
**Doctorate in Educational Psychology Professional Training Programme**

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# Autism Spectrum Conditions and Anxiety in Mainstream Secondary Schools: An Investigation with Pupils, Parents and Learning Support Assistants

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**Part A**: Major Research Literature Review

**Part B**: Empirical Study

**Part C:** Reflective Summary

## *Summary*

This document contains three parts. Part A, the Literature Review, explores research relating to Autism Spectrum Conditions (ASC) and anxiety. The concepts are critically explored before links between the two conditions are identified and discussed. Psychological theories explaining some of the key characteristics of ASC and anxiety are appraised and similarities between psychological models are highlighted, before the literature on ASC and anxiety is analysed. Gaps in the current literature are identified along with a clear rationale for the current study. Part B, the Empirical Study, provides further exploration, detailing evidence gathered during semi-structured interviews with secondary school pupils who have a formal diagnosis of ASC, their parents and learning support assistants working with them. Findings are discussed in relation to the need for educational psychologists, school staff and other professionals working with pupils with ASC to understand better the impact anxiety has on such pupils' thoughts, feelings and behaviours in the school environment. Part C, the Reflective Summary, reviews the research process as a whole. The first section of the Reflective Summary considers the researcher's contribution to knowledge. The second section provides an account of the research practitioner in relation to the present study.

# *Declaration*

This work has not previously been accepted in substance for any other degree or award at this or any other university or place of learning, nor is being submitted concurrently in candidature for any degree or other reward.

Signed: *Abigail Wicks* Date: *29th April, 2014*

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This thesis is being submitted in partial fulfillment of the requirements for the degree of DEdPsy.

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This thesis is the result if my own independent work/investigation, except where otherwise stated. Other sources are acknowledged by explicit references.

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# *Table of Contents*

## *Abbreviations*

| | |
|---|---|
| ACT | Attentional Control Theory |
| ARB | Autism Resource Base |
| AS | Asperger Syndrome |
| ASC | Autistic Spectrum Conditions |
| ASD | Autistic Spectrum Disorders |
| CYP | Children and Young People |
| DSM | Diagnostic and Statistical Manual of Mental Disorders |
| EP | Educational Psychologist |
| ICD | International Classification of Diseases |
| PET | Processing Efficiency Theory |
| TA | Thematic Analysis |
| ToM | Theory of Mind |
| SEN | Special Educational Needs |
| LA | Local Authority |


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**Part A: Major Literature Review**

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# 1 OVERVIEW OF LITERATURE REVIEW

## 1.1 Introduction

The number of school-age children and young people (CYP) in the UK who have an autistic spectrum condition (ASC) has been increasing since the 1990s (Taylor, Hick & MacLaughlin, 2013). The debate surrounding the causes of this is on-going (King & Bearman, 2009). The most prevalent primary need amongst pupils with statements of Special Educational Needs (SEN) in mainstream secondary schools in England is ASC (Department for Education, 2012) making research in this area of particular relevance to educational psychologists (EPs). It is widely recognised that educating CYP with ASC is complex, with outcomes for these pupils being significantly lower than the outcomes for the general school population (Barnard, Prior, & Potter, 2000). It could be argued that EPs are well placed to provide on-going research, support and guidance to help raise outcomes for these pupils from an educational perspective.

While ASC is one of the largest groups of SEN in mainstream schools (Department for Education, 2013a), the most common mental health issue for school-age CYP at large is anxiety (Tomb & Hunter, 2004), which is particularly common in CYP with ASC (White, Oswald, Ollendick, & Scahill, 2009). Chalfant (2011) postulated that anxiety in the ASC population is high because of a number of interrelated factors. First, core social difficulties associated with ASC may exacerbate anxiety. Secondly, characteristic 'rule-driven' thinking typically seen in individuals with ASC could intensify anxious beliefs. Thirdly, the emotional regulation often thought to be limited in those with ASC could arguably predispose CYP to extremes of anxiety reactions.

ASC and anxiety can be thought of as distinct, multi-faceted concepts with an interwoven and complex relationship. It is argued in this review that the 'thinking styles' of those with ASC are, in part, similar to those of highly anxious individuals. This may, in turn, predispose those with ASC to high levels of anxiety. While anxiety has been associated with ASC since the pioneering work of Leo Kanner in the early 1940s, scant attention has been paid to the intricate connection between the two concepts until recently (White et al., 2009).

Because of the complex nature of both ASC and anxiety, they are first examined separately in chapters two and three in order to give a clear picture of their definition, prevalence and impact on CYP, with a particular focus on education. Psychological theories seeking to explain the characteristic behaviours and cognitions associated with ASC and anxiety will be critically appraised. The concepts will be brought together in chapter four. In this chapter the

psychological models used to explain ASC and anxiety will be examined and the author will seek to explain the connection between the conditions before a rationale for further research is proposed.

### 1.2 Relevance to EP Practice

EPs can be thought of as "scientist-practitioners who utilise for the benefit of children and young people psychological skills, knowledge and understanding through the functions of consultation, assessment, intervention, research and training at organisational, group or individual level" (Fallon, Woods, & Rooney, 2010, p. 4). For this reason it can be argued that EPs are well placed to transfer theoretical concepts into real world practice to facilitate positive change for CYP with ASC. Managing levels of anxiety in CYP with ASC has been described as "…the key to successful inclusion" (Hampshire Educational Psychology Service, 2009). Inquiry in this under researched area is therefore relevant to EP practice in order to develop EPs' understanding of how anxiety presents itself in CYP with ASC in the school environment. Through better understanding of the presentation of anxiety in CYP with ASC further support and interventions could be instigated at the individual, whole class and strategic levels within the school system to drive further positive change for the ASC population.

### 1.3 Key Sources

The literature cited in the present study was found using PsychInfo, ERIC and Science Direct. The literature search was based on ASC, anxiety and the psychological theories of both concepts. Search terms included 'ASC and anxiety', 'ASC and education', 'anxiety and education', 'ASC psychological theory' and 'anxiety psychological theory'. The search was completed in December 2013.

# 2 AUTISM SPECTRUM CONDITIONS

## 2.1 Overview

In this section, the term 'autism spectrum conditions' (ASC) will be introduced along with the current literature surrounding issues concerning the definition, prevalence and impact of ASC, particularly in the context of education. This overview will seek to highlight the scale of the condition and why research in the area of ASC and its impact on education, in particular, is paramount for positive change for the school-aged ASC population. Following this, there will be a critical discussion of the research literature surrounding the dominant psychological theories of ASC, which seeks to understand and explain the behaviours associated with the condition in a psychological context. The theories will be considered further in the context of education to anticipate how ASC may affect CYP's ability to access education and to manage and thrive in the school environment.

## 2.2 Defining Autism Spectrum Conditions

The phrase 'autism spectrum disorder' (ASD) is a generally accepted term in medical literature used to label those with various autistic traits and behaviours in to an appropriate clinical category. It is the author's view that the word 'disorder' highlights a medical perspective, in which a set of behaviours represent an illness that requires treatment to reduce the symptoms. In an attempt to portray a less stigmatising and more holistic view of autism and related conditions, the term Autistic Spectrum Conditions will be used throughout this literature review. The term ASC reflects that individuals not only have a disability requiring medical diagnosis, but that they also have areas of cognitive strength (Baron Cohen et al., 2009). While the term ASC will be used throughout, the author will be referring to the same set of characteristic behaviours that have been described in medical literature under the term ASD.

Until recently the 'autism spectrum' characterised a variety of distinct developmental conditions categorised as Pervasive Developmental Disorders (American Psychiatric Association, 1994). The conditions most typically associated with the term 'ASC' were autism and Asperger syndrome [AS] (Myers & Johnson, 2007). Autism and AS were seen as separately diagnosable conditions, both of which were defined by significant difficulties in reciprocal social interaction, difficulties with communication and stereotyped or repetitive behaviours, often thought of as a 'triad of impairment' (Wing, Gould, & Gillberg, 2011). As well as the core features of ASC, there are many other characteristics associated with the

condition that are thought to be typical but not universal, such as motor stereotypies including rocking and hand-flapping (Happé, 1994).

While autism and AS are both thought to be defined by the 'triad' described above, the distinction between the conditions was predominantly associated with the extent of cognitive ability and language skills, both of which were seen as reduced in CYP with autism (Lotspeich et al., 2004). There were further categorisations within the autism diagnosis, those of 'high' or 'low' functioning autism. Low functioning autism was generally regarded as being present if the individual had an IQ of 70 or below; high functioning autism (HFA) was diagnosed if the IQ of the individual was greater than 70 (American Psychiatric Association, 1994). Because of the similarities between AS and HFA in particular, there was heated debate over the existence of these conditions as separate categories (Baron Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001; Klin, Volkmar, Sparrow, Cicchetti, & Rourke, 1995; Macintosh & Dissanayake, 2004; Verte, Geurts, Roeyers, Oosterlaan, & Sergeant, 2006).

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders [DSM-5] (American Psychiatric Association, 2013) states that autism and AS no longer exist as singular conditions. CYP will receive the umbrella diagnosis, ASC. There are concerns that the more cognitively able CYP will not be eligible for a diagnosis and the subsequent support this could instigate. A large-scale study looking at 933 young people with a diagnosis of ASC under the criteria published in the fourth edition of the DSM found that under the DSM-5 criteria 39.4% would no longer received such a diagnosis (McPartland, Reichow, & Volkmar, 2012).

The definition of ASC is further complicated by the different definitions proposed in the DSM-5 and the International Classification of Disease, 10$^{th}$ edition (ICD-10). Both of these manuals are recognised diagnostic instruments in the UK. While the DSM-5 has stated that there are no longer thought to be distinct categories of ASC, the ICD-10 (World Health Organization, 1992) has a more international focus than the DSM-5 and states that various divisions of ASC exist, including Asperger syndrome. The divergence between the two diagnostic manuals perhaps highlights the varying social constructions regarding ASC and, importantly, reminds us that there is no universal 'truth' concerning the term and its presentation.

Despite the diagnostic differences between the DSM-5 and the ICD-10, it is widely accepted that the autistic spectrum encompasses an extensive range of behavioural characteristics, which can vary dramatically from person to person (First, 2009). Perhaps then it is not

surprising that creating an appropriate categorisation system for such a condition has caused much debate and continued modification. Predictably, prevalence rates of ASC are also under debate. It could be argued that until there is agreement over what is being measured, then accurate prevalence rates will be difficult to quantify.

### *2.2.1 Prevalence*

When there was an initial move away from the early construction that autism was a unitary condition and it was accepted as part of a spectrum of difficulties, in the early 1980s and 1990s, the number of prevalence studies increased as did the reported numbers of individuals with ASC in the population (Wing & Potter, 2002). However, many studies are hard to compare, due to different population samples, disparities in diagnostic criteria used and general methodological variances (Baron Cohen et al., 2009). ASC has been described as a low incidence disability, which has increased in prevalence because of a number of factors, including media exposure (Fogt, Miller, & Zirkel, 2003). Wing and Potter (2002) suggest that the increased prevalence is likely to be due to improved recognition of the condition, increased awareness on the part of both parents and professionals and improving diagnostic techniques.

Despite the debate over the reasons for increasing prevalence numbers, it is generally accepted that the number of individuals with ASC being diagnosed is on the increase (Baron Cohen et al., 2001). A recent US government report claims that ASC is diagnosed in approximately two percent of CYP in the USA, a figure up from 1.6 percent in 2008 (Blumberg et al., 2013). A similar pattern is reported in the UK (Department for Education [DfE], 2012).

In summary, it is evident that the terminology and categorisation of ASC are evolving and diagnosis rates are increasing in the general population. The next section moves beyond definition and prevalence of ASC and seeks to understand the psychological theories that attempt to explain the behaviours associated with the condition, paying particular attention to how such behaviours might affect CYP in an educational setting. The school environment has been described as challenging for CYP with ASC because of their inherent difficulties with social situations and communication and their sensory sensitivities. The theories discussed below will attempt to explain the reasons why this may be.

## 2.3 Psychological theories

It is generally accepted that ASC is a predominantly genetic, neuro-developmental disorder with a biological basis (Medical Research Council [MRC], 2001). However, there are several prevalent psychological theories that seek to explain the characteristic behaviours of those with ASC. It has been argued that the established psychological theories of ASC are cognitive theories and sit between the biological and behavioural levels of explanation (Frederickson, Miller, & Cline, 2008).

While each cognitive theory was initially suggested as a single explanation for all behavioural characteristics associated with the ASC diagnosis (Happé, 2003), it is now thought that there are a number of core cognitive processes that are involved with ASC. Consequently, the different cognitive theories can account for distinctive elements of behaviour (Happé, Ronald, & Plomin, 2006). The predominate theories are 'theory of mind' (Baron-Cohen, Leslie & Frith, 1985), 'central coherence theory' (Frith, 1989) and 'executive dysfunction' (Ozonoff, Pennington, & Rogers, 1991). Each of these theories will be considered in turn as complementing, rather than competing, theories in an attempt to explain the characteristic behaviours of those with ASC. There will be a particular emphasis on the relevance of these theories to education and the school environment.

### *2.3.1 Theory of Mind*

Theory of mind (ToM) seeks to explain the social communication difficulties experienced by those with ASC. ToM has been described as an individual's ability to 'mind-read' others in order to predict behaviour (Frith & Happé, 1994). It is the intuitive ability individuals have to recognise other people's thoughts, feelings and intentions, as well as their own, which enables the internal construction of a social world (Baron Cohen, Tager-Flusberg, & Cohen, 2000). The essence of the ToM model is that CYP with ASC do not have this mind-reading capacity, a process called 'mentalising'(Baron Cohen, Leslie, & Frith, 1985). This model was originally tested using the false belief task, more commonly known as the 'Sally-Anne' experiment, which supported the theory. While various other tests of ToM have been developed, there is evidence to suggest that differences between CYP with ASC and typically developing peers occur on some tasks, but not all (Frederickson et al., 2008). This suggests that different tests may gauge varying aspects of an underlying construct labelled ToM (Yirmiya, Erel, Shaked, & Solomonica-Levi, 1998).

There have been some concerns over the applicability of ToM to the 'real world' (Volkmar, Lord, Bailey, Schultz, & Klin, 2004). One study suggested that, despite an 18-week intervention teaching ToM skills to a group of adolescent boys, there was no advancement in

their real-life social competence (Ozonoff & Miller, 1995). However, this study comprised only four participants, and it could be argued that the relative timescale of the intervention was too short. A meta-analysis of the literature suggests that a ToM deficit does characterise individuals with ASC. It is not, however, a construct unique to those on the autistic spectrum. What was found to be unique to ASC was the severity of the ToM impairment compared to typically developing CYP and those with other learning difficulties (Yirmiya et al., 1998).

Despite the critiques of the ToM framework, there has been considerable evidence over the years that suggests that CYP with ASC have disproportionate difficulties with mentalising (Frith, 2003). This helps explain why everyday social situations for CYP in school are so challenging (Goldstein & Winner, 2012). CYP who experience such difficulties are likely to find it hard to make friends, because of their reduced ability to read non-verbal cues from peers – such as boredom or annoyance. Furthermore, they will experience a lack of understanding of the unwritten social rules that often change in different social contexts (Gross, 1994).

There is a belief that those with ASC prefer isolation and do not wish to engage with others (O'Neill, 1998). However, it may be that they are acutely aware of their difficulties with social scenarios and avoid them to escape the accompanying anxiety that prevails. Indeed, this is supported by a study suggesting children with ASC experience high levels of loneliness, inferring that they have "social desires" (Bauminger & Kasari, 2000, p. 452). Therefore, while ToM may explain why socialising with peers is challenging, it may be the accompanying anxiety that causes the avoidance of social situations and increases the likelihood of CYP with ASC becoming isolated.

### *2.3.2 Central Coherence Theory*

Central coherence theory seeks to explain elements of learning and social skills in those with ASC. Central coherence is a term used to describe an individual's ability to focus on, or conceptualise, whole chunks of information, rather than individual parts (Happé & Frith, 2006). Central coherence is thought to be lacking in those with ASC and thus they are more likely to focus on individual details, at the expense of global information, making them extremely skilled at absorbing intricate details. This ability is demonstrated in persons with ASC who display heightened performance in tasks requiring the ability to focus on individual parts, such as the 'block design' element of IQ tests, which measure non-verbal reasoning skills (Shah & Frith, 1993).While this might mean that individuals with ASC have exceptional perceptual skills, this reduced central coherence can also be maladaptive in that

small changes in the environment are noticeable and can cause distress (Happé & Frith, 2006). This could explain why such small changes to school and classroom routines, as well as unpredictable free-time scenarios, can cause high anxiety and distress.

Central coherence theory has also been used to attempt to explain the inherent difficulties those with ASC have with social situations. Because of the difficulty CYP with ASC have linking parts of information to create context in a more global sense, subtle cues that create meaning in a social context may be missed, causing confusion and misunderstanding (Winner, 2002). However, there is little direct research evidence for the implications of 'weak central coherence' in social processing (Volkmar et al., 2004).

Further criticism of the central coherence model relates to the inconsistency of the research findings. One study looking at only group differences on a range of global-local visual tasks reported that while CYP with ASC did show superior performance in some tasks (and therefore demonstrating good processing of individual details), this was not consistently the case (Mottron, Burack, Iarocci, Belleville, & Enns, 2003). However, only persons with Asperger Syndrome were included in the study and the number of participants was below 20, which makes it hard to draw conclusions when discussing central coherence in terms of the ASC population more generally.

While there have been conflicting experimental findings, a robust review of the literature suggests that the evidence for central coherence theory is sizeable and growing with the use of neuroimaging research (Volkmar et al., 2004). The debate continues.

### *2.3.3 Executive Dysfunction*

Executive dysfunction has been described as a blanket term for myriad cognitive functions linked to the commencement and monitoring of actions including inhibition, flexibility, impulse control and working memory (Stuss & Knight, 2013). The broadness of the term makes it hard to pinpoint what researchers are measuring when they refer to 'executive function'. Indeed, creating standardised measures for such an array of possible cognitive functions is challenging, especially when trying to control for related and influential factors such as language ability and attention (Pennington & Ozonoff, 1996). Executive dysfunction has been reported in other neuro-developmental disorders such as Attention Deficit Hyperactive Disorder (ADHD), creating a lack of specificity to ASC. However, there is evidence that there are elements of executive dysfunction that are specific to ASC (Hill, 2006). A review paper, looking at studies from 1986 to 2006, suggested that the most striking

executive difficulties school-age CYP with ASC face, regardless of ability, are concerned with planning and flexibility (Hill, 2006).

Difficulties with planning, flexibility and other executive functions such as working memory can cause a range of learning challenges for CYP with ASC. For example, in the secondary school environment homework and coursework are commonplace and require a great deal of planning. Not having the skills to execute appropriate planning is likely to result in high levels of anxiety and possible avoidance of such tasks. Couple this with group exercises, where good social communication is needed and it begins to become clear how challenging and anxiety-provoking the school environment may be for CYP with ASC.

In summary, this section contains a critical discussion on the dominant psychological theories that attempt to explain the characteristic behaviours of those with ASC. It could be argued that, while these theories can explain the behavioural aspects of ASC, little attention has been paid to the re-occurring theme of anxiety, which seems to be an apparent consequence of each area of difficulty discussed. The next section of the current chapter seeks to move away from the psychological explanations of ASC and look more closely at the ramifications of ASC in the school environment, in order to examine how ASC affects CYP in their education.

### 2.4 ASC in the context of education

The number of CYP with ASC who are being educated in mainstream school environments has increased over the years (Humphrey & Lewis, 2008; Michael, 1999). There is some suggestion from a nationwide survey, representing a pupil population of 13,264, that the number of CYP with ASC in the United Kingdom surpasses the reported prevalence rates (Barnard, Steve, Potter, & Prior, 2002).

Despite the surge in pupil numbers and the emphasis on inclusion (Department for Education, 2001) there is still a substantial number of CYP with ASC attending special schools. Recent statistics suggest the figure to be 20.5%, which is disproportionate to CYP with disabilities other than severe learning difficulties (Department for Education, 2012). While it is acknowledged that a high number of pupils with ASC are still educated in specialist provisions (Department for Education, 2013a), the literature on specialist provisions will not be considered in this literature review, as the focus of the Empirical Study (see Part B) is on mainstream experiences of pupils with ASC, albeit in schools with specialist ASC units.

Educating CYP with ASC can be complex (Iovannone, Dunlap, Huber, & Kincaid, 2003) and it has been argued that the placement of CYP in an inclusive environment is alone an inadequate response to the challenge (Ochs, Kremer-Sadlik, Solomon, & Sirota, 2001). This is accentuated by the high number of exclusions that CYP with ASC experience, which is 20 times higher than the rate for pupils without ASC in mainstream schools (Barnard et al., 2000). Suggestions for increasing mainstream schools' abilities to support those with ASC are: increased training and support from local authorities; better links with special schools for advice and guidance; and increased access to professionals, including educational psychologists (Barnard et al., 2002).

A number of charities and government bodies have published advice and information on the education of CYP with ASC (Autism Working Group, 2002; Charman et al., 2011; Department for Education, 2009; Jordan, Jones, & Murray, 1998). The Autism Education Trust (AET), a charitable body dedicated to improving education for all CYP with ASC, published a comprehensive research report in 2011 investigating elements of good practice in autism education (Charman et al., 2011). Teachers from 16 secondary schools were interviewed. The secondary schools included in the study comprised specialist ASC schools and mainstream schools with a specialist Autism Resource Base (ARB) attached. The Office for Standards in Education (OFSTED) rated all schools included in the study 'outstanding' or 'good with outstanding features'. Charman et al., (2011) concluded that key features of successful schooling for pupils with ASC included the following: high expectations from staff; a range of assessment measures to monitor individual progress; effective and sustainable relationships with health and social care professionals; good communication with families; and staff training, which was made a priority. While this paper gives clear guidance on good practice guidelines, it lacks practical advice for teachers at the classroom level.

The Department for Education (2009) published the Inclusion Development Programme (IDP), which was created specifically to help teachers support CYP with ASC. The IDP provided a range of materials to support teaching professionals in their daily working with pupils with ASC. The aim of the IDP was to increase outcomes for those on the autistic spectrum by increasing teachers' knowledge and understanding of ASC. It provides clear and accessible information about the presentation of ASC and general guidance for the classroom.

A publication from the Autism Working Group (2002) provides more practical information for teachers about how to teach children with ASC in the classroom. Clear and concise strategies for teaching social interaction and communication are provided, as well as ideas for promoting positive behaviour management in the classroom. The National Autistic Society

(NAT) also published a guide for teachers, which offers more practical solutions at the classroom level (National Autistic Society, 2014). The publication suggests professionals teaching CYP with ASC use the 'Structure, Positive, Empathy, Low Arousal and Links' (SPELL) framework (National Autistic Society, 2014). This framework provides a combination of a structured approach to meeting the needs of CYP with ASC in the classroom and flexibility when it comes to meeting individual's needs.

There is a limited amount of literature depicting what school is like for CYP with ASC. While the guidance available to schools from charitable bodies and government departments provides comprehensive information about the schooling of pupils on the autistic spectrum, the literature lacks in-depth views from individuals' perspectives and there is little focus on the impact that anxiety has on the behavioural presentations of those with ASC. The studies that do exist are small scale and qualitative in nature and give insight into individual experiences. One such paper highlighted the difficulties adolescent boys have navigating the social element of school and how developing friendships is a stressful and upsetting process, due to ToM difficulties coupled with wanting to fit in (Carrington & Graham, 2001). Another prominent difficulty highlighted in the Carrington and Graham paper contributed evidence to support the notion that ASC is linked to weak central coherence as the participants in the study highlighted the challenge of 'shutting out' their special interests in order to focus on learning. This may also be true when the pupils are trying to shut out classroom distractions such as noise (Humphrey & Lewis, 2008). A further thought-provoking observation from the Carrington and Graham study was that CYP hide stress and anxiety at school and let out their emotions at home, a term described as 'masquerading' (Carrington & Graham, 2001). However, based on only two male pupils, the results must be considered with caution as insights rather than generalisable findings.

In terms of subject preference, a further qualitative study with a larger number of secondary school age participants (16 in total) suggested that factual and practical subjects were favoured over lessons that required lengthy writing, discussion or peer interaction (Connor, 2000). If this is taken in the context of central coherence theory, it could be hypothesised that this finding supports the detailed focus-processing style (Happé & Frith, 2006) of people with ASC and their difficulty with ambiguous or global tasks such as essay writing. Interestingly, a number of respondents in Conner's paper cited physical education as a preferred subject, despite the social element often associated with such lessons (Connor, 2000). However, it was not stated whether participants enjoyed team or individual sports, where the relevance of the social element would be clearer.

A more recent paper that obtained the views of 20 secondary school pupils with ASC brought to the fore individuals' interpretations of ASC and what it meant to them. The majority of respondents had a negative view of ASC and wanted to 'be normal'. Interestingly, a sub-group of two CYP who both had developed peer friendships had a more positive view of themselves and of ASC (Humphrey & Lewis, 2008). Indeed, there is evidence to suggest that peer friendships impact on psychological adjustment and is important for both emotional and social development in those with ASC (Bagwell, Newcomb, & Bukowski, 1998).

In summary, there is research coming to the fore about what schooling is like for CYP with ASC from both social and academic perspectives. However, despite the large number of children with ASC attending mainstream school it seems that the process of facilitating their learning and participation may continue to be inadequate (Humphrey & Lewis, 2008). There is often the assumption that, because a pupil with ASC may be able academically, he or she should be able to cope with mainstream school (Moore, 2007). However, this is arguably not the case when the literature on pupil outcomes are considered (Barnard et al., 2000).

# 3 ANXIETY

## 3.1 Overview

In this chapter, the term 'anxiety' will be introduced, along with an examination of the current literature surrounding issues of definition and prevalence. Following this, there will be a critical discussion of the research literature on the dominant psychological theories of anxiety, which seek to understand and explain anxiety in a psychological context. These theories will be considered further in relation to ASC, with regard to psychological theories explaining ASC discussed in section 2.3. Finally, anxiety will be considered in the educational context, with a focus on the difficulties that CYP with ASC may encounter in the learning environment.

## 3.2 Defining Anxiety

Anxiety can be thought of as a preparatory mood-state that is orientated towards the possibility of future negative events (Barlow, 2002). This separates it from fear, which is experienced when a danger is nearby and looming (Rachman, 2004). It is a concept associated with notions such as 'nervousness' and 'worry'; indeed the words are often used interchangeably to describe anxiety. The many uses of the term and varying constructions make it problematic to define. However, it is generally accepted in the literature that anxiety is a complex threat-response that varies in severity, involving behavioural, physiological and cognitive components (Stallard, 2009).

Anxiety can be conceptualised as a natural reaction to facilitate self-protection (Stallard, 2009) and has been described as a "defensive emotion" (Barlow, 2000, p. 1249). Anxiety can become severe and persistent, causing personal distress, reduced functionality and a reduction in an individual's quality of life. In such incidences an anxiety disorder is often diagnosed (Martin-Merino, Ruigomez, Wallander, Johansson, & Garcia-Rodriguez, 2010). While there remains controversy over the categorisation of anxiety disorders and the diagnostic procedures for identifying them (Craske et al., 2009), there are currently 12 diagnosable varieties of anxiety disorder, including "social phobia" and "generalised anxiety disorder" (American Psychiatric Association, 1994). Extreme anxiety does not only present itself in anxiety disorders; it has also been described as a central feature of many psychological conditions, such as depression (Rachman, 2004) and ASC (Kanner, 1943).

### *3.2.1 Prevalence*

The World Health Organisation conducted a mental health survey on over 60,000 adults across 14 countries. The results suggest that anxiety was the most common mental health problem reported (Demyttenaere et al., 2004). Most epidemiological studies and reviews have focused on the presence of anxiety in specific age groups or focused on the aetiology of a particular anxiety disorder such as social phobia or generalised anxiety disorder, making comparisons and generalisations difficult. A longitudinal study looking at anxiety more generally suggested the prevalence of anxiety in the UK population to be 7.2% (Martin-Merino et al., 2010). However, the study only sought participants from primary-care settings, making this clinical sample difficult to generalise to the population at large.

Focusing on CYP in particular, it has been suggested that anxiety disorders in all children are common and constitute the largest group of mental health problems during childhood (Beesdo, Knappe, & Pine, 2009; Stallard, Richardson, Velleman, & Attwood, 2011). A meta-analysis of the main prevalence studies in the USA concluded that anxiety in CYP had increased substantially between 1952 and 1993, indicating that anxiety levels had risen by one standard deviation in 41 years (Twenge, 2000). In contrast, another longitudinal study that collected data from three substantial community settings in 1979, 1988 and 1999 found that prevalence rates of anxiety in CYP between the ages of four and sixteen to be relatively stable (Achenbach, Dumenci, & Rescorla, 2003). The latter study may be more robust because it used the same measures of anxiety throughout the analysis, while the former study did not control for this variable.

In summary, while there is on-going debate surrounding the rise in anxiety disorders, it is generally accepted that they constitute a substantial psychopathology that affects a significant number of CYP and adults alike (Costello, Egger, Copeland, Erkanli, & Angold, 2011). This is problematic because of the known vulnerabilities associated with anxiety, including poor educational, social and mental health outcomes (see section 3.4). The next section moves away from the definition and prevalence of anxiety and scrutinises the psychological explanations that seek to explain the aetiology of anxiety, which are important in providing theories on which to base interventions and support.

## 3.3 Psychological theories

In a review paper Strongman (1995), categorises the theories of anxiety into six epistemological positions. These include four dominant fields of thought, namely psychoanalytic theories, cognitive explanations, learning theories and biological explanations, as highlighted by Rachman (2004). Psychodynamic approaches are important historically in

the development of anxiety theory, but the evidence base and applicability to real life scenarios is questionable (Rachman, 2004), and as a result will not be considered in this review. As in the literature on ASC (see section 2.3), cognitive explanations sit between biological and behavioural levels of explanation and will be the main focus here. Biological explanations could be thought to lack psychological input, as they tend to focus on explaining particular anxiety disorders, rather than providing a general model of anxiety. Consequently, they will also be excluded from the critique. However, bio-psychological elements of anxiety are acknowledged in both learning and cognitive models and will be discussed. The theories will be considered in the order in which they evolved so that, while they have been separated into categories for the purpose of review, the connections between the theories will be considered.

### *3.3.1 Learning Theories*

The underlying premise of learning theories is that all behaviours, including anxiety reactions, are acquired and maintained through interactions with the environment also known as learning processes (Watson, 1994). It is postulated that anxiety is a learned fear response that results in avoidance or escape behaviours. These behaviours are thought to persist because of the reduction in anxiety caused by the escape or avoidance, thus reinforcing the successful anxiety-reducing behaviour (Rachman, 2004). While the majority of early experiments in this area were carried out on animals, such pioneering concepts have good explanatory power. Nevertheless, they cannot alone explain anxiety acquisition and maintenance in its entirety (Rachman, 2004). Further, pioneering learning theorists took little or no account of individual differences in personality, cognitions or genetics. Despite this, traditional learning theories such as classical conditioning are the bases of many later learning theories that take into account the role of personality and biological contributions in the aetiology and maintenance of anxiety (Eysenck & Rachman, 1965; Gray, 1987). Learning theory forms the foundations of cognitive and cognitive-behavioural theories of anxiety, which are highly influential today in the treatment of anxiety disorders (Stallard, 2009).

### *3.3.2 Cognitive Explanations*

The underlying assumptions of the cognitive approaches, which display a marked shift from the traditional learning theories, is the belief that the interpretation, or cognitive processing, of an object or an event causes anxiety, not the object or event itself. The influence of other factors such as the mood of the person and his or her past experiences are also acknowledged (Salkovskis, Clark, & Gelder, 1996). The first cognitive model of anxiety proposed that anxiety arises because of the selective processing of information that signifies psychological or physical danger and the individual's tendency to underestimate his or her ability to cope with it (Beck & Rush, 1985). This results in a complex pattern of cognitive, physiological,

behavioural and affective changes that are generally accepted as the defining characteristics of anxiety in the current literature.

In an attempt to elaborate on these complex processes, a three stage information processing model was proposed ten years after the original cognitive model of anxiety was created (Beck & Clark, 1997). The first stage of the model suggests that there is an automatic, unconscious recognition of stimulus that acts as an "early warning detection system" (Beck & Clark, 1997, p. 51) for threat or danger. While this evolutionary process is evident in all individuals, those with anxiety are likely to give greater attention to negative or personally relevant stimuli than those without (Waters, Wharton, Zimmer-Gembeck, & Craske, 2008). Furthermore, it has been suggested that a bias towards threat signals can lead to misinterpretation of ambiguous information as anxiety-provoking, because of a reduced consideration of the global context (Kendall, 1985). Interestingly, this information processing style is similar to that observed in those with ASC, proposed by central coherence theory [see section 2.3] (Happé & Frith, 2006). It is possible that individuals with ASC think in a similar manner to those with anxiety disorders. There is, in other words, a narrowing of attention, possibly making them vulnerable to experiencing high levels of anxiety because of their tendency to focus on specific rather than global information.

The second stage of the information-processing model of anxiety is referred to as 'immediate preparation' (Beck & Clark, 1997). At this stage there is a conscious effort to reduce the danger presented by the perceived threat and to increase personal safety. Thinking in this stage becomes rigid and inflexible; thoughts are negative, involuntary and repetitive. Attentional resources are consumed by the threat stimulus, so that the global context is ignored. The resulting behaviours range from a flight or fight reaction to behavioural immobilisation. Avoidance can also take place (Beck & Clark, 1997). Avoidance behaviour can be explained by learning theory, which suggests that the temporary relief gained from avoiding the anxiety-provoking situation is rewarding and encourages repetition of the behaviour. However, in the long-term, avoidance serves to strengthen the anxiety and encourages escape behaviours (Mowrer, 1960). Again there are parallels between this stage of the model and cognitive explanations of behaviours associated with ASC. The executive dysfunction theory (Hill, 2006) [see section 2.3] suggests that those with ASC have difficulty controlling and regulating thought processes, which leads to the rigid, inflexible thinking style also seen in anxious individuals.

The final stage of the information-processing model, 'contextual processing' (Beck & Clark, 1997), is of particular interest in the context of ASC because it is described as "…a type of

contextual processing involving the self-in-relation-to-the-world." (Beck & Clark, 1997, p. 53). This ability to understand the self in relation to the world is something known to be challenging for those with ASC, because of their reduced capacity of ToM (Baron Cohen, 1997). Therefore, this final processing stage is unlikely to take place for those with ASC. Research suggests that an inability to partake in this final stage of 'secondary elaboration' may be a key part of anxiety maintenance (Zinbarg, Barlow, Brown, & Hertz, 1992), which may make those with ASC more vulnerable to experiencing anxiety. It is also thought that the lack of secondary elaboration could exacerbate anxiety levels, because of an inability to re-assess the anxiety provoking situation (Beck & Clark, 1997), making CYP with ASC particularly susceptible to high levels of anxiety.

In summary, the theories of anxiety presented show a clear progression from a learning paradigm to a more complex intergratory model of cognitive theories, which are more inclusive of biological factors and individual differences. The psychological theories of anxiety show some interesting links to the psychological theories of ASC and it could be tentatively suggested that there are similarities between the psychological mechanisms of both conditions.

### 3.4 Anxiety in the context of education

CYP who suffer from prolonged periods of excessive anxiety are at substantial risk of adverse long-term outcomes (National Scientific Council on the Developing Child, 2010). Anxiety can interfere with CYP's ability to engage with home life, community activities and school. It has been argued that high levels of anxiety can have a negative effect on early learning in young children and a continued negative influence in later school academic performance (Middlebrooks & Audage, 2008), making further research in this area of particular relevance to EPs.

A small-scale study (Owens, Stevenson, Hadwin, & Norgate, 2012) investigated the effects of anxiety, worry and depression on academic achievement in UK school children. Anxiety, depression and worry levels were measured using psychometrically validated self-report measures with a group of year eight pupils in one school. The scores were then compared to the results these pupils obtained in their National Curriculum standard assessment tests. Results showed that anxiety, worry and depression were related to lower academic performance (Owens et al., 2012). While this study replicated previous findings (Putwain, 2009), causality cannot be determined, making it difficult to interpret whether the low-test scores caused anxiety or if the anxiety caused the lower test scores. Further, anxiety and depression were highly correlated in this study, making it difficult to disentangle the effect of

one mood-state over the other. Despite the limitations of this study, there is a general acceptance in the literature that anxiety and academic performance are related, albeit modestly (Seipp, 1991).

It is thought that academic performance, and learning more generally, are adversely affected by anxiety because of its effect on cognitive processing and performance. One of the first theories to explain this was proposed by Eysenck and Calvo (1992) in their 'Processing Efficiency Theory' (PET), which is based on the fundamental assumption that task performance is reliant on two concepts, 'effectiveness' and 'efficiency'. In terms of academic performance, effectiveness refers to the quality of the work produced, whereas efficiency signifies the association between the effectiveness component and the attentional resources used to achieve the goal. It is hypothesised that anxiety creates worry, which has a detrimental affect on an individual's efficiency, not his or her effectiveness.

The model suggests that anxiety affects the efficiency of the 'central executive' section of working memory (Baddeley, 1992), which is responsible for the regulation and control of cognitive processes, such as shifting between tasks, selective attention and integrating information from a range of sources (Baddeley, 1992). Worry takes up these resources, leaving the individual unable to carry out these central executive tasks efficiently. Many of the learning activities that CYP engage with in the classroom place a sizeable load on the working memory system, as all school subjects typically require the CYP to hold some information in-mind to some degree (Gathercole & Alloway, 2007). In the context of school, this would mean that anxious pupils would typically find it difficult to keep on task, particularly when completing complicated undertakings.

There are limitations in the model. First, the central executive is thought to be responsible for a variety of functions within working memory, which have been shown to be independent processing systems (Miyake et al., 2000). There is no specificity in PET as to which of these systems anxiety interferes with. Secondly, the cognitive tasks used in the experiments that support PET used only neutral stimuli, as opposed to 'threat-related stimuli', which are thought to affect the performance of anxious individuals more readily than neutral cognitive tasks (Eysenck, Derakshan, Santos, & Calvo, 2007).

In response to the limitations of PET, Eysenck et al. (2007) developed 'Attentional Control Theory' (ACT), which has the fundamental assumption that anxiety disrupts efficiency by affecting two of the three functions of the central executive, namely, 'inhibition' and 'shifting' (Miyake et al., 2000). The former is thought to be involved in resisting interference

from stimuli unrelated to the task at hand, the latter being responsible for shifting attention between multiple tasks.

In the context of education, the argument might be that pupils with high levels of anxiety would require significantly greater effort to compensate for the interruption to attentional resources than those with low anxiety, resulting in more time needed to complete tasks effectively. It could be argued, therefore, that in busy classrooms, where time is always limited, the learning of an anxious individual may be adversely affected.

In summary, CYP with high trait anxiety are likely to have disruption of cognitive processes, which in turn affects their ability to complete more complex tasks without a significantly greater amount of effort. It is therefore understandable that CYP with high levels of anxiety are at substantial risk from serious educational problems in the broader context, which is linked to underachievement in later life, substance abuse and other psychiatric symptoms (Velting, Setzer, & Albano, 2004).

# 4 AUTISM SPECTRUM CONDITIONS AND ANXIETY

## 4.1 Overview

Until this point ASC and anxiety have been discussed independently in order to provide the reader with a comprehensive account of the two concepts. The topic of education has been a uniting theme throughout the chapters. Psychological theories presented in chapters two and three will be utilised in this section, and an examination of the complex, interwoven relationship between ASC and anxiety will be further explored. The research to date surrounding anxiety and ASC will first be critically evaluated before a closer examination of the literature surrounding education, ASC and anxiety is presented. The chapter closes with an academic rationale for future research in the area, based on the literature explored throughout the review.

## 4.2 A critique of current research

The hypothesised relationship between ASC and anxiety is not a new phenomenon; indeed, the connection was first proposed in the early accounts of autism and hypothesised to underlie many of the behaviours thought to define ASC (Kanner, 1943). However, while anxiety is considered to be an associated feature of ASC, it is not thought of as a key characteristic (American Psychiatric Association, 1994). Anxiety has been in the background of ASC research for many years; indeed, it is thought that the assessment and management of anxiety occurring in the ASC population "…has only recently received the attention it deserves." (White et al., 2009, p. 2).

Research indicates that anxiety difficulties occur more frequently in children with ASC than they do in other groups of children with SEN (Chalfant, 2011; Steffenburg, Gillberg, Steffenburg, & Kyllerman, 1996). Furthermore, anxiety has been described as the most common presenting problem for school-age CYP with ASC (Ghaziuddin, 2002). In a review paper which considers 11 studies regarding the prevalence of anxiety in the ASC population, it is estimated that between 18% and 84% of CYP with ASC will experience some degree of impairing anxiety (White et al., 2009). While the disparity in this percentage range is clear, it is perhaps representative of the complex relationship between ASC and anxiety and highlights the individual differences that may exist in terms of anxiety prevalence, intensity and presentation in the ASC population.

Few studies have explored associated difficulties in the ASC population. One such study that examined the comorbidity of ASC with other psychological conditions found that 41.9% of

CYP with ASC had some form of anxiety disorder, the most prevalent of which was social anxiety disorder, which affected 29.2% of CYP with ASC (Simonoff et al., 2008). While this study had a robust sample of 112 CYP, the ratio of male to female participants was 7:2, making it difficult to consider gender effects. Further to this, assessment of comorbid psychological conditions was based solely on parental reports, which arguably gives a restricted picture of symptoms experienced by the individual child or young person concerned. Despite this, the results have been replicated (White et al., 2009), and the notion of CYP suffering from social anxiety disorder is conceivable when it is considered that the main features of ASC are inextricably linked with social interaction and communication difficulties.

One study looked at the cognitive factors associated with anxiety in CYP with ASC using a combination of parent-reports and self-reports. Two comparison groups were provided to increase experimental validity. One group consisted of individuals with diagnosed anxiety disorders and the second group was a non-clinical sample, representative of the general population (Farrugia & Hudson, 2006). Connections between anxiety symptoms, negative automatic thoughts, behavioural problems and life interference were researched. The results showed support for the notion that those individuals with ASC experience anxiety significantly more so than those in the general population (de Bruin, Ferdinand, Meester, de Nijs, & Verheij, 2007). Further, those with ASC had self-report scores of anxiety that were of a comparable intensity to those with diagnosed anxiety disorders (Farrugia & Hudson, 2006). Interestingly, anxiety in the ASC population was synonymous with higher levels of negative automatic thoughts, behavioural problems and life interference when compared to both the general population group and the anxiety disorder group. This study suggests that those with ASC are particularly susceptible or vulnerable to the negative effects of anxiety. Indeed, they are at more risk than not only the general population, but also those with diagnosable anxiety disorders as well. However, this study was specific to those with a diagnosis of Asperger syndrome and the sample number was small, making generalisability to the entire ASC population difficult. Despite this, the results allow the reader to think about cognitions and their role in anxiety. The study is particularly useful for those embarking on interventions to support those with ASC and high anxiety, particularly from a cognitive-behavioural epistemology.

In a review of the literature, White et al. (2009) suggested that it is likely that presentation of anxiety experienced by those with ASD varies with age, cognitive ability and IQ. There is evidence to suggest that anxiety disorders (among other mood disorders) may be more likely to appear in adolescence because of significant alterations in hormones, powerful emotional

responses to social stimuli and swift changes in motivational and reward systems (Paus, Keshavan, & Giedd, 2008). A large study comprising 487 participants across 37 school districts in the USA found that, in a sample of CYP between the ages of three and 21, the severest levels of anxiety were reported in the 13 to 21 age group (Lecavalier, 2006). Younger children (between the ages of three and six) had significantly lower anxiety scores than any other age groups, albeit only on one of the three sub-scales used to measure anxiety in this study.

Research looking at the effects of cognitive ability (among other measures) on anxiety found that higher levels of IQ were significantly related to higher levels of anxiety (Sukhodolsky et al., 2008). Those with low non-verbal communication skills were thought to experience lower levels of anxiety. It could be, however, that participants experiencing communication difficulties were less able to express their anxieties in such a way that was measurable by standardised anxiety surveys. In a review of the current literature White et al. (2009) highlight that not one study used an anxiety-measurement tool that had been adapted for the ASC population.

In summary, the literature to date on the prevalence, presentation and influencing factors associated with anxiety and ASC is broadly in agreement that anxiety is a common emotional state experienced by CYP, although the nature of anxiety differs greatly between individuals. It is likely that those with higher cognitive abilities are more likely to suffer from anxiety, particularly social anxiety, and that adolescence may be a particularly vulnerable time for those with ASC. This is likely to be due to a combination of biological and psychosocial factors. For instance, normal hormonal changes may cause heightened anxiety. The combination of this, however, with the unpredictable and noisy secondary school environment, and difficulty with peer interaction, may cause significantly higher levels of worry and distress in the ASC population.

### *4.2.1 Psychological theories*

Psychological theories of both anxiety and ASC have been discussed separately in chapters two and three. To the author's knowledge, there has been no attempt to create an integrated model seeking to explain how the core features of ASC and anxiety interact or co-exist. To explain the notion that those with ASC are likely to experience high anxiety and suffer more negative effects from it than others, it may be prudent to consider the similarities between the psychological theories of both anxiety and ASC and seek to explain the undeniably complex relationship between the two concepts.

It is conceivable that those with ASC have similar processing styles to those with anxiety. Central coherence theory postulates that individuals are likely to process information globally to make sense of the world at the expense of finer details, whereas those with ASC are more likely to focus on the specific details of incoming information at the expense of the global context (Happé & Frith, 2006). If cognitive explanations of anxiety are considered, such as the model proposed by Beck and Rush (1985), a fundamental assertion is that those who suffer from anxiety have a bias for selective processing of information that results in a narrowing of attention on the fearful situation or object and the negative cognitions associated with it. It appears that these two dominant theories in the field of anxiety and ASC share a common element of narrowed attentional focus.

It is possible to tentatively suggest that those with ASC are more susceptible to anxiety because of their tendency to focus on specific details, making them vulnerable to increased attention on anxiety provoking stimuli. This narrowed attention combined with poor executive function, which can result in a difficulty in filtering out unwanted stimuli, could make the negative effects of anxiety more intense and harder to shift. This may explain the results found by Farrugia and Hudson (2006), which suggest those with ASC have more negative thoughts, behavioural problems and life interference as a result of anxiety.

In order to understand better the relationship between anxiety and ASC more research on the complex nature of anxiety in the population needs to be carried out in a range of settings. The research described above has focused on the prevalence and presentation of anxiety in clinical populations, with participants' results often compared against other clinical groups or controls. Furthermore, many studies have been carried out in the USA. The applicability and usefulness of the results to community or educational settings is questionable. Further to this, the method of data collection in the studies described had an overwhelmingly experimental epistemology. Subsequently, information was gained mostly through standardised questionnaires and surveys, typically filled out by parents, although a small number of studies used self-report measures. What appears to be lacking from the above literature is any descriptive research about the nature of anxiety, which is arguably imperative when thinking about suitable support and interventions. In order to understand the experiences of CYP with ASC it may be of fundamental importance to talk to them in an accessible way to get a better understanding of their experiences, to inform future practice. Indeed, White et al. (2009) suggested a "…thorough empirically based understanding of the characteristics associated with ASC, including the thinking, behaving and emotional patterns that may underlie anxiety with ASC, is important in informing how traditional treatment approaches will need to be adapted for this population." (p. 20).

### 4.3 A critique of research directly related to the current study

While there are few qualitative studies looking at ASC and anxiety specifically, a number of qualitative papers have looked at the experience of schooling for pupils with ASC, where anxiety has been prominent in the findings (Carrington & Graham, 2001; Humphrey & Lewis, 2008; Tobias, 2009).

In order to explore the views of CYP with ASC, Humphrey and Lewis (2008) used a case study design that utilised semi-structured interviews, diaries and drawings to understand better the experiences of CYP with ASC in the mainstream school environment. While the sample consisted of only 20 pupils, the exploratory nature of the research meant that a larger sample was not required. One of the key findings from the study was that the school environment was a particular source of stress, which was thought to be responsible for overwhelming anxiety for some pupils. Anxiety was also present in other themes such as 'peer relationships' (Humphrey & Lewis, 2008). This study highlights the impact of anxiety so clearly demonstrated by prevalence studies discussed in chapter three. There is, however, little research on how CYP with ASC can cope with anxiety or how it may be alleviated in the school environment.

A further small scale qualitative study sought to understand better the support needs of pupils in secondary school with ASC (Tobias, 2009). A creative person-centred approach based on Kelly's personal construct psychology (Kelly, 1955) was employed to elicit participant's views, in which students were asked to contribute to the description and drawing of three fictional students in their school, using the headings, 'successful', 'unsuccessful' and 'with ASC'. While the data collection method varied from the studies described above, anxiety appeared again as a key element of the results. In the context of support needed to alleviate anxiety, participants highlighted the need for a quiet, calm space to which they could retreat, typically because of the noisy, stressful and complex social elements of the secondary school environment (Tobias, 2009).

To the author's knowledge, only one qualitative study to date has sought to explore the nature of anxiety more closely in the ASC population. Trembath, Germano, Johanson, and Dissanayake (2012) looked specifically at the triggers for, and behavioural consequences of, anxiety in adults with ASC, as well as the solutions individuals sought to alleviate such feelings. This was done using a focus group methodology, which is often chosen to gain greater insight into complex issues from the participants' unique perspective. A common

criticism of focus groups is that those who have difficulty communicating are often denied a voice (Cohen, Manion, & Morrison, 2011).

In order to remedy this, the researchers encouraged those who did not want to speak either to draw or write their views on paper. Eleven adults with ASC between the ages of 18 and 35 took part in a focus group, of which nine participants were male and two were female. While there is a clear gender imbalance observable here, it is arguable that this ratio of males to females is recognisable in the ASC population at large (Baron Cohen, 2002) and, therefore, the study portrays a representative sample. A second focus group comprised four carers and five professionals, with one participant filling both these roles. Both groups were asked to discuss the nature of anxiety and given a framework in which to do this. The results of the study clearly indicated that anxiety affects young adults with ASC and the people around them. Central to the paper was the indication that the nature of anxiety is highly individualised and that a unitary solution was not the answer to helping individuals with ASC cope with anxiety (Trembath et al., 2012). The researchers indicated that further studies should be carried out with other data collection methods and on a larger scale to improve generalisability and validity of the findings (Trembath et al., 2012).

To date there has been a focus on the prevalence and presentation of anxiety, but little research has been conducted on interventions. There is limited empirical evidence of beneficial interventions to help school age CYP with ASC who suffer from anxiety or other emotional or behavioural difficulties (White et al., 2009). Despite this, some promising interventions with CYP with ASC and comorbid anxiety using cognitive-behavioural therapy (CBT) have been reported (Sofronoff, Attwood, & Hinton, 2005). However, to date, CBT programmes have not been developed specifically for those with ASC and the existing research is based on modified versions of CBT programmes used for typically-developing CYP.

### 4.4 Rationale for current study based on the literature to date

ASC in the general population is thought to be increasing. One of the biggest challenges for this population, who are of school age, is thought to be anxiety (Greig & MacKay, 2005). Anxiety alone is thought to be one of the commonest mental health difficulties affecting the population at large (Demyttenaere et al., 2004). For these reasons, further enquiry in the field of ASC and anxiety is relevant to the field of education research in order to drive positive change. Further enquiry in this area is particularly relevant for EPs who are well placed to support CYP in schools at a range of levels within the educational system.

Psychological models of both ASC and anxiety have similarities, which may explain the tendency for those with ASC to be particularly vulnerable to anxiety. There is no psychological model, however, that integrates the two conditions, or seeks to explain their co-occurrence. While there has been considerable research investment into managing anxiety in the school-age population, there is a dearth of research and guidance as to how to support those with ASC, who are at great risk of experiencing clinical levels of anxiety. This in part may be because of the lack of in-depth exploratory research in the field, which is arguably crucial for the basis of evidence-based interventions and in the postulation of explanatory theories and models.

Research to date has involved experimental approaches focusing on prevalence and presentation of anxiety, often using standardised measures that have not been adapted to cater for the ASC population. It is possible that unadapted closed-question tools such as surveys and questionnaires could ignore the factors that are most significant in explaining important realities from the perspective of the participants with ASC. Furthermore, the majority of research has been based on parental reports, using a survey methodology or questionnaires, which are not only retrospective, but ignore the voice of the CYP. The importance of the voice of the child was highlighted in the Salamanca statement (UNESCO, 1994) and further in UK policy documentation (Department for Education, 2001, 2013a). The few qualitative studies discussed in this chapter do accommodate the voice of the child, but most of the existing studies have focused solely on CYP with high-functioning ASC. This is likely to be due to the inherent difficulties CYP with ASC experience with social interaction and communication. Adapted research tools, however, may allow for insight into the views of those who find verbal expression challenging, adding to the knowledge base that may inform future interventions for positive change.

CYP with ASC are likely to be most vulnerable to the negative effects of anxiety during adolescence (Paus et al., 2008). Adolescence occurs when CYP are at secondary school age and the secondary school environment has been cited as a place of high anxiety for children on the autistic spectrum. The reasons for this include: frequent transition between classrooms; different members of staff and class composition; and more complex social situations (Tobias, 2009). Few studies on anxiety have taken place using community samples; the majority have been through indirect methods, such as parental questionnaires, usually involving a clinical sample. Therefore, conducting research in a secondary school setting, and having face-to-face contact with the participants may be beneficial. Carrington and Graham (2001) comment specifically on the experience of schooling for two pupils with AS, stating that "…more qualitative research in the field of ASD is necessary to achieve an in-depth

exploration of the real life experiences of these individuals from their own perspective." (p. 47).

### 4.5 Research aims and research questions

While there have been a small number of studies using qualitative approaches seeking to understand better CYP experience of school (Carrington & Graham, 2001; Humphrey & Lewis, 2008; Tobias, 2009) and one qualitative study looking at the nature of anxiety in an adult population (Trembath et al., 2012), to date there have been no studies looking specifically at the nature of anxiety in the school-age population from a qualitative epistemology. Indeed, a review of the literature on anxiety and ASC suggests more attention needs to be given to school and community samples (White et al., 2009).

The purpose of this study is to add a unique contribution to the ASC knowledge base by taking a qualitative approach to enquiry into the nature of anxiety in the ASC population, using a secondary school-based, community sample. A further novel aspect of the study will the adapted data collection method that will endeavour to enable those with ASC to communicate their views. A cognitive-behavioural framework of questions will be used to help identify the triggers of anxiety and the accompanying thought and feelings, as well as subsequent behaviours, in the hope of informing future intervention research. It is anticipated that, by incorporating the views of pupils, support staff and parents, a rich picture of the nature and experience of pupils' anxiety will emerge from a range of informants. It is intended that this research will help to drive positive change by increasing knowledge and understanding of the nature, experiences and challenges associated with anxiety in the ASC population. The research questions are listed below:-

- What are participants' views of the nature and severity of anxiety in school for pupils with ASC?
- What are the thoughts and feelings that pupils with ASC associate with anxiety provoking situations in school?
- How do pupils with ASC express their anxiety in school?
- What strategies have pupils with ASC developed to cope with their anxieties in school?
- What are participants' views of the changes that would need to take place to make school a less anxious place for pupils with ASC?


**Doctorate in Educational Psychology Professional Training Programme**

**2014**

# Autism Spectrum Conditions and Anxiety in Mainstream Secondary Schools: An Investigation with Pupils, Parents and Learning Support Assistants

**Part B: Empirical Study**

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# 5 EMPIRICAL STUDY

## 5.1 Abstract

Despite the increasing prevalence and diagnosis of Autism Spectrum Conditions (ASC) and the increasing number of children and young people (CYP) with ASC in mainstream schools, there is little qualitative research exploring a common element of the condition, anxiety. This study adopts a qualitative research paradigm and attempts to develop understanding of and insight into the lives of CYP with ASC by giving a voice to these pupils, their parents/carers and members of staff who support them. Adapted, semi-structured interviews using a cognitive-behavioural framework were used to elicit participants' views. The data were triangulated and analysed using thematic analysis to ensure detailed analysis of the topic. The themes highlighted a number of school scenarios that cause anxiety and distress for pupils, as well as the negative thoughts, feelings and behaviours associated with such situations. Psychological explanations for these findings were examined. Pupils found talking about their anxieties and using distraction techniques to be helpful anxiety-management strategies. For school to be 'anxiety free' participants alluded to a setting in which the CYP would be understood and accepted. The environment would be calm and predictable. Implications of the study, its relevance to the EP profession and further areas for research are discussed.

## 5.2 Introduction

### *5.2.1 Defining Autism Spectrum Conditions*

Autism Spectrum Conditions (ASC) form a category of developmental disorder typically characterised by difficulties in reciprocal social interaction, communication skills and behavioural inflexibility (Wing & Potter, 2002). There are features not included as part of the diagnostic criteria that are common in those with ASC, such as sensory sensitivities (Wing & Gould, 1979). The severity of these difficulties can range significantly from individual to individual and can be thought of as existing along a spectrum (American Psychiatric Association, 2013).

While it is generally accepted that ASC has a neuro-biological basis (Frith, Morton, & Leslie, 1991), three principal theories seek to explain the cognitive processing behind the behavioural characteristics associated with the condition, namely 'theory of mind' (Baron Cohen et al., 1985), 'executive dysfunction' (Pennington & Ozonoff, 1996) and 'central coherence theory'(Frith, 1989). These models endeavour to explain the difficulties those with ASC have with social interaction and communication, information processing and the regulation, control and management of cognitive processes. They have a large research base and, while not the only models, they have dominated the field of thought in recent decades (Volkmar et al., 2004).

### *5.2.2 Prevalence in school-age children*

There has been a range of prevalence studies carried out on ASC in the general population (Newschaffer, Falb, & Gurney, 2005; Powell et al., 2000). They can not, however, be directly compared due to the varying methodologies used in terms of case-finding, sampling and the diagnostic definitions used (Baron Cohen et al., 2009). Despite the difficulty in comparing individual studies, several robust review papers indicate that the prevalence of ASC is rising substantially (Elsabbagh et al., 2012; Fombonne, 2003; White et al., 2009).

The majority of CYP with ASC in the United Kingdom are educated in mainstream schools (Jones, 2006). Recent figures from the Department for Education [DfE] suggest that currently 71% of CYP are so educated (DfE, 2012). Research indicates that only 22% of teachers in mainstream schools accommodating children with ASC had received relevant ASC training (Barnard et al., 2002). A more recent paper suggests that the amount of 'ASC specific' training offered to teachers is variable (Barnhill, Polloway, & Sumutka, 2011). It could be suggested that more research and training is needed in the school setting to help teachers and other professionals involved in education learn about the condition and its ramifications, particularly in light of the increasing numbers of pupils with ASC being educated in

mainstream schools. It could be argued that better understanding and awareness could lead to CYP's needs being met more consistently.

### *5.2.3 Anxiety*

Anxiety is generally thought of as a feeling of fear, apprehension, nervousness or worry (Chalfant, 2011). Anxiety is not just a unitary event; it is a process in which a number of components are involved, such as memory, attention, perception and reasoning (Rachman, 2004). Rachman (2004) describes it as a pervasive and prominent emotion and states that it can be excessive in large numbers of people. Spence (1998) described anxiety disorders as the most common form of childhood psychopathology. More recent research suggests this high prevalence in CYP remains unchanged (Stallard et al., 2011).

### *5.2.4 Anxiety and ASC*

Brewin (1988) was one of the first researchers to suggest that people vary in their susceptibility to experiencing uncomfortable levels of anxiety. Anxiety is thought to be particularly common in those with ASC (Bellini, 2006; Russell & Sofronoff, 2005; Trembath et al., 2012). Furthermore, anxiety difficulties are thought to be significantly more common in children with ASC than they are in other groups of children with special educational needs [SEN] (Steffenburg et al., 1996).

Psychological theories may be able to explain tentatively why anxiety is high in those with ASC. Some theories of anxiety suggest that when individuals are anxious their attentional focus is narrowed to the anxiety producing trigger (Eysenck et al., 2007). This narrowing of attention is, in part, similar to what is proposed to occur, according to the central coherence theory of ASC (Happé & Frith, 2006), which suggest those with ASC focus on small detail and find it difficult to take in the bigger picture. This similarity of cognitive processing style between anxious individuals and those with ASC may explain why CYP with ASC are more likely to be anxious than their typically developing peers. They may also suffer from the negative effects of anxiety more so than others because of an inherent difficulty with executive functioning, which is responsible for inhibiting negative thoughts and feelings.

### *5.2.5 ASC, anxiety and education*

Research suggests that a child's ability to participate in home, school and community activities is negatively affected by anxiety (Reaven, 2009; Russell & Sofronoff, 2005; Stallard, 2009). The experience of anxiety can be especially debilitating for individuals with ASC by impacting on their school performance, peer relationships and family functioning (Bellini, 2006).

CYP with ASC are likely to find the secondary school setting especially challenging and anxiety provoking for a number of reasons. First, the frequent transition between classrooms, the different members of staff and the regular changes to class composition interfere greatly with the need for predictability and familiarity. Secondly, the increased focus on peer relationships and more complex social structures highlight the difficulties children with ASC experience with social interaction and communication, which are likely to exacerbate anxiety levels (Tobias, 2009). While it is generally accepted that anxiety levels tend to increase when children reach adolescence, Farrugia and Hudson (2006) highlight how this effect is marked for the ASC population.

### 5.3 Academic Rationale

From the above review of the literature it is conceivable to suggest that anxiety is a common difficulty experienced by CYP with ASC, particularly those in secondary education. Such anxiety can have dramatic effects on an individual's ability to access school and education, making it a pertinent subject area for the EP profession. Further research focused towards understanding the nature of such anxieties at a cognitive-behavioural level is needed to help develop professionals' awareness of such a common difficulty. Asking how pupils are currently dealing with anxiety and their perspective on what could be done to help them are both imperative to develop knowledge of this topic from the view of the child.

Research into ASC and anxiety has been dominated by experimental studies that have largely focused on prevalence, assessment and diagnosis of anxiety in CYP with ASC (Humphery & Parksinson, 2006). While such research approaches are popular, there is consequently a shortage of qualitative research in the field of ASC, resulting in few in-depth accounts of real life experiences (Carrington & Graham, 2001).

Qualitative research focuses on individual accounts and perspectives. The view of the CYP is, however, seldom sought in ASC research (Sofronoff et al., 2005), despite the importance of seeking CYP's views being made clear in government policy (Department for Education, 2013a). It is feasible that, because of the difficulty CYP with ASC have with communication and interaction, eliciting their views may be challenging. However, understanding the views of children has immense value for professionals and could give further insight into the nature of anxiety and enable the production and application of appropriate interventions (Trembath et al., 2012). Parents and support staff can also give a voice to the topic, adding richness to the study by lending different perspectives.

### *5.3.1 Relevance to the profession*

ASC is one of the most prominent areas of SEN in UK schools. The importance of the role of EPs in contributing to 'whole school' understanding of SEN has been highlighted in recent legislation (Department for Education, 2013a). EPs are also well placed to bridge the gap between research and practice in the field of ASC and are able to deliver support at an individual, class and whole school level (Williams, Johnson, & Sukhodolsky, 2005). The need for training in the field of ASC for teachers has been highlighted (Barnard et al., 2002; Barnhill et al., 2011), as has the need for practical interventions to support progress and well-being of ASC pupils (Machalicek et al., 2008). The intention of this study is to provide in-depth information to base further research in areas such as training, intervention and whole school support.

## 5.4 Aims and Research Questions

From the above review of the literature, the research questions below have been devised. The constructions of pupils, their parents/carers and support staff will be sought. It is anticipated that, through rich descriptions, insights into ASC and anxiety will be gained.

- What are participants' views of the nature and severity of anxiety in school for pupils with ASC?
- What are the thoughts and feelings that pupils with ASC associate with anxiety provoking situations in school?
- How do pupils with ASC express their anxiety in school?
- What strategies have pupils with ASC developed to cope with their anxieties in school?
- What are participants' views of the changes that would need to take place to make school a less anxious place for pupils with ASC.

## 5.5 Methodology

Mainstream secondary schools with an Autism Resource Base (ARB) on site were chosen as a focus for the research, primarily because the ARB supports some of the most vulnerable pupils in the school setting. Academically, these pupils perform within the average range, but the associated difficulties of ASC mean that the mainstream environment provides challenges that many of these pupils cannot overcome. It was considered important to understand the experience of anxiety in school for CYP who are on the periphery of the mainstream environment in order to increase the knowledge and understanding for professionals engaged in supporting such pupils, including EPs.

### *5.5.1 Data collection methods*

While the methodology used was not participatory in nature, the techniques used for gathering data were chosen to increase accessibility for the pupils with ASC who participated. Semi-structured interviews were employed to obtain the views of pupils, parents and support staff from their unique perspective (see Appendix A1-A3). The interview schedules were created using guidance from academic papers (Bouchard, 2009; Cohen et al., 2011) and followed a cognitive-behavioural framework. Interview schedules were tailored to each group of participants (parents, pupils, support staff). The method was conducive to the qualitative research paradigm underpinning the study and provided a medium through which the researcher was able to gain insight into the complex issues surrounding the anxiety young people experience in school that would not be possible using quantitative methods such as questionnaires or surveys (Cohen et al., 2011). Visual cues, adapted from Talking Mats (Murphy, 1997), were incorporated into the pupil interviews to aid and facilitate understanding and communication.

### *5.5.2 Participants*

Within the local authority (LA) in which the researcher was based, all three schools with ARBs agreed to participate. Each ARB comprised approximately ten pupils. Three pupils from each ASC were asked to participate as part of a judgement sample (Marshall, 1996). Seven secondary school-age male pupils took part in the study and two pupils chose not to be interviewed on the day. The seven pupils taking part in the study had a formal diagnosis of ASC, which was their primary SEN need. Pupils were, at the time of interview, attending the majority of mainstream lessons with one-to-one support.

Pupils who were part of an ARB at the time of interview had staff supporting them in school on a daily basis for at least 19 hours a week. Each supporting member of staff consented to taking part. The parents of each participating pupil were also interviewed. In some cases both

parents attended. Twenty-one interviews were carried out in total, comprising 24 participants (for further information see Appendix B1).

### *5.5.3 Pilot study*

Due to the small sample of participants used and the limited ARBs available to the researcher, careful piloting techniques were needed. ARB managers were asked to read through the interview schedules, share them with staff and parents if possible and give feedback if necessary. Pilot interviews were carried out on the first pupil, parent and support staff with whom interviews had been arranged. No changes were needed to the interview schedule; consequently the interviews obtained from the pilot participants were incorporated into the main data set.

### *5.5.4 Procedure*

The study was given ethical clearance from the School of Psychology ethics board prior to the start of research. Consent from the head-teacher and ARB manager of each school was obtained (See Appendices B2 and B3). Once such consent was given, the researcher requested that the ARB managers identify three children who were able to take part; this was a judgement sample (Marshall, 1996). The decision was made on ethical grounds. Some pupils might have become distressed by the process and therefore random selection was not justifiable on this occasion. Parents were then contacted individually by letter, which clearly described the study (see Appendix A4). The aim of this was to seek consent to contact their child and also to ask for their participation.

The pupils and the support staff were then visited at school by the researcher at a pre-arranged time. The purpose of this was to explain the nature of the research and build a rapport with the participants, particularly the pupils, in order to make them more comfortable with the interview process.

Pupils and support staff who were happy to proceed signed the consent forms provided before the interviews took place (see Appendices B2-5). Ethical guidelines were adhered to and confidentiality, right to withdraw and data anonymity were discussed and clarified in an accessible manner with each individual participant; a familiar member of the support staff team was with the pupils during this time.

Before each pupil's interview, his or her construction of the term 'anxiety' was explored using a simple and familiar emotional literacy game to ensure understanding of the interview topic. This was also addressed informally at the pre-interview meetings. The emotional literacy game was also used to help the pupils relax and feel at ease before the recording of

the interview process. Interviews took place in an ARB, which was familiar to the pupils and convenient for staff. A familiar member of the support staff team was present throughout each pupil interview to help the pupil concerned feel comfortable during the process. Staff interviews took place at a separate time that was suitable for them. Parent interviews were arranged separately and took place in the home setting.

At the end of the process, debrief forms were disseminated (see Appendix A5). To ensure understanding, pupils were debriefed verbally with a member of the support staff team present and were also given the opportunity to ask any questions.

## 5.6 Data Analysis

### *5.6.1 Epistemology*

The research design has been underpinned by social constructionism (Holstein & Gubrium, 2008), which is linked to a range of qualitative methods such as grounded theory (Glaser, Strauss, & Strutzel, 1968) and narrative analysis (Riessman, 1993). Grounded theory was not selected because of the emphasis on theory development. This approach did not fit with the exploratatory nature of the current study. Narrative analysis was also rejected as a method of data-analysis because it is suited to a transformational research approach, exploring change over time (Reis & Judd, 2000). Social constructionism also lends itself to thematic analysis [TA] (Braun & Clarke, 2006). TA was selected as a method of data-analysis because multiple theories and approaches can be applied to the process and while the approach allows for flexibility it follows a systematic and clear set of steps (Guest, MacQueen, & Namey, 2011).

### *5.6.2 Thematic analysis*

To increase reliability, validity and confidence in the ensuing findings, the Braun and Clarke (2006) analysis process was followed. This comprised six stages of analysis, which sought to consolidate and refine the raw data into meaningful and representative themes. Initially familiarisation with the data took place through transcribing the interviews verbatim and reading through them. Initial note taking took place at this stage.

Initial coding in relation to each research question occurred next (see Appendix C1). Due to the triangulation element of the research each trio of pupil, parent and support staff was grouped (forming seven groups in all) and within-method, data triangulation took place (Denzin, 1970). Triangulation of the data added a sense of richness and complexity to the enquiry, thus enhancing the credibility and persuasiveness of the research account.

Initial codes for each research question from each group of participants were listed (see Appendix C2) and then stage three (searching for themes) occurred. Codes that had been applied to the data of at least two participants in each group, or where present across groups, provided the basis on which to develop the emerging themes. At this stage the themes for each research question were reviewed before they were defined and named for the initial thematic maps (see Appendix C3).

Finally these initial themes were refined to produce super-ordinate themes (see Appendix C3). Reliability of the themes derived was additionally increased by colleague review. The super-ordinate themes are discussed below. Supporting quotes are presented in Appendix C4, representing a range of responses from pupils, parents and support staff.

## 5.7 Results

### *5.7.1 RQ1. What are participants' views of the nature and severity of anxiety in school for pupils with ASC?*

Theme One: Expectations

This core theme relates to the pupils' expectations of their work and achievements, as well as other peoples' expectations of them and the subsequent anxiety that could ensue. Pupils had high expectations of their work and results, so much so that, often, anything that was not perfect according to the pupil's individual standards would result in high anxiety.

Pupils in this study not only had high expectations of themselves but of their peers. High anxiety ensued if other students did not follow the school rules, such as running in the corridors when they know this is not acceptable behaviour. This could be linked with a number of factors associated with ASC, including the inherent need for consistency and predictability. A further dimension of rule breaking was in relation to sensory sensitivities. Noisy peers, who talked when they should not, increased pupils' anxiety levels. Increased anxiety is thought to reduce the ability to shift attention from the anxiety stimuli (Eysenck et al., 2007). It could be postulated that pupils not only had difficulty shifting attention away from the anxiety stimuli, but because of their sensory sensitivities, there were particularly aware of the noise in the classroom, increasing anxiety further.

A sub-theme of the core theme (expectation) is 'uncertainty'. Uncertainty can be caused by a change in routine, rule breaking, consequences of actions or unpredicted events during the day. This could be linked to difficulties with executive functioning, particularly planning and inhibition (Hill, 2006) and reduced central coherence (Happé & Frith, 2006), resulting in small environmental changes being anxiety-provoking.

Theme Two: Social concerns

The data lends support to the notion that social interaction and communication can cause a great deal of anxiety for CYP with ASC. This could be because of the characteristic difficulties linked to theory of mind (Baron Cohen & Swettenham, 1997) and central coherence (Happé, 1996). Anxiety was prominent when social interaction occurred, typically because social cues were hard to decipher. Pupils spent their free time in the Autism Research Base (ARB), which was a space not occupied by their mainstream peers. This was to avoid the anxiety caused by being in the socially complex world of the playground setting.

The social element was one cause of high anxiety in the playground. However, anxiety was also caused by the uncertainty of the environment and the sensory elements, such as close proximity and loud noises. This is consistent with the previous qualitative literature in the field (Humphrey & Lewis, 2008).

A sub-theme of social concerns that emerged was 'language'. This relates to the anxiety caused by the difficulty pupils have in understanding ambiguous language used by peers and teachers. This may be linked to pupils' difficulty with figurative elements of language and could suggest a processing bias for local patterns and details (such as the grammatical elements of language) rather than a more global understanding of language beyond the literal interpretation (Vulchanova, Talcott, Vulchanov, Stankova, & Eshuis, 2012).

Theme three: Boundaries

Homework caused pupils a great deal of distress and anxiety for several reasons. The first and most prominent reason was the difficulty pupils had with the concept of doing school work at home, which is likely to be linked to rigid thinking associated with ASC (Wing & Potter, 2002). Another concern pupils had about homework links back to expectations. Some pupils expended a great deal of energy worrying about submitted homework and the marks they would receive subsequently.

A sub-theme of boundaries is 'time.' For example, pupils worried about getting homework in on time, or specifically, getting it in on the right day. Time has emerged as a prominent element of anxiety for pupils because of its connection to routines and rules.

Theme 4: Sensory Sensitivities

Sensory sensitivities have been threaded throughout the responses to this RQ. The dominant sensory anxiety was in relation to noise, not just unexpected or sudden noise, but the classroom noise and the volume in the playground and in other social areas. It is possible that the inability to filter out general noise caused great anxiety for several students and lends support to the executive dysfunction model of ASC (Hill, 2006).

*5.7.2 RQ2. What are the thoughts and feelings that pupils with ASC associate with anxiety provoking situations in school?*

Theme One: Negative feelings

Anxiety induced some degree of negative feelings in pupils, which in the long-term may be detrimental to their psychological well-being. The 'type' of negative feeling experienced typically fell into one of the following sub-themes:-

- Not in control

'Not in control' relates to the panic associated with high levels of anxiety caused by a 'loss of control'.

- Forceful

'Forceful' relates to the strong feeling of anger and frustration felt by most pupils when anxious.

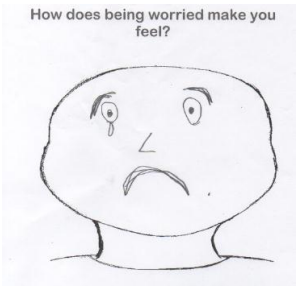
- Passive

'Passive' relates to a more inward reaction to anxiety that is linked to low self-esteem and sadness.

The drawings presented in figures A and B below are a powerful illustration of the two ends of the negative spectrum felt by two of the pupils interviewed, the first figure representing 'forceful' and the second 'passive'.

Figure A: Forceful


Figure B: Passive



Theme Two: Magnified negative thoughts

The recurring theme of magnified negative thoughts was extremely consistent. Not only were the thoughts of pupils described as 'magnified', they were, generally speaking, uncontrollable thoughts or indeed images that the pupils found hard to control.

A sub-theme, 'perplexity', encompasses the distress and confusion that the pupils associated with negative thoughts and highlights their lack of understanding surrounding the anxiety triggers discussed in RQ1. It could be argued that there is a link between this theme and the notion of weak central coherence discussed by Happé and Frith (2006). Weak central coherence refers to the detailed processing style that is thought to be a feature of ASC (Happe & Frith, 2006). Because of the difficulty that those with ASC have with processing information in a more global sense, they can find it challenging to understand thoughts and feelings in context, leading to distress, confusion and further anxiety.

A second sub-theme, 'overwhelming', stems from confusion and perplexity, which is intrinsically linked to a previously discussed sub-theme, uncertainty (see RQ1). The anxiety caused by negative thoughts was overwhelming for the pupils, particularly when the negative feelings associated with the negative thoughts were hard to label and understand. It is conceivable that the negative thoughts are over-whelming and perplexing because of the difficulty children with ASC can experience with executive skills, such as filtering out information (Happé & Frith, 2006).

### *5.7.3 RQ3. How do pupils with ASC express their anxiety in school?*

Theme 1: Non-verbal actions

The range of non-verbal actions extended from chewing one's tie to self-harm. It was reported that the more extreme non-verbal actions were likely to occur before the pupil was about to withdraw or lose control. Stereotypical or repetitive movements were also reported to increase when the pupil was anxious, in line with previous research findings (Zandt, Prior, & Kyrios, 2007). Parents were particularly sensitive to non-verbal signs of anxiety, which were, in the majority of cases, a precursor to more extreme reactions resulting from increasing anxiety levels.

Theme 2: Verbal Responses

In the majority of cases pupils would display heightened verbal activity when anxious. This ranged from raising of the voice to being acrimonious, short-tempered and often rude. As

with the previous theme, this was often a precursor to a more extreme reaction if the anxiety levels continued to rise. A verbal reaction is also linked to the theme 'loss of control' whereby a pupil would lose the ability to restrain his language in the heat of an anxious moment. This was often accompanied by a deep sense of guilt and resulted in the pupil getting upset about his outburst after the incident. This links in with the concept of 'expectation' discussed in RQ1, where pupils felt anxious if they did not live up to their own expectations of themselves. Thus, pupils were often worried about the consequences of outbursts and what would happen as a result of that rule breaking, resulting in a heightened level of anxiety.

Theme 3: Withdrawal

There are a number of levels at which it was found that pupils would withdraw from an anxiety-provoking situation. One level was to actively withdraw physically by leaving the anxiety-provoking situation. At another level pupils would withdraw by 'shutting out' their surroundings and narrowing their focus. Pupils also actively shut out the anxiety by curling up in a ball, sitting low to the ground or placing their hands over their ears. This appeared to be linked to a sensory anxiety. The ultimate act of 'withdrawal' for pupils was a refusal to attend school, which was highlighted by one parent.

A sub-theme of 'withdrawal' was 'holding anxiety', described previously in the literature as "masquerading" (Humphrey & Lewis, 2008, p. 40). This refers to pupils' ability to contain their anxiety throughout the day, so their true feelings would not be apparent to teaching staff, before getting home and releasing their feelings of anger and frustration. This makes identification of anxiety especially challenging in the school environment.

Theme 4: Loss of control

This theme relates to the time when anxiety is so high that the pupil is unable to hold or contain it any longer and the anxiety results in an 'explosion', typically, of anger or fear. Linked to a fight or flight reaction (Selye, 1936), a pupil may flee, which is different from 'withdrawal', when pupils still have a element of control. The 'fight' element of this reaction is also embedded within the 'loss of control' theme, which is split into two sub-themes.

Sub-theme 1: 'People directed' outbursts were predominantly verbal in nature and often resulted from social anxiety. Anxiety caused by rule-breaking behaviour by peers resulted in such a reaction, as did misread social scenarios.

Sub-theme 2:'Object directed' outbursts were the most common among the pupils in this sample. The outbursts ranged in severity from snapping a pencil to turning over tables. Outbursts of this nature typically resulted from a period of increasing anxiety or retained anxiety. Some participants reported that an outburst of this type from a pupil could occur without prior warning. Pupils who had greater difficulty expressing their feelings were the most likely to react in this way.

### *5.7.4 RQ4. What strategies have pupils with ASC developed to cope with their anxieties in school?*

Theme 1: Reassurance

Pupils coped well with their anxiety when familiar teachers were available to talk through the anxiety-provoking situation with the pupil and react in a consistent and calm manner. Pupils felt talking through the scenario helpful and allowed them to understand where the feeling had come from and how the situation could be better dealt with next time. Emotional literacy programmes may, therefore, be extremely useful. Good communication between home and school was also seen as invaluable, particularly by parents. This also helped to create consistency when managing pupils' anxiety in both the home and the school.

Theme 2: Safe, quiet space

Pupils very much valued a quiet and familiar place to retreat to when anxiety rose to levels that became uncomfortable. However, retreating in such a fashion may in turn increase anxiety about the stimulus from which escape is sought (Rachman, 2004). While this is closely linked to avoidance, in that 'withdrawal' is a result of anxiety, a safe haven was an essential for the pupils interviewed. Perhaps this highlights a need for a secure base, although pupils are actively engaging regularly in the rest of the school, to give them the confidence to confront the wider environment once the anxiety levels have reduced.

Theme 3: Distraction

The most common response from pupils as to how they coped with their anxiety was 'distraction'. Often pupils liked to distract themselves with humour or thinking about positive things.

A sub-theme of distraction, a fall back to an 'own world', refers to the retreat to a fantasy world that pupils found safe or comforting, perhaps because they could be in control and dictate how things would be; thus, reducing the anxiety caused by uncertainty and unpredictability in the school context.

Theme 4: Sensory comforts

Sensory comforts helped pupils to contain their anxiety. Some would seek sensory stimulation, such as chewing items of clothing. Anxiety often resulted in pupils seeking comfort from eating, where others liked to block out the anxiety-provoking trigger by listening to music using headphones. One ARB had a sensory room. This room was designed to develop pupils' senses through the use of special lights, music and objects. This was a safe place where pupils could go if they felt anxious.

Theme 5: Therapeutic techniques

Breathing techniques and counting to ten were the most commonly cited therapeutic techniques. Support staff also discussed supporting strategies such as rehearsing difficult situations via comic strip conversations and social stories, which were not highlighted by pupils or parents. This may be an area to develop in collaboration with both parents and pupils. Participants discussed relaxation, although this was more in terms of periods of quiet-time and of video games, from the pupils' perspectives, rather than in terms of systematic relaxation.

### *5.7.5 RQ5. What are participants' views of the changes that would need to take place to make school a less anxious place for pupils with ASC?*

Theme 1: Environment

When asked what would make school 'worry free', each group alluded to an environmental change. Being able to have control and predictability throughout the day was important, as was to have space and fewer physical restrictions. Opportunities to be outdoors without the threat of noise, chaos or challenging social scenarios were also highlighted. Wider corridors and orderly queues were popular requests among pupils. A less restrictive uniform was also a common wish, likely to be linked to sensory sensitivities causing the uniforms to feel uncomfortable.

Theme 2: Social opportunities

Pupils often requested that peers keep to the rules; parent and staff were more likely to highlight the need for more social opportunities with like-minded peers. Parents, pupils and support staff were keen for more intimate class sizes for pupils, with peers who wanted to learn and would cause little distraction. Many participants had worries about social interactions and expressed a wish that these concerns be ameliorated.

Theme 3: Inclusion

A whole-school awareness of ASC was highlighted consistently by all groups, as was training for staff in the wider school environment. Knowledge of the characteristic behaviours associated with ASC by itself did not seem adequate to participants, as they felt it was important to understand the pupil's individual needs, such as one pupil's need to leave class early, or another pupil's worry over homework. Consistency of reaction to behaviours in the classroom was felt necessary to reduce the anxiety caused by uncertainty.

### 5.8 Summary of results

Participants indicated that there was a range of school scenarios that caused anxiety. The main themes were in relation to expectations, social concerns, boundaries and sensory sensitivities. Pupils found it difficult to block out triggers for anxieties and, if anything, they were more likely to focus on them. Thoughts and feelings associated with anxiety were overwhelmingly negative. Negative thoughts tended to be magnified and intrusive. Negative feelings often manifested themselves in fear or panic, this suggests that the severity of anxiety was high in most cases. Anxiety was expressed in a number of ways, from non-verbal responses to unpredictable outbursts. Pupils found talking particularly helpful and, for those who found talking difficult, sensory comforts and distractions proved useful strategies. To make school a less anxious place for pupils it is clear that pupils would like space in a controlled and predictable environment, but more than that they require understanding, tolerance and acceptance from peers and teaching staff outside of the ARB.

## 5.9 Discussion

### *5.9.1 Sources of anxiety*

The sources of anxiety varied among pupils. Anxieties were, however, typically linked with specific difficulties that CYP who have ASC experience, such as difficulties with social communication and interaction (Bellini, 2006), as well as environmental sensitivities and unexpected changes (Trembath et al., 2012). The consequences on their academic achievements are less well known from this study. However, the anxiety literature points towards a direct and negative effect on pupils' ability to engage with learning because of the marked shift of attentional resources when anxiety occurs (Baddeley, 1992; Eysenck et al., 2007).

The insights into the everyday nuances of the pupils' day that are not immediately obvious are perhaps the most compelling aspects of the research. An example of this is the science lesson. Several participants mentioned this as a source of great anxiety because of the unpredictable nature of experiments and the risk of rule breaking from other students. Appreciating these small but pertinent aspects of everyday school life for these pupils is essential to increase understanding and compassion and to enable more individualised interventions.

### *5.9.2 Experiences of anxiety and interventions*

Participants were encouraged to discuss their thoughts, feelings and behaviours associated with anxiety. Overwhelming negative thoughts and feelings were apparent for all pupils, which could have a significant impact on the emotional well-being of such pupils. It is thought that such strong emotions may be linked to inflexible thinking as well as a narrowed attentional focus (Happé & Frith, 2006; Hill, 2006). Cognitive restructuring may be an important element of intervention. The benefit of cognitive based interventions with CYP on the autistic spectrum is slowly coming to fruition (Lang, Regester, Lauderdale, Ashbaugh, & Haring, 2010). However, further research to understand better their applicability to the ASC population is required. Actions of pupils tended to follow a 'fight or flight' reaction (Selye, 1936) when the anxiety was severe. When anxiety was at a lower level, coping techniques such as distraction proved beneficial. Avoidance is a substantial coping strategy for pupils, the long-term outcomes of which are not conducive to overcoming anxiety (Rachman, 2004). This lends credence to the notion that some cognitive-behavioural intervention programmes may prove beneficial to reducing the anxiety experienced by those with ASC.

### *5.9.3 Reducing anxiety in the mainstream environment*

A number of suggestions were made for reducing anxiety in school. Pupils described a quiet environment with order and routine, where they were free to study subjects of interest. Perhaps access to quiet areas during break times, where structured activities could take place, would prove beneficial. The National Autistic Society (NAS) has published a framework, to be used in the classroom to support pupils with ASC (NAS, 2014). The key elements of the framework are Structure, Positivity, Empathy, Low Arousal and Links. The framework provides practical steps for meeting the needs of CYP with ASC, particularly in relation to their need for order and routine (.NAS, 2014).

Understanding of ASC in the wider school environment, as well as the individual needs of the pupils, was also thought to be crucial for reducing anxiety. Awareness and understanding of ASC through regular training for teachers was highlighted as good practice in the education of CYP with ASC (Charman et al., 2011). This could be addressed through a regular programme of staff development, which EPs would be well placed to provide. Peer interaction was another area that caused high anxiety. Strategies for managing peer interactions have been highlighted by guidance published by the government and charitable organisations (Charman et al., 2011; Department for Education, 2009). However, it could be argued that the impact of anxiety on such interactions has been neglected. Again, the EP could play a vital role in supporting pupils and staff to understand and manage such interactions.

### *5.9.4 Opportunities and restrictions*

This research has explored the experience of anxiety through the eyes of the pupils and those who know them well, using rich and detailed accounts as opposed to standardised measures and formal tests that are thought to dominate the ASC literature (Humphery & Parksinson, 2006). While the use of triangulation has increased the validity of the study, it is difficult to generalise the findings of this study beyond the participants who took part. Further, pupils' views may have been diluted by the use of triangulation because the data was analysed collectively.

The cognitive-behavioural framework used in this study may be particularly useful for EPs in forming the basis on which to build future interventions, support strategies, training for staff and policy development within schools.

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### *5.9.5 Further research*

This study has been exploratory in nature and it is anticipated that more research would build on these findings. EPs would be well placed to conduct school-based action research to facilitate and develop interventions in this area. It may be useful to look at the difference in anxiety experienced between males and females, with ASC as this study only comprised male pupils. Further attention to age and how this affects the nature of anxiety may also help chart the specific anxieties experienced through the school year groups. Accompanying quantitive or mixed-method approaches on this topic would increase the validly and applicability of the results to a wider population.

### 5.10 Conclusion

Previous research has indicated that there are high levels of anxiety experienced by CYP with ASC (White et al., 2009), and this study supports this finding. It is clear from this paper and previous studies that anxiety stems from situations that bring to the fore core difficulties people with ASC experience, such as difficulties with social communication and change in routine. To date, there has been little research on interventions for anxiety in the ASC population; this study takes the first tentative steps towards this by exploring coping techniques with school-age participants from their unique perspectives. This research also explores anxiety at a number of levels, using a cognitive-behavioural style framework in the hope of understanding the thoughts, feelings and behaviours that stem from anxiety triggers for this population as well as informing further intervention research in this area. Importantly, this study has focused on the voice of the CYP, parents and support staff and sought to gain understanding from their personal experiences. Further research could focus on intervention, whole-school awareness and coping strategies to enable CYP with ASC, their schools and families to manage anxiety in a unified manner.


**Doctorate in Educational Psychology Professional Training Programme**

**2014**

# Autism Spectrum Conditions and Anxiety in Mainstream Secondary Schools: An Investigation with Pupils, Parents and Learning Support Assistants

**Part C: Reflective Summary**

**Student name**: Abigail Rebecca Wicks

**Student number:** C1117883

# 6 REFLECTIVE SUMMARY

## 6.1 Abstract

This reflective, analytic and personal account will attempt to elucidate the experience of my research journey in which I fit the role of both applied psychologist and researcher. In order to explore the contribution to knowledge that I have made, a critical reflection of my own beliefs and personal experiences is discussed with a critical examination of how these influenced the study that was subsequently conducted on Autism Spectrum Conditions (ASC) and anxiety. Decisions made throughout the research process are deliberated and the impact this process has had on the knowledge produced is considered. A focus on the role of 'researcher practitioner' will then be scrutinised, both in terms of the opportunities and the challenges this position posed. Applicability in the context of educational psychology is discussed along with an appraisal of the novel contribution made to the literature.

## 6.2 Background

This paper is based on a research project I undertook for the Thesis element of the DEdPsy professional training programme. The research explored the experience of anxiety for children and young people (CYP) who are on the autistic spectrum and how this may affect their thoughts, feelings and behaviour in school. Coping strategies were also explored. The study was qualitative in nature and sought views from CYP, support staff in school and parents. The aim was to gain a rich and detailed insight into individuals' experiences. Participants were acquired using a judgement sample and experienced members of staff at the schools selected participants. Data was collected using a semi-structured, in-depth interview approach. Interview data were triangulated and analysed using thematic analysis. The results highlighted myriad causes of anxiety for CYP with ASC, but such causes typically focused on social communication, unpredictability, sensory sensitivities and changes in routine. The thoughts and feelings accompanying the anxiety were overwhelming negative, leading to a range of externalising and internalising behavioural reactions. Participants talked about their coping strategies, which for the majority of young people were in the form of distraction. Participants also commented on what would reduce anxiety for them in the school setting. Environmental as well as social and systemic changes within the school are recommended.

## 6.3 Part A: Contribution to Knowledge

In order to understand the impact of the knowledge produced from any research conducted, it is important to analyse and reflect on the process as a whole and appreciate the influence of the underlying beliefs and assumptions held by the researcher. Belief systems are thought to drive the direction of enquiry and underpin the research paradigms chosen by the researcher.

Mertens (2009) argued that these not only influences the construction, execution, examination and reporting of research findings, but also the way in which researchers contribute knowledge to the research literature. The perceived value of such knowledge will not only depend on the belief systems of the researcher, but of the reader as well.

In this section I will critically explore the development of the study, from the initial motivations and ideas to the finished article, attempting to address along the way philosophical positions and their impact on the knowledge produced at the end of the process.

*The development of the research idea*

The development of a research project looking at how anxiety affects children with ASC in school was influenced by distinctive factors, from both a personal and professional perspective. I was initially concerned that my prior interest in ASC, spurred in a previous job role, might be regarded as an unsuitable starting point because it was closely connected with a role in clinical psychology, as opposed to educational psychology. On further reading, however, it became apparent that personal interest and experience were valid reasons to begin research in a particular area (Lowe, 2007). Moreover, considering ASC from an educational perspective was the starting point of the novel element of the research. Most published research available on ASC was clinical in nature and focused predominantly on diagnosis and prevalence, see White et al. (2009) for an overview. Training in the field of educational psychology has encouraged me to move my thinking away from the positivist approach to ASC, in which the formulation of the clinical label and the treatment of ASC are advocated. The more humanistic and constructionist stance advocated by the educational psychology professional training programme has encouraged me to think more about how the experience of education could be improved for pupils with ASC. My training has also made me think more about the voice of the pupil and how to make research accessible to young people. Not only was looking at ASC and anxiety through an educational lens novel, but combining my interest in ASC with education, made it relevant to my past experience in clinical psychology, and to my current role as an applied educational psychologist in training.

I was aware that there was a large ASC research base and I decided that coupling it with another area, such as anxiety, would add focus to my thinking and target my literature review to a more restricted and manageable brief. My desire to study the link between ASD and anxiety also evolved from questions that were formed whilst working in the field with CYP in previous and current roles. Anxiety in school was a common problem for the CYP with whom I had worked. Initial thoughts around research in the field of ASC and anxiety were sparked by a piece of casework that I carried out in the field and submitted as an academic process

account in the second year of the DEdPsy professional training programme. I worked with a child who had a diagnosis of ASC. She suffered a great deal of anxiety in school, which affected her ability to engage with the curriculum. Why this might be interested me. On further reading it became evident that literature on support and interventions for CYP with ASC who experience anxiety was sparse, albeit developing (McNally Keehn, Lincoln, Brown, & Chavira, 2013; Storch et al., 2013; Sung et al., 2011; White et al., 2009). Anne Chalfant, a clinical psychologist working in the field, has highlighted this. She said, "despite the fact that anxiety difficulties seemingly go hand in hand with ASD, there is so little practical information available regarding how to manage it." (Chalfant, 2011, p. 3).

It has been recently highlighted in English government policy that educational psychologists (EPs) have an important role to play in supporting schools and colleges to implement interventions and provide training that will support the progress and well-being of pupils (Department for Education, 2013b). Indeed, intervention is increasingly becoming a core element of EP work (Boyle & Lauchlan, 2009). In order for interventions to be put in place, research needs to be carried out, not just to create an evidence base for existing interventions, but also to help inform the process of creating them in the first place. As the research I carried out was a novel and small-scale study, the intention was not to develop an intervention to tackle anxiety in the ASC population, but to provide insight into the nature of anxiety, from the perspective of those who experience and manage it on a daily basis. This information was purposely gathered in a cognitive-behavioural framework (Simos, 2008) to explore systemically the triggers, cognitions and behavioural reactions of anxiety experienced by pupils with ASC in an educational setting, for further research to build on. It was anticipated that gathering in-depth information of the everyday experiences of those who encounter the difficulties associated with ASC and anxiety first-hand would add to the literature base and help inform future researchers looking to develop evidence based programmes.

A further drive behind the research was creating knowledge at a local level. The three Autism Research Bases (ARBs) in which the research was conducted wanted to create a collective voice to inform the wider school of the difficulties and needs of the CYP in order to help, and increase, whole school understanding. It is thought that empowerment for change can be gained through knowledge and understanding (Humphrey & Lewis, 2008). By giving a voice to those affected by ASC and anxiety, and providing a window into their thoughts, feelings and experiences, it was hoped that the information could be fed back to the wider school to stimulate support at a whole-school level. This approach had an action research element, as improvement in understanding and practice could ensue from the findings (Elliott, 1991). However, on further reading and reflection the research design did not fit a 'true' action

research paradigm, as change was not planned or monitored throughout the process, as would be expected from using such a framework (Elliott, 1991). This made it clear to me that the study was purely exploratory in nature and this would be the basis of the researcher's unique contribution to the literature.

### *6.3.1 Designing the research*

At this stage in the process I had a clear picture of the motivations driving the study and subsequently began to think about the most suitable research paradigm for the study. It seemed advantageous to use a qualitative approach to explore the views of the CYP as this would mean rich and detailed information could be gained. It was evident that an in-depth exploratory study would contribute the personal insights into ASC and anxiety that appeared to be lacking from the existing literature. It was also an attractive prospect to move away from the experimental field of ASC research that focuses on doing research *on* people (rather than *with* them), in an impersonal manner. Indeed, there has been concern highlighted by other researchers about the dominance of experimental research in the field of ASC (Humphery & Parksinson, 2006).

On reflection, I felt positive about taking a new research direction; however, I did have concerns over the face validity of the study. Gaining the views of CYP alone appeared to lack validity, particularly as it is well known that CYP with ASC struggle with communication and interaction. In addition, the study was not limited to CYP with Asperger syndrome (who generally have better language skills), as previous qualitative studies into CYP with ASC had been (Humphrey & Lewis, 2008; Russell & Sofronoff, 2005). For these reasons, it was decided that triangulating data from parents and support staff, with the information from the CYP, would help increase the strength of the research findings and subsequent value of the results gained.

### *6.3.2 Data collection methods*

As stated above, I chose to work in a qualitative framework, which emphasises the contribution that personal accounts from individual perspectives make to knowledge. This framework acknowledges that statistics and surveys are insufficient in the study of human affairs (Holliday, 2007). The beliefs of qualitative researchers tend to be constructionist in nature, i.e., they believe that people interpret their realities differently. It is this individual interpretation of reality that is of value to the researcher taking a qualitative approach. The underpinning epistemological position is social constructionism. If you hold the belief, as I do, that no objective reality exists, as reality is what individuals construct it to be, the quantitative notion of testing hypothesis for objectifiable truths becomes incompatible with such belief systems.

Had I believed that reality was objectifiable and 'truths' could be found, the research approach would have been very different at each stage of the process. I reflected on how my beliefs could have been different and how this would have changed the research I constructed. If my beliefs were that objectifiable truths could be found, a more experimental design might have been used. Initially I would have developed testable hypotheses and then set out to explore them using objective research methods on a large number of participants to increase the strength and validity of the findings. However, a problem with such approaches in ASC research is the focus on 'child outcomes' which has been said to ignore environmental factors and strengthen a 'within child' stance (Humphery & Parksinson, 2006). I was keen to move away from child outcomes and look more at how individuals' interactions with the environment affected them.

I was aware that my philosophical position influenced the design of the methodology, which needed to both satisfy the aims of the research and be suitable when considering my personal assumptions, epistemology and theoretical beliefs. Semi-structured interviews were used to gather qualitative information in a flexible way. It was felt that this method of data collection was personal and interactive, rather than objective. I designed the questionnaires, which were tailored to explore my research questions, using guidance from the literature (Bouchard, 2009; Cohen et al., 2011) and I adapted the interview schedules for the pupils by incorporating visual aids inspired by Talking Mats (Murphy, 1997). The adaptations were to increase accessibility for the pupils was a further novel aspect of the research. While person-centred approaches have been used in the past for accessing the child's voice in ASC research (Tobias, 2009), I am unaware of any interview techniques used that have attempted to make the process more accessible for the child with an ASC. On reflection I feel my role as a practitioner helped me think about how to access the voice of the child, as this is something I have to think about in my day-to-day work. I also benefited from attending an 'Interviews in Social Research' training day run by Cardiff University, where my questions about interview design could be answered and this, on reflection, gave me confidence in the formulation of my interview schedules.

Another aspect of data collection that was initially incorporated into the research design was a diary activity to try to record 'anxious moments' experienced by participants as they happened. The thought behind this was to counterbalance the validity-reducing effects of retrospective accounts from participants, which can be thought of as unreliable (Blane, 1996). While the layout of the diary activity was discussed with support staff and had their approval, putting the diary idea into practice was not successful. I reflected on why this might have

been and concluded that, in the real world environment, where anxious children are having behavioural reactions to anxiety, neither the child nor the member of staff supporting them would be in the right frame of mind to fill out the diary at that moment in time. Some members of staff would fill the diaries out at the end of the day, while others only filled the diary out just before returning it to me. As there was so much variation of information collected and the diaries were all filled out retrospectively it did not seem appropriate to incorporate them into the data analysis or subsequent results. I did keep them to hand during the interviews in case children or staff needed prompts re: anxiety causing events or scenarios, but had no cause to use them. I learned from this that data collection methods cannot be constructed without careful appreciation of the context in which they are expected to be used.

### *6.3.3 Data analysis*

In terms of contribution to knowledge, the path chosen for the data analysis and the subsequent results presented were crucial factors in determining the *type* of knowledge that would be produced. Because I chose to create an exploratory study, rich descriptions were seen as crucial to provide insight into an under-researched area. Thematic analysis (Braun & Clarke, 2006) was chosen to analyse the data for two reasons. First, it is thought to be the most appropriate method of qualitative analysis that seeks to uncover meaning through interpretation (Boyatzis, 1998). Secondly, Boyatiz (1998) also suggested that, when using thematic analysis, data analysis could begin at any time during the data collection process, which is not the case for other qualitative methods. As the data collection process took place over a relatively long period of time and I was attempting to balance the research with placement demands, being able to begin the data-analysis process as the data was being collected was an attractive option.

I made sure that the data analysis process could take place during a time when there were no other conflicting demands on my time. This ensured immersion in the data and allowed for flow and continuation of the data-analysis process. The themes developed over a number of weeks using the six steps recommended for thematic analysis by Braun and Clarke (2006). I felt that a challenging aspect of the data analysis was remaining succinct in the in-depth description of the findings. Because I had chosen an in-depth data analysis process, it made the word count element of the thesis more of a challenge than if I had decided to produce a quantitative piece of research. I was aware that my contribution to the knowledge base was one of rich description and, therefore, I strove to capture as much detail as possible without pushing the parameters of the word count. On reflection, this was a vital part of the data analysis process, as it forced me to be mindful of the commonality of the themes and the

importance of representation of the participants in order to produce meaningful and useful knowledge in a concise and well-defined way.

### *6.3.4 Results*

In terms of the results produced there are several unique aspects that I felt were useful to reflect on. The most pertinent aspects of the study for me was the insight the young people interviewed had into their own difficulties and their braveness and honesty when taking part in the process. An element that was particularly interesting in terms of research findings was the small details that the young people highlighted that gave such clarity to their underlying difficulties. The science lesson is something that was mentioned by different pupils. Such a 'normal' lesson in the school day may be full of anxiety provoking elements for a pupil with ASC because of the inherent unpredictability of the class. Information like this, in my view, is vital in helping anxious pupils with ASC access the curriculum. Having this knowledge allows teachers and other professions to put in place measures to reduce such anxiety and work with pupils to help them overcome their anxieties. Such findings arguably highlight the importance of in-depth qualitative research and the difference it can make at the individual level.

## 6.4 Part B: Critical Account of Research Practitioner

This section is a reflection on my experience of carrying out a study while in the role of a trainee EP and the opportunities and challenges this created at a theoretical and practical level.

### *6.4.1 Ethical issues*

On reflection my role as an applied psychologist in the field made me acutely aware of the ethical issues surrounding working with children and young people, particularity those with special educational needs (SEN). I feel that I have developed a good knowledge base of ethical issues at a theoretical level, which has been strengthened through awareness and understanding of government policy and the history of SEN legislation. University assignments have also helped me to 'tune into', and better understand, ethical issues. My understanding of ethical issues has also been developed through the practical work undertaken in the field. EPs have a professional obligation to act ethically; indeed, this is required by the guidelines set out by the Health and Care Professionals Council (HCPC), a professional body with which EPs are registered. This has meant that my role as a practitioner has provided an in-depth awareness of ethics, which has allowed me to think critically about how this knowledge can be applied to the research context.

The construction of the research design was based on the ethical principle of involving CYP in research. The fundamental aspect of this was to carry out research by working with the relevant CYP, rather than doing research *on* them. This was very much based on the now commonly accepted notion that the voice of the child is of utmost importance. The importance of children's views was first highlighted in 1989 under Article 12 of the UN Convention on the Rights of the Child (UN General Assembly, 1989). Subsequently, the UK Government created a range of initiatives that sought to allow the voice of the child to be heard. Some have argued, however, that the voice of the child has become a 'token gesture' and that more needs to be done to ensure CYP's voices are truly heard (Lewis & Porter, 2004). It is my view that empowering the CYP taking part in my research to be actively involved, heard and understood at each stage of the research process was crucial. Guidance from the literature was used to inform decisions at each stage. I found the paper by Lewis and Porter (2004) particularly helpful.

### *6.4.2 Sampling Challenges*

I was aware from the outset that involving CYP with ASC was going to be challenging on a number of practical and ethical levels. Recruiting willing participants who were able to take part was the primary challenge. In order to do this a conversation with the manager of each enhanced provision for communication and interaction (ARB) was undertaken in order to put together a 'judgment sample' (Marshall, 1996) of participants . On reflection this was a key part in the process as it allowed for dialogue about pupils and parents needs. It was clear from the start that involving some pupils and their parents would not be viable ethically. One pupil, for example, was soon to be taking exams, which he found very anxiety-provoking. Discussing this in an interview with me might have increased his anxiety and caused him problems in the subsequent exams and therefore involving him was not conducive to his wellbeing. A parent of another pupil at an ARB had recently been having some family difficulties and so asking her to participate would also have been inappropriate.

I thought carefully about the implications of requesting the ARB managers to select pupil and parent combinations to participate. This was against the traditional idea of validating research by ensuring random selection. However, on further reading and reflection it became apparent to me that random selection was perhaps inappropriate for research with a qualitative design. Marshall (1996) argued that, "studying a random sample provides the best opportunity to generalize the results of a population, but it is not the most effective way of developing an understanding of a complex issue relating to human behavior." (p. 523). This allowed me to feel confident that selecting a 'judgment sample' was acceptable from an ethical and a theoretical position.

### *6.4.3 Informed Consent*

Informed consent was a topic that also needed careful consideration. As a trainee EP in the field, I was able to reflect on the importance of informed consent, as this is something that is integral to the day-to-day work of the EP. However, the process of gaining informed consent from CYP on the autistic spectrum was a challenging process because of their inherent difficulty with communication and interaction. It was imperative that consent from the CYP was truly informed. Reflecting on this process, the key points that I wanted to ensure, using guidance from the literature, was that the participants understood what their involvement would entail, the purpose of the research and what the outcomes would be (Lewis & Porter, 2004). To ensure these key points were fully communicated and understood I encouraged parents and staff to discuss the research with the pupils. Once this had taken place I went into school to reiterate the research aims and objectives and explained what would be expected of the CYP. Finally the pupils had a child friendly consent form to sign, which addressed the key points using simple language. On reflection, while this was a time consuming process, I felt it was necessary to ensure truly informed consent on the part of the pupil.

### *6.4.4 Data Collection from a Research Practitioner Perspective*

On reflection, one of the most important aspects of the data collection process was spending time getting to know the individual pupils before the formal data collection process commenced. This was crucial for working with pupils with ASC because of their dislike of change. Whilst this was an anxiety provoking time for me, because of constraints of time, the act of physically spending time in each of the three ARBs was very useful. It meant that the pupils and staff met me, asked questions and simply become familiar with this new person. This familiarisation process was achieved not only through meeting with the CYP, but also through talking to the support staff about things that would help each child engage and communicate in the interview process. I felt that talking to school staff and forming relationships with children was a competence drawn very much from my practitioner role, using key skills, such as those proposed by Rogers (1969), to enable dialogue. It is possible that the staff and pupil familiarisation with me was a key element of the research process in that it helped facilitate the relaxed and open environment in which the interviews took place, leading ultimately to good quality data for the data-analysis stage of the process. However, I was aware that, while a genuine attempt to get to know the CYP was made, it was me who ultimately had the control over the data collection process and decided on the selection and presentation of the results, making it an ultimately impossible task to have the CYP as equals in the research process.

Collecting data from parents was also a challenge. In order to make them feel at ease I gave all parents the opportunity to be interviewed in the school setting or in their own homes. I found it interesting that all parents chose for me to come to their own home to conduct the interviews. Reflecting on this from a practitioner perspective, I realised that I rarely offered home visits when in the role of a trainee EP. The fact that parents all felt more comfortable talking to me in their own home made me wonder if parents would feel more comfortable talking to EPs in the home setting and whether this is something that EPs should be offering more often.

The interview process itself was an interesting experience and similar issues to working in schools as a trainee EP arose, such as fitting around individual pupil's timetables, finding suitable rooms to conduct interviews in and having enough time to complete the process. On reflection, my work as a trainee EP allowed me to prepare for such logistical difficulties and ensure timings and room bookings were all discussed with key members of staff beforehand. The actual interviews were a humbling experience and I was grateful for the openness and honesty of the pupils, staff and parents.

One of the most challenging aspects of the interview process was the involvement of school staff in the pupil interviews. In the pilot pupil interview, the member of staff in the room, who was there to support the pupil, began to answer questions for him. It was difficult to manage this situation once the interview had begun. On reflection, I should have briefed the member of staff about her role in the process, so they she knew what was expected of her during the pupil interview. Consequently, I made this clear to members of staff before the beginning of each pupil interview. This highlighted to me the value of the piloting process.

### *6.4.5 Data Analysis from a Research Practitioner Perspective*

Once the data collection had taken place the next challenge was transcribing the interviews verbatim for the data-analysis process. Braun and Clarke (2006) argue that the transcribing process is part of the data analysis and is integral for familiarising oneself with the data set. I reflected on my previous experience of transcribing from the Small Scale Research Project and was aware that the process could be incredibly time consuming. I was keen to strike a balance between immersion in the data and overwhelming myself with the challenge of transcribing 20 hours of interviews. In order to remain immersed in the data without becoming overwhelmed I planned time into the day, which was set aside for transcribing. This was typically a three-hour slot that allowed for a flow to develop. It became evident that I became more efficient at transcribing as time went on.

On reflection, it was important to set personal deadlines for each stage of the data-transcription process to keep up motivation and drive when juggling the demands of a four day week placement in the local authority setting. The understanding and support received from colleagues in the workplace, and the flexibility of time made available to me during this process was immensely helpful. I reflected on the psychology of social support, and how integral this was to the process.

The rest of the data-analysis process took place in the summer-term, once I had completed the year two trainee EP placement. Even though I was no longer with the local authority at this time, my experience there as a research practitioner was helpful throughout the data-analysis process. I was familiar with working to deadlines, doing in-depth written work and analysing data – albeit in a different format, such as psychometric assessment data. These skills, I believe, made the data-analysis process an easier task.

### *6.4.6 Relevance to EP Practice*

I reflected on the study and thought about how to incorporate what I had learned from the process, as well as the results of the study, into post-qualification work. One critical observation from the process was the strength of the child's voice and the insight a child has into issues concerning him or her. The value of adapting the interviews to enable dialogue with the pupils was something that I will certainly take with me into the profession. Spending time understanding the best way to enable the voice of the child is something that, as a trainee EP, I feel is vitally important. I also found it useful to incorporate views of parents and professionals, as this added a collective strength to the child's voice. Notwithstanding, the CYP interviewed could, with the right support and approach, give immensely in-depth and perceptive responses.

Another important element of working with CYP that was highlighted through the process of this study was the value of asking CYP simple questions that explored their day-to-day life at school. It was apparent from talking to CYP that often something seemingly inconsequential to most children can cause huge difficulties for those with ASC. The science lesson was a prominent example of this. Several CYP in the study found the lack of predictability of a simple experiment so hard to cope with that their behaviour became unmanageable. This could have been avoided by letting the CYP know from the beginning that only one of two things might happen during the experiment, so they were less overwhelmed by the unpredictability of the scenario.

Understanding the point of view of the child in the classroom situation is one of the EPs' biggest and arguably, most important, roles. Helping others understand those with complex SEN needs is also imperative to the role of the EP, and something I feel is fundamental, particularly for mainstream teachers who have children in their classroom with SEN. Post-qualification, I would use the study to inform how I think about delivering training on ASC and anxiety, using it to highlight myriad behavioural consequences of anxiety in the school setting and how to help those with ASC manage their anxiety.

Post-qualification, the study will also help me to think about whole-school approaches to managing anxiety for CYP with ASC who are in mainstream settings. Thinking systemically, whole class awareness as well as teacher training may also be extremely helpful in providing an environment for CYP with ASC that they find manageable, for them to access the curriculum.

The new Education, Health and Social care plan extends EP involvement with CYP from 18 to 25 years of age (Department for Education, 2013a). This new way of working will mean that EPs are likely to be involved with supporting CYP with ASC through further transitional periods i.e., from school to college to independent living and into the workplace. All these transitional times will be challenging for a CYP with ASC, and anxiety is likely to be a significant factor. Research into the area of ASC and anxiety is therefore particularly relevant when thinking about post-qualification work and thinking about how to support these young people in the next chapter of their lives.

Reflecting on the process as a whole, I feel that I have developed as a research practitioner and have learnt a great deal from the process in its entirety, from the initial ethical proposal, through to the production of the final research report. One of the greatest lessons of the process was the need for flexibility and adaptability to change, not just on a practical level but also on an academic level.

I felt that my practitioner role as a trainee EP gave me valuable skills that perhaps I would not have acquired from a research position alone, such as talking to children, compiling and adapting scripts and meeting with parents and school staff. On reflection this was a huge advantage to the research process and made the data collection phase a less daunting process. As noted by Lee-Treweek and Linkogle (2000), "Unlike a social worker or qualified counsellor, a researcher is rarely trained in such issues as managing distress [or] ending difficult interactions" (p. 15). I feel that as a research practitioner I have had the privilege of acquiring the aforesaid mentioned skills to an appropriate level. These skills have been

extremely useful throughout the process of conducting research with a range of people at different levels.

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**Doctorate in Educational Psychology Professional Training Programme**

**2014**

# Autism Spectrum Conditions and Anxiety in Mainstream Secondary Schools: An Investigation with Pupils, Parents and Learning Support Assistants

## Appendices

**Student name**: Abigail Rebecca Wicks

**Student number:** C1117883

**Appendix A: Information Related to Data Collection**



**Appendix B: Information Related to Participants**



**Appendix C: Information Relating to Data Analysis**



**Appendix D: Original Transcriptions Provided Electronically**

# *Appendix A: Information Related to Data Collection*

**Appendix A1 - Interview Schedule (Children)**

Please note: Visual aids such as the 'Incredible 5 Point Scale', 'Comic Strip Conversations' and 'Talking Mats' may be used in conjunction to the interview questions if necessary.

***Introduction to the interviewer***

Hello, my name is Abby Wicks. I would like to talk to you today about your worries. We all have worries, I'm interested about hearing about yours. During our chat we will talk about different things. They are:

1. Your worries (or anxieties).
2. The thoughts and feeling you have about worries
3. What you do when you get worried.
4. How you cope with worries.
5. How worries could be reduced for you at school.
6. How people help you when you are worried.

First, why don't you tell me about things in school that make you happy? We can talk about these things more when we have finished

***Your worries in school***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • We all worry about different things. Tell me what worries you in school? | • When does the worry happen?<br>• Do you worry more about some things than others? | • Can you give me any examples? |
| • How much do you worry about these things? | | |

***The thoughts and feeling associated with your worries in school***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • Can you tell me about any feelings that you have when you are worried? | • How strong are the feelings you have when you are worried?<br>• Do you have different feelings about different worries? | • Can you expand a little on this?<br>• Can you tell me anything else? |
| • Are there any thoughts that you have when you are worried? | | |

***Showing your worry in school***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • What do you do when you are worried?<br>• How do other people know when you are worried? | • How are you different when you are worried? | • Can you expand a little on this?<br>• Can you tell me anything else?<br>• Can you give me any examples? |

***Coping with worries in school***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • Can you tell me what you do to try and stop worries?<br>• If someone were worried about a maths test, what advice would you give him or her to make him or her less worried? | • How do other people help you with your worries? | • Can you expand a little on this?<br>• Can you tell me anything else?<br>• Can you give me any examples? |

***Changes needed to make school a less anxious place***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • What would have to change for your worries in school to be less?<br>• If you came to school with no worries in your head, what would be different? | | • Can you expand a little on this?<br>• Can you tell me anything else?<br>• Can you give me any examples? |

***Attitudes towards help or support***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • How do people in school help you with your worries? | • What sort of help does AA receive?<br>• How do they respond to this? | • Can you expand a little on this?<br>• Can you tell me anything else?<br>• Can you give me any examples? |

**Appendix A2 - Interview Schedule (Parents)**

***Introduction to the interviewer***

Hello, my name is Abby Wicks. I would like to talk to you today about your views concerning anxiety experienced by your child. During the interview I would like to discuss the following topics:

1. The nature and severity of your child's anxiety.
2. The thoughts and feeling your child associates with anxiety.
3. How your child expresses anxiety.
4. The strategies your child uses to deal with his or her anxiety.
5. What would help to reduce your child's anxiety?
6. Your child's feelings towards help and support for their anxiety.

With these topics in mind…

***The nature and severity of your child's anxiety in school***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • Can you tell me about your child's anxieties? | • Do they occur at specific times?<br>• Do they range in severity? | • Can you expand a little on this?<br>• Can you tell me anything else?<br>• Can you give me any examples? |
| • Can you tell be about the severity of your child's anxieties? | | |

***The thoughts and feeling your child associates with anxiety in school***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • Can you tell me about any feelings that you think accompany your child's anxiety? | • Can you give me any examples? | • Can you expand a little on this?<br>• Can you tell me anything else? |
| • Can you tell me about any thoughts that accompany your child's anxiety? | | |

***How your child expresses anxiety in school?***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • What happens when your child is anxious?<br>• How does your child express his or her anxiety? | • Are there different consequences to anxiety in different situations?<br>• How does he/she behave differently when anxious? | • Can you expand a little on this?<br>• Can you tell me anything else?<br>• Can you give me any examples? |

***The strategies your child use to deal with his or her anxiety in school***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • How does your child cope with anxiety provoking situations?<br>• Are there any techniques that your child has developed to calm down when anxious? | • How independently can your child use coping strategies?<br>• Do you have any techniques you use at home to reduce your child's anxiety? | • Can you expand a little on this?<br>• Can you tell me anything else?<br>• Can you give me any examples? |

***Changes needed to make school a less anxious place for your child***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • What would have to change in order for your child to be less anxious in school?<br>• For your child to be free of anxiety in school, what would the school setting be like? | • What could the school do make your child's anxiety less? | • Can you expand a little on this?<br>• Can you tell me anything else?<br>• Can you give me any examples? |

***Attitudes towards help or support***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • Does your child receive any help or support to manage his or her anxiety in or out of school<br>• How would your child respond to help and support with anxiety? | • What sort of help does your child receive?<br>• How do they respond to this? | • Can you expand a little on this?<br>• Can you tell me anything else?<br>• Can you give me any examples? |

**Appendix A3 - Interview Schedule (School Staff)**

***Introduction to the interviewer***

Hello, my name is Abby Wicks. I would like to talk to you today about your views concerning anxiety experienced by the child you support in school (AA). During the interview I would like to discuss the following topics:

1. The nature and severity of AA's anxiety.
2. The thoughts and feeling AA associates with anxiety.
3. How AA expresses anxiety.
4. The strategies AA uses to deal with his or her anxiety.
5. What would help to reduce your AA anxiety?
6. AA's feelings towards help and support for their anxiety.

With these topics in mind…

***The nature and severity of AA's anxiety in school***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • Can you tell me about AA's anxieties? | • Do they occur at specific times?<br>• Do they range in severity? | • Can you expand a little on this?<br>• Can you tell me anything else?<br>• Can you give me any examples? |
| • Can you tell be about the severity of AA's anxieties? | | |

***The thoughts and feeling AA associates with anxiety in school***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • Can you tell me about any feelings that you think accompany AA's anxiety? | • Can you give me any examples? | • Can you expand a little on this?<br>• Can you tell me anything else? |
| • Can you tell me about any thoughts that accompany AA's anxiety? | | |

***How AA expresses anxiety in school?***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • What happens when AA is anxious? | • Are there different consequences to anxiety in different situations?<br>• How does he/she behave differently when anxious? | • Can you expand a little on this?<br>• Can you tell me anything else?<br>• Can you give me any examples? |
| • How does AA express his or her anxiety? | | |

***The strategies AA use to deal with his or her anxiety in school***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • How does AA cope with anxiety provoking situations? | • How independently can AA use coping strategies?<br>• Do you have any techniques you use at home to reduce AA's anxiety? | • Can you expand a little on this?<br>• Can you tell me anything else?<br>• Can you give me any examples? |
| • Are there any techniques that AA has developed to calm down when anxious? | | |

***Changes needed to make school a less anxious place for AA***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • What would have to change in order for AA to be less anxious in school? | • What could the school do make AA's anxiety less? | • Can you expand a little on this?<br>• Can you tell me anything else?<br>• Can you give me any examples? |
| • For AA to be free of anxiety in school, what would the school setting be like? | | |

***Attitudes towards help or support***

| Main Questions | Further Questions | Clarifying Questions |
|---|---|---|
| • Does AA receive any help or support to manage his or her anxiety in or out of school | • What sort of help does AA receive?<br>• How do they respond to this? | • Can you expand a little on this?<br>• Can you tell me anything else?<br>• Can you give me any examples? |
| • How would AA respond to help and support with anxiety? | | |

**Appendix A4 - Information Letter to Parents**

Dear .....
I am a trainee educational psychologist from Cardiff University and I am spending a year working with the local authority. Part of my time here is dedicated to research. I am interested in understanding the experience of anxiety in school for pupils who are on the autistic spectrum.

**What is it about?**
The purpose of the research is to gain a greater understanding of the nature and experience of anxiety felt by pupils on the autistic spectrum in the school setting. It is hoped that by including the views of school support staff who work closely with pupils, as well as the parents and the pupils themselves, a rich picture of the nature of pupils' anxiety will emerge from a range of sources.

**Why me?**
The head of ARB at ***** school has identified several pupils who would be able to contribute to the research I am doing. Your child was one of those pupils.

**What do you hope to gain from my involvement and the involvement of my child?**
It is hoped that this research will help to drive positive change by increasing knowledge and understanding of the experiences and challenges associated with anxiety in the school setting for pupils on the autistic spectrum.

**What do I need to do?**
I would like to invite you to an informal interview, where we can discuss your child's anxiety in greater depth.

**What would my child need to do?**
I would first need your permission to ask your child if he or she would like to take part. I will be visiting the school to explain the study and have a 'get to know you' session with the pupils involved. Pupils will be invited to participate. They will be asked to keep a short diary for approximately a week, detailing any worries that they experience. I will then interview your child, with a familiar adult present, if necessary, about his or her anxieties. This will be a child friendly process, and a range of fun visual techniques will be used to help elicit the views of your child.

The interview with yourself will last approximately 45 minutes; the interview with your child will be approximately 30 minutes. Both will be recorded so that I don't have to write everything down during the discussions. However, this recording will remain strictly confidential and I will be the only person allowed to listen to it.

Taking part is voluntary and the decision about participation will not affect your rights or access to services. You will of course have a right to withdraw from the

interview at any time. Your child will have the right to withdraw from the diary keeping exercise and the interview at any stage. If you decide you don't want your views included in the research after the interview has taken place that is fine too.

When I later use the information from the interviews your personal details and those of your child will be removed and will not be traceable to either of you by name. Once personal details have been removed from the information provided it will not be possible to remove individuals from the study because I will have no way to trace people by name.

Please find below a consent slip that can be returned to a member of staff in the Enhanced Provision for Interaction or posted to me in the stamped address envelope provided.

Thank you for taking the time to read this letter,

Best wishes,

Abby
Abigail Wicks
Trainee Educational Psychologist

……
……

I am happy for my child to take part in the study if he/she gives consent

Signed……  Date……..

I would like to be contacted by the researcher to arrange a time and date that is convenient for me to be interviewed for the purpose of the study.

Signed…….  Date……..

……
……..……..

Please contact me if you have any further questions or if you require further information. My supervisor for this research is Mr John Gameson, Professional Director of the DEdPsy course. In the case of complaint please contact the chairman of the Ethics Committee, Dr Michael Lewis, who can be contacted via the ethics committee secretary.

Regards,

Abigail Wicks

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CF10 3AT
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John Gameson
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Secretary of the Ethics
Committee
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psychethics@cardiff.ac.uk

**Appendix A5 - Debriefing Form for Participants (Parents & Support Staff)**

Thank you for taking part in the project. I will be using the information you have provided me with to gain a better understanding of the experience of anxiety for pupils on the autistic spectrum. The interview recordings will be kept confidential and then anonymised after the interviews and will be destroyed after 18 months. If you would like a summary of the results when the research is complete please contact me on the email address provided.
If you have any further questions please do not hesitate to contact me by email: wicksar@cardiff.ac.uk

Alternatively, contact my supervisor, Mr John Gameson who can be contacted on the address below:
School of Psychology,
Tower Building
Cardiff University
Park Place
Cardiff
CF10 3AT
02920 875393
gamesonj@cardiff.ac.uk

If the case of complaint please contacts the Chairman of the ethics committee, Dr Michael Lewis who can be contacted via the details below:

Secretary of the Ethics Committee
School of Psychology
Cardiff University
Tower Building
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Cardiff
CF10 3AT
Tel: 029 2087 0360
Email: psychethics@cardiff.ac.uk

# *Appendix B: Information Related to Participants*

**Appendix B1 - Participant Information**

| Pupil (Participant number/year group/sex) | Interview Length | Parents (Participant number/relation) | Interview Length | Support Staff (Participant number/sex) | Interview Length (minutes: seconds) |
|---|---|---|---|---|---|
| 1 (year 10) Male | 23.37 | 8 Mother | 23.01 | 18 Female | 23.37 |
| 2 (year 8) Male | 18.31 | 9 & 10 Mother & Father | 40.26 | 19 Female | 18.31 |
| 3 (year 11) Male | 21.30 | 11 Mother | 29.28 | 20 Female | 25.20 |
| 4 (year 8) Male | 21.42 | 12 & 13 Foster Carers | 57.08 | 21 Female | 20.30 |
| 5 (year 9) Male | 35.58 | 14 Mother | 34.08 | 22 Female | 28.54 |
| 6 (year 8) Male | 26.39 | 15 & 16 Mother & Father | 43.19 | 23 Female | 39.49 |
| 7 (year 9) Male | 35.54 | 17 Mother | 28.14 | 24 Female | 14.57 |

**Appendix B2 - Gatekeeper Letter to Head Teacher of Schools**

Address and Date

Dear **** (Head Teacher)

I am a trainee educational psychologist, enrolled at the School of Psychology, Cardiff University. Currently, as part of my course, I am working in the Local Authority (LA) Educational Psychology Service as a Trainee Educational Psychologist. As part of my degree I am carrying out a study on autism and anxiety in mainstream school. I am writing to enquire whether you would give permission for this research to take place within the Autism Resource Base (ARB) at your school. I am hoping to include the three mainstream secondary schools in the LA that have ARB.

The purpose of this research is to gain insight and increase knowledge about the nature and experience of anxiety felt by pupils on the autistic spectrum. It is hoped that by including the views of support staff, pupils and parents, a rich picture will emerge. Information will be gathered through the medium of semi-structured interviews (with parents, pupils and support staff) and a simple diary activity (pupils).

If permission from you is given, I will ask the head of ARB to identify two to three pupils who would be able to participate in the study. I would then ask parents for consent to approach their children for the purpose of the study. This would be in the form of a letter that would also detail the nature of the research. Parents will also be given the opportunity to participate in the study through the medium of a semi-structured interview.

If consent were obtained from the pupils' parents, I would then visit the pupils at school and the support staff, at a pre-arranged time and explain the nature of the research. I may need to visit the school on more than one occasion to build rapport with the students, if necessary. Pupils and support staff who would like to take part in the study will be asked to sign a consent form. Confidentiality, right to withdraw and data anonymity will be discussed and clarified. When discussing this with the pupils, I will do so in a way that is age appropriate and accessible, with a familiar adult present.

If the pupils agree to participate I will explain to them that I would like them to keep a simple diary for one week, where they can document any worries they have throughout the day. After one week I will return to school to meet with the pupils individually. I will use the diary as the basis for the semi-structured interview in which I hope to elicit the pupils' views about their anxiety. The pupils will be reminded about their right to withdraw at any point during the interview if they wish, without giving a reason for doing so.

Support staff of pupils will be invited to take part in semi-structured interviews on a day and time to suit them.

It will be made clear to participants that all information provided by them will remain confidential. When the information provided by participants is transcribed, it will be done anonymously. No participant's views will be traceable to a named individual from this point forward.

Before each interview commences, participants will be made aware that, if they do not want to continue at any point during the interview, they have the right to withdraw from the study without giving a reason. It will be made clear to participants after the interview that they have a right to withdraw their data at any stage in the process up until the interviews are transcribed. Data from the interviews will be transcribed anonymously; therefore, once the transcription has taken place, I will be unable to identify a named individual and remove his or her data from the study.

The data will be analysed using thematic analysis, as this qualitative approach will give a rich and detailed picture of pupils' experience of anxiety from multiple perspectives.
I would require permission from you to contact the head of ARB at your school to begin the process. I would also require permission to carry out interviews with pupils, staff and possibly parents, on the school grounds.

Many thanks in advance for your consideration of this project. Please contact me if you have any further questions or if you require further information. My supervisor for this research is Mr John Gameson, Professional Director of the DEdPsy course. In the case of complaint please contact the chairman of the Ethics Committee, Dr Michael Lewis, who can be contacted via the ethics committee secretary.

Regards,

Abigail Wicks


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Email: psychethics@cardiff.ac.uk

**Appendix B3 - Gatekeeper Letter to Head of ARB**

Address and Date

Dear **** (Head of ARB)

I am a trainee educational psychologist, enrolled at the School of Psychology, Cardiff University. Currently, as part of my course, I am working in *** Educational Psychology Service as a Trainee Educational Psychologist. As part of my degree I am carrying out a study on autism and anxiety in mainstream school. I am writing to enquire whether you would give permission for this research to take place within the Autism Resource Base (ARB) at your school. I am hoping to include the three mainstream secondary schools in the local authority that have an ARB.

The purpose of this research is to gain insight and increase knowledge about the nature and experience of anxiety felt by pupils on the autistic spectrum. It is hoped that by including the views of support staff, pupils and parents, a rich picture will emerge. Information will be gathered through the medium of questionnaires (for the parents), semi-structured interviews (with parents, pupils and support staff) and a simple diary activity (pupils).

I would require you to identify two to three pupils who will be able to participate in the study. An information letter will be sent out to their parents initially informing them of the study, requesting their permission to contact their child, and finally asking them to fill in a short questionnaire about their child's anxiety levels. If consent is given, I will come into school to introduce myself to the pupils and explain to them the nature of the study before asking them if they would be willing to participate.

If a child agrees to participate I will explain to him or her that I would like them to keep a simple diary for one week, where they can document any worries they have throughout the day. They will be able to express this in a manner of their choice and will be encouraged to write or draw pictures. I will seek guidance from your team about the format of the diary.

After one week I will return to school to meet with the pupils individually. I will use the diary as the basis for the semi-structured interview in which I hope to elicit the pupil's views about anxiety in school. Support staff of the pupils taking part will be invited to take part in a semi-structured interview on a day and time to suit them.

It will be made clear to participants that all information provided by them will remain confidential. When the information provided by participants is transcribed, it will be done anonymously. No participant's views will be traceable to a named individual from this point forward.

Before each interview commences, participants will be made aware that if they do not want to continue at any point during the interview they have the right to withdraw from the study without giving a reason. It will be made clear to participants after the interview that they have a right to withdraw their data at any stage in the process up until the interviews are transcribed. Data from the interviews will be transcribed anonymously; therefore, once the transcription has taken place, therefore I will be unable to identify a named individual and remove his or her data from the study.

The data will be analysed using thematic analysis, as this qualitative approach will give a rich and detailed picture of pupil's experience of anxiety from multiple perspectives.

I would require permission from you for this study to take place within the ARB. I will work closely with your staff to ensure my presence causes as little interruption as possible to the pupils and staff during the research process.

Many thanks in advance for your consideration of this project. Please contact me if you have any further questions or if you require further information. My supervisor for this research is John Gameson, Professional Director of the DEdPsy course. In the case of complaint please contact the chairman of the Ethics Committee, Dr Michael Lewis, who can be contacted via the ethics committee secretary.

Regards,

Abigail Wicks


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**Appendix B4 - Consent Form for Participants (Support Staff/Parents)**

I understand that my participation in this project will involve me taking part in an interview about my views about the anxiety (child's name here) experiences in school. I understand this will take approximately 45 minutes.

I understand that participation in this study is entirely voluntary and I can withdraw from the interview at any time without giving a reason. I understand that I have a right to withdraw the data I provided during the interview at any stage in the process up until the interviews are transcribed by the researcher. Data from the interviews will be transcribed anonymously, therefore, once the transcription has taken place, the researcher will be unable to identify a named individual and remove any data from the study.

I understand that I am free to ask any questions at any time. I am free to withdraw or discuss my concerns with the researcher's supervisor, Mr John Gameson. If I wish to make a complaint I can contact the Chairman of the ethics committee, Dr Michael Lewis, who can be contacted through the secretary of the ethics committee.

I understand that the information provided by me will be held confidentially, such that only the researcher, Abigail Wicks, can trace this information back to me individually. I understand that my data will be anonymised when transcribed and that after this point no one will be able to trace my information back to me. The information recorded by Dictaphone will be retained for up to 18 months, when it will be destroyed. I understand that I can ask for the information I provide to be deleted/destroyed at any time up until the data has been anonymised and I can have access to the information up until the data has been anonymised.

I, _____(NAME) consent to participate in the study conducted by Abigail Wicks, School of Psychology, Cardiff University with the supervision of Mr John Gameson.

Signed: Date:

Abigail Wicks
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Tower Building
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Tel: 02920875393
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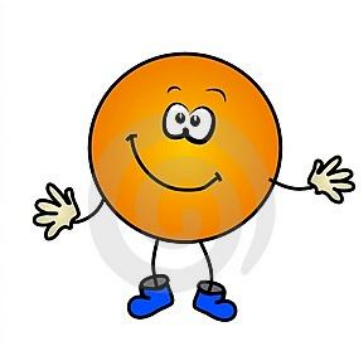
**Appendix B5 - Consent Form for Participants (Pupils)**



I understand that taking part in this project means that I will fill in a dairy for one week before having a talk (or interview) with Abby, who I have met. Taking part is up to me and if at any point I decide that I don't want to do the diary or the interview I don't have to. I don't have to give a reason for this.

I understand that I have a right to withdraw the information I provided in the diary or during the interview at any stage in the process up until Abby writes it all down. This is because Abby will write down the information without including my name on it.
I understand that I am free to ask any questions at any time. I am free to withdraw or discuss any problems with Abby, a member of staff, my parents or another adult I feel comfortable talking to.
I, _____(NAME) consent to participate in the study conducted by Abby.

Signed: Date:

**Please note that the diary element was omitted from the study. Please see reflective summary section for further details**

# *Appendix C: Information Relating to Data Analysis*

**Appendix C1 - Initial Coding Research Question One (Example)**

Code Tables (Research Question: 1, Group 1)

| Data Extract | Coded for |
|---|---|
| Pt. 1: lots of work! | 1. Overwhelming academic demands<br>28. Overwhelming |
| Pt. 1: I really hate crowds. | 2. Volume of people |
| Pt. 1: Lots of noise. Things that are loud. All other people talking at once. Other people talking to me! | 3. Sensory volume<br>4. Interruptions<br>40. Disorder |
| AW: Have a look at this worry thermometer (uses visual prompt). If 10 is the worst feeling and 0 is completely relaxed, where would you put 'noise.'<br>Pt. 1: Six point five.<br>AW: OK, so noise worries you quite a lot. And your other worries, so we had crowds; how much does that worry you?<br>Pt. 1: Urm, about five.<br>AW: OK so that is quite worrying as well. And what was our other one…work. How much does work worry you?<br>Pt. 1: Probably a two. | 16. Differing levels of severity<br>19. Medium anxiety |
| Pt. 8: Everything worries him. He is definitely a worrier without a doubt. Even little things could get him worried. Worried about how he interacts with other children or how they are going to interact with him. Whether his is going to make mistakes, which he absolutely hates making mistakes and that can be a real trigger of his anxieties. It's hard to say what his anxieties are because he doesn't talk about them at home, It's hard to… | 5. General worry<br>6. Social concerns<br>7. Perfectionism<br>41. Expectation<br>30. Fear of failure |
| Pt. 8: With the previous driver, it didn't happen very often, but occasionally he would swear, once in a blue moon, usually because … its impulse, you do it. **Pupil** absolutely detests swearing of any sort especially the "f" word is his worst one and he can retreat into himself. By the time he has got to school, he's rigid, head down. Another incidence once was the taxi driver was late; he picked **Pupil** up first even though he was late. So he still had to get S*** the other child and on the way to get S*** they had a little prang. You can imagine the state he would be in by the time he got to school: he's had the guy late, not the normal guy, not his usual guy, an accident. | 8. Rule-breaking<br>9: Change in routine |
| He wants to be friends with people and he wants to make friends but he doesn't pick up of when they are joking and messing about like we would and he can take things very personally, even if it wasn't intended against him he could take it that way. | 6. Social concerns<br>10. Mis-read social scenarios<br>17. Forming friendships |
| Pt. 8: 'Cus there are lots of people moving around it would be… crowds.<br>Pt. 8: he doesn't like crowds anywhere. He really doesn't like crowds. It takes somebody to bump into him and he'll.... doesn't like… | 2. Volume of people<br>42. Physical proximity |
| Pt. 8: Getting the work right will worry him definitely and if | 7. Perfectionism |

| | |
|---|---|
| he starts making a mistake you can see he will start pressing harder with the pen and get crossing out. And he will do that three or four times and that is when he will go "umph**"** a big explosion. | |
| Pt. 18: **Pupil** worries about everyday life; he worries about exams, he worries about homework, he may worry if he has forgotten a bottle of squash, he worries if there is a change of the circumstances in school, so like if I'm off school sick and its immediately, "Oh **Pupil** you have got a cover TA, Mrs. J is off sick." He will worry about that, how he's going to get through the day with someone who doesn't know him. Are they going to be able to manage his anxieties? "What happens if I can't tell the TA what my worries are?" So he does worry about everyday life. | 5. General worry<br>9: Change in routine<br>11: Homework<br>1. Overwhelming academic demands<br>30. Fear of failure<br>38. The unknown |
| Pt. 18: With **Pupil** it's unpredictable. So he could come in, he could be high as a kite like this morning, but as the day goes on his mood could gradually decrease. That signifies that he is now starting to withdraw and he is not managing the anxieties as best as he could. So it just means that we have to jolly him along and I have to put a quick action in plan. So that might mean, right actually what we will do is stay down here, we will work quietly down in the ARB to get you through to the end of the day. So with **Pupil** every day is different and you cannot predict how the day… | 12. Building anxiety<br>16. Differing levels of severity<br>13. Unpredictable anxiety<br>2. Withdraw (coded for RQ2) |
| Pt. 18: But then there is the opposite side if something has happened on the way to school with the taxi. He could come in, in an enormous stress, anxiety, mood even, he could be shut down in the car so that means that it's the opposite way around. He could be really distressed in the morning but by the afternoon he could be a hyper, happy chappy. | 13. Unpredictable anxiety<br>16. Differing levels of severity<br>43. Pre/post school concerns |
| Pt. 18: The choice behaviours is when he is finding work difficult but also he won't take advice or the support so he will then to hide away from that difficult question, he will choose to shut down. For example, yesterday he was struggling with a 'mind maths' question so the strategy would be to minimise the screen, because it was on the computer, do something different or go for a walk or help me in the kitchen with washing-up after the break and then go back to the question. But **Pupil** decided to choose not to follow any of those strategies. So **Pupil** looked at me immediately and then shut down completely. | 1. Overwhelming academic demands<br>18. High anxiety |
| Pt. 18: Not getting the best grades possible. GCSEs coming up, he's already worrying about that. What we are finding is that as we are reducing coursework and as coursework is being handed in, so those lessons become less, those lessons don't exist. So of course that means he has a lot more one-to-one time down in the ARB to focus on the maths and science that he does struggle with every day. | 7. Perfectionism<br>1. Overwhelming academic demands<br>30. Fear of failure |
| Pt. 18: I think it's the classroom noise which can be an impact, especially in science, if they are told there are going to do an experiment right there and then for which he has not been pre-tutored that can send his stress levels soaring. But it could be any kind of tapping noise. So if it doesn't conform to his rules, then it can have an impact on his | 14. Unpredictability<br>3. Sensory volume<br>8. Rule-breaking |

| | |
|---|---|
| anxieties. | |
| Pt. 18: The last time he was in Biology, what we call, quote "monster" came out and he ended up running into the middle of town and was stood in a cul-de-sac for two hours. We had to stop traffic; we had to go around knocking on people's doors and just to explain that we have a distressed student can we be vigilant with cars? Mum was on her way by this time and basically it takes all our staff up there to manage it. | 14. Unpredictability<br>15. Fight/flight response<br>16. Differing levels of severity<br>18. High anxiety<br>12. Externalisation (coded for RQ2) |

**Appendix C2 - Initial Codes Generated from Triangulation (Example)**

Research Question (RQ) 1 Common Codes

Group ONE

*Codes that have been applied to data in at least 2/3 participants in each group OR are present across groups (mentioned by at least 2 pupils/parents or support staff)*

Volume of people
Sensory volume
Interruptions
Physical proximity
Social concerns
Mis-read social scenarios
Overwhelming academic demands
Homework
Perfectionism
Fear of failure
Rule-breaking
Change in routine
Building anxiety
Unpredictable anxiety
Fight/flight response
Differing levels of anxiety
Quick escalation (present across groups)
Overwhelming (present across groups)

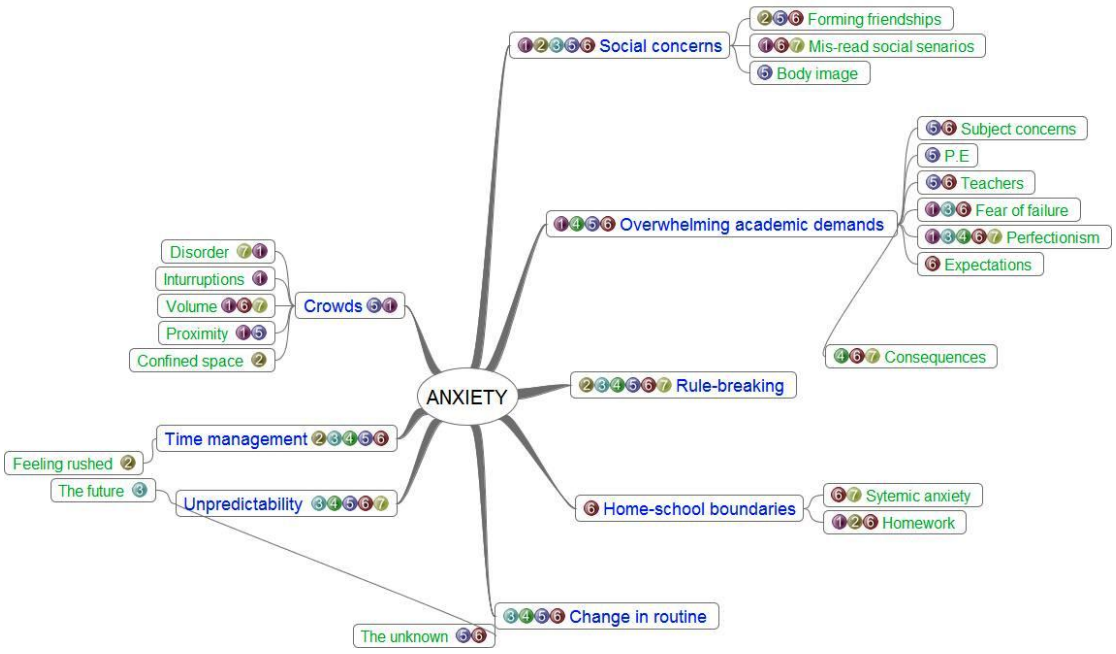
*Pre/post school concerns (parents)
*Disorder (child)

**Appendix C3 - Thematic Maps (Research Question 1-5)**

*Each individual transcription was coded (see Appendix C1) and initial themes present in each group of pupil, parent and support staff (n = 7) were established (see Appendix C2). The common themes across the groups were merged to produce initial thematic maps. Each thematic map was then modified into final thematic maps and super-ordinate themes were created.*

**Research Question ONE**

Initial Thematic Map:

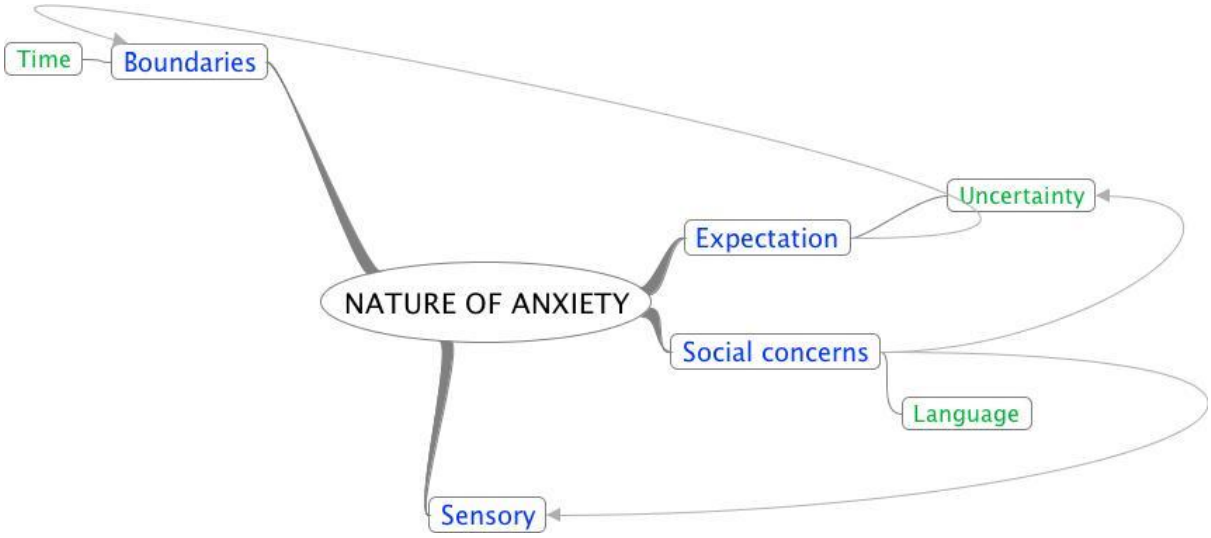



Themes for RQ1 were as follows.

- Social concerns.
- Overwhelming academic demands.
- Rule-breaking.
- Home-school boundaries.
- Unpredictability.
- Time-management.
- Crowds.

The seven initial themes were reviewed and it was found that some themes were too narrow; for example, the ‘crowds’ theme, which covered a range of sensory anxieties. Other themes were too broad; for example, ‘rule-breaking’ and ‘change in routine’. These themes were encompassed by another presenting theme, ‘unpredictability’. RQ1 also addresses the participants’ view of the ‘severity of anxiety’. The responses to this element of the question are threaded throughout the results section and have not been coded as a separate entity.

Final Thematic Map:



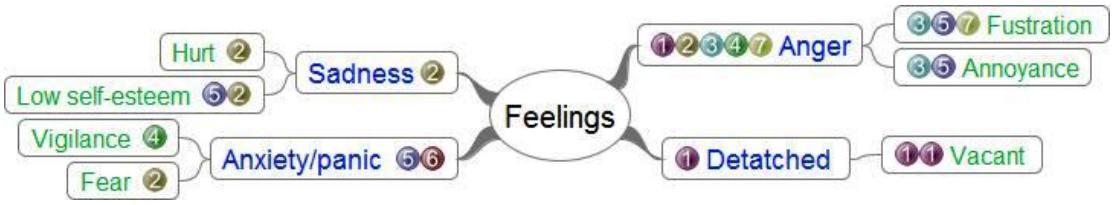

After constructing the initial thematic map, the themes were reviewed and modified into four final 'super-ordinate' themes.

The final super-ordinate themes suggest anxiety is being caused by:-

- expectation;
- social concerns;
- boundaries; and
- sensory sensitivities.

**Research Question TWO**

Initial Thematic Map:




Initial themes for the 'feelings' element of the question were as follows.

- Anger
- Sadness
- Anxiety/panic
- Detached

The four initial themes were reviewed. Some initial sub-themes were omitted because of low representation such as, 'vacant' and 'vigilant'. Other sub-themes were absorbed into appropriate larger themes; for example, 'fear' was incorporated into the 'anxiety/panic' theme and 'sadness' was absorbed into the passive theme.

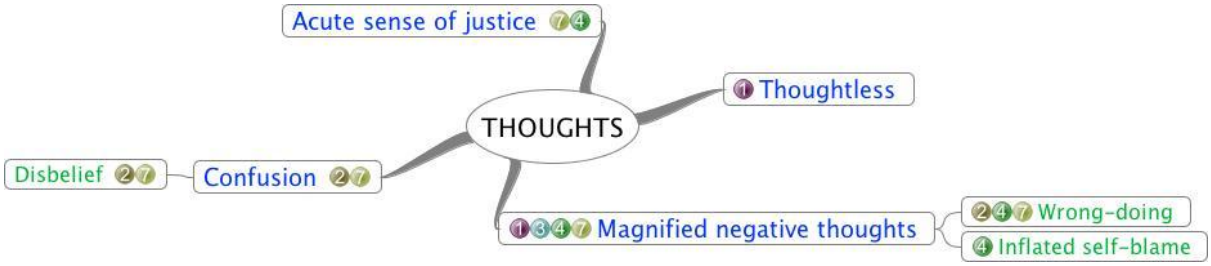
Final Thematic Map:


After the initial thematic map was created, the themes were reviewed and modified into one super-ordinate theme (see Diagram 2a). This was:-

- Negative feelings.

The second part of the question related to 'thoughts'.

Initial Thematic Map:



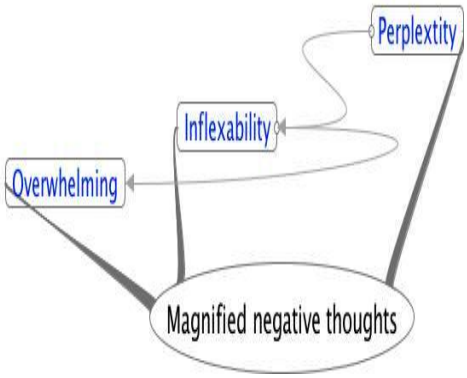

Initial themes for the 'thoughts' element of the question were as follows.

- Acute sense of justice

- Confusion
- Thoughtless
- Magnified negative thoughts

The four initial themes were reviewed. The core theme ‘magnified negative thoughts’ was encompassing of the other themes including ‘inflated self blame’. Some themes, such as ‘confusion’ were better described by a broader sub-theme, ‘perplexity’. The sub-theme ‘overwhelming’ was created to capture the over-riding strength of the negative thoughts and encompassed the theme ‘thoughtless’.

Final Thematic Map:

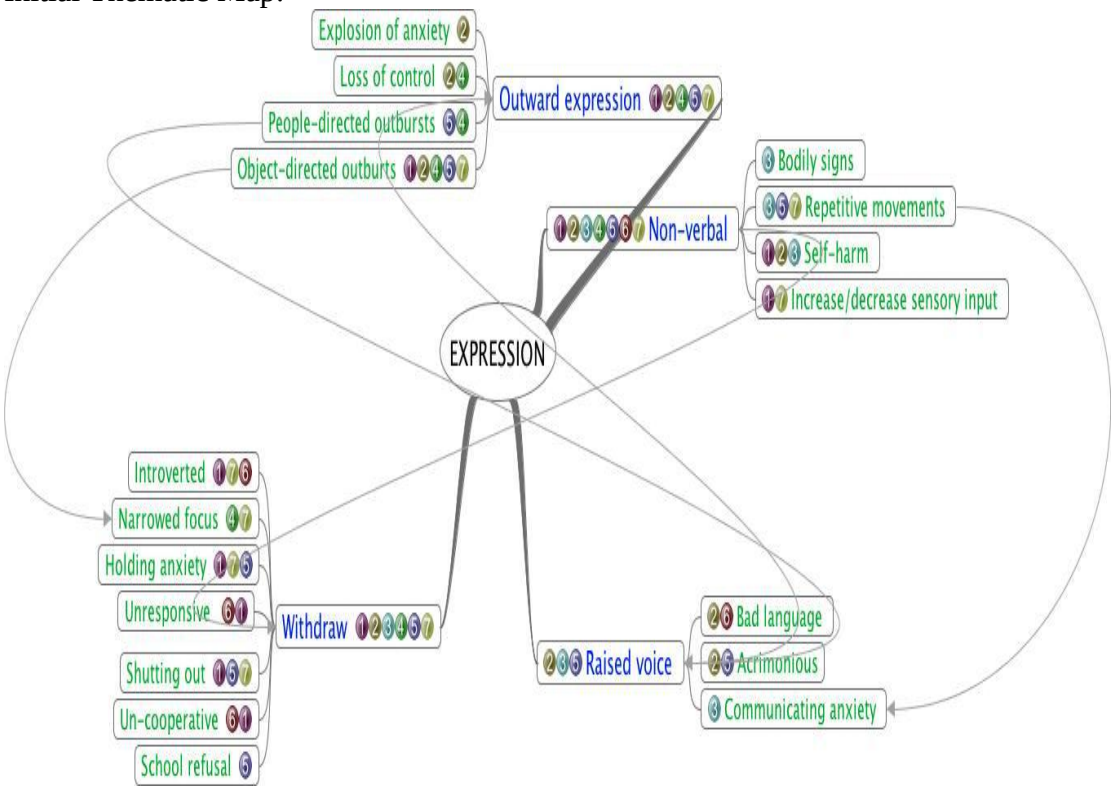



After the initial thematic map was created, the themes were reviewed and modified into one super-ordinate theme. This was:-

- Magnified negative thoughts

**Research Question THREE**

Initial Thematic Map:

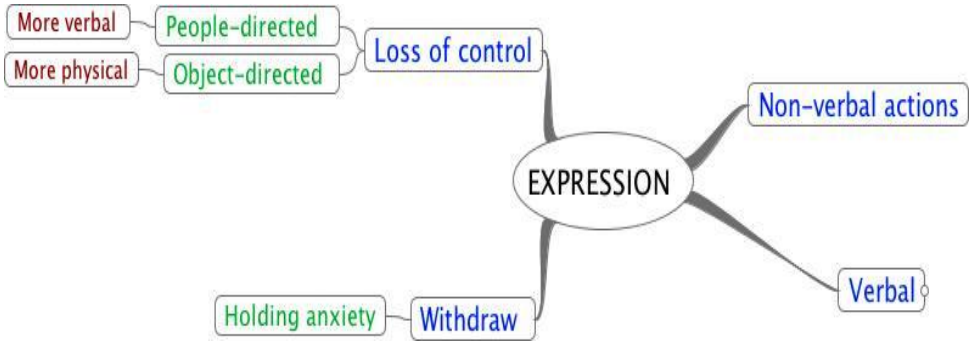



Initial themes were as follows.

- Outward expression
- Non-verbal
- Raised voice
- Withdraw

After the initial thematic map, the themes were reviewed and modified into another four final super-ordinate themes. It was conceded by the researcher that all pupils went through these ranges of reactions; there were not particular pupils who consistently withdrew or others that tended to predictably loose control.

Final Thematic Map:



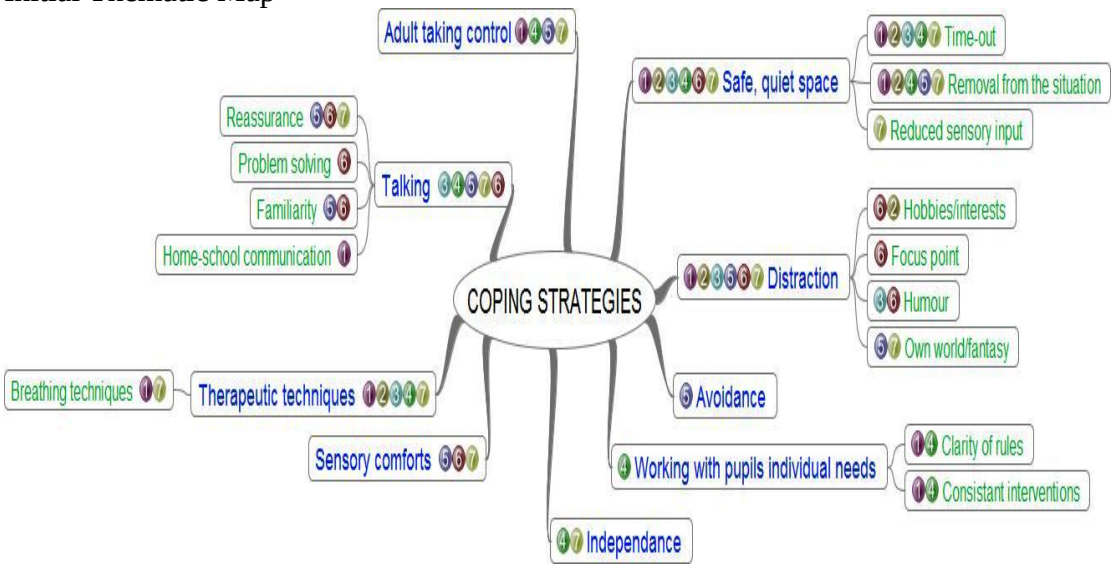
Each pupil appeared to follow a trajectory of reactions as their anxiety levels increased, which followed the order in which the themes have been displayed below.

These final themes were:-

- non-verbal actions;
- verbal;
- withdrawal; and
- loss of control.

**Research Question FOUR**

Initial Thematic Map




Initial themes were as follows.

- Talking
- Adult taking control
- Safe, quiet space
- Distraction
- Avoidance
- Working with pupils individual needs
- Independence
- Sensory comforts
- Therapeutic techniques

The nine initial themes were reviewed and it was felt that some sub-themes were better represented as a wider label; for example, ‘own-world’, ‘hobbies’ and ‘humour’ were better described within the context of the wider theme ‘distraction’ and did not warrant separate discussion points. On further analysis several sub-themes fit more appropriately into different super-ordinate themes, i.e., ‘familiarity’ was moved from the ‘talking theme’ to ‘adults taking control’. Some super-ordinate themes were absorbed into more appropriate wider labels, i.e., ‘adult taking control’ into ‘reassurance’. Some themes/superordinate themes were removed because of low representation.

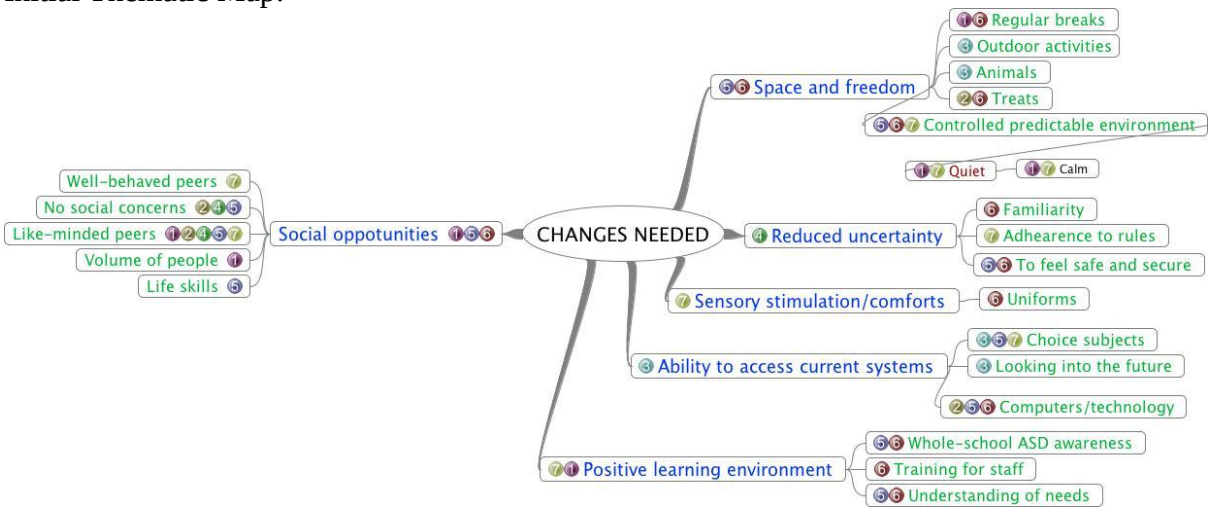
Final Thematic Map:

After the initial thematic map was created, the themes were reviewed and modified into five super-ordinate themes. These were:-

- reassurance;
- safe, quiet space;
- distraction;
- sensory comforts; and
- therapeutic techniques.

**Research Question FIVE**

Initial Thematic Map:

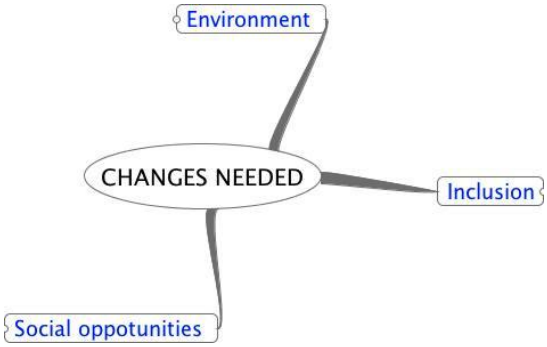



Initial themes were as follows.

- Space and freedom
- Social opportunities
- Positive learning environment
- Ability to access current systems
- Sensory stimulation/comforts
- Reduced uncertainty

The six initial themes were reviewed, at this stage some themes were excluded because of low representation, such as 'sensory stimulation/comforts'. As this question brought about a range of individual responses the themes needed to be grouped in such a way as to encompass the range of themes but to keep high representation across the groups.

Final Thematic Map:




After the initial thematic map was created, the themes were reviewed and modified into three final super-ordinate themes. These were:-

- environment;
- inclusion; and
- social opportunities.

**Appendix C4 - Supporting Quotes**

| RQ | Theme number /Sub-theme (ST) and title | Supporting Quotes | Reference: (See Appendix D for full scripts, quotes used are highlighted in red) |
|---|---|---|---|
| 1 | 1. Expectation | "All right...OK, well there is one key thing that I am most worried about in school, that is the end. When I get the exam results, because I am aiming to get a grade D in English and Maths and I am very, very worried that I might not achieve it."<br><br>"Well not getting my work done mean that the teacher might say, "You weren't listening, you only did that bit of work, that means you are not going to get a good grade for that." And I think to myself, why does the teacher think that?" | Pupil: Participant 3, page 1<br><br>Pupil: Participant 7, page 1 |
| 1 | ST. *Uncertainty* | "Because it's a little bit more unpredictable, whether the children are actually going to follow the rules of the experiment, whether a chemical is going to get spilled or someone's going to get burned, or you know and if the kids aren't actually following the rules he gets really anxious about that because he'll come home and say, "I've had a terrible, terrible science lesson today mum." And if I ask more about it, it's generally for that reason so yeah." | Parent: Participant 17, page 1 |
| 1 | 2. Social concerns | "Not having much friends…Cus L*** is the only friend I've got now."<br><br>"I think I'd have to mention the social situations because [child], he finds it very difficult to join in. He doesn't know cues that we take for granted – we have an instinct for it and so he needs like Miss W to prompt him. If it is something he is very interested in it can go very well but if it is something that doesn't interest him he just doesn't know what to say." | Pupil: Participant 2, page 1<br><br>Parent: Participant 11, page 3 |

| RQ | Theme number /Sub-theme (ST) and title | Supporting Quotes | Reference: (See Appendix D for full scripts, quotes used are highlighted in red) |
|---|---|---|---|
| 1 | ST. *Language* | " I mean the most recent case we had of extreme anxiety was when that teacher threatened to put them all into detention or something wasn't it? Do you remember?"<br><br>"…He read 'the riot act' with them on the first lesson and Pupil got very, very anxious about that because he thought he'd have to be repeatedly writing things out and if it wasn't neat to start with then they'd get detentions and that, and he did, he twiddles his hair and knots it and he is doing this repeatedly wasn't he?" | Parents: Participant 15 & 16, page 1 |
| 1 | 3. Boundaries | "Why should we do work at home; we have enough to do at school already!"<br><br>"Well it is not homework is it? It's schoolwork. So why is it called homework? You know his homework is prating about at home, you know? You know, it's not school." | Pupil: Participant 6, page 10<br>Parent: Participant 10, page 4 |
| 1 | ST. *Time* | "Sometimes I worry that I haven't done my homework on the due date, but then it turns out I did!"<br><br>"He's worried about being late but the clock watching is…if he is not out of that classroom at the twenty-five past and the 5 to, you won't get any more work out of done out of him. Coming towards when the time is for him to go. You pack up and then the concentration is out of the window, he is just fixated then on clock watching and its time for him to go. If the teacher says, "Now hang on a minute, you cant go yet." He gets all agitated then and he gets a bit angry to think that they can keep him and it's 'his right' for him to go." | Pupil: Participant 3, page 1<br>Support staff: Participant 22, page 1 |
| 1 | 4. Sensory sensitivities | "Noise and people. Noise is just…well he just needs time to have quiet. That is where the ARB centre has been invaluable. It recharges his batteries and then he can cope a bit better for short spells…you know, around people and then he needs another quiet time and urm as far as the noise is concerned, he can't concentrate. It is a huge distraction, noise." | Parent: Participant 11, page 2 |

| RQ | Theme number /Sub-theme (ST) and title | Supporting Quotes | Reference: (See Appendix D for full scripts, quotes used are highlighted in red) |
|---|---|---|---|
| | | "Lots of noise" " Things that are loud" "All other people talking at once" "Other people talking to me!"<br><br>"Eating. He's very fussy about what he will eat. He will try different food, so it's not like he wont but with autism it's quite common to find that it's not so much always about taste, it's about texture, look smell and those are more overwhelming that the food." | Pupil: Participant 1, page 1<br>Parent: Participant 12, page 7 |
| 2 | 1. Negative feelings | "That's a tough one 'cause I have asked him that and he says he doesn't know, he says its just like. I think he has described it as like a red cloud or a dark cloud that takes over and his mind goes blank. So he doesn't know what's going on."<br><br>"I just keep thinking about them (negative thought) and I just…get in a really bad mood for as long as I remember them." | Parent: Participant 8, page 4<br><br>Pupil: Participant 4, page 6 |
| 2. | ST. *Not in control* | "…he was absolutely beside himself you know, to the point where he would almost get hysterical." | Parent: Participant 14, page 2 |
| 2 | ST. *Forceful* | "…with the anger he can express himself and he will say, 'I'm so angry I could snap this pencil…' | Support staff: Participant 24, page 2 |
| 2 | ST. *Passive* | "He has got no self-worth, no self-confidence, so he is as low as anybody can go. I mean he is 13, he should be full of the joys of spring but…" | Parent: Participant 10, page 6 |
| 2 | 2. Magnified negative thoughts | "There is also another threat I have…mind pop-ups…They are events that occur in your mind that show you images that you either don't want to see or distract you from something important."<br><br>"I think he thinks everybody hates him, nobody likes him, I want to get out of here, I hate this school ...I don't want to be here." | Pupil: Participant 3, page 7<br><br>Support staff: Participant 19, page 3 |

| RQ | Theme number /Sub-theme (ST) and title | Supporting Quotes | Reference: (See Appendix D for full scripts, quotes used are highlighted in red) |
|---|---|---|---|
| 2 | ST. *Perplexity* | "Anxious and scared…and hurt. And shocked that people do it to me. I haven't done anything to them…(I think) 'Why me?' 'Why is this happening?'…because I have never seen anyone else being bullied." | Pupil: participant 2, page 5 |
| 2 | ST. Overwhelming | "Well, it's…that question for me, I would answer it…I'd say for that like…the thoughts that I have in class are like…what can possibly go through these guys heads? These urm people's heads, what is going through their minds? Why are they doing this? Why are they trying to wreck my education? And why are they just trying to make school a place of horror and frustrations that…I just feel like I wanna stand up to them and tell them, 'You know what you are doing, don't you? You are trying to wreck everybody's education.' I think if I could, I would put them in jail…" | Pupil: Participant 7, page 5 |
| 3 | 1. Non-verbal actions | "He picks. Either pick his lip, his has got scabs on his head where he has picked and scratched his head. His hands or if he is working it's the crossing out or pressing harder with his pen when he writing."<br><br>"OK, first thing that you will notice, if it's in a lesson, he will sit there and he won't engage with the lesson at all. He won't pick up his pen. He will stare down at the desk and start going red through frustration and anger at himself and then it could build up." | Parent: Participant 8, page 4<br><br>Support staff: Participant 20, page 4 |
| 3 | 2. Verbal | "Well he just gets…he can be very belligerent and rude. At the same time he will apologise because he knows what he is saying. He can get a bit…I don't know really…he can get a bit threatening…"<br><br>"I never really swear at her (support staff)…just swearing in general" | Support staff: Participant 22, page 6<br>Pupil: Participant 2, page 6 |

| RQ | Theme number /Sub-theme (ST) and title | Supporting Quotes | Reference: (See Appendix D for full scripts, quotes used are highlighted in red) |
|---|---|---|---|
| 3 | 3. Withdrawal | "But then his eyes can go a grey colour but also he can start twitching and he will refuse to co-operate, he will refuse to conform to expectations of school, he will ignore you completely. He can sometimes stare vacantly so you know if he is staring vacantly and he is unresponsive you have got to now think right okay, it's an automatic pilot thing with me, because every day is different…"<br><br>"When I am normal I'm like (gestures sitting up tall, looking relaxed) and when I'm worried I'm like (gestures elbows on table, head in hands, looking down)" | Support staff: Participant 18, page 4<br><br>Pupil: Participant 3, page 4 |
| 3 | ST. *Holding anxiety* | "That he's held it in all day I think. He tries to hold it in all day and when he gets home he can let go." | Parent: Participant 17, page 6 |
| 3 | 4. Loss of control | "Yeah, yeah, he will, he will just go 'whoop'. So it's not directed at a person. Because he hasn't got a mean bone in his body has he? You know, sort of, he will hit at an object. Yeah and it will be anything."<br><br>"Sometimes it can be that quick, you don't know he is getting angry. Sometimes he will thump the table, make a noise and you think, oh dear here we go. But he can do it quick, it doesn't build up." | Parent: Participant 10, page 7<br><br>Support staff: Participant 21, page 3 |
| 3 | ST. *People-directed* | "…he might suddenly realise that he's in a vulnerable position that actually it's not working out and people are taking the mick out of him and he will then be, straight away, switched onto aggression. There isn't a noticeable build-up. Like, the rest of us get angry sometimes and start thinking, "I'm getting annoyed with you now, you need to back off." He doesn't do that he just suddenly goes and it's like the switch goes and he's in there and he's straight in that zone of being, "I want to kill you." | Parent: Participant 12, page 13 |
| 3 | ST. *Object-directed* | Pt. 2: "When I'm in the retreat I'll throw cushions around."<br><br>TA: "Sometime you stand in the corner don't you?"<br><br>Pt. 2:" Yeah and bang my head on the door. That's in DT because there is not much walls in there." | Pupil: Participant 2, page 6 |

| RQ | Theme number /Sub-theme (ST) and title | Supporting Quotes | Reference: (See Appendix D for full scripts, quotes used are highlighted in red) |
|---|---|---|---|
| 4 | 1. Reassurance | "Urm I suppose people help me with my worries by just advising me and putting me in the right direction I guess…You know, just like…because when I get panicky I can be really…I can be really flighty and really clumsy and it's just sometimes I think I need a nudge in the right direction. When I'm worried you know."<br><br>"Yeah and he can talk to Mrs S or Mrs J and he knows he will be listened to, I think is…and they will help if they can. It's good." | Pupil: Participant 5, page 6<br><br>Parent: Participant 15, page 7 |
| 4 | 2. Safe, quiet space | "It's his safe zone. (Pupil) is completely different here (in the ARB) than what he is in the school….He is a lot more relaxed and he is more animated. You can just tell, you can completely tell, that this is his comfort zone. He knows he is safe here."<br><br>"We are directed by professionals at the moment. We have the retreat, which he knows is his safe place."<br><br>Aw: "Does he use it?"<br><br>" Yes he does. The ARB is his safe haven. So he will go out, he will pop into classes, he will try to talk about something different." | Parent: Participant 24, page 4<br><br>Support staff: Participant 18, page 7 |
| 4 | 3. Distraction | " Urm...I try and think of something funny."<br><br>"So he will put his headphones on and listen to music." | Pupil: Participant 3, page 4<br>Parent: Participant 9, page 12 |
| 4 | ST. *Own world* | "I sort of imagine myself in movies. You know…I sort of drift into a fantasy world sometimes." | Pupil: Participant 5, page 5 |
| 4 | 4. Sensory comforts | " When I'm a but stressed out at home, I'm like urr, 'I wonder what's for tea?' And I go, 'mum what's for tea?' | Pupil: Participant 6, page 6 |

| RQ | Theme number /Sub-theme (ST) and title | Supporting Quotes | Reference: (See Appendix D for full scripts, quotes used are highlighted in red) |
|---|---|---|---|
| | | "He reverted to sucking his thumb recently, didn't he? Yeah, he has done. The clothes chewing is the big one. He has reverted. Eating is another one, isn't it? He will go and eat." | Parent: Participant 10, page 8 |
| 4 | 5. Therapeutic techniques | "Trying to get him to open up to things by the use of writing it down on paper. We could have Mind maps. I can ask him simple questions, giving him a choice on how he is feeling. I could use mood cards. We can use Social Stories."<br><br>"He has got a picture of a horse, a picture of Halo – Halo the game. There is a picture of the master chief because he likes that; he's his hero, and a picture of some kittens in a suitcase! And they all calm him down." | Support staff: Participant 18, page 7<br>Parent: Participant 11, page 8 |
| 5 | 1. Environment | "It would not be noisy" "And no crowds."<br><br>"Just so much easier to get around, if crowds were spaced out and people were almost lined up to get to their lessons." | Pupil: Participant 1, page 5<br>Pupil: Participant 5, page 8 |
| 5 | 2. Social opportunities | "They might be like-minded students, like **Pupil** has got a friend - at the ARB centre called M******, and he is quite passive and they get along really well together. They are both quiet and sometimes I think if they could just work together in the same class they would get on beautifully, you know. They have got the same kind of anxieties; they've got the same sort of manner but they work on different levels. So, if they could do that that would be brilliant."<br><br>"I think there should be more for these children socially, relating to school…" | Parent: Participant 17, page 8<br><br>Support staff: Participant, page 10 |

| RQ | Theme number /Sub-theme (ST) and title | Supporting Quotes | Reference: (See Appendix D for full scripts, quotes used are highlighted in red) |
|---|---|---|---|
| 5 | 3. Inclusion | " Choice about how you feel. Because I find trying to explain your feelings to a TA or someone in here (ARB) is OK for me, but trying to express my feelings to a teacher outside of school…outside of here I mean (ARB) can be really difficult. It is like selfish in a way. I mean what if they had problems and people just ignored them completely, you know?"<br><br>"It's that. It's the security of knowing he can go there, he can stay and its making staff more knowledgeable about autism so that they are aware of his problems and they know how to help him and they can be prepared for anything that might happen in lessons. Especially next year where he won't have the level of support at college that he has always enjoyed throughout school. That might be a barrier for learning for him next year." | Pupil: Participant 5, page 8<br><br>Parent: Participant 20, page 6 |

# *Appendix D: Original Transcriptions Provided Electronically*

## Appendix D1 – Sample Transcript

**Participant SEVEN (PUPIL)**

***Pupil SEVEN chose to use the visual prompts. His teaching assistant was present throughout.***

AW: So **Pupil**, we have these pictures out to help you think about the school day and things that happen in school. My first question is this one, we all worry about different things, can you tell me what worries you in school?

Pt. 7: Technically, it is usually the class because they usually really get on my nerves and it gets really frustrating. It's a little bit hard for me to actually concentrate and get on with my work. I try to but it's just…that noise is…well they stoop me from doing that.

AW: So they noise people make in class worries you because it stops you focusing on your work.

Pt. 7: Yeah.

AW: So what else worries you about that, when it's noisy in class?

Pt. 7: Well usually I get a little bit worried that I am not gonna…get very good work done. And that is really what's making me feel very, very worried and it's starting to get really…getting a little bit, yeah…frustrating.

AW: That must be frustrating to feel that you are not going to get your work done. So why would not getting your work done worry you?

Pt. 7: Well not getting my work done mean that the teacher might say, "You weren't listening, you only did that bit of work, that means you are not going to get a good grade for that." And I think to myself, "Why does the teacher think that?"

AW: So you are worried you will not get the work done and the teacher will blame you for that and then you are worried that you might not get a good grade.

Pt. 7: Yeah.

AW: So is that something that worries you, not getting good grades?

Pt. 7: It angers me.

AW: So that's another feeling you have, you get angry about it. Is that worry about not getting your work done because of the noise in class a small worry a medium worry or a big worry?

Pt. 7: A big worry.

AW: Is it your main worry about school?

Pt. 7: Yep.

AW: Are there any other worries, they don't have to be as big as the big worry, they can be medium or small ones that worry you. Think through the school day…what else might worry you?

Pt. 7: Sometimes, It's like…well there is nothing really else to say, there is one worry that I have and it's just the…it's just the class. It is just one big worry.

AW: OK, it's one big worry, so there are no little worries that creep in. It's about the class, and how that impacts on you getting your work done and then worries about results you might get because of that. Is that right?

Pt. 7: Nods in agreement.

AW: So how much do you worry about these things, the class and the grades?

Pt. 7: Quite a lot because I think that sometimes my parents are not going to be very happy about it and sometimes I think, "Oh I haven't told them what's really worrying me." And now my parents are going to get cross with me because I didn't tell them and then I think…this is just, well at the moment this is too much for me.

AW: So it kind of, it builds up then…

Pt. 7: They always tell me to just ignore it but I just…I cannot ignore it because my worries are just too bad. When they tell me to ignore it, it gets to hard for me and I just really get frustrated and then I'm like 'I can't ignore this'. I can't listen to my parents, and then I worry. I don't want them to think that…it's just something that gets in the way.

AW: It's something that gets in the way, and then you are told to ignore it, which can be frustrating because you can't ignore it because it is a big thing. Thank you **Pupil**, it is really good of you to talk to me in such detail. So how do your worries interfere with you day?

Pt. 7: It interferes with my day, say I come home and mum says, "Hi **Pupil**, have you had a good day?" And sometimes I don't know what to say. I don't know what to tell them. I don't want to say it's rubbish because they will get upset about me and I want to upset anybody by saying that I have had a really bad day. You know, It's kind of a bit…it urm, I think that sometimes parents wont really like to talk to me about it because if I told them, "I've had a bad day." They'll just say, "yeah?" And it just makes me feel that they are not happy with me which is…hard.

AW: So you don't want to upset your parents. You find it hard to be truthful because you don't want to worry them. So that can interfere with your day. Ok. Any other ways that your worries get in the way at school, how might it get in the way at school?

Pt. 7: Well usually I like to be a happy person. I don't want to be someone who has things that makes me cross or upset and when I get home I don't know what to do, I'm like, "Shall I be happy or shall I be sad." I just don't know. It's really, really confusing. It's confusion as well for me.

AW: And is that confused about how to act…how to express when you are worries…what's the confusion?

Pt. 7: It affects my urm…like, physical appearance. I'm just like ughh (**Pupil** demonstrates flopping in chair).

AW: So you flop in your chair, your arms go by your sides…

Pt. 7: Sometimes I just do that (mimes action of head on hands)

AW: Yeah…

Pt. 7: And sometimes I just sit there and just, pull my hair.

AW: So it interferes with your day by making you sad and confused?

Pt. 7: Yeah.

AW: Ok, happy to move onto the next bit?

Pt. 7: Yep.

AW: OK, this bit is about the thoughts and feelings that are associated with your worries. So you have described some of these already, but lets have them in a bit more details. You obviously have your worry, what other feelings go along with that when you are worries? You have said some lovely ones already but what else…

Pt. 7: The feeling that I have are usually, sometimes when there is noise about I do get a bit depressed and sometimes, you know, when people are…so the teacher is talking and delivering out a lesson and someone distracts them by saying something and everyone in the class urm supports them by laughing.

AW: Right.

Pt. 7: And it is really, really making me feel angry.

AW: Angry, OK.

Pt. 7: And in some cases I can get fuming, which makes me all…makes my head fill up with anxiety and worry. It's like, "What am I going to do?" Then I can't stay in the class, I have to come out. I do not like coming out the class because I really want to…get a lot of work done and that's what I come to school for. The thing I don't come to school for is like to hold my head on my hands like, "oh they are being noisy, I'll just put my head on my hand." And then, I come here to get work done, and then later on in my live get to a good place and a place where I really want to be. I just don't want to come to school, school is not a place for frustration and anger, its usually…its much more important.

AW: Well said. So when you are in the situation, and you are feeling really worried, how strong is that feeling? (Shows **Pupil** the anxiety thermometer and explains)

Pt. 7: About 10.

AW: About 10, a really strong worry. You mentioned the anger feeling. How strong is that when this is going on.

Pt. 7: I get furious and start…the fact is, I just get so fuming in there that I just like… sometimes I pick up my pencil and really feel like I am going to break it. It's something I really don't want to do, because like I have said before…about school not being a place for frustration and stuff…

AW: it's a feeling you don't want isn't it.

Pt. 7: Feelings I really do not want to manoeuvre into my head.

AW: And anger, is it up here as well (AW points to anxiety thermometer)

Pt. 7: Yeah a 10.

(AW shows **Pupil** the visual feeling exercise, which he completes at the end.)

AW: OK so they are the feelings that you have, and we have talked about how strong they are. What does it feel like physically when you are worries? You showed me earlier when you were doing the action…could you tell me what it is like for your body when you get really worried?

Pt. 7: Well usually I get stiffened up and like (points to tummy) still.

AW: Tense?

Pt. 7: Does the action of putting his head in his hands.

AW: And what's that for, putting your head in your hands? What is going on for you there?

Pt. 7: It's just like…I've got my head in my hand. So this is what it's like at the time, and I'm thinking 'what's happening' and it's like… "Why does this keep happening to me?" And when I've got my head on my hands, that's usually…what I think when there is too much noise going on around.

AW: So it's almost like to shut it out when you put you head on your hands.

Pt. 7: Yeah, sometimes I just do that (puts hand on forehead). And sometimes I just go (folds arms and looks away).

AW: OK, so you have described your feelings beautifully Pupil. The next one is about the thoughts. So when you are getting really worried about the situation in class, what thoughts are going through your head at that moment? What are you thinking?

Pt. 7: Well, it's…that question for me, I would answer it…I'd say for that like…the thoughts that I have in class are like…what can possibly go through these guys heads? These urm people's heads, what is going through their minds? Why are they doing this? Why are they trying to wreck my education? And why are they just trying to make school a place of horror and frustrations that…I just feel like I wanna stand up to them and tell them, "You know what you are doing, don't you? You are trying to wreck everybody's education." I think if I could, I would put them in jail. I would lock them up and leave them there and when they had thought through the rest of their life, when they knew what they were doing at school, they can come out. And they think… "I have been a little bit of a terrible appearance to people, in the class. It's time to change and be a better person." And that is what I would do to try and make them realise what they are doing. And then soon they would be a better person.

AW: That was a brilliant description of your thoughts. Are there anymore you wanted to tell me about?

Pt. 7: Well one of them is…one of the other thoughts is…this is just an outrage and it is time for me to react upon people and tell them, well above all I'd like to be the one person who can go up to them, hold their head and go, "You are going nowhere mate, you ain't going to get anywhere in your life, you better realise what you are doing to peoples education otherwise you are going to be on the streets buddy." And that is what I would like to tell them.

AW: So you want to tell them that they are getting in the way of your learning, but not just that, how they are ruining their own learning. Is that something you would like to say?

Pt. 7: Nods.

AW: OK, thank you **Pupil**, very insightful. Are you happy to move on?

Pt. 7: Yep, very happy to.

AW: OK, now this is about what you actually do when you are worried. So, can you take me through what you do when you are worried and what happens? Do you go anywhere or do anything?

Pt. 7: Usually…this is something I also think about at home.

AW: OK, go on…

Pt. 7: I think, one of the things that I do if…(this is in my own imagination).

AW: OK, yeah…

Pt. 7: In my imagination I stand up and just tell them all what they are doing, how they are going to wreck my education and theirs (as I have said before) and then silence them and they wont have a single sound affect coming out of their throat. They are not ever, ever again going to wreck someone else's education and their own.

AW: So in your head, in your imagination, they wouldn't be able to make that noise that is getting so much in the way for you and for them.

Pt. 7: Yep.

AW: OK, thank you **Pupil**. So that is something you imagine you so when you are worried. Is there anything else that you do?

Pt. 7: The other thing I do is just like…have to wait for them all to be quiet sometimes. It just ends up in a way that it doesn't really go to plan, and it doesn't happen at all when I am just waiting for them all to be quiet. And sometimes then…I think to myself, one day these people are going to realise what they are doing to their lives, and to others and later on in their life they are going to be like, "I realise I have been a terrible person to peoples education." And education wise they will realise…

AW: **Pupil**, how do you think other people in school know you are worried? How might Miss know that you are worried?

Pt. 7: Well I'd say the anger on my face, and my head in my hands and all my actions that I do when I'm frustrated, worried, angry, anxious, you name it.

AW: They would see that.

Pt. 7: Yeah.

AW: And are they all mixed together these feelings of worry and anger and frustration. Do they all happen at once?

Pt. 7: Yep.

AW: OK. How do you think you are different to be around when you are worried?

Pt. 7: I'm different when I'm worried, of being a person who is angry, who wants to stand up to someone and really…I'm not saying I would have a go at them, but just be angry at them and say, "You are probably a disgrace to yourself and other people, but mostly to yourself, because you know what you are doing to yourself, you are going to soon realise that I really, really am 100% sure that that is going to happen."

AW: So your different when you are worried because you feel like saying that sort of thing to people, but that's only when you get angry, worried and frustrated that you want to say these things?

Pt. 7: Um hum.

AW: OK, brilliant. Are you happy to move on?

Pt. 7: Yep.

AW: If there is anything else that comes into your head, that's OK you can say it. This bit is about how you deal with your worries in school, how you cope with them. So tell me what you do to try and stop your worries…

Pt. 7: Cover my ears sometimes. Usually I put my hands behind my back and go…lean back and go (mimes taking a deep breath).

AW: So what are you doing there?

Pt. 7: Heavy breathing.

AW: Heavy breathing, good one.

Pt. 7: Huffing and puffing.

AW: And that helps? Anything else you do to try and stop the worries?

Pt. 7: Hum. Another thing I do to try and stop my worries is…just show miss sometimes that I am too frustrated that I cannot stay in the class. I need to come and calm down, take deep breaths and just zone out for a bit and then go back to class, and then…if they then turn out to be a quieter class, then I will stay in there.

(Interruption from intercom)

Pt. 7: As I was saying, so I go, show Miss I am frustrated and need to come out, take some deep breaths and all that. I will only be out for five minutes, then come back to class and see…if they got quieter then I'd stay in there…if they had the guts to be a better class. That is a rare case that that would happen.

AW: But ideally, you would go out, take five, go back in and everything would be quiet and you could get on.

Pt. 7: Yep.

AW: OK, so you have sort of said this, but who helps you with your worries in school?

Pt. 7: My mum.

AW: OK and what does she do to help?

Pt. 7: Well, I was there one day talking to her about my worries and she told me, "**Pupil**, you have just got to think of one word, perspective. Just remember that one word and you are going to be fine." And sometimes Miss is good for helping me with that, saying like, :OK just take some deep breaths and you are going to be really fine."

AW: OK, so miss helps you b reminding you to do your strategies and your breathing and your mum helps you by reminding you to keep perspective on things.

Pt. 7: Yep.

AW: OK, brilliant answers. Are there any other ways people help you with your worries?

Pt. 7: Another way is…well I help myself with my worries.

AW: Go on…

Pt. 7: I think about the things that really make me happy and really want me to be…I don't want to think about these people behind me, I want to think about what makes me happy and just think, "OK that was some time ago now it's time to thinks about the happy things that are in my life."

AW: And what sort of things do you think about that are happy things?

Pt. 7: Aeroplanes. Also I went to Enfield about a month ago.

AW: Ah OK so that was another happy thing to think about. So you thing about Enfield and you think about your aeroplanes and that makes it better.

Pt. 7: Yep.

AW: OK, this is a good one. I want you to think about one of your friends, say they were worried about a test; maybe they had a maths test. What advice could you give them if they were worried?

Pt. 7: If they were upset if they only got one mark in the test, I would say I'd come up to them and tell them, "you know what, there is always another time when you can really get a brilliant mark in your test and you will be…if you think about what I have just said, that will build you up until you become untouchable."

AW: Fantastic. If they were upset afterwards you would talk them up…

Pt. 7: I would tell the teachers as well, "You have got to realise, they may have got one mark today only, but one day they are going to get much better and they are going to show you that they are going to be…absolutely, well no one can touch them. They are never, ever going to get anything wrong."

AW: And is that important, not to get anything wrong?

Pt. 7: Yeah. You know what they say that two wrongs don't make a right, but two rights don't make a wrong…but they can think of that and always realise that there is always another time when you can have another good test.

AW: OK, very good advice. So that's what you would tell them afterwards. Think about before the exam and they have that worried feeling. Would there be other advice you would give them at that point when they are worrying about it?

Pt. 7: Yep, so first of all, just remember that before you start a test, think of the things that really, really make you feel happy. And then you've done a few questions, think of that again and then you can just get on with it and then like, this is relaxing for me. And then they'd feel much more comfortable when they are doing the test.

AW: OK, good advice, are you ready to move onto the last section?

Pt. 7: Yep.

AW: OK, you are doing a really good job. Right **Pupil** this is my favourite question. We have to pretend that we have got a magic wand, and we wave it around to create a school that is worry free for you, where nothing causes you worries. What would have to change in school for your worries to be less? Remember we can do anything with the magic wand.

Pt. 7: Well, there would be people who do not ever cause any disruption and that can help me pull a smile on my face and never get frustrated and angry and I'm just a happy person with a good life and I have an environment in which I can triumph in any way and just move on with the things that I just really need to do and things I really want to do with my life and just do it in a calm and happy way.

AW: So what would that environment be like?

Pt. 7: Peaceful, no trouble and just a basic attitude to learning.

AW: Is there anything else that you would have if we can dream…

Pt. 7: I would only have the lessons, like technology and you could do aircraft design and you could design anything that you could ever wish for and you could have fun lessons as well.

AW: And what would be a fun lesson?

Pt. 7: English, I used to have fun lessons in Year 7 that were not boring. You know Mr W…the English lesson would be the kind of lesson that he used to do when he was over here.

AW: And what was good about that?

Pt. 7: He didn't mess around. He just did what he wanted to do, he just did all the fun that he wanted to do, that he thought was fun and he just tried…and…I will tell you one thing, he made me feel happy. He didn't make me feel frustrated or anything.

AW: So you would have a teacher who made you feel happy, you would be doing lots of aircraft design…it would be calm…sounding like a good school. Anything else that would be different that would mean that there would be no worried in your head?

Pt. 7: Well…if I came to school with no worries I would just walk in through the gates, just feeling like I usually feel like in my normal life. Just a normal life…when you walk through the gates, that is what I want it to feel like. I'm just going to feel like a normal person.

AW: And what is normal, describe that feeling…

Pt. 7: Just like, happy, wise and, you know…just a proper civilian…just like that.

TA: Would the school actually look different?

Pt. 7: Actually I don't like the school being blue.

AW: What colour would you have?

Pt. 7: Red! And from now on this tie is going to be all red and the PE kits are going to be Liverpool colours, with the red shirt.

AW: Fantastic. Anything else before we stop **Pupil**?

Pt. 7: I think I would just like to say something.

AW: Of course.

Pt. 7: All those things that I have said throughout this talk…are going to be things that are never, never going to make me feel sad ever again in my whole entire life.

AW: So all things you want to go away so you wont be sad.

Pt. 7: Yeah.

AW: OK, thank you **Pupil**, are you happy to stop there.

Pt. 7: Yep.

**END**