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FACULTY OF SOCIAL, HUMAN AND MATHEMATICAL SCIENCES

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Volume 1 of 1

An exploration of how the secondary school experience contributes to elevated anxiety levels for adolescents on the autism spectrum

by

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ABSTRACT

FACULTY OF SOCIAL, HUMAN AND MATHEMATICAL SCIENCES

Psychology

Thesis for the degree of Doctorate in Educational Psychology

AN EXPLORATION OF HOW THE SECONDARY SCHOOL EXPERIENCE CONTRIBUTES TO ELEVATED ANXIETY LEVELS FOR ADOLESCENTS ON THE AUTISM SPECTRUM

Children and young people on the autism spectrum show elevated anxiety levels in comparison to typically developing peers and those with other special educational needs. However, despite the significant time spent in school, few researchers have focused on how the school environment contributes to elevated anxiety levels in autism. A systematic review of the literature was conducted, exploring causes of anxious affect for autistic adolescents attending mainstream school. Experiences in the school environment that were highlighted as sources of anxiety included adverse noises, the behaviour of others and the social identity of autistic pupils. Additionally, academic pressure, transitions, disliked subjects, homework and handwriting were highlighted as sources of anxiety. Key frameworks of anxiety and autism (Boulter et al., 2014; Wood & Gadow, 2010) were used to understand these findings.

An empirical study was also conducted to explore how the secondary school experience contributed to elevated anxiety following the Intolerance of Uncertainty framework of anxiety and autism proposed by Boulter et al. (2014). A school-based sample of 30 autistic adolescents aged 11-14, took part in the study. Parents completed measures of anxiety, sensory processing, autism symptom severity, and teachers completed a measure of social skills. Participants on the autism spectrum completed a measure of the number and types of experiences causing feelings of anxiety in the school social and learning environment. Indirect pathways from sensory sensitivities and social and environmental experiences in school to anxiety symptoms through intolerance of uncertainty were then tested. Findings supported and extended the key framework of anxiety in autism proposed by Boulter et al. (2014), demonstrating significant indirect pathways from experiences in school, sensory sensitivities and autism traits to anxiety through intolerance of uncertainty.

Eleanor Hayes

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Academic Thesis: Declaration Of Authorship

I Eleanor Hayes declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

An exploration of how the secondary school experience contributes to elevated anxiety levels for adolescents on the autism spectrum

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission:

Signed: .....

Date: .....

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Abbreviations

α	Cronbach alpha
AQ	The Autism-Spectrum Quotient
ASC-ASD	Anxiety Scale for Children with Autism Spectrum Disorder
ASD	Autism Spectrum Disorder
ß	Beta coefficient
BCa	The bias-corrected and accelerated bootstrap interval
CASP	Critical Appraisal Skills Programme
CBT	Cognitive Behavioural Therapy
CI	Confidence Intervals
DSM	Diagnostic and Statistical Manual of Mental Disorders
EHCP	Educational Health and Care Plan
fMRI	Functional Magnetic Resonance Imaging
FSIQ-2	Full Scale IQ from two subtests
IU	Intolerance of uncertainty
IQ	Intelligence quotient
M	Mean
NICE guidelines	The National Institute for Health and Care Excellence
p	Significance value
P	Spearman's Rho
PDD-NOS	Pervasive Developmental Disorder-Not Otherwise Specified
PE	Physical Education
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses

Abbreviations

r	Pearson correlation coefficient
SD	Standard deviation
SEN	Special educational needs
SENCo	Special Educational Needs Coordinator
SSiS-RS	Social Skills Improvement System Rating Scales
SSP-2	Short Sensory Profile 2
t	t value
TD	Typically Developing
UK	United Kingdom
USA	United States of America
W	Shapiro Wilk
WASI-II	Wechsler Abbreviated Scale of Intelligence – Second Edition
YAM	Youth Anxiety Measure

Chapter 1 Literature Review

What Aspects of the Secondary School Experience Cause Anxiety for Young People on the Autism Spectrum?

1.1 Introduction

Autism spectrum disorder (ASD – heretofore referred to as autism) is described in the DSM-5 as a dyad of difficulties with social communication and restricted or repetitive patterns of behaviour (DSM-5; APA; American Psychiatric Association, 2013). This term refers to spectrum of strengths and areas of difference. Challenges with social communication may include difficulties with initiating and responding to social interaction, and nonverbal communication including eye-contact and facial expressions. This can also extend to difficulties understanding certain aspects of language, for example sarcasm or metaphors, and to develop and maintain social relationships in same way as typically developing peers (APA, 2013). Restricted and repetitive patterns of behaviour and interests encompass sensitivity to sensory stimuli such as noise, touch, lights and smell, alongside intense interests or skills. This area also includes repetitive movements, speech or play, as well as difficulty with change, transitions and a preference for routine and predictability.

It is difficult to estimate the true incidence of autism due to differences in local policies, resources and autism awareness in areas of studies (Mandell & Lecavalier, 2014), changes in diagnostic criteria, and tools used to make the diagnosis (Fisch, 2012). Despite these difficulties, researchers estimate the prevalence to be 1 in 59 children in the USA (Baio et al., 2018) to 1.7% in a UK based cohort study (Russell, Rodgers, Ukoumunne, & Ford, 2014). Autism is the most common primary need listed on Educational Health and Care Plans (EHCP) in the UK (Department for Education, 2017b). EHCPs are a legal document describing a statutory duty for schools to provide additional support with funding from the Local Authority in the UK. Of the children listed as having autism as their primary need in UK schools, over 70% of these are educated in mainstream settings (Department for Education, 2017b).

1.1.1 Anxiety and Autism

A recent meta-analysis demonstrated that children and adolescents on the autism spectrum experience significantly higher levels of anxious affect than typically developing children and adolescents (van Steensel & Heeman, 2017). A further meta-analysis concluded that nearly 40% of children with a diagnosis of autism also met the criteria for an anxiety disorder (van Steensel, Bögels, & Perrin, 2011). The most common comorbid anxiety disorder identified was specific phobia, followed by social anxiety disorder. Specific phobia is described as "anxiety about a specific object or situation" (p. 197) such as animals, a source in the natural environment, a medical related phobia, or a phobia of situations (APA, 2013). Social anxiety disorder refers to an ongoing fear about social situations including unfamiliar people, or where there is the possibility of scrutiny from others such as in performance situations (APA, 2013). Both disorders are associated with avoidance of anxiety-provoking situations and significant distress which can impact upon functioning. Kerns et al., (2014) reported that 17% of their sample of autistic[1] children and adolescents met the criteria for an anxiety disorder (Kerns et al., 2014). The most prevalent anxiety disorder experienced in this sample was specific phobia, followed by generalised anxiety disorder. Generalised anxiety disorder is described in the DSM-5 as excessive worry across multiple contexts which is difficult to control, and is associated with impairing symptoms such as fatigue, irritability or restlessness, muscle tension and concentration difficulties (APA, 2013). Separation anxiety disorder was also prevalent in their sample, and refers to excessive fear about separating from, or anticipation of harm towards an attachment figure (APA, 2013). This can be a barrier to daily functioning, such as attending school or sleeping at night, and can cause physical symptoms such as headaches, stomach-aches, or nausea.

In addition to these DSM based anxiety disorders, researchers also noted that 46% of a sample of autistic children and adolescents showed symptoms of anxiety seemingly specific to autism, but not captured by typical anxiety measures (Kerns et al., 2014). These autism specific symptoms included unusual specific fears, such as spider webs or supermarkets, anxiety around rituals including doors being closed and sleeves rolled down, or excessive worry about changes to a routine.

Increased symptoms of anxiety have been shown to predict poorer physical health in autistic adults (Lin & Huang, 2017). Symptoms of anxiety have also been associated with a reduced quality of life including difficulties with sleep and gastrointestinal symptoms such as

[1] 'autistic' is identified as the preferred term by autistic community, along with 'person with autism' and 'on the autism spectrum' (Kenny et al., 2016). All three terms will be used to respect the differing views of members of the autistic community.

abnormal bowel movements, nausea and pain for autistic children and adolescents (Williams, Leader, Mannion, & Chen, 2015). It is important therefore to better understand why individuals on the autism spectrum experience elevated anxiety levels to improve quality of life.

1.1.2 Pathways to anxiety in autism

1.1.2.1 Intolerance of Uncertainty

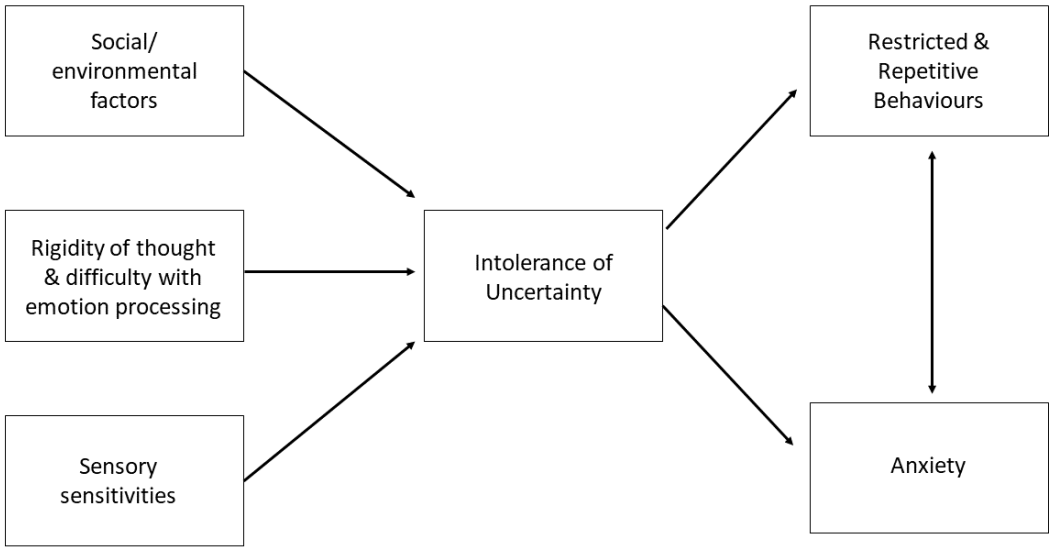

Figure 1. A proposed model of anxiety in autism by Boulter et al. (2014) (p. 1399)

The intolerance of uncertainty model proposed by Boulter, Freeston, South, and Rodgers (2014) suggests that the relationship between autism and anxiety is mediated by intolerance of uncertainty, a key construct in the development of anxiety disorders in typical populations (Boswell, Thompson-Hollands, Farchione, & Barlow, 2013; Dugas, Gagnon, Ladouceur, & Freeston, 1998; Norr et al., 2013). Autistic children and adolescents show higher levels of intolerance of uncertainty than typically developing children and adolescents (Boulter et al., 2014; Neil, Olsson, & Pellicano, 2016; Vasa, Kreiser, Keefer, Singh, & Mostofsky, 2018). The intolerance of uncertainty model of anxiety in autism as shown in Figure 1 proposes that social and environmental factors, rigidity of thought, emotional processing difficulties, and sensory sensitivities all increase intolerance of uncertainty (Boulter et al., 2014). This increased intolerance of uncertainty leads to increased anxious affect. The pathway from sensory sensitivities to anxious affect and restricted and repetitive behaviours through intolerance of uncertainty has been supported by mediational analysis (Wigham, Rodgers, South, McConachie, & Freeston, 2015). Researchers analysed parent reports of sensory processing, intolerance of uncertainty, anxious affect and restricted and repetitive behaviour of 53 autistic children, aged 8-16 years. There were significant pathways

from both over and under responsiveness to sensory input to anxious affect and restricted and repetitive behaviours through intolerance of uncertainty, supporting Boulter et al. (2014).

An alternative pathway where increased intolerance of uncertainty remained a key construct in anxiety for autistic children and adolescents was found by Neil et al. (2016). Through parent report for 64 autistic children and adolescents and 85 typically developing aged 6-14, a significant indirect pathway from intolerance of uncertainty to sensory sensitivities through anxiety was found. Further semi-structured interviews with parents of autistic children supported these models by showing that intolerance of uncertainty was a relevant and identifiable construct in their child's presentation of anxiety (Hodgson, Freeston, Honey, & Rodgers, 2016). Examples of situations that were provided by parents included anxiety around unexpected or unpredictable events, and even seemingly neutral or positive events which could include uncertainty, for example anxiety about a pen running out in school, or a wrapped present.

1.1.2.2 Environmental

Stressful life events have been shown to play a role in the onset and experience of anxiety disorders in typically developing individuals (Faravelli et al., 2012) and contribute to lower wellbeing lasting into adulthood (Hughes, Lowey, Quigg, & Bellis, 2016; Kessler et al., 2010). There is comparatively little research on possible environmental risk factors for the development of anxiety in autistic individuals however.

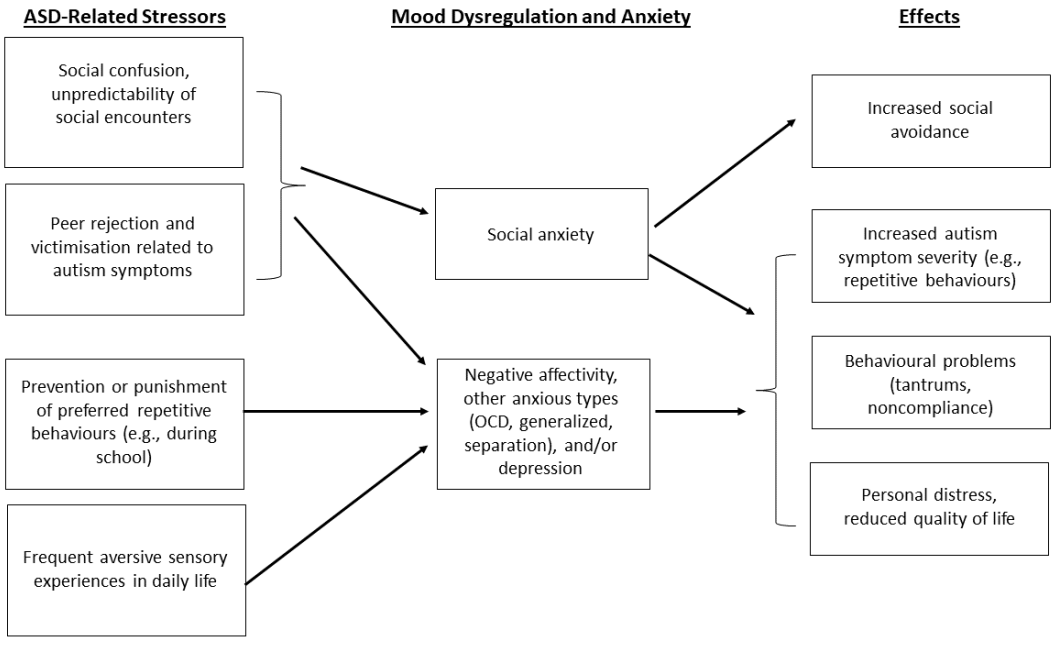

Figure 2. Wood and Gadow's (2010) Hypothetical model of clinical anxiety in autism (p. 287)

A model proposed by Wood and Gadow (2010) described the interplay between aspects of the environment which are stressful due to the dyad of difficulties associated with autism, described as 'ASD related stressors' and the subsequent feelings and effects of these experiences (See Figure 2). Symptoms such as social communication and social interaction difficulties make social situations unpredictable or can lead to rejection or victimisation from others. This social confusion and rejection from peers can cause negative emotions including social anxiety and anxious affect. Restricted and repetitive patterns of behaviour or interests can cause distress if such preferred behaviours are prevented or punished by others, and everyday experiences such as touch, noises or light can be stressful for those with sensory sensitivities. Again this prevention of repetitive behaviours and frequent aversive sensory experiences can cause negative emotions such as anxious affect. In the model, anxious affect may then cause distress, reduced quality of life or behavioural problems, and may also increase autism symptom severity including repetitive behaviours, and increase difficulties with social communication. In addition to this pathway described, the model also suggests that anxiety may moderate the relationship between these autism related environmental stressors and negative effects such as distress, behaviour problems and an increase in the severity of autism related symptoms. Autistic individuals experiencing high levels of anxious affect may experience stressors in the environment as more stressful than those without high levels. This model therefore is key in demonstrating how there are aspects of the environment which are more challenging for autistic individuals and can play a role in the development of increased anxious affect.

1.1.3 The school environment

Children and adolescents spend a significant proportion of their day in the school environment, so it is important to consider how their school experience contributes to the development and maintenance of anxiety. As proposed by Boulter et al. (2014), social and environmental factors can increase anxious affect for autistic individuals through an increase in intolerance of uncertainty. Social experiences, including rejection from peers and unpredictable social encounters, are also highlighted by Wood and Gadow (2010) as contributors to anxious affect for autistic individuals. Additionally, adverse sensory experiences in the environment are highlighted by both models as contributors to anxious affect (Boulter et al., 2014; Wood & Gadow, 2010). Given the social nature of schools in the UK where pupils are taught in class alongside approximately 30 other children, it is possible that the demands of the school environment contribute to elevated anxiety levels in autistic pupils.

For example, teachers in mainstream schools rated higher levels of anxious behaviours measured by subscales of items across two questionnaires for a sample of 28 autistic children

aged 6-10 years compared to 51 typically developing controls with no comorbid physical or cognitive impairments (Ashburner, Ziviani, & Rodger, 2010). Parents also report higher social anxiety levels in autistic pupils attending mainstream schools compared to children and adolescents attending specialist schools matched for gender, age, functioning and autism symptom severity scores (Zainal & Magiati, 2016). This suggests that the mainstream school environment could play a part in the link between autism and anxiety levels, however the specific aspects of the school environment that are particularly or disproportionately anxiety provoking is as yet unclear.

In the UK, children transition from primary to secondary school the academic year after their eleventh birthday. This involves significant environmental changes for pupils including a larger pupil population, change in the curriculum, rules, and the physical building (Neal & Frederickson, 2016). Autistic pupils often feel anxious about this transition to secondary school (Dann, 2011), highlighting uncertainty around the rules and expectations, what would happen each day, and concerns around if they would be bullied (Neal & Frederickson, 2016). This transition can be successful for autistic pupils if teachers are perceived as kind and understanding of individual needs, the new environment is familiar, and the school day is predictable with clear structure and routines (Dann, 2011). This would suggest that difficulties can arise if teachers are not perceived as understanding of autism related needs, including social communication and restricted and repetitive behaviour, which may lead to stressful experiences related to these needs as highlighted by Wood and Gadow (2010). Additionally, a high number of challenging environmental factors in secondary school for autistic pupils may increase intolerance of uncertainty, and subsequently, feelings of anxiety (Boulter et al., 2014).

The social environment in school may also be particularly difficult for autistic pupils. In mainstream secondary schools, autistic pupils reportedly experience higher incidents of bullying than both those with a diagnosis of dyslexia and those without Special Educational Needs (SEN; Humphrey & Symes, 2010). Whilst higher social support from peers was associated with lower levels of bullying, autistic pupils felt the lowest amount of social support from peers. This was supported by research which found that 4 out of 6 participants who attended a mainstream secondary school had experienced bullying (Cook, Ogden, & Winstone, 2016). The risk factors for bullying included social communication difficulties, for example not understanding sarcasm, and sensory processing difficulties causing over-reactions to what was described as a small trigger, such as a peer tapping a pencil. Social confusion, being bullied and sensory difficulties were highlighted by Wood and Gadow (2010) as stressors in the school environment which may contribute to the development of anxiety in autistic individuals. Additionally, a high number of

challenging social situations and unpredictable sensory experiences may cause anxiety through an increase in intolerance of uncertainty (Boulter et al., 2014).

Other important elements of the school environment were highlighted by autistic pupils when designing an ideal school (McAllister & Sloan, 2016). These elements included having an individual play area that was separate from other pupils, and a feeling of safety provided by the close presence and availability of staff, which may be a response to increased experiences of bullying previously discussed. Noise was also highlighted by all pupils in this study, with some describing a desire for rooms to be soundproofed, a change in the school bell, quiet rooms to escape to, and support around a noisy dining hall. This difficulty with unpredictable and unpleasant noise, and unpredictable social interactions are consistent with Wood and Gadow's (2010) model, and the intolerance of uncertainty framework by Boulter et al. (2014) as possible triggers for anxiety.

1.1.4 The current review

Research indicates that a mainstream school context (Zainal & Magiati, 2016) and the move to secondary school (Dann, 2011) are associated with increased levels of anxiety for autistic pupils. This review aimed to extend this research and focused on understanding which features of the secondary school context and setting were linked to increased reports of anxiety. One tool used to explore the aspects of the school environment that lead to increased feelings of anxiety for secondary school pupils refers to a 'landscape of fear' where perceived threats unique to the school experience are explored under three categories: the physical environment, the social environment and the learning environment (Ripley, 2015). The physical environment refers to perceived threats associated with the physical building, the social environment captures social situations outside of lessons in school, and the learning environment refers to the within-class curriculum demands and learning styles.

To further understand and classify the aspects of the physical, social and learning environment in mainstream secondary schools that cause anxiety for autistic adolescents, a systematic literature search was conducted to identify papers that explored the secondary school experience *from the pupil's perspective*. This is because research has identified discrepancies in reports of anxiety from parents, teachers and children and young people themselves (De Los Reyes & Kazdin, 2005). Whilst parents and teachers often agree and attribute behaviours observed to a child's mood or personality, children are more likely to describe their behaviours in response to a trigger in the environment. Key legislation in both the UK and the United Nations reinforce this by emphasising the importance of children being able to form and share their views

on their educational experiences, and for these to be taken into account when making decisions (Department for Education, 2015; United Nations, 1989). Whilst this review only sought papers that included the pupil's voice, it also took into account the views of parents and school staff included alongside pupil voice.

1.2 Method

1.2.1 Search Terms

Table 1.

Systematic review search terms

Category	Search term
Diagnosis	Autis*
	Asperger*
	"pervasive developmental disorder"
	ASD
School setting	School
	Classroom*
	Mainstream
	Pupil*
	Student*
Experience	Experience*

The search terms outlined in Table 1 were generated to capture individuals with a diagnosis of autism, the school setting, and the experience of school (see Appendix A for full search strategy). Synonyms included in the search for the terms autism and school were identified by looking through the title and abstract of papers known to be relevant (e.g., Humphrey & Lewis, 2008), and at a previous literature review of autism and the school setting (Williams, Gleeson, & Jones, 2017). Asterisks were used to capture words with different endings (e.g., autis* to capture autism and autistic) and quotation marks were used to capture full phrases (e.g., "pervasive developmental disorder"). The terms 'Anxiety' and 'anxious' were not entered as search terms to ensure papers demonstrating this theme in figures or tables were not missed. Instead, this was captured in the inclusion and exclusion criteria (Table 2).

1.2.2 Search Strategy

The search terms (see Table 1) were entered into the following databases on 14.02.18: PsycINFO, PsychARTICLES, CINAHL Plus and MEDLINE (via EBSCO), ERIC and Web of Science (see Appendix A). The terms were searched for in the title and abstracts of records in the EBSCO and ERIC databases, and topics were searched for in Web of Science. The results were then limited to peer reviewed academic journals that were written in English.

1.2.3 Inclusion and Exclusion Criteria

Based on the rationale for this literature search, the inclusion and exclusion criteria were defined (see Table 2 below). The inclusion and exclusion criteria ensured that only papers uncovering an aspect of the secondary school experience associated with feelings of anxiety were included for analysis. The criteria also eliminated papers demonstrating anxiety anticipating the transition to secondary school as participants had not yet experienced secondary school. Additionally, samples which included participants with other neurodevelopmental disabilities as well as autistic participants where findings were not separated out by diagnosis were eliminated to ensure the findings were unique to the experiences pupils on the autism spectrum.

Table 2.

Inclusion and exclusion criteria

	Inclusion criteria	Exclusion criteria
Publication	Published in English. Peer-reviewed academic journal. Access to full paper.	Book chapter, book review, magazine article, editorial letter.
Study design	Empirical paper.	Meta-synthesis, meta-analysis, or literature review.
Sample	Participants with a diagnosis of autism spectrum disorder. Secondary school aged (11-16). Must include pupil voice.	Participants not predominately secondary school age (11-16). Participants without autism spectrum disorder diagnosis, or other diagnoses included in sample for which findings were not separated out by diagnosis. Parent or teacher report with no pupil voice.
Setting	Attending mainstream school.	Not a mainstream setting (special education settings, clinical setting, primary school, transition period between primary and secondary school).
Findings	Description of feelings of anxiety which were attributed to an aspect of the school environment or experience.	Description of feelings of anxiety which were not attributed to an aspect of the school environment or experience. Anxiety about upcoming transition to secondary school.

All search results were entered into 'Covidence,' a literature review tool, and a flow chart of the process is shown in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009) flow diagram (see Figure 3). Once duplicates across the databases were automatically removed by Covidence, the titles and abstracts of all articles were manually screened against the inclusion criteria (see Table 2). The papers that did not meet these criteria were excluded (n= 986). The full text of the remaining articles were screened (see Appendix B for a full list of full text papers and reasons for exclusion at this stage) giving a total of 14 articles which met the inclusion criteria. Using the search terms and inclusion criteria of pupil voice and feelings of anxiety attributed to the school experience, this led to the inclusion of only qualitative research.

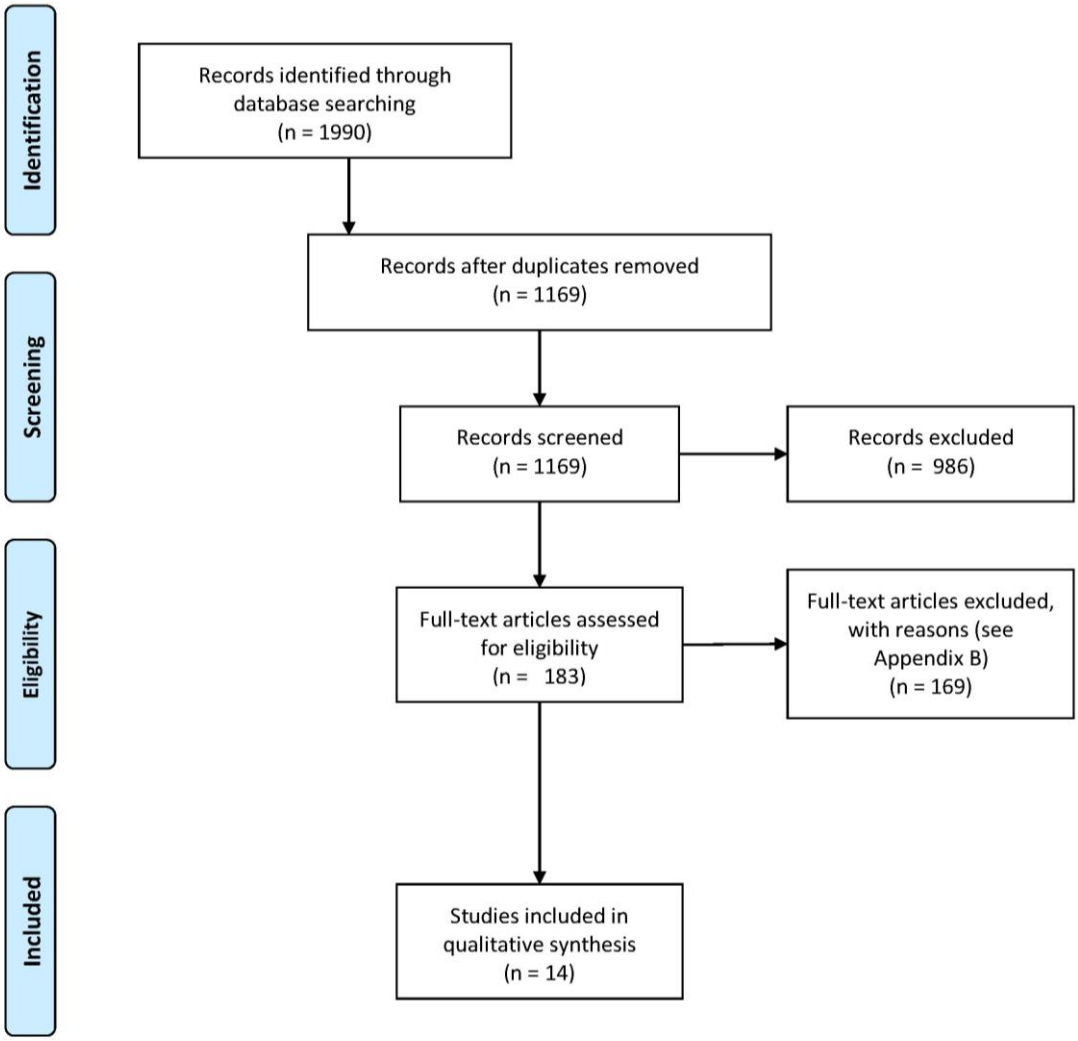

Figure 3. PRISMA flowchart showing search process.

1.2.4 Quality Control

The quality of each of the included studies was assessed by using the Critical Appraisal Skills Programme (CASP, 2017) checklist for qualitative research. This is a checklist containing 10 items with additional information to prompt the assessment for each item. Each item can be rated as 'yes,' 'no' or 'can't tell'. For the purpose of this review, the rating system was adapted to create a scoring system to allow for comparison between studies. The three responses possible were "clearly reported/comprehensive" scored as 2, "partially reported/considered" as 1, and "no/not reported/flawed" scored as 0. This gave a possible range of scores from 0 to 20.

1.3 Results

1.3.1 Quality assessment

The fourteen papers identified are summarised in Table 3. Eight papers reported research conducted with pupils in schools in the UK (2, 3, 4, 5, 6, 7, 8, 10), two were conducted in the USA (11, 14), one in Singapore (12) and three took place in Australia (1, 9, 14). The overall quality of the papers scored using the CASP (Critical Appraisal Skills Programme, 2017) ranged from 4/20 to 17/20, with a median score of 12/20 (see Appendix C for full breakdown of scoring). Eleven of the papers identified had a qualitative research design (1, 3, 5, 6, 7, 8, 9, 10, 11, 12, 13). Three papers used mixed methods, collecting quantitative data alongside qualitative, and included measuring the effectiveness of a school-based intervention on anxiety levels (2), identifying mental health profiles of children on the autism spectrum (4) and reporting on the presence of sensory difficulties (6). Seven of the 14 papers focussed on capturing the pupil's voice (4, 5, 6, 7, 10, 12, 13). Two papers captured the views of parents alongside the pupil (1, 2), and two papers captured the views of parents of current pupils alongside the views of autistic adults reflecting on their school experience (9, 14). Three papers captured the pupils' voice alongside parents and/or other professionals (3, 8, 11). When focussing on the qualitative aspect of the papers, this included the experiences of 253 pupils.

All papers used qualitative methodology to gain insight and understanding of the views of autistic pupils. The authors explained and justified the research design chosen at least partially for all but one study (3). Similarly, 12 out of the 14 papers gave information about the data collection procedure, either providing full or partial justification of why they chose a particular method, or describing a replicable procedure. Two papers did not provide such information (3, 8).

Across the 14 studies identified, there were seven semi-structured interviews with pupils (1, 2, 4, 7, 11, 12, 13), with one paper also including pupil diaries (7), however only three provided an interview schedule (1, 2, 12). Two papers (3, 8) reported using interviews however did not describe whether these were structured or unstructured, and only one schedule was provided (3). Three studies used questionnaires (6, 9, 14), and all provided the questions for reference. The final two papers (5, 10) used photo-elicitation alongside unstructured interviews to capture the pupil voice. This method involved pupils taking pictures of meaningful areas of school before being asked about the photos. Whilst the interview schedule was not provided for all papers, it did not appear that any paper directly asked which aspect or the school environment led to the experience of anxious affect.

Two papers (2, 6) provided information about the recruitment strategy used and refusal and dropout rates, one provided some information (12) whereas the remaining 11 did not provide key information including demographics of schools, participants and how this would influence the conclusions drawn. Only three of the fourteen papers considered the relationship between the researcher and participants (5, 7, 10) and none explicitly explored any bias that could arise because of this. Five of the papers identified did not report on ethical issues or the ethical procedure taken (3, 5, 8, 11, 14).

A range of analysis techniques were used including thematic analysis, content analysis, constant comparative analysis and interpretative phenomenological analysis. Only two of the fourteen papers provided sufficient information to determine that the analysis was robust and replicable (6, 14), and six did not provide information on the data analysis procedure, only stating the analysis used (2, 3, 9, 8, 11, 14). Three papers did not give a clear summary of the findings, provide adequate evidence or consider triangulation of points made (3, 11, 14). Similarly, four of the fourteen papers did not make clear the contribution the paper made to the existing literature, future directions for research or the implications of the findings (3, 10, 11, 14).

Table 3.

Summary of papers identified

Ref	Author (year) country	Pupil characteristics	Voice	Objectives	Method	Analysis	CASP score
1	Carrington and Graham (2001) Australia	Two males (age 13), two schools Asperger syndrome diagnosis, one with comorbid ADD No academic achievement or ethnicity data provided	Pupil, parent	"To provide teachers with an insight into the social world of Asperger syndrome" (p. 38)	Semi-structured interview	Constant comparison (Glaser & Strauss, 1967)	11/20
2	Clarke, Hill, and Charman (2017) UK	Nine male (aged 11-14), six schools All with autism diagnosis No specific age, achievement or ethnicity data provided for those interviewed	Pupil, parent	To look at "the way they cope with stressors in their environment that could cause anxiety" (p. 3887) following a manualised CBT intervention	Semi-structured interview	Thematic analysis (Braun & Clarke, 2006)	13/20
3	Connor (2000) UK	15 male, 1 female (five year 7, seven year 8, two year 9, two year 11), nine schools Asperger syndrome diagnosis No specific age, achievement or ethnicity data provided	Pupil, SENCo	"To gain insight into the opinions and experiences of a sample of young people diagnosed with Asperger's syndrome" and to identify any common themes linked to anxiety or stress in young people" (p. 287)	Interviews with pupils Discussions with SENCOs	No clear method	4/20

Ref	Author (year) country	Pupil characteristics	Voice	Objectives	Method	Analysis	CASP score
4	Hebron and Humphrey (2014) UK	Four male, one female (aged 11-17) ASD diagnosis, no comorbid conditions No specific school, age, achievement or ethnicity data provided for those interviewed Academic achievement within normal range	Pupil	"To identify influences on and responses to mental health difficulties of adolescents on the AS from their perspective" (p. 24)	Semi-structured interview	IPA following six steps of Thematic coding (Braun & Clarke, 2006)	14/20
5	Hill (2014) UK	Six (gender not provided), two schools ASD diagnosis No specific age, achievement or ethnicity data provided	Pupil	"To explore the mainstream secondary school experiences of young people with ASD" (p. 81)	Photo elicitation discussions	IPA	12/20
6	Howe and Stagg (2016) UK	12 male, 4 female (aged 12-17, mean 14.4), three schools ASD diagnosis, no co-morbid learning disabilities No specific achievement or ethnicity data provided	Pupil	Investigate "the experiences of children with ASC whilst they are in a classroom at school… to access the children's subjective experiences of sensory issues within this environment" (p. 1658)	Questionnaire	Content analysis (Marks & Yardley, 2004)	17/20
7	Humphrey and Lewis (2008a) UK	20 (gender not provided; aged 11-17), four schools Asperger syndrome or high functioning autism diagnosis No specific achievement or ethnicity data provided	Pupil	Explore views of pupils with Asperger's or high functioning autism about mainstream education" and "to document the everyday experiences of such pupils" (p. 25)	Semi-structured interviews (n = 20, pupil diaries (n = 9), pupil drawings (n = 1)	Interpretive phenomenological framework	15/20

Ref	Author (year) country	Pupil characteristics	Voice	Objectives	Method	Analysis	CASP score
8	Humphrey and Lewis (2008b) UK	19 (gender not provided; aged 11-17), four schools Appears to be same sample as Humphrey and Lewis (2008a) ASD diagnosis No specific achievement or ethnicity data provided	Pupil, staff, parents	Determine "What barriers to learning and participation are evident for students on the autistic spectrum in mainstream secondary schools" and how "practices in mainstream schools facilitate or constrain participation of children on the autistic spectrum" (p. 133)	Interviews, classroom observations and examination of school documents	Pragmatic content analysis (Mayring, 2004)	7/20
9	Jarman and Rayner (2015) Australia	15 parents of school aged girls (aged 5-18), and 30 adult females reflecting on school experience Asperger syndrome diagnosis No specific achievement, school or ethnicity data provided	Pupil (retrospectively), parent	Examine "the school experiences of females with Asperger Syndrome" (p. 3)	Online questionnaire	Inductive reasoning (O'Leary, 2004)	9/20
10	Lamb, Firbank, and Aldous (2016) UK	Four male, one female (aged 12, 14, 15, 15 & 16), one school ASD diagnosis, one with comorbid ADHD No specific achievement or ethnicity data provided	Pupil	"Understand how pupils with ASD experience… Physical Education" (p. 702)	Photo-elicitation and unstructured interviews	Thematic analysis (Johnson, Chambers, Raghuram, & Tincknell, 2004)	12/20
11	Marks, Schrader, Longaker, and Levine (2000) USA	Three male (aged 13, 15 and 15), two schools Asperger Syndrome diagnosis Two Caucasian, one African American No specific achievement data provided	Pupil, parent and staff	"To provide an insider's view of the disability to professional working with students with Asperger's syndrome" (p. 4)	Semi-structured interview (pupils), focus groups (staff), telephone interview (parents)	Themes and classifications (Patton, 1990) then pupil portraits (Seidman, 1991)	6/20

Ref	Author (year) country	Pupil characteristics	Voice	Objectives	Method	Analysis	CASP score
12	Poon et al. (2014) Singapore	Three male, one female (aged 12, 13, 14, 16), two schools Asperger syndrome or high functioning autism diagnosis All within or above average range and working within or above typical curriculum	Pupil	"to understand the perspectives of youth with HFA attending mainstream secondary schools in Singapore." (p. 1072)	Semi-structured interview	Interpretive phenomenological framework (Bogdan & Biklen, 2003)	15/20
13	Saggers (2015) Australia	Seven male, two female, one school ASD diagnosis No specific age, ethnicity or achievement data provided	Pupil	"To identify aspects of schooling that were considered positive and enabling, … to pinpoint common inhibitors that may prevent students with ASD taking full advantage of their educational experiences" (p. 36)	Semi-structured & unstructured interview	Constant comparison (Glaser, 1992), mapping onto Humphrey and Lewis (2008a)	10/20
14	Sciutto, Richwine, Mentrikoski, and Niedzwiecki (2012) USA	94 participants (59 parents, 8 did not specify, 27 adults with diagnosis - 4 male, 19 female, 4 unspecified) Asperger syndrome diagnosis 88% white Caucasian, 22% other No specific school or achievement data provided	Pupil (retrospectively), parent	"To examine school-related challenges and instructional practices through the unique perspectives of individuals with ASD and their caregivers" (p. 178)	Online questionnaire	Thematic analysis (Braun & Clarke, 2006)	13/20

1.3.2 The physical environment.

The aspects of the physical environment in school which were reported to cause feelings of anxiety for autistic pupils included noises in school, corridors, and crowds.

1.3.2.1 Noise

Many of the identified studies described noise as a cause of anxiety in school. Parent report on the school experience of a 13 year old described feelings of anxiety that were attributed to the noise amongst other triggers in school (11). Findings from a non-standardised questionnaire created by the authors found that sensory experiences in school caused feelings of anxiety for a sample of 14 pupils with a diagnosis of autism attending mainstream secondary school (6). The most common trigger for this feeling was aversive noises. Pupils particularly reported feeling anxious because they anticipated or worried that they would hear aversive noises, such as a fire drill, or anxiety about a lesson because of the sound of a specific teacher. Pupils reported that this anxiety about noise made it difficult to concentrate. Research using photo-elicitation (5) also found that the school bell was a source of anxiety for one pupil. Another pupil described anxiety about exams because the sports hall was too loud which made it difficult to concentrate. Further research using photo-elicitation to capture views of physical education (PE) of pupils reported feelings of anxiety about the noise at the start of lesson, attributed to the PE corridors, which then impacted upon concentration (10).

Through the use of semi-structured interviews with nine pupils, many reported that classroom noise was difficult to cope with and impacted upon concentration, thus captured under the theme of anxiety and stress in schools (13). This section also described teachers shouting as a source of classroom noise. This was supported by a summary of interview findings from 16 students with autism who noted that they felt anxious about not feeling able to work in groups that were noisy (3). Similarly, an adult who identified as having autism reflected back on their school experience to describe how the noise in school felt overwhelming and caused high anxiety levels which made it difficult to concentrate (14). This was supported by research capturing noise and disruption under a key finding of anxiety and stress in school from semi-structured interviews, pupil diaries and drawings constructed by 20 participants with a diagnosis of autism (7). Quotes were provided by two pupils describing noise in school, which made one pupil want to leave the classroom.

1.3.2.2 Crowds

The presence of crowds was another aspect of the physical environment that was associated with the experience of anxiety in school. Under a key theme of anxiety and stress in school arising from semi-structured interviews with nine pupils, crowds were described as difficult to manage (13). Similarly under the theme of anxiety arising from photo-elicitation research looking at the school experiences of six pupils, one pupil captured the reception area that was described as a route to avoid crowds of people in the school entrances (5). This pupil also described crowds of people as unpredictable. A second pupil showed similar avoidance of crowds under this theme, including taking the long route to avoid a crowded playground, and choosing a seat in class without too many other pupils nearby. In a second photo-elicitation study looking specifically at PE experiences, the PE corridor was described as crowded, which was reported to cause feelings of anxiety for the pupils (10). Whilst not directly mentioning crowds, a pupil described a disorganised rush of people, which was interpreted by the authors as a source of anxiety (4).

1.3.2.3 Corridors

Finally, corridors were described in the research as a source of anxiety in the physical environment. The PE corridors were highlighted as a key cause of feelings of anxiety, partly due to the noise and crowds as previously discussed (10). In a second photo-elicitation study, corridors were concluded to be a significant source of anxiety for one pupil (5), who referred to the size of corridors and how this made him feel which was captured under the theme of anxiety. Corridors were also described under the theme of anxiety and stress in school in research combining semi-structured interviews and pupil diaries, this time being described as small in size, causing pushing and shoving (7).

1.3.3 The learning environment

Aspects of the learning environment throughout the school day were also highlighted to cause feelings of anxiety for autistic secondary school pupils. Research looking at the experiences of two pupils and their parents concluded that the demands of the mainstream classroom can cause feelings of anxiety for autistic pupils (1). Whilst this study did not specify the demands that caused feelings of anxiety, the literature highlighted themes in the lack of routine and predictability, transitions between lessons, the need to demonstrate ability and the curriculum.

1.3.3.1 Lack of predictability in school day

Also captured by the theme of anxiety and stress in school, the feeling of being unable to influence the order and predictability in the mainstream school environment was highlighted from semi-structured interviews with pupils and pupil diaries (7). Research using semi-structured interviews with six pupils concluded that disruption to existing routines and structure in school can cause feelings of anxiety (4). Furthermore, photo-elicitation research indicated corridors as a source of anxiety for one pupil who attributed this partly due to the size as previously discussed, but also described not knowing who was coming or what would happen when in a corridor as anxiety provoking (5). A second pupil in this research highlighted the need to watch the clock to ensure they could anticipate the sounding of school bell as they felt anxious about being caught off guard by the unexpected noise.

1.3.3.2 Transitions between lessons

As is typically the norm in secondary school, each lesson involves a different teacher in a different classroom. The transitions between lessons were also highlighted as a source of anxiety for autistic pupils. As previously discussed, one pupil captured the school bell as a source of anxiety in photo-elicitation research (5). This was interpreted to be partly because of the aversive sound and the suddenness of the noise, but also because it indicated the need to transition to the next lesson, which caused feelings of anxiety. In a semi-structured interview, one parent described the transitions between lessons in different classrooms as one source of anxiety for their child (11).

1.3.3.3 Academic pressure

The pressure associated with academic achievement was evident as a source of anxiety for autistic pupils. One paper described the academic work as a source of anxiety, noting one pupil's comments about fear of failure (12). Under the theme of anxiety and stress in school, exam nerves were listed as a source from semi-structured interviews and pupil diaries (7). This was also highlighted by research that concluded anxiety about exam performance was prevalent in pupils taking part in photo-elicitation research (4), along with significant worries about getting answers wrong. This was also experienced in situations outside of an exam context. For example, pupil portraits described a pupil pushing himself to do well and demonstrate perfection in his work, not wanting to make mistakes or fail, which led to high levels of anxiety (11). This was supported by conclusions generated from an online questionnaire completed by parents of daughters with autism and adult females with autism reflecting on their school experience (9). Overall this research concluded that the pupils needed to put in extra effort to demonstrate high ability in

school, which caused feelings of anxiety and stress. Furthermore, a summary of interviews with autistic pupils also concluded that anxiety about performing in front of other pupils was experienced (3), which could be attributed to the need to demonstrate their ability to others.

1.3.3.4 The curriculum

In secondary school, there are typically a broader range of subjects on the curriculum than in primary school. For some young people this may provide the opportunity to excel in subjects of interest. However, for others, this was experienced as a source of anxiety. Under the theme of anxiety and stress in school, subjects that were disliked by the pupils was captured as a source of stress through pupil interviews and diaries (7). Similarly, work that the pupils did not like completing was identified as a contributor to feelings of anxiety about school through interviews with pupils (13). One pupil reported that they often worried that they would not understand something in class (2), suggesting possible anxiety about the lesson content or reaction from the teacher.

Other findings from semi-structured interviews identified the high workload, which included homework and having many deadlines to meet within a short timeframe as sources of anxiety (13). This was supported by reports from an adult female with autism who reported feeling anxious about assignments because they took her additional time to ensure she understood what she needed to do (9).

The need to produce neat and legible handwriting was also described as challenging for a female on the autism spectrum, making basic learning tasks more difficult and leading to feelings of anxiety and stress (9). This was supported by a report from a pupil via semi-structured interview who highlighted the high volume of handwriting required in the curriculum as a source of anxiety (13).

1.3.4 The social environment

The social environment in mainstream secondary schools was also reported to cause feelings of anxiety for autistic pupils. The themes that arose from the research reviewed included the social identity, or how pupils made sense of themselves in relation to others in school, and how others in school behaved towards them.

1.3.4.1 Social identity

One area of the social environment highlighted to cause feelings of anxiety was the feeling of being different to other pupils in school. The desire to fit in, but feeling different from peers,

was concluded as a source of anxiety in semi-structured interviews with two males and their mothers (1). It was reported that they want to be treated the same but also felt different from others, and this was also captured as a contributing factor to anxiety in a model depicting findings from semi-structured interviews with six pupils (4). Negotiating difference was also captured as a cause of anxiety in a network of themes from semi-structured interviews and pupil diaries (7). Pupils conceptualised this as being made to feel odd, feeling as though something was wrong with their brain, and not feeling as though they were accepted by others in school.

1.3.4.2 Behaviour of others in school

The actions of others in school was also considered to be a source of anxiety in the research identified. An incident of name-calling by a peer was described as a source of anxiety for one pupil by a Special Educational Needs Co-Ordinator (SENCo) (8). This was supported by one parent's report during semi-structured interviews that negative behaviours from peers contributed to high anxiety levels for the pupil (11). This was further depicted in findings of semi-structured interviews with six pupils that reported bullying and being isolated from peers as contributors to feelings of anxiety in school (4). Anxiety about spending time with peers outside of lessons was identified in a summary of interviews with pupils, as well as working with peers where "behaviour is lively or noisy" (3; p. 293).

Under the theme of anxiety and stress in school, teachers shouting was identified as anxiety provoking through semi-structured interviews with pupils (13). Similarly during a semi-structured interview, one pupil reported feeling anxious about the teacher being annoyed with the pupil, along with findings suggesting anxious affect around others staring or being angry with them (4).

1.4 Discussion

The literature identified three areas of the physical environment associated with feelings of anxiety for secondary school pupils with autism: adverse noises, crowds and corridors. Characteristics of the learning environment associated with feelings of anxiety were the lack of predictability in school, frequent transitions across the school day, academic demands, including aspects of the curriculum that the young people reported as disliking, as well as homework. The social environment in school, both in terms of behaviour from others and the social identity shaped by others in school caused feelings of anxiety for autistic pupils.

Adverse noises in school were identified as a source of anxiety for autistic pupils in 8 of the 13 studies identified (3, 5, 6, 7, 10, 11, 13, 14). When autistic pupils experienced these adverse noises, they described physical discomfort such as pain or a strange feeling in their stomach (6). A

strange feeling in the stomach is recognised as a symptom of anxiety in children, as well as other physiological symptoms including muscle tension, trembling and increased heart rate (Spence, 1997). It may be that this physical discomfort is a further symptom of the anxiety they are feeling.

Researchers have also demonstrated that autistic children show higher levels of sensitivity for sensory stimuli and subsequently avoid this stimuli more than both typically developing children and those with an intellectual disability (Joosten & Bundy, 2010). This finding is supported by fMRI research showing increased activation in sensory areas of the brain in response to mildly aversive noises and visual stimuli, which correlates with parent reported sensory behaviours (Green et al., 2013) . Further fMRI research has shown increased activity in sensory regions and difficulties habituating to mildly aversive noises and touch (Green et al., 2015) in comparison to typically developing children. The DSM-5 criteria also notes atypical responses to sensory input such as sounds as a feature of autism (APA, 2013). If autistic pupils show sensitivity to noises, this could explain the physical discomfort and anxiety about hearing noises as aversive that may be seemingly innocuous to others. This would be supported by a report from a pupil who described the exam hall as too loud (5). As exam conditions would typically mean no talking, the participant may have been demonstrating sensitivity to noises that others may not have perceived, such as many students using a pen, moving in their chairs, or teachers walking around the room. This would support the model proposed by Wood & Gadow (2010) which identified adverse sensory stimuli in the environment as a source of feelings of anxiety. As described by Howe and Stagg (2016), strategies that involve anticipating when an adverse noise might occur may be employed to reduce uncertainty. This was supported by reports from autistic adults who emphasised the importance of feeling in control of adverse sensory experiences (Robertson & Simmons, 2015). These findings are consistent with the intolerance of uncertainty model of anxiety where increased sensory sensitivities lead to a lower tolerance for uncertain situations such as unexpected noises, and subsequent anxious feelings around this unexpected adverse noise (Boulter et al., 2014).

It is important to also note the effect that anxiety has on the senses. When feeling anxious, autistic children may be in a hypervigilant state where sensory processing is heightened (Green & Ben-Sasson, 2010). With regards to the alternative pathway from intolerance of uncertainty to increased anxiety then sensory sensitivities (Neil et al., 2016) autistic pupils who need a sense of routine and predictability may feel more anxious in an uncertain environment, thus feel sensitive to unexpected noises. Similarly, for an autistic pupil who is already feeling anxious at school, noises may feel more aversive and threatening as outlined by the alternative pathway proposed by Wood and Gadow (2010), where feeling anxious makes autism related stressors more challenging and in turn, increases anxiety.

Adverse noises in school were also described as impairing concentration (3, 5, 10, 13, 14), which is in line with typical models of anxiety. Anxious affect can increase sensory perception, and individuals with anxious affect show an attention bias towards this perceived threat, for example an adverse noise, which can impact upon ability to filter out this perceived threat and focus on a task (Robinson, Vytal, Cornwell, & Grillon, 2013). Difficulties concentrating can cause pupils to miss key lesson content which could also be a further source of worry, particularly given feelings of anxiety around the academic pressure and the need to demonstrate their ability in school (3, 5, 7, 9, 11). There will always be an element of uncertainty around how a piece of work or a performance will be evaluated by others, and a pupil is unlikely to get the same mark or feedback each time. This is evident from a description of one pupil who did not want to get less than a grade A, which led to feelings of anxiety (11). Another paper highlighted a pupil's fear of failure as a source of anxiety (12). Whilst this paper was rated of relatively high quality, the study was designed to be specific to the school experience of autistic adolescents in Singapore as researchers had stressed differences in the school experience and inclusion practice in this country. Whilst this might limit the generalisability of this particular finding, other papers also supported this finding (3, 5, 7, 9, 11). Academic pressure may act as an environmental factor in the intolerance of uncertainty model of anxiety (Boulter et al., 2014). Such environmental factors could then increase intolerance of uncertainty, making uncertainty about outcomes more anxiety provoking.

Focussing on the curriculum specifically, a high level of non-preferred work in school could be considered an environmental factor increasing the intolerance of uncertainty of pupils and subsequent feelings of anxiety (Boulter et al., 2014). Whilst neither paper identified the subjects that were disliked or which non-preferred work caused feelings of anxiety, both homework (9, 13) and handwriting were identified as sources of anxiety (9, 13). Anxiety around homework could again be due to the need to achieve academically previously discussed, or the uncertain nature of whether homework will get set for each lesson, what the homework could be, and how long it may take. Research has also noted that parents of autistic pupils reported more homework difficulties than pupils without autism (Endedijk, Denessen, & Hendriks, 2011). It may be that homework may act as an environmental factor that increases intolerance of uncertainty for autistic pupils, thus increasing feelings of anxiety. Difficulties with homework have been associated with greater difficulties with executive functioning, thus the ability to plan, monitor and think flexibly, which are also reported difficulties for autistic pupils (Endedijk et al., 2011).

Whilst also having difficulties with planning, thinking flexibly and monitoring work, many autistic pupils also have high levels of handwriting difficulties (Fuentes, Mostofsky, & Bastian, 2009; Kushki, Chau, & Anagnostou, 2011). Handwriting was associated with feelings of anxiety in

the studies reported in this review (9, 13), highlighting that aspects of the secondary school curriculum including homework and high handwriting demands, both of which are understood to be difficult for autistic pupils, lead to feelings of anxiety. Whilst academic demands are not included as an autism related stressor in the model proposed by Wood and Gadow (2010), both of these demands could be captured as environmental challenges for pupils on the autism spectrum in the intolerance of uncertainty model of anxiety (Boulter et al., 2014). Both papers highlighting homework and handwriting however failed to provide adequate detail regarding the recruitment procedure described and the data analysis procedure reported (see Appendix C) (9, 13) making it difficult to judge the reliability and validity of their conclusions.

The lack of predictability in the school day was also referred to as a source of feelings of anxiety (4, 5, 7). Preference for routine and predictability associated with autism (APA, 2013) could make this lack of predictability an environmental factor in the intolerance of uncertainty model of anxiety and autism (Boulter et al., 2014). A lack of predictability could increase intolerance of uncertainty, thus causing feelings of anxiety. There was limited evidence to support this in the papers highlighted however. One pupil's need to predict the school bell, an aversive noise, and not knowing who will be in a corridor or how they will act was described as sources of anxiety (5). Both points however can be interpreted in many different ways. Corridors, crowds, aversive noises and the behaviour of others were all included as separate sources of anxiety. Two studies concluded that disruption to routines and not having order and predictability were sources of anxiety for autistic pupils (4, 7). However, neither of these studies provided data evidence to support this theme, and the data analysis procedure was not fully described in either paper so it is unclear how this theme arose. It could be that lack of predictability is not a direct source of anxiety for autistic pupils. Instead, it may increase anxiety indirectly though intolerance of uncertainty following other sensory, social or environmental stressors as highlighted by Boulter et al. (2014). Is important to also note that each school will have different support mechanisms in place for pupils with additional needs such as those associated with autism. Some may have supports such as personalised timetables and preparation for changes in routine meaning unpredictability is not a significant issue for autistic pupils, whilst others may not provide any additional support. To determine if unpredictability in the school day is a source of anxiety for those without such support, further research would need to control for the amount of support the pupil has in place around predictability and structure, and their individual intolerance of uncertainty level.

Transitions between lessons in secondary school caused feelings of anxiety for autistic pupils. One paper included parent report attributing their child's anxiety levels to many causes including transitioning between lessons (11). It is important to note that this paper was rated

relatively low in quality (see Table 3), particularly lacking rigour in data analysis and reporting of findings (see Appendix C). The second paper referring to transitions as a source of anxiety for a pupil made this interpretation based on a child feeling anxious about the school bell (5). Whilst the researcher would have been immersed in the data, which may have influenced this interpretation, transitions between lessons are not stated as a source of anxiety by any pupil in the research highlighted. It is possible that the noise, crowds and corridors associated with transitioning between lessons is the underlying cause of any difficulties seen, rather than the actual transition between lessons.

Pupils did explicitly refer to corridors in school as a source of anxiety. Two pupils across two studies referred to the size of the corridor, one describing corridors as large, the other as small (5, 7), whilst a third pupil referred to the noise and crowds in the corridors (10). Feelings of anxiety about corridors in school could be due to sensory experiences in such a confined space including those from lights, noises or smells, or it could be that the crowds often found in such confined spaces cause feelings of anxiety. Crowds were highlighted as a source of anxiety in school for autistic pupils in a number of studies (4, 5, 10, 13). By definition, a crowd refers to a disorganised group of people, and crowd a space that is full leaving little room for movement. Regular transitions between lessons could mean regular need to be in corridors, which may act as an environmental factor along with sensory sensitivities leading to an increased intolerance of uncertainty (Boulter et al., 2014). This increased intolerance of uncertainty may make disorganised groups of people less tolerable, thus elevate anxious affect. A crowd of people may also bring many aversive sensory experiences for an autistic pupil, including adverse noise, sights, smells or touch from crowded bodies bumping into each other, with all modalities highlighted as causing anxiety and discomfort in school (6). These frequent aversive sensory experiences would also fit with the model proposed by Wood and Gadow (2010).

Consistently, the behaviour of others in school was described as causing feelings of anxiety for autistic pupils. Negative behaviour from peers was described as a source of anxiety by one SENCo (8) and one parent (11), however negative behaviour from others was not directly reported directly by pupils and both studies lacked rigour overall (see Appendix C), particularly in terms of the data analysis procedure. One paper concluded bullying and isolation from peers as causing feelings of anxiety (4). Whilst this was a relatively good quality paper (see Table 3), evidence to support this conclusion was not provided. Other, more neutral behaviours by both peers and teachers were also cited as anxiety provoking (3, 4, 5, 13). This could be due to difficulties in social communication, such as interpreting others behaviour, associated with autism (APA, 2013). This confusion could mean taking sarcasm from others literally or not understanding metaphors or sayings. This social confusion is highlighted as an autism related stressor which can

contribute to feelings of anxiety for autistic individuals (Wood & Gadow, 2010). Similarly, such social factors could increase intolerance of uncertainty (Boulter et al., 2014). If autistic pupils have difficulties interpreting others' behaviour, these social challenges could feel less tolerable, thus causing feelings of anxiety (Boulter et al., 2014).

The social identity, or how pupils make sense of themselves based on others in school, was cited as another cause of feelings of anxiety. One paper reported that pupils felt different from their peers but wished to fit in which caused feelings of anxiety (1). The quote given to support this included a pupil describing how upsetting it was when others did not know how it feels to be on the autism spectrum. This quote does not seem directly focussed on a need to fit in, more of a need to be understood or accepted for who they were. However this may have been more apparent to the researchers who were immersed in the data. It is important to note that only limited information was given about the data analysis procedure in this study so it is unclear how such themes arose. This wish to be treated the same as peers, however feeling different from others at school, came through as a theme in two other papers (4, 7), however direct evidence was again not provided to support this. Being made to feel different in the school environment may vary between schools as some may have strong inclusion procedures and have created an environment tolerant of difference. It may also be shaped by the number of other children with diverse needs in school. A qualitative meta-synthesis on the mainstream school experiences of autistic pupils concluded that many pupils felt different to their peers in school (Williams et al., 2017), suggesting however that this feeling was consistent across multiple school settings.

1.4.1 Conclusion

In conclusion, noise in the school environment was the most prevalently described source of anxiety for autistic pupils. Both the behaviour of others in school and the social identity shaped by peers in school were also associated with feelings of anxiety for autistic pupils. Aspects of the learning environment such as transitions, subjects, homework, handwriting, and the need to achieve academically were all associated with feelings of anxiety, although the research in this latter category was, overall, more limited and of lower quality.

Overall, sensory sensitivities, social and environmental factors and the presence of autism related stressors seemed to have utility in understanding the aspects of secondary school which caused feelings of anxiety for autistic pupils, supporting both the intolerance of uncertainty model of anxiety (Boulter et al., 2014) and the model by Wood and Gadow (2010).

1.4.2 Future directions

None of the included studies *directly* asked autistic pupils about the elements of the school environment that may lead to feelings of anxiety, and future research should look to explore this directly. Future research should also look to address the limitations of the research discussed in this literature review such as ensuring methods are replicable, and that the recruitment procedure is appropriate to address the aims of the research. If research is looking to identify the causes of anxious affect in mainstream secondary schools for autistic pupils, researchers should look to recruit all autistic participants within a setting, providing clear reasoning for non-participation. This is to avoid a recruitment bias where only those who see utility in taking part in research on anxiety in secondary school are included in the sample, or those who feel high levels of anxiety avoid taking part because they feel anxious about participation.

It is important that researchers explore using different tools to elicit views and voice, for example photo-elicitation as utilised in two papers discussed (5, 10). Research has highlighted how many autistic children and adolescents find it difficult to engage in traditional consultation methods, particularly finding difficulty with open choice questions and the presence of unknown adults, and that visual methods aid communication (Preece, 2002). Further research highlighted how social communication difficulties can be a barrier in engagement in research for autistic children and adolescents, and highlighted how photographs taken by participants can support this (Beresford, Tozer, Rabiee, & Sloper, 2004).

Additionally, whilst both the model proposed by Wood and Gadow (2010) and the intolerance of uncertainty model of anxiety in autism (Boulter et al., 2014) fit with the findings of this review, neither model has been directly tested in relation to school. Researchers should look to test whether the presence of social and environmental challenges in school increase intolerance of uncertainty, and subsequently increase anxious affect for autistic pupils. Researchers should also seek to identify if autism related stressors including social confusion, peer rejection, prevention of preferred behaviours, and the number of adverse sensory experiences in the environment predict anxious affect.

Chapter 2 Empirical Paper An exploration of how the secondary school experience contributes to elevated anxiety levels for adolescents on the autism spectrum

2.1 Introduction

Autism Spectrum Disorder (commonly abbreviated to 'ASD' or 'autism') is a term coined in the DSM-5 (APA; American Psychiatric Association, 2013) to encompass a spectrum of conditions previously known as autistic disorder, Asperger's, childhood disintegrative disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) (APA, 1994). 'Autistic' is identified as the preferred term by the autistic community, along with 'person with autism' and 'on the autism spectrum' (Kenny et al., 2016)[2]. Globally, 1 out of 132 individuals were estimated to be on the autism spectrum in 2010 (Baxter et al., 2015). The prevalence of individuals on the autism spectrum in the USA rose from 1.25% between 2011-2013, to 2.24% of the population in 2014 (Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). The prevalence in the UK was estimated to be between 0.38% of boys and 0.08% girls annually between 2004-2010 (Taylor, Jick, & MacLaughlin, 2013), to 1.7% seen in a 2008-2009 cohort study (Russell et al., 2014).

Individuals with autism are typically identified by a spectrum of strengths and difficulties with both social communication and restricted and repetitive behaviours (APA, 2013). Social communication challenges outlined in the DSM-5 include differences in the use of and interpretation of nonverbal behaviours such as eye-contact, gestures and facial expressions, and difficulties sharing interests and others' emotions. This can also include a reduced ability to flexibly adjust behaviour to a context, and a tendency to understand language literally, causing difficulties with sarcasm and metaphors. The second area of difference outlined in the DSM-5 surround restricted and repetitive behaviours which include consuming or intense interests, and a need for sameness where changes to routine and transitions are challenging. This area can also include repetitive speech, including a preference for certain phrases or echolalia, and a need for

[2] All three terms will be used interchangeably to respect the differing preferences of members of the autistic community.

routine and repetition in play. Autistic individuals may also show increased sensitivity to sensory stimuli including touch or pain, sounds, smell and visual triggers including lights or movement.

2.1.1 Anxiety and autism

Researchers have been interested in the prevalence of anxiety for children and adolescents on the autism spectrum, and van Steensel and colleagues have carried out two meta-analyses to systematically assess the literature in this area. The most recent of these meta-analyses reported that across a diverse range of measures in 83 research articles, autistic children and adolescents showed significantly higher levels of anxiety compared with typically developing (TD) children (van Steensel & Heeman, 2017). This paper concluded that high functioning autistic adolescents were particularly at risk of developing an anxiety disorder. The first of these meta-analyses focussed on prevalence of the specific anxiety disorder presented (van Steensel et al., 2011). The analysis showed that just under 40% of the autistic children and adolescents included would be classified as meeting the criteria for an anxiety disorder, most commonly specific phobia or social anxiety disorder. The DSM-5 (APA, 2013) describes specific phobias as feelings of anxiety around certain situations, for example medical procedures or objects including animals. Social anxiety disorder is categorised in the DSM-5 as an excessive and persistent fear of social situations which may include new people, or a fear of embarrassment or humiliation causing distress and avoidance. In addition to specific phobias and social anxiety disorder, further research identified generalised anxiety disorder and separation anxiety as amongst the most severe anxiety disorders experienced by a sample of children and adolescents with autism (Kerns et al., 2014). The DSM-5 defines generalised anxiety disorder as disproportionate worry across many different situations which is unmanageable and impacts upon daily functioning. Separation anxiety disorder relates then to fears around leaving a figure of attachment, such as a parent or carer, because of worries around something bad happening to this person when they are not together, such as being hurt. Further research has highlighted additional sources of anxiety that are seemingly unique to autistic individuals and not captured by the criteria above. These sources of anxiety seem to vary between individuals but can include specific unusual phobias, for example of coughing, or the 'happy birthday' song (Kerns et al., 2014). Additional areas identified include anxiety around routines, change, or restricted interests, social anxiety without fear of negative evaluations, and sensitivity to sensory stimuli (Kerns & Kendall, 2012; Ollendick & White, 2012).

Increased anxiety symptoms have been associated with a reduced quality of life for autistic children and adolescents, which has been identified across subscales including pain and physical discomfort, mobility, self-care and engagement in daily activities (van Steensel, Bögels, & Dirksen, 2012). Further research has shown similar associations between anxiety symptoms and

psychosomatic symptoms in a sample of autistic children and adolescents (Williams et al., 2015). Anxiety symptoms were associated with sleep disturbance as well as gastrointestinal symptoms including pain, nausea, and bloating.

2.1.2 Intolerance of uncertainty (IU) and autism

There has been an increase in research over the past decade focussing on the mechanisms that underlie the vulnerability individuals with autism have to experiencing high levels of anxiety, with the view to inform effective interventions and improve quality of life.

Intolerance of uncertainty (IU), worries associated with ambiguity and avoidance of novelty are features associated with anxiety in TD populations and have been argued to be collectively characterised by a superordinate construct "fear of the unknown" (Carleton, 2016, p.31). Links between IU and anxiety have been developed over the last decade (Behar, DiMarco, Hekler, Mohlman, & Staples, 2009; Dugas et al., 2007), stemming from models of anxiety that focus on behavioural inhibition (a temperamental style characterised by increased negative affect and avoidance of novel and unfamiliar situations, e.g., Kagan, Reznick, Clarke, Snidman, & Garcia-Coll, 1984) as a risk factor for anxiety. In addition, IU is a core construct within theoretical frameworks associated with generalised anxiety and worry and where ambiguous, uncertain or unexpected situations are distressing, and lead to negative cognition and avoidance (Birrell, Meares, Wilkinson, & Freeston, 2011). While IU has been proposed as a key component in the development of generalised anxiety disorder (Dugas, Gagnon, Ladouceur, & Freeston, 1998), further research has demonstrated links across anxiety disorders including panic disorder (Boswell et al., 2013) and social anxiety disorder (Carleton et al., 2012; McEvoy & Mahoney, 2012; Norr et al., 2013). This has been supported by research with adolescents demonstrating IU as a key distinguishing factor between children who do and do not meet the criteria of an anxiety disorder (Comer et al., 2009), and between adolescents reporting a moderate or high level of worries (Laugesen, Dugas, & Bukowski, 2003).

Building on the identified anxiety around routine, uncertainty and challenges associated with change for children and adolescents with autism (Kerns et al., 2014; Kerns & Kendall, 2012; Ollendick & White, 2012), researchers have proposed that IU is a core mechanism in the onset and maintenance of anxiety and autism (Boulter et al., 2014; Chamberlain et al., 2013; Hodgson et al., 2016; Neil et al., 2016; Rodgers et al., 2016; Wigham et al., 2015). For example Boulter et al. (2014) used data from over 200 children and adolescents aged 8-18 years across the UK and USA, to investigate the relationship between child and parent reported IU and anxiety for typically developing (TD) and autistic children and adolescents. The results demonstrated that autistic

children and adolescents showed higher anxiety levels and higher IU than the TD control group. They also noted that increases in anxiety were a result of increases in IU regardless of diagnosis. Using mediational analysis, the researchers determined that IU explained the increased levels of anxiety presented in autistic children and adolescents, whereby a diagnosis of autism increased IU, which in turn increased anxiety. The researchers proposed a theoretical model of anxiety in autism (Figure 4) where IU was proposed to mediate between anxiety and three areas: sensory sensitivities, social and environmental factors, and difficulties with emotion processing and rigidity of thought. This framework also suggests that IU underpins (i.e., increases) restricted and repetitive behaviours evident for individuals with autism.

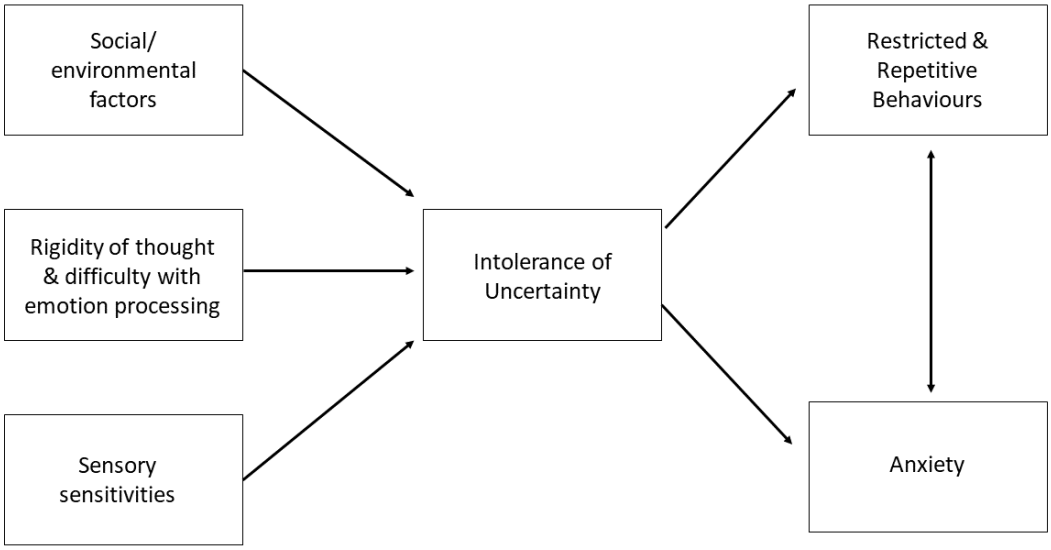

Figure 4. A proposed model of anxiety in autism by Boulter et al. (2014) (p. 1399)

Research has shown support for construct of IU by demonstrating a significant positive association between both parent and self-reported IU and anxiety for 13 autistic adolescents and young adults aged 13-20 (Joyce, Honey, Leekam, Barrett, & Rodgers, 2017). Children and adolescents aged 7-16 with a diagnosis of autism also showed elevated IU and anxiety compared to typically developing control children (Vasa et al., 2018). This sample also demonstrated a significant positive correlation between IU and autism, even when anxiety levels were controlled for. Furthermore, IU was found to significantly predict anxiety for autistic young adults aged between 14-24, mediating between emotion regulation and anxiety (Cai, Richdale, Dissanayake, & Uljarević, 2018).

There is research to provide support for the direction of the path from sensory sensitivities to anxiety for individuals with autism. One longitudinal study with toddlers with a diagnosis of autism showed that sensory sensitivity significantly predicted changes in anxiety levels a year

later, over and above parent reported anxiety, autism symptom severity and non-verbal ability (Green, Ben-Sasson, Soto, & Carter, 2012). This direction was supported by research showing increased activation in areas of the brain responsible for emotion regulation and response to threat following aversive sensory stimuli for autistic adolescents and sensory sensitivity, compared to both those without sensory sensitivity and TD adolescents (Green et al., 2013).

To directly test part of the IU model proposed by Boulter et al. (2014), Wigham et al. (2015) used mediational analysis to determine if there was an indirect path from sensory sensitivities through IU to anxiety. Just over 50 autistic children and adolescents aged 8-16 were recruited from local autism research databases and measures of autistic traits, anxiety, sensory processing, IU were taken. Results of the mediation analysis supported the model proposed by Boulter et al. (2014) demonstrating significant indirect pathways from sensory sensitivity to increased IU, then increased anxiety.

In contrast, researchers sought to explore an alternative path where an IU meant that ambiguous sensory information was less tolerable, thus leading to sensory sensitivities and anxiety (Neil et al., 2016). The study again found that the parent reported anxiety and IU was higher for a community-based sample of children and adolescents aged between 6-14 with a diagnosis of autism than those who were typically developing. There was also a significant indirect path from autism diagnosis to IU then anxiety levels supporting Boulter et al. (2014). However, in contrast to the direction proposed by Boulter et al. (2014), using mediational analysis they concluded that IU significantly predicted sensory sensitivities even when anxiety was controlled for.

2.1.3 Exploring IU and the school environment

Research has shown that young people who experience elevated anxiety also show difficulties in a school environment. A high proportion of children who refuse to attend school meet the criteria for separation anxiety disorder (Kearney & Albano, 2004). In addition, elevated levels of trait anxiety have been found to be negatively associated with attendance in adolescence (Richards & Hadwin, 2011), where reasons for non-attendance were most clearly linked to challenges in the social environment in school. A review of the literature has demonstrated that for typically developing individuals, stressful life events can influence both the onset and experience of anxiety disorders (Faravelli et al., 2012).

The education system in the UK can vary depending on the setting the child attends. For example, pupils attending mainstream school in the UK will typically attend primary school with one classroom, set of peers and teacher throughout the school day, transitioning to secondary

school age 11 with a vastly different environment. Those who are home-schooled or attending the same special needs school aged 4 to 16 may have a different experience of school which may not compare to those attending a mainstream environment.

School is recognised to be a challenging place for autistic children. In the UK, children with autism were given exclusions from school on just over 9,000 occasions during the 2015-2016 academic year, which was nearly a 25% increase from the previous academic year (Department for Education, 2017a). A study looking at over 200 children and adolescents aged 9 to 16 in Norway found that autistic children with no co-occurring intellectual disability were more likely to verbally or physically refuse to attend school, and do so for longer than typically developing children (Munkhaugen, Gjevik, Pripp, Sponheim, & Diseth, 2017). A smaller sample of children and adolescents with autism who showed increased verbal and physical school refusal behaviour also showed increased withdrawn and depressed symptoms, anxious symptoms, and somatic symptoms (Munkhaugen et al., 2017).

Research has noted that specific elements of the mainstream secondary school environment cause feelings of anxiety in young people with autism. This includes sensory experiences such as sudden and adverse noises (Connor, 2000; Hill, 2014; Howe & Stagg, 2016; Humphrey & Lewis, 2008a; Lamb et al., 2016; Marks et al., 2000; Saggers, 2015; Sciutto et al., 2012) and crowds of people (Hebron & Humphrey, 2014; Hill, 2014; Lamb et al., 2016; Saggers, 2015). Aspects of the social environment in school including wanting to fit in but feeling different or isolated (Carrington & Graham, 2001; Hebron & Humphrey, 2014; Humphrey & Lewis, 2008a), bullying (Hebron & Humphrey, 2014) and disruptive behaviour from peers (Humphrey & Lewis, 2008a) were also identified as sources of anxiety for mainstream secondary school pupils with autism. Similarly aspects of the learning environment in school including transitions between lessons (Marks et al., 2000), handwriting (Saggers, 2015), and academic pressure (Clarke et al., 2017; Hill, 2014; Marks et al., 2000; Poon et al., 2014; Saggers, 2015) were also sources of anxiety for autistic adolescents attending mainstream schools. Whilst sensory experiences, social and environmental factors have been identified as key sources of anxiety in school, research is yet to focus on the school environment within the IU model proposed by Boulter et al. (2014).

2.1.4 Aims

This study aims to explore how the secondary school experience contributes to elevated anxiety for a school based sample children with autism and following the IU framework (Figure 4) proposed by Boulter et al. (2014). Specifically, it tested several pathways within the model that

highlight that IU may play a part mediating the link between sensory sensitivity and social and environmental challenges with anxiety across the learning and social environments in school.

2.1.5 Hypotheses

Following previous research (Kerns et al., 2014; van Steensel et al., 2011) it was anticipated that around half of autistic adolescents in this sample would show elevated anxiety levels.

Consistent with previous research (Boulter et al., 2014; Neil et al., 2016), it was anticipated that increased autistic traits would predict increased anxiety symptoms, indirectly through parent and child reported IU. Consistent with the theoretical framework (Figure 4) proposed by Boulter et al. (2014), it was anticipated that increased sensory sensitivity, increased challenges in the school social and learning environment, and poorer teacher reported social skills would all indirectly predict increased anxiety symptoms through parent and child reported IU.

2.2 Method

2.2.1 Inclusion and exclusion criteria

Participants were required to be in years 7, 8 or 9, thus aged 11-14, attending a mainstream secondary school. Participants were required to have an autism diagnosis on school records, and schools were asked to identify pupils with a formal diagnosis that would be recognised by the Local Authority. This would typically require a multi-disciplinary assessment following the NICE guidelines for autism assessment (National Institute for Health and Care Excellence, 2017) Participants were excluded if they did not have an IQ above 70 due to the use of questionnaires as a data collection method. Based on this, no participants were excluded from the study.

2.2.2 Participants

All secondary schools in one Local Authority in the South East of England were emailed details of the study and invited to take part. Out of the 53 schools contacted in this Local Authority, 11 replied expressing an interest and 9 consented to take part and sent out consent forms to eligible pupils. In addition to this, 21 mainstream secondary schools across a further 4 Local Authorities (selected due to either close proximity to the schools recruited, or through existing connection with the researcher or university). Out of this 21, 5 schools responded indicating an interest in taking part, and 2 consented to take part sent out consent forms to eligible pupils.

In total, 144 consent forms were sent out and 30 were returned (See Appendix D for full details). Full data was collected for 30 adolescents (Male = 20, Female = 10) from 10 schools. Full sets of parent data were received for 27 participants, with an additional parent returning all but one measure (the Short Sensory Profile). The school measures were provided for 28 out of the 30 pupils. One identified staff member was not in school on the data collection day and the measure was left for them to complete but was not returned. A second staff member did not give a response for 5 items, and the response circled was unclear for a further 8 out of 46 items so the measure was not used in the analysis.

The final sample consisted of 8 participants in year 7, 14 participants in year 8, and 8 participants in year 9. The participants were aged between 11.3-14 years (*M* = 12.67, *SD* = 0.79), and cognitive ability ranged between 75-127 (*M* = 98.80, *SD* = 13.54). Whilst ethnicity data was not provided for two participants, 25 participants identified as White British, 1 Asian/British Indian, 1 mixed white and Asian, and 1 mixed white and black Caribbean. There were 10 participants with an Educational Health and Care Plan (EHCP; a legal document describing and funding additional support in schools in England), 18 without such plan, and this information was not provided for 2 participants. Attendance was provided for 29 of the 30 participants with a Mean of 96.3% ranging from 84.2-100%. The number of years since autism diagnosis was provided for 25 of the 30 participants with a mean of 4.58 years and a range of 0 to 10 years since diagnosis.

2.2.3 Measures

2.2.3.1 Cognitive ability

The Wechsler Abbreviated Scale of Intelligence – Second Edition (WASI-II; Wechsler, 2011) was used to measure cognitive ability. The vocabulary subtest of the WASI-II gives an indication of verbal ability. This subtest requires participants to give a description of a word read out by the researcher which measures use of and understanding of vocabulary. The matrix reasoning subtest gives an indication of non-verbal ability by requiring participants to choose a picture to fit an incomplete pattern from an array. This looks at ability to recognise relationships between pictures and sets of shapes, and use rules to problem solve. A measure of intelligence was calculated by summing the t-score on both subscales then using the manual to determine Full Scale IQ from the two subtests (FSIQ-2; *M* = 98.80, *SD* = 13.54).

2.2.3.2 Autistic traits

The parent report of The Autism-Spectrum Quotient (AQ) adolescent version (Baron-Cohen, Hoekstra, Knickmeyer, & Wheelwright, 2006) and the total score was used to determine autistic traits. The adolescent version of the AQ gives a measure of autistic traits in high functioning children aged 12-15 years through caregiver report. Caregivers respond to 50 items on a four-point Likert Scale (definitely agree to definitely disagree) to measure functioning across five areas: social skills, attention switching, attention to detail, communication and imagination. Each item is scored as 0 or 1, giving a possible range of total scores from 0 to 50. Using a clinical cut-off where scores greater than or equal to 30 were considered consistent with the autistic profile, Baron-Cohen et al. (2006), reported strong sensitivity and specificity for high-functioning girls (100%) and boys (86.8%) with autism, high test-retest reliability (r = .92) and acceptable internal consistency and (α= .79). The internal consistency of the total score for this sample was good (α= .88). There were four items missing from three questionnaires returned, with no questionnaire having more than two items missing. Missing data was handled by dividing the average of the subscale score by the number of items scored and using this average score.

2.2.3.3 Sensory processing

The Short Sensory Profile 2 (SSP-2; Dunn, 2014) is a shortened version of the Sensory Profile 2, and is an updated version of the Sensory Profile tool (McIntosh, Miller, Shyu, & Dunn, 1999). The SSP-2 consists of 34 items for caregivers to report the frequency of atypical responses to sensory experiences for participants aged 3-14. Internal consistency of the total and subscale scores for the original SSP is considered good (α = .70 – .90; McIntosh, Miller, Shyu, & Dunn, 1999) and internal consistency in parents of children with autism has been shown to be excellent (α = .93; Neil, Olsson, & Pellicano, 2016). Whilst data has not been provided for the updated profile, the authors report an increase in reliability and validity (Dunn, 2014). Each item was scored on a Likert Scale from 0 (does not apply) to 5 (almost always) giving a total range from 0-170 across four subscales: seeking (the extend a child obtains input), avoiding (the extent to which a child is bothered by input), sensitivity (the extent a child detects input) and registration (the extent a child misses input). These four subscales were collapsed into low threshold for sensory input (sensitivity and avoiding) and a high threshold for sensory input (seeking and registration), as outlined in the manual (Dunn, 2014). Internal consistency of both were good to excellent for this sample (High threshold α =.89, low threshold α = .90). High scores on the low threshold measure would correspond with increased sensitivity to sensory input, thus sensory sensitivity, and this was the focus of this current study. One questionnaire was missing a response for two items from different subscales, and a second questionnaire was missing one item. Missing data was handled

by dividing the average of the subscale score by the number of items scored and using this average score.

2.2.3.4 Social skills

Social skills were determined using the Social Skills Improvement System Rating Scales (SSiS-RS) – teacher version (Gresham & Elliott, 2008). This tool is used by school staff to record the frequency of behaviours related to the social skills of children aged 3-18 in school. The social skills scale of the tool contains 46 items covering seven subscales: communication, cooperation, assertion, responsibility, empathy, engagement, and self-control. Items were rated on a four-point Likert scale ranging from 0 (Never) to 3 (Almost always) with total scores ranging from 0-138, with total scores being used for analysis and higher scores indicating greater social functioning observed in school. Research demonstrates excellent internal consistency (α= .97) and high test-retest reliability (r = .82) (Gresham, Elliott, Vance, & Cook, 2011), and the internal consistency for this current sample was excellent (α = .90). Four questionnaires were returned with missing items, two questionnaires were missing four responses each, and two questionnaires were missing one response each. The total number of missing responses allowed for the questionnaire is specified in the manual as four, and missing items were scored according to the manual. Six items across three questionnaires had a circle across two numbers making it unclear which was circled, and these were handled by choosing which of these was closest to the subscale average.

2.2.3.5 Anxiety symptoms

Anxiety symptoms were measured using the Youth Anxiety Measure for DSM-5 (YAM-5-II & II) – parent report (Muris et al., 2017). The YAM-5 is a new scale created in collaboration with researchers and clinicians in the field of childhood anxiety to map directly on to the DSM-5 diagnostic criteria for anxiety disorders. The tool is designed to measure symptoms of anxiety in young people aged 8-18 years The YAM has two scales, the first (YAM-5-I) containing 28 items covering anxiety disorders with subscales of separation anxiety disorder, social anxiety disorder, selective mutism, panic disorder and generalised anxiety disorder with a possible range of scores from 0-84. Part two (YAM-5-II) contains 22 items to look at specific phobias with a total range of scores from 0-66. All items were reported on a four-point Likert scale from 0 (never) to 3 (always) with higher scores indicating greater anxiety symptoms. Total score can be calculated for each subscale, domain, and a total score. For this current study, both the total anxiety disorders score (YAM-5-I) and the total phobias score (YAM-5-II) were used as a measure of anxiety symptoms. Research using parent report for a clinically referred sample of youth has demonstrated acceptable to excellent internal consistency for YAM-5-I (α = .91) and YAM-5-2 (α = .77), with

good parent-child agreement YAM-5-I (r = .69) and YAM-5-II (r = .7) (Muris et al., 2017). Because of this, the parent report will be used to minimise the time participants spend out of class. In this current study, the internal consistency for both the YAM-5-I (α = .95) and YAM-5-II (α = .93) version were excellent. There was one item missing a score on one questionnaire, this was handled by dividing the average of the subscale score by the number of items scored and using this average score.

2.2.3.6 Intolerance of uncertainty (IU)

The full version of the Anxiety Scale for Children with Autism Spectrum Disorder (ASC-ASD) (Rodgers et al., 2015) were completed by both parent and adolescent. The tool is aimed at autistic children and adolescents aged 8-16, and contains 24 parallel items on both tools covering four sub-scales: separation anxiety, uncertainty, performance anxiety, and anxious arousal. Each item was rated on a four-point Likert scale from 0 (never) to 3 (always). The total anxiety score (range 0-72, with scores ≥ 20 indicating elevated anxiety) is reported. The scale has good internal consistency (αs >.90) and good test-retest reliability (rs > .80) for parent and child (Rodgers et al., 2016) and in the current study internal consistency was good (αs >.90) for parents and adolescents. There were six items missing from three questionnaires which were handled by dividing the total by the number of items completed.

The uncertainty subscale of this tool was used in analysis. It consists of eight items selected from the Intolerance of Uncertainty Scale (Freeston, Rhéaume, Letarte, Dugas, & Ladouceur, 1994), and was used as a measure of intolerance of uncertainty in the sample. Previous research showed good to excellent internal consistency for this subscale for both parent (α = .91) and child (α = .88 child) report. Internal consistency for this sample was high for both the parent (α = .92) and child (α = .84) uncertainty subscale, and parent-child agreement was significant (ρ = .51, p =.005).

2.2.3.7 School environment factors

Social and environmental challenges in school were measuring using the tool “Mapping the Landscape of your School” (Ripley, 2015). This resource includes a questionnaire for participants to rate the level of anxious affect they feel about different aspects of the social and learning environment they experience at school. The social environment is explored by 15 items related to social experiences outside of learning in the classroom (for example “lining up to go into the classroom before a lesson” and “changing for PE”). The learning environment is explored by 30 items focussed on working in class (for example “asking a teacher for help when I have not understood something” and “when I have to stop what I am doing before I am finished”). Each

item is scored on a five-point Likert scale from 1 (I avoid this if I can), to 2 (I am very anxious about this) to 3 (I feel anxious/uncomfortable about this) to 4 (I feel comfortable about this) to 5 (I enjoy this). A score was obtained for both the social (range = 15-60) and learning environment (range = 30 – 150). High scores were indicative of greater enjoyment of these experiences in school, and low scores indicative increased concerns and worries in the environment. The internal consistency for this measure was good for the social scale *(α* =.89), and excellent for the learning scale *(α* = .92).

2.3 Results

2.3.1 Data Analysis Plan

Firstly, a percentage of participants who scored above suggested clinical cut-off on both anxiety measures will be calculated. Correlational analysis will be carried out to explore associations between key variables. Explorations of the distribution of data via histogram, normal Q-Q plots, detrended Q-Q plots, box plots and Shapiro Wilk showed that the data did not appear normally distributed for all factors (Disorders: W = .91, p = .034; Parent Uncertainty: W = .90, p = .021). There were also outliers for some variables. Due to the sample size, Spearman Correlation Coefficient was chosen to be more suitable than Pearson's analysis to overcome these violations of assumptions (de Winter, Gosling, & Potter, 2016). The Spearman correlations between variables are outlined in Table 5.

PROCESS v3 (Hayes, 2017) was used to test the total direct and indirect effects via mediating factors from autistic traits to anxiety symptoms (disorders or phobias) via child reported or parent reported IU. A second mediational analysis tested the pathway from sensory sensitivity to anxiety symptoms (disorders or phobias) via child reported or parent reported IU. A third mediational analysis tested the pathway from social skills to anxiety symptoms (disorders or phobias) via child reported or parent reported IU. A fourth mediational analysis tested the pathway from school social environment factors to anxiety symptoms (disorders or phobias) via child reported or parent reported IU. A final mediational analysis tested the pathway from school learning environment factors to anxiety symptoms (disorders or phobias) via child reported or parent reported IU.

2.3.2 Descriptive statistics

Descriptive statistics for the sample are outlined in Table 4. Table 4 shows that elevated levels of anxiety ranged from 57.14%-66.67% across measures. Over 75% of the participants

showed levels of autistic traits in line with the cut-off on the measure, and 81.48% of the sample indicated elevated levels of sensitivity to sensory input.

Further analysis considered whether there were any gender differences for each variable. This showed no significant difference between male and female for anxiety disorder ($t(26) = -1.94$, $p = .063$) or phobia symptoms ($t(26) = -1.77$, $p = .088$). There were no gender differences observed for autistic traits ($t(26) = 0.32$, $p = .975$), social skills ($t(26) = -1.39$, $p = .176$), social environment factors ($t(28) = 1.89$, $p = .069$), learning environment factors ($t(28) = 1.87$, $p = .072$) or child reported IU ($t(28) = -1.43$, $p = .163$). There were significant gender differences for parent reported IU ($t(26) = -2.31$, $p = .029$) where parents reported significantly lower IU for males ($M = 9.42$, $SD = 5.96$) compared with females ($M = 15.22$, $SD = 6.70$). There were also significant gender differences for sensory sensitivity ($t(25) = -2.84$, $p = .009$), where parents reported significantly lower sensitivity for males ($M = 57.94$, $SD = 14.83$) than females ($M = 74.44$, $SD = 12.89$).

Table 4.

Data Summary Table

	n	*M (SD)*	Sample range	Possible range	Elevated scores	n elevated scores (% of sample)
Age (years)	30	12.67 *(0.79)*	11.3-14.0	11-14	-	-
Cognitive ability						
FSIQ-2	30	98.80 *(13.54)*	75-127	-	-	-
Autistic traits						
The Adolescent AQ (Parent)	28	35.07 *(7.98)*	19-49	0-50	30≤	22 (78.6%)
Anxiety						
YAM-1 Disorders (Parent)	28	24.39 *(16.72)*	2-65	0-84	18*≤	17 (60.71%)
YAM-2 Phobias (Parent)	28	19.89 *(14.95)*	1-59	0-66	16*≤	16 (57.14%)
ASC-ASD (Parent)	28	26.5 *(16.36)*	5-65	0-72	20≤	16 (57.14%)
ASC-ASD (Child)	30	26.80 *(16.07)*	0-66	0-72	20≤	20 (66.67%)
Intolerance of uncertainty						
Parent	28	11.29 *(6.68)*	3-23	0-24	-	-
Child	30	9.83 *(5.41)*	0-22	0-24	-	-
Sensory processing						
SSP2 (parent)						
Sensory sensitivity	27	63.44 *(16.06)*	33-95	0-95	48**≤	22 (81.48%)
High threshold		42.52 *(15.45)*	10-68	0-75	35**≤	17 (62.96%)
Social skills						
SSiS (teacher)	28	75.46 *(15.04)*	42-102	0-138	-	-
School environment						
Social environment (Child)	30	53.5 *(12.16)*	24-73	15-75	-	-
Learning environment (Child)		97.33 *(20.59)*	54-137	30-150	-	-

* based on mean YAM-I+II scores for clinically anxious group in previous research (Simon, Bos, Verboon, Smeekens, & Muris, 2017)
** based on adding together AV + SN threshold, and RG + SK threshold (Dunn, 2014)

Considering associations between parent and child report anxiety symptoms with other measured constructs, Table 5 shows that parent reported anxiety disorder and phobias were positively correlated. In addition, it highlights that parent reported anxiety disorder symptoms were significantly negatively correlated with IQ, indicating increased anxiety symptoms with a decrease in cognitive ability. It also shows that parent reported anxiety was significantly linked to sensory sensitivity; as anxiety increased, sensitivity towards sensory input increased. There was also a significant negative correlation between parent reported anxiety disorders and social

environment factors indicating higher anxiety symptoms were associated with increased anxiety about social elements of the school environment.

Increased autistic traits were significantly associated with increased parent and child reported IU, and increased sensory sensitivity. Increased parent reported IU was significantly associated with increases children reported IU, and with increased anxiety disorder symptoms and sensory sensitivity. Increases in parent reported IU was also significantly associated with lower social environment factors, meaning an increased number of challenges in the social environment. Child reported IU was significantly negatively correlated with both social and learning environment factors in school meaning higher IU was associated with increased challenges in the social and learning environment. Sensory sensitivity and high threshold scores were significantly correlated. Only high threshold for sensory input was significantly negatively correlated with learning environment factors. This meant that a high threshold for registering sensory input was associated with increased anxiety in the learning environment. Both social and learning environment factors in school were significantly positively correlated.

Table 5. Spearman's Rank correlations

	1	2	3	4	5	6	7	8	9	10	11
1. IQ	--										
2. Autistic traits	-.198	--									
Anxiety symptoms											
3. Disorders	-.413*	.172	--								
4. Phobias	-.277	.266	.617**	--							
Intolerance of uncertainty											
5. IU parent reported	-.260	.416*	.679**	.666**	--						
6. IU child reported	-.117	.412*	.367	.230	.511**	--					
Sensory processing											
7. Sensory Sensitivity	-.149	.388*	.420*	.445*	.498**	.308	--				
8. High Threshold	-.071	.144	.109	.254	.210	.215	.713**	--			
9. Social skills	-.185	-.144	-.154	.004	-.112	-.060	.159	.266	--		
School environment											
10. Social environment	.310	-.264	-.496**	-.308	-.521**	-.685**	-.207	-.177	.269	--	
11. Learning environment	.281	.010	-.223	-.109	-.311	-.570**	-.270	-.436*	.080	.731**	--

*. Correlation is significant at the 0.05 level (2-tailed); **. Correlation is significant at the 0.001 level (2-tailed).

2.3.3 Exploring pathways to anxiety

Following Boulter et al. (2014), a mediation model using PROCESS v3 (Hayes, 2017) through SPSS Statistical Package for Social Science Software, version 25 was carried out to explore both the direct effect between key independent variables (autistic traits, sensory sensitivity, school social and learning environment factors), and dependent variables (anxiety disorder and phobia symptoms), and the indirect effect through parent and child reported IU. The analysis used 95% confidence intervals and bootstrapping across the default 5000 resamples. Indirect effects between variables were determined by confidence intervals that did not cross 0, thus the possibility of no effect between variables. Completely standardised indirect effect sizes were then calculated and interpreted in line with the rule of thumb proposed by Cohen (1988). Only significant models are shown in Figures 5-9, see Appendix E for non-significant models.

2.3.4 Autistic traits and anxiety via IU

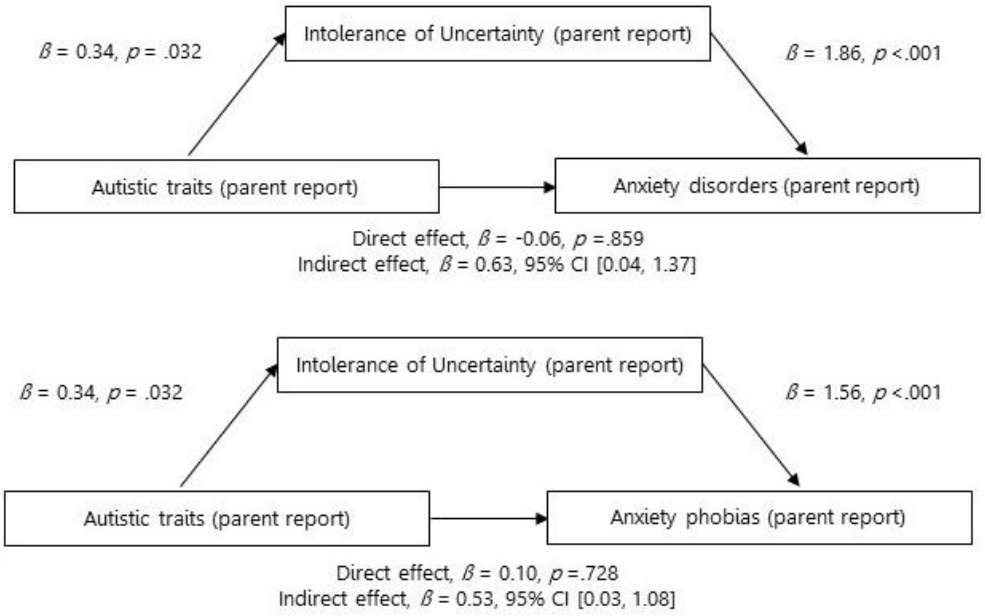

Figure 5. Autistic traits and anxiety via IU

There was a significant indirect effect of autistic traits on anxiety disorder and phobia symptoms through parent reported IU, and no direct effect (Figure 5). Using a standardised index of mediation, this represented a small effect for disorders (*ß* = .30, 95% BCa CI [0.02, 0.60]) and phobias (*ß* = .28, 95% BCa CI [0.02, 0.51]). This meant as autistic traits increased, parent reported IU increased, which was then associated with an increase in anxiety phobia symptoms. When the

model was reversed, the pathways were not statistically significant. There were no significant direct or indirect effects of autistic traits on disorder or phobia symptoms through child reported IU.

2.3.5 Sensory sensitivity and anxiety via IU

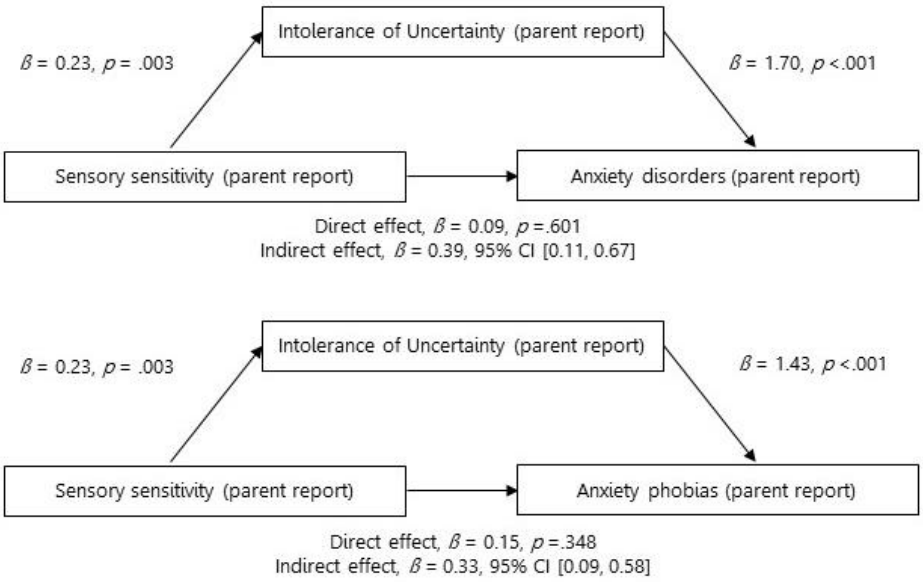

Figure 6. Sensory sensitivity and anxiety via IU

There was a significant indirect effect of sensory sensitivity on anxiety disorders and phobias through parent reported IU, and no direct effect observed (Figure 6). Using a standardised index of mediation, this represented a small effect for anxiety disorders (*ß* = .37, 95% BCa CI [.12, .57]) and phobias (*ß* = .35, 95% BCa CI [.11, .58]). This meant as sensitivity to sensory input increased, parent reported IU increased, which was then associated with an increase in both anxiety disorder and phobia symptoms. When the model was reversed, the pathways were not statistically significant. There were no significant direct or indirect effects of sensory sensitivity on symptoms of anxiety disorders through child reported IU. There was a significant direct effect of sensory sensitivity on phobia symptoms, but no significant indirect effect through parent reported IU.

2.3.6 Social environment factors and anxiety via IU

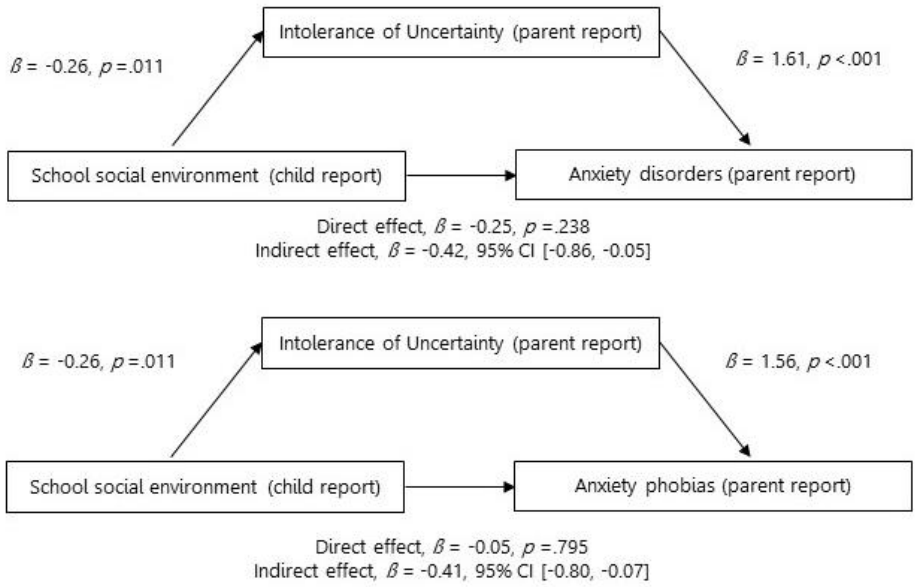

Figure 7. Social environment factors and anxiety via IU

There was a significant indirect effect of child reported school social environment on parent reported anxiety disorders and phobias through parent reported IU, and no direct effect (Figure 7). Using a standardised index of mediation, this represented a small effect for anxiety disorders (*ß* = -.31, 95% BCa CI [-.59, -.04]) and phobias (*ß* = -.33, 95% BCa CI [-.63, -.05]). This meant that as young people reported increased concerns and worries in the social environment, parent reported IU increased, which was then associated with an increase in both anxiety disorder and phobia symptoms. When the model was reversed, the pathways were not statistically significant. There were no significant direct or indirect effects of school social environment factors on symptoms of anxiety disorders or phobias through child reported IU.

2.3.7 Learning environment factors and anxiety via IU

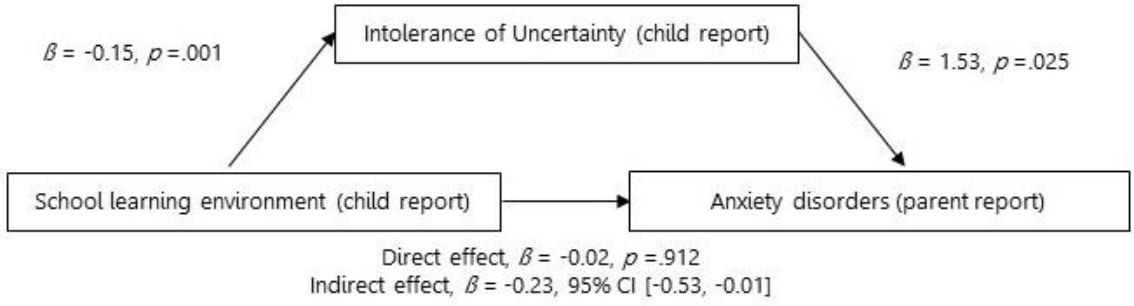

Figure 8. Learning environment factors and anxiety via IU

There was a significant indirect effect of child reported school learning environment on anxiety disorders through child reported IU. Using a standardised index of mediation, this represented a small effect (*ß* = .29, 95% BCa CI [-.64, -.02]). This meant that as young people reported increased concerns and worries in the learning environment, child reported IU increased, which was then associated with an increase in anxiety disorder symptoms. When the model was reversed, the pathways were not statistically significant. There were no significant direct or indirect effects of anxiety in the school learning environment on symptoms of anxiety disorders or phobias through parent reported IU, or between experiences in the school learning environment and phobia symptoms through child report IU.

The significant indirect pathways through IU are summarised below in Figure 9, along with beta coefficients for each pathway. Figure 9 also includes Spearman Correlation Coefficients between key variables.

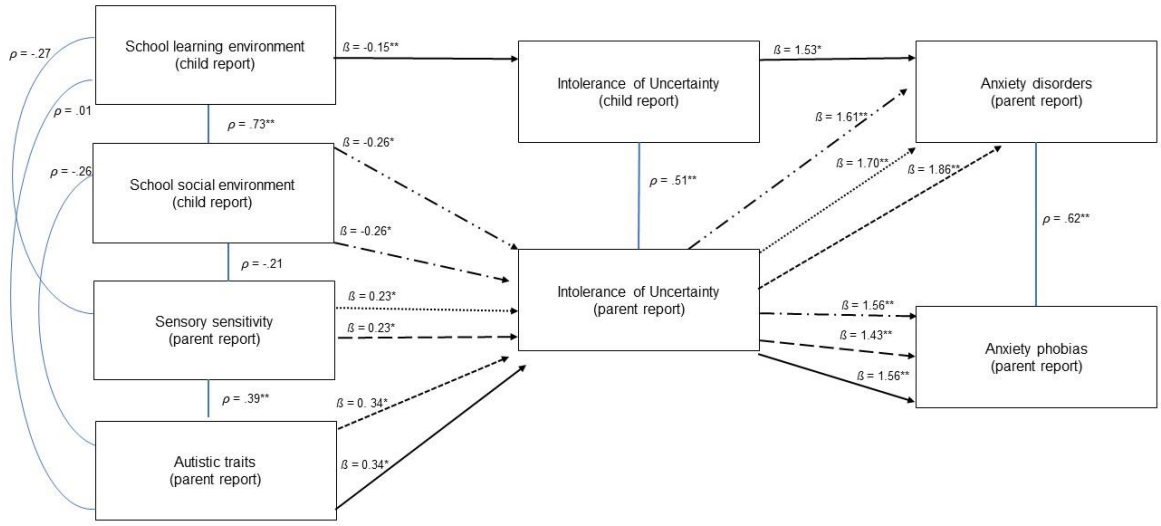

Figure 9. Summary of indirect effects highlighted by findings, and correlations between key variables. * is significant at p<.05 level, ** is significant at p<.001.

2.4 Discussion

The aim of this study was to demonstrate IU as a significant construct in understanding associations between sensory sensitivity and experiences in the social and learning environment with symptoms of anxiety disorders and phobias. It aimed to replicate and extend existing literature by using a school-based sample of autistic adolescents and focussing on sensory sensitivities and social and environmental factors that reflect both teacher reported social skills, as well as adolescent reported concerns and worries in the school environment.

There was evidence for indirect pathways from parent reported autistic traits and sensory sensitivities to symptoms of anxiety disorders and phobias through parent reported IU. There was also evidence for a significant indirect pathway from increased worries and concerns in the school social environment reported by adolescents, and increased parent reported symptoms of anxiety and phobias through parent reported IU. There was a further significant indirect pathway from worries and concerns in the school learning environment reported by adolescents to parent reported anxiety disorder symptoms through adolescent reported IU. These findings fit within the framework proposed by Boulter et al. (2014) of anxiety in autism.

2.4.1 Associations between variables

Over half of the participants that took part in this study reported elevated anxiety levels across both parent and child tools which measured symptoms of anxiety. The reported prevalence of elevated anxiety levels in this school-based sample ranged from 57-67% across the measures used, with child reported anxiety symptoms being the highest. Just over 80% of the school-based sample were reported by parents to have a higher level of sensory sensitivity than what would typically be expected on the Short Sensory Profile 2 (Dunn, 2014).

Previous research has found elevated anxiety levels in autistic children and adolescents both in a meta-analysis of research on the prevalence of anxiety (van Steensel et al., 2011) and a sample recruited through research pathways (Kerns et al., 2014). The current study extends these findings to demonstrate comparably high levels of anxious affect for autistic adolescents across multiple mainstream secondary schools. Similar findings around elevated levels of sensory sensitivities in the current study are comparable to existing literature on atypical sensory processing in children and adolescents with autism recruited through clinic settings (Green et al., 2013, 2015) and special school provisions (Joosten & Bundy, 2010). The importance of this statistic being supported within a mainstream secondary school setting would suggest these individuals have been functioning well and able to access the same learning environment as their

typically developing peers, despite elevated levels of anxiety and sensory sensitivities, as reported by parents.

The current study found a negative association between adolescent cognitive ability and parent reported symptoms of anxiety disorders. The literature shows mixed findings on cognitive ability and anxiety levels for children with autism. Some researchers suggest there is not an association (Kerns et al., 2014; Strang et al., 2012), whereas others have demonstrated a positive relationship where increases in ability are associated with increases in anxiety symptoms (Gotham, Brunwasser, & Lord, 2015; Mayes, Calhoun, Murray, & Zahid, 2011). In contrast, there is research to show a negative relationship between cognitive ability and separation anxiety in children with autism (Hallett et al., 2013). Whilst it is unclear why such differences have been found across the literature, it may be important to note that these studies did not control for the school environment meaning some participants may have been attending specialist settings, be home-schooled or attend mainstream settings. Having lower cognitive ability may or may not influence participants ability to access the curriculum in school depending on the setting they attend and the support in place, making this a potential confounding variable in any relationship observed.

2.4.2 Autistic traits and anxiety via IU

There was no significant association between parent report of autistic traits and symptoms of anxiety disorders and phobias, however there was a significant indirect pathway through parent reported IU. This would support previous research which does not demonstrate a direct link between autism symptom severity and anxiety (Strang et al., 2012). This is in line with research which has demonstrated that parent and child IU is responsible for the relationship between autism diagnosis and elevated anxiety levels (Boulter et al., 2014; Neil et al., 2016). Whilst this current study did not use a control group of TD adolescents, this study builds on the literature by demonstrating that increased autistic traits reported by parents, rather than discrete diagnosis categories, were associated with increased parent and child reported IU. The framework of anxiety in autism by Boulter et al. (2014) does not include autistic traits as a factor, however does include emotional processing difficulties and rigidity of thought which was not measured in this current study. It is possible that items on the measure of autistic traits used in this current study, the AQ (Baron-Cohen et al., 2006), tap into this construct. Possible items could be taken from the attention switching subscale, for example “frequently gets so strongly absorbed in one thing that s/he loses sight of other things” or the communication subscale, such as “knows how to tell if someone listening to him/her is getting bored.” Research should look to explore whether “rigidity of thought and difficulty with emotion processing”(Boulter et al., 2014) has a significant

indirect pathway to anxiety through IU, or if this captures the same construct as autistic traits found in this current study.

2.4.3 Sensory sensitivity and anxiety via IU

There were significant associations between parent reported sensory sensitivity and symptoms of anxiety disorders and phobias, and parent reported IU. This would support research showing that there is an association between symptoms of anxiety and sensory processing atypicalities (Green et al., 2013, 2012). However when sensory sensitivity and anxiety were included in the mediational analysis with parent reported IU, there was no significant direct effect between the two variables, and the indirect pathway through IU was instead significant. This indirect pathway through parent reported IU supports that proposed by Boulter et al. (2014) and since supported by mediation analysis using parent report by Wigham et al. (2015). This would suggest that this relationship between sensory sensitivities and anxiety symptoms could be better explained by IU. As parent reported sensitivity to sensory input increased, the difficulties autistic pupils have managing uncertain situations as reported by parents increased. This was then associated with elevated feelings of anxiety, particularly showing symptoms of anxiety disorders and phobias as reported by parents.

In a school context, having high levels of sensory sensitivity could mean that everyday experiences in the school environment, such as noise and crowds, would feel aversive for pupils with autism. This may lead to more difficulties with uncertainty, which then increases feelings of anxiety. This model fits with findings from previous semi-structured interviews reporting that unexpected adverse noises in particular cause feelings of anxiety for pupils with autism attending mainstream secondary school (Hill, 2014; Howe & Stagg, 2016).

Again whilst child and parent reported IU was significantly associated, there was not a significant indirect pathway from parent reported sensory sensitivities to anxiety disorder or phobia symptoms through child reported IU. There was a direct effect from parent reported sensory sensitivity to symptoms of anxiety phobias when child reported IU was included in the model. As parent reported sensory sensitivities and anxiety symptoms were significantly associated, and there was significant indirect effect through parent reported IU, it is likely that this explains the direct effect seen when child reported IU is included in the model.

In addition to this significant pathway, a high threshold for sensory stimuli was significantly associated with adolescent reported worries and concerns in the learning environment. Increased sensory seeking behaviours in children aged 6-10 has shown significant associations with academic underachievement (Ashburner, Ziviani, & Rodger, 2008). It could be that pupils with

such high threshold for sensory input are distracted by sensory seeking behaviours thus miss learning content. It may also be that participants with a need for seeking sensory input felt anxious within the classroom as they were not able to engage in sensory seeking behaviours due to punishment or rejection from others as proposed by Wood and Gadow (2010). It would be valuable for future research to further explore this association between a high threshold for sensory stimuli and adolescent reported worries about the learning environment.

2.4.4 Social and environment factors and anxiety via IU

The current study did not find a significant direct or indirect association between teacher reported social skills to anxiety symptoms through parent or child reported IU. Considering adolescent reported challenges and concerns about the social and learning environment in school, there was a significant indirect path from the school social environment through parent reported IU to parent reported symptoms of anxiety disorders and phobias. By using a measure of the school social environment along with the social skills of the participants, this allowed the current study to determine that anxiety appeared a result of challenges in the social environment rather than within-child social skills. Considering challenges in the school learning environment, the findings showed an indirect path to parent reported anxiety disorders via child reported IU. This finding extends existing research to suggest that the social and learning environment in mainstream schools can play a role in the development of anxiety symptoms through IU.

Previous research has found that stressful life experiences play a part in the onset and trajectory of anxiety disorders (Faravelli et al., 2012). In support, the current study found that increased worries and concerns across elements of the social and learning environment in school were associated with increased IU which appeared to result in increased parent reported symptoms of anxiety. The items used to measure the school social environment included out of class experiences such as lining up, buying food and sitting in the canteen, PE or games, talking to staff or classmates, breaktimes and going out with peers. These environments are less structured than the environment that would be expected within a lesson and may fit with previous research on sources of anxiety in school for pupils with autism. Crowds of people (Hebron & Humphrey, 2014; Hill, 2014; Lamb et al., 2016; Saggers, 2015), feeling different or isolated from peers (Carrington & Graham, 2001; Hebron & Humphrey, 2014; Humphrey & Lewis, 2008a), bullying (Hebron & Humphrey, 2014) and disruptive behaviour (Humphrey & Lewis, 2008a) have all been identified as sources of anxiety in the literature. An increased number of such social factors indirectly led to increased parent reported anxiety symptoms through IU in this current study.

2.4.5 Implications

By understanding the nature and presentation of anxiety in adolescents with autism, and how environmental factors such as school and sensory demands including as noise and touch can contribute, this gives professionals, schools and parents areas to target to reduce anxiety levels and the impact this has on quality of life. The school day should be designed for autistic children and young people to reduce stressors in the social and learning environment to enable inclusion for autistic pupils. Whilst there is qualitative research identifying aspects of school which cause feelings of anxiety for secondary school pupils with autism, larger scale research should look to explore themes across schools and pupils and ensure this is communicated directly to relevant school staff. Interventions on increasing tolerance to sensory stimuli should be further researched to build on psychological research emerging in this area including CBT based interventions (Edgington, Hill, & Pellicano, 2016), and sensory processing interventions (Case-Smith, Weaver, & Fristad, 2015).

Secondly, as uncertainty will always be unavoidable, more research should be carried out on interventions which may increase tolerance for uncertain situations for pupils with autism. Research has demonstrated that for autistic children, pre-treatment IU levels predicted a poorer response to Cognitive Behaviour Therapy (Keefer et al., 2017). Early research on developing an intervention to target IU for participants with autism has shown promising results (Rodgers, Hodgson, et al., 2016), and this is an area which should get increased attention by researchers.

2.4.6 Limitations

It is important to note that the only significant pathway through child reported IU was from the school learning environment to parent reported anxiety disorder symptoms. Researchers have demonstrated differences between parent and child reports, with parents typically attributing behaviours to mood or personality, whilst children attribute behaviours to triggers in the environment (De Los Reyes & Kazdin, 2005). Parents may be more likely to observe their children's social behaviour and subsequent feelings outside of school, whereas opportunities to observe their responses to learning environments would be fewer. Participant's ratings of worries and concerns in the learning environment include items such as reading aloud in class, when the teacher is marking work, when a teacher introduces a new topic, or class tests. These challenges in the learning environment increase child reported IU thus symptoms of anxiety reported by parents, of which parent report may be more accurate from the behaviours they observe. Future research should look to explore why such difference arose by including child report of sensory sensitivities, autistic traits and anxiety disorder and phobia symptoms.

Additionally, whilst information was collected from a range of sources, there was no child-reported measure of sensory symptoms, DSM-5 based anxiety symptoms, nor school report of uncertainty or anxiety related behaviours to include in the analysis. Further research should seek to triangulate findings across multiple informants. It may also be important to note that the only measure of social skills was provided by teachers. Whilst this was considered to be a good indication of how the participants functioned within the school social environment, it is possible that the teacher selected to complete this measure did not have a full picture of the participants' social behaviour across the school day. This is because mainstream secondary school classes in the UK typically have a different teacher for each subject, meaning the same adult would not see the participant across the school day. Results would be strengthened by including parent, adolescent and multiple teacher ratings of social skills.

As information was not collected from parents who declined to take part in this study, it is possible that the sample is biased towards those whose parents saw utility in taking part in research on anxiety and autism in secondary schools. This could mean that the sample is skewed towards high levels of anxiety or difficulties functioning in secondary school, and further research should look at ways to gather higher respondent rates from eligible participants identified within schools. It is also important to note that as a control group was not included, it is not possible to determine how findings compare to those from typically developing pupils, those with other neurodevelopmental disorders or those with autism attending special school provisions. Future research would benefit from including a control group to increase understanding in this area.

As the sample size is relatively low for the type of analysis carried out and the number of effects explored, this could limit both the generalisability and replicability of these significant pathways and effect sizes. Future research should look to replicate these findings with a larger sample to strengthen these results. Additionally this was cross-sectional research as information was collected at one time-point. There would be further benefit in carrying out longitudinal research where both anxiety symptoms and IU are taken across multiple time points to increase the validity of these findings. The mediation models explored in the analysis were based on the direction of the pathway from sensory sensitivity to IU then to anxiety symptoms in the framework proposed by Boulter et al. (2014) and supported by Wigham et al. (2015). It is possible however that alternative indirect pathways exist between the variables to better explain these findings, such as that from IU to anxiety symptoms then sensory sensitivity proposed by Neil et al. (2016).

2.4.7 Conclusions

Taken together, the findings of this study highlight key pathways from sensory sensitivities, social and environmental factors in school, and autistic traits to symptoms of anxiety disorders and phobias indirectly through IU (see Figure 9). Collectively, they provide support for the model of anxiety and autism (see Figure 4) proposed by Boulter et al. (2014) where both social environmental factors in school and sensory sensitivity led to elevated anxiety through IU. The findings extend previous research to focus on the elements of the social environment that might be especially challenging for adolescents diagnosed with autism, using a sample from multiple mainstream school settings. The directional pathway from sensory sensitivity to anxiety symptoms fit with previous research testing this pathway by Wigham et al. (2015). This model contrasts with research demonstrating an alternative pathway from increased IU leading to increased anxiety levels then sensitivity to sensory stimuli (Neil et al., 2016), however this was not supported by the current study.

Appendix A Search terms and results

EBSCO host databases (PsycINFO, PsychARTICLES, CINAHL Plus with full text and MEDLINE)

Title OR abstract search: (autis* OR Asperger* OR "pervasive developmental disorder" OR ASD) AND (school OR classroom* OR mainstream OR pupil* OR student*) AND (Experience*)

Results search 14.02.2018: **1666** (PsycINFO **1175**, PsychARTICLES **9**, CINAHL Plus with Full Text **229** and MEDLINE **253**)

Search limited to English and academic journals: **919**

Web of Science Core Collection

Topic search: (autis* OR Asperger* OR "pervasive developmental disorder" OR ASD) AND (school OR classroom* OR mainstream OR pupil* OR student*) AND (Experience*)

Results search 14.02.2018: **830**

Search limited to English and articles: **680**

ProQuest databases (ERIC)

Document title OR abstract search: (autis* OR Asperger* OR "pervasive developmental disorder" OR ASD) AND (school OR classroom* OR mainstream OR pupil* OR student*) AND (Experience*)

Results search 14.02.2018: **602**

Search limited to English and scholarly journals: **391**

Appendix B Journals excluded from review

	Reference	Main reason(s) for exclusion
1	Angell, A. M., & Solomon, O. (2017). Understanding parents' concerns about their children with autism taking public school transportation in Los Angeles County. Autism: The International Journal Of Research And Practice, 1362361316680182–1362361316680182.	Participants not secondary school age (11-16)
2	Campbell, M., Hwang, Y.-S., Whiteford, C., Dillon-Wallace, J., Ashburner, J., Saggers, B., & Carrington, S. (2017). Bullying Prevalence in Students With Autism Spectrum Disorder. AUSTRALASIAN JOURNAL OF SPECIAL EDUCATION, 41(2), 101–122.	No reference to anxiety in school or anxiety related to school experience Not pupil voice
3	Collet-Klingenberg, L., Neitzel, J., & LaBerge, J. (2012). Power-PALS (Peers Assisting, Leading, Supporting): Implementing a Peer-Mediated Intervention in a Rural Middle School Program. Rural Special Education Quarterly, 31(2), 3–11.	No reference to anxiety in school or anxiety related to school experience
4	Goodman-Scott, E., Carlisle, R., Clark, M., & Burgess, M. (2017). "A Powerful Tool": A Phenomenological Study of School Counselors' Experiences with Social Stories. Professional School Counseling, 20(1), 25–35.	No pupil voice
5	Hwang, S., Kim, Y. S., Koh, Y.-J., & Leventhal, B. L. (2017). Autism spectrum disorder and school bullying: Who is the victim? Who is the perpetrator? Journal of Autism and Developmental Disorders.	Participants not secondary school age (11-16) No reference to anxiety in school or anxiety related to school experience
6	Landor, F., & Perepa, P. (2017). Do resource bases enable social inclusion of students with Asperger syndrome in a mainstream secondary school? SUPPORT FOR LEARNING, 32(2), 129–143.	No pupil voice
7	Liu, M.-J., Ma, L.-Y., Chou, W.-J., Chen, Y.-M., Liu, T.-L., Hsiao, R. C., … Yen, C.-F. (2018). Effects of theory of mind performance training on reducing bullying involvement in children and adolescents with high functioning autism spectrum disorder. PLOS ONE, 13(1).	Participants not predominately secondary school age (11-16) No reference to anxiety in school or anxiety related to school experience
8	Sumiya, M., Igarashi, K., & Miyahara, M. (2018). Emotions surrounding friendships of adolescents with autism spectrum disorder in Japan: A qualitative interview study. Plos One, 13(2), e0191538–e0191538.	Not mainstream school setting
9	Strang, J. F., Meagher, H., Kenworthy, L., de Vries, A. L. C., Menvielle, E., Leibowitz, S., … Anthony, L. G. (2018). Initial Clinical Guidelines for Co-Occurring Autism Spectrum Disorder and Gender Dysphoria or Incongruence in Adolescents. JOURNAL OF CLINICAL CHILD AND ADOLESCENT PSYCHOLOGY, 47(1), 105–115.	No pupil voice No reference to anxiety in school or anxiety related to school experience
10	Sahin, N. T., Keshav, N. U., Salisbury, J. P., & Vahabzadeh, A. (2018). Second Version of Google Glass as a Wearable Socio-Affective Aid:	No reference to anxiety in school or

Appendix B

	Positive School Desirability, High Usability, and Theoretical Framework in a Sample of Children with Autism. JMIR Human Factors, 5(1), e1–e1.	anxiety related to school experience
11	Sehlin, H., Ahlstrom, B. H., Andersson, G., & Wentz, E. (2018). Experiences of an internet-based support and coaching model for adolescents and young adults with ADHD and autism spectrum disorder - a qualitative study. BMC PSYCHIATRY, 18.	Participants not predominately secondary school age (11-16)
12	Wijnhoven, L. A. M. W., Creemers, D. H. M., Engels, R. C. M. E., & Granic, I. (2015). The effect of the video game Mindlight on anxiety symptoms in children with an Autism Spectrum Disorder. BMC Psychiatry, 15.	Not mainstream school setting
13	Knight, V. F., Wood, C. L., Spooner, F., Browder, D. M., & O'Brien, C. P. (2015). An exploratory study using science eTexts with students with autism spectrum disorder. Focus on Autism and Other Developmental Disabilities, 30(2), 86–99.	No reference to anxiety in school or anxiety related to school experience
14	Sreckovic, M. A., Hume, K., & Able, H. (2017). Examining the efficacy of peer network interventions on the social interactions of high school students with autism spectrum disorder. Journal of Autism and Developmental Disorders, 47(8), 2556–2574.	No reference to anxiety in school or anxiety related to school experience
15	Koning, C., Magill-Evans, J., Volden, J., & Dick, B. (2013). Efficacy of cognitive behavior therapy-based social skills intervention for school-aged boys with Autism spectrum disorders. Research in Autism Spectrum Disorders, 7(10), 1282–1290.	No reference to anxiety in school or anxiety related to school experience
16	Twyman, K. A., Saylor, C. F., Saia, D., Macias, M. M., Taylor, L. A., & Spratt, E. (2010). Bullying and Ostracism Experiences in Children With Special Health Care Needs. JOURNAL OF DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS, 31(1), 1–8.	Participants without ASD diagnosis, or other diagnoses included in sample
17	Tomasik, M. (2007). Effective inclusion activities for high school students with multiple disabilities. Journal of Visual Impairment & Blindness, 101(10), 657–659.	Participants without ASD diagnosis, or other diagnoses included in sample
18	Tan, L., Hughes, C., & Foster, J. (2016). Abilities, Disabilities and Possibilities: A qualitative study exploring the academic and social experiences of gifted and talented students who have co-occurring learning disabilities. JOURNAL OF PEDAGOGIC DEVELOPMENT, 6(2).	Participants without ASD diagnosis, or other diagnoses included in sample
19	Tobin, H., Staunton, S., Mandy, W., Skuse, D., Hellriegel, J., Baykaner, O., … Murin, M. (2012). A qualitative examination of parental experiences of the transition to mainstream secondary school for children with an autism spectrum disorder. Educational and Child Psychology, 29(1), 75–85.	No pupil voice
20	Towle, P. O., Vacanti-Shova, K., Shah, S., & Higgins-D'alessandro, A. (2014). School-aged functioning of children diagnosed with autism spectrum disorder before age three: Parent-reported diagnostic, adaptive, medication, and school placement outcomes. Journal of Autism and Developmental Disorders, 44(6), 1357–1372.	Participants not predominately secondary school age (11-16)
21	Longhurst, J., Richards, D., Copenhaver, J., & Morrow, D. (2010). "Outside In": Group Treatment of Youth with Asperger's. Reclaiming Children and Youth, 19(3), 40–44.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
22	Lilly, J. D. J. D., Reed, D., & Wheeler, K. G. (2004). Perceptions of psychological contract violations in school districts that serve children with Autism Spectrum Disorder: An exploratory qualitative study. Journal of Applied School Psychology, 20(1), 27–45.	No pupil voice
23	Picard, R. W. (2009). Future affective technology for autism and	Incorrect research

	emotion communication. Philosophical Transactions of the Royal Society of London. Series B, Biological Sciences, 364(1535), 3575–3584.	design (e.g. literature review, meta-analysis, not empirical paper)
24	Schlieder, M., Maldonado, N., & Baltes, B. (2014). An Investigation of "Circle of Friends" Peer-Mediated Intervention for Students with Autism. Journal of Social Change, 6(1), 27–40.	No pupil voice
25	Markley, J. (2008). Reflections on the school experiences of a student with autism spectrum disorders. In S. Rotatori, AF and Obiakor, FE and Burkhardt (Ed.), utism and Developmental Disabilities: Current Practices and Issues (Vol. 18, pp. 157–162).	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
26	Gore Langton, E., & Frederickson, N. (2016). Mapping the educational experiences of children with Pathological Demand Avoidance. Journal of Research in Special Educational Needs, 16(4), 254–263.	Participants not predominately secondary school age (11-16)
27	Kloosterman, P. H., Kelley, E. A., Parker, J. D. A., & Craig, W. M. (2014). Executive functioning as a predictor of peer victimization in adolescents with and without an Autism Spectrum Disorder. Research in Autism Spectrum Disorders, 8(3), 244–254.	No reference to anxiety in school or anxiety related to school experience
28	Houghton, C. (2014). Capturing the Pupil Voice of Secondary Gifted and Talented Students Who Had Attended an Enrichment Programme in Their Infant School. Gifted Education International, 30(1), 33–46.	No reference to anxiety in school or anxiety related to school experience
29	Polley, B., Wheeler, K., & Percy, M. (2009). Most pressing environmental hazards affecting children and youth and the connection with intellectual and developmental disability — Results from Canadian high school student focus groups. Journal on Developmental Disabilities, 15(2), 114–124.	Participants without ASD diagnosis, or other diagnoses included in sample
30	Rossetti, Z. S. (2011). "That's How We Do It": Friendship Work between High School Students with and without Autism or Developmental Disability. Research and Practice for Persons with Severe Disabilities (RPSD), 36(1), 11.	Participants without ASD diagnosis, or other diagnoses included in sample
31	Rose, C. A., Stormont, M., Wang, Z., Simpson, C. G., Preast, J. L., & Green, A. L. (2015). Bullying and Students With Disabilities: Examination of Disability Status and Educational Placement. School Psychology Review, 44(4, SI), 425–444.	Participants without ASD diagnosis, or other diagnoses included in sample
32	McLaughlin, S., & Rafferty, H. (2014). Me and "it": Seven young people given a diagnosis of Asperger's Syndrome. Educational and Child Psychology, 31(1), 63–78.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
33	Jamison, T. R., & Schuttler, J. O. (2017). Overview and preliminary evidence for a social skills and self-care curriculum for adolescent females with autism: The girls night out model. Journal of Autism and Developmental Disorders, 47(1), 110–125.	No reference to anxiety in school or anxiety related to school experience
34	Jamison, T. R., & Schuttler, J. O. (2015). Examining social competence, self-perception, quality of life, and internalizing and externalizing symptoms in adolescent females with and without autism spectrum disorder: a quantitative design including between-groups and correlational analyses. Molecular Autism, 6.	No reference to anxiety in school or anxiety related to school experience
35	Hong, E. R., Neely, L., & Lund, E. M. (2015). Addressing Bullying of Students with Autism: Suggestions for Families and Educators. Intervention in School and Clinic, 50(3), 157–162.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
36	Hess, K. (2003). Keep the Change: A Hard-Earned Success. Young Children, 58(4), 30–32.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
37	Halpern, W. I. (1970). The schooling of autistic children: Preliminary	Participants not

	findings. American Journal of Orthopsychiatry, 40(4), 665–671.	predominately secondary school age (11-16)
38	Fittipaldi-Wert, J., & Mowling, C. M. (2009). Using Visual Supports for Students with Autism in Physical Education. Journal of Physical Education, Recreation & Dance (JOPERD), 80(2), 39–43.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
39	Ratey, J. J., Grandin, T., & Miller, A. (1992). Defense behavior and coping in an autistic savant: The story of Temple Grandin, PhD. Psychiatry: Interpersonal and Biological Processes, 55(4), 382–391.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
40	Humphrey, N. (2008). Autistic Spectrum and Inclusion: Including Pupils with Autistic Spectrum Disorders in Mainstream Schools. Support for Learning, 23(1), 41–47.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
41	Humphrey, N. (2008). Including pupils with autistic spectrum disorders in mainstream schools. Support for Learning, 23(1), 41–47. https://doi.org/10.1111/j.1467-9604.2007.00367.x	Duplicate of above Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
42	Grandin, T. (2007). Autism from the Inside. Educational Leadership, 64(5), 29–32.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
43	Grandin, T. (1990). Needs of high functioning teenagers and adults with autism: Tips from a recovered autistic. Focus on Autistic Behavior, 5(1), 16.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
44	Grandin, T. (2006). Perspectives on Education from a Person on the Autism Spectrum. Educational Horizons, 84(4), 229–234.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
45	Foley, K.-R., Blackmore, A. M., Girdler, S., O'Donnell, M., Glauert, R., Llewellyn, G., & Leonard, H. (2012). To Feel Belonged: The Voices of Children and Youth with Disabilities on the Meaning of Wellbeing. Child Indicators Research, 5(2), 375–391.	Participants without ASD diagnosis, or other diagnoses included in sample
46	Dixon, M. R., Whiting, S. W., & Miller, J. R. (2013). Discounting of restraint usage, problem behavior management, and risk of autism severity. Research in Autism Spectrum Disorders, 7(10), 1211–1220.	Participants without ASD diagnosis, or Participants without ASD diagnosis, or other diagnoses included in sample
47	Diehl, S. F. (2011). ASD and Middle School Challenges: A Case Example. Perspectives on School-Based Issues, 12(3), 77–83.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
48	Dillenburger, K., Jordan, J. -A., McKerr, L., Lloyd, K., & Schubotz, D. (2017). Autism awareness in children and young people: Surveys of two populations. Journal of Intellectual Disability Research.	Participants without ASD diagnosis, or other diagnoses included in sample
49	Fisher-Polites, C. (2004). "PBS" Spelled "Friends". Journal of Positive Behavior Interventions, 6(3), 178–180.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
50	DePape, A.-M., & Lindsay, S. (2016). Lived experiences from the perspective of individuals with autism spectrum disorder: A qualitative meta-synthesis. Focus on Autism and Other Developmental Disabilities, 31(1), 60–71.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)

51	Darretxe, L., & Sepúlveda, L. (2011). Educational strategies to address the educational needs of students with Asperger syndrome in the mainstream classroom. Electronic Journal of Research in Educational Psychology, 9(2), 869–892.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
52	Cappadocia, M. C., Weiss, J. A., & Pepler, D. (2012). Bullying experiences among children and youth with autism spectrum disorders. Journal of Autism and Developmental Disorders, 42(2), 266–277.	Participants not predominately secondary school age (11-16)
53	Broun, L. (2009). Take the Pencil out of the Process. TEACHING Exceptional Children, 42(1), 14–21.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
54	Breivik, I., & Hemmingsson, H. (2013). Experiences of handwriting and using a computerized ATD in school: Adolescents with Asperger's syndrome. Scandinavian Journal of Occupational Therapy, 20(5), 349–356.	No reference to anxiety in school or anxiety related to school experience
55	Benton, L., & Johnson, H. (2014). Structured approaches to participatory design for children: Can targeting the needs of children with autism provide benefits for a broader child population? Instructional Science, 42(1), 47–65.	Participants not predominately secondary school age (11-16)
56	Beckman, L., Janson, S., & von Kobyletzki, L. (2016). Associations between neurodevelopmental disorders and factors related to school, health, and social interaction in schoolchildren: Results from a Swedish population-based survey. Disability and Health Journal, 9(4), 663–672.	Participants without ASD diagnosis, or other diagnoses included in sample
57	Mount, N., & Dillon, G. (2014). Parents' experiences of living with an adolescent diagnosed with an autism spectrum disorder. Educational and Child Psychology, 31(4), 72–81.	No pupil voice
58	Vincelette, B. (2000). My Early Years. Focus on Autism and Other Developmental Disabilities, 15(4), 236–238.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
59	Renty, J., & Roeyers, H. (2006). Satisfaction with formal support and education for children with autism spectrum disorder: The voices of the parents. Child: Care, Health and Development, 32(3), 371–385.	No pupil voice
60	Mintz, J. (2008). Working with children with Asperger's Syndrome in the mainstream classroom: A psychodynamic take from the chalk face. Psychodynamic Practice: Individuals, Groups and Organisations, 14(2), 169–180.	No pupil voice
61	Whitaker, P. (2007). Provision for Youngsters with Autistic Spectrum Disorders in Mainstream Schools: What Parents Say--and What Parents Want. British Journal of Special Education, 34(3), 170–178.	No pupil voice
62	Wilkerson, C. L., & Wilkerson, J. M. (2004). Teaching Social Savvy to Students with Asperger Syndrome. Middle School Journal (J3), 36(1), 18–24.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
63	Tippett, J. (2004). The Educational Experiences of Students with Asperger Syndrome. Kairaranga, 5(2), 12–18.	Participants not predominately secondary school age (11-16)
64	Jones, R. S. P., & Meldal, T. O. (2001). Social relationships and Asperger's syndrome. Journal of Learning Disabilities, 5(1), 35–41.	No reference to anxiety in school or anxiety related to school experience
65	Portway, S., & Johnson, B. (2003). Asperger Syndrome and the Children who "Don"t Quite Fit In'. Early Child Development and Care, 173(4), 435–443.	No reference to anxiety in school or anxiety related to school experience

66	Levy, A., & Perry, A. (2008). Transition of children with autism from intensive behavioural intervention programs into the school system. Journal on Developmental Disabilities, 14(1), 1–10.	No pupil voice
67	Jewell, J. D., Grippi, A., Hupp, S. D. A., & Krohn, E. J. (2007). The effects of a rotating classroom schedule on classroom crisis events in a school for autism. North American Journal of Psychology, 9(1), 37–52.	Not mainstream school setting
68	Rodger, S., Ireland, S., & Vun, M. (2008). Can cognitive orientation to daily occupational performance (CO-OP) help children with Asperger's syndrome to master social and organisational goals? The British Journal of Occupational Therapy, 71(1), 23–32.	Participants not predominately secondary school age (11-16)
69	Emam, M. M., & Farrell, P. (2009). Tensions experienced by teachers and their views of support for pupils with autism spectrum disorders in mainstream schools. European Journal of Special Needs Education, 24(4), 407–422.	No pupil voice
70	Glashan, L., Mackay, G., & Grieve, A. (2004). Teachers' Experience of Support in the Mainstream Education of Pupils with Autism. Improving Schools, 7(1), 49–60.	Participants not predominately secondary school age (11-16)
71	Robledo, J. A., & Donnellan, A. M. (2008). Properties of supportive relationships from the perspective of academically successful individuals with autism. Intellectual and Developmental Disabilities, 46(4), 299–310.	Participants not predominately secondary school age (11-16)
72	Sherratt, D., & Donald, G. (2004). Connectedness: Developing a Shared Construction of Affect and Cognition in Children with Autism. British Journal of Special Education, 31(1), 10–15.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
73	Carnahan, C. R. (2006). Photovoice: Engaging Children with Autism and Their Teachers. TEACHING Exceptional Children, 39(2), 44–50.	No pupil voice
74	Leblanc, L., Richardson, W., & Burns, K. A. (2009). Autism Spectrum Disorder and the Inclusive Classroom: Effective Training to Enhance Knowledge of ASD and Evidence-Based Practices. Teacher Education and Special Education, 32(2), 166–179.	No pupil voice
75	Stevenson, K., Cornell, K., & Hinchcliffe, V. (2016). "Let"s Talk Autism' –a school-based project for students to explore and share their experiences of being autistic. Support for Learning, 31(3), 208–234.	No reference to anxiety in school or anxiety related to school experience
76	Ward, M., & Alar, N. (2000). Being Autistic Is Part of Who I Am. Focus on Autism and Other Developmental Disabilities, 15(4), 232–235.	No reference to anxiety in school or anxiety related to school experience
77	Zablotsky, B., Bradshaw, C. P., Anderson, C. M., & Law, P. (2014). Risk factors for bullying among children with autism spectrum disorders. Autism, 18(4), 419–427.	No reference to anxiety in school or anxiety related to school experience
78	Rowley, E., Chandler, S., Baird, G., Simonoff, E., Pickles, A., Loucas, T., & Charman, T. (2012). The experience of friendship, victimization and bullying in children with an autism spectrum disorder: Associations with child characteristics and school placement. Research in Autism Spectrum Disorders, 6(3), 1126–1134.	No reference to anxiety in school or anxiety related to school experience
79	Edgington, L., Hill, V., & Pellicano, E. (2016). The design and implementation of a CBT-based intervention for sensory processing difficulties in adolescents on the autism spectrum. Research in Developmental Disabilities, 59, 221–233.	No reference to anxiety in school or anxiety related to school experience
80	Cridland, E. K., Caputi, P., Jones, S. C., & Magee, C. A. (2015). The perceptions and experiences of adolescent boys with autism spectrum disorder: A personal construct psychology perspective. Journal of Intellectual and Developmental Disability, 40(4), 354–367.	Not mainstream school setting

81	Neal, S., & Frederickson, N. (2016). ASD transition to mainstream secondary: A positive experience? Educational Psychology in Practice, 32(4), 355–373.	Not mainstream secondary school setting – focus on transition
82	Carrington, S., Campbell, M., Saggers, B., Ashburner, J., Vicig, F., Dillon-Wallace, J., & Hwang, Y.-S. (2017). Recommendations of school students with autism spectrum disorder and their parents in regard to bullying and cyberbullying prevention and intervention. International Journal of Inclusive Education, 21(10), 1045–1064.	No reference to anxiety in school or anxiety related to school experience
83	Dann, R. (2011). Secondary transition experiences for pupils with Autistic Spectrum Conditions (ASCs). Educational Psychology in Practice, 27(3), 293–312.	Not mainstream secondary school setting – focus on transition
84	Zeedyk, S. M., Rodriguez, G., Tipton, L. A., Baker, B. L., & Blocher, J. (2014). Bullying of youth with autism spectrum disorder, intellectual disability, or typical development: Victim and parent perspectives. Research in Autism Spectrum Disorders, 8(9), 1173–1183.	No reference to anxiety in school or anxiety related to school experience
85	Cook, A., Ogden, J., & Winstone, N. (2016). The experiences of learning, friendship and bullying of boys with autism in mainstream and special settings: A qualitative study. British Journal of Special Education, 43(3), 250–271.	Not mainstream setting
86	Rubenstein, L. D., Schelling, N., Wilczynski, S. M., & Hooks, E. N. (2015). Lived experiences of parents of gifted students with autism spectrum disorder: The struggle to find appropriate educational experiences. Gifted Child Quarterly, 59(4), 283–298.	Participants not predominately secondary school age (11-16)
87	Ung, D., McBride, N., Collier, A., Selles, R., Small, B., Phares, V., & Storch, E. (2016). The relationship between peer victimization and the psychological characteristics of youth with autism spectrum disorder. Research in Autism Spectrum Disorders, 32, 70–79.	No reference to anxiety in school or anxiety related to school experience
88	Begeer, S., Fink, E., van der Meijden, S., Goossens, F., & Olthof, T. (2016). Bullying-related behaviour in a mainstream high school versus a high school for autism: Self-report and peer-report. Autism, 20(5), 562–571.	No reference to anxiety in school or anxiety related to school experience
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90	Bradley, R. (2016). “Why single me out?” Peer mentoring, autism and inclusion in mainstream secondary schools. British Journal of Special Education, 43(3), 272–288.	No reference to anxiety in school or anxiety related to school experience
91	Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A. (2014). Being a girl in a boys’ world: Investigating the experiences of girls with autism spectrum disorders during adolescence. Journal of Autism and Developmental Disorders, 44(6), 1261–1274.	No reference to anxiety in school or anxiety related to school experience
92	Kloosterman, P. H., Kelley, E. A., Craig, W. M., Parker, J. D. A., & Javier, C. (2013). Types and experiences of bullying in adolescents with an autism spectrum disorder. Research in Autism Spectrum Disorders, 7(7), 824–832.	No reference to anxiety in school or anxiety related to school experience
93	Endedijk, H., Denessen, E., & Hendriks, A. W. (2011). Relationships between executive functioning and homework difficulties in students with and without autism spectrum disorder: An analysis of student- and parent-reports. Learning and Individual Differences, 21(6), 765–770.	No reference to anxiety in school or anxiety related to school experience
94	Dillon, G. V, Underwood, J. D. M., & Freemantle, L. J. (2016). Autism and the U.K. Secondary school experience. Focus on Autism and Other Developmental Disabilities, 31(3), 221–230.	No reference to anxiety in school or anxiety related to

		school experience
95	Falkmer, M., Parsons, R., & Granlund, M. (2012). Looking through the Same Eyes? Do Teachers' Participation Ratings Match with Ratings of Students with Autism Spectrum Conditions in Mainstream Schools? Autism Research And Treatment, 2012, 656981.	No reference to anxiety in school or anxiety related to school experience
96	Fisher, M. H., & Taylor, J. L. (2016). Let's talk about it: Peer victimization experiences as reported by adolescents with autism spectrum disorder. Autism, 20(4), 402–411.	No reference to anxiety in school or anxiety related to school experience
97	Fortuna, R. (2014). The social and emotional functioning of students with an autistic spectrum disorder during the transition between primary and secondary schools. Support for Learning, 29(2), 177–191.	Not mainstream secondary school setting – focus on the transition
98	Healy, S., Msetfi, R., & Gallagher, S. (2013). "Happy and a bit nervous": The experiences of children with autism in physical education. British Journal of Learning Disabilities, 41(3), 222–228.	Participants not predominately secondary school age (11-16)
99	Hebron, J., Oldfield, J., & Humphrey, N. (2017). Cumulative risk effects in the bullying of children and young people with autism spectrum conditions. Autism, 21(3), 291–300.	No reference to anxiety in school or anxiety related to school experience
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101	Saggers, B., Hwang, Y.-S., & Mercer, L. K. (2011). Your Voice Counts: Listening to the Voice of High School Students with Autism Spectrum Disorder. Australasian Journal of Special Education, 35(2), 173–190.	No reference to anxiety in school or anxiety related to school experience
102	Locke, J., Ishijima, E. H., Kasari, C., & London, N. (2010). Loneliness, friendship quality and the social networks of adolescents with high-functioning autism in an inclusive school setting. Journal of Research in Special Educational Needs, 10(2), 74–81.	No reference to anxiety in school or anxiety related to school experience
103	Rosso, E. G. F. (2016). Brief report: Coaching adolescents with autism spectrum disorder in a school-based multi-sport program. Journal of Autism and Developmental Disorders, 46(7), 2526–2531.	No reference to anxiety in school or anxiety related to school experience
104	O'Hagan, S., & Hebron, J. (2017). Perceptions of friendship among adolescents with autism spectrum conditions in a mainstream high school resource provision. European Journal of Special Needs Education, 32(3), 314–328.	No reference to anxiety in school or anxiety related to school experience
105	Hebron, J. S. (2017). School connectedness and the primary to secondary school transition for young people with autism spectrum conditions. British Journal of Educational Psychology.	No reference to anxiety in school or anxiety related to school experience
106	Hedges, S. H., Kirby, A. V, Sreckovic, M. A., Kucharczyk, S., Hume, K., & Pace, S. (2014). "Falling through the cracks": Challenges for high school students with autism spectrum disorder. The High School Journal, 98(1), 64–82.	No reference to anxiety in school or anxiety related to school experience
107	Symes, W., & Humphrey, N. (2010). Peer-group indicators of social inclusion among pupils with autistic spectrum disorders (ASD) in mainstream secondary schools: A comparative study. School Psychology International, 31(5), 478–494.	No reference to anxiety in school or anxiety related to school experience
108	Humphrey, N., & Symes, W. (2010). Perceptions of social support and experience of bullying among pupils with autistic spectrum disorders in mainstream secondary schools. European Journal of Special Needs Education, 25(1), 77–91.	No reference to anxiety in school or anxiety related to school experience

109	Symes, W., & Humphrey, N. (2011). The Deployment, Training and Teacher Relationships of Teaching Assistants Supporting Pupils with Autistic Spectrum Disorders (ASD) in Mainstream Secondary Schools. British Journal of Special Education, 38(2), 57–64.	No reference to anxiety in school or anxiety related to school experience
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111	Able, H., Sreckovic, M. A., Schultz, T. R., Garwood, J. D., & Sherman, J. (2015). Views from the Trenches: Teacher and Student Supports Needed for Full Inclusion of Students with ASD. Teacher Education and Special Education, 38(1), 44–57.	Participants not predominately secondary school age (11-16)
112	Stokes, M. A., Kornienko, L., Scheeren, A. M., Koot, H. M., & Begeer, S. (2017). A comparison of children and adolescent's self-report and parental report of the PedsQL among those with and without autism spectrum disorder. Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation, 26(3), 611–624.	Not mainstream school setting
113	Shogren, K. A., & Plotner, A. J. (2012). Transition planning for students with intellectual disability, autism, or other disabilities: Data from the National Longitudinal Transition Study-2. Intellectual and Developmental Disabilities, 50(1), 16–30.	Not mainstream school setting Participants without ASD diagnosis, or other diagnoses included in sample
114	Nadeau, J. M., Arnold, E. B., Keene, A. C., Collier, A. B., Lewin, A. B., Murphy, T. K., & Storch, E. A. (2015). Frequency and Clinical Correlates of Sleep-Related Problems Among Anxious Youth with Autism Spectrum Disorders. Child Psychiatry and Human Development, 46(4), 558–566.	Not mainstream school setting
115	Hurlbutt, K., & LaPlante, E. (2010). Social Issues Surrounding the Adolescent with Asperger Syndrome: Perceptions of Parents and Teachers. Journal of the American Academy of Special Education Professionals, 82–95.	No pupil voice
116	Storch, E. A., Larson, M. J., Ehrenreich-May, J., Arnold, E. B., Jones, A. M., Renno, P., … Wood, J. J. (2012). Peer Victimization in Youth with Autism Spectrum Disorders and Co-occurring Anxiety: Relations with Psychopathology and Loneliness. Journal of Developmental and Physical Disabilities, 24(6), 575–590.	Not mainstream school setting
117	Lyons, J., Cappadocia, M. C., & Weiss, J. A. (2011). Social characteristics of students with autism spectrum disorders across classroom settings. Journal on Developmental Disabilities, 17(1), 77–82.	Participants not predominately secondary school age (11-16)
118	Potvin, M.-C., Snider, L., Prelock, P. A., Wood-Dauphinee, S., & Kehayia, E. (2015). Health-related quality of life in children with high-functioning autism. Autism, 19(1), 14–19.	Not mainstream school setting
119	Iadarola, S., Hetherington, S., Clinton, C., Dean, M., Reisinger, E., Huynh, L., … Kasari, C. (2015). Services for children with autism spectrum disorder in three, large urban school districts: Perspectives of parents and educators. Autism, 19(6), 694–703.	Not mainstream school setting
120	Segall, M. J., & Campbell, J. M. (2012). Factors relating to education professionals' classroom practices for the inclusion of students with autism spectrum disorders. Research in Autism Spectrum Disorders, 6(3), 1156–1167.	No pupil voice
121	Maddox, L. L., & Marvin, C. A. (2013). A Preliminary Evaluation of a Statewide Professional Development Program on Autism Spectrum Disorders. Teacher Education and Special Education, 36(1), 37–50	No pupil voice
122	Zainal, H., & Magiati, I. (2016). A Comparison Between Caregiver-Reported Anxiety and Other Emotional and Behavioral Difficulties in	Not mainstream school setting

	Children and Adolescents with Autism Spectrum Disorders Attending Specialist or Mainstream Schools. Journal of Autism and Developmental Disorders.	No pupil voice
123	Little, L. M., Ausderau, K., Sideris, J., & Baranek, G. T. (2015). Activity Participation and Sensory Features Among Children with Autism Spectrum Disorders. Journal of Autism & Developmental Disorders, 45(9), 2981–2990.	Participants not predominately secondary school age (11-16)
124	Sedgewick, F., Hill, V., Yates, R., Pickering, L., & Pellicano, E. (2016). Gender Differences in the Social Motivation and Friendship Experiences of Autistic and Non-autistic Adolescents. Journal of Autism and Developmental Disorders, 46(4), 1297–1306.	Not mainstream school setting
125	Williams, E. I., Gleeson, K., & Jones, B. E. (2017). How pupils on the autism spectrum make sense of themselves in the context of their experiences in a mainstream school setting: A qualitative metasynthesis. Autism: The International Journal Of Research And Practice,	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
126	Holcombe, W., & Plunkett, M. (2016). The Bridges and Barriers Model of Support for High-Functioning Students with ASD in Mainstream Schools. Australian Journal of Teacher Education, 41(9).	No pupil voice
127	Hanley-Hochdorfer, K., Bray, M. A., Kehle, T. J., & Elinoff, M. J. (2010). Social stories to increase verbal initiation in children with autism and Asperger's disorder. School Psychology Review, 39(3), 484–492.	Participants not predominately secondary school age (11-16)
128	Hallett, V., Ronald, A., Colvert, E., Ames, C., Woodhouse, E., Lietz, S., … Happe, F. (2013). Exploring anxiety symptoms in a large-scale twin study of children with autism spectrum disorders, their co-twins and controls. Journal of Child Psychology and Psychiatry, 54(11), 1176–1185.	Not mainstream school setting
129	Deacy, E., Jennings, F., & O'Halloran, A. (2015). Transition of students with autistic spectrum disorders from primary to post-primary school: A framework for success. Support for Learning, 30(4), 292–304.	Not mainstream school setting
130	de Jager, P., & Condy, J. (2017). The influence of executive function challenges on the behavioural adaptation of one learner with autism spectrum disorder. South African Journal of Childhood Education, 7(1).	Participants not predominately secondary school age (11-16)
131	Goodall, E. (2014). Supporting Teachers' Journeys towards Full Inclusion of Students on the Autism Spectrum in New Zealand. Journal of the International Association of Special Education, 15(2), 133–141.	No pupil voice
132	Altomare, A. A., McCrimmon, A. W., Cappadocia, M. C., Weiss, J. A., Beran, T. N., & Smith-Demers, A. D. (2017). When Push Comes to Shove: How Are Students With Autism Spectrum Disorder Coping With Bullying? Canadian Journal of School Psychology, 32(3–4, SI), 209–227.	Participants not predominately secondary school age (11-16)
133	Sasaki, Y., Usami, M., Sasayama, D., Okada, T., Iwadare, Y., Watanabe, K., … Saito, K. (2015). Concerns expressed by parents of children with pervasive developmental disorders for different time periods of the day: A case–control study. PLoS ONE, 10(4).	Not mainstream school setting
134	Hwang, S., Kim, Y. S., Koh, Y.-J., & Leventhal, B. L. (2018). Autism spectrum disorder and school bullying: Who is the victim? Who is the perpetrator? Journal of Autism & Developmental Disorders, 48(1), 225–238.	Not mainstream school setting
135	Power, A., & Costley, D. (2014). Preservice teachers' learning among students with autism spectrum disorder. Australasian Journal of Special Education, 38(1), 34–50.	Not mainstream school setting
136	Kuhaneck, H. M., & Kelleher, J. (2015). Development of the Classroom Sensory Environment Assessment (CSEA). American	Not mainstream school setting

	Journal of Occupational Therapy, 69(6, SI).	
137	Lindsay, S., Proulx, M., Scott, H., & Thomson, N. (2014). Exploring Teachers' Strategies for Including Children with Autism Spectrum Disorder in Mainstream Classrooms. International Journal of Inclusive Education, 18(2), 101–122.	No pupil voice
138	Sterponi, L., & de Kirby, K. (2016). A Multidimensional Reappraisal of Language in Autism: Insights from a Discourse Analytic Study. Journal of Autism & Developmental Disorders, 46(2, SI), 394–405.	Participants not predominately secondary school age (11-16)
139	Reddington, S., & Price, D. (2016). Cyborg and autism: Exploring new social articulations via posthuman connections. International Journal of Qualitative Studies in Education, 29(7), 882–892.	Participants not predominately secondary school age (11-16)
140	Kossyvaki, L., Jones, G., & Guldberg, K. (2016). Training teaching staff to facilitate spontaneous communication in children with autism: Adult Interactive Style Intervention (AISI). Journal of Research in Special Educational Needs, 16(3), 156–168.	Not mainstream school setting
141	Hatfield, M., Ciccarelli, M., Falkmer, T. T., & Falkmer, M. (2018). Factors related to successful transition planning for adolescents on the autism spectrum. Journal of Research in Special Educational Needs, 18(1), 3–14.	Duplicate
142	Frederickson, N., Jones, A. P., & Lang, J. (2010). Inclusive provision options for pupils on the autistic spectrum. Journal of Research in Special Educational Needs, 10(2), 63–73.	No pupil voice
143	Dixon, R. M., & Tanner, K. (2013). The experience of transitioning two adolescents with Asperger syndrome in academically focused high schools. Australasian Journal of Special Education, 37(1), 28–48.	Not mainstream school setting
144	Colombo-Dougovito, A. M. (2015). "Try to Do the Best You Can": How Pre-Service APE Specialists Experience Teaching Students with Autism Spectrum Disorder. International Journal of Special Education, 30(3), 160–176.	Participants not predominately secondary school age (11-16)
145	Bolic Baric, V., Hellberg, K., Kjellberg, A., Hemmingsson, H., Baric, V. B., Hellberg, K., … Hemmingsson, H. (2016). Support for learning goes beyond academic support: Voices of students with Asperger's disorder and attention deficit hyperactivity disorder. Autism, 20(2), 183–195.	Participants not predominately secondary school age (11-16)
146	Bottema-Beutel, K., Mullins, T. S., Harvey, M. N., Gustafson, J. R., & Carter, E. W. (2016). Avoiding the "brick wall of awkward": Perspectives of youth with autism spectrum disorder on social-focused intervention practices. Autism, 20(2), 196–206.	Participants not predominately secondary school age (11-16)
147	Chiang, H. H.-L., & Gau, S. S. S.-F. (2016). Comorbid psychiatric conditions as mediators to predict later social adjustment in youths with autism spectrum disorder. Journal of Child Psychology and Psychiatry, 57(1), 103–111.	Not mainstream school setting
148	Chiang, H. H.-L., & Gau, S. S. S.-F. (2016). Comorbid psychiatric conditions as mediators to predict later social adjustment in youths with autism spectrum disorder. Journal of Child Psychology and Psychiatry, 57(1), 103–111.	Duplicate of above record
149	Blood, G. W., Blood, I. M., Coniglio, A. D., Finke, E. H., & Boyle, M. P. (2013). Familiarity breeds support: Speech-language pathologists' perceptions of bullying of students with autism spectrum disorders. Journal of Communication Disorders, 46(2), 169–180.	No pupil voice
150	Bitsika, V., & Sharpley, C. F. (2014). Understanding, experiences, and reactions to bullying experiences in boys with an autism spectrum disorder. Journal of Developmental and Physical Disabilities, 26(6), 747–761.	Not mainstream school setting
151	Bell, S., Devecchi, C., McGuckin, C., & Shevlin, M. (2017). Making the	Participants not

	transition to post-secondary education: Opportunities and challenges experienced by students with ASD in the Republic of Ireland. European Journal of Special Needs Education, 32(1), 54–70.	predominately secondary school age (11-16)
152	Barnhill, G. P., Sumutka, B., Polloway, E. A., & Lee, E. (2014). Personnel preparation practices in ASD: A follow-up analysis of contemporary practices. Focus on Autism and Other Developmental Disabilities, 29(1), 39–49.	No pupil voice
153	Beamer, J. A., & Yun, J. (2014). Physical educators' beliefs and self-reported behaviors toward including students with autism spectrum disorder. Adapted Physical Activity Quarterly, 31(4), 362–376.	No pupil voice
154	Bellesi, G., Jameel, L., Vyas, K., Crawford, S., & Channon, S. (2016). Using and reasoning about social strategies in autism spectrum disorder in everyday situations. Research in Autism Spectrum Disorders, 25, 112–121.	Participants not predominately secondary school age (11-16)
155	Ashburner, J., Ziviani, J., & Pennington, A. (2012). The introduction of keyboarding to children with autism spectrum disorders with handwriting difficulties: A help or a hindrance? Australasian Journal of Special Education, 36(1), 32–61.	Participants not predominately secondary school age (11-16)
156	Aiello, R., Ruble, L., & Esler, A. (2017). National study of school psychologists' use of evidence-based assessment in autism spectrum disorder. Journal of Applied School Psychology, 33(1), 67–88.	No pupil voice
157	Inclusion in the schools: A parent/teacher/researcher perspective. (2010). Journal on Developmental Disabilities, 16(1), 67–75.	Incorrect research design (e.g. literature review, meta-analysis, not empirical paper)
158	Trillingsgaard, A., & Sørensen, E. U. (1994). School integration of high-functioning children with autism: A qualitative clinical interview study. European Child & Adolescent Psychiatry, 3(3), 187–196.	No access to full paper
159	Zablotsky, B., Bradshaw, C. P., Anderson, C., & Law, P. (2012). Involvement in Bullying among Children with Autism Spectrum Disorders: Parents' Perspectives on the Influence of School Factors. Behavioral Disorders, 37(3), 179–191.	No pupil voice
160	Zablotsky, B., Bradshaw, C. P., Anderson, C., & Law, P. A. (2013). The association between bullying and the psychological functioning of children with autism spectrum disorders. Journal of Developmental and Behavioral Pediatrics, 34(1), 1–8.	No access to full paper
161	Woodcock, A., Woolner, A., & Benedyk, R. (2009). Applying the Hexagon-Spindle Model to the design of school environments for children with autistic spectrum disorders. Work: Journal of Prevention, Assessment & Rehabilitation, 32(3), 249–259.	No access to full paper
162	Sterzing, P. R., Shattuck, P. T., Narendorf, S. C., Wagner, M., & Cooper, B. P. (2012). Bullying Involvement and Autism Spectrum Disorders Prevalence and Correlates of Bullying Involvement Among Adolescents With an Autism Spectrum Disorder. Archives of Pediatrics & Adolescent Medicine, 166(11), 1058–1064.	No reference to anxiety in school or anxiety related to school experience No pupil voice
163	Schopler, E., & Olley, J. G. (1980). Public school programing for autistic children. Exceptional Children, 46(6), 461–463.	No access to full paper
164	Reupert, A., Deppeler, J. M., & Sharma, U. (2015). Enablers for inclusion: The perspectives of parents of children with autism spectrum disorder. Australasian Journal of Special Education, 39(1), 85–96.	No access to full paper
165	Kootz, J. P., Marinelli, B., & Cohen, D. J. (1982). Modulation of response to environmental stimulation in autistic children. Journal of Autism and Developmental Disorders, 12(2), 185–193.	Not mainstream school setting No reference to anxiety in school or anxiety related to

		school experience
166	Guevremont, D. C., MacMillan, V. M., Shawchuck, C. R., & Hansen, D. J. (1989). A peer-mediated intervention with clinic-referred socially isolated girls. Generalization, maintenance, and social validation. Behavior Modification, 13(1), 32–50.	Participants not predominately secondary school age (11-16)
167	Hatfield, M., Ciccarelli, M., Falkmer, T. T., & Falkmer, M. (2018). Factors related to successful transition planning for adolescents on the autism spectrum. Journal of Research in Special Educational Needs, 18(1), 3–14. https://doi.org/10.1111/1471-3802.12388	Anxiety related to transition to secondary school, not secondary school experience.
168	Saggers, B., Campbell, M., Dillon-Wallace, J., Ashburner, J., Hwang, Y.-S., Carrington, S., & Tones, M. (2017). Understandings and Experiences of Bullying: Impact on Students on the Autism Spectrum. AUSTRALASIAN JOURNAL OF SPECIAL EDUCATION, 41(2), 123–140. https://doi.org/10.1017/jse.2017.6	No reference to anxiety in school or anxiety related to school experience
169	Chiu, Y.-L., Kao, S., Tou, S.-W., & Lin, F.-G. (2018). Effects of heterogeneous risk factors on psychological distress in adolescents with autism and victimization experiences in Taiwan. DISABILITY AND REHABILITATION, 40(1), 42–51. https://doi.org/10.1080/09638288.2016.1242173	No reference to anxiety in school or anxiety related to school experience

Appendix C CASP Table

Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist. Responses scored as: "clearly reported/comprehensive" scored as 2, "partially reported/considered" scored as 1, and "no/not reported/flawed" scored as 0.

		Aims	Qualitative	Research design	Recruitment strategy	Data collection	Relationship	Ethical issues	Data analysis	Findings	Valuable research	Score
1	Carrington and Graham (2001)	1	2	1	0	2	0	2	1	1	1	11
2	Clarke, Hill, & Charman (2017)	2	2	2	2	1	0	1	0	1	2	13
3	Connor (2000)	2	2	0	0	0	0	0	0	0	0	4
4	Hebron and Humphrey (2014)	2	2	2	0	1	0	2	1	2	2	14
5	Hill (2014)	2	2	2	0	1	1	0	1	1	2	12
6	Howe and Stagg (2016)	2	2	2	2	1	0	2	2	2	2	17
7	Humphrey and Lewis (2008a)	2	2	2	0	1	1	2	1	1	2	14
8	Humphrey and Lewis (2008b)	2	2	1	0	0	0	0	0	1	1	7
9	Jarman and Rayner (2015)	2	2	1	0	1	0	1	0	1	1	9
10	Lamb, Firbank, and Aldous (2016)	2	2	2	0	1	1	2	1	1	0	12
11	Marks, Schrader, Longaker, and Levine (2000)	2	2	1	0	1	0	0	0	0	0	6
12	Poon et al. (2014)	2	2	2	1	2	1	1	1	1	2	15
12	Saggers (2015)	2	2	2	0	2	0	2	0	0	0	10
13	Sciutto, Richwine, Mentrikoski, and Niedzwiecki (2012)	2	2	2	0	1	0	0	2	2	2	13

Appendix D Participation table

	Eligible pupils	N Participants	N Full parent data returned	N Full school data
School 1	20	4	4	4
School 2	10	3	3	3
School 3	15	1	0	1
School 4	5	1	1	0
School 5	8	1	1	1
School 6	26	8	7	7
School 7	17	8	6	8
School 8	15	0	0	0
School 9	6	0	0	0
School 10	7	1	1	1
School 11	5	1	1	1
School 12	10	2	2	2
Total	144	30	26	28

Appendix E Example information and consent form

Exploring school anxiety in adolescents with autism spectrum disorder

Who am I?

My name is Ellie Hayes and I am training as an Educational Psychologist with the University of Southampton. As part of my training I am carrying out research to better understand how anxiety affects children with autism or Asperger's in secondary school.

What is the project?

The aim of my research is to look at whether pupils with autism who show high or low school anxiety have a certain pattern of scores, for example high sensory needs, high autism symptom severity, or maybe low social skills. The hope is that if we can pull apart which is most related to school anxiety and autism, we can understand how best to prevent this and support pupils in secondary school. I will be sending questionnaires to parents, working with the pupil out of class, and asking a member of school staff to complete a questionnaire.

What is needed from parents?

- ✓ Please ensure you and your child read the attached information sheets.
- ✓ Then just sign the consent forms (making sure you initial the boxes by each statement), and return them free-post to the address in the envelope provided.
- ✓ Once I have received your consent form, I will send you the questionnaires to complete either by email (an online survey) or by post (to be returned to a free-post address), depending on which you choose on the consent form.

What is the benefit for families to take part?

Once I have worked with your child in school, they will be sent a £5 amazon voucher to thank them for the time they have spent out of class. Once I have completed the project, I will create an information leaflet to feedback to you what I have found. This will also be shared with schools and the Educational Psychology service.

If you have any questions, please contact me on **eh3g15@soton.ac.uk**
I look forward to hearing from you ☺

UNIVERSITY OF Southampton
School of Psychology

Appendix E

PARTICIPANT INFORMATION SHEET FOR PARENTS 4th August 2017, VERSION 4

Researcher names: Eleanor Hayes, Caitlin Murray; ERGO study ID number: 25392

Exploring school anxiety in adolescents with Autism Spectrum Disorder

Dear parent/carer,

I am a student from the University of Southampton training on the Doctorate in Educational Psychology programme, where my focus is in supporting children to learn better in school. As part of the course, I am carrying out a research project to explore school anxiety in adolescents with autism.

Before you decide to take part, please read the information below. If you are happy for your child to take part, you will be asked to sign a consent form.

What is the project about?

Research suggests that young people with autism show high levels of anxiety. Anxiety can cause distress, challenging behaviours, difficult relationships with friends and adults, and can have an impact on daily living and social activities. Some educators and researchers argue that the point of transition from primary to secondary school is anxiety provoking for all children, including children with autism. This may be because secondary schools are typically larger than primary schools, each lesson is often with a different teacher in a different room, requiring multiple transitions within the school day. Research suggests that young people with autism report feeling anxious in secondary school and describe it as chaotic and unpredictable.

I am interested in exploring which aspects of the school environment are particularly challenging for adolescents with autism or Asperger's syndrome. I also want to look at what factors might influence anxiety experienced at school, including the severity of autism symptoms, anxiety symptoms, sensory processing needs and social behaviour in school.

Why has my child been asked to take part?

I am interested in exploring the school experiences of adolescents with a diagnosis of autism, whether they present with anxious symptoms or not. Your child has been identified because they have a diagnosis of autism or Asperger's syndrome, are aged 11-14 and in year 7, 8 or 9 at a mainstream secondary school in the local area.

What will happen if they take part?

Once I receive a consent form signed by both you and your child, you will be posted a pack of 4 questionnaires. There will be two questionnaires asking about your child's symptoms of anxiety, one asking about their autism symptoms, and one asking about their sensory needs. Each should take no longer than 10 minutes to complete and you will be given a stamped addressed envelope to post the forms back as

soon as possible. Alternatively, you can choose to be emailed a link to complete these questionnaires anonymously online.

A member of staff who works closely with your child at school will be asked to complete a questionnaire about their social behaviour and provide information on their school, attendance, and achievement.

A researcher will then meet with your child out of class to complete a range of tasks which will last no longer than 90 minutes. During this time, a task to measure their verbal and non-verbal ability will be completed. They will also complete an anxiety questionnaire and a task to look at their experiences of school and any elements which may cause anxiety.

Your child will be offered a break after each task and will also be told they can request a break at any time. If they do not wish to continue after taking a break, they will be offered the option to stop completely and withdraw from the study with no consequences, or for the researcher to return another day.

Are there any benefits to taking part?

Your participation can help us to understand more about what may cause school anxiety in adolescents with autism. I hope that the findings of this project will then help schools and Educational Psychologists to understand how best to support adolescents with autism in secondary school. Your child will be sent a £5 amazon voucher to thank them for the time that they have spent out of class.

What are the possible disadvantages?

Whilst your child will be taken out of class to work with me, I will work with the SENCo to identify a suitable time for your child to be out of class to ensure they do not miss out on key lesson content. I do not think there will be any risks or dangers from taking part in the project. As we will be talking about what might make a young person feel anxious at school, there is the possibility that talking about this may make a young person feel upset. If this happens, the young person will be encouraged to share this with their parent/carer and the SENCo, who can support the young person. The Educational Psychologist (EP) linked to the school will also be aware of the research project. If you have any further questions or concerns, there are details below that you can contact.

Will people find out about what young people say?

Everything participants say or report will be kept 'confidential'. This means that the researchers will not tell anyone what you or your child have reported. This also means we will not store any information that can identify either your or your child such as names or schools. A document containing participant's names and their participant number will be kept separately on a secure password protected device that only the researchers can access. This will ensure that if you or your child change your mind after completing the tasks, you can contact us to withdraw the data up until December 2017 when the data is analysed.

However, if a participant says something which makes us worry about their safety or the safety of others, we do have to share this information with the appropriate agency.

What will happen to the results of the project?

I will collect the data from all participants and look for patterns or trends to help us understand school anxiety in adolescents with autism. I will then write a report about the findings (your child's name or school will not be identified in this report) which may then be shared with other professions in the format of a journal article or presentation. You will also be sent a leaflet summarising this report and the findings.

Do I have to take part?

You do not have to give permission for your child to take part if you do not want to. Your child does not have to take part if s/he does not want to. They may also ask to stop taking part at any time during the session with a researcher if they do not want to carry on.

What if there is a problem or I change my mind?

If you are worried about taking part or have any questions either before providing consent, whilst completing the forms, or after the study, you can contact me using the information below. If you or your child change your mind and wish to withdraw after completing the measures, you can contact the researchers and request that the data is deleted. This can be done up until the results are analysed in December 2017. There will be no consequence if you withdraw, and your child will still receive the £5 amazon voucher.

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 3856, email fshs-rso@soton.ac.uk

Contact details

Ellie Hayes

Email address: eh3g15@soton.ac.uk

Educational Psychology, Building 44a, University of Southampton, University Road, Southampton SO17 1BJ

PARENTAL CONSENT FORM

(*Version 4, 8th August 2017*)

Study title: Exploring school anxiety in adolescents with Autism Spectrum Disorder (ASD)

Researcher name: Eleanor Hayes and Caitlin Murray Ethics reference: 25392

Please initial the box(es) if you agree with the statement(s) to consent to participate:

I have read and understood the participant information sheet for parents (4th August 2017, Version 4) and have had the opportunity to ask questions about the study	☐
	☐
	☐
I agree that my child,_____, can take part in this research project and agree that their data can be used for the purpose of this study	☐
withdraw at any time without our legal rights being affected	
I agree to take part in this research project and agree for my data to be used for the purpose of this study	
	☐
I agree that as part of the research project, information on my child can be requested from his/her teacher or another key member of staff	

Contact Details: Please could you include your postal address below. This will only be used to send out the forms to complete and to provide a leaflet summarising the research findings.

Name of Child	
School Name	
Your Name	
Address	
Postcode	
Email address	
Please send questionnaires to complete by (please tick one) Email ☐ Post ☐	

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

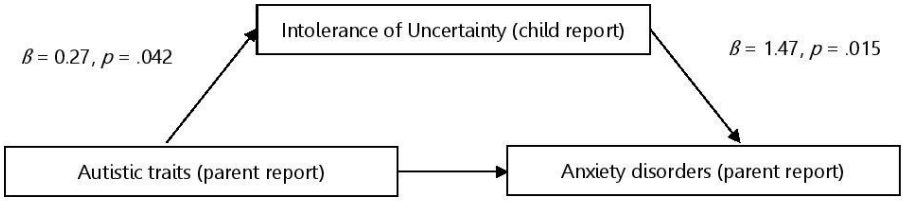
Name of participant (parent name) ……..

Signature of participant (parent signature) ……

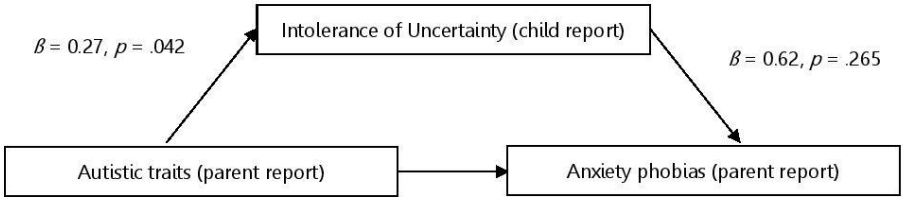
Date……

Appendix F Non-significant mediation models

Autistic traits to DSM based anxiety disorders and phobias, via child reported or parent reported IU.

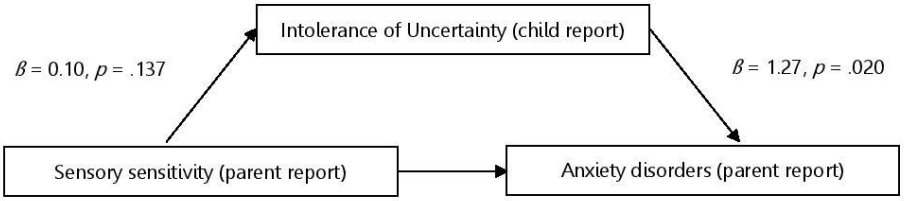


Direct effect, ß = 0.18, p = .641
Indirect effect, ß = 0.39, 95% CI [-0.03, 0.80]



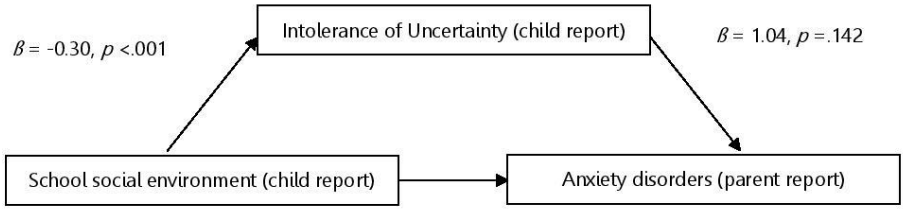
Direct effect, ß = 0.46, p = .226
Indirect effect, ß = 0.17, 95% CI [-0.22, 0.48]

Sensory sensitivity and DSM based anxiety disorders and phobias, via child reported or parent reported IU.

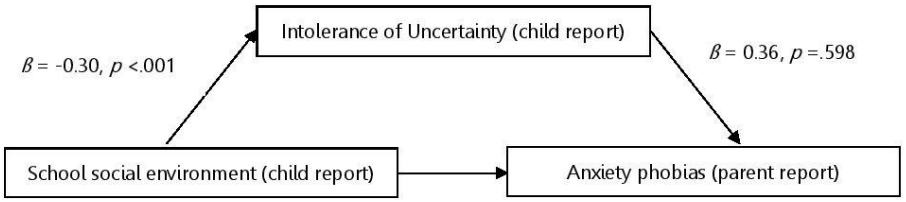


Direct effect, ß = 0.35, p = .059
Indirect effect, ß = 0.13, 95% CI [-0.06, 0.42]

Social environment and DSM based anxiety disorders and phobias, via child reported or parent reported IU.

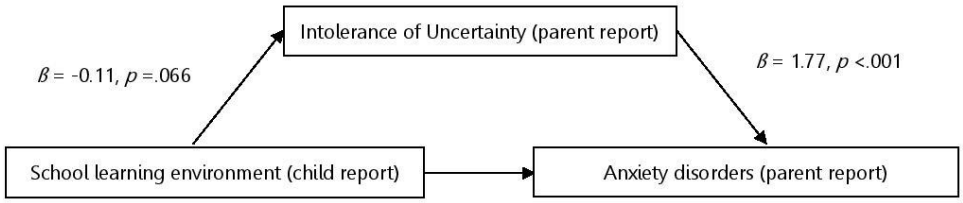


Direct effect, ß = -0.35, p = .267
Indirect effect, ß = -0.32, 95% CI [-0.85, 0.19]

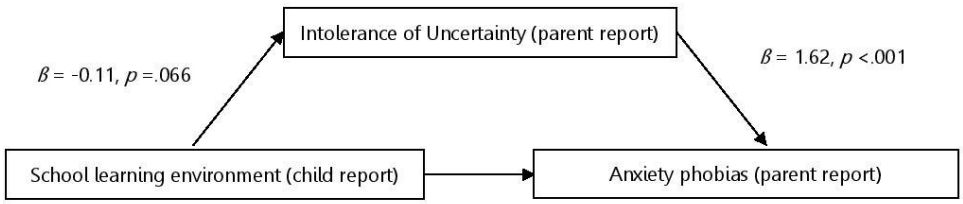


Direct effect, ß = -0.35, p =.270
Indirect effect, ß = -0.11, 95% CI [-0.62, 0.36]

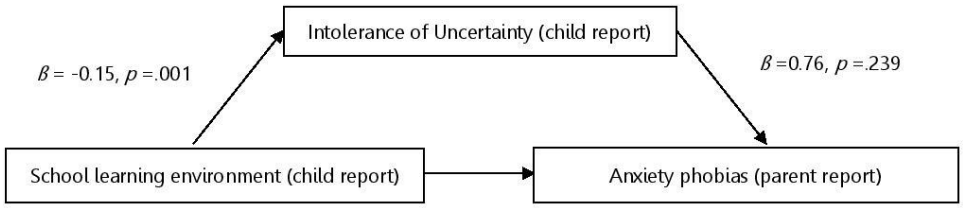
Learning environment and DSM based anxiety disorders and phobias, via child reported or parent reported IU.



Direct effect, ß = -0.05, p =.669
Indirect effect, ß = -0.20, 95% CI [-0.43, 0.002]

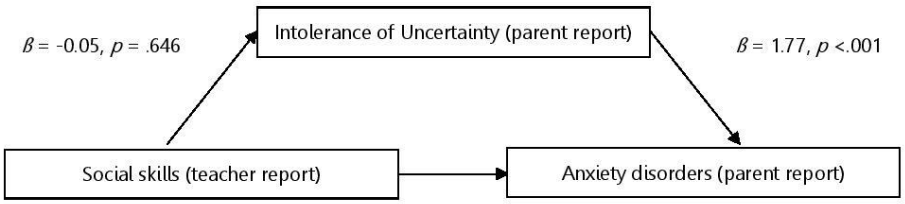


Direct effect, ß = 0.01, p =.910
Indirect effect, ß = -0.18, 95% CI [-0.39, 0.001]

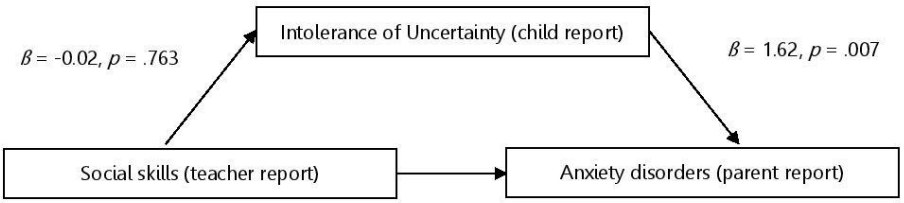


Direct effect, ß = -0.05, p =.742
Indirect effect, ß = -0.11, 95% CI [-0.43, 0.04]

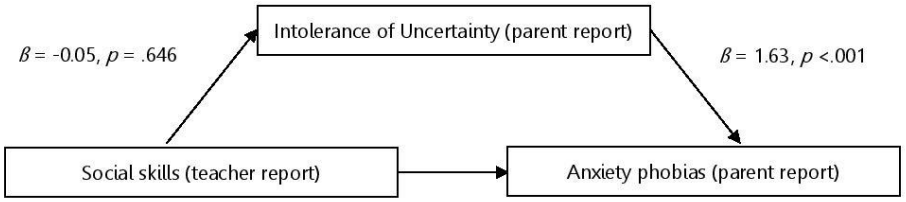
Social skills and DSM based anxiety symptoms, mediated by parent and child reported IU



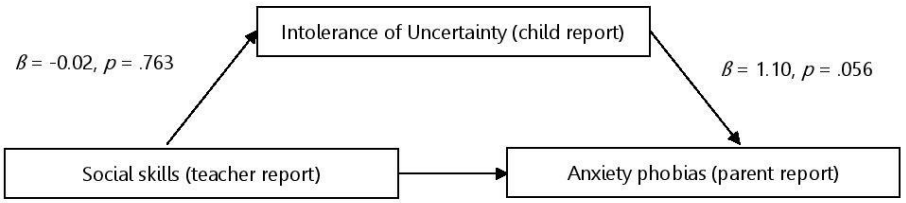
Direct effect, ß = -0.04, p =.799
Indirect effect, ß = -0.08, 95% CI [-0.43, 0.32]



Direct effect, ß = -0.08, p =.683
Indirect effect, ß = -0.04, 95% CI [-0.30, 0.36]



Direct effect, ß = 0.01, p =.940
Indirect effect, ß = -0.08, 95% CI [-0.43, 0.26]



Direct effect, ß = -0.04, p =.861
Indirect effect, ß = -0.03, 95% CI [-0.24, 0.23]

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