobson & Newman, 2017). Those diagnosed with co-occurring anxiety and

depression report severe and chronic symptoms that significantly impair daily living when compared to those without comorbid diagnoses. The bidirectional relationship between anxiety and depression is, in part, accounted for by the neurophysiological response to stress (Jacobson & Newman, 2017; Duval et al., 2022). The fight or flight response is activated by an anxiety-inducing event notifying the amygdala, dorsal anterior cingulate cortex, hippocampus, hypothalamus, basal ganglia, and brainstem to release a surge of cortisol into the bloodstream (Duval et al., 2022). As the body begins to settle and cortisol release diminishes, the drastic change from high to low stress can result in depression. The neurophysiological cycle of anxiety followed by depression is common among those diagnosed with anxiety or those experiencing anxiety symptoms, and makes it largely ineffective to treat anxiety without also treating depressive symptoms. Clearly, anxiety in children with ASD presents a serious safety risk, and improved understanding of factors that influence anxiety is needed (Oliphant et al., 2020).

It is challenging to tease apart symptoms of anxiety from ASD symptomatology, particularly among those children who display low cognitive functioning (Lecavalier et al., 2014; Vasa et al., 2018; & White et al., 2015). Children and adolescents with anxiety disorders often present with symptoms from different diagnostic categories. For example, a child may insist on sameness, but also struggle to connect socially with peers. In turn whether these behavioural characteristics are reflective of ASD, generalized anxiety, or social anxiety disorder is challenging to assess. Finally, nearly 40 different measures have been used to assess anxiety in autistic children and adolescents. However, the majority of instruments have yet to be validated for use within the

ASD population and may overlook a range of anxiety symptoms exclusive to or heightened within the ASD community (Den Houting et al., 2019).

A comprehensive understanding of the risk factors associated with anxiety in autistic children and adolescents is needed (Den Houting et al., 2018; Duvekot et al., 2018; Lau et al., 2020; & Van Steensel et al., 2011). In order to investigate the presentation of anxiety in children and adolescents who have ASD compared to peers who do not have ASD, we applied an artificial neural network analysis to standardized assessments of anxiety, internalizing and externalizing behaviours, and emotional symptoms. An artificial neural network, in the form of a self-organized map (SOM), was created to reflect unique anxiety-related behavioral profiles in children with and without ASD. We further extracted the unique features associated with each behavioral profile to identify characteristics that are unique to individuals with ASD who experience anxiety. It was hypothesized that autistic children and adolescents who experience high levels of anxiety would be associated with features of ASD symptomatology.

2.1 Methods

2.1.1 Participants

Neurotypical and neurodiverse children and adolescents were recruited by the Healthy Brain Network (HBN), an initiative to create an inventory of biological markers of mental health disorders in the developing brain (Alexander et al., 2017). Neurodiverse children were diagnosed using the Autism Diagnostic Observation Schedule (ADOS-2) and the Kiddie Schedule for Affective Disorders and Schizophrenia-Children's Version (K-SADS). Youth with no diagnosis resulting from the K-SADS were classified as TD. Both TD and autistic children and adolescents completed testing over the course of

two years. Measures of behaviour, family structure, stress and trauma, substance use, and language were collected, as well as physiological and diagnostic assessments. The data used in the present study were obtained from the Child and Mind Institute, Healthy Brain Network (<https://data.healthybrainnetwork.org/main.php>). The current work utilized 262 observations comprised of TD children and adolescents as well as those with a primary clinical diagnosis of ASD. Ethical approval was obtained by the Chesapeake Institutional Review Board (IRB). Written and verbal informed consent was collected from adults prior to data collection, as well as verbal assent in participants 17 and under.

2.1.2 Materials and Measures

Demographics

Through self and parent-report questionnaires, demographic information was collected including biological sex, age, and parental relationship status (Alexander et al., 2017).

Socioeconomic Status

The Barratt Simplified Measure of Social Status (BSMSS) was administered to measure socioeconomic status (SES) (Barratt, 2006). Marital and employment status, educational accomplishments, and occupational prestige are used to orient one's SES. The BSMSS is strictly ordinal for the purpose of clustering participants into like-groups. It is important to note that the BSMSS does not indicate one's social class (e.g., middle-class), and reliability statistics cannot be applied. For example, level of education choices are less than grade seven (score = 3), less than ninth grade (score = 6), less than 11th grade (score = 9), high school graduate (score = 12), at least one year of college

(score = 15), college education (score = 18), and graduate degree (score = 21).

Depending on the sample scores obtained, a mean value will be determined within the sample. This mean value will be used to group participants into similar educational attainment categories.

Diagnostic Assessments

The K-SADS is a semi-structured interview used to measure current and past symptoms of anxiety, mood, psychotic, and disruptive behavioral disorders in children and adolescents ages six to 18 (Chambers et al., 1985). Questions such as “Have you been having any worries lately?” and “Did you look forward to doing the things you used to enjoy?” are asked by the examiner. Questions are designed to elicit responses that indicate the presence of depressive disorders, anxiety disorders, eating disorders, conduct disorders, substance use disorders, and other mental health concerns. Items are scored from zero (no information) to three (feels the queried symptom most of the day more days than not). Interviews were conducted with both participants and parents in order to determine or rule out a clinical diagnosis. Children and adolescents suspected of having ASD symptoms were referred for further diagnostic assessment using the ADOS-2.

The Autism Spectrum Screening Questionnaire (ASSQ) is among the most widely used tools to identify children and adolescents ages six to 17 who may have ASD (Gillberg Neuropsychiatry Centre, 2023). In this instrument, 27 items are completed by parents and/or teachers of youth displaying symptoms that are characteristic of ASD (Ehlers et al., 1999). Participants are asked to state no (0), somewhat (1), or yes (2) to each question with regard to their child or

student. The ASSQ contains questions such as “this child has markedly unusual posture” and “this child accumulates facts on certain subjects but does not really understand the meaning” (Gillberg Neuropsychiatry Centre, 2023). Parents and/or teachers are asked to report based on how this child differs from other children or adolescents of the same age (Ehlers et al., 1999). Total scale scores range from zero to 54, with higher scores indicating the presence of more severe ASD symptoms. Research has demonstrated that there is a 90% positivity rate of an ASD diagnosis among those who score 13 or above (Ehlers et al., 1999; Posserud et al., 2009). The ASSQ demonstrates excellent test-retest reliability ($r = .90, p < .001$) and good inter-rater reliability ($r = .79, p < .001$) between parents and teachers. Additionally, this assessment has been found to have 91% sensitivity, and 86% specificity, indicating that the ASSQ produces few false negatives (sensitivity) and few false positives (specificity).

The ADOS-2 is a play and activity-based assessment that allows for the real-time observation of ASD symptoms and behaviors (Lord et al., 2000). The test is designed for youth ages 12 months into adulthood who do not have significant sensory or motor impairments. An appropriate module is selected based upon the participant’s age, language, and level of development. The ADOS-2 is comprised of various activities, including a construction task, make-believe play, joint interactive play, a demonstration task, a description of a picture, and understanding of friends, relationships, and marriage. Activities are completed and scored using a coding

system that examines the presence or absence of abnormality on a given task. The ADOS-2 is considered the “gold standard” in the diagnosis of ASD.

Autism Symptom Severity

The Social Communication Questionnaire (SCQ) developed by Rutter and colleagues (2003) is used to assess communication skills among youth with and without ASD.

Forty items are completed by the primary caregiver of the child or adolescent aged four or older. Caregivers are asked questions such as “does she/he ever have any interests that preoccupy her/him and might seem off to other people (e.g., traffic lights, drainpipes, etc.)?” or “does she/he nod her/his head to indicate yes?”. Items are answered using a yes or no response system, whereby no = zero and yes = one. The first instrument item regarding the use of language is not scored, and is used to determine whether the abnormal language section is applicable to the specific child. As such, total scale scores range from zero to 39 (if the abnormal language section is completed) or zero to 32 (if not). A total score is obtained based upon the sum of all items, and a cut-off score of 15 is suggested to indicate those with more severe ASD symptoms who may need further clinical evaluation. Research has found the SCQ to have strong internal consistency ($\alpha = .80$), and test-retest reliability ranging from $r = .87$ to $.96$ ($p < .0001$) (Avcil et al., 2015).

The Social Responsiveness Scale (SRS-2)-School Age is comprised of 65 items to identify the presence and severity of social impairment related to ASD (Constantino & Gruber, 2012; Constantino & Todd, 2003). The SRS-2 is completed by parents or teachers of youth ages four to 18, and asks responders to consider statements

concerning social awareness, social cognition, social communication, restricted interests and repetitive behavior, social motivation, and social interaction. The SRS-2 includes statements such as “expressions on his or her face don’t match what he or she is saying” and “my child knows when he or she is talking too loud or making too much noise”. Each item is scored on a Likert scale ranging from not true (0) to almost always true (3) and scores are summed for each subscale as well as a total scale score. Higher scores indicate greater severity of social skill deficits, with T scores of 76 or higher representing severe deficits and those under 60 falling within the typical range. The SRS-2 demonstrates strong rest-retest reliability ($r = .80$ to $.95$, $p < .001$) and interrater reliability ($r = .75$ to $.77$, $p < .001$). Total internal consistency is excellent, at $\alpha = .95$.

The Repetitive Behaviors Scale-Revised (RBS-R) provides a quantitative, continuous measure of repetitive behaviors that are often attributed to ASD (Bodfish et al., 1999; Bodfish et al., 2000). Stereotypic behavior, self-injurious behavior, compulsive behavior, ritualistic/sameness behavior, and restricted interests are measured using 43 items. There is also an additional item that asks reporters to rate the overall severity of behaviors on a range of zero to 100. The RBS-R is completed by parents of participants ages six to 17, and includes items such as “my child flaps hands, wiggles or flicks fingers, claps hands, waves or shakes hands or arms” and “my child hits or bangs head or other body part on the table, floor or other surface”. Items are rated on a 4-point Likert scale (0 = behavior does not occur, 1 = behavior occurs and is a mild problem, 2 = behavior occurs and is a moderate problem, and 3 = behavior occurs and

is a severe problem) and responses should be based upon behavior within the past month (Hooker et al., 2019). Scores for each subscale are totaled to determine the area of greatest concern. Subscale internal consistency is good, ranging from $r = .73$ to $.95$ ($P < .001$) (Hooker et al., 2019; Mirenda et al., 2010). Both participants with and without ASD completed ASD diagnostic assessments.

Anxiety Symptoms

The Screen for Child Anxiety Related Disorders-Parent Report (SCARED-P) contains 41 items assessing a child's (aged eight to 18) anxiety symptoms within the last three months (Behrens et al., 2019). The SCARED-P uses a 3-point Likert scale (0 = not true, 1 = somewhat true, and 2 = very true) to examine five subcategories of anxiety including generalized, separation, social, panic/somatic, and school avoidance. A sample-item from the separation anxiety subscale is *My child worries about sleeping alone*. Possible scores range from zero to 82, with a total score of 25 or more indicating the likely presence of an anxiety disorder. The SCARED-P demonstrates high reliability across the literature (average $\alpha = .95$), even among ASD populations (Van Meter et al., 2018).

Emotional and Behavioral Problems

The Strengths and Difficulties Questionnaire (SDQ) is a 25-question Likert assessment of behavioural and psychosocial concerns in children ages two to 17 (Goodman, 1997). This questionnaire is used to assess internalizing (e.g., internalizing, depression) and externalizing behaviours (e.g., aggression). Five subscales consisting of emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behaviour are included in the questionnaire. The SDQ-internalizing subscale

(SDQ-I) consists of both the emotional and peer relationship problem subscales. The emotional problems subscale measures depression, worry, fear, nervousness, and somatic symptoms. In the present study, the SDQ-I was used to assess both anxiety and depressive symptoms. Example statements from the emotional problems subscale include *I worry a lot* and *I am often unhappy, depressed or tearful*. A sample statement from the peer relationship subscale is *Other children or young people pick on me*. Questions are answered using a 3-point system (0 = not true, 1 = somewhat true, and 2 = certainly true). Both children and parents completed this inventory. SDQ-I scores can be calculated by adding up the scores for the emotional and peer relationship problem subscales, resulting in a score range between zero and 20. An SDQ-I score of 20 indicates severe emotional and relational concerns. Each of the SDQ-I subsections, emotional and peer relationship problems, are scored from zero to 10. A score of six or higher on the emotional problems subscale indicates very high difficulties, while a score of four or higher on the peer relationship problems subscale indicates severe social deficits. The SDQ demonstrates good reliability ($\alpha = .75$).

ADHD Symptoms

The Strengths and Weaknesses Assessment of Normal Behavior (SWAN) Rating Scale for ADHD consists of 18 items used to assess both the presence and severity of ADHD symptoms (Swanson et al., 2001). The SWAN is completed by a caregiver, teacher, and/or physician on behalf youth ages six to 17. Adults are asked to answer each item with respect to how the youth in question compares to their peers of the same age over the past month. Questions around sustained attention, ability to remain seated and focused, and turn-taking are included in the assessment. Items are scored on a 7-point

Likert scale (-3 = far above average, -2 = above average, -1 = slightly above average, 0 = average, 1 = slightly below average, 2 = below average, and 3 = far below average), with weaknesses scored positively and strengths scored negatively. An inattention average and hyperactivity average score are calculated by totalling each item score and dividing by the number of items in each subscale. An additional SWAN total average score is calculated based on each of the two subscales. The more attention or activity problems displayed by the child, the lower their total SWAN score. The SWAN demonstrates excellent total scale internal consistency ($\alpha = .88$ to $.95$) with subscale internal reliability ranging from $r = .72$ to $.90$ (Arnett et al., 2013; Burton et al., 2019).

Cognitive Ability

The Wechsler Intelligence Scale for Children-Fifth Edition (WISC-V) was used to assess cognitive ability in the children (Wechsler, 1949; Wechsler, 2014). Subtests covering a range of abilities, including verbal comprehension, visual spatial skills, and processing speed, were completed by all children and adolescents ages six to 16. Average scores range from 90 to 109, with exceptionally low scores falling below 79 and high above 120. The WISC-V is often used to identify intellectual exceptionalities among school-age children, such as giftedness or IDs. Test scores have been repeatedly validated as useful for identification, placement, and resource allocation. Furthermore, the WISC-V is supported by strong split-half reliability ($r = .96$, $p < .001$), subtest reliability ($r = .80$ to $.94$, $p < .001$), and test-retest reliability ($r = .71$ to $.90$, $p < .001$).

2.1.3 Procedure

Email and poster advertisements were distributed among community members, educators, care providers, and parents in the New York City area (Alexander et al.,

2017). Advertisements stressed the value of participation for families whose children could benefit from learning accommodations at school, such as an individualized education program (IEP). All participants were screened over the phone by HBN researchers prior to answering questionnaires to ensure inclusion criteria was met. In order to meet inclusion criteria, one must identify as a male or female person between the ages of five and 21, with parents (or a caregiver) who are capable of providing verbal and written consent. Youth between five and 17 years of age must provide verbal assent, which is the clear expression of agreement to participate. Information regarding psychiatric and medical history was collected during the screening call, including the use of stimulant medication. Given that stimulant use may influence one's performance on cognitive and behavioral measures, all individuals taking stimulants were required to document the medication taken on the day of their participation. Exclusion parameters include acute safety concerns, cognitive or behavioural impairments that may interfere with the child's participation (e.g., nonverbal), or medical issues that might confound brain scan results.

Those participants enrolled in the study following the screening call were administered a semi-structured diagnostic interview by an HBN licensed clinician. Appropriate follow-up measures were completed when necessary by participants and/or their parents depending on the child's age. For example, if the diagnostic interview yielded a suspected language disorder, the Clinical Evaluation of Language Fundamentals (CELF) would be completed by the participant in question. Participants completed all language and intelligence testing with supervision from a qualified clinician. Self-

administered questionnaires, such as the SDQ and SWAN, were completed using an online patient portal system called NextGen. All assessments were completed over the course of four visits.

2.2 Analysis

Statistical analyses were performed using R (Version 4.2.0) software (R Core Team, 2021). To address the first aim to identify anxiety-related behavioral profiles, an unsupervised machine learning algorithm was used to generate a self-organizing map (SOM) (Kohonen, 2013). A SOM is an artificial neural network used to map and cluster large data sets, and have been used previously to characterize autistic children (Al-Saoud et al., 2023; Astle et al., 2021; & Hennessy et al., 2023). In the present study, the SOM contained a node (or neuron) representing the unique profile of each participant within a two dimensional plane. Initial data points, referred to as input data, were used to generate the first several nodes within the model. This served as the framework for the model, within which the remainder of the data points were statistically compared. The nodes with the closest weight vector to the input data were selected by the SOM as the best-matching unit. This process allowed for all data points (nodes) to be appropriately categorized in the model. The statistical model was trained using 262 observations and a learning rate of $\alpha = 0.05$, which is a standard SOM value (Kohonen, 2013). The number of resulting clusters was informed through visual inspection of elbow graphs prior to SOM development.

Scores from the ASSQ, SCQ, SRS, SWAN, SCARED-P, and SDQ-I were used to create a five by five hexagonal topology (Inyang et al., 2019; Kohonen, 2013) resulting

in three anxiety-related behavioral clusters. A hexagonal method is used to preserve topographical distances between nodes and reduce distortions from mapping.

Participant age, sex, family SES, intelligence, and parental age were statistically controlled for throughout all analysis procedures by including them as covariates in a linear regression model and extracting the residuals associated with each variable. In the final model, a node representing the unique behavioral profile of each participant was mapped in a two-dimensional framework. Each cluster was formulated irrespective of diagnosis. Nodes that fell within a similar location were representative of participants with a similar profile (Kohonen, 2013). For example, if two participants with ASD both display high levels of social anxiety and low separation anxiety, it was expected that their respective nodes would fall in close proximity within the model. The goal was to determine if diagnosis was predictive of cluster (or group) membership, regardless of the broad spectrum of characteristics displayed within each group. For example, the behavioral profile of a child with high anxiety may be characteristically distinct from those with low anxiety.

To address the second aim of identifying factors that determined cluster membership, recursive feature elimination (RFE) was conducted. Using RFE, the measures that contributed the most to the differences between cluster membership were identified.

RFE is a statistical process in which the key features that contribute to the SOM model are isolated (Guyon & Elisseeff, 2003). RFE scores and ranks features by permutation importance, and removes those features with limited input to the model. This process is repeated until one feature with the largest contribution to the model remains.

Permutation importance considers a variable of great importance only with respect to improving the predictive accuracy of the model.

2.3 Results

2.3.1 Participants

Of the 262 children and adolescents who participated in the current study, 111 were diagnosed with ASD (42%), and the remaining participants were typically-developing. Participants were between the ages of five and 17 and the mean age was 10.5 years. The majority of autistic participants were boys ($n=86$, 77.4%). Both ASD and TD participants reported similar SES scores on the BSMSS, with all other scale scores being significantly larger among participants with ASD.

2.3.2 Anxiety-Related Behavioral Profiles

Three anxiety-related behavioral profiles were identified using the SOM, with the data forming three distinct clusters (Figure 1a). Cluster 1 was comprised of participants who report moderate levels of anxiety (Figure 1b), cluster 2 was composed of participants reporting high levels of anxiety, and cluster 3 was characterized by low levels of anxiety.

Those in the low anxiety cluster (cluster 3), consisting primarily of TD participants (80%), demonstrated low depressive ($M = 5.69$; $SD = 4.35$) and anxiety ($M = 7.91$; $SD = 6.93$) symptoms, and also had strong communication skills ($M = 5.36$; $SD = 3.39$).

In contrast, nearly all participants diagnosed with ASD (94%) fell within the moderate and high anxiety clusters. The high anxiety cluster was composed primarily of male-identifying autistic participants.

This cohort was characterized by high ASSQ ($M = 27.67$; $SD = 7.85$), SRS ($M = 116.31$; $SD = 14.47$), and anxiety scores (SCARED-P) ($M = 24.94$; $SD = 13.63$), ADHD symptoms ($M = 1.38$; $SD = .75$), social communication challenges ($M = 16.92$; $SD = 4.17$), repetitive behaviors ($M = 79.19$; $SD = 35.74$), and emotional and behavioral problems ($M = 19.98$; $SD = 4.83$). Those participants in cluster two also reported the most severe depressive symptoms ($M = 9.63$; $SD = 3.03$) on the SDQ-I, suggesting that depression is a critical indicator of anxiety in autistic children and adolescents.

With respect to anxiety measures, peer problems ($M = 5.49$; $SD = 2.03$) were the most reliable factor in determining cluster membership. The majority of participants who reported having significant peer problems (e.g., difficulty engaging in conversations, trouble making friends, and/or victimization of bullying/harassment) occupied the high anxiety cluster. Secondary factors associated with the high anxiety group were SDQ impact supplements ($M = 6.41$; $SD = 1.89$), total difficulties ($M = 19.98$; $SD = 4.83$), and hyperactivity concerns ($M = 7.57$; $SD = 2.11$).

Cluster one, moderate anxiety, was comprised of both ASD and TD participants.

Participants in this cluster had low ADHD ($M = 0.16$; $SD = 1.20$) and excellent social responsiveness skills ($M = 58.34$; $SD = 39.04$) along with average ASSQ ($M = 11.50$; $SD = 7.92$), RBS-R ($M = 34.41$; $SD = 41.92$), depressive ($M = 13.57$; $SD = 4.60$), and anxiety ($M = 14.96$; $SD = 9.21$) scores.

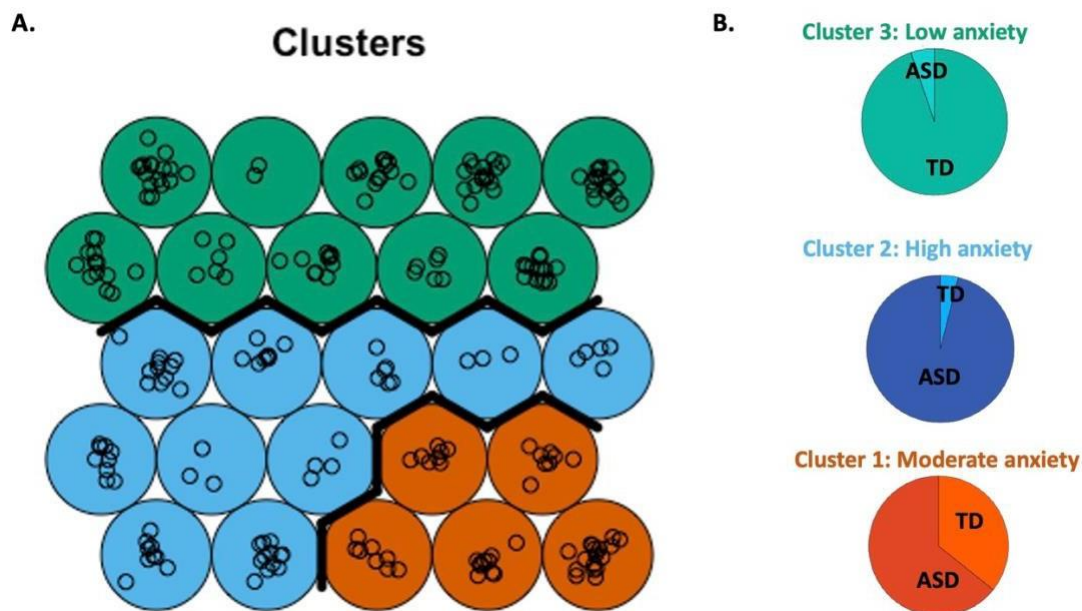


Figure 1. Anxiety-related behavioral profiles in children and adolescents with ASD and TD children and adolescents.

Note. A. Cluster profiles identified using Self Organizing Maps. B. Cluster membership by diagnosis.

RFE results displayed in Figure 2 demonstrate that depression (measured using the SDQ-I) was the most robust indicator of high anxiety among both ASD and TD participants (11.71). Therefore, severe and frequent depressive symptoms, such as social isolation and unhappiness, are characteristic of high anxiety. Additionally, generating impact statements (11.15), anxiety related to peer problems (11.07), total difficulties (10.77), and hyperactivity (10.39) scores on the SDQ were also among the most prominent contributors to the SOM model. Anxiety assessments (SDQ-I, SCARED-P) account for

the first 15 features within the RFE, and are therefore the only features included in Figure 2.

On the other hand, RFE findings indicated that total (3.62), generalized (3.33), social (3.10), and separation (1.86) anxiety as well as school avoidance (2.44) and panic disorder (0.47) on the SCARED-P were the weakest distinguishing factors between behavioral clusters, along with conduct problems (1.36) as measured with the SDQ.

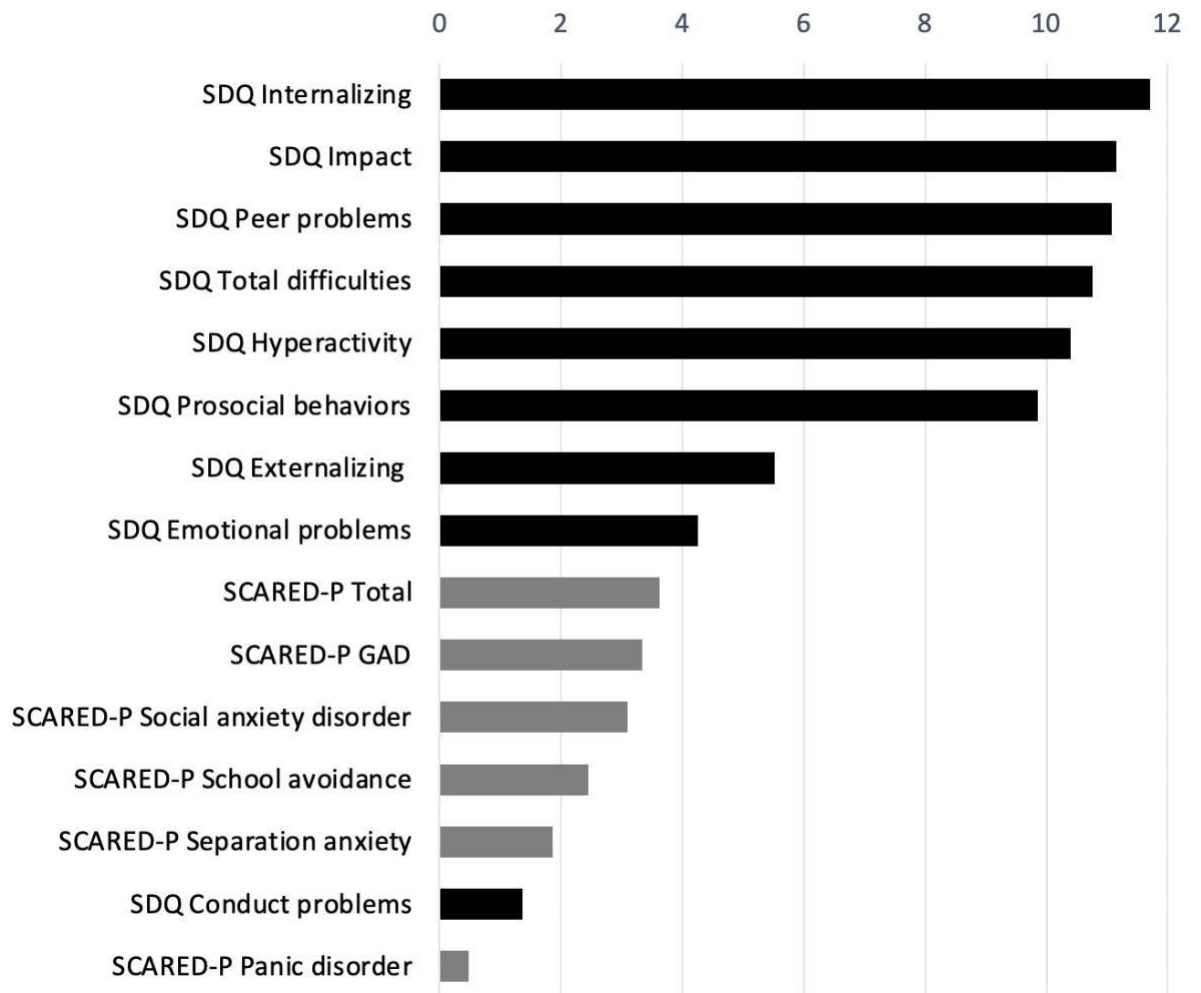


Figure 2. Recursive Feature Elimination (RFE) Applied to Anxiety Measures
Feature ranking was performed using permutation importance. SDQ (black);
SCARED-P (dark grey).

2.4 Discussion

The current study sought to identify anxiety-related behavioral profiles in a heterogenous cohort of children with ASD and those who are typically-developing. By using a well-phenotyped cohort, we were able to apply an artificial neural network analytic method applied to anxiety measures in children with and without ASD. Using this analysis, we found

distinct clusters of children who have various levels of anxiety, depression, and ADHD symptomatology. We found that children with ASD generally had moderate or high anxiety. Some TD children had moderate anxiety; however, most TD children had low anxiety, and depression was strongly associated with high anxiety in both groups. Peer problems were an additional reliable factor in determining cluster membership; most participants who reported having significant peer problems (e.g., difficulty engaging in conversations, trouble making friends, and/or victimization of bullying/harassment) occupied the cluster two, characterized by high anxiety. It can be theorized that autistic children and adolescents with anxiety are more likely than their TD peers to experience serious and disruptive peer interactions.

Anxiety in autistic children is extremely common and is associated with increased social impairment and isolation over time, commonly resulting in a reduced QoL compared to TD youth (Adams et al., 2019; Duvekot et al., 2018; & White et al., 2014). Previous reports have also noted that specific types of anxiety in older adolescents are particularly resistant to CBT when early treatment is not sought (Vasa et al., 2020). Efforts by healthcare providers, therapists, parents, and educators are essential to the success and development of children and adolescents with anxiety. Previous and ongoing investigations into the implementation of CBT modified for use among children with anxiety in children with ASD shows promising results (Erps et al., 2023; Guzick et al., 2022; Storch et al., 2013; & Vasa et al., 2020). CBT adapted to meet the unique needs and barriers of working in the ASD community includes greater flexibility in techniques, heavy familial involvement, frequent use of

exposure tasks, and the establishment of a reward system to promote engagement and trying new skills. Early interventions that focus on exposure and social skill development should begin as early as three years of age, allowing for the greatest possible reduction in future challenges (Erps et al., 2023; Fuller & Kaiser, 2020; & Wood et al., 2020). In addition to working with a therapist or other healthcare provider, parents can expect frequent and unique expressions of anxiety from their autistic children. They should also focus on becoming directly involved in the therapeutic process, both in and outside of sessions. Educators should maintain an open line of communication with parents (and healthcare providers when appropriate) to ensure they are providing the best learning and social environment possible for each child.

Hyperactivity, social isolation, rigid expectations, and differences in communication styles, which some children with ASD may express in school settings, may be an area of key focus for educators. It may also be helpful for educators to implement various therapeutic strategies in the classroom, such as creating a token economy, tailoring homework to fit the learning style of the child, and avoiding group projects that often further highlight social isolation and rejection.

Depression was far more common among participants with high anxiety (predominantly ASD) and was the most prominent factor in differentiating cluster membership. High depression among autistic youth with anxiety is largely attributed to frequent experiences of social isolation, often stemming from impaired social communication and interaction skills inherent to ASD (Duan et al., 2022; Fung et al., 2015; & Pascoe et al., 2023). Peer problems were also strongly indicative of high anxiety. Clearly, depression is a significant predictor of high anxiety in both ASD and TD populations. In addition to the cortisol-related stress cycle, depression among youth with ASD who have anxiety may be accounted for by more frequent challenges in seeking out and

maintaining social relationships. Additionally, children and adolescents with ASD are more likely to report feeling ostracized from their TD peers, which may contribute to high levels of depression among this group.

Children and adolescents with ASD who have anxiety should be assessed for possible comorbid depression. Given the bidirectional relationship between anxiety and depression, it may be ineffective to treat one without consideration for the other. The current findings also point to early intervention to develop and strengthen social and communication skills as critical to preventing and managing depression among youth with ASD-specific anxiety. Improved social engagement and conversational skills may reduce the occurrence of peer problems, consequently decreasing symptoms of depression and anxiety.

Relative to previous work exploring the relationship between ASD and anxiety (Conner et al., 2020; Frank et al., 2022; Hallett et al., 2013; & Jefferson & Erp, 2022), using the current approach we analyzed data from a small sample of children and adolescents with ASD ($N = 111$). Given that youth with ASD were the population of interest in the present study, the small sample is a significant limitation to generalizing findings to the ASD community as a whole. As well, just over 22% of those diagnosed with ASD identified as female, meaning results are predominantly reflective of the male

perspective of ASD-specific anxiety symptoms. It is plausible that female-identifying participants may experience anxiety differently than their male counterparts. For example, previous literature indicates that females with ASD often experience more internalized anxiety (e.g., sleep disruption and/or fear of change) while males express more outward behavioral concerns (e.g., hyperactivity, relational issues, and/or learning difficulties) that create more noticeable challenges both at home and school (Beggiato et al., 2017). The notable importance of peer problems in the current analysis may be more representative of male-identifying autistic children and adolescents than females, potentially overlooking therapeutic and social interventions that could benefit female children with ASD. Finally, it is difficult to determine if the high anxiety cluster (cluster two) is a result of ASD symptoms worsening anxiety or anxiety exacerbating core ASD symptoms, however this was not within the scope of the current study.

2.5 Conclusion

Depression and peer problems were prominent factors that distinguished children and adolescents with ASD with high anxiety from children with and without ASD and those

who are TD with low to moderate anxiety. Additionally, peer relationship problems pose a notable challenge to youth with ASD, and exacerbate both depression and anxiety symptoms. Total emotional difficulties and hyperactive behaviour also predispose children and adolescents with ASD to more frequent and pronounced experiences of anxiety. Specific types of anxiety, including generalized, social, and separation, do not account for a significant difference between high and low levels of anxiety in youth with ASD. Findings indicate that early interventions, focused on family-involvement, emotional regulation, and the development of social and communication skills, must be consistently implemented among autistic children and adolescents who have anxiety. Exposure to various social interactions and education on emotion management has shown promising results in reducing depression and anxiety among children and adolescents with ASD, while simultaneously fostering a sense of belongingness. Future investigations should explore the influence of parental mental health on the development and maintenance of anxiety and depression in children and adolescents with ASD. Another avenue of inquiry would be to apply modified CBT principles into educational settings to support youth with ways of learning that differ from the traditional curriculum. Finally, consideration must be given to the bidirectional relationship between ASD and anxiety. Developmental researchers should attempt to isolate whether anxiety worsens core symptoms of ASD, or if ASD heightens one's experience of anxiety. A clear understanding of strategies to improve mental health among children and adolescents with ASD will enhance social engagement, communication, adjustment, and overall fulfillment and satisfaction throughout the lifespan.

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Chapter 3

3 Discussion

The present study explored the behavioral phenotypes of ASD-related anxiety as well as factors that distinguish those with ASD-related anxiety from TD youth with and without anxiety. Using an artificial neural network analytic method known as a self-organizing map (SOM), three anxiety-related behavioral profiles were isolated within the cohort. Children and adolescents with and without ASD fell within clusters representing moderate, high, and low anxiety behaviours. The majority of those diagnosed with ASD occupied the high anxiety cluster, with the low anxiety group composed primarily of TD participants. The moderate anxiety cluster represented a more even distribution between ASD and TD youth. High and moderate anxiety clusters reported more severe ASD core symptoms, poor social responsiveness skills, high anxiety and ADHD symptoms, peer relationship issues and severe depressive symptoms. This finding is consistent with previous literature indicating that the occurrence of frequent and debilitating anxiety is significantly higher among those with ASD when compared to TD counterparts (Adams et al., 2019; Andrews et al., 2022; Den Houting et al., 2018; Duvekot et al., 2018; Lau et al., 2020; & Van Steensel & Heeman, 2017). Recursive feature elimination (RFE) was used to identify factors that determined high anxiety cluster membership. Depression, along with ADHD and social relationship problems are characteristic of ASD-related anxiety and TD children and adolescents with moderate to high anxiety.

Depressive symptoms, including loneliness, were the strongest predictor of high anxiety among both autistic and TD youth. It can be inferred that depressive symptoms are

characteristic of ASD-related anxiety, likely stemming from feelings of social isolation. Depression playing such a significant role in ASD-related anxiety is supported by previous works, suggesting over half of those with ASD report severe depressive symptoms (Duan et al., 2022; Fung et al., 2015; & Pascoe et al., 2023). Additionally, depression is highly correlated with anxiety and ASD symptoms in the literature (Conner et al., 2023). Depressive symptoms are more common among those with higher cognitive functioning, as those children and adolescents are more aware of the social challenges and exclusion they face daily (Duan et al., 2022; Fung et al., 2015). Both familial and environmental stressors play a role in the development and maintenance of depressive symptoms, with negative life events often acting as a predecessor to depression among autistic children (DeFillipis, 2018; Hosozawa et al., 2020). The prevalence of depression among those with ASD highlights the need for further exploration into this construct, and greater awareness among parents, educators, and mental health professionals.

With respect to anxiety measures, peer relationship problems were the greatest separating features of the high anxiety cluster, which was predominantly comprised of autistic children. Difficulty engaging, trouble making and maintaining friends, and peer victimization were among common reported issues. It is proposed that peer relationship challenges are directly linked to the severity of core ASD symptoms, such as repetitive and restricted behaviors and limitations in social communication and engagement skills. Additionally, there is a close bidirectional relationship between depressive symptoms and social problems. More frequent, negative social interactions heighten depressive symptoms among youth with ASD, and vice versa. Anxiety measures (SDQ-I, SCARED-P) accounted for the majority of the separating features between the anxiety clusters.

Although not the greatest predictor, anxiety symptoms such as peer problems, hyperactivity, externalizing behaviors, and emotional problems assist in determining cluster membership. In contrast, generalized, social, and separation anxiety along with school avoidance, panic disorder, and conduct problems have little impact on anxiety levels experienced by both ASD and TD youth.

2.6 Implications

The current work highlighted specific behavioral phenotypes characteristic of autistic children and adolescents. Depression and peer relationship problems were the strongest predictors of high anxiety among children and adolescents with ASD. Considerable attention should be given to the heightened risk of depression among youth with ASD-related anxiety, especially given the increased risk of suicidal behaviors and self-harm within this population (Hirvikoski et al., 2020; Oliphant et al., 2020). Mental health professionals, parents, and educators should be made aware of elevated safety concerns among youth with ASD-specific anxiety, and questions around suicide and self-harm should not be avoided.

With respect to treatment of depression, CBT demonstrates inconsistent outcomes in the literature (Menezes et al., 2020). Furthermore, it can be very difficult to assess depression in youth with ASD due to the similarities between depressive and ASD symptoms (e.g., social isolation, sleep disturbances, changes in appetite, low energy) (Pascoe et al., 2023). It is also challenging for youth with ASD to recognize and convey emotional problems, increasing the likelihood of mental health professionals and parents missing important indicators of depression (Fung et al., 2015). Mental health professionals can also benefit from the knowledge concerning depression in children and adolescents with ASD-related anxiety. As depression may be

more prominent among those with higher cognitive and intellectual abilities (Fung et al., 2015; Pascoe et al., 2023). Children and adolescents with ASD and higher intellectual abilities are likely to engage in more social interactions, more likely to be bullied, and can recognize their differences from peers and challenges with communication more readily than those with ASD and lower intellectual and cognitive functioning (Pascoe et al., 2023). Additionally, social demands tend to be greater among those with higher intellectual functioning. These conclusions are based on the premise that an autistic child or adolescent must be aware of the social difficulties they face to be negatively affected by them.

The current literature is limited with respect to the treatment of depression in youth with ASD and high anxiety. The few studies exploring the use of antidepressants and psychotropic medications have found little evidence to support their use for the treatment of depression in the ASD community (King et al., 2009; Menezes et al., 2020; Owley et al., 2005; Steinsiek et al., 2023; & Williams et al., 2013). Regardless of the lack of supportive evidence, antidepressants are still commonly prescribed to autistic youth (Steinsiek et al., 2023). Most psychosocial interventions focus on adults and the treatment of core ASD symptoms rather than depression (DeFilippis, 2018). Both individual and group CBT along with mindfulness-based therapy (MBT) have shown mixed evidence in the treatment of depression among autistic children. To date, there is no universal, evidence-based treatment for depression in autistic children and adolescents (Steinsiek et al., 2023).

Despite the lack of standardized treatments for depression in autistic children and adolescents, current literature indicates that the most promising approach are social skills

training programs (Jonsson et al., 2019; Pascoe et al., 2023). Jonsson and colleagues (2019) found promising results in the improvement of depressive symptoms in youth with ASD using social skills group training. Those in the intervention group received training on social motivation, awareness of self and others, problem-solving skills, and strategies to improve self-confidence. This program included computer-based training, behavior activation, psychoeducation, observational learning, and parent/guardian involvement. All children and adolescents with ASD reported improvements in depressive symptoms, which were maintained at a three-month follow-up. Another study conducted a randomized controlled trial that utilized a digital version of the PEERS (program for the education and enrichment of relational skills) program (Lee et al., 2022). Virtual reality sessions included psychoeducation, conversational skills, electronic communication, choosing appropriate friends, use of humor, peer entry and exit strategies, understanding get togethers, showing good sportsmanship, navigating teasing and bullying, resolving disagreements, and managing gossip and rumors. The virtual environment is easily accessible, affordable, can be used in home, school, and therapeutic settings, and offers a unique opportunity to practice new skills in a safe environment. This virtual program can also detect emotional changes that are important for therapists to be aware of. Therapists and other mental health professionals can use this information to teach autistic children to recognize and express emotions in a healthy way. The virtual PEERS program was found to be very successful in improving social skills, thereby reducing anxiety, stress, and depressive symptoms.

In the context of counselling psychology for ASD-related anxiety, implementing social skills training programs, either in-person or virtually, into treatment among autistic children and adolescents with depression may be beneficial. Such training can easily be incorporated into all therapeutic modalities and should not be ignored in this population.

Early intervention that targets the improvement of social and communication skills in youth with ASD can improve the development and maintenance of social relationships throughout the lifespan. As well, improved social skills reduce the likelihood of experiencing peer victimization, social isolation, and judgement. In turn, a reduction in social challenges will improve symptoms of depression and anxiety that often stem from social exclusion. The use of mindfulness-based therapy (MBT) in higher functioning clients with ASD may also offer benefits. MBT offers tools that help regulate emotions and redirect negative feelings. Finally, counsellors should be aware of the high usage of antidepressants among autistic youth, while understanding that these medications often target core ASD symptoms as opposed to depression or anxiety.

2.7 Limitations

This study has several strengths related to the inclusion of well-characterized heterogenous cohorts of autistic children and adolescents and those that are neurotypical. Using machine learning methods, the majority of ASD and TD with either high or low anxiety were classified based on distinctive features. However, the study also had several limitations. First, the sample size of children and adolescents with ASD ($N = 111$) was relatively small when compared to existing literature (Conner et al., 2020; Frank et al., 2022; & Jefferson & Erp, 2022). The small sample size may have led to the lack of an ASD-specific anxiety group, given that there were two TD participants in the high anxiety group. Therefore, it was not possible to identify features solely associated with ASD-specific anxiety. Additionally, the ASD sample was predominantly male

(77.4%), potentially limiting findings to work with male autistic youth. More general limitations include potential discrepancies between self-report and parent-reports throughout the data collection process. For example, the SDQ was completed by participants while the SCARED-P was completed by parents or teachers. Children and adolescents likely experience anxiety differently than their parents or teachers may indicate. It is also impossible to control for other contributing mental health issues, such as undiagnosed ADHD, mood disorders, or conduct disorders. Although participants had a primary diagnosis of ASD or no diagnosis, diagnosis can be a subjective process in which other comorbidities are included under the umbrella of ASD. A final limitation is that results are representative of youth with ASD who have average to above average intellectual abilities. Therefore, it is difficult to determine if those with low cognitive abilities experience anxiety differently than their peers with higher abilities. Youth with ASD and low cognitive abilities continue to be largely excluded from the literature, which is widely attributed to challenges in data collection and reporting.

2.8 Future Directions

Given the limited understanding of ASD-related anxiety and the relationship to depression, there is significant opportunity for exploration in this area. Further projects exploring the effectiveness of social skills training (both in-person and virtually) should be conducted across both young children and older adolescents. Specifically, researchers should explore the influence of a social skills training program, like PEERS, on depression outcomes among autistic youth. There are very few studies working to advance and develop a wide-ranging treatment protocol for autistic youth with comorbid depression. Future work may strive to build standard protocols that are typed

based on ASD and depression symptoms and severity. A greater understanding of the impact of antidepressants within this population is also needed to augment psychosocial approaches with medication regimens, especially given the high prescription rate of antidepressants among youth with ASD. Most studies that currently address the treatment of depression among those with ASD focuses on adults. MBT has also been proposed in the existing literature as a possible treatment for depression among youth with ASD. Randomized controlled trials that investigate this potential treatment are needed. Clinicians may also investigate somatic experiencing (SE) techniques in the treatment of depression and anxiety for autistic adolescents who have difficulty verbally expressing their thoughts and feelings. Finally, future hypothesis-driven research focused on isolating the direction of the relationships between symptoms of ASD, depression and anxiety.

2.9 Conclusions

The current study provides insight into the behavioral and emotional symptoms of ASD-related anxiety, namely depression and peer relationship problems. These findings highlight the need for education and training focused on depression and the safety risks that may accompany anxiety symptoms in autistic children and adolescents. Future psychosocial treatments for anxiety in children with ASD could also focus on social skills training programs, through which depressive symptoms can be managed. Future work should further explore the relationship between ASD-related anxiety and depression, evaluate the use of MBT, or social-skills training programs with the goal of building a standard treatment protocol for children and adolescents with ASD-related anxiety and depression. Furthermore, the use of antidepressants within this population should be

incorporated into treatment on a case-by-case basis, and only prescribed by those with extensive knowledge of the inconclusive literature. The early intervention and improvement of social and communication skills may reduce both depressive and anxiety symptoms, improving the quality of life among youth with ASD throughout the lifespan.

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Appendices

Appendix A

The Barratt Simplified Measure of Social Status (BSMSS)

Circle the appropriate number for your Mother's, your Father's, your Spouse/Partner's, and your level of school completed and occupation. If you grew up in a single parent home, circle only the score from your one parent. If you are neither married nor partnered circle only your score. If you are a full time student circle only the scores for your parents.

<u>Level of School Completed</u>	<u>Mother</u>	<u>Father</u>	<u>Spouse</u>	<u>You</u>
Less than 7th Grade	3	3	3	3
Junior High/Middle School (9th Grade)	6	6	6	6
Partial High School (10th or 11th Grade)	9	9	9	9
High School Graduate	12	12	12	12
Partial College (at least one year)	15	15	15	15
College Education	18	18	18	18
Graduate Degree	21	21	21	21

Circle the appropriate number for your Mother's, your Father's, your Spouse/Partner's, and your occupation. If you grew up in a single parent home, use only the score from your parent. If you are not married or partnered, circle only your score. If you are still a full-time student only circle the scores for your parents. If you are retired use you most recent occupation.

<u>Occupation</u>	<u>Mother</u>	<u>Father</u>	<u>Spouse</u>	<u>You</u>
Day laborer, janitor, house cleaner, farm worker, food counter sales, food preparation worker, busboy	5	5	5	5
Garbage collector, short-order cook, cab driver, shoe sales, assembly line workers, masons, baggage porter	10	10	10	10
Painter, skilled construction trade, sales clerk, truck driver, cook, sales counter or general office clerk	15	15	15	15
Automobile mechanic, typist, locksmith, farmer, carpenter, receptionist, construction laborer, hairdresser	20	20	20	20
Machinist, musician, bookkeeper, secretary, insurance sales, cabinet maker, personnel specialist, welder	25	25	25	25
Supervisor, librarian, aircraft mechanic, artist and artisan, electrician, administrator, military enlisted personnel, buyer	30	30	30	30

Nurse, skilled technician, medical technician, counselor, manager, police and fire personnel, financial manager, physical, occupational, speech therapist	35	35	35	35
Mechanical, nuclear, and electrical engineer, educational administrator, veterinarian, military officer, elementary, high school or special education teacher	40	40	40	40
Physician, attorney, professor, chemical and aerospace engineer, judge, CEO, senior manager, public official, psychologist, pharmacist, accountant	45	45	45	45

<u>Level of School Completed Scoring</u>	
1.	<p>If you grew up with both parents add Mother + Father and divide by 2</p> <p>If you grew up with one parent enter that score to the right</p>
2.	<p>If you are married or partnered add Spouse + You and divide by 2</p> <p>If you live alone enter Your score to the right</p> <p>If you are a full-time student leave this blank</p>
3.	<p>Double your score from line 2</p> <p>If you are a full-time student leave this blank</p>

4.	<p>If you are a full-time student enter only your parents' score. Add line 1 and line 3 then divide by 3 for a TOTAL EDUCATION</p> <p>Score should be between 3 and 21</p>	
<u>Occupation Scoring</u>		
1.	<p>If you grew up with both parents add Mother + Father and divide by 2</p> <p>If you grew up with one parent enter that score to the right</p>	
2.	<p>If you are married or partnered add Spouse + You and divide by 2</p> <p>If you live alone enter Your score to the right</p> <p>If you are a full-time student leave this blank</p>	
3.	<p>Double your score from line 2</p> <p>If you are a full-time student leave this blank</p>	
4.	<p>If you are a full-time student enter only your parents' score. Add line 1 and line 3 then divide by 3 for TOTAL OCCUPATION</p> <p>Score should be between 5 and 45</p>	

<u>Total Score</u>	
Add TOTAL EDUCATION + TOTAL OCCUPATION	

(Score should be between 8 and 66)	
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Appendix B

Autism Spectrum Screening Questionnaire (ASSQ)

Instructions: Below is a list of statements that may or may not describe your child. Read each statement carefully and decide if it is “Not True”, “Somewhat True”, or “True” of your child. For each statement, fill in one circle that corresponds to the response that best describes your child. Please respond to all statements as best as you can, even if some do not seem to concern your child.

1. Is old-fashioned or precocious
2. Is regarded as an ‘eccentric professor’ by the other children
3. Lives somewhat in a world of his/her own with restricted idiosyncratic intellectual interests
4. Has a literal understanding of ambiguous and metaphoric language (i. e. takes things literally; troubles understanding expressions or metaphors)
5. Has a deviant style of communication with a formal, fussy, ‘old-fashioned’ or ‘robotlike’ language (i. e. talks differently than other children, in a formal or stilted way)
6. Invents idiosyncratic words and expressions (i. e. makes up his or her own words, expressions or names for things)
7. Has a different voice or speech
8. Expresses sounds involuntarily; clears throat, grunts, smacks, cries or screams
9. Is surprisingly good at some things and surprisingly poor at others
10. Uses language freely but fails to make adjustments to fit social contexts or the needs of different listeners

11. Lacks empathy (i. e. tends to see things only from his/her own perspective, and has troubles seeing things from other's perspective)
12. Makes naïve and embarrassing remarks
13. Has a deviant style of gaze (e.g., may range from not looking people in the eye, to the other extreme of staring directly at people to the point it makes them uncomfortable)
14. Wishes to be sociable but fails to make relationships with peers
15. Can be with other children but only on his/her terms
16. Lacks best friend
17. Lacks common sense
18. Is poor at games; no idea of cooperating in a team, scores 'own goals'
19. Has clumsy, ill coordinated, ungainly, awkward movements or gestures
20. Has involuntary face or body movements (i. e. any tics?)
21. Has difficulties in completing simple daily activities because of compulsory repetition of certain actions or thoughts (i. e. any habits that she/he just has to do?)
22. Has special routines; insists on no change (i. e. may need to have exactly the same change; troubles with even the slightest change in his/her environment, or routines or activities)
23. Shows idiosyncratic attachment to objects (i. e. may get strangely attached to objects as if they were people)
24. Is bullied by other children
25. Has markedly unusual facial expression

26. Has markedly unusual posture

Appendix C
Social Communication Questionnaire (SCQ)

Instructions: Please answer each question by selecting “Yes” or “No” with respect to your child. A few questions ask about several related types of behavior. Please select “yes” if any of these behaviors were present during the past 3 months. Although you may be uncertain, please answer either “Yes” or “No” to every question on the basis of what you think.

1. Is he/she now able to talk using short phrases or sentences? If no, skip to question 8
2. Do you have a to and fro “conversation” with her/him that involves taking turns or building on what you have said?
3. Does she/he ever use odd phrases or say the same thing over and over in almost exactly the same way (either phrases that she/he hears other people use or ones that she/he makes up?)
4. Does she/he ever use socially inappropriate questions or statements? For example, does she/he ever regularly ask personal questions or make personal comments at awkward times?
5. Does she/he ever get her/his pronouns mixed up (e.g., saying you or she/he for I)?
6. Does she/he ever use words that she/he seems to have invented or made up her/himself; put things in odd, indirect ways; or use metaphorical ways of saying things (e.g., saying hot rain for steam)?
7. Does she/he ever say the same thing over and over again?
8. Does she/he ever have things that she/he seems to have to do in a very particular way or order or rituals that she/he insists that you go through?

9. Does her/his facial expression usually seem appropriate to the particular situation, as far as you can tell?
10. Does she/he ever use your hand like a tool or as if it were part of her/his own body (e.g., pointing with your finger or putting your hand on a doorknob to get you to open the door?)
11. Does she/he ever have any interests that preoccupy her/him and might seem off to other people (e.g., traffic lights, drainpipes, or timetables?)
12. Does she/he seem to be more interested in parts of a toy or an object (e.g., spinning the wheels of a car), rather than in using the object as it was intended?
13. Does she/he ever have any special interests that are unusual in their intensity but otherwise appropriate for her/his age and peer group (e.g., trains or dinosaurs)?
14. Does she/he ever seem to be unusually interested in the sight, feel, sound, taste, or smell of things or people?
15. Does she/he ever have any mannerisms or odd ways of moving her/his hands or fingers, such as flapping or moving her/his fingers in front of her/his eyes?
16. Does she/he ever have any complicated movements of her/his whole body, such as spinning or repeatedly bouncing up and down?
17. Does she/he ever injure her/himself deliberately, such as by biting her/his arm or banging her/his head?
18. Does she/he ever have any objects (other than a soft toy or comfort blanket) that she/he has to carry around?
19. Does she/he have any particular friends or a best friend?
20. Does she/he ever talk with you just to be friendly (rather than to get something)?

21. Does she/he ever spontaneously copy you (or other people) or what you are doing (such as vacuuming, gardening, or mending things)?
22. Does she/he ever spontaneously point at things around her/him just to show you things (not because she/he wants them)?
23. Does she/he ever use gestures, other than pointing or pulling your hand, to let you know what she/he wants?
24. Does she/he nod her/his head to indicate yes?
25. Does she/he shake her/his head to indicate no?
26. Does she/he usually look at you directly in the face when doing things with you or talking with you?
27. Does she/he smile back if someone smiles at her/him?
28. Does she/he ever show you things that interest her/him to engage your attention?
29. Does she/he ever offer to share things other than food with you?
30. Does she/he ever seem to want you to join in her/his enjoyment of something?
31. Does she/he ever try to comfort you if you are sad or hurt?
32. If she/he wants something or wants help, does she/he look at you and use gestures with sounds or words to get your attention?
33. Does she/he show a normal range of facial expressions?
34. Does she/he ever spontaneously join in and try to copy the actions in social games, such as The Mulberry Bush or London Bridge is Falling Down?
35. Does she/he play any pretend or make-believe games?

36. Does she/he seem interested in other children of approximately the same age whom she/he does not know?
37. Does she/he respond positively when another child approaches her/him?
38. If you come into a room and start talking to her/him without calling her/his name, does she/he usually look up and pay attention to you?
39. Does she/he ever play imaginative games with another child in such a way that you can tell that each child understands what the other is pretending?
40. Does she/he play cooperatively in games that need some form of joining in with a group of children, such as hide-and-seek or ball games?

Appendix D
Social Responsiveness Scale (SRS-2)-School Age

Instructions: For each of the following statements, please select “Not True”, “Sometimes True”, “Often True”, or “Almost Always True” with respect to your child over the past 6 months. Please answer each question to the best of your ability and knowledge.

1. Seems much more fidgety in social situations than when alone
2. Expressions on his or her face don't match what he or she is saying
3. Seems self-confident when interacting with others
4. When under stress, he or she shows rigid or inflexible patterns of behavior that seem odd
5. Doesn't recognize when others are trying to take advantage of him or her
6. Would rather be alone than with others
7. Is aware of what others are thinking or feeling
8. Behaves in ways that seem strange or bizarre
9. Clings to adults, seems too dependent on them
10. Takes things too literally and doesn't get the real meaning of a conversation
11. Has good self-confidence
12. Is able to communicate his or her feelings to others
13. Is awkward in turn-taking interactions with peers (e.g., doesn't seem to understand the give-and-take of conversations)
14. Is not well coordinated

15. Is able to understand the meaning of other people's tone of voice and facial expressions
16. Avoids eye contact or has unusual eye contact
17. Recognizes when something is unfair
18. Has difficulty making friends, even when trying his or her best
19. Gets frustrated trying to get ideas across in conversations
20. Shows unusual sensory interests (e.g., mouthing or spinning objects) or strange ways of playing with toys
21. Is able to imitate others' actions
22. Plays appropriately with children his or her age
23. Does not join group activities unless told to do so
24. Has more difficulty than other children with changes in his or her routine
25. Doesn't seem to mind being out of step with or "not on the same wavelength" as others
26. Offers comfort to others when they are sad
27. Avoids starting social interactions with peers or adults
28. Thinks or talks about the same thing over and over
29. Is regarded by other children as odd or weird
30. Becomes upset in a situation with lots of things going on
31. Can't get his or her mind off something once he or she starts thinking about it
32. Has good personal hygiene

33. Is socially awkward, even when he or she is trying to be polite
34. Avoids people who want to be emotionally close to him or her
35. Has trouble keeping up with the flow of a normal conversation
36. Has difficulty relating to adults
37. Has difficulty relating to peers
38. Responds appropriately to mood changes in others (e.g., when a friend's or playmate's mood changes from happy to sad)
39. Has an unusually narrow range of interests
40. Is imaginative, good at pretending (without losing touch with reality)
41. Wanders aimlessly from one activity to another
42. Seems overly sensitive to sounds, textures, or smells
43. Separates easily from caregivers
44. Doesn't understand how events relate to one another (cause and effect) the way other children his or her age do
45. Focuses his or her attention to where others are looking or listening
46. Has overly serious facial expressions
47. Is too silly or laughs inappropriately
48. Has a sense of humor, understands jokes
49. Does extremely well at a few tasks, but does not do as well at most other tasks
50. Has repetitive, odd behaviors such as hand flapping or rocking
51. Has difficulty answering questions directly and ends up talking around the subject

52. Knows when he or she is talking too loud or making too much noise
53. Talks to people with an unusual tone of voice (e.g., talks like a robot or like he or she is giving a lecture)
54. Seems to react to people as if they are objects
55. Knows when he or she is talking too loud or making too much noise
56. Walks in between two people who are talking
57. Gets teased a lot
58. Concentrates too much on parts of things rather than seeing the whole picture. For example, if asked to describe what happened in a story, he or she may talk only about the kind of clothes the characters were wearing
59. Is overly suspicious
60. Is emotionally distant, doesn't show his or her feelings
61. Is inflexible, has a hard time changing his or her mind
62. Give unusual or illogical reasons for doing things
63. Touches others in an unusual way (e.g., he or she may touch someone just to make contact and then walk away without saying anything)
64. Is too tense in social settings
65. Stares or gazes off into space

Appendix E
Repetitive Behaviors Scale (RBS-R)

Instructions: Please carefully read each of the statements listed below. Answer each question with “Behavior Does Not Occur”, “Behavior Occurs and is a Mild Problem”, “Behavior Occurs and is a Moderate Problem”, or “Behavior Occurs and is a Severe Problem” with respect to the child in question. Please answer all questions to the best of your ability. For question 44 only, please rate on a scale from 1 to 100, where 1 = not a problem at all, and 100 = as bad as you can imagine.

1. Body rocking, body swaying
2. Rolls head, nods head, turns head
3. Flaps hands, wiggles or flicks fingers, claps hands, waves or shakes hand or arm
4. Turns in circles, whirls, jumps, bounces
5. Spins or twirls objects, twiddles or slaps or throws objects, lets objects fall out of hands
6. Covers eyes, looks closely or gazes at hands or objects, covers ears, smells or sniffs items, rubs surfaces
7. Hits or slaps head, face, or other body area
8. Hits or bangs head or other body part on table, floor or other surface
9. Hits or bangs head or other body area with objects
10. Bites hand, wrist, arm, lips or tongue
11. Pulls hair or skin
12. Rubs or scratches marks on arms, leg, face or torso
13. Eye-poking, ear-poking

14. Picks at skin on face, hands, arms, legs or torso
15. Arranges certain objects in a particular pattern or place; Need for things to be even or symmetrical
16. Must have doors opened or closed; Takes all items out of a container or area
17. Excessively cleans certain body parts; Picks at lint or loose threads
18. Repeatedly checks doors, windows, drawers, appliances, clocks, locks, etc
19. Counts items or objects; Counts to a certain number or in a certain way
20. Collects, hoards or hides specific items
21. Need to repeat routine events; In/out door, up/down from chair, clothing on/off
22. Need to touch, tap, or rub items, surfaces, or people
23. Strongly prefers/insists on eating/drinking only certain things; Eats or drinks items in a set order; Insists that meal related items are arranged in a certain way
24. Insists on certain pre-bedtime routines; Arranges items in room-“just so” prior to bedtime; Insists that certain items be present with him/her during sleep; Insists that another person be present prior to or during sleep
25. Insists on specific order of activities or tasks related to using the bathroom, to washing, showering, bathing or dressing: Arranges items in a certain way in the bathroom or insists that bathroom items not be moved; Insists on wearing certain clothing items
26. Insists on taking certain routes/paths; Must sit in a specific location in vehicles; Insists that certain items be present during travel, e.g., toy or material; Insists on seeing or touching certain things or places during travel such as a sign or store

27. Insists on certain play activities; Follows a rigid routine during play/leisure;
Insists that certain items be present/available during play/leisure; Insists that other persons do certain things during play
28. repeats same topic(s) during social interactions; Repetitive questioning; Insists on certain topics of conversation; Insists that others say certain things or respond in certain ways during interactions
29. Insists that things remain in the same place(s) (e.g., toys, supplies, furniture, pictures, etc.)
30. Objects to visiting new places
31. Becomes upset if interrupted in what he/she is doing
32. Insists on walking in a particular pattern (e.g., straight line)
33. Insists on sitting at the same place
34. Dislikes changes in appearance or behavior of the people around him/her
35. Insists on using a particular door
36. Likes the same CD, tape, record or piece of music played continually; Likes same movie/video or part of movie/video
37. Resists changing activities
38. Insists on same routine, household, school or work schedule everyday
39. Insists that specific things take place at specific times
40. Fascination, preoccupation with one subject or activity (e.g., trains, computers, weather, dinosaurs)
41. Strongly attached to one specific object

42. Preoccupation with part(s) of an object rather than the whole object (e.g., buttons on clothes, wheels on toy cars)
43. Fascination, preoccupation with movement/things that move (e.g., fans, clocks)
44. Overall, if you “lump together” all of the behaviors described in this questionnaire, how much of a problem are these repetitive behaviors (both for the person with autism, as well as how they affect the people around them)? Please rate on a scale from 1 to 100, where 1 = not a problem at all, and 100 = as bad as you can imagine

Appendix F

Screen for Child Anxiety Related Disorders-Parent Version (SCARED-P)

Instructions: Below is a list of statements that describe how people feel. Read each statement and carefully decide if it is “Not True or Hardly Ever True” or “Somewhat True or Sometimes True” or “Very True or Often True” for your child. Then for each statement, fill in one circle that corresponds to the response that seems to describe your child for the last 3 months. Please respond to all statements as well as you can, even if some do not seem to concern your child.

1. When my child feels frightened, it is hard for them to breathe
2. My child gets headaches when they are at school
3. My child doesn't like to be with people they don't know well
4. My child gets scared if they sleep away from home
5. My child worries about other people liking them
6. When my child gets frightened, they feel like passing out
7. My child is nervous
8. My child follows me wherever I go
9. People tell me that my child looks nervous
10. My child feels nervous with people they don't know well
11. My child gets stomach-aches at school
12. When my child gets frightened, they feel like they're going crazy
13. My child worries about sleeping alone
14. My child worries about being as good as other kids

15. When they get frightened, they feel like things are not real
16. My child has nightmares about something bad happening to their parents
17. My child worries about going to school
18. When my child gets frightened, their heart beats fast
19. My child gets shaky
20. My child has nightmares about something bad happening to them
21. My child worries about things working out for them
22. When my child gets frightened, they sweat a lot
23. My child is a worrier
24. My child gets really frightened for no reason at all
25. My child is afraid to be alone in the house
26. It is hard for my child to talk with people they don't know well
27. When my child gets frightened, they feel like they are choking
28. People tell me that my child worries too much
29. My child doesn't like to be away from their family
30. My child is afraid of having anxiety (or panic) attacks
31. My child worries that something bad might happen to their parents
32. My child feels shy with people they don't know well
33. My child worries about what is going to happen in the future
34. When my child gets frightened, they feel like throwing up

35. My child worries about how well they do things
36. My child is scared to go to school
37. My child worries about things that have already happened
38. When my child gets frightened, they feel dizzy
39. My child feels nervous when they are with other children or adults and they have to do something while others watch them (for example: read aloud, speak, play a game, play a sport)
40. My child feels nervous when they go to parties, dances, or any place where there will be people that they don't know well
41. My child is shy

Appendix G
Strengths and Difficulties Questionnaire-Parent Form (SDQ-PF)

Instructions: For each item, please mark Not True, Somewhat True, or Certainly True. It would help if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of this young person's behavior over the last six months or this school year.

Emotional Subscale:

1. Often complains of headaches, stomach-aches or sickness
2. Many worries or often seems worried
3. Often unhappy, depressed or tearful
4. Nervous in new situations, easily loses confidence
5. Many fears, easily scared

Peer Relationship Problems Subscale:

1. Would rather be alone than with other youth
2. Has at least one good friend
3. Generally liked by other youth
4. Picked on or bullied by other youth
5. Gets along better with adults than with other youth

Appendix H
Strengths and Difficulties Questionnaire-Child Form (SDQ-CF)

Instructions: For each item, please mark Not True, Somewhat True, or Certainly True in the box. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of how things have been for you over the last six months.

Emotional Subscale:

1. I get a lot of headaches, stomach-aches or sickness
2. I worry a lot
3. I am often unhappy, depressed, or tearful
4. I am nervous in new situations. I easily lose confidence
5. I have many fears, I am easily scared

Peer Relationship Problems Subscale:

1. I would rather be alone than with people my age
2. I have one good friend or more
3. Other people my age generally like me
4. Other children or young people pick on me or bully me
5. I get along better with adults than with people my own age

Appendix I
The Strengths and Weaknesses Assessment of Normal Behavior (SWAN) Rating
Scale for ADHD

Instructions: For each item, select “Far Above Average”, “Above Average”, “Slightly Above Average”, “Average”, “Slightly Below Average”, “Below Average”, or “Far Below Average” with respect to this child over the past 6 months. Please answer all questions to the best of your ability.

1. Gives close attention to detail and avoids careless mistakes
2. Sustains attention on tasks or play activities
3. Listens when spoken to directly
4. Follows through on instructions and finishes school work and chores
5. Organizes tasks and activities
6. Engages in tasks that require sustained mental effort
7. Keeps track of things necessary for activities (doesn't lose them)
8. Ignores extraneous stimuli
9. Remembers daily activities
10. Sits still (controls movement of hands or feet or controls squirming)
11. Stays seated (when required by class rules or social conventions)
12. Modulates motor activity (inhibits inappropriate running or climbing)
13. Plays quietly (keeps noise level reasonable)
14. Settles down and rests (controls excessive talking)
15. Modulates verbal activity (controls excessive talking)

16. Reflections on questions (controls blurting out answers)
17. Awaits turn (stands in line and takes turns)
18. Enters into conversation and games without interrupting or intruding

Appendix J

Wechsler Intelligence Scale for Children-Fifth Edition (WISC-V)

Instructions: Guidance varies depending on the section the child is working on. Children and adolescents are encouraged to complete each task to the best of their ability and to ask questions as needed.

1. Block design raw score
2. Block design scaled score
3. Similarities raw score
4. Similarities scaled score
5. Matrix reasoning raw score
6. Matrix reasoning scaled score
7. Digit span raw score
8. Digit span scaled score
9. Coding raw score
10. Coding scaled score
11. Vocabulary raw score
12. Vocabulary scaled score
13. Figure weights raw score
14. Figure weights scaled score
15. Visual puzzles raw score
16. Visual puzzles scaled score

17. Picture span raw score
18. Picture span scaled score
19. Symbol search raw score
20. Symbol search scaled score
21. Visual spatial sum of scaled scores
22. VSI composite score
23. Visual spatial percentile rank
24. Verbal comprehension sum of scaled scores
25. VCI composite score
26. Verbal comprehension percentile rank
27. Fluid reasoning sum of scaled scores
28. FRI composite score
29. Fluid reasoning percentile rank
30. Working memory sum of scaled scores
31. WMI composite score
32. Working memory percentile rank
33. Processing speed sum of scaled scores
34. PSI composite score
35. Processing speed percentile rank
36. Full scale sum of scaled scores

37. FSIQ composite score

38. Full scale percentile rank

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