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# **Exploring anxiety at home, school and in the community through self-report from children on the autism spectrum**

**Short Title:** Children's self-report of anxiety across settings

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Dawn Adams declares that she has no conflict of interest with respect to this publication.

Kate Simpson declares that she has no conflict of interest with respect to this publication.

Deb Keen declares that she has no conflict of interest with respect to this publication.

## **Exploring anxiety at home, at school, and in the community through self-report from children on the autism spectrum**

### **Abstract:**

Research investigating anxiety in children on the autism spectrum usually reports caregiver rather than self-report perspectives. This study aimed to document children's own descriptions of their anxiety symptomatology by combining profiles on a standardised autism-specific self-report measure of anxiety (ASC-ASD-C) with the answers from closed- and open-answer questions about anxiety across home, school, and community settings. Across the sample of 113 children on the spectrum aged 6-14 years, the two most frequently endorsed items on the ASC-ASD-C were from the Uncertainty and Performance Anxiety subscales, and the least endorsed were both from the Anxious Arousal subscale. Almost all (96.5%) of the children on the spectrum reported experiencing anxiety in at least one setting, with 40.7% reporting anxiety in all three contexts (home, school, and community). Approximately half of the sample felt their anxiety goes unrecognised by others at school and almost 60% felt it was unrecognised by others when out in the community. The proportion of children reporting having someone to help reduce their anxiety differed across home (86%), school (76%), and community (45%) settings. This highlights the importance of understanding anxiety and its impact, not only within the context of autism, but for each particular child.

### **Lay summary:**

There has been a lot of research focussing upon anxiety and autism, but most of it has used parent reports, rather than asking the child themselves. This study summarises data from 113 children on the autism spectrum, aged 6-14 years. It reports the symptoms of anxiety that these children most and least commonly experience. The results suggest only 40-50% of children feel that others are able to recognise their anxiety at school and when out in the community, suggesting that more training is needed to help adults in these settings to recognise and support anxiety.

### **Keywords:**

autism, anxiety, mental health, first-person perspective, support, parents

Anxiety disorders are recognised as one of the most commonly co-occurring conditions within autism spectrum disorders, with meta-analyses suggesting prevalence rates of clinically significant anxiety of 40% (van Steensel, Bogels, & Perrin, 2011) compared to 13.4% of children worldwide without autism (Polanczyk, Salum, Sugaya, Caye, & Rohde, 2015). There is also an increasing recognition that many children on the autism spectrum experience “subclinical anxiety” (Vasa et al., 2013) which may still impact upon their daily life. Recent work suggests that anxiety symptomatology is reported at elevated levels by both parents (Keen, Adams, Simpson, den Houting, & Roberts, 2017) and teachers (Adams, Simpson, & Keen, 2018) in children on the autism spectrum as young as 5 years old. Anxiety symptomatology continues to be present and to impact upon daily life through primary school-aged children (den Houting et al., 2018b) and into adolescence (Boulter, Freeston, South, & Rodgers, 2014), persisting into adulthood (Mazefsky, Folstein, & Lainhart, 2008).

Vasa, Keefer, Reaven, South, and White (2018) note that there has been increased research activity in the area of autism and anxiety, with a six-fold increase in publications within the last 10 years. Research in the area has been advanced with the concepts of typical and atypical anxiety, and two autism-specific measures of anxiety which aim to capture both typical (DSM-consistent) and atypical (autism-specific) anxiety: the Anxiety Scale for Children – Autism Spectrum Disorder (ASC-ASD; Rodgers et al. 2016) and the Parent-Rated Anxiety Scale for Youth with Autism Spectrum Disorder (Scahill et al., 2019). Whilst the development of sensitive and specific measurements of anxiety in individuals on the spectrum is critical, in order to fully understand anxiety for individuals on the spectrum, studies must go beyond including only parent report.

Systematic reviews of anxiety studies (e.g., Adams, Young, & Keen, 2019; van Steensel et al., 2011; White, Oswald, Ollendick, & Scahill, 2009) have highlighted that the majority of the work exploring anxiety in children on the spectrum has focussed upon parent or teacher reports or reports from a combination of adult informants. Within White et al.’s (2009) review, only 25% of the studies included self-reports from individuals on the autism spectrum, with a similar rate of 22.5% being reported in the review by van Steensel et al. (2011). Studies that have included child reports in addition to those of parents and/or teachers often report informant discrepancy, with some authors concluding that due to the combination of limited insight and communication difficulties, children on

the autism spectrum are unable to coherently and/or reliably report upon their emotional or internal states (e.g., Losh & Capps, 2006). However, a review by Stratis and Lecavalier (2015) concluded that children with autism were able to self identify feelings of anxiousness, and that the inter-informant discrepancy reported between parents and children on the autism spectrum is no larger than that reported for typically developing children and their parents. When combined with the finding that the self-reports of anxiety from children on the autism spectrum are more aligned with physiological markers of anxiety (e.g., salivary cortisol; Bitsika, Sharpley, Andronicos, & Agnew, 2015; sympathetic arousal; Keith, Jamieson, & Benneto, 2019) than with parent ratings, it cannot be assumed that parent reports are superior or that they alone are sufficient to understand the internal experiences of children on the autism spectrum (Ooi et al., 2016). Instead of focussing upon who may provide the “correct” information, a number of researchers are now advocating that each informant is a potentially important source of information (Adams, Young, Simpson, & Keen, 2019; De Los Reyes et al., 2015) and that each informant, including the child on the autism spectrum, is an expert of their own experience (McLaughlin & Rafferty, 2014; Milton, 2012). It may be that measures which use combined multiple informant reports, such as the Pediatric Anxiety Rating Scale (PARS: Ginsburg et al., 2011; Ginsburg, Keeton, Drazdowski, & Riddle, 2011; RUPP Autism Study Group, 2005), are most informative in extending our knowledge of anxiety in individuals on the spectrum (see Lecavalier et al. [2014] for a review of the PARS in individuals on the autism spectrum).

In their review of child self-report measures in mental health for typically developing children, Greco, Lambert, and Park (2016) highlight that nearly all (87.9%) studies collected self-report experiences through questionnaires. Although such methods are widely used and easily assessed in terms of their reliability, the methods used to develop such questionnaires influence the validity of the data collected. For example, Greco et al. (2016) note that items included in self-report questionnaires are typically pre-determined and selected by adults, predominantly researchers (see review by Cremeens, Eiser, & Blades, 2006). Some studies have found that children can find written questionnaires boring, which can evoke “subversive” responses (see review by Hill, 2006). The cognitive processes that are required for a child to accurately complete a written self-report questionnaire (e.g., reading and comprehending the question, retrieving from memory the information

required to answer it, making a judgement relating to the scale in the question, and communicating the response) are thought to be sufficiently developed by the age of 7 (Bell, 2007; Borgers, Hox, & Sikkel, 2003). However, adaptations, such as using yes/no responses, adding in visual supports, and reducing literacy demands by reading questions can enable younger children to begin to engage in self-report survey methodology (e.g., Borgers & Hox, 2001). Using such adapted methodologies, it is possible to gather substantial amounts of important information from children as young as 4 years old (Lamb et al., 2003).

In summary, there is increased recognition of the elevated prevalence of anxiety in individuals on the autism spectrum, but to date, the majority of research on this topic has focused upon parent-report and predominantly uses standardised questionnaires designed to document levels of anxiety symptomatology. The slow but increasing recognition of the obligation on researchers and professionals to reduce reliance on researcher-created questionnaires and to develop and use different means of gaining the views of all participants to supplement standardised questionnaires, regardless of their age or abilities (Fayette & Bond, 2018), have resulted in studies beginning to use alternative approaches to further the available knowledge about the nature of anxiety and to provide important insights from individuals on the autism spectrum. Some examples of such approaches include Joyce, Honey, Leekham, Barrett, and Rodgers (2017) who triangulated standardised questionnaires with interviews and drawings of experiences, and Rodgers, Herrema, Honey, and Freeston (2018) who used daily diary templates alongside standardised questionnaires. This would seem particularly important in the area of anxiety and mental health, where developing methods of self-report will not only extend the research literature, but will also give parents and therapists a greater understanding of the child's experiences and needs.

This study addresses the limitations of previous research by focussing upon children aged 6-14 years to complete standardised questions about their anxiety symptomatology as well as to share more about their experience of anxiety through closed and open responses to additional questions. It is recognised that asking children about their experience of anxiety has its limitations, but this is approached with the acceptance that children are experts in their own experience, and their insights can provide a valuable addition to our understanding of their experience. The first aim of this research

was therefore to document the symptomatology of anxiety reported by children on the autism spectrum when completing an autism-specific standardised anxiety measure. Anxiety, though, is more than a profile of symptoms on a checklist and whilst cut-offs and scores are important, children can report feeling impacted by their anxiety without meeting a specific score on a measure (see discussion in Vasa et al., 2013). Given this, and the recent discussions around the possibility that signs of anxiety may differ across different environments (e.g., Adams, Young, Simpson, et al., 2019), the second aim was to explore whether children on the autism spectrum report experiencing anxiety at home, school, and community settings. Finally, given the recent findings concerning difficulties with accessing support for children on the autism spectrum who are experiencing mental health difficulties (e.g., Crane, Adams, Harper, Welch, & Pellicano, 2019), the third aim was to document whether and to whom children reported having somebody they could talk to when they were anxious across different settings. In order to meet these aims, the following research questions were asked:

- 1) What is the profile of anxiety symptoms self-reported on an autism-specific measure of anxiety?
- 2) What proportion of children identify as being anxious at home, at school, or during community activities?
- 3) Do children on the autism spectrum report having somebody they can talk to when they are anxious and if so, to whom do they find it helpful to talk and does this differ across settings?

## **Methods**

Ethical approval for this study was obtained from all participating universities and health authorities. The authors complied with ethical standards throughout the duration of the study.

### ***Recruitment procedures***

All children of the parents participating in the Longitudinal study of Australian Students with Autism (LASA), a 6-year, cross-sequential study described in Roberts et al. (2018), were invited to participate in this self-report study. The parent-report study had originally recruited parents of children on the autism spectrum aged 4-5 (hereafter referred to as the younger cohort) or 9-10 years



(hereafter referred to as the older cohort) through clinics and advertisements on social media. Upon entry into the parent-report study, all parents were requested to provide copies of their child's diagnostic reports as well as to complete a measure of autism characteristics (Social Communication Questionnaire [SCQ]; Rutter, Bailey, & Lord, 2003). Children with an SCQ below 15 only remained in the study if parents had provided a copy of their child's community diagnostic report.

The self-report questionnaire was initiated in the third year and repeated in the fourth year of the longitudinal study. All 272 parents enrolled in the longitudinal parent-report study were emailed information about the self-report study and asked to discuss it with their child if they felt it was appropriate. Both the parents and children who wished to participate were asked to read through their respective information sheets and provide consent (parents) and assent (children) to participate before completing the questionnaires online through Qualtrics. Parents and children were informed that parents could be present when their child was completing the survey, but parents were asked to neither assist with the answers nor include their own perspectives. Where children provided responses in both years of the self-report study, the most complete dataset was selected. If both datasets were complete, the dataset from the latter year of data collection was used.

Two studies from the LASA study have previously reported upon self-report anxiety data from this cohort: den Houting et al. (2018a) explored concurrent validity of the ASC-ASD (self- and parent-report) with the Spence Child Anxiety Scale self- and parent-report; none of those data are reported upon in this study (i.e., they were collected separately to this study). Adams, Clark, and Keen (2019) used the ASC-ASD self-report as a predictor of quality of life in 71 children; the ASC-ASD-C data from some of these children are included in the larger sample reported upon in this paper. However, as Adams, Clark, and Keen (2019) did not describe the profile or scores of the ASC-ASD-C (they only used the ASC-ASD-C as a predictor variable), nor did they report on any of the responses to the open-ended questions, there is no overlap in findings or analysis presented below.

## ***Participants***

A total of 113 children provided responses for the questions relevant to this study. There were no significant differences in responders and non-responders in child gender ( $\chi^2(1) = .10, p = .11$ ), SCQ score at enrolment into the study ( $t(270) = -.26, p = .80$ ), child age at enrolment into the study within the younger ( $t(130) = .30, p = .77$ ) or older ( $t(138) = -.75, p = .46$ ) cohorts, parent education ( $U = 7953, p = .09$ ), family income ( $U = 8157, p = .32$ ), or anxiety score on the ASC-ASD-Parent questionnaire at either timepoint from which the self-report is drawn ( $t(183) = -1.65, p = .10, t(186) = -1.3, p = .20$ )

Due to the study design, at the time the questionnaire was completed the 43 children from the younger cohort were aged between 6 years 7 months and 9 years 9 months ( $\bar{x} = 100.3$  months,  $SD 9.0$ ) and the 70 children from the older cohort were aged between 11 years 4 months and 14 years 8 months ( $\bar{x} = 157.4$  months,  $SD 9.0$ ). The mean SCQ score for the sample was 21.32 ( $SD 6.4$ ). The sample demographics are presented in Table 1. Rates of additional diagnoses were in line with estimates stated by reviews (e.g., Leitner, 2014; van Steensel et al., 2011). Parent-reported family income (where disclosed) indicated that the majority (68.9%) of children lived in family homes with an income above the median annual household income of AUD\$74,776.

++Insert Table 1 about here++

## ***Measures***

***Anxiety symptomatology.*** The Anxiety Scale for Children with Autism Spectrum Disorder Child form (ASC-ASD-C; Rodgers et al., 2016) was completed for 111 children in this sample (two children, one from the younger cohort and one from the older cohort, provided answers to the open questions but did not complete any questions in this questionnaire. As none of the questions from the ASC-ASD-C questionnaire was completed by these participants, values were not replaced and were left as missing data). The ASC-ASD-C consists of 24 items which can be summed into a total score and four subscales: Performance Anxiety, Anxious Arousal, Separation Anxiety, and Uncertainty. Severity was rated on a 4-point scale ranging from 0 (*never*) to 3 (*always*). The scale was originally

developed for children aged 8 or above so must be interpreted with caution in the younger cohort, of whom 13 (11.5%) were under 8 years old. The scale has good validity, reliability, and internal consistency and is highly correlated with the Screen for Child Anxiety Related Emotional Disorders (SCARED) and the Spence Child Anxiety Scale (SCAS) (Rodgers et al., 2016; den Houting, Adams, Roberts, & Keen, 2018a), both of which are robust measures of anxiety in the general population. In the current study, internal consistency for the total sample was identified as good to excellent for all subscales based on Cronbach's alpha: Anxious Arousal  $\alpha=.85$ , Separation Anxiety  $\alpha=.81$ , Performance Anxiety  $\alpha=.84$ , and Uncertainty  $\alpha=.88$ . Cronbach's alpha were similar across the younger and older cohorts: Anxious Arousal younger cohort  $\alpha=.86$ , older cohort  $\alpha=.85$ ; Separation Anxiety younger cohort  $\alpha=.84$ , older cohort  $\alpha=.81$ ; Performance Anxiety younger cohort  $\alpha=.86$ , older cohort  $\alpha=.82$ ; and Uncertainty both cohorts  $\alpha=.88$ .

***Questions on children's experiences of anxiety and sources of support in different settings.***

Children were asked a combination of closed- and open-answer questions regarding their anxiety profile across home, school, and community settings. Firstly, children were asked what words they use to describe their anxiousness or worries with the following question: "Most people have times that they feel worried, anxious, afraid, jumpy or scared but lots of us use different words to describe this. What sort of words do you use to explain how you feel in these times?" They were then asked if they felt those feelings (e.g., anxiousness or worries) at home and, if they did, children were then asked if (a) they think people at home know when they are feeling anxious, and (b) whether there is somebody at home they can talk to. If the child answered "yes" to (b), they were then asked to whom they find it helpful to talk when they feel anxious at home. The questions were then repeated for school and then for the community. The "community" was described to the child as things or activities they may do outside of home or school, such as clubs, sports, or activities.

***Data analysis***

To explore the anxiety symptoms most and least frequently endorsed on the ASC-ASD-C (Rodgers et al., 2016), scores were reported at item and subscale level for the full sample. A within-subjects ANOVA was used to compare the ASC-ASD-C subscales. The closed questions were explored using

SPSS descriptive statistics. To provide an assessment of concurrent validity for these questions, scores on the ASC-ASD-C autism-specific measure of anxiety, the total score of the ASC-ASD-C, was compared based upon the number of settings in which children self-reported to be anxious.

Children's responses to the open-ended answers (words used to describe anxiety, sources of help for anxiety) were analysed by one of the authors using content analysis, as used in previous autism research (e.g., Adams, Young, Simpson, et al., 2019; Baron-Cohen & Wheelwright, 1999). The co-author followed the four steps described by Dey (1993): (1) divide the data into manageable parts, (2) collect responses together that relate to the areas or questions of interest, (3) create categories that describe similar responses within these general groupings, and (4) combine or split categories where data can best be described in a rearranged structure. Reliability of the categories developed through the content analysis was assessed through a second, independent person (a research assistant with experience in qualitative research, autism, and anxiety) placing 20% of the responses into categories. The extent of agreement between the two coders was calculated using the Kappa coefficient, where the strength of the Kappa coefficients = 0.01-0.20 slight; 0.21-0.40 fair; 0.41-0.60 moderate; 0.61-0.80 substantial; 0.81-1.00 almost perfect (Landis & Koch, 1977). The Kappa coefficient for agreement of the final coding was .96 ( $p < .001$ ), which is considered almost perfect agreement.

## **Results**

### ***Profile of scores on the ASC-ASD-C***

The ASC-ASD-C subscale scores ranged from the minimum to maximum for all subscales. The mean and SD for the subscale scores (and SCQ score) for the total sample as well as for the younger and older cohort are presented in Table 2. As there were no significant differences in the total or subscale scores between the younger and older cohorts, further analyses were undertaken on the total sample. Skew and Kurtosis were within the range of  $\pm 1$  for all subscales except Anxious Arousal, which had a slightly positive skew (1.2) and Kurtosis (1.7).

+Insert Table 2 about here++

A within-subjects ANOVA identified a significant difference between the mean score per question of the four subscales with a large effect size [ $F(3, 330) = 35.17, p < .001, \eta p^2 = .24$ ]. Post-hoc paired-samples  $t$ -tests note that all subscales differed significantly from each other (all  $p < .002$ , all  $d > .29$ ) with the exception of the Uncertainty subscale and the Performance Anxiety subscale, which did not differ significantly from each other ( $t(110) = -.67, p = .49$ ).

Figure 1 presents the profile of scores at item level and highlights the range of response patterns for each question. The most endorsed items (i.e., those with the highest proportion of children rating the item at least “sometimes”) were “*I always need to be prepared before things happen*” from the Uncertainty subscale, which was endorsed by 91% of children, and “*I worry when I think I have done poorly at something*” from the Performance anxiety subscale, which was endorsed by 83.8% of children. The two least endorsed items were both from the Anxious Arousal subscale: “*I suddenly become dizzy or faint when there is no reason for this*” (endorsed by 31.5% of children) and “*I suddenly feel as if I can't breathe when there is no reason for this*” (endorsed by 43.2%).

++Insert Figure 1 here++

### ***Words used to describe anxiety***

To add additional information to the standardised questionnaire, children were asked to list the words they used to describe anxiety. Children provided words which were coded into between one and five categories, with the mean average being 2 words. The most commonly reported words used by children to describe anxiousness in children on the spectrum were “scared” ( $n = 40, 35.4\%$ ), “worried” ( $n = 29, 25.7\%$ ), “anxiety”/“anxious” ( $n = 23, 20.4\%$ ), “upset”/“sad” ( $n = 18, 15.9\%$ ), “nervous” ( $n = 11, 9.7\%$ ), “sick”/“butterflies” ( $n = 11, 9.7\%$ ), “angry” ( $n = 10, 8.8\%$ ), and “frightened” ( $n = 9, 8.0\%$ ). No children listed all of the example words from the question in their response and two of the words within the question (jumpy, afraid) were only listed by five (4.4%) and six (5.3%) of children respectively. Five example words were given within the question asked in the questionnaire (worried, anxious, afraid, jumpy, scared), two of which were used in less than 5% of the

the responses by children ( $n = 5$  “jumpy”;  $n = 5$  “afraid”), providing some face validity for respondents providing their own responses rather than just those suggested within the question. Importantly, there were a notable number of responses to this question which were unusual ( $n = 11$ , 9.7%), or unique (i.e., only reported by one or a few children,  $n = 17$ , 15.3%), including “uncomfortable”, “engine's pumped up”, “the jiggers”, and “cat scared”.

### ***Anxiety across multiple settings***

The ASC-ASD-C provides a standardised profile of anxiety symptomatology, but to explore whether or not children perceive themselves as experiencing anxiety, children were asked to state *yes* or *no* to whether they felt anxious when at home, at school, and out in the community. Of the 113 children who provided answers to questions about all three settings, four (3.5%) stated that they did not experience any anxiousness in any of these settings, 18 (15.9%) reported anxiousness in one setting, 45 (39.8%) in two settings, and 46 (40.7%) in all three settings.

In order to assess the concurrent validity of this question against a standardised measure of anxiety, the total score on the ASC-ASD-C was explored dependent upon the number of settings in which children had rated themselves as being anxious (0 – 3). Children who self-reported being anxious across a higher number of settings had a significantly higher total score on the ASC-ASD-C with a large effect size ( $F(3,110) = 6.3, p = .001, \eta^2 = .15$ ). The total ASC-ASD-C score increased with the number of settings in which children reported experiencing anxiety: no settings  $\bar{x} = 11.0, SD = 7.0$ , one setting  $\bar{x} = 22.8, SD = 12.7$ , two settings  $\bar{x} = 24.7, SD = 13.6$ , three settings  $\bar{x} = 33.5, SD = 13.8$ ). This highlights that the ASC-ASD-C score for children who reported anxiety in three settings was almost 150% of the score for children to be experiencing anxiety in only one setting.

### ***Anxiety at home***

As documented in Table 3, 85 (75.2%) children stated that they experienced anxiousness at home. Of these 85 children, 66 (77.6%) felt that others at home knew when they were experiencing anxiety and the majority ( $n = 73, 85.9%$ ) stated that they had somebody they could go to and/or talk to who helped them feel less anxious. An additional table provided in the supplementary material reports

these results for each age cohort, with Chi-square comparisons reporting no cohort-based differences ( $p > .05$ ). When asked whom it was that they found helpful to go to and/or talk to, 34 (46.6%) children listed their mother, 26 (35.6%) listed both parents, 10 (13.7%) listed family other than parents (e.g., grandparents, sister), six (8.2%) listed pets, and two (2.7%) listed their father.

### ***Anxiety at school***

As summarised in Table 3, 94 (83.2%) children stated that they experienced anxiousness at school. Of these 94 children, 46 (50.5%) felt that others at school knew when they were experiencing anxiety and 79 (76.1%) stated that they had somebody they could go to and/or talk to who helped them feel less anxious. An additional table provided in the supplementary material reports these results for each age cohort, with Chi-square comparisons reporting no cohort-based differences ( $p > .05$ ). When asked whom it was that they found helpful to go to and/or talk to, 42 (53.2%) children stated their teacher, 22 (27.8%) stated their friends (with many noting “close friends” only, or noting that they only confide in their friends “sometimes”), and 9 (11.4%) stated other staff at school (e.g., teacher aide, chaplain).

### ***Anxiety during community activities***

As summarised in Table 3, 66 (58.4%) children stated that they experienced anxiousness during community activities. Of these 66 children, 26 (40.6%) felt that others at their clubs, sports, or activities knew when they were experiencing anxiety and 29 (49.3%) stated that they had somebody they could go to and/or talk to who helped them feel less anxious. An additional table provided in the supplementary material reports these results for each age cohort, with Chi-square comparisons reporting no cohort-based differences ( $p > .05$ ). When asked whom it was that they found helpful to go to and/or talk to, 10 (34.4%) children reported that they went to or talked to their mother or parents, 10 (34.4%) the club leader/teacher/coach, six (20.1%) their friends, and two (6.7%) members of their family.

++Insert Table 3 about here++

## Discussion

The use of self-report to increase knowledge and understanding of the nature and experience of anxiety in individuals on the autism spectrum is a small but growing area. This study adds to this literature base by being the first study to use standardised questionnaires along with additional questions with children aged 6 to 14 on the autism spectrum to share their perspectives of their experiences of anxiety at home, at school, and during community activities.

### *Profile of scores on the self-report measure of anxiety*

Children's scores on the ASC-ASD-C ranged from the minimum to two points below the maximum. The total mean score of 27.36 in this sample can be interpreted in relation to the average of 25.32 reported from the 157 children in Rodgers et al.'s (2016) original paper describing the development of the measure. As this is the first paper to describe the profile of the self-report version of the ASC-ASD, the only comparisons in the profile that can be made is to previous studies reporting on the parent version. Within this sample, the highest mean score per question on the ASC-ASD-C was for the Uncertainty subscale ( $\bar{x} = 1.32$ ) and the lowest was for the Anxious Arousal subscale ( $\bar{x} = .75$ ). The pattern is the same as that reported in a sample of parents of children aged 5-16 (Adams, Clark, & Simpson, 2019), parents of children aged 4-7 (Glod, Riby, & Rodgers, 2019), as well as parents of 5-6-year-olds (Keen et al., 2019) and 10-12-year-olds (den Houting, Adams, Roberts, & Keen, 2018b), although it is important to note that the latter two studies report on samples which include some of the children in this study. Although not explored statistically, the mean score per item for the Uncertainty scale was in line with that reported by parents in Adams, Clark et al. ( $\bar{x} = 1.33$ ), Keen et al. ( $\bar{x} = 1.36$ ), den Houting et al. ( $\bar{x} = 1.39$ ), and to some extent Glod et al. ( $\bar{x} = 1.27$ ). In contrast, the mean score per question for the Anxious Arousal subscale shows more variability in scores across studies ( $\bar{x} = .54 - 1.0$ ). Previously, the low endorsement of Anxious Arousal has been explained by the difficulty that parents may have in identifying internal symptoms (such as dizziness) in their child. However, the Anxious Arousal items were also the lowest on self-report, suggesting that other factors, such as difficulties with interoception, may be impacting this finding. Garfinkel et al. (2016) suggest that individuals on the spectrum have reduced interoception, so an alternative



hypothesis could be that the children on the spectrum do experience the physiological symptoms of anxiety, but lack the interoceptive awareness to identify these symptoms, and possible alexithymia may make it difficult to describe or label such experiences. It may also reflect the developmental age and stage of the sample, as panic disorder (with which many of the internal anxiety symptoms are experienced) increases in adolescence and this sample was only aged 6-14.

South and Rodgers (2017) suggest that anxiety in individuals on the spectrum needs to be considered in relation to (atypical) sensory functioning, alexithymia, and intolerance of uncertainty, a model that requires further research to explore the contribution of, and possible relationships between, each factor. This model has the potential to explore the impact of both hypo- and hyper-sensory sensitivity on interoception and recognition of the physiological symptoms of anxiety. For example, if an individual is already highly aroused, they may not be able to experience and/or interpret the physical experiences of anxiety beyond what they are already experiencing. Similarly, with hypo arousal, an individual may not experience or recognise the physiological experiences of anxiety until they are very high.

### ***Children's self-report of anxiety across settings***

Almost all children (96.5%) within this sample of 113 children aged 6-14 reported experiencing anxiety in at least one setting and 40.7% of children stated that they experience anxiety in all three settings. Interestingly, similar rates were reported when parents of children on the autism spectrum are asked similar questions; for example, 88.9% of 272 parents of children on the spectrum in Australia (Adams, Young, Simpson, et al., 2019) and 85% of 455 parents within the UK reported that their child experienced anxiety (Madders, 2010).

The prevalence of children self-reporting to experience anxiety at home (75.9%) and at school (83.2%) was higher than the prevalence of children reporting to experience anxiety during community activities (58.4%). This may be because children were only considering clubs or sports that they engage in or attend, and perhaps did not consider other community activities such as shopping or non-preferred activities, or it may be that they do not attend clubs or activities that evoke anxiety. Given that both cross-sectional and longitudinal studies have documented that children on the autism

spectrum have lower participation in community-based activities (Simpson, Adams, Bruck, & Keen, 2019; Simpson, Keen, Adams, Alston-Knox, & Roberts, 2018), further research could explore whether anxiety is a contributing factor to this.

### *Language used to describe anxiety*

Asking children on the spectrum a small number of open-ended questions about their anxiety allowed for a wide variety of responses which were not restrained by forced-choice questions developed by researchers. The range of words used and both the commonality and diversity of responses highlight the importance of developing a shared vocabulary and understanding around anxiety for each particular individual. Some of the terms reported may not be those that would typically be seen to be reflective of anxiety, but many of these, such as “angry”, have been identified as markers and clinical correlates of anxiety and internal psychopathology in typically developing children with anxiety disorders (e.g., Johnco et al., 2015) and align with indicators of anxiety reported by parents in other qualitative studies (e.g., Adams, Young, Simpson, et al., 2019). The terms reported by the children within this paper are not meant to be an exhaustive list of those which may be used by children on the autism spectrum to describe anxiety.

When this variability in vocabulary is coupled with the finding that more than half of children do not feel that others recognise their anxiety at school or in community settings, it highlights the importance of combining information from children on the autism spectrum, their parents or caregivers, and those who work with or support the child. As suggested by Adams, Young, and Keen (2019), information from multiple informants across multiple settings could be used to develop each child’s “anxiety signature”: an individualised profile of emotions, behaviours, expressions, verbalisations, or actions that indicate elevated anxiety for that child in that particular setting. Such an approach is recommended to help people identify other internal experiences of children on the spectrum (e.g., pain; Oliver & Richards, 2015).

### ***Recognition of anxiety and access to support across settings***

Most (85.9%) of the children who reported experiencing anxiety at home stated that they had somebody to talk to at home who was able to help their anxiety, most frequently their mother (46.6%) or mother/father (35.6%). During community activities, only 45.3% of children stated that they had somebody to go to or talk to who was able to help their anxiety, with the child's parents (34.4%) again being the most frequently reported person that the child seeks out. Within the school setting, a notable proportion of children stated that they go to or speak to their friends (27.8%). Aside from being noted in one qualitative study (e.g., Robertson et al., 2018), the critical role of family members and friends in the management of anxiety in individuals on the autism spectrum has received little attention. These informal supports may be an important area for further research, given the difficulties that individuals on the spectrum can have with accessing formal support services for mental health difficulties (Weiss et al., 2018). Given that most parents and/or friends will not have training or experience in how best to support or reduce anxiety, this may also provide an important avenue for anxiety intervention research.

Only 40-50% of the children in this study felt that others were able to recognise when they were anxious at school or in community settings. While there is evidence to suggest that teachers are relatively accurate in identifying and understanding anxiety in typically developing students (Headley & Campbell, 2013), this ability may not translate to identifying anxiety in students on the spectrum due to the presence of both typical and atypical symptoms and the possibility of diagnostic overshadowing (e.g., Kerns & Kendall, 2012). The potentially complex interaction of anxiety and autism may mean that many teachers do not feel confident in making informed decisions about what are age-appropriate or autism-related behaviours and what are normal variations of behaviour and/or mental health within the context of autism (Kerns & Kendall, 2012; Wood & Gadow, 2010) and consequently respond differently to the same behaviour depending on whether or not the child has a diagnosis on the spectrum (Adams, Macdonald, & Keen, 2019). It is therefore important that efforts are made to increase recognition of anxiety both in school and community settings as it may influence success in that setting; for example, teacher understanding of anxiety and stress has been highlighted

by students on the spectrum as an important factor in their successful participation in mainstream education (Humphrey & Lewis, 2008; Sagers et al., 2016) and parents identify that teacher support of anxiety is related to their understanding of anxiety in autism (Simpson, Adams, Wheeley, & Keen, 2019). Recent work also suggests that anxiety symptomatology, but not autism characteristics, predicts the school functioning subscales on both parent and self-report measures of child quality of life (Adams, Clark, & Keen, 2019; Adams, Clark, & Simpson, 2019). Such efforts should also take into consideration the potential for masking or camouflaging of such symptoms (reported in almost 10% of children in this study in both home and community settings) as these may not only impact upon recognition of anxiety, but may be directly or indirectly contributing to levels of anxiety experienced (Hull et al., 2017).

### ***Limitations and future research***

Due to the methodology (an online survey requiring typing of open-ended answers), it was deemed appropriate to allow parents to be with their children when the child completed the survey. Even though both parents and children were informed that the researchers were interested in the child's thoughts and answers and that the adult was not to influence the responses, there is no way to be certain about the extent to which the caregiver being present may have influenced responses. Allowing children to participate at home with somebody they trust present, rather than with a stranger in a research setting, has no doubt been a factor in the large sample size of this study; however, it also has obvious limitations which must be considered when interpreting the results of this study.

Internet surveys with children are becoming increasingly popular in health (e.g., Cantrell & Lupinacci, 2007) and social sciences research (e.g., Lloyd & Devine, 2010) due to their ability to reach a large pool of participants and the ability for participants to respond anonymously and at their own pace. Any data collection method which does not involve the researcher observing the respondent complete the questionnaire has a risk of bias; this is not a risk that is unique to this study and is not unique to collecting data from children on the autism spectrum. Given that best practice guidelines (Lobe, Livingstone, Olafsson, & Simoes, 2012) recommend collecting data from children in a setting where they feel the most comfortable and able to open up, if research is to work towards

including self-report on issues that may be difficult for children to discuss, and/or collecting information from younger children on the autism spectrum, then methodological approaches which foster inclusiveness whilst ensuring both the reliability and the validity of the data need to be developed, trialled, and evaluated. Future research may wish to consider the use of face-to-face or online focus groups, although these have been shown to be more accessible and enjoyable for adolescents and adults than for children (Zwaanswikk & Dulmen, 2014), and those conducted online do not necessarily provide any additional assurance that the responses have been provided by the child themselves. Future research could further explore the results of this study using approaches such as computer-assisted approaches, which offer potential as a consultation tool for children on the spectrum as they provide a shared focus from the outset whilst allowing the interviewee to use his or her own vocabulary for feelings, people, and places (Barrow & Hannah, 2012).

Whilst the online questionnaire enabled children across a diverse geographical area to complete the questions in their own settings and in their own time, this was at the expense of more in-depth probing or clarification that could have been obtained in an interview setting and at the expense of conducting additional assessments (e.g., IQ testing) to further characterise the sample. The lack of a control group of typically developing children limits the extent to which these results can be interpreted as autism-specific. As all children had phrase speech, it is acknowledged that it may not be possible to generalise these findings to those who have not developed phrase speech and/or those with severe or profound intellectual disabilities.

The yes/no format of some of the questions was designed to be accessible to the younger cohort but provides relatively limited information on the significance or severity of anxiety experienced at home/school/community, so future research could consider using a graded scale with visual supports to gain additional information. It is possible that children may have repeated back some of the terms used within the question (e.g., words used to describe anxiety), misinterpreted some of the questions, or lost focus when answering a question. This may have impacted upon their answers and their descriptions of their indicators of anxiety across different settings. Further work is needed to explore how children on the spectrum understand and experience their anxiety, both behaviourally

and physiologically (i.e., how could they or others recognise that they are anxious?), and their perception of its interaction with, and differentiation from, their autism characteristics.

## **Conclusion**

The findings from this study emphasise the complexity of recognising anxiety symptomatology and the importance of understanding anxiety, not only within the context of autism, but also for that particular child in that specific setting. The finding that children do not feel that others recognise their signs of anxiety (which was predominantly in the school and community contexts) and do not feel that support personnel are always available highlights the need for sharing the child's anxiety signature within and across settings. Working with children on the autism spectrum, their families, and those who support them to increase recognition of anxiety profiles is critical to enhance support and outcomes for children on the autism spectrum who experience anxiety.

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Table 1

*Participant and Child Characteristics Based Upon Parent Report*

		Total sample (N = 113)	
		N	%
Gender of child	Male	94	83.2
Co-occurring diagnoses	Anxiety	50	44.2
	ADHD	47	41.6
	Intellectual Disability/Global Developmental Delay	0	0
Taking medications or supplements		50	53.1
Family income	Up to \$37,000	12	10.6
	\$37,001 - \$80,000	20	17.7
	\$80,001 - \$180,001	58	51.3
	\$180,001 and above	13	11.5
	Did not wish to disclose	10	8.8

Table 2

*Means and Standard Deviations of ASC-ASD-C Total and Subscale Scores for the Total Sample and Younger and Older Cohorts*

	Mean score per item (SD)			Comparison
	Total sample ( <i>n</i> = 111)	Younger cohort ( <i>n</i> = 42)	Older cohort ( <i>n</i> = 69)	
Total score	1.14 (.60)	1.13 (.62)	1.15 (.59)	<i>t</i> (109) = -.21, <i>p</i> = .83
Uncertainty	1.36 (.75)	1.35 (.73)	1.37 (.76)	<i>t</i> (109) = .34, <i>p</i> = .93
Performance Anxiety	1.32 (.77)	1.20 (.80)	1.38 (.75)	<i>t</i> (109) = -1.16, <i>p</i> = .25
Separation Anxiety	1.08 (.76)	1.13 (.82)	1.06 (.73)	<i>t</i> (109) = .52, <i>p</i> = .61
Anxious Arousal	.75 (.65)	.75 (.62)	.75 (.66)	<i>t</i> (109) = -.01, <i>p</i> = .99



Table 3.

*Children's Responses to Questions about Experiencing Anxiety at Home, School, and in the Community for the Total Sample (Total Sample N = 113)*

		Feels anxious <i>n</i> (%)	Feels others able to identify when anxious <sup>1</sup> <i>n</i> (%)	Reports having somebody who helps them feel less anxious <sup>1</sup> <i>n</i> (%)
Home	Yes	85 (75.2%)	66 (77.6%)	73 (85.9%)
	No	28 (24.8%)	19 (22.4%)	12 (14.1%)
School	Yes	94 (83.2%)	46 (50.5%)	70 (76.1%)
	No	19 (16.8%)	45 (49.5%)	22 (23.9%)
Community <sup>2</sup>	Yes	66 (58.4%)	26 (40.6%)	29 (45.3%)
	No	46 (40.7%)	38 (59.4%)	35 (54.7%)

<sup>1</sup> Question only asked to children who reported experiencing anxiety in that setting.

<sup>2</sup> One child did not select an answer to this question as he said "I do not do any activities".

Supplementary Material Table A

*Children's Responses to Questions about Experiencing Anxiety at Home, School, and in the Community for the Total Sample (by Cohort)*

		Feels anxious		Feels others able to identify when anxious <sup>1</sup>		Reports having somebody who helps them feel less anxious <sup>1</sup>	
		<i>n (%)</i>		<i>n (%)</i>		<i>n (%)</i>	
		<i>Younger</i>	<i>Older</i>	<i>Younger</i>	<i>Older</i>	<i>Younger</i>	<i>Older</i>
Home	Yes	34 (81%)	49 (71%)	30 (88.2%)	25 (71.4%)	31 (91.2%)	50 (81.6%)
	No	9 (19%)	20 (29%)	4 (11.8%)	14 (28.6%)	3 (8.8%)	9 (13%)
School	Yes	37 (88.1%)	55 (79.6%)	19 (55.9%)	27 (49.1%)	28 (80%)	31 (74.5%)
	No	5 (11.9%)	14 (20.3%)	15 (44.1%)	28 (50.9%)	7 (20%)	14 (25.5%)
Community <sup>2</sup>	Yes	27 (64.3%)	37 (54.4%)	12 (46.2%)	14 (37.8%)	13 (50%)	16 (43.2%)
	No	15 (35.7%)	31 (44.9%)	14 (52.8%)	23 (62.2%)	13 (50%)	21 (56.8%)

<sup>1</sup> Question only asked to children who reported experiencing anxiety in that setting.

<sup>2</sup> One child did not select an answer to this question as he said "I do not do any activities".