

**Parent-reported signs of anxiety in minimally verbal autistic children**

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Parent-Reported Signs of Anxiety in Minimally Verbal  
Autistic Children

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Bachelor of Speech Pathology (Hons); Grad. Cert. in Autism Studies

Submitted in fulfilment of the requirements of the degree of Master of  
Education and Professional Studies-Research

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Lastly, I would like to thank the Autism CRC for their support of this project and for the use of the LASA data which was used within this study.

## **Statement of Originality**

*This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.*

(Signed)

Rhiannon Harrison-Claridge

## Abstract

Autistic children<sup>1</sup> with minimal verbal language are thought to present with mental health conditions in similar prevalence to their verbal autistic peers. However, little is known about the ways in which minimally verbal autistic children demonstrate anxiety symptomatology. Research to date involving this population is scarce, with most of the information being small-scale qualitative studies investigating parent experiences of managing their child's anxiety and the impact their child's anxiety has on the parent themselves. This significant gap within the research severely impacts on minimally verbal autistic children's ability to be understood and to have services provided that cater to their needs. The aim of this study was to gain a clearer understanding of broader experiences of anxiety in minimally verbal autistic children from the perspective of their parents.

This study used data on a subgroup of autistic children identified as minimally verbal who participated in the Longitudinal Study of Australian Students with Autism (LASA). The LASA was a cross-sequential study that aimed to investigate the educational experiences and outcomes of Australian students on the autism spectrum over a period of 6 years from 2015 to 2021. The data used in this study were from 33 participants who were identified by their parents to be minimally verbal, presenting with anxiety at the third timepoint. Data analysis involved descriptive statistics analysing the most and least commonly reported symptoms on the standardised measure of anxiety. In addition, the qualitative information gathered through the open-ended responses were coded through inductive content analysis.

The results of the current study indicated that minimally verbal autistic individuals present with a variety of signs that suggest to their parents they are feeling anxious. Some of the most reported signs were related to behaviours that challenge, including aggression towards others and self-injurious behaviour such as biting their hand, as well as other observable indicators,

<sup>1</sup> Identity first language has been identified by the autistic community to be their preference; this paper will use a variety of identity first language to acknowledge this.

such as scared or worried looks, signs of upset, increased movement, and increased sensitivity to sensory stimuli. These signs were reported at a much higher rate than internalised signs or physiological manifestations of anxiety, such as increased heart rate, difficulties focussing, and feeling sick or unwell, suggesting that parents are more comfortable using observable signs and the presence or absence of harm towards self and others as an indicator of anxiety.

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## Chapter 1 Introduction

The aim of this study was to document parent-reported signs of anxiety in minimally verbal autistic children through the analysis of both qualitative and quantitative data. An overview of the study will be provided in this chapter. This will provide the context that led to the research questions the study aimed to answer. In addition, this chapter will provide the theoretical framework that framed the development of the study and the interpretation of the results.

### 1.1 Background

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterised by differences in social communication and sensory processing skills as well as patterns of restricted and repetitive behaviours and interests (American Psychiatric Association [APA], 2013). The term *autism spectrum disorder* is an umbrella term encompassing a range of different strengths and difficulties among individuals across the lifespan (Anagnostou et al., 2014). The breadth and variation in skill across autistic individuals is considerable; as a result, some autistic individuals require support with activities of daily living and in developing new skills to support increased independence across the lifespan, whilst others require less support or are independent in some or all of their activities of daily living (Hus Bal et al., 2015)

Communication can be an area of challenge for autistic children, with more than 57% of these children presenting with an expressive or receptive language disorder (Kwock et al., 2015). As a result, a large proportion of clinical and research work supports the investigation of communication needs across autistic individuals (Brynskov et al., 2016; Carruthers, Pickles, et al., 2020). Various studies have found that approximately 25% of autistic children present as minimally verbal (Anderson et al., 2007; Norrelgen et al., 2015; Rose et al., 2016), meaning that they present with profoundly delayed language skills in comparison to their age

and other developmental milestones (Koegel et al., 2020). In addition to variations in developmental skill such as language skills, children on the autism spectrum can also present with a range of co-occurring conditions. Some of the most common of these are anxiety disorders, with it being found through systematic review that between 75% and 80% of children on the autism spectrum present with some level of anxiety, be it clinical or subclinical, that impacts their daily functioning (van Steensel et al., 2011; Vasa et al., 2013).

At present, there is a lack of knowledge regarding the prevalence and symptomatology of anxiety in minimally verbal autistic children. Current estimates from the broader disability literature suggest that approximately four to five times more children with an intellectual disability present with a co-occurring mental health condition when compared with their typically developing peers (Emerson & Hatton, 2007). However, compared to the considerable research regarding children on the autism spectrum who are able to communicate verbally, little is known about the presentation of anxiety in autistic minimally verbal children (Adams & Emerson, 2021; Ambler et al., 2015; den Houting et al., 2020; Ung et al., 2015; Van Stensel et al., 2017). As a result, there is a significant lack of knowledge regarding how to best assess and support these individuals and their co-occurring anxiety symptomatology to improve their overall quality of life (Tarver et al., 2021).

Given the need to better understand the needs of autistic minimally verbal children with co-occurring anxiety, Tarver et al. (2021) conducted 17 semi-structured interviews with the parents of autistic children averaging 14 years of age. Their research used these interviews to focus on understanding how parents perceived anxiety presenting in their children and to understand how these parents attempted to manage their child's anxiety. Tarver reported the theme of communication breakdowns contributing to difficulties determining whether the child is or is not experiencing anxiety symptomatology as well as the person's knowledge of the child and their sensitivity in being able to detect what parents

report are signs of anxiety (Tarver et al.). Tarver et al. identified the need for further research into the area, suggesting that larger sample sizes were needed in order to gain a more generalisable insight into anxiety in minimally verbal autistic children and the ways in which they demonstrate their anxiety.

In order to better understand the experiences of autistic children presenting with co-occurring anxiety, it is important to investigate the key behavioural indicators parents report that indicate their children are anxious (Skwerer et al., 2019). This information can then be used to support clinicians to improve their identification of the signs with which minimally verbal autistic children may present and which indicate they may also need to be investigated for a possible co-occurring anxiety disorder.

## **1.2 Purpose of the Study**

The purpose of the proposed study is to investigate the anxiety profiles of children on the autism spectrum, aged 6 to 13 years, who were reported by their parents to be a limited verbal language user at the time of completing the assessment measures. In order to understand the anxiety profile of each individual, two different forms of data on anxiety were examined: the Anxiety Scale for Children-Autism Spectrum Disorder-Parent (ASC-ASD-P) (Rodgers et al., 2016) and parent responses on open-ended questions about anxiety presentation. When these quantitative and qualitative data are combined, they form a unique opportunity to further our understanding of how anxiety presents in this group of children.

## **1.3 Theoretical Framework**

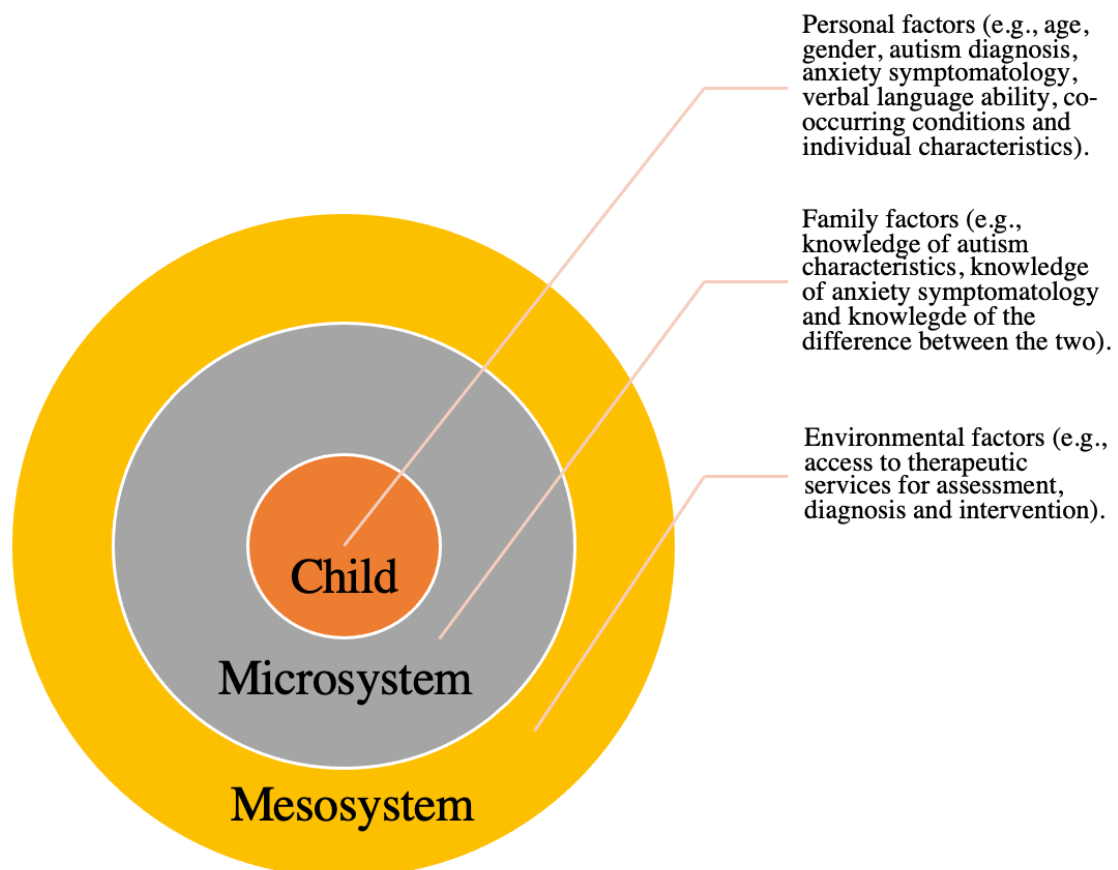
The proposed study's rationale and design is informed by the ecological model of human development (Bronfenbrenner & Ceci, 1994), which proposes that a child's development is influenced by their interaction with and between several different environmental systems. A child's microsystem is the child's direct environment, such as the interactions they have with their family and friends. In addition, the microsystem accounts for

the environments children find themselves being influenced by, for example, school, childcare, and the community. The child's mesosystem represents the relationship between microsystems, for example, the relationship between the child's school and their family, or the child's friends and their family. The exosystem represents societal systems that influence the child, despite the child not being directly involved in them, for example, the parents' workplace and other community-based resources, such as the media. Moving further out again is the macrosystem. This layer of Bronfenbrenner's model represents cultural values, laws, and customs of each society. Finally, the model looks at the chronosystem which accounts for the effect of the child's development and how this can increase or decrease the effect the microsystem has on the child. For example, the impact of a strained relationship between home and school might be more difficult for a younger child than for an older child.

Figure 1 presents a summary of the relationship between the proposed study and Bronfenbrenner's ecological model of human development (Bronfenbrenner & Ceci, 1994). Potential factors that may influence the participant's language use and the presence of anxiety can be viewed within the context of the environmental systems in which the child is directly involved: (a) the child, (b) the microsystem, and (c) the mesosystem. For example, the child may be impacted by personal factors related to their age, gender, autism diagnosis, anxiety symptomatology, verbal language ability, other co-occurring conditions, and individual personality traits. At the level of the microsystem, the child may be impacted by the family and their knowledge of autism and anxiety and their ability to differentiate between characteristics of the two. Finally, the mesosystem sees the child most greatly impacted by environmental factors such as access to therapeutic services for the assessment, diagnosis, and intervention of anxiety.

## Figure 1

*Summary of the Relationship Between the Proposed Study and Bronfenbrenner's Ecological Model of Human Development*



### 1.4 Research Questions

The following research question (RQ) and sub-questions were developed to address the proposed study's aims:

1. What is the profile of anxiety symptoms reported in minimally verbal autistic children?
  - a. What is the profile of anxiety symptoms in minimally verbal autistic children, as reported by parents on a standardised, autism-specific assessment of anxiety?

- b. What are the indicators of anxiety of minimally verbal autistic children as reported by their parents through open-ended responses?
- c. What are the similarities and differences between parent reported indicators of anxiety on the qualitative and quantitative data?

### **1.5 Significance of the Study**

In 1989, The United Nations adopted The Convention on the Rights of the Child, largely considered an extension of the Universal Declaration of Human Rights (United Nations General Assembly, 1948). Article 23, Point 3 dictates that children with additional needs should be afforded the appropriate health care that sees them continue to develop as an individual as well as engaging in the community as much as is possible (United Nations Children's Fund, 1989). Currently, due to the lack of knowledge regarding how anxiety presents in minimally verbal autistic children, there is a lack of appropriate tools to assist in the assessment, diagnosis, and intervention of these children. Parents report that it is extremely difficult to receive any form of assistance for their child's anxiety symptoms (Tarver et al., 2021). This lack of knowledge and support leads to parents feeling isolated and unsure of what to do to support their child to lead the most fulfilled life possible (Tarver et al., 2021). In addition, the impact of difficulties in managing anxiety and difficulties finding appropriate services to support their child is reported by parents as significantly impacting the quality of life (QoL) of the entire family (Tarver et al., 2021). The parents participating in Tarver et al.'s (2021) study reported that the entire family experiences a "restricted world" where there is reduced participation in the community, which can result in decreased QoL not only for the child with autism but also for the family (Tarver et al., 2021).

The current body of research regarding the assessment, diagnosis, and intervention for anxiety in autistic children is dependent on their ability to verbally communicate (Tarver et al., 2021). Some research has suggested that those who are unable to communicate verbally



are more likely to engage in behaviours to get their needs and wants met (Hagopian et al., 2017). These behaviours can range in intensity, duration, and frequency depending on factors specific to the individual child, how well their needs are understood, and the impact of the environment (Tarver et al., 2021). However, Skwerer et al. (2019) reported that it is important to exercise caution when using behaviour to infer meaning as this relies on specific people's knowledge of the child and can encourage biases and reliance on previous experiences. Other researchers have argued that considering only behavioural indicators would fail to take into account the considerable variation in each limited verbal language user's cognition, social skills, and non-verbal communication skills (Kraepel et al., 2017).

Overall, the impact of undiagnosed mental health conditions on autistic individuals is thought to be profound. The broader autism literature, focussing on adolescents and adults with and without a co-occurring intellectual disability, indicates that individuals aged over 65 years with a co-occurring intellectual disability are less likely to have their co-occurring conditions, regardless of the subtype, diagnosed compared to autistic adults aged over 65 years without an intellectual disability (Gilmore et al., 2021). Further studies have found that autistic adults with undiagnosed co-occurring medical or psychiatric conditions are more likely to present with suicidal ideation and subclinical levels of anxiety and depression (Rimmer et al., 2010).

It is clear, from the lack of research available, that there is a need to understand more about how minimally verbal autistic children communicate that they are anxious. Ultimately, it is hoped the current research will assist clinicians, parents, and researchers to understand more clearly the cues and behavioural indicators that could indicate a child is anxious. Understanding the anxiety symptomatology with which minimally verbal autistic children may present has the potential to empower parents and professionals alike to support anxious minimally verbal autistic children.

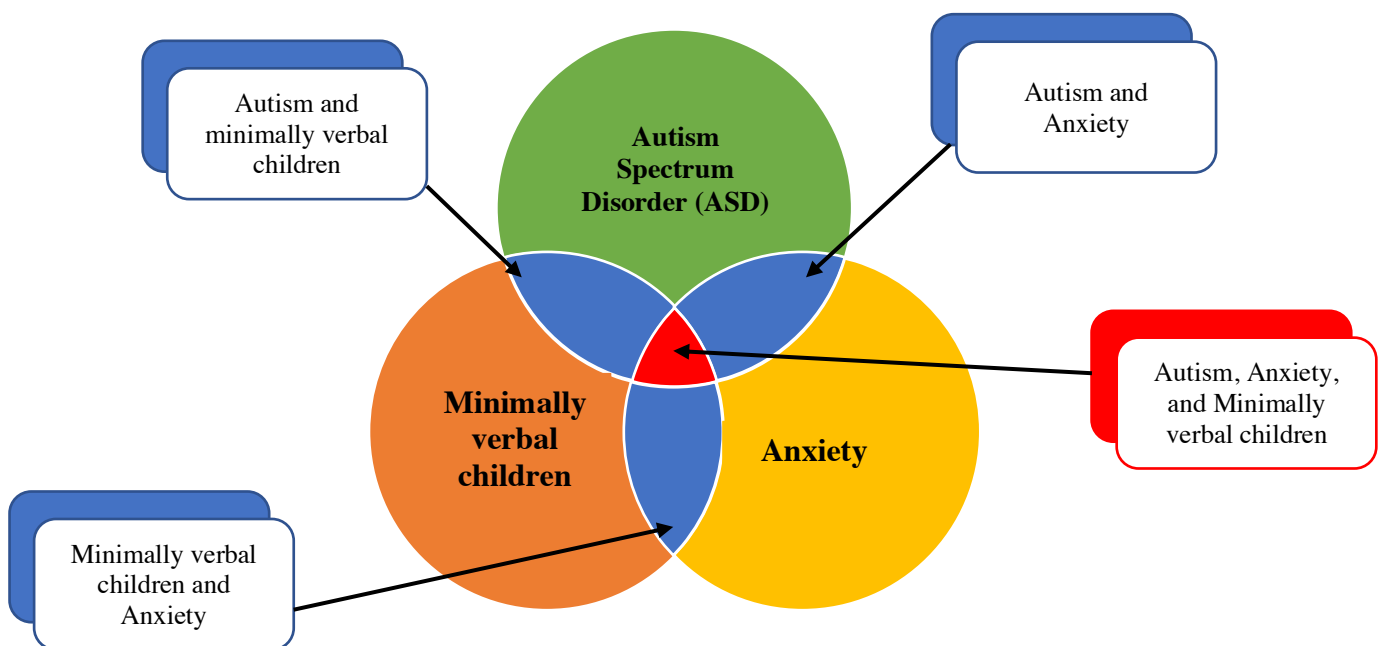


## Chapter 2 Literature Review

This chapter provides an overview of the existing literature on the three main topics pertinent to this research: autism (ASD), anxiety, and minimally verbal children. This review will also cover the intersection between the topics, as illustrated in Figure 2. Particularly pertinent to this thesis is the evidence base situated within the intersection of autism, anxiety, and minimally verbal children.

**Figure 2**

*Fields of Research Relevant to the Proposed Thesis*



### 2.1 Autism

Understanding of ASD has grown and developed since Leo Kanner's first descriptions of early infantile autism in 1943 (Kanner, 1943) and Hans Asperger's account of Asperger's syndrome in 1944 (Frith, 1991). From a diagnostic point of view, the most recent change to the way we consider autism came about with the introduction of different

diagnostic criteria within the *Diagnostic and Statistical Manual of Mental Disorders-5* (DSM-5; APA, 2013). The shift in the DSM-5 diagnostic criteria was made in an effort to reflect the shifting knowledge base regarding the presentation of autism within the community (Mahjouri & Lord, 2012). The DSM-5 diagnostic criteria changed the conceptualisation from multiple separate diagnoses (e.g., Asperger’s syndrome, pervasive developmental disorder- not otherwise specified [PDD-NOS] and autistic disorder) into a single diagnostic term of autism spectrum disorder (Mahjouri & Lord, 2012). The DSM-5 requires an individual to present with differences or difficulties in the three specified areas of social communication alongside differences or difficulties in at least two of four areas specified under restricted and repetitive behaviours (RRBs), as presented in Table 1.

**Table 1**

*Summarised Diagnostic Criteria for Autism Spectrum Disorder as per the DSM-5 (American Psychological Association [APA], 2013)*

Social communication	<p>The use of or understanding of non-verbal communication</p> <ul style="list-style-type: none"> <li>- Having difficulties with using and responding to facial expressions, gestures and eye contact</li> </ul>
	<p>Social reciprocity</p> <ul style="list-style-type: none"> <li>- Having difficulties with social approaches, sharing, engaging, and responding to social interactions</li> </ul>
	<p>Deficits in developing, maintaining, and understanding relationships</p> <ul style="list-style-type: none"> <li>- Ranging from difficulties adjusting behaviour to suit different social situations, to difficulties in sharing in imaginative play with peers</li> </ul>

Restricted and repetitive behaviours (RRBs)	Stereotyped or repetitive motor movements, use of objects or speech - Behaviours such as lining up objects, repetitive motor movements as well as the presence of echolalia
	Insistence on sameness - Individual struggles with inflexibility when it comes to routines etc., as well as rigid thought patterns
	Circumscribed interests - Interests that are fixated or abnormal in intensity or focus
	Sensory responsivity - Underresponding or overresponding to sensory input or showing an unusual interest in the sensory aspects of their environment (e.g., a visual fascination with lights and movement)

### ***2.1.1 Autism Diagnosis and Prevalence***

Once an individual is found to have met the criteria for a diagnosis of autism, their differences or difficulties in social communication and RRBs are given a level. The level outlines the amount of support an individual on the autism spectrum needs to manage their differences or difficulties in social communication and RRBs. Levels range from 1–3, with 1 indicating some support is needed, to 3 indicating very substantial support is needed (APA, 2013). It is worth noting, that the DSM-5 is not the only way to receive a diagnosis of autism, in other countries The International Classification of Diseases- 10 (World Health Organisation, 2004) is used as the diagnostic criteria for autism spectrum disorders.

Rydzewska et al. (2019) noted that since the introduction of diagnosis of autism under the DSM-5 there has been a shift in the rate of diagnosis and therefore the prevalence of autism within the general population. In Australia, it is estimated that upwards of 4.4% of children are diagnosed with autism (May et al., 2020). Loomes et al. (2017) reported in their systematic review and meta-analysis of the gender ratio in ASD involving upwards of 13 million participants, that the ratio of autism diagnosis of females to males is closer to 1:3 than

the commonly reported 1:4. From this we can see that there is clear evidence to suggest a large proportion of the community is diagnosed as being on the autism spectrum.

### ***2.1.2 Autism and Co-Occurring Conditions***

Co-occurring conditions are difficulties or diagnoses that present alongside diagnoses such as autism. There is evidence that between 70% and 90% of individuals on the autism spectrum have one co-occurring condition, while more than 40% present with two or more co-occurring conditions (Jang & Matson, 2015; Soke et al., 2018). Table 2 provides examples of the most common co-occurring conditions experienced alongside autism, as reported by various authors.

**Table 2**

#### *Common Co-Occurring Conditions in Autistic Children*

Co-occurring conditions	Reported prevalence
Anxiety	40% (van Steensel et al., 2011)
Expressive and receptive language impairments	57% (Kwock et al., 2015)
Intellectual disability	33% (Zeidan et al., 2022)
Attention deficit hyperactivity disorder	28% (Lai et al., 2019)

## **2.2 Anxiety**

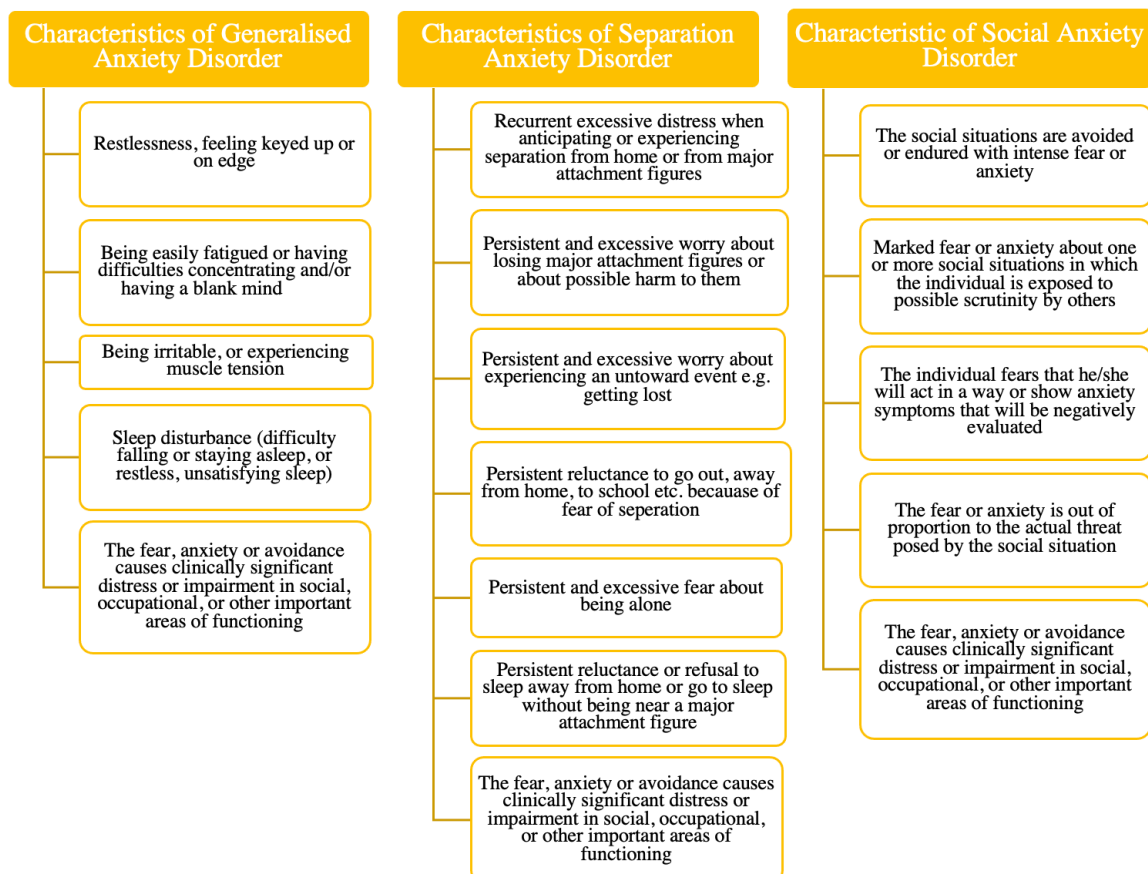
Anxiety is common across the lifespan; it is estimated that upwards of 284 million people worldwide live with an anxiety disorder (Institute for Health Metrics and Evaluation, 2018). In Australia, more than 26% of the population are reported to live with an anxiety disorder (ABS, 2018; The Royal Australian and New Zealand College of Psychiatrists, 2016). Part of what makes anxiety so prominent within the global community is the broad range of anxiety disorders. Under the DSM-5, the following are considered anxiety disorders:

generalised anxiety disorder, separation anxiety disorder, selective mutism, social anxiety disorder, specific phobia, panic disorder, and agoraphobia (APA, 2013).

Anxiety disorders present with an array of similarities, but also differences, in terms of symptomatology as outlined by the DSM-5 (APA, 2013). These include differences in the domains of cognition, behaviour, affect, and physiological arousal which intersect with each other in varied and complex ways (Adams, Young, Simpson et al., 2019). Spence et al. (2018) suggested that the three most common anxiety diagnoses that impact Australian children are generalised anxiety disorder, separation anxiety, and social phobia. Based on this information and the DSM-5 (APA, 2013), Figure 3 outlines common symptomatology of anxiety across these three types of anxiety disorders.

**Figure 3**

*Symptomatology of Anxiety Subtypes Common in Australian Children (APA, 2013).*



### 2.2.1 Assessment of Anxiety

The best practice assessment of anxiety in children is complex and multifaceted and calls upon the skills of paediatric mental health professionals, such as psychologists or psychiatrists (Silverman & Ollendick, 2005). Initially, diagnosticians gather information from a range of sources, such as parents, teachers, paediatricians, allied health professionals and, when appropriate, the child themselves, to gain a holistic understanding of the child and their presentation across settings (Khlyavich Freidl et al., 2017). From here, formalised assessments can be administered, or behavioural observations may be recommended for the clinician to gain a more in-depth understanding of the child's presentation (Moses et al., 2020).

An example of a self-report assessment tool which is used to investigate the presence of anxiety in children is the Spence Children's Anxiety Scale (SCAS). The SCAS is a 46-item questionnaire that investigates the experiences of children aged 8–17 years with anxiety (Spence, 1998). The SCAS plots the frequency with which children experience anxiety symptoms on a scale from zero (0) being *never* to three (3) being *always*. The SCAS is considered a useful tool by clinicians due to its ability to inquire about the six most common anxiety disorders experienced by children (Orgilés et al., 2019). In addition, the SCAS presents with excellent internal consistency and fair-good parent and child agreement when used with the prescribed age group (Carruthers, Kent, et al., 2020; Orgilés et al., 2019).

In order to gain additional perspectives regarding a child's presentation, the SCAS-Parent (SCAS-Parent) was developed (Orgilés et al., 2019). The SCAS-Parent is similar to the SCAS in that both use the 0–3 Likert scale; however, the parent questionnaire includes 38 items and asks parents to rate the frequency with which they observe their child experiencing a symptom of anxiety. The SCAS-Parent reflects the importance of obtaining clear and reliable information from those who are most familiar with their child, as the child



themselves does not yet possess the language or cognitive skills required to objectively report on their experiences (Carruthers, Pickles, Slonims, Howlin & Charman, 2020). Versions of the SCAS have been refined for use with younger children, where parents report upon the anxiety symptomatology with which their child presents. Parent report for children younger than 8 years of age is considered most appropriate due to children typically having difficulties explaining and understanding complex, abstract concepts such as emotions and internal experiences, which is appropriate considering stages of emotional development (Orgilés et al., 2019).

### ***2.2.2 Impact of Anxiety***

The accurate assessment and diagnosis of anxiety disorders across the lifespan is important because the effect of anxiety disorders is vast and wide reaching, impacting every domain of life (e.g., social, occupational) in both neurotypical adults and children (Olatunji et al., 2007). In an earlier study, based on a meta-analysis of anxiety and QoL, Olatunji et al. (2007) reported that those living with an anxiety disorder experience significantly poorer QoL in the domains of physical and mental health, as well as the domains of work, social, home, and family, than non-anxious people. More recent studies have confirmed this finding. For example, Karaaslan and Hacimulsalar (2018) found that adult females presenting with generalised anxiety disorder experienced more body dysmorphia than healthy controls. Rao et al. (2020) expanded on this, finding that adults with anxiety disorders commonly present with lower self-esteem levels than adults who did not experience an anxiety disorder. In addition to this, having an anxiety disorder sees adults at risk of engaging in violent behaviour or substance abuse, which has been shown to lead to an increase in symptoms of depression (Rao et al., 2020).

In children, Vilaplana-Pérez et al. (2021) found that those with social anxiety disorder can be more likely to experience academic underachievement, to the point where they are less

likely to finish high school or to commence tertiary education than their non-anxious peers. Meers et al. (2020) discussed the impact of generalised anxiety disorder on children's sleep outcomes. The impacts on children of poor sleep persist into adulthood, with those experiencing poor sleep having poorer emotional memory and cognitive processing as well as difficulties with attending to and engaging in both tasks of learning and of everyday living (Meers et al., 2020). Overall, anxiety places a huge burden on Australian society in a variety of ways. Anxiety and similar mental health conditions cost the Australia economy over 11 billion dollars during the 2019–2020 financial year, with those costs expected to continue rising (Australian Institute for Health and Welfare, 2022) if action is not taken to understand, identify, and prevent anxiety disorders from a young age.

### **2.3 Minimally Verbal**

People can be minimally verbal (i.e., have difficulty using expressive language) for a range of reasons, this contributes to significant difficulties defining the term (Koegel et al., 2020), which is discussed below in section 2.5. Law et al. (2017) suggested the following two overarching terms in their systematic review: “primary,” where there is no known cause, and “secondary,” where the delay or disorder can be linked to a condition with which the individual presents. Individuals who present with developmental language disorder, an idiopathic language disorder typically present with either receptive or expressive language delays, or a combination of the two, rarely meet criteria to be considered minimally verbal (Law et al., 2017). Being minimally verbal is more commonly linked to primary diagnoses, making it a secondary condition. For example, an individual may present with an acquired language or speech disorder following a neurological event such as a stroke or traumatic brain injury (Palmer et al., 2018). Individuals may also present with neurodevelopmental conditions such as intellectual disability (Norbury et al., 2016).

Given the substantial functional impact a lack of language has on not only the child, but also the family, speech pathologists commonly recommend alternative and augmentative communication (AAC) methods to support both expression and understanding. AAC is defined as a collection of tools and strategies that focus on adding to and/or replacing the verbal communication of individuals with complex communication needs (Moorcroft et al., 2020). Whilst the recommendation of AAC is important for both minimally verbal children and their families, the results of its use are variable (Moorcroft et al., 2021), with many AAC users continuing to experience substantial communication challenges.

### ***2.3.1 Prevalence***

Individuals can be considered minimally verbal following a range of acquired and neurodevelopmental conditions affecting individuals across the lifespan (ABS, 2015a). In 2015, the ABS completed an investigation into the number of people in Australia presenting with a communication disability. It was reported that upwards of 1.2 million people in Australia aged between 0 and 65 presented with a communication disability, resulting in many of them having significant difficulties communicating verbally or being unable to communicate verbally (ABS, 2015a). The ABS reported that these statistics are comprised of people presenting with developmental language disorder, expressive and receptive language impairments post neurological event (e.g., stroke and acquired brain injury), as well as those with learning disabilities and neurodevelopmental conditions such as autism. Furthermore, this study found that the number of people experiencing a severe to profound communication disability is gradually increasing (ABS, 2015a).

### ***2.3.2 Assessment***

Despite the gradual increase in individuals presenting with severe to profound communication disabilities, the assessment of minimally verbal individuals remains very complex and difficult to conduct. When focussing on children with neurodevelopmental

disabilities, researchers Kasari et al. (2013) and Key et al. (2020) both found the assessment of speech and language processing to be challenging due to the absence of reliable, valid, and appropriate standardised assessments for the population. Furthermore, Key et al. explained that the assessment of receptive language is difficult because it commonly relies on a child's ability to respond to directions and prompts given by the examiner as well as their ability to reason and problem solve. A suggestion made by Key et al. to ensure the true isolation of receptive language was that researchers employ eye-tracking or technologies that measure brain activity when assessing minimally verbal individuals; however, it has been noted that this is not a tool that could or should be used for all children.

More practically for clinicians, Kasari et al. (2013) suggested that assessment should incorporate a combination of standardised and experimental approaches. Rose et al. (2016) acknowledged that the insights into the expressive and receptive language abilities of children considered minimally verbal can be gleaned from parent reports which investigate a child's communicative skill across environments. While evidence from each of these areas is important in understanding and beginning to address children's needs, evidence derived from research examining the intersection is particularly relevant (see Figure 1 earlier in this chapter).

## **2.4 Autism and Anxiety**

Leo Kanner's descriptions of *early infantile autism* outlined the presentation of intense fears and worries in his patients, suggesting an early recognition of the link between anxiety and autism (Kanner, 1943). However, it was not until relatively recently that researchers have focussed on this topic, with Vasa et al. (2020) reporting that the phenomenon of anxiety and autism has been of increasing interest to researchers for approximately the last 15 years.

As mentioned in Section 2.1.2, co-occurring conditions are common among children on the autism spectrum, with anxiety being considered one of the most common. Prevalence data suggest that approximately 40% of children on the spectrum have a formal anxiety disorder diagnosis; a further 40% present with some of the symptomatology of anxiety, but do not meet the criteria for diagnosis under the DSM-5 (van Steensel et al., 2011). In total, approximately 80% of children on the autism spectrum are diagnosed with anxiety or are likely to display signs that make them likely to meet the criteria for diagnosis. This is significantly different in typically developing (TD) children who present with a clinical diagnosis of anxiety at a rate of 7–15% (Keen et al., 2019; Simpson et al., 2020; van Steensel et al., 2011). The prevalence data discussed demonstrate how individuals on the autism spectrum are at least four times more likely than their neurotypical peers to be impacted by clinical diagnoses of anxiety. Research has shown that even short-term difficulties with anxiety have significant long-term impacts, with autistic individuals presenting with co-occurring anxiety experiencing poorer vocational outcomes and generalised underachievement, secondary to increased school refusal and poorer academic outcomes compared to their skills in these areas (Adams, Malone, et al., 2021).

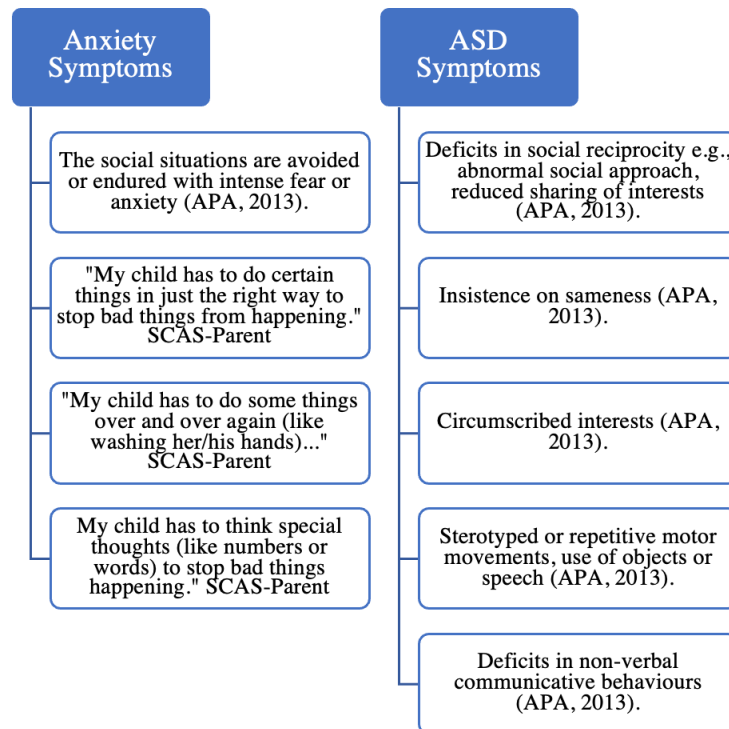
#### ***2.4.1 Distinguishing Between Anxiety and Autism***

Identification of anxiety in autism is complex due to the overlap of anxiety symptomatology and the clinical presentation of autism (van Steensel et al., 2011). For example, a child may be hesitant or reluctant to engage in social interaction because they experience challenges in social communication and interactions (reflective of autism) or because they fear that their attempts at social interaction will be negatively perceived by their peers (reflective of anxiety; den Houting et al., 2020). The similarities between the requirements for diagnoses of autism and anxiety are highlighted in Figure 4. The information presented was gathered from the DSM-5 criteria for autism and anxiety

diagnoses as well as the SCAS-Parent, where statements from this assessment have been directly quoted to show relationship.

#### Figure 4

##### *Similarities Between Clinical Presentations of Autism and Anxiety*



Kerns et al. (2016) suggested that the differential diagnosis of autism and anxiety is fundamentally difficult due to the close relationship between the two. They elaborated that individuals on the autism spectrum may experience anxiety for the same reasons their neurotypical peers do; however, they may also experience anxiety due to reasons specific to being autistic, for example, due to difficulties with emotional regulation, skill differences, and being at differing developmental levels in relation to age (Kerns et al., 2016). White et al. (2014) reported similar findings, the authors proposing a bidirectionality between autism and anxiety where anxiety is seen in children on the autism spectrum due to their difficulties with academic demands and social communication (among other domains) secondary to their autism characteristics (Adams, Young, Simpson et al., 2019). For example, having autism

may make social interaction more difficult by nature of the diagnosis, which may make the child anxious about social interactions.

Despite the close relationship between anxiety and autism, it has been suggested by researchers such as Kerns et al. (2014) that individuals on the autism spectrum can present with *traditional anxiety*, *atypical anxiety*, and both *traditional* and *atypical anxiety*.

Traditional anxiety refers to anxiety as that described within the DSM-5 while atypical anxiety refers to anxiety symptoms related to or specific to autism. In a small-scale study of autistic males, Kerns et al. found that individuals with anxious cognitive styles, hypersensitivity, and strong language abilities were more likely to present with traditional anxiety. In contrast, individuals who presented with greater ASD severity (i.e., compulsive behaviour and social discomfort not associated with fear as well as highly specific phobias) and anxious cognitive styles were at greater risk of atypical anxiety. Notably, this study found that sensory hypersensitivity and both language and intellectual abilities explained only a small amount of the variance in atypical anxiety (Kerns et al., 2014).

Some researchers have argued that autistic people are more likely to present with autism-specific anxieties that are related directly to their diagnosis (Carruthers, Kent, et al., 2020). For example, Green and Ben-Sasson (2010) found associations between sensory hyper- and hypo-responsivity and increased anxiety in those on the autism spectrum. They posed two models that aim to explain the relationship between sensory hyperresponsivity and autism. One model suggests that if an individual on the autism spectrum presents with traditional anxiety, their experience of sensory hyperresponsivity may be linked to generalised hyperarousal which many individuals, both neurodiverse and neurotypical, present with when experiencing traditional anxiety. Alternatively, sensory hyperresponsivity may result in atypical anxiety depending on environmental factors which contribute to sensory stimuli the individual may fear.

Adding to the breadth of research on the topic, Ozsivadjian et al. (2012) asked parents to identify some of the biggest anxiety triggers in their children. Parents reported that changes or disruption to the child's routine, social or language difficulties, and specific fears and phobias were what parents struggled with most. A small number of children also participated in focus groups and, when asked the same question, reported similar findings to their parents; however, the researchers noted the difficulties the children had in explaining their experiences.

Further to previously reported studies focussing on the presentation of traditional anxiety in people on the autism spectrum, Mayes et al. (2013) investigated how atypical anxiety may present in people on the autism spectrum. The authors suggested that varied sensory responsivity as well as insistence on sameness and circumscribed interests can lead to very specific fears and phobias that only those on the autism spectrum present with. These findings suggest that the type of anxiety presenting in those on the autism spectrum can be specific to them and therefore needs to be assessed appropriately in order to reflect this variability in presentation (Mayes et al., 2013).

#### ***2.4.2 Assessment of Anxiety in Autism***

The above studies have shown the substantial variability in the research, particularly in relation to atypical and traditional anxiety. Based on the significant differences between anxiety presenting in neurotypical individuals and in individuals on the autism spectrum, researchers have questioned the efficacy of using assessments designed for the neurotypical population on those on the autism spectrum (Lecavalier et al., 2014). In fact, Lecavalier et al. (2014) and Wigham and McConchie, (2014), concluded that clinicians need to be cautious when using these tools to investigate the presence of anxiety in their clients on the autism spectrum. Furthermore, the authors reported that using the following anxiety measurement tools designed for use in TD children led to less than satisfactory outcomes for children with



ASD; specifically, these tools were not sensitive enough to capture signs of anxiety in autistic children. The tools included the Revised Children's Manifest Anxiety Scale (Reynolds & Richmond, 1978), the Nisonger Child Behaviour Rating Form (Aman et al., 1996; Lecavalier et al., 2004), and the Child Behaviour Checklist (Achenbach, 1991; Achenbach, 2005; Achenbach & Rescorla, 2001; Dutra et al., 2004).

Researchers have been unable to come to a consensus regarding the validity and reliability of other assessment tools initially designed for use with the TD population (Carruthers, Kent, et al., 2020). For example, The SCAS and the SCAS-Parent were found to have excellent internal consistency for total scores across both assessment tools, indicating that the parent and child reports are valid when used together to explore anxiety symptoms in those on the autism spectrum (Carruthers, Kent, et al., 2020; Jitlina et al., 2017). However, other researchers have found there to be poor consistency between reports made by children on the autism spectrum and parents of those children when using the SCAS and SCAS-Parent (May et al., 2014; Toscano et al., 2020). Magiati, Lerh, et al. (2017) suggested that the findings regarding the validity of the SCAS and the SCAS-Parent may vary so much due to the variability in the presentation of autism. For example, some people on the autism spectrum present with more externalising behaviours in reaction to feeling anxious, while others do not (Carruthers, Kent, et al., 2020; Magiati, Lerh, et al., 2017). Therefore, in those who do not externalise behaviour as much as others, the SCAS and SCAS-Parent may be appropriate, but in those who do it may not be as appropriate (Magiati, Lerh, et al., 2017).

Acknowledging the need for an assessment tool specific to children on the autism spectrum, the Anxiety Scale for Children-Autism Spectrum Disorder (ASC-ASD) and the Anxiety Scale for Children-Autism Spectrum Disorder-Parent (ASC-ASD-P) were developed (Rodgers et al., 2016). Both tools were developed by adapting and expanding on the existing assessment, the Revised Children's Anxiety and Depression Scale (RCADS; Chorpita et al.,

2000) which was found by Wigham and McConachie (2014) to be a robust measure for determining the presence of anxiety in children on the autism spectrum. Rodgers et al. (2016) adapted the RCADS by adding three areas specific to how people with ASD experience anxiety: sensory hypersensitivities, uncertainty, and phobias (Carruthers, Kent, et al., 2020; Magiati, Ozsivadjian, et al., 2017). Rodgers et al. also reduced the number of questions from 47 to 24 and ensured the tool covered parent-reported signs of anxiety in the areas of performance anxiety, anxious arousal, separation anxiety, and uncertainty.

In order to determine reliability and validity, the ASC-ASD-P was completed by parents of children on the autism spectrum aged between 8–15 years who communicated verbally (Rodgers et al., 2016), and was found to have sound reliability and validity for use with that population. Keen et al. (2019) and Adams, Young, Simpson et al. (2019) both found the tool to be useful for determining the presence of anxiety in children younger than 8 years with ASD; however, the efficacy of this has not been formally assessed. The ASC-ASD was also assessed on the same age group of children (8–15 years) and found to be effective in capturing the experience of anxiety specific to children on the autism spectrum (Rodgers et al., 2016). The creation of the ASC-ASD-P further reflected the importance of including parent report in clinical investigations into the presence or absence of anxiety in children on the autism spectrum. Several researchers within the field of autism have found that parent report closely aligns with self-reported experiences made by children who are fluent, verbal communicators (Blakeley-Smith et al., 2012; Carruthers, Pickles, et al., 2020; Magiati, Ozsivadjian et al., 2017).

As previously mentioned, formal assessment is not the only method available to determine the presence or absence of anxiety symptoms in children on the autism spectrum. Kaat and Lecavalier (2015) stated that parents, because of their understanding of their child and their willingness to report the symptoms of anxiety they observe in their children, are

crucial in the recognition, diagnosis, and appropriate management of clinically significant anxiety in children on the autism spectrum. Without the inclusion of parents and their expert knowledge of their children during the assessment phase, many children would not gain access to the supports they need to help manage their mental health and anxiety in effective ways (Kaat & Lecavalier, 2015).

### ***2.4.3 Functional Impact of Anxiety in Autism***

The functional impact of anxiety on the mental health of individuals on the autism spectrum is significant. Children presenting with co-occurring autism and anxiety are more likely to experience poorer academic outcomes compared to skill, poorer social skills, poorer executive functioning skills, and poorer adaptive functioning skills compared to their non-anxious peers (Adams et al., 2018; Adams & Emerson, 2021). Additionally, autistic children with co-occurring anxiety are more likely to experience school refusal and disengagement from social and physical recreational activities over time than their peers who did not present with anxiety (Simpson et al., 2019). This impacts on quality of life (QoL) significantly as these children are engaging in fewer activities that promote happiness and enjoyment. In a study conducted by den Houting et al. (2020), 30 autistic children who were able to verbally communicate and their parents completed the Child Anxiety Life Interference Scale and the SCAS to determine the impact of anxiety on the lives of the children. This study found that 79% of children reported believing that their anxiety symptomatology had a negative impact on their lives and the lives of those around them; 83% of parents reported their child's anxiety to have some effect on their stress levels. Further to this, 50% of parents reported their child's anxiousness had a great impact on their (parents') careers (den Houting et al., 2020).

Several studies have shown that anxiety symptoms often have a more significant impact than autism characteristics in both children and adults on the autism spectrum (Adams

et al., 2019; Simpson et al., 2019; van Steensel et al., 2012). Parent and child data both show that autistic children with co-occurring anxiety experienced poorer QoL than those without anxiety (Adams et al., 2019). Further, even short-term difficulties with anxiety can have long-term impacts on an autistic child's future outcomes, with more individuals with ASD and anxiety experiencing poorer vocational outcomes and generalised underachievement (Adams & Emerson, 2021) compared to their non-anxious, neurotypical peers. In addition, autistic children with co-occurring anxiety are also more likely than their non-anxious peers to develop other mental health conditions such as depression both in childhood and adulthood, further impacting on their QoL and potential future outcomes (Dickerson-Mayes et al., 2011).

It is not just the autistic child with co-occurring anxiety whose QoL is impacted. Much like the empirical evidence evaluating the impacts of QoL in children on the autism spectrum presenting with anxiety, the evidence regarding the impact of anxiety on families is significantly lacking. A few studies, such as that by Adams and Emmerson (2021), investigated the impact of a child's co-occurring autism and anxiety diagnoses on parents, finding that parents' working lives are impacted as they often are required to work fewer hours or miss out on work to support their child. In addition, parents reported that they attended fewer social events and activities due to their child's inability or lack of wanting to attend (Adams & Emerson, 2021).

## **2.5 Autism and Minimally Verbal**

As previously mentioned, "minimally verbal" is one of a myriad of terms to describe individuals who have limited expressive language (Koegel et al., 2020). Koegel et al. (2020) conducted a systematic review of the literature available from the last 50 years to determine what researchers are defining as minimally verbal; concluding that the definitions of minimally verbal used throughout the literature were inconsistent. For example, some studies defined individuals with as few as five words as minimally verbal whilst others included

individuals using phrases (Koegel et al., 2020). Due to the considerable amount of inconsistency found through the research, Koegel et al. suggested that the term may be unable to be exclusively defined, and perhaps should be aligned with developmental milestones. To put this into context, the developmental continuum suggests that children aged between 9 and 10 years who have 2,200 or fewer words would be considered minimally verbal (Roth & Worthington, 2011).

The number of words an individual presents with is just one way the literature suggests we can determine communicative competence. Crais and Ogletree (2016) suggested that another way is to establish the individual's language profile to understand what they are able to do with their language, or what communicative functions they are observed to use. Communicative functions are the reasons why we communicate and can be observed verbally and nonverbally (La Valle et al., 2021). For example, someone who communicates verbally may use the communicative function of requesting to ask someone for some more food, while someone who is minimally verbal may use gestures such as pointing or pulling their communication partner to what they want (Paul & Norbury, 2012). Keen et al. (2002) reported nine communicative functions that cover the basic reasons why humans communicate, those being: requesting an object, requesting an action, attention to self, commenting, social convention, rejecting/protesting, responding, requesting information, and imitation. Several authors have found that those with limited receptive and expressive language skills possess limited communicative functions (Brady et al., 2004; Kasari et al., 2013; Rose et al., 2016).

### ***2.5.1 Prevalence of Minimally Verbal Autistic People***

Little is known about autistic minimally verbal people and their experiences, or how to best support them in terms of clinical based supports (Rose et al., 2016). Although the definitions vary significantly within the research, it appears that findings are similar between

papers with respect to the prevalence of minimally verbal within the autistic community. Overall, Lord et al. (2004) found that between 7% and 14% of 9-year-old children on the autism spectrum were minimally verbal, although their sample was unable to be generalised to the autistic population as a whole due to not all the children included in the study having a diagnosis of autism. A similar result, in terms of percentages, was reported by Anderson et al. (2007). More recently, Norrelgen et al. (2015) found that 25% of their sample of 4- to 6-year-old children met their prescribed criteria for being classed as minimally verbal. Rose et al. (2016) reported that 26.3% of children on the autism spectrum in their community-based early intervention program sample did not develop functional language skills while 36.4% of the children studied did not use two-word phrases. Both statistics are reported, as both definitions have previously been used to define the term “minimally verbal”.

### ***2.5.2 Minimally Verbal, Autism, and Co-occurring Conditions***

Many researchers have hypothesised that there are further links between verbal ability and autism that help to determine why some children on the autism spectrum develop verbal language skills while others do not. For example, Norrelgen et al. (2015) reported that an important factor providing a link to verbal ability is general cognitive functioning. It was found that all children classified in the study as non-verbal or minimally verbal presented with co-occurring intellectual disability (ID; Norrelgen et al., 2015). As presented in Table 2, approximately 33% of children on the autism spectrum present with a co-occurring ID diagnosis (Zeidan et al., 2022). When comparing findings from studies investigating the prevalence of ID in individuals on the autism spectrum and prevalence of children classified as minimally verbal, it can be seen that the reported range is from 25-35% (Anderson et al., 2007; Lord et al., 2004; Norrelgen et al., 2015; Rose et al., 2016) for minimally verbal status and is consistently reported at 30% for individuals experiencing co-occurring ID and autism (Thurm et al., 2019).

Notably, cognition and intellectual quotient (IQ) are not the only factors researchers have found to be significantly correlated with verbal ability. For example, Bal et al. (2020) reported that motor imitation, joint attention, play skills, and number of hours attending speech and language intervention were significantly correlated with improved verbal ability in a group of 4-year-old children who were defined as language delayed following an Autism Diagnostic Observation Schedule assessment, which found the children to be using single words at time of assessment. In addition, Bal et al. reported that delayed fine motor skills were causally correlated with verbal language abilities at 19 months of age. When these findings are pulled together, it can be hypothesised that those with more severe developmental delays are more likely to have poorer verbal language skills than their peers, and therefore can be considered minimally verbal. A recent article by Rinaldo et al. (2021) investigated the link between language and IQ, concluding that significantly more research is needed to better understand the link between the two.

### ***2.5.3 Functional Impact of Being Minimally Verbal and Autistic***

In Australia, more than 50% of autistic individuals present with a severe to profound communication impairment (ABS, 2015b). Despite a large proportion of the autistic community experiencing difficulties within the domain of communication, very little is known about the impacts on autistic children of being minimally verbal. From what is known, it can be seen that children who present as minimally verbal are more likely to engage in behaviours of concern than their peers, although this was noted to range from a moderate to a very low certainty of evidence (Chan et al., 2023). Additionally, Harrop et al. (2018) who investigated how and why parents of minimally verbal autistic children intervene regarding sensory needs. Harrop et al. found that parents most commonly intervened when their children engaged in behaviours of concern in response to hypo- or hyper-responsivity to sensory stimuli, most commonly of an auditory or visual nature. Behaviours of concern, as

they are otherwise known, are a common cause of increased stress in parents and carers of children on the autism spectrum. Lindo et al. (2016) found, in a meta-analysis of parental stress levels, that parents of children on the autism spectrum who engage in behaviours of concern are more stressed than parents of children with other disabilities. In addition, autistic individuals who display these types of behaviours have been found to be perceived more negatively by others (Westphal, 2017).

## **2.6 Anxiety and Minimally Verbal**

When considering the research base covering minimally verbal, one must look outside the autism research base to consider what is known more broadly. This is because, one can be minimally verbal for a range of reasons, that is not secondary to being autistic. For example, in the broader disability research, those investigating intellectual disabilities have found that children with ID are four to five times more likely to experience a mental health condition than their neurotypical peers and these conditions are more likely to persist over time for those with more severe to profound ID than for those with milder ID diagnoses (Emerson & Hatton, 2007). Much like the research that has been conducted into the subgroup of autistic people with intellectual disabilities, the research is limited in this area and therefore little is known about the mental health of individuals with intellectual disability.

Adams and Oliver (2011) reviewed the literature on the ability of those with severe to profound intellectual disability to physically produce facial expressions and their understanding of emotions. This paper highlighted the considerable debate within the literature regarding the experience and expression of emotions in people with severe to profound ID. From their review, Adams and Oliver concluded that individuals with severe to profound ID were capable of experiencing a range of emotions and were able to express these through behaviour as well as through facial expression. However, there was a lack of



knowledge regarding the most appropriate ways to assess these individuals as well as a lack of appropriate assessment tools to do so.

Six years after the Adams and Oliver (2011) review, Flynn et al. (2017) conducted a review of the literature on assessment measures of emotions and mental health in those with severe or profound ID, noting that there were no assessment tools developed specifically for the measurement of mental health conditions or well-being of children or adolescents with severe to profound ID. For those individuals with mild to moderate ID, 12 proxy assessment tools were found to have been developed, through 32 papers focussing on a range of mental health conditions. When investigated for methodological rigour, only three of the assessments were found to have good methodological quality to assess for mental health conditions in those with ID, with one of those being deemed appropriate for the assessment of anxiety in individuals with severe to profound ID. However, further investigation determined that the assessment tool deemed methodologically appropriate for assessing for anxiety symptoms did not have any validity data available to be reviewed. Ultimately, the tool was deemed inappropriate due to its poor internal consistency (Flynn et al., 2017).

Overall, the research in this area is significantly lacking, with researchers yet to develop an appropriate subjective or objective measure for determining the presence or absence of anxiety in those with severe to profound ID, who have been considered by the research more likely to display significantly delayed or disordered language skills. Due to the lack of assessment tools, our knowledge regarding the impact of anxiety on those with severe to profound ID and their families is also significantly limited, as it is an under researched area.

## **2.7 Autism, Anxiety, and Being Minimally Verbal**

This final section of the literature review will explore the intersection of autism, anxiety, and minimally verbal, highlighted in red in Figure 1 earlier in the chapter. Although

research on autism and anxiety is growing, as evidenced by Vasa et al. (2020), this is predominantly focussed on individuals presenting with typically developing receptive and expressive language skills (Reaven, 2011). For example, in Adams et al.'s (2019) systematic review of school anxiety in autism, only two of the 34 studies reported on included participants with an ID. Similarly, in Ambrose et al.'s (2021) systematic review of studies exploring the impact of anxiety on academic and social outcomes of individuals on the autism spectrum, almost half of the 50 included studies excluded participants with an ID.

There is a growing empirical research base investigating the experiences of co-occurring anxiety in autistic individuals who can communicate verbally, which is resulting in advances in our knowledge, understanding, and treatment of the phenomenon with these individuals. However, in comparison, the knowledge of anxiety in those who find it challenging to communicate verbally has not advanced to the same degree. This divide may in part be due to a fundamental element of the assessment, diagnosis, and intervention of anxiety being linked to an ability to communicate. For example, both subjective and objective reporting measures include questions which can only be answered if a child had been able to both understand the concept (receptive language) and express their internal experiences (expressive language). Examples of this include the following statements from the SCAS-P: "My child complains of feeling afraid" and "My child worries that something bad will happen to him/her" (Spence, 2000).

There are currently no objective or subjective assessments of anxiety validated for use with children presenting with severe or profound ID and therefore having limited verbal communication skills (Flynn et al., 2017). The signs typically used to conclude that a child may be experiencing anxiety in other populations, including neurotypical and neurodiverse children who verbally communicate, cannot be exclusively linked to anxiety, for example, the presence of behaviours of concern. When a limited verbal language user engages in

behaviour, they may be using this to communicate for a range of reasons, as behaviour is often described as their most effective means of communication (Molyneux, 2019). In addition, researchers such as Kerns et al. (2014) suggested that traditional anxiety may be more difficult to detect in individuals on the autism spectrum who also present with co-occurring language disorders due to their reduced ability to communicate and understand their internal experiences (Kerns et al., 2014).

Hagopian et al. (2017) suggested that in the event that a child on the autism spectrum cannot communicate in a way that is readily understood by others, it is important to instead investigate behavioural cues that indicate anxiety. This is done by comparing the behavioural cues children on the autism spectrum present with and the behaviours that indicate anxiety symptomatology to anxious avoidant behaviours. For example, a child may engage in the same avoidance behaviour to avoid an academic task, avoid sensory stimuli, and avoid an event that increases their anxiety. Hagopian et al. suggested that avoidance behaviours and anxiety symptomatology can be more exclusively linked when those assessing for anxiety based on the behavioural indicators look for “overt indicators of anxiety” (p. 194) by further categorising avoidant behaviours into simple and anxious avoidant behaviours. Therefore, if a limited verbal language user presents with behaviours considered anxious avoidance (e.g., fearful facial expression), they are more likely to have an anxiety disorder than those who do not present with these anxious avoidant behaviours (Hagopian et al., 2017).

Skwerer et al. (2019) reported on the prevalence and correlations of psychiatric symptoms in minimally verbal children and adolescents on the autism spectrum, noting the degree of variation in prevalence data within the literature. Citing papers reporting prevalence of anxiety in minimally verbal children between 11% and 84%, Skwerer et al. concluded that it is difficult to understand what additional mental health conditions an individual on the autism spectrum who is minimally verbal may be presenting with; they aired caution, stating

that the behaviours a child engages in are not enough to determine the presence or absence of psychopathology. Importantly, Skwerer et al. reported that co-occurring mental health conditions should not be thought to impact a small subsection of minimally verbal autistic people; rather, clinical and subclinical (of which the difference is focussed on whether the child presents with anxiety at a higher or lower level than defined by the DSM-5 (Muir, 2019) levels of anxiety should be thought to affect at least the same proportion of autistic minimally verbal people as is seen in the broader autistic population. Therefore, more knowledge is needed about their experiences to ensure we are providing the most appropriate case to these individual and their families.

The limited literature therefore suggests that anxiety is experienced by a large proportion of the population but is difficult to identify in individuals on the autism spectrum with minimal verbal language. In one of the only studies to explicitly investigate anxiety, autism, and limited verbal language use, Tarver et al. (2021) conducted semi-structured interviews with parents of 17 children with a median age of 14 years. They focussed on anxiety presentation, parental experience, and how parents manage anxiety in these children. Thematic analysis revealed that parents acknowledged their pivotal role in recognising signs of anxiety in their minimally verbal children. In addition, parents reported the complexities of identifying the differences between behaviour related to anxiety and behaviour related to core autism characteristics (Tarver et al., 2021). Parents also acknowledged the impact anxiety has on themselves and the rest of the family, citing the lack of available strategies and how the world of the family is restricted as parents attempt to balance exposure with ensuring the child feels safe. Whilst this provides an initial description, this study is the only piece of peer-reviewed, empirical research investigating the complex interplay of autism, anxiety, and limited verbal language use, highlighting a significant need for further work in this area.

## 2.8 Summary of the Literature Review

The literature review conducted has demonstrated that anxiety is highly prevalent in children on the autism spectrum. The impacts of clinical and subclinical levels of anxiety in autistic children are multifaceted and profound. The children's overall QoL is considered to be significantly reduced, with research demonstrating that autistic children with co-occurring anxiety symptomatology are more likely to experience poorer social, adaptive, and academic outcomes compared to their neurotypical peers (Adams et al., 2018; Adams & Emerson, 2021). Long term, children on the autism spectrum presenting with anxiety symptomatology have poorer vocational outcomes and experience generalised underachievement when compared to their TD peers (Adams et al., 2021). Whilst there has been an increase in research conducted into co-occurring autism and anxiety symptomatology, some subgroups of the autistic community remain under researched, including autistic children who present as minimally verbal. Without the ability to diagnose or identify anxiety symptomatology in this population of autistic children, appropriate interventions and supports are unable to be put in place, in direct violation of Article 23, Point 3 of The Convention on the Rights of the Child, which states that children with additional needs should be afforded the appropriate health care that sees them continue to develop as an individual as well as engaging in the community as much as is possible (United Nations Children's Fund, 1989).

At this time, few studies have been conducted investigating the presentation of anxiety symptomatology in minimally verbal autistic children. Tarver et al. (2021) found in their study that the impact of anxiety symptomatology is significant, not just to the child but also to the wider family, with parents in the study also citing a lack of professional support and knowledge in the area of co-occurring anxiety and autism. Further work is needed to broaden our understanding of this phenomenon. Combining multiple sources of information is needed to develop the research, for example through learning from the parents and

caregivers of autistic minimally verbal who support these children and their anxiety across environments and situations regularly allows for more in-depth knowledge to be gathered to inform our understanding of how anxiety presents in minimally verbal autistic children.

Therefore, the aim of the proposed study is to investigate the anxiety profiles of children on the autism spectrum, aged 4 to 13 years, who were reported by their parents to be minimally verbal at the time of completing assessment measures, to better understand how autism-specific, standardised measures and open-ended responses converge, diverge, and reflect upon each other.

## Chapter 3 Method

### 3.1 Theoretical Framework

The current study aligns with the with the discipline of psychology. Psychology is an ever-evolving discipline of research that initially aligned itself with the positivist/ post-positivist paradigm, with its focus on objectivity and scientific rigour (Mitchell, 2003). However, in the 21<sup>st</sup> century there has been a clear shift in psychological research wherein, lived experiences of those with the conditions being studied, or whom support individuals with these conditions are being increasingly valued and evaluated (Kendler, 2006). Kendler (2006) hypothesises that this is due to the need to bridge the gap between lived experience, research and clinical practice. The current research aims to support this move in psychological research by learning more about how anxiety symptomatology is perceived to present by parents of minimally verbal autistic children.

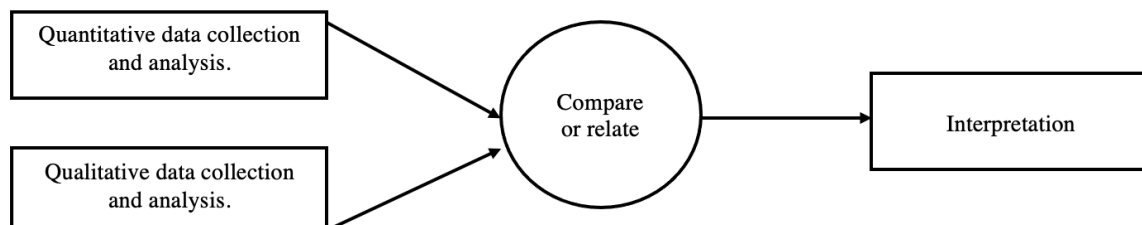
With the shift in what the discipline of psychology will accept and value within research, comes a shift from the positivist/ post-positivist paradigm to the pragmatic paradigm with influences from the interpretivist/ constructivist paradigms. These paradigms focus on understanding lived experience from multiple perspectives (Feilzer, 2010; Clark & Creswell, 2018). This research is clearly aligned with this value as all perspectives are taken and valued, for the contribution they make to improving understanding of how anxiety symptomatology can present in minimally verbal autistic children. This is critical as autism is a spectrum condition with no one experience being the same as another's, therefore gathering a wide variety of information allows researchers to reflect the broader autistic community (Roberts et al., 2018; Adams, Young, Simpson et al., 2019).

### 3.2 Study Design

A convergent parallel study design was used to explore the autism-specific, standardised measure and the open-ended responses to look at the similarities and differences in how these measures captured parent-reported signs of anxiety (Creswell & Plano Clark, 2017). The convergent parallel study design sees the collection of both qualitative and quantitative data take place concurrently. Once the information has been obtained and analysed, convergent parallel study design allows for comparison of the two findings to take place before the interpretation of the comparison or relationship between the quantitative and qualitative data occurs, as per Figure 5.

**Figure 5**

*Convergent Parallel Study Design*



*Note.* From *Designing and Conducting Mixed Methods*, by J. Creswell and V. L. Plano-Clark, 2017, 3<sup>rd</sup> ed., p. 69. Sage Publishing.

Convergent parallel study designs are often used when researchers are aiming to gain a complete picture of how qualitative and quantitative findings can converge and diverge (Creswell & Plano Clark, 2017). This synergistic approach to mixed methods research design

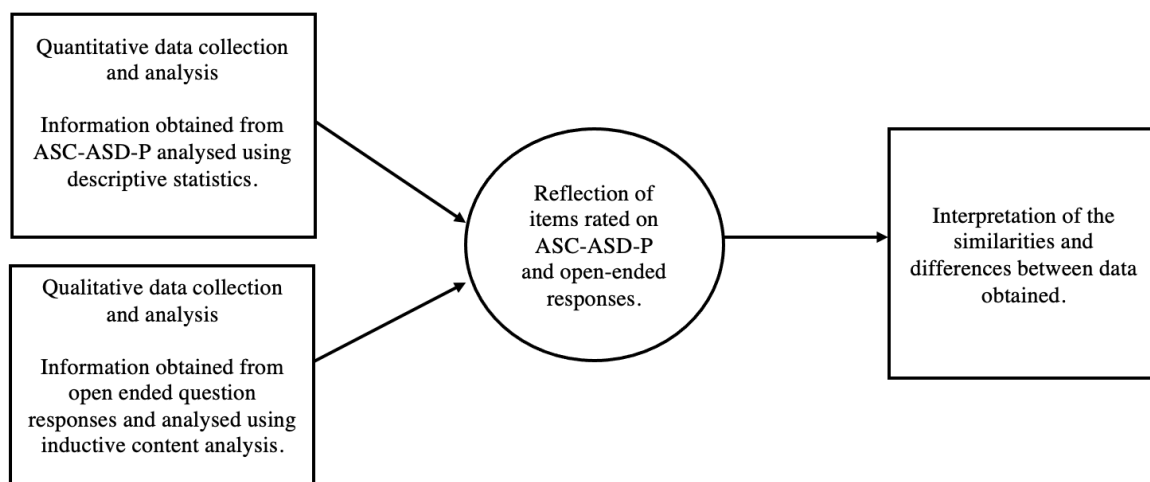


acknowledges that combining the two types of data collection is far more powerful than considering just one (Hall & Howard, 2008), particularly when little is known about the subject field, in this case minimally verbal children on the autism spectrum and the ways in which they demonstrate they are anxious.

In the case of this study, a comparison of the qualitative and quantitative findings was undertaken to determine the similarities and differences between what was found with a formal assessment tool (ASC-ASD-P) and what parents reported when given the opportunity (open-ended question responses). The interpretation of the similarities and differences between the data sets was completed to further outline the similarities and differences between findings made using the formalised assessment tool and the findings made through parent report (see Figure 6). This helped to determine whether the ASC-ASD-P enables parents of minimally verbal autistic children to report on some or all of their child's anxiety symptomatology.

### Figure 6

#### *Convergent Parallel Study Design Applied to Proposed Study*



*Note.* Convergent parallel study design applied to the current study. Adapted from *Designing and Conducting Mixed Methods Research*, by J. Creswell and V. L. Plano Clark, 2017, 3<sup>rd</sup> ed., p. 66, Sage Publishing.

### **3.2.1 Data Used For the Study**

This study utilised quantitative and qualitative data collected through the Longitudinal Study of Australian Students with Autism (LASA). The LASA is a cross-sectional, prospective, longitudinal study conducted annually across six time points (Roberts et al., 2018). The aim of the study is to investigate the personal and environmental factors associated with educational and participation outcomes of students on the autism spectrum (Roberts et al., 2018). The LASA was funded by the Cooperative Research Centre for Living with Autism (Autism CRC), a federally funded program which supports collaboration between industry, researchers, and the autistic community (Roberts et al., 2018). Data was extracted from Time 3 (the first year at which the anxiety open-ended questions were collected). Data from Times 4 and 5 were also screened for any additional participants who did not participate in T3, and this data were added to the study. This resulted in a sample size of 33 participants. Data from 31 participants were gathered from Time 3 of the LASA, with the other two participants' data being gathered from Time 5.

### **3.3 Participants**

The LASA originally recruited 272 autistic children between the ages of 4 and 5 years and 9 and 10 years at entry into the LASA project. The LASA only had inclusion criteria of age range (as per above) and diagnosis: participants had a previous diagnosis of ASD which was confirmed upon entry to the study through a copy of diagnostic reports and the Social Communication Questionnaire (SCQ; Rutter et al., 2003). Children were recruited through social media, centre networks, and a range of different services operating nationally, for example, early intervention services and children's hospital services. In order to recruit a

sample of autistic individuals representative of the broader autistic population, children were not excluded on the basis of presenting with co-occurring conditions such as intellectual disabilities, attention deficit hyperactivity disorder, or other like conditions.

Participants for the current study were selected from Time 3 using the following inclusion criteria:

- (a) The child was reported to be minimally verbal if they scored never (0) or (1) partially using Item 20 on the Vinelands Adaptive Behaviour Scale- II (VABS-II): “says at least 50 recognisable words” (Sparrow et al., 2005) through the Communication Domain of the VABS-II.
- (b) Parents completed the Anxiety Scale for Children with Autism Spectrum Disorder- Parent (ASC-ASD-P) and the open-ended questions on anxiety presentation. The ASC-ASD-P was added to the LASA from timepoint 3 and by the nature of what assessments were administered in various timepoints, the ASC-ASD-P was administered in timepoint 3 and timepoint 5.

This resulted in data from parents of 33 autistic children (8 female (24.24%) and 25 male (75.76%)) who identified their child as minimally verbal. The children were aged between 6 and 13 years, with the mean age of the sample being 7.96 years ( $SD = 2.42$ ). Of the 33 parents, eight were fathers and 25 were mothers. These parents reported that their children presented with the following co-occurring conditions.

**Table 3**

*Co-occurring Conditions Reported by Parents of the Sample*

Co-occurring Condition	Percentage of sample reported to present with Co-occurring condition/s.
Anxiety	27.27%
Attention Deficit Hyperactivity Disorder (ADHD)	33.34%

Attention Deficit Disorder (ADD)	6.06%
Childhood Degenerative Disorder (CDD)	0.00%
Dyspraxia	18.18%
Epilepsy	12.12%
Fragile X Syndrome	0.00%
Rett Syndrome	0.00%
Pervasive Developmental Disorder- Not Otherwise Specified	6.06%
Sensory Processing Disorder	27.27%
Tourette's Syndrome	3.33%
No Co-occurring conditions	27.27%

Other conditions reported

Motor Coordinator Disorder  
 Severe Intellectual Delay  
 Global Development Delay  
 Cystic Fibrosis  
 11p13 Chromosome Disorder  
 Partial WAGR Syndrome  
 Tuberous Sclerosis  
 Low Tone  
 Hypermobility Joints  
 Motor Tics  
 Intellectual Disability  
 Suspected Dyslexia/ Dysgraphia  
 Speech Impairment  
 Borderline IQ  
 Incontinence  
 Constipation  
 Hypermetropia  
 Esotropia  
 Macrocephaly  
 Eczema  
 Psoriasis

Asthma  
 Hearing Impairment  
 Bilateral Pes Plano Valgus  
 Calf Contractures  
 Post Traumatic Stress Disorder (PTSD)  
 Blinking tics  
 Schizotypal [Pernalty] Personality Disorder  
 Scoliosis  
 Dymenorrea  
 Protein, Calcium and Vitamin D deficiency

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### 3.4 Measures

The measures selected from the LASA for the purposes of the current study included the VABS-II, the ASC-ASD-P, and open-ended responses on the presentation of anxiety in specific environments. VABS-II (Sparrow et al., 2005) is a norm-referenced measure that uses parent report to obtain information relating to a child's functioning in terms of activities of daily living. It assesses functional skills and adaptive behaviours across four domains: communication, daily living skills, socialisation and, for children aged 0–6, motor skills. Chatham et al. (2018) determined that this measure was a clinically appropriate and relevant tool for assessing autistic children with a range of functional abilities.

The ASC-ASD-P (Rodgers et al., 2016) is a 24-item, parent-report questionnaire which asks parents to rate the frequency at which their child experiences specific indicators of anxiety. It is based on the Revised Child Anxiety and Depression Scale (RCADS; Chorpita et al., 2000) to specifically assess the range of anxiety symptoms reported in individuals on the autism spectrum (Lecavalier et al., 2014; Wigham & McConachie, 2014). Rodgers et al. (2016) achieved this through collaborating with the autistic community to refine the 47-item RCADS and create a parent-report tool that assesses for signs of typical as well as autism-

specific anxiety phenomena, including sensory processing, uncertainty, and phobias. This led to the ASC-ASD-P being comprised of 24 items organised into four subscales: Performance Anxiety (Items 2, 4, 7, 15, and 17), Anxious Arousal (Items 1, 3, 8, 12, 13, and 22), Separation Anxiety (Items 11, 18, 19, 20, and 24) and Uncertainty (Items 5, 6, 9, 10, 14, 16, 21, and 23). Rodgers et al. (2016) reported that individuals presenting with a total score equal to or above 20 may be “experiencing significant levels of anxiety” (p. 2).

In addition to the listed formal measures, parents were given the opportunity to write short responses to the following three questions (no word limits were applied) if they agreed that their child was anxious at home, at school, or in the community:

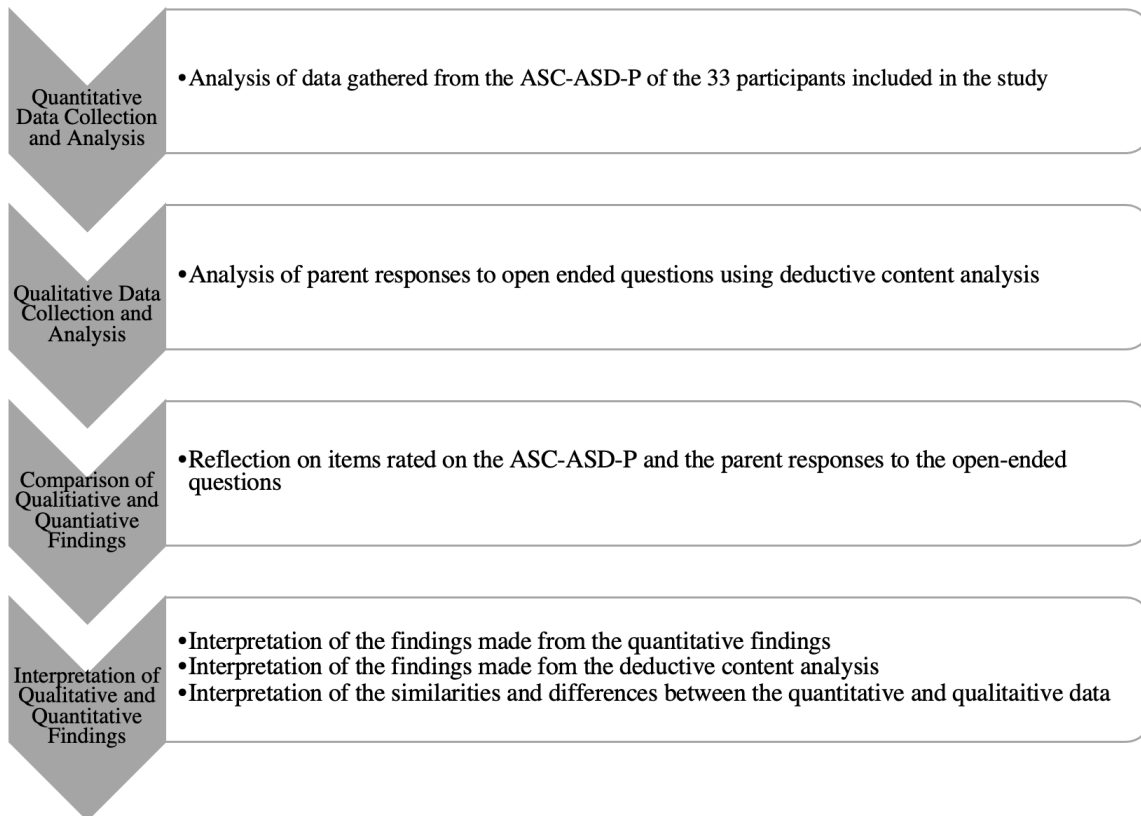
- (a) What are signs of their anxiety at home?
- (b) What are signs of their anxiety at school?
- (c) What are signs of their anxiety in the community?

### **3.5 Data Analysis**

Following the administration of these measures, analysis of the data took place in the following manner to ensure it complied with the convergent parallel study design discussed in section 3.1. The application of this to the present study is shown in Figure 7.

#### **Figure 7**

*Convergent Parallel Study Design Data Analysis*



Quantitative data collection and analysis involved the ASC-ASD-P results being analysed using descriptive statistics (i.e., using means, medians, minimum and maximum scores) and were analysed at total raw score, subscale raw score, and item level raw score. This was done in order to understand the most and least commonly reported subscales from the standardised measure. In addition, item-level analysis was completed to contribute to understanding more about the specific ways in which minimally verbal children on the autism spectrum demonstrate they are anxious. Analysis of the quantitative data in these two ways addressed research question 1a: “What is the profile of anxiety symptoms reported by parents of minimally verbal children on the autism spectrum through standardised assessment questions?”

Qualitative data analysis saw the open-ended responses given by parents to the questions listed above analysed using deductive content analysis, with reference to Adams,

Young, Simpson et al. (2019)'s coding framework (please see attached appendix). This coding framework was developed based on Dey (1993) which has previously been used in research focussing on autistic people (e.g., Baron-Cohen and Wheelwright, 1999; Johnson and Hastings, 2002). Under this framework the data is (1) broken down in order to be manageable, (2) collated together by area or items of interest, (3) organised into categories that describe similar responses within these non-specific groupings, and (4) combine or split categories to more accurately represent the content of the categories. This study utilised Dey (1993)'s process, however instead of developing codes in stages three and four, the same codes and categories developed by Adams, Young, Simpson et al. (2019) were used.

Inductive content analysis was completed on the specific information parents provided on the open-ended questions. This allowed the researcher to generate themes or concepts directly from the qualitative data's most frequent, dominant, and significant themes (Thomas, 2006). Thomas (2006) noted that inductive content analysis is particularly valuable for developing an understanding of lived experience evident from the data, such as that available for the proposed study. Analysis of the qualitative data by means of inductive content analysis will be beneficial in answering RQ1b: "What are the indicators of anxiety reported by parents of minimally verbal children on the autism spectrum through open-ended responses?"

Content analysis was chosen as the qualitative method for this study as the responses were short and written by the nature of the LASA. As a result, this excluded qualitative analysis options such as discourse analysis, narrative analysis and conversational analysis (Busetto et al., 2020). Additionally, due to the pre-existing knowledge of the student conducting the analysis, grounded theory analysis was deemed inappropriate due to the need for biases and previous knowledge to be put aside (Tie et al., 2019). Additionally, using inductive content analysis based on the coding framework by Adams, Young, Simpson et al. (2019) would allow for comparison of findings between sub-groups of autistic people. This



helps to better understand how anxiety symptomatology can manifest in autistic children who can verbally communicate and autistic children who cannot verbally communicate.

In order to examine in more depth, the relationship between parent open-ended responses and items rated on the ASC-ASD-P, the researcher and the primary supervisor coded the item descriptors used within the ASC-ASD-P to the category coding element used for completing the content analysis, as presented in Table 5. The two researchers were blinded to each other's results until these results were collated for comparison. The items discussed here are those that were blind rated by the student and primary supervisor as aligning. The raters agreed on 80% of the indicated matches and discussed via email the remaining two items until consensus, and therefore 100% agreement, was reached.

### **3.6 Ethics**

Ethical clearance for the current study was received from Griffith University's Human Research Ethics Committee (GU Ref no: 2022/071). Information regarding the ethical approval of the broader LASA study was also provided.

Now that the context for the study has been outlined and the methodology and study design have been discussed, the following chapter outlines the findings of the research study in relation to the defined research questions.

## Chapter 4 Results

### 4.1 Quantitative Analysis: Standardised Measure of Anxiety (ASC-ASD-P)

In order to build an initial understanding of the parent-reported profile of anxiety symptoms in minimally verbal autistic children and answer research question 1a, (“What is the profile of anxiety symptoms in minimally verbal autistic children, as reported by parents on a standardised, autism-specific assessment of anxiety?”) the data collected from the ASC-ASD-P were analysed at total raw score, subscale raw score, and item level raw score.

Rodgers et al. (2016) defined a score  $\geq 20$  being indicative of significant levels of anxiety.

#### 4.1.1 ASC-ASD-P Total Score and Subscale Scores

The lowest ASC-ASD-P total score reported by parents was 0 (minimum score possible on measure) and the highest score reported was 63 (maximum possible on measure = 72). The average total score reported by the parents on the ASC-ASD-P was 22.88 ( $SD = 17.61$ ). The mean scores for the different subscales are displayed in Table 4, accounting for the differing number of questions per subscale.

**Table 5**

*Subscale and Item-Level Statistics for ASC-ASD-P Data*

Subscale	Number of items in subscale	Min and max mean score per item	Standard deviation (min and max mean score)	Mean score per item	Standard deviation (mean per item)
Performance Anxiety	5	0.58–0.64	0.06	0.64	0.85
Anxious Arousal	6	0.33–1.12	0.30	0.78	0.78
Separation Anxiety	5	0.27–1.15	0.43	0.89	0.76
Uncertainty	8	0.85–1.55	0.27	1.32	0.88

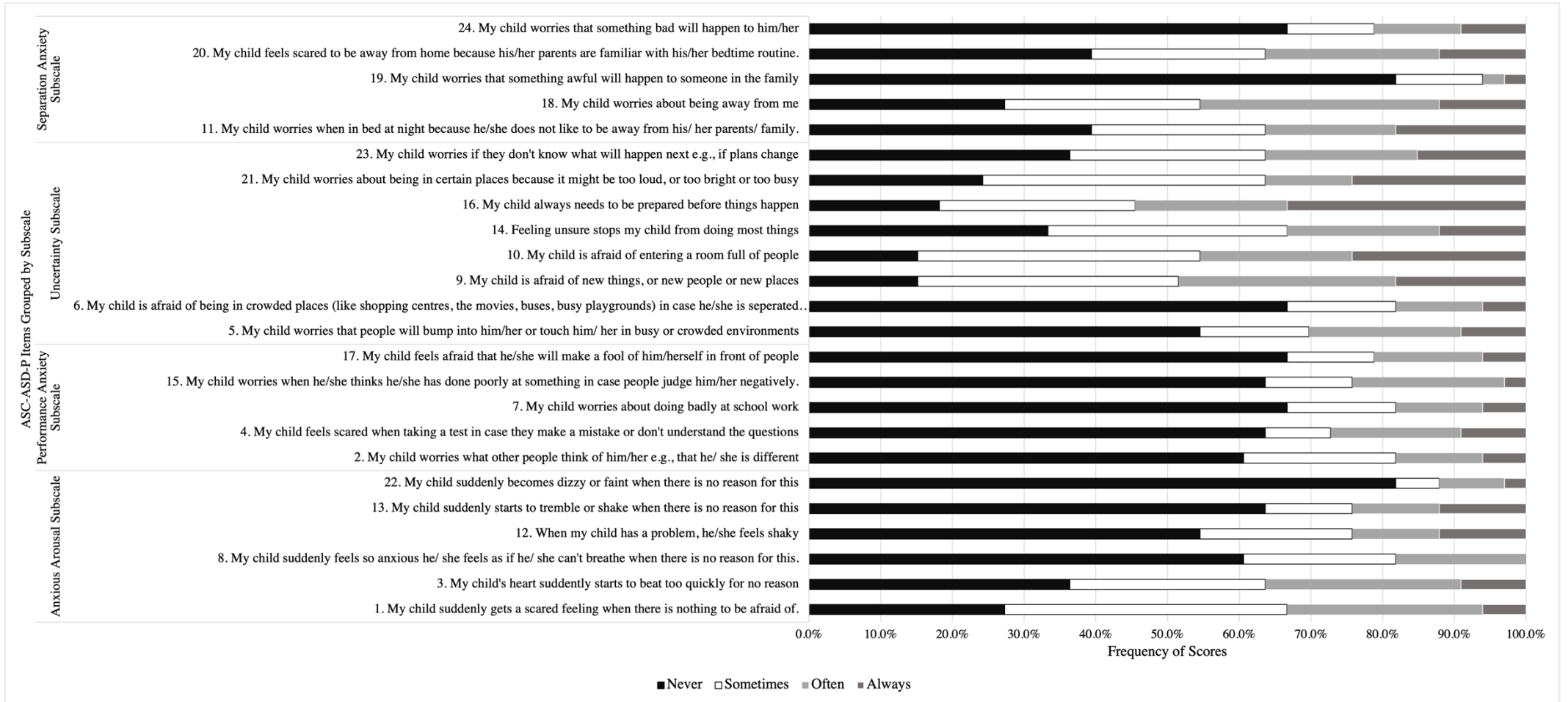
As shown in Table 5, the most highly rated subscale across all items was the Uncertainty subscale, with the average score per question being 1.32 ( $SD = 0.88$ ). Variability between minimum and maximum mean scores across the subscales was significant across the Anxious Arousal, Separation Anxiety, and Uncertainty subscales. Performance Anxiety had the smallest amount of variability in scores.

#### ***4.1.2 ASC-ASD-P Exploration at Item Level***

In order to further examine parent-reported profiles of anxiety symptoms in minimally verbal autistic children, the ASC-ASD-P ratings were explored at item level. As Figure 2 illustrates, the items with the highest mean score on the ASC-ASD-P were all from the Uncertainty subscale. Questions 10 and 16 (for question wording, see Figure 2) had the same highest mean score across participants of 1.32. Question 9 had the next highest average score of 1.70. The least commonly reported items were from the Separation Anxiety (Question 19) and Anxious Arousal subscales (Question 22). These items scored an average of 0.27 and 0.33, respectively, across all participants.

**Figure 8**

*Profile of Scores from the ASC-ASD-P (Rodgers et al., 2016)*



## **4.2 Qualitative Analysis**

In order to better understand the signs that minimally verbal autistic children display to indicate they are anxious, the qualitative data gathered through short response questions were analysed to learn more about how parents perceive anxiety to present in their children in the home, at school, and while accessing the community. Analysis of these data answered the second research sub question, “What are the indicators of anxiety of minimally verbal autistic children as reported by their parents through open-ended responses?” The responses to questions regarding experiencing anxiety in specific environments (yes/no) and the parent descriptors of anxiety were explored using content analysis.

Parents reported a range of indicators suggesting their child may be experiencing signs of anxiety. The number of anxiety indicators for the home setting ranged from 1–8 across participants, with a mean of 3.74. For the school setting, 22 parents reported a total of 75 indicators of anxiety, with the minimum number of reported signs ranging from one to eight. The mean number of responses across the parents who reported indicators of anxiety at school was 3.41. Twenty-six parents reported that their child displayed signs of anxiety within the community; response-level analysis indicated the minimum number of signs of anxiety being one and the maximum being eight. The average number of responses per parent was 3.08.

### ***4.2.1 Anxiety at Home***

In response to the question, “Is your child anxious at home?” (which could only be answered yes/no), 15 (45.45%) parents reported that they thought their child was anxious at home. Those 15 parents were then asked to describe what they felt were the signs of their child’s anxiety at home. These responses were deductively coded in the same codes as Adams, Young, Simpson et al. (2019), allowing for similarities or differences in anxiety

presentation in minimally verbal children on the autism spectrum to be identified. All responses were coded, with Table 5 displaying the proportion of responses.

The most frequently reported signs of anxiety in minimally verbal autistic children at home were repetitive behaviours or movements ( $n = 5$ , 33.34%; e.g., stimming, pacing) and harming others ( $n = 5$ , 33.34%; e.g., aggression, hitting, lashes out, throwing). With LASA participant 21's parent writing, "hitting," and LASA participant 97's parent writing "lashing out" in response to this question. In addition, screaming and yelling, and the child repeatedly questioning them, were noted as signs of anxiety by four (26.67%) parents. LASA participant 31's parent noted that their child would repeatedly ask for things using his AAC system. More than a quarter of parents ( $n = 4$ , 26.67%) reported that their child looked anxious, with qualitative comments stating that this was noticeable through facial expression and body language. LASA participant 110's parent reported that their child was "jittery, scared and jumpy." Four parents (26.67%) reported that their children engage in self-injurious behaviour when anxious, with examples including skin-picking, chewing their clothing and hands, and punching themselves. LASA participant 63 noted their child, "sucking the neck of his clothing," as a sign of anxiety.

#### ***4.2.2 Anxiety at School***

Twenty-two (68.75%) parents reported that their child was anxious at school. The most frequently reported signs of anxiety were engaging in self-injurious behaviour ( $n = 8$ , 36.36%; e.g., picks skin/nails, chews hand, punches self). LASA participant 143 reported their child engages in "self-harm, biting self, chewing on fingernails and clothing." Additionally, for six (27.28%) children, crying or displaying signs of upset was perceived to be a sign of anxiety/ anxiousness at school. For five (22.73%) children, parents reported that increased movement (e.g., fidgeting, rocking, and hyperactivity) indicated anxiety or

anxiousness at school. LASA participant 182's parent reported "mainly fidgety body, he holds it in and will explode as in the gate."

#### ***4.2.3 Anxiety in the Community***

Twenty-six (78.79%) parents reported that their children were anxious within the community. The most frequently reported signs of anxiousness when out in the community were crying ( $n = 9$ ; 34.62%) or engaging in repetitive behaviours or movements ( $n = 8$ ; 30.77%). LASA participant 267's parent reported that in the community their child displays signs of anxiety by being, "overactive, running, pacing and repetitive touching." Six (23.16%) parents reported increased movement, with examples provided including quick movements, fidgeting, and running around. Six (23.16%) parents noted non-compliance behaviours (e.g., refusal to participate) As an example, parent of LASA participant 64 reports their child, "Refusal to get out of car or go to new public places. Vomit on the way to new places or in new environments. Screams and refuses to comply. Drops to the floor."

Additionally, six (23.16%) reported increased sensitivity to sensory stimuli as signs of their child's anxiety when accessing the community. LASA participant 22's parent gave an example saying, "Fingers in ears. Stimming. Trying to get rid of hearing to focus better with eyesight. Whinging."

#### ***4.2.4 Signs of Anxiety Reported Across Multiple Settings***

The two most commonly reported signs of anxiety across all three settings were "crying or signs of upset" and "increased movement." Twenty percent of parents ( $n = 3$ ) reported that their children were seen to cry, look tearful, or be frequently upset at home; 27.28% of parents ( $n = 6$ ) reported that their children displayed these signs at school, and 34.62% of parents ( $n = 9$ ) reported that their children displayed these signs of anxiety within the community. Similarly, 20% of parents ( $n = 3$ ) also reported their children would run

around, fidget, rock, engage in quick movements, or be hyperactive at home, 22.73% ( $n = 5$ ) of parents reported that their children engaged in this movement at school and 23.16% ( $n = 6$ ) of parents reported their child would engage in this movement as an indicator of anxiety in the community.

Three signs were also reported as indicators of anxiety in two of the three settings enquired about. These included repetitive behaviours or movements, such as stimming or pacing, which parents reported were common signs of anxiety in the home (5 parents, 33.34%) and the community (8 parents, 30.77%). Parents also reported that their child engaged in behaviour that could harm themselves commonly as a sign of anxiety at home (4 parents, 26.67%) and at school (8 parents, 36.36%). Additionally, parents reported that behaviours such as aggression, hitting, lashing out, and throwing were common indicators of anxiety both at home (5 parents, 33.34%) and at school (7 parents, 31.81%).



**Table 6**

*Content Analysis of Open-Ended Responses Provided by Parents Outlining Indicators of Anxiety Across Home, School, and Community*

Area	Category	Examples	Total number and percentage of parents reporting this as a sign of anxiety		
			Home <i>n</i> = 15	School <i>n</i> = 22	Community <i>n</i> = 26
Vocalisations	Vocalisations become louder, faster or shouts	Screaming, gets louder, yelling	4 (26.67%)	3 (13.64%)	5 (19.23%)
	Repetitive requests or questions	Repeated questions and requests	4 (26.67%)	1 (4.55%)	1 (3.85%)
	Repeats or makes repetitive noises, words, or phrases	Repetitively states “I no go anywhere”, making repetitive noises	2 (13.34%)	0 (0.00%)	2 (7.78%)
	Argues or uses rude/ inappropriate language	Argues with siblings	1 (6.67%)	0 (0.00%)	0 (0.00%)
	Says that they are anxious, worried, or scared	Says that they are anxious, worried, or scared	0 (0.00%)	0 (0.00%)	0 (0.00%)
	Reduces verbal output or becomes non-verbal	Has difficulties verbally communicating	0 (0.00%)	1 (4.55%)	2 (7.78%)
Mood/ Affect/ Emotions/ Cognitions	Appears anxious, worried, or scared	Facial expressions, worried looks, looks afraid	4 (26.67%)	0 (0.00%)	3 (11.54%)
	Crying or signs of upset	Crying, tearful, frequently upset	3 (20.00%)	6 (27.28%)	9 (34.62%)

	Angry or overactive	Angry, outbursts	1 (6.67%)	1 (4.55%)	0 (0.00%)
	Difficulties with focus or concentration or completing mental tasks	Unable to focus	1 (6.67%)	2 (9.00%)	1 (3.85%)
	Agitated or restless mood	Agitated, restless, distressed	1 (6.67%)	1 (4.55%)	0 (0.00%)
	Meltdown	Meltdown	1 (6.67%)	1 (4.55%)	1 (3.85%)
	Excitable or silly mood	Excitement that turns into distress	1 (6.67%)	0 (0.00%)	0 (0.00%)
	Signs of low self-esteem	Says cannot do the task, believes not good enough	0 (0.00%)	1 (4.55%)	0 (0.00%)
Movement	Repetitive behaviours or movements	Stimming, pacing	5 (33.34%)	1 (4.55%)	8 (30.77%)
	Increased movement	Runs around, fidgeting, rocking, hyperactivity, quick movements	3 (20.00%)	5 (22.73%)	6 (23.16%)
	Decreased movement	Rigid body, freezes, looks down	0 (0.00%)	3 (13.67%)	0 (0.00%)
Physiological	Difficulties with sleeping	Difficulties falling asleep	0 (0.00%)	0 (0.00%)	0 (0.00%)
	Feels sick or unwell	Sickness in stomach, sore stomach, headaches	1 (6.67%)	3 (13.67%)	1 (3.85%)
	Increased breathing or breathing difficulties	Rapid breathing	0 (0.00%)	0 (0.00%)	0 (0.00%)
	Toileting problems	Toileting accidents, unable to go to the toilet	1 (6.67%)	3 (13.67%)	1 (3.85%)

	Sweating	Sweating	1 (6.67%)	0 (0.00%)	1 (3.85%)
Behaviour	Hides, shuts down, withdraws, or removes self from situation	Hides, withdraws	3 (20.00%)	4 (18.18%)	3 (11.54%)
	Non-compliance or refusal	Refusal to participate or engage in tasks, becomes reactive	2 (13.34%)	1 (4.55%)	6 (23.16%)
	Needing routine or predictability	Low threshold for change	3 (20.00%)	4 (18.18%)	3 (11.54%)
	Tense behaviour	Trouble relaxing, ripping items, jittery, jumpy	3 (20.00%)	1 (4.55%)	1 (3.85%)
	Harms others	Aggression, hitting, lashes out, throwing	5 (33.34%)	7 (31.81%)	3 (11.54%)
	Harms self	Self-harm, picks skin/nails, chews hand, punches self	4 (26.67%)	8 (36.36%)	2 (7.78%)
	Bites, licks, or mouths objects	Bites, chews, or sucks clothing	1 (6.67%)	3 (13.67%)	1 (3.85%)
	Needing or wanting a specific person	Sicks close to a parent, is “clingy”, brings picture of parent to other parent	2 (13.34%)	0 (0.00%)	5 (19.23%)
	Avoids or delays tasks	Avoidant of tasks	0 (0.00%)	0 (0.00%)	0 (0.00%)
	(Over) sensitive to sensory stimuli	Has to cover ears, annoyed with noise, too many people	1 (6.67%)	2 (9.00%)	6 (23.16%)
	Difficulties completing physical tasks	Tasks taking a long time, e.g., needing constant reassurance	0 (0.00%)	2 (9.00%)	0 (0.00%)

Changes in appetite/food-related behaviours	Over eats/ will not eat	0 (0.00%)	0 (0.00%)	0 (0.00%)
Avoids social interaction	Avoids others, indicates for others to leave	1 (6.67%)	0 (0.00%)	0 (0.00%)
Reluctant or expresses discontent	Complains, reluctant	0 (0.00%)	1 (4.55%)	0 (0.00%)
Runs away	Absconds, runs away, elopes	0 (0.00%)	0 (0.00%)	2 (7.78%)
Rushes or impatient behaviour	Impatient, rushes	0 (0.00%)	0 (0.00%)	0 (0.00%)
Wants or asks to go home	Asks to go home, wants to go home early	N/A	3 (13.67%)	1 (3.85%)
Difficulty or refusal to attend school	Resists going to school, experiences difficulties transitioning to school	N/A	3 (13.67%)	N/A
Difficulties with peer interactions	Sits alone	N/A	1 (4.55%)	N/A

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#### ***4.2.5 Responses Not Fitting Under the Deductive Codes***

Two parents of minimally verbal children on the autism spectrum reported signs of anxiousness that were not covered by Adams, Young, Simpson et al.'s (2019) coding system. One parent noted that their child tiring quickly is a sign of anxiety when accessing the community. Another parent noted that her child experiences disfluency in his verbal communication and stutters when he is experiencing feelings of anxiousness; however, no further detail regarding how regularly this occurs or what environment this occurs in was provided.

### **4.3 Similarities and Differences Between the Quantitative and Qualitative Data on Anxiety in Minimally Verbal Autistic Children**

#### ***4.3.1 ASC-ASD-P Total Score Data Compared with Parent Responses to yes/no Questions About Context-Specific Anxiety***

Having data from a standardised questionnaire on anxiety (ASC-ASD-P) and the open questions from the same participants allows for a comparison to take place between the two data sets, potentially resulting in a more complete understanding of the signs of anxiety that minimally verbal autistic children display to their parents.

The ASC-ASD-P total scores of all 33 children from the sample were visually explored by the number of environments in which the parent reported their child experiences anxiety (see Table 6). The mean ASC-ASD-P total scores are, on a group level, visually lower for those who are reported to experience in 0–1 settings compared to those who experience anxiety in 2–3 settings. Although this suggests some alignment between the responses, there were some discrepancies at an individual level. Some discrepancies may be explained by participant demographics. For example, the highest scoring participant on the ASC-ASD-P (total score 63 out of a possible 71) was reported to experience anxiety within

their home and the community but not at school. However, this can be explained by the child's parent reporting in the additional response area that their child was being home-schooled due to a significant increase in self-injurious behaviour and increased anxiety regarding explicit learning within the school setting. In contrast, another parent reported that their child presented with significant levels of anxiety (ASC-ASD-P total score = 39) but reported that their child was not anxious in any of the settings enquired about (within the home, school, or community environments), with this response not explained through any additional comments or information.

**Table 7**

*ASC-ASD-P Total Score and Number Above Anxious Cut-Off (20) Presented by Number of Environments Parent Reported their Child to Displays Signs of Anxiety*

	Parent-reported signs of anxiety in following settings	Number of children who displayed anxiety in the identified settings	ASC-ASD	
			Range	Mean
	None of the settings enquired about	6	0–12	3.83
One setting	Home only	0	-	-
	School only	1	25	-
	Community only	3	4–15	7.67
	Home and school	0	-	-
	Home and community	2	7–63	35.00
	School and community	8	12–52	30.00
	Home, school, and community	13	0–51	27.54

The ASC-ASD-P responses by 17 parents (51.52%) were above 20, which is considered by Rodgers et al. (2016) to be a score indicative of co-occurring anxiety. Twenty-three children (69.69%) were reported by their parents to demonstrate signs of anxiety across two or three settings enquired about. A further six parents (18.18%) reported their child did not experience anxiety across any of the environments surveyed (home, school, community); however, they were identified by the ASC-ASD-P to likely be presenting with co-occurring anxiety as they scored equal to or above 20.

#### ***4.3.2 Alignment Between Parent Open-Ended Responses and Items on the ASC-ASD-P***

The category that aligned with the highest number of items in the ASC-ASD-P was “needing routine or predictability.” Three items on the ASC-ASD-P were rated as aligning with this category: Item 9 (“My child is afraid of new things, or new people, or new places”), Item 16 (“My child always need to be prepared before things happen”) and Item 23 (“My child worries if they don’t know what will happen next e.g., if plans change”). These three items were found within the Uncertainty subscale of the ASC-ASD-P. As previously noted, the Uncertainty subscale had the highest mean score per question of 1.32 ( $SD = 0.88$ ) across all the subscales. Looking at the items rated to align closely with the open-ended questions, Item 9 ( $M = 1.52$ ,  $SD = 0.97$ ), Item 16 ( $M = 1.70$ ,  $SD = 1.13$ ), and Item 23 ( $M = 1.36$ ,  $SD = 1.11$ ) were highly rated items by parents. On the open-ended questions, three parents (20.00%) reported that their children needed routine or predictability within the home, four (18.18%) reported the same for school, and three (11.54%) reported seeing their child’s need for routine and predictability while accessing the community.

Alignment was also noted across five categories and ASC-ASD-P items: “difficulty sleeping” and ASC-ASD-P Item 11, “My child worries when in bed at night because he/she does not like to be away from his/ her parents/family”; “feels sick or unwell” and ASC-ASD-P Item 22, “My child suddenly becomes dizzy or faint when there is no reason for this”;

“increased breathing or breathing difficulties” and ASC-ASD-P Item 8, “My child suddenly feels so anxious he/she feels as if he/she can’t breathe when there is no reason for this”; “breathing difficulties,” as well as “(over) sensitive to sensory stimuli,” and ASC-ASD Item 21, “My child worries about being in certain places because it might be too loud, or too bright, or too busy”; and “reluctant or expresses discontent” and ASC-ASD-P Item 14, “Feeling unsure stops my child from doing most things”.

Item 11 of the ASC-ASD-P scored a mean score of 1.15 ( $SD = 1.15$ ), with parents on the open-ended questions reporting across home, school, and community that none of their children displayed difficulties falling asleep (0, 0.00% across all environments). ASC-ASD-P Item 22 scored a mean score of 0.33 ( $SD = 0.78$ ). On the open-ended responses, one parent (6.67%) reported that their child feels sick or unwell because of feeling anxious at home, three parents (13.67%) reported this to occur whilst at school, and one parent (3.85%) reported this occurring within the community.

Item 16 on the ASC-ASD-P, “My child suddenly feels so anxious he/she feels as if he/she can’t breathe when there is no reason for this” (Rodgers et al., 2016) generated a mean score of 0.58 ( $SD = 0.79$ ); no parents reported any breathing difficulties in any of the environments surveyed (0, 0.00% across all environments).

ASC-ASD-P Item 21 scored a mean score of 1.36 ( $SD = 1.11$ ), on the open-ended questions: one parent (6.67%) reported that their child was oversensitive to sensory stimuli within the home as a result of feeling anxious, two (9.00%) reported that this happened to their child at school, whilst six (23.16%) reported this occurred within the community.

Item 14 on the ASC-ASD-P, “Feeling unsure stops my child from doing most things,” scored a mean score of 1.12 ( $SD = 1.02$ ). On the open-ended question responses, one parent (4.55%) reported that their child is reluctant or expresses discontent while at school, while this was not reported by any other parents at home or while accessing the community.



### ***4.3.3 Common Indicators of Anxiety Suggested by Parents in the Open-Ended Responses Potentially Not Rated as Part of the ASC-ASD-P***

Fifteen parents (45.45%) reported in their open-ended responses that their children engage in behaviours that can harm others when they are experiencing feelings of anxiety, while 14 parents (42.42%) reported that their children engage in behaviours that can harm themselves when experiencing feelings of anxiety. Examples of these behaviours towards self and others include aggression, lashing out and throwing, or engaging in self-harm behaviours such as picking skin. Self-harm and engaging in behaviours that can harm others as an indicator of anxiety is not explored by the ASC-ASD-P.

Further, nine parents (34.62%) reported that their child cries or displays signs of upset in the community when they are feeling anxious. Eight parents (30.77%) reported that their children engaged in repetitive behaviours or movements, such as stimming or pacing when accessing the community, and that when this occurred their parents perceived this to be a sign of anxiety. The ASC-ASD-P does not ask about children crying or the frequency of repetitive behaviours as indicators of anxiety.

The results of this study will now be discussed in relation to the broader literature focussing on both autistic people and the broader disability population. In order to structure the discussion, the research questions have been used to frame the discussion with reference to the convergent parallel study design.

## Chapter 5 Discussion

This study is an important addition to the growing body of literature investigating the presentation of anxiety in minimally verbal autistic people, a group considerably underrepresented within research (Tager-Flusberg & Kasari, 2013). By combining findings from an autism-specific standardised measure with parental experience and expertise shared through open-ended responses, the information gathered helps to create a holistic picture of how anxiety can present in minimally verbal autistic children. In keeping with the convergent parallel design employed in this study, whilst also considering the research questions, the quantitative results will first be examined, followed by the qualitative results, before the two are brought together to help us understand the broader implications of these findings to research and clinical practice.

### **5.1 Research Question (RQ) 1a: What is the Profile of Anxiety Symptoms in Minimally Verbal Autistic Children, as Reported by Parents on a Standardised, Autism-Specific Assessment of Anxiety?**

#### ***5.1.1 Parent-Reported Signs of Anxiety in Minimally Verbal Autistic Children on a Standardised Measure***

The first aim of the current study was to examine the profile of parent-reported signs of anxiety in minimally verbal autistic children on a standardised quantitative measure. The sample experienced a range of levels of anxiety, with slightly over half of the children involved in this study presenting with significant levels of anxiety (mean ASC-ASD-P score = 22.88) as defined by Rodgers et al. (2016). Therefore, the findings are relevant to community as well as clinical samples of verbally communicating autistic children. A similar mean score of 25.32 was reported by Rodgers et al. Additionally, Keen et al. (2019) reported an average score of 22.82 (in children aged 5–6), den Houting et al. (2018) reported a mean

total score of 26.7 (in children aged 10–12), and Adams and Emerson (2020) reported a mean score of 26.2. Although some of the participants from Keen et al. (2019) and den Houting et al. (2018) overlap with this study, the ASC-ASD scores were from a different timepoint. Combining the findings of the current study with the broader research demonstrates how common experiences of anxiety are for autistic children regardless of their age or their subgroup (i.e., minimally verbal, verbal, co-occurring condition, etc.).

The ASC-ASD-P total scores within this sample demonstrate significant variability; the lowest total score was 0, and the highest was 63. This suggests that some parents noted that their child never displayed any of the signs of anxiety listed, while others reported their children sometimes, often, or always experienced the signs of anxiety described by the ASC-ASD-P. Rodgers et al. (2016) reported similar variability in both parent and child reporting, with parents reporting a minimum score of 1 and a maximum score of 67. Adams and Emerson (2021) also reported significant variability in total ASC-ASD-P scores in their study in which 121 parents of autistic children aged between 5 and 17 years used the ASC-ASD-P to report on their child's signs of anxiety. The scores in that study ranged from 6 to 70; the average score was reported to be significantly higher than those reported in previous studies, with Adams and Emerson finding an average score of 39.9 ( $SD = 15.1$ ). Similar findings were reported by Adams et al. (2020); the parents who participated in this study reported a minimum score of 3 and a maximum score of 70, with the average score across the 64 children being 25.9 ( $SD = 14.6$ ). This variability in the minimum and maximum scores found across various studies using the ASC-ASD-P suggests that some children with autism are severely impacted by anxiety and others less so. This is supported by previous research findings suggesting that 40% of autistic children present with co-occurring clinical diagnoses of anxiety, while a further 40% present with subclinical levels of anxiety (van Steensel et al., 2011). Further, several researchers have found that those with "elevated anxious

symptomatology” (i.e., a score of 20 or higher on the ASC-ASD-P; Rodgers et al., 2016, p. 2) are more likely to experience poorer quality of life (Adams & Emerson, 2020, 2021; Smith et al., 2019). Various researchers have noted that anxiety has a bigger impact on some facets of children’s lives than their autism characteristics (e.g., emotional and school functioning; Adams & Emerson, 2021; Matherson & Nebel-Schwalm, 2007). Further studies have noted the significant impact anxiety has on the lives of those around the child, with parents in both Tarver et al. (2021) and Adams et al. (2020) reporting on the impact of anxiety on the broader family’s life.

The highest scoring items reported by parents of minimally verbal autistic children on the ASC-ASD-P were from the Uncertainty subscale. This subscale was added to items from the RCADS to make the ASC-ASD-P more sensitive to non-traditional, or atypical, presentations of anxiety which were noted across the research to be commonly seen in autistic children (Rodgers et al., 2016). The Uncertainty subscale covers items that examine the child’s ability to tolerate new experiences, change, and situations outside of their control, such as other people and sensory stimuli (e.g., light, sound, etc.). Adams and Emerson (2021) reported that the most commonly reported items were also from the Uncertainty subscale, with the parents in their study reporting that their children commonly needed advanced warning of, and to be prepared for, change. Adams and Emerson also reported that many of the children within their study were afraid when walking into a room of strangers. Additionally, in a study of Singaporean youth with average language skills commensurate to their age, parents and their children most commonly reported the items within the Uncertainty subscale (Soh et al., 2021). Further findings into the presentation of anxiety in autistic individuals with co-occurring intellectual disabilities found that parents more frequently endorsed items from the Uncertainty subscale compared with any other subscale on the ASC-ASD-P (Groves et al., 2022).

The items within the Uncertainty subscale have been noted to be either observable behaviours, or activities/ outcomes that parents are able to associate with a particular trigger or stimuli quickly and easily. For example, one of the items on the subscale discusses a child being afraid of being in crowded places. A parent might be able to observe this through non-verbal communication, such as body language or facial expression. They are also more likely to be able to easily identify that their child might be afraid because of all the people. The other subscales of Performance Anxiety, Separation Anxiety, and Anxious Arousal offer fewer observable behaviours; for example, internal feelings (e.g., a scared feeling) or physiological responses (e.g., heart beating quickly; Groves et al., 2022).

Of late there has been an increasing interest between the link between difficulties with change and uncertainty and the role this plays in anxiety. Intolerance of Uncertainty (IU) is one of those concepts. Whilst difficult to exclusively define, IU is generally regarded as a way of thinking that leads to negative beliefs about uncertainty with the implications of this leading to the tendency to react negatively on an emotional, cognitive or behavioural level to uncertain situations or events (Buhr & Douglas, 2009). It is important to note that not every autistic person will present with IU, however the link between IU and anxiety has been established by many authors. For example, Jenkinson et al. (2020) conducted a systematic review and meta-analysis of the relationship between IU and anxiety presentation in autistic people. Whilst few papers included autistic people with a co-occurring ID, this meta-analysis regression found the relationship between IU and anxiety strengthened as IQ increased (Jenkinson et al., 2020). A similar finding was made by van Steensel and Heeman (2017), who suggested that children with higher IQs have more difficulties with IU because they have increased insight into their difficulties and the demands that are placed upon them, leading to feelings of anxiety. In another study involving the parents of autistic children with a co-occurring ID, Groves et al. (2022) found that IU was strongly correlated with restricted

preferences and insistence on sameness, suggesting that difficulties with IU underpin individual presentations of anxiety within this population.

In summary, the most frequently reported items on the ASC-ASD-P were all from the Uncertainty subscale, in which the items are more observable or are more easily linked to causation (Groves et al., 2022). This finding also speaks to the increasing interest within the literature regarding autistic people's IU (Soh et al., 2021). Many have hypothesised on the relationship between IU, autism, and anxiety, with several researchers postulating the importance of developing tools to help with assessment and management of IU within this population (Groves et al., 2022; Hodgson et al., 2017; Rodgers et al., 2016; Wigham et al., 2015).

### ***5.1.3 Rarely Reported Items by Parents and Children Using Standardised Measures***

Parents in the current study rarely reported items from the subscales of Performance Anxiety subscale and the Anxious Arousal subscales. In addition to this, Adams and Emerson (2021), Groves et al. (2022), and Soh et al. (2021) also reported that the least commonly reported items on the ASC-ASD-P were found in the Anxious Arousal subscales, which discuss physiological reactions to anxiety within their research. Many of these items relate to physiological responses or items related to highly specific stimuli that might be hard for parents to readily identify. Some research notes the difficulties parents may have with being able to identify their child's intrinsic experiences of anxiety as these are not as observable, or not as easily matched to an outward cause (Ernst et al., 2013; Longarzo et al., 2015; Palser et al., 2019).

Recently there has been increasing interest from the academic community in utilising alternative methods to gain insights into physiological and less observable behaviours. These include, using alternative technologies such as, low-cost non-invasive sensors (Panju et al. (2015). Through the use of this system, Panju et al. were able to detect anxiety arousal in

autistic children with 99% sensitivity and 92% specificity, suggesting this may be an alternative method to determine the presence or absence of anxiety within this population, and with higher levels of accuracy, improving long-term outcomes by ensuring appropriate access to services. Sarahadani et al. (2020) also noted the effectiveness of respiration rate, heart rate, temperature measures, and electrocardiograms to learn about the emotional states of autistic children using objective measures.

## **5.2 Research Question 1b: What Are the Indicators of Anxiety of Minimally Verbal Autistic Children as Reported by Their Parents Through Open-Ended Responses?**

### ***5.2.1 Most Commonly Reported Open-Ended Responses Provided by Parents Outlining how Anxiety can Present at Home, at School, and in the Community***

The second aim of the current study was to examine the profile of parent-reported signs of anxiety in minimally verbal autistic children through the use of open-ended responses.

***Anxiety Presentations at Home.*** The current study builds on previous findings which suggests that anxiety is prevalent within the home. Almost half of the parents who participated in the study reported that their child displayed signs of anxiety within the home. Adams, Young, Simpson et al. (2019) reported that over 75% of their sample of autistic children reported that they feel anxious within the home. Further, over half of the parents who completed the Adams, Young, Simpson et al. (2019) study investigating parent-reported indicators of anxiety reported that they thought their child displayed signs of anxiety within the home. This suggests there is some disconnect between what parents are perceiving as anxiety and what the autistic children themselves are feeling within the home.

The current study also found the most commonly reported signs of anxiety to be the child engaging in repetitive movements and engaging in behaviour that could cause harm to others, for example, hitting and throwing. Additionally, parents in the current study reported that their child could engage in screaming, yelling, and repetitive questioning when experiencing feelings of anxiety. However, Adams, Young, Simpson et al. (2019) found that the most common signs reported by parents that their child was experiencing feelings of anxiety were appearing anxious, worried, or scared (25.3%), shouting/ louder/ faster vocalisations (23.1%), and repetitive behaviours. Some of these findings are significantly different between studies, taking into consideration the likelihood that many of the participants were common to the current study and to the Adams, Young, Simpson et al. (2019) study. One possible reason for this varied reporting noted between the current study and Adams et al. could be related to communicative ability. In Adams et al.'s study, 21 parents reported that their child increases their vocal volume or shouts/yells when they are experiencing a feeling of anxiety. Children within the current study were reported to experience this at a far lower rate, with only four children reported to display this as a sign of anxiety at home. Further, six parents in Adams et al. reported that their children would argue or use inappropriate language within the home, while five parents reported inappropriate language and arguments at school and in the community. This current study found that only one parent (6.67%) reported that their child argues or uses inappropriate language at home as a sign of anxiety. Edirisooriya et al. (2020), in a study investigating the link between IQ and internalising of anxiety symptoms, reported that difficulty expressing feelings communicatively was negatively associated with lower verbal IQ scores and greater internalising behaviour. Further, it was noted that Adams et al. Parents reported some changes in appetite or food-related behaviour in some children across home, school, and the community. Additionally, physiological signs of anxiety were reported more frequently by



parents in Adams et al. than in the current study. These included difficulties sleeping, feeling sick or unwell, increased breathing and/or breathing difficulties, and toileting problems.

The research community has been increasingly interested in the role interoception plays in autistic children's understanding of their anxiety symptoms (Palser et al., 2019). Interoception is defined as the perception and integration of autonomic, hormonal, and homeostatic signals that are collated by the brain to understand the physiological state of the body (Barrett & Simmons, 2015). Researchers have conducted several qualitative and quantitative studies that suggest autistic individuals have significant difficulties with interoception across the spectrum, from awareness of bodily signals to integrating the meaning of these signals (DuBois et al., 2016; Elwin et al., 2012; Musser, 2018). In a small-scale study of 49 autistic children, it was found that those with a higher severity of autism, as determined by the Autism Diagnostic Observation Schedule-2, had poorer interoceptive abilities despite having higher confidence levels, such as ability to indicate when their heart rate would increase in the presence of anxiety-inducing stimuli (Palser et al., 2019). However, it was noted that those who experienced higher levels of interoceptive sensibility were more likely to present with higher levels of anxiety compared with those with lower levels of interoceptive abilities (Ernst et al., 2013; Longarzo et al., 2015; Palser et al., 2019). Impaired interoception has been linked to impaired receptive and expressive language skills, in a study conducted on individuals with an acquired traumatic brain injury (Hobson et al., 2018). Whilst direct links cannot be made between the children involved in the current study and those from Hobson et al. (2018), links can be hypothesised. The children in the current study also presented with expressive and receptive language disorders, meaning their ability to use and understand language is significantly impacted. This affects their ability to verbally express internal feelings to their parents, but also impacts on their ability to understand their

internal experiences and equate these with an emotional state or situation, which is the goal of interoception (Hobson et al., 2019).

Additionally, difficulties with alexithymia can also be experienced by autistic people, which is defined as the ability to recognise and label an emotion (Hobson et al., 2019). While reviewing the research, it became apparent that there are few studies where investigations took place into interoceptive abilities in autistic individuals who had IQs of less than 100; both Griffin et al. (2015) and Gerber et al. (2019) studied populations with an IQ of between 101 and 107. Hobson et al. (2019) suggested that, based on the research that has been conducted, it is clear that a link exists between verbal IQ, interoception, and alexithymia; however, the role of language delays and disorders within this, and the impacts these have on autistic people and their understanding of interoception and alexithymia, remains unclear.

***Anxiety Presentations at School.*** The current study found that, of the children who were reported to experience anxiety at school, many engaged in self-harming behaviours, such as picking at their skin or biting their hands, or behaviours that could cause harm to someone else, for example, biting, scratching, hitting, lashing out, and other forms of aggression. Finally, crying and signs of upset were also commonly reported in the current study. Twenty-two parents (66.67%) who participated in this study reported that they felt their child was anxious at school. According to Adams, Young, Simpson et al. (2019), the most commonly reported signs of anxiety while at school were hiding/shutting down, crying, or displaying signs of upset and non-compliant behaviours. As previously mentioned, many of the participants from the current study, particularly those in the older cohort, are likely to have been a part of Adams et al.'s (2019) study, so interpretation of similarities is made with caution.

The externalised behaviours reported by families within the study are significant in their impact on the child, their family, and their school. Research from Conner et al. (2020)

reported that autistic children and co-occurring anxiety symptomatology are likely to experience significant differences in their emotional regulation skills. Emotional regulation is defined as the ability to adapt arousal and emotional responses in response to events and behaviours that occur, both desired and not desired (Conner et al., 2020). Emotional regulation is also thought to be closely correlated with cognitive flexibility and IU (Cai et al., 2018; Conner et al., 2020). Whilst most of the research that has been conducted into the relationship between emotional regulation and anxiety has been done in conjunction with autistic verbal communicators, links are able to be hypothesised as emotional regulation skills cover a broad array of responses. For example, differences in emotional regulation skills have also been linked to behaviours that can cause harm to self and others, such as irritability and aggression (White & Mazefsky, 2014), which many of the parents in the current study reported as a sign their child was experiencing anxiety at school. The absence of these skills may result in children who are unable to communicate or regulate their own emotions turning to behaviour as a consistent and effective method of communication (Bearss et al., 2016; Molyneux, 2019).

In order to build our understanding of the role of emotional regulation and IU Sáez-Suanes et al. (2020) conducted a study into understanding the role of emotional regulation skills and IU in autistic adults with co-occurring ID. It was reported that IU is significantly correlated with elevated levels of anxiety within autistic adults with co-occurring ID (Sáez-Suanes et al., 2020). In terms of emotional regulation skills, both Sáez-Suanes et al. and Samson et al. (2015) reported that poor emotional regulation skills lead to lower levels of internalised behaviours and higher levels of externalising behaviours, compared to other autistic people presenting with stronger emotional regulation skills, such as the ability to re-evaluate and other executive functioning skills. This suggests that some autistic people with co-occurring ID who present with differences in their emotional regulation skills are at higher

risk of engaging in behaviours of concern in relation to self-harm and/or harm towards others as a sign of anxiety. This indicates that the results of this study, suggesting that one of the most common signs of anxiety children demonstrate at school is related to challenging behaviours that pose a risk to self and others is common in autistic people who may also present with difficulties in the areas of emotional regulation and IU and that this may need to be explored further in terms of its application to minimally verbal autistic children.

*Anxiety Presentations in the Community.* The current study saw more than 70% of parents report that their child experiences signs of anxiety within the community. It found that anxiety was perceived by parents to manifest most commonly through their child crying and displaying other signs of upset, or engaging in repetitive behaviours such as self-stimulatory behaviours, or pacing. Parents also reported that their child displays their feelings of anxiousness by increasing their movement (fidgeting, running, etc.), engaging in non-compliant behaviours (i.e., refusal), and demonstrating an increased sensitivity to sensory stimuli.

The difficulties reported by families within the current study, including children being upset, increasing their self-stimulatory behaviour, or pacing align with what parents report as the most common signs of anxiety they see their children demonstrating, across various studies. For example, Bearss et al. (2016) convened a focus group of 48 parents to discuss what they considered were signs of anxiety demonstrated by their autistic children. This research found that parents reported signs that could be categorised into six broad themes: triggers, setting events, observable behaviours, coping, parental management, and hold in-escalation-release. Parents in the current study most commonly reported examples within the themes of coping (increase in repetitive behaviours), observable behaviours (increased movement, self-injurious behaviour, behaviour that could cause harm to others, crying or being tearful, looking anxious), and triggers (increased sensitivity to sensory stimuli).

In addition, many of the parents of minimally verbal autistic children surveyed in Tarver et al.'s (2021) study reported similar externalising behaviours as signs of anxiety in their children. For example, parents in Tarver et al.'s study reported to have relied heavily on behavioural cues to recognise when their child was experiencing feelings of anxiety, although these parents, like those in the current study and those interviewed by Simpson et al. (2020), reported how difficult it is to distinguish between what is a sign of feelings of anxiety and what is not. The parents of autistic children who participated in Adams, Young, Simpson et al.'s (2019) study investigating the signs of anxiety parents report identifying within their autistic children most commonly reported increased sensitivity to sensory stimuli, asking or wanting to go home, and avoiding social interactions with others, which were commonly reported also by parents involved in the current study. It can be seen from the similarities between the current study and the three studies discussed that the similarities in findings are significant; therefore, it is probable that anxiety is more likely to be displayed as an externalised behaviour in autistic children than it is to be an internalised experience in neurotypical children (Bearss et al., 2016; Hallett et al., 2013; Kerns et al., 2014; Witwer & Lecavalier, 2010).

Importantly, Bearss et al. (2016), Hallett et al. (2013), Kerns et al. (2014), White and Mazefsky (2014), and Witwer and Lecavalier (2010) acknowledged the difficulties in distinguishing between examples of these behaviours of concern (i.e., self-injurious behaviour), and knowing for certain that these are signs of anxiety in autistic children. For example, parents in the Bearss et al. study reported that the importance of routines for their child was indicative of a convergence of being autistic, whilst also demonstrating their child was being hypervigilant and experiencing feelings of anxiety in regard to the routine changing. There were several examples of this phenomenon noted through the abovementioned papers which led the researchers to question the appropriateness of using

symptomatology of autism to investigate for the presence or absence of feelings of anxiety in autistic children (e.g., sensory processing differences, social communication differences, restricted and repetitive behaviours).

### ***5.2.2 Uniquely Reported Open-Ended Responses Provided by Parents Outlining How Anxiety Can Present at Home, at School, and in the Community***

This study utilised the coding framework set forth by Adams, Young, Simpson et al. (2019) to allow for broader comparison between subgroups and ages within the research. However, as this coding framework was based on a different population of autistic children, it is important to also consider the uniquely reported items of parents of minimally verbal autistic children in this study.

Two parents provided additional information regarding how anxiety presents for their child across the three environments surveyed. One parent reported that feelings of anxiety cause her child to tire quickly, particularly when accessing the community; the other reported that her child experienced dysfluencies within his speech, causing him to stutter when he experiences feelings of anxiety. Research looking at the causes, frequency, and intensity of primary (blocking, prolongations, etc.) and secondary (e.g., eye blinking, twitching, etc.) stuttering behaviours considered whether the person was experiencing feelings of anxiety (Iverach et al., 2009; Rodgers et al., 2022). In other research, it was found that people who stutter are more likely to experience anxiety related to the presence of their stutter when they verbally communicate (St Clare et al., 2009). More broadly, within the population of neurotypical people it is widely accepted that activities perceived as stressful can be a trigger for an increased number of natural dysfluencies in speech (e.g., using filler words, pausing, looking away from communication partner, talking faster, etc.; Montes et al., 2019). Given the lack of knowledge within this subgroup of autistic children, considering their unique

perspective is critical in order to build our understanding of the various presentations of anxiety within minimally verbal autistic children.

### **5.3 Similarities and Differences Between Standardised Measure and Parent-Reported Anxiety at Home, at School, and in the Community**

This study found that 26 (78.79%) of the children involved in this study experienced anxiety in all three environments surveyed (home, school, and community). These children tended to have significantly higher levels of anxiety as seen through the responses generated by the ASC-ASD-P questionnaire than children who were identified to not experience anxiety across any of the three environments surveyed (based on total score averages).

This finding is consistent with those made by Adams, Young, Simpson et al. (2019) who found that autistic children who were experiencing anxiety across all three settings (home, school, and community) had ASC-ASD-P scores three to four times higher than children who, by parent report, did not experience anxiety across any of the settings, in all subscales excluding Performance Anxiety (Adams, Young, Simpson et al., 2019). Whilst no children were excluded from the study based on co-occurring conditions, Adams et al. reported that a limitation of the study was not having the means to determine who presented with a co-occurring ID. Therefore, a direct link between these findings is unable to be made.

In order to understand more about the possible relationship between the open-ended responses and the relationship between these and the results of the ASC-ASD-P, the student researcher and primary supervisor coded where ASC-ASD-P items might be represented based on the open-ended response results. Open-ended responses for these items, such as needing routine or predictability as well as being oversensitive to sensory stimuli and being reluctant or expressing discontent, were among some of the most frequently rated items on the ASC-ASD-P. This suggests that the ASC-ASD-P is able to reflect how minimally verbal autistic children's presentation of anxiety may be undermined by difficulties with uncertainty.

Groves et al. (2022) found similar results in their study, where autistic children with co-occurring intellectual disabilities were found to have higher scores on the Uncertainty subscale of the ASC-ASD-P, suggesting that anxiety within this population may be impacted by underlying uncertainty.

The parental report of perceived feelings of anxiety provided via the open-ended call into question how well the ASC-ASD-P questionnaire reflects the types of signs parents report to indicate that their child is experiencing feelings of anxiety at a broader level. It can be seen, from Table 6 in Chapter 4, that there are many ways anxiety can present amongst different children. These include through changes in vocalisation, mood, affect, emotions, cognition, movement, physiological arousal, and behavioural changes (Adams, Young & Keen, 2019). Increasingly, researchers have been noting the bidirectionality between autistic experiences of anxiety and externalised behaviour/behaviours of concern, in both autistic adults and autistic children (Bearss et al., 2016; Groves et al., 2022; Ozsivadjian et al., 2012; Robertson et al., 2018; Trembath et al., 2012). These authors all noted commonalities between parent and caregiver reports of externalised behaviour and/or behaviours of concern, indicating feelings of anxiety for the autistic person. Similar behavioural presentations were reported by the participants of the current study, where the category “behaviour” has the highest number of reports compared to the other categories. Similarly, the most highly rated items on the ASC-ASD-P represent observable phenomena that parents can directly attribute to feelings of anxiety in their minimally verbal autistic children. Further, items which were found by the student and the primary supervisor outside of the Uncertainty subscale, which reflected parent-reported signs of anxiety from the Adams, Young, Simpson et al. (2019) coding framework and, thus, the current study’s coding framework, were either not at all reported by the parents involved in the current study (i.e., difficulties with sleeping and feels



sick and increased breathing or breathing difficulties) or reported by very few parents (feels sick or unwell).

The results of not just this study, but those such as Bearss et al. (2016), Magiati, Ozsivadjian and Kerns (2017), Ozsivadjian et al. (2012), Robertson et al. (2018), and Trembath et al. (2012), suggest that further work is needed, as the current assessment tools do not offer the flexibility required to capture the large variation in presentations of anxiety across autistic people. For example, in the ASC-ASD-P, several items refer to behaviours but ask parents to rate these in the presence of a specific cause (e.g., Item 15: “My child worries when he/she thinks he/she has done poorly at something in case people judge him/ her negatively”; Rodgers et al., 2016). Four parents (26.67%) reported that their child would appear anxious, worried, or scared as a sign of anxiety at home and at school; however, no information was collected about situations that cause these feelings. Magiati, Ozsivadjian and Kerns (2017) concluded that work needed to be done on ensuring that reporting on the presence or absence of anxiety in autistic children goes beyond subscales and total scores to ensure clinicians and researchers are capturing the breadth of autistic experiences of anxiety.

## **5.4 Limitations**

There are several limitations seen within the study that need to be considered when interpreting its findings and results. Firstly, despite the LASA being a large study of more than 270 parents/caregivers of autistic children, the sample size of minimally verbal autistic children was small, which reduces the generalisability of this study. Parents of autistic children who engage in challenging behaviour, as many minimally verbal children are more stressed than parents of children without developmental disabilities (Lindo et al., 2016). Therefore, parents may be less likely to engage in research because they are increasingly busy and stressed. This study was also limited in that it was only able to explore the signs of anxiety from a parental perspective. Given the emerging research in the area, involving

measures of physiological signs of anxiety (e.g., heart rate monitors, temperature monitoring, etc.) would have been useful; however, it is noted that it was outside the scope of this study to include these items given the nature of the data collection.

In addition to this, the ASC-ASD-P (Rodgers et al., 2016) has not been studied for use with minimally verbal autistic children or those presenting with a co-occurring intellectual disability. This reduces the tool's validity for use with the current population, however it is important to note that there are few tools available that are specific to capturing 'autism-specific' anxiety. This tool is also difficult for parents to use in relation to some of the questions asked of them, for example those in the performance anxiety subscale where the items ask parents for insight into their child's thoughts and opinions, which due to the nature of their expressive language is not possible to know. Therefore, it is recommended that these results be interpreted with caution.

## **5.5 Considerations for Future Research**

Given the breadth and scope of the presentation of anxiety in autistic children, there are many considerations for future research to continue developing and solidifying the knowledge and support that can be given to underrepresented populations of autistic children, such as those with co-occurring language disorders and/or intellectual disabilities. First, the development of semi-structured interview assessment tools that are structured around autism-distinct anxiety and traditional anxiety are required, to be able to capture the presentation of both. Additionally, this tool should be less specific than tools such as the ASC-ASD-P in terms of the situations or environments in which the observable signs of anxiety, such as behaviours of concern or externalising behaviour, can occur. This tool could be used to support investigating for the presence or absence of anxiety in both minimally verbal and verbal autistic children. This is because, the tool is based around observable behaviours and observable physiological signs that could indicate the person is experiencing anxiety

(Edwards et al., 2023). This removes the need for insight into the child's mind and experiences, which the ASC-ASD-P does call for on occasion. For example, item one, "my child suddenly gets a scared feeling when there is nothing to be afraid of," and item two, "my child worries what other people think of him/her e.g., the he/she is different." This calls into question the validity of using this tool with minimally verbal children and their families.

Further, conducting research into how to effectively utilise physiological measures such as heart rate and respiration monitors as well as temperature measures within a clinical environment would be useful in supporting clinicians in being able to better understand their client's anxiety presentation. For example, a systematic review conducted into the neurobiological and physiological presentation in autistic individuals suggested that well-validated neurological markers of anxiety could be used effectively in conjunction with questionnaire-based measures to gain a holistic understanding of the child's presentation of anxiety (McVey, 2018), particularly with reference to the minimally verbal population. For example, McVey (2018) found in their review of the literature that the current, well-validated tools used to detect neurological markers of anxiety include electroencephalogram (EEG), wherein information is able to be gathered in response to different, although specific, stimuli. Further, three studies reviewed by McVey et al. demonstrated that children who were found to have anxiety symptoms that could be seen to be coming from the anterior cingulate cortex and the medial prefrontal cortex were more linked with greater disruptive behaviour. Whilst the research in this area is still emerging, there is evidence that suggests that the neurobiological and physiological impacts of anxiety on minimally verbal autistic children are important and measurable in a way that helps researchers and families learn more about the specific child's experience of anxiety, allowing for better support for the autistic individual and their unique needs in the long term.

Thinking about research more broadly, and the forgotten end of the spectrum (Tager-Flusberg & Kasari, 2013) more specifically, researchers as a community need to attempt to include autistic individuals with co-occurring conditions into their research.

Underrepresenting this population skews results, contributing to under-coverage bias which impacts upon the application of findings to the broader autistic community (Tarver et al., 2021). Some researchers suggest using more creative methodologies, such as using talking mats to evaluate and understand the experiences of those with intellectual disabilities. Stewart et al. (2018) utilised this methodology successfully with a very small sample size to understand individual experiences with support offered in supported independent living. This study also noted using this method with caution, particularly when considering the participants receptive language skills (Stewart et al., 2018). Similarly, Klein (2022) conducted research into considering the photographs that autistic people take as a communication tool, however caution must be taken when using this approach as there is little research in this area and what has been conducted has taken place with very small sample sizes of autistic adults who are able to verbally communicate.

Further to this, future research may wish to include other methods of qualitative data collection such as the use of semi-structured interviews as well as written information or survey results. Whilst written open-ended responses are often time and cost effective (Hunter et al., 2013), using other qualitative measures can help to give a more holistic view of the issue and allow for quality control measures to be applied to determine consistency across methods and cohorts, which ultimately improves understanding of minimally verbal autistic children (Busetto et al., 2020).

Finally, a limitation of this study was the inability to assess for causal factors that may have caused or contributed to the child being minimally verbal. As such, further studies may like to include screening or assessment for conditions such as Childhood Apraxia of Speech

in their research to rule out causal factors and increase the likelihood that the information captured is linked to language deficits. In addition to this at a sample level, information about whether the children used or did not use an AAC system was not collected, nor was the subscale or composite score of the Vinelands assessment provided. As a result, it is difficult to interpret these results in comparison to other groups, autistic or allistic which reduces generalisability.

## **5.6 Clinical Implications**

The variability of parent-reported signs or symptoms of anxiety suggests that, much like the anecdotal phrase, “If you’ve met one person with autism, you’ve met one person with autism,” the presentation of anxiety within this population can be just as varied and diverse. The findings of this research suggest that researchers and clinicians need to take an individualised approach to the assessment of anxiety symptomatology within autistic people to ensure accurate insights into the individual and their presentation are established so that any interventions or supports given are more likely to be successful. One way to do this is to conduct informal interviews with families of autistic children being screened for co-occurring anxiety symptomatology to determine what the child’s parents and family determine are signs of anxiety within the child.

Additionally, whilst the findings regarding the efficacy of using neurobiological, physiological and physical to determine the child’s internal experiences of anxiety (i.e., physiological symptoms) is useful for the research community, currently it is extremely difficult, or impossible to access tools such as these or to understand the results of these tools within broader clinical practice. Given the affordability of many of these machines (i.e., heart rate monitor), it might be useful to start considering training clinicians in how to use these tools, so they too can use effective, evidence-based, objective free measures to understand their client and their internal experiences.

Further, educating clinicians on ‘autism specific anxiety’ as termed by Kerns et al. (2014) and why community based or unfamiliar environments may cause increased stress levels may help clinicians to better understand the children they work with and allow them to consider and make appropriate adjustments to support the child’s learning. For example, within the home the child has more control over the sensory environment (e.g., how loud it is in their bedroom, parents and visitors not wearing perfume) and their routines are typically structured and predictable at home, whilst in the community this is not always the case.

## **5.7 Conclusions**

This is one of the first studies to investigate the indicators of anxiety in minimally verbal autistic children using a mixed methodologies approach to build an understanding of how parents perceive anxiety to present in their minimally verbal autistic children through the use of standardised and non-standardised measures. Using the coding framework developed by Adams, Young, Simpson et al. (2019) to compare for similarities and differences between parent perceptions of anxiety in autistic children who could verbally communicate and parent perceptions of anxiety in autistic children who had minimal verbal communication skills, all but two open-ended responses fit the coding framework used, suggesting similarities in the way anxiety presents in minimally verbal and verbal autistic children. Parents reported that their minimally verbal autistic children would commonly engage in repetitive movements, increased movements, crying or signs of upset, self-harm, or harm toward others consistently across home, school, and the community as a sign of anxiety.

The most frequently reported items on the standardised measure, the ASC-ASD-P, were noted to be observable behaviours. This further supports the conclusion that parents utilise observable behaviours, such as reactions to sensory overstimulation and reactions to changing plans, and so on, to inform their understanding of when their child is presenting with feelings of anxiety. The items on the ASC-ASD-P which were least frequently reported

included items that required insight into the child's physiological state, for example, their heart rate. This also speaks to parents using observable behaviours as their main reference to their child experiencing feelings of anxiety. Additionally, among the least reported items on the ASC-ASD-P were those that listed specific contexts or that were situationally dependent (e.g., a child is scared because they are afraid to be away from their family). This finding further supports the conclusion that minimally verbal autistic children can present with anxiety for a range of reasons, across a range of situations and contexts, and that these presentations can be varied, requiring individualised approaches.

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## Appendix

### Adams et al. (2019) Coding Framework

Area	Category	Frequently reported example	Total number (%) of parents reporting this as a sign of anxiety		
			Home N=91	School N=128	Community N=125
Nothing/not sure			0 (0%)	9 (7%)	0 (0%)
Vocalisations	Vocalisations become louder, faster or shouts	Becomes loud, increased volume	21 (23.1%)	15 (11.7%)	18 (14.4%)
	Repetitive questions or requests	Repeated questions	14 (15.4%)	8 (6.3%)	8 (6.4%)
	Repeats or makes repetitive noises, words or phrases	Repetition of words/phrases	9 (9.9%)	4 (3.1%)	4 (3.1%)
	Argues or uses rude/inappropriate language	Swearing, arguments	6 (6.6%)	5 (3.9%)	5 (4%)
	Says that they are anxious, worried or scared	Verbally says 'I am worried/anxious'	4 (4.4%)	4 (3.1%)	2 (1.6%)
	Reduces verbal output or becomes non-verbal	Goes quiet/shy	2 (2.2%)	9 (7%)	15 (12%)
	Mood/Affect/ Emotions/ Cognitions	Appears anxious, worried or scared	Facial expressions, appears worried	23 (25.3%)	11 (8.6%)
Crying or signs of upset		Crying/teary	20 (22%)	22 (17.2%)	18 (14.4%)
Angry or over-reactive		Angry, outbursts	11 (12.1%)	20 (15.6%)	9 (7.2%)
Difficulties with focus or concentration or completing mental tasks		Unable to focus/think logically	8 (8.8%)	11 (8.6%)	7 (5.6%)
Agitated or restless mood		Agitated	8 (8.8%)	6 (4.7%)	4 (3.2%)
Meltdown		Meltdown	6 (6.6%)	6 (4.7%)	7 (5.6%)
Excitable or silly mood		Laughs at irrelevant things	3 (3.3%)	0 (0%)	1 (0.8%)
Signs of low self-esteem		Says cannot do task, believes not good enough	0 (0%)	9 (7%)	3 (2.4%)
Movement	Repetitive behaviours or movements	Stimming, pacing	22 (24.2%)	9 (7%)	21 (16.8%)
	Increased movement	Runs around, fidgety	13 (14.3%)	10 (7.8%)	16 (12.8%)
	Decreased movement	Rigid body, freezes	3 (3.3%)	3 (2.3%)	5 (4.0%)
Physiological	Difficulties with sleeping	Difficulty falling asleep	10 (11%)	N/A	N/A
	Feels sick or unwell	Sickness in stomach	8 (3.3%)	10 (7.8%)	4 (3.2%)
	Increased breathing or breathing difficulties	Rapid breathing	3 (3.3%)	0 (0%)	0 (0%)
Behaviour	Toileting problems	Toilet accidents	1 (1.1%)	5 (3.9%)	1 (0.8%)
	Hides, shuts down, withdraws or removes self from situation	Hides, withdraws	16 (17.6%)	28 (21.9%)	16 (12.8%)
	Noncompliance or refusal	Refusal to do tasks	12 (13.2%)	22 (17.2%)	14 (11.2%)
	Needing routine or predictability	Low threshold for changes to routine, becomes controlling	11 (12.1%)	8 (6.3%)	3 (2.4%)
	Tense behaviour	Clenches fists, trouble relaxing	8 (8.8%)	2 (1.6%)	3 (2.4%)
	Harms others	Aggression	7 (7.7%)	14 (10.9%)	11 (8.8%)
	Harms self	Self-harm, picks skin/nails	7 (7.7%)	13 (10.2%)	9 (7.2%)
	Bites, licks or mouths objects	Bites, chews or sucks clothing	7 (7.7%)	7 (5.5%)	5 (4.0%)
	Needing or wanting a specific person	Sticks close to parent, 'clingy'	7 (7.7%)	3 (2.3%)	24 (19.2%)
	Avoids or delays tasks	Avoidant of tasks	4 (4.4%)	12 (9.4%)	7 (5.6%)

(Continued)

Area	Category	Frequently reported example	Total number (%) of parents reporting this as a sign of anxiety		
			Home N= 91	School N= 128	Community N= 125
Nothing/not sure			0 (0%)	9 (7%)	0 (0%)
	(Over) sensitive to sensory stimuli	Has to cover ears, annoyed with noise	3 (3.3%)	7 (5.5%)	20 (16.0%)
	Difficulties completing physical tasks	Tasks taking a long time, for example, due to losing objects	3 (3.3%)	1 (0.8%)	0 (0%)
	Changes in appetite/food-related behaviours	Overeats/will not eat	2 (2.2%)	2 (1.6%)	1 (0.8%)
	Avoids social interaction	Does not speak to others, avoids others	1 (1.1%)	5 (3.9%)	16 (12.8%)
	Reluctant or expresses discontent	Complains, reluctant	1 (1.1%)	5 (3.9%)	6 (4.8%)
	Runs away	Absconds, runs away	0 (0%)	8 (6.3%)	14 (11.2%)
	Rushes or impatient behaviour	Impatient, rushes	0 (0%)	1 (0.8%)	3 (2.4%)
	Wants or asks to go home	Asks to go home	N/A	0 (0%)	18 (14.4%)
	Difficulty or refusal to attend school	Resists going to school	N/A	7 (5.5%)	N/A
	Difficulties with peer interactions	Misunderstands interactions, begins to get into arguments with friends	N/A	6 (4.7%)	0 (0%)