

**Promoting Mental Health and Wellbeing for Autistic  
Students in Mainstream Secondary School**

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## **Abstract**

Autistic young people experience significantly higher rates of mental health difficulties than their neurotypical peers. These often develop as they transition to secondary school and coincide with a low sense of belonging. The review paper was undertaken to critically analyse and synthesise findings from 13 studies exploring views from autistic students about their experiences in mainstream secondary school. Findings pertaining to the challenges of their educational experiences were reviewed with thematic synthesis to identify potential barriers to their sense of belonging and psychological wellbeing. Twelve descriptive themes and four analytical themes emerged from the synthesis and are discussed with suggestions for practice and future research.

Furthermore, anxiety is the most common co-occurring difficulty in autism and many autistic students experience feelings of loneliness. Yet, no known research has explored the relationship between anxiety and social support for autistic students in mainstream secondary school. The empirical paper sought to address this gap. Linear regression was used to analyse data from 60 autistic students who completed an online survey to measure their levels of social support and anxiety. No significant relationship between the variables was found, which suggests that social support is unlikely to be a protective factor for anxiety for autistic students, though it was hypothesised that it could aid them to cope with anxiety. Nine students who reported high levels of both social support and anxiety took part in semi-structured

interviews to explore this and their responses were analysed with reflexive thematic analysis. Two research questions were posed and three themes emerged within each to outline how social support helped students cope with anxiety and the features of an 'ideal' peer group. Findings extend those from previous research and uniquely contribute to the evidence base. Implications for professional practice, teaching and pedagogy are suggested, alongside ideas for future research and dissemination.

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## **Chapter 1: Introduction**



## **1.1 A Note on Terminology**

While there is no universally accepted way to refer to autism, the terminology used throughout this thesis has been informed by findings from a large-scale online survey conducted in the UK exploring preferred language from the autism community (Kenny et al., 2016). The findings suggest that despite professionals using a range of person-first medicalised language (e.g. “person with Autism Spectrum Disorder/Condition”) to describe autism, diagnosis-first language that omits terms associated with a ‘disorder’ or ‘condition’ (e.g. “autistic person”) is generally preferred by the autism community. Therefore, the terms ‘autism’ and ‘autistic’ are used throughout this review.

## **1.2 Rationale for Thesis Topic**

Autism is a neurodevelopmental difference associated with persistent difficulties in areas of social communication and interaction, alongside restricted and repetitive behaviours (American Psychiatric Association, 2013). Prevalence research have estimated that approximately 1% of the population have an autism diagnosis currently, though rates of autism identification continue to exponentially increase (Zeidan et al., 2021; Tinsley, 2020; Russell, 2022). The 2022 Special Educational Needs in England report identified autism as the most common need among students with Education Health Care Plans (EHCPs) and demonstrated an annual increase in the number of students with EHCPs in mainstream secondary school (DfE,

2022). However, autistic students are also vastly overrepresented in data on permanent exclusions from mainstream schools (DfE, 2022), which suggests that while more autistic students are enrolling into mainstream secondary schools, many experience significant difficulties while they are there.

A low sense of belonging has been identified as a common theme among students who have been excluded from mainstream settings (Graham et al., 2019). A sense of belonging in school has been defined as feeling accepted, valued, included, supported and encouraged by others (Goodenow, 1993). It is categorised as a basic human need in Maslow's hierarchy of needs (Maslow, 1943) and described by Baumeister and Leary (1995) as a "fundamental human motivation" that positively influences emotional and cognitive processes. Theorists have suggested that belongingness is a key determinant of educational participation and successful learning (Finn, 1989; Combs, 1982) and more contemporary research has identified it as a protective factor for psychological wellbeing (Department of Education and Skills, 2019).

Furthermore, research suggests that autistic individuals have disproportionately low levels of psychological wellbeing and experience significantly poorer mental health than other students with special educational needs in mainstream school (Hebron & Humphrey, 2014).

Studies have found that more than 80% of autistic young people experience mental health difficulties, which often develop as they enter adolescence

(Levy & Perry, 2011; Crane et al., 2017). Additionally, 85% of autistic young people felt that their mental health got worse through the pandemic (National Autistic Society, 2020). Moreover, research suggests that the mental health difficulties autistic students experience often continue beyond school, even when their life outcomes, such as, employment and independence are considered to be 'good' (Gotham et al., 2015). Autistic adults experience significantly higher rates of mental health difficulties and suicidal ideation and behaviour than neurotypical adults (Cassidy et al., 2014; Hirvikoski et al., 2016). As a consequence, understanding the relationship between autism and mental health has been identified as a research priority by the autism community (Roche et al. 2021) and various theories have been proposed to explore possible causes.

### **1.2.1 The Evolution of Autism Understanding**

Historically, autism has been viewed through a medical model of disability, that considers autistic difference as symptomatic of a within-person disorder. Therefore, traditional autism theories tend to attribute mental health difficulties autistic individuals experience to specific cognitive and social deficits. Regarding cognition, the Central Coherence Theory (Frith, 1989) suggests that autistic individuals find it difficult to integrate information and often focus their attention on small details. This aligns with the Executive Dysfunction Hypothesis (Pennington et al., 1997), which suggests that autistic individuals exhibit difficulties with areas, such as, attention, planning and working memory. These difficulties can make it challenging for autistic

students to access and engage with mainstream learning environments which can impact their mental health and wellbeing. Additionally, regarding the social theories of autism, differences in autistic social processing have been attributed to difficulties with Theory of Mind (Baron-Cohen, 2000). This refers to the ability to perspective take and empathise with the mental states of others. Research suggest that Theory of Mind difficulties can cause anxiety around not being able to understand and predict others' thoughts and behaviour (Fletcher-Watson and Happé, 2019).

While traditional autism theories provide a helpful overview of some of the specific difficulties autistic individuals can experience, which may contribute towards poor mental health, they often fail to explore the interaction between autistic individuals and their environment. However, more recent theories have begun to view autism more holistically and the 'Double Empathy Problem' (Milton, 2012) can be used to consider the ways in which systemic factors can increase the risk of mental health difficulties. The Double Empathy Problem submits that individuals who experience the world differently from one another find it difficult to empathise with each other. Therefore, this infers that autistic students in a mainstream school experience a disproportionately large lack of empathy and understanding from others in their environment. This is likely to pose as a barrier to their strengths and needs being fully understood and them experiencing a sense of belonging and psychological wellbeing. Therefore, this suggests that the

mental health difficulties many autistic students experience may result from the way they are treated by others, rather than a within-person factor.

Moreover, there is a growing body of evidence to support the claims made by Milton (2012) with regard to the Double Empathy Problem. Research has found that neurotypical people are less able to interpret the mental states and actions of autistic people than those of other neurotypical people (Edey et al., 2016; Sheppard et al., 2016). Additionally, research into first impressions has found that neurotypical people rate autistic children and adults less favourably across various measures and indicate reduced interest in interacting with them (Alkhaldi et al., 2019; Sasson et al., 2017; Scheerer et al., 2022). Research has also compared autistic people's experiences of socialising with neurotypical people versus other autistic people and found that difficulties with 'cross-neurotype' understanding and being a minority impacted their sense of belonging (Crompton et al., 2020).

However, it has been argued that a number of studies that claim to support the Double Empathy Problem only consider one side of double empathy. Chown et al. (2020) suggested that some of the research seems to selectively report findings that suggest neurotypical people demonstrate reduced empathy towards autistic people. However, their results may actually infer that both autistic and neurotypical people find autistic people "hard to read". It is also important to consider that autistic people are not a homogenous group, therefore will not necessarily experience the Double

Empathy Problem in the same way in all interactions with neurotypical people. It has been acknowledged that the Double Empathy Problem could be viewed as reductionist if the intersecting aspects of individuals' identities are not considered (Milton et al., 2023). For instance, whether cross-neurotype interactions would be facilitated if both individuals were of the same ethnicity, gender or education level. Nevertheless, the Double Empathy Problem provides a useful framework that reconceptualises autistic social communication deficits as social differences. This aligns with the neurodiversity movement that views autistic difference as part of natural variation and rejects ideology behind interventions that seek to 'normalise' autistic individuals (Den Houting, 2019).

In addition, due to the historic emphasis on medical models and within-person deficit theories, there has been a focus on eliciting third person neurotypical accounts of autistic experiences. This has resulted in a lack of meaningful participation from autistic individuals in research (Fletcher-Watson et al., 2019). While professional and stakeholder views can provide valuable insights and advocacy, they also hold the potential to misrepresent aspects of the autistic experience which can ultimately misinform policy and practice recommendations. Research has highlighted that listening to and learning from autistic young people is crucial to ensuring their mental health needs are met (Coleman-Fountain et al., 2020). Therefore, active participation from autistic individuals has been identified as a key priority for autism

research and prompted the development of protocol to promote the inclusion of autistic voices in research (Lebenhagen, 2020; Courchesne et al., 2022).

Overall, a rationale for research exploring ways to promote mental health for autistic students in mainstream secondary school has been presented, alongside an argument for the importance of actively including autistic individuals in research. This is particularly relevant for Educational Psychologists (EPs), given that autism is likely to be the most common special educational need they encounter (DfE, 2022). EPs are also ideally placed to promote mental health in education settings, given the working relationships they have with schools and ability to work at different levels. Supporting mental health is also becoming a growing area for EP involvement, due to mental health services becoming increasingly stretched. Therefore, EP involvement to promote the mental health of autistic students in mainstream secondary schools should be considered an important and contemporary issue.

### **1.3 Epistemological Considerations and Theoretical Perspectives**

In the seminal publication, 'The Social Foundations of Research', Crotty (1998) argues that considerable thought should be put into developing research. He highlights four specific elements that should be considered sequentially when conceptualising a research proposal: 'epistemology', 'theoretical perspective', 'methodology' and 'methods'. These elements are

considered to remain of high relevance to contemporary research and are therefore described below with relation to this thesis. Furthermore, the philosophical approach of making decisions, with regard to 'axiology', is also highlighted as a key element that should be considered when developing research (Finnis, 1980; Khatri, 2020). Therefore, a discussion around the researcher's axiology and how this informed the foundations of the research is also included below.

### **1.3.1 Epistemology**

Epistemology is described as the theory of knowledge embedded in the research (Crotty, 1998). This is understood as the philosophy behind how we come to acquire knowledge and believe in it.

Crotty (1998) outlined three epistemological positions within social research which exist on a continuum: objectivism, constructionism and subjectivism. Objectivism posits that meaningful reality exists independently of the researcher. This suggests that there is an objective truth to be discovered and it is the task of the researcher to uncover what this may be. Conversely, at the opposite end of the continuum, subjectivism postulates that meaning is imposed by the subject and the beliefs they hold about the world. This suggests that there is no objective truth to be discovered, but rather a subjective meaning that will be different for each individual. Lastly, constructionism sits in the middle of the continuum and supposes that meanings are constructed through interactions, rather than discovered. This

suggests that different individuals will construct different meanings from the same situation, that develop both in and out of their engagements with reality.

The epistemological stance of both the review and empirical papers is constructionism, as it suggests that we construct meaning through our interactions, which can differ between people. The review paper is synthesising research exploring the experiences of autistic students in mainstream secondary school and the empirical paper is exploring the relationship between social support and anxiety for autistic students in mainstream secondary school. These topics both focus on the ways in which the students construct meaning through their interactions with the school environment and individuals within it. Both papers also follow the assumption that while many of the students have experienced the same situations within school, they have taken unique meaning and understanding from these based on their individual interactions. These individual differences were recognised within the papers. However, both papers also sought to find commonalities between the experiences of autistic students to generate themes related to their experiences from which meaning and suggestions for practice could be inferred.

### **1.3.2 Theoretical Perspective**

Theoretical perspective is described as the philosophical stance informing the methodology (Crotty, 1998). There are a variety of different theoretical

perspectives, suited to different epistemological positions that can be taken within research.

For the review paper, a social constructivist perspective was chosen, as this posits that knowledge is developed through the interactions that individuals have and the learning they gain from the interaction process (Taylor, 2018). This aligns with constructionist epistemology, though is positioned slightly more towards the subjectivist side. This presumes that reality is constructed through human activity, knowledge is constructed with relation to social and cultural expectations and learning is a social process (Kim, 2001). This perspective seeks to find consistency between different accounts of knowledge and experience to identify the current state of a situation for particular groups of individuals. It was therefore felt to be the most appropriate perspective for the review which sought to identify the common experiences and understandings from autistic students in mainstream secondary school about their educational experiences.

In contrast, for the empirical paper, a critical realist perspective was chosen. This perspective also supports the view that all accounts of knowledge are dependent on conceptual, contextual and cultural variables and still sits within a constructionist epistemology. However, it is positioned directly in the middle of the objectivist-subjectivist continuum, whereas social constructivism is positioned slightly more towards the subjectivist side (Taylor, 2018). It therefore maintains a commitment to seeking the truth,

while considering the impact that individual differences make to the ways in which this truth is understood and experienced, described as 'epistemic relativism' (Archer et al., 2016). This is felt to be particularly important for the empirical paper, as it seeks to uncover the truth as to whether social support could be a protective factor for anxiety, while also exploring individual accounts related to the features of social support valued by different students.

### **1.3.3 Methodology and Methods**

Methodology refers to the strategy or process chosen, which relates to the research design and links the methods to the desired outcomes (Crotty, 1998). Certain methodologies are suited to particular epistemological positions, theoretical perspectives and research questions. The methodology selected consequently informs the methods chosen, which are described as the techniques used to gather and analyse the data (Crotty, 1998).

For the review paper, a qualitative evidence synthesis was chosen and an adapted version of thematic synthesis (Thomas & Harden, 2008) was utilised as the method to review the literature. This approach fits within the social constructivist perspective and was appropriate for the review question, as it is both inductive and integrative in nature. It seeks to identify themes between different accounts of experience to develop an understanding of a situation for a particular group.

For the empirical paper, a mixed methods approach was employed, as the critical realist perspective highlights the value of methodological pluralism to encourage deep and broad insights (Archer et al., 2016). Critical realism advocates for quantitative and qualitative research being carried out together to tackle the relative limitations and build upon the strengths of each approach (Shannon-Baker, 2016). This approach also supported the implementation of a sequential explanatory study design (Creswell et al., 2003), which involves quantitative data being collected and analysed first to find the 'truth', before qualitative information is gathered to explore how different individuals experience it.

Moreover, the methodology utilised for the empirical paper informed the methods chosen. Data from the online surveys were analysed first to understand the broad influence of social support on anxiety, before the semi-structured interviews and drawing task were undertaken. This allowed for the results from the survey to inform the research aims for the qualitative phase to facilitate a deeper exploration of the aspects of the social world. This was further supported by the approaches to qualitative analysis chosen, with Personal Construct Psychology (Kelly, 1955) utilised to identify the constructs students held and reflexive thematic analysis (Braun & Clarke, 2019) used to discuss key themes. These approaches allowed for the recognition of individual differences in students' experiences as well as the commonalities to address the research aims.

#### **1.3.4 Axiology**

Axiology considers the ethics and values that researchers hold and the ways in which these interact with the decisions they make when developing their research (Khatri, 2020). Biedenbach and Jacobsson (2016) emphasise the importance of axiology and advocate for researchers engaging in reflexivity around their values. This advocates for including first-person reflexive accounts to publications. They propose a framework that outlines the different ways in which values can intersect with research. This includes intersections where values are present through the focus of the research, guide the research and are shaped by the outcome of the research. It also highlights the influence of 'epistemic values' that influence the epistemological stance taken within the research.

With regard to the current thesis, I hold values related to equity and social inclusion that inspired me to train as an EP. I feel that these values were shaped by my life experiences, growing up in a neurodiverse family, and strongly influenced the current thesis topic selection. Moreover, these values underpin my passion for eliciting student voice and encouraging active participation from marginalised communities. This influenced the epistemological position taken by the research and the consequent research design.

## **1.4 Thesis Orientation**

This chapter has provided an overview of the rationale for the thesis topic and a discussion of the epistemological considerations and theoretical perspectives considered for the thesis. An outline of the subsequent chapters is provided below to demonstrate the organisation of the thesis and conceptual link between the chapters.

Chapter two presents a scoping review that synthesises research exploring views from autistic students about their experiences in mainstream education. The review question focuses on the challenges of the mainstream secondary school experience, in relation to the potential barriers to a sense of belonging and psychological wellbeing. Thirteen studies were critically appraised within a Weight of Evidence framework (Gough, 2007), using coding protocol for qualitative research (Long et al., 2020), recommendations for eliciting autistic students' views (Fayette & Bond, 2018) and criteria for relevance to the review question. An adapted version of thematic synthesis (Thomas & Harden, 2008) was utilised to synthesise the findings. Twelve descriptive themes emerged from the data, which were conceptualised into four analytical themes, with one related to feeling unsupported and misunderstood by peers. The strengths and limitations of the included studies are discussed with reference to future research and suggestions for Educational Psychology practice.

Chapter three explores the relationship between anxiety and social support for autistic students in mainstream secondary school. This was developed following the aforementioned theme identified in the review paper and a gap in the literature exploring these variables. The study used linear regression to analyse data survey data from 60 autistic students and reflexive thematic analysis (Braun & Clarke, 2019) to analyse semi-structured interviews from nine students. The findings present themes that explore key features of social support that helped the students cope with anxiety and factors that contribute towards an 'ideal' peer group. These therefore extend those from chapter two and uniquely contribute to the evidence base. Strengths and limitations of the research are discussed, alongside directions for future research and the implications for professional practice, teaching and pedagogy.

Chapters two and three are conceptually linked as they both explore autistic students' experiences of mainstream secondary school and the ways in which these interact with their mental health and wellbeing. Chapter two considers the school environment broadly and identifies particular challenges and chapter three focuses in on social support as a one of these challenges that previous research has not explored. In addition, both chapters are positioned within the social model of disability (Oliver, 1996) and seek to explore the features of the environment that impact on mental health and wellbeing for autistic students, rather than within-person factors. This also links to the neurodiversity movement (Den Houting, 2019) that views autistic

difference as part of natural variation. Therefore, the recommendations made in both chapters promote interventions related to psychoeducation on autism and environmental accommodations, rather than those that seek to 'normalise' autistic behaviour.

Finally, chapter four presents a critique of evidence-based practice and practice-based research, with respect to the EP role. The chapter subsequently discusses the importance of effective research dissemination and the potential impact this thesis could have on a range of audiences. Implications for future research, practice and policy are reflected on, alongside a plan for dissemination. Lastly, approaches for evaluating the impact of the research on autism understanding, practice and policy are discussed.

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## **Chapter 2: Review Paper**

### **The Challenges of Mainstream Secondary School: A Synthesis of Qualitative Views from Autistic Students**



## 2.1 Summary

The current review synthesises research exploring the views from autistic students about their experiences in mainstream education. Autism is the most common need listed on Education Health Care Plans (EHCPs) and there has been annual increases in the number of students with EHCPs attending mainstream secondary schools. However, autistic students experience significantly higher rates of mental health difficulties compared with their neurotypical peers and are vastly overrepresented in permanent exclusions. Research has identified low sense of belonging as a common experience among excluded students, however, there remains a relative paucity of research exploring autistic students' perspectives on their educational experiences. It is therefore important to undertake a review of research exploring autistic students' views on the challenges of mainstream secondary school in order to identify the potential barriers to their sense of belonging and psychological wellbeing. Thirteen studies were critically appraised in relation to the review question and an adapted version of thematic synthesis was utilised to synthesise the findings. Twelve descriptive themes emerged from the data, which were conceptualised into four analytical themes: 'feeling unsupported and misunderstood by peers', 'experiencing sensory overload in the school environment', 'feeling inappropriately supported with academic work' and 'feeling misjudged and undervalued by teaching staff'. The strengths and limitations of the included

studies are discussed alongside recommendations for future research and Educational Psychology practice.

## **2.2 Introduction**

### **2.2.1 Autism and Inclusion in Mainstream Education**

The DSM-5 describes autism as a neurodevelopmental disorder that causes “persistent difficulties with social communication and interaction” and “restricted and repetitive patterns of behaviours, activities or interests”, which “limit and impair everyday functioning” (American Psychiatric Association, 2013). The 2021 Special Educational Needs in England report identified autism as the most common need among students with Education Health Care Plans (EHCPs) and demonstrated an annual increase in the number of students with EHCPs in mainstream secondary schools since 2018 (DfE, 2022).

The rise in the number of students with Special Educational Needs (SEN) attending mainstream provision is likely to in part stem from the legislative changes seen over the past decade, following the publication of The Equality Act (HMG, 2010). Mainstream schools have a legal obligation to promote inclusion by making reasonable adjustments to prevent students with SEN from being substantially disadvantaged (DfE & DoH, 2015). They are required to appoint a staff member to coordinate provision for those with EHCPs and SEN support (DfE, 2014). However, The Permanent Exclusions and Suspensions in England: 2021-2022 report (DfE, 2022) demonstrated that autistic students are vastly overrepresented in data on permanent exclusions from mainstream schools, which suggests that although more

autistic students are enrolling in mainstream secondary schools, many are experiencing significant difficulties while they are there.

### **2.2.2 Belonging and Psychological Wellbeing**

Moreover, a literature review that explored the potential driving factors for school exclusion highlighted low sense of belonging as a common theme among students who had been excluded from mainstream settings and associated this with the social, emotional, behavioural and mental health difficulties that often underpin “disruptive behaviour” (Graham et al., 2019). In school, a sense of belonging has been defined as feeling accepted, valued, included, supported and encouraged by others (Goodenow, 1993) and research has identified it as a protective factor for psychological wellbeing (DES, 2019). This is supported by psychological theories, such as Maslow’s hierarchy of needs (Maslow, 1943), that identifies ‘belonging’ as a basic human need that must be met before an individual can experience ‘esteem’ and ultimately reach their potential. This posits belonging as a fundamental need and highlights the negative impact that not experiencing a sense of belonging can have on students’ wellbeing and access to education.

Recent research has indirectly explored the concept of belonging with autistic students through systematic literature reviews investigating social inclusion and sense of self. Findings have suggested that common difficulties experienced by autistic students in areas of social relationships, cognition and sensory sensitivities make autistic students aware of their differences

and pose barriers to their inclusion (Bailey & Baker, 2020; Williams et al. 2019). These findings have also been associated with increased anxiety levels and research has found that autistic students experience significantly higher rates of mental health difficulties than other students with SEN in mainstream schools (Hebron & Humphrey, 2014).

Furthermore, the 'double empathy problem' (Milton, 2012) provides a potential explanation for why autistic students may experience a particularly low sense of belonging in mainstream secondary school. The theory posits that individuals struggle to empathise with those who experience the world differently from them. Therefore, it is likely that autistic students receive a disproportionately low level of empathy and understanding from their neurotypical peers and equally may struggle to relate and empathise with them. Research has also focussed specifically on the period of adolescence and suggested that students who have difficulties with aspects of perspective taking or emotional regulation may be at increased risk of developing mental health difficulties (Andrews et al. 2020). This further demonstrates the link between sense of belonging and psychological wellbeing.

In addition, cognitive theories of autism may provide further insight into the challenges some autistic students face in mainstream secondary school with regard to learning. The Executive Dysfunction Hypothesis (Pennington et al., 1997) highlights the difficulties that some autistic individuals have with cognitive skills, such as planning, working memory and concentration. These

difficulties impact on students' access to learning in school without appropriate support and influence their academic self-concept. Additionally, research into sensory integration and perceptual load suggests that autistic individuals have an increased perceptual capacity that contributes towards their executive functioning difficulties and makes aspects of the sensory environment overwhelming (Iarocci & McDonald, 2006; Remington et al., 2009). With appropriate support and reasonable adjustments, these difficulties may not significantly impact autistic students' experience in secondary school. However, if these needs are not appropriately understood and supported, they are likely to influence students' relationships with staff, which emerged as a prominent theme in the research exploring students' sense of belonging in school (Graham et al., 2019).

### **2.2.3 Rationale**

The aforementioned theories and research provide possible theoretical explanations for why autistic students may experience low sense of belonging and psychological wellbeing in mainstream secondary school. However, there remains a paucity of research exploring autistic students' own views and opinions around what they feel are the most significant challenges they face in school.

Individual studies exploring the views of autistic students provide interesting insights into the experiences of small groups of individuals in particular areas. However, the extent to which the findings can transfer to other students or

inform practice are often uncertain. Autistic students are not a homogenous group, therefore there will be a limit to the transferability of any findings in the autism literature. However, qualitative evidence syntheses provide a useful tool for identifying themes which can alter perceptions and influence the way in which professionals work with students and view their behaviour.

Moreover, following the recent events associated with Covid-19, mental health and outreach services are becoming increasingly stretched and growing pressure is being placed on schools to support the social, emotional and mental health needs of their students internally. Educational Psychologists (EPs) are in a unique position in being able to work at both individual and systemic levels with schools, therefore have opportunities to provide bespoke support tailored towards specific students' needs.

The current review seeks to enhance EP practice by illuminating unique insights from the autistic community around some of the factors that can impact their sense of belonging and psychological wellbeing in school. EPs can consider these factors within consultations and explore them as potential hypotheses when gathering student views around their school experiences. It also aims to extend the literature that may contribute towards in-service training and professional development that would help to build autism awareness and understanding within the education system. This would improve the delivery of pastoral and academic support for autistic students,

with the ultimate aims of making mainstream secondary school a more positive experience for them and reducing rates of mental health difficulties.

#### **2.2.4 Review Question**

The current review explored the question: *‘what are the barriers to autistic students’ sense of belonging and psychological wellbeing in mainstream secondary school?’* by synthesising research exploring the perspectives of autistic students in the UK.

### **2.3 Critical Review of the Evidence Base**

#### **2.3.1 Search Strategy**

Comprehensive literature searches were carried out in August 2021 and August 2022 on the electronic databases: Web of Science, ERIC and PsycInfo. Search terms related to autism (Autis\* OR ASD OR Asperger\* OR ASC) and secondary school (“High School” OR “Secondary School” OR “Secondary Education” OR “Senior School” OR “Upper School”) were combined and the results were collated in reference management software. The initial search yielded 4120 results, which were filtered by publication year (2000-2022) (all databases), peer reviewed status (all databases), publication in the English language (all databases) and the location that the research took place in (United Kingdom) (Web of Science and ERIC). The results were then screened for duplication and the remaining 460 articles were systematically evaluated against the inclusion/exclusion criteria delineated in

Table 2.1<sup>1</sup>. The PRISMA flow chart (see Figure 2.1) demonstrates this process and details of the 13 studies included in the current review can be seen in Table 2.2 and Appendix A.

Table 2.1.

*Inclusion/Exclusion Criteria*

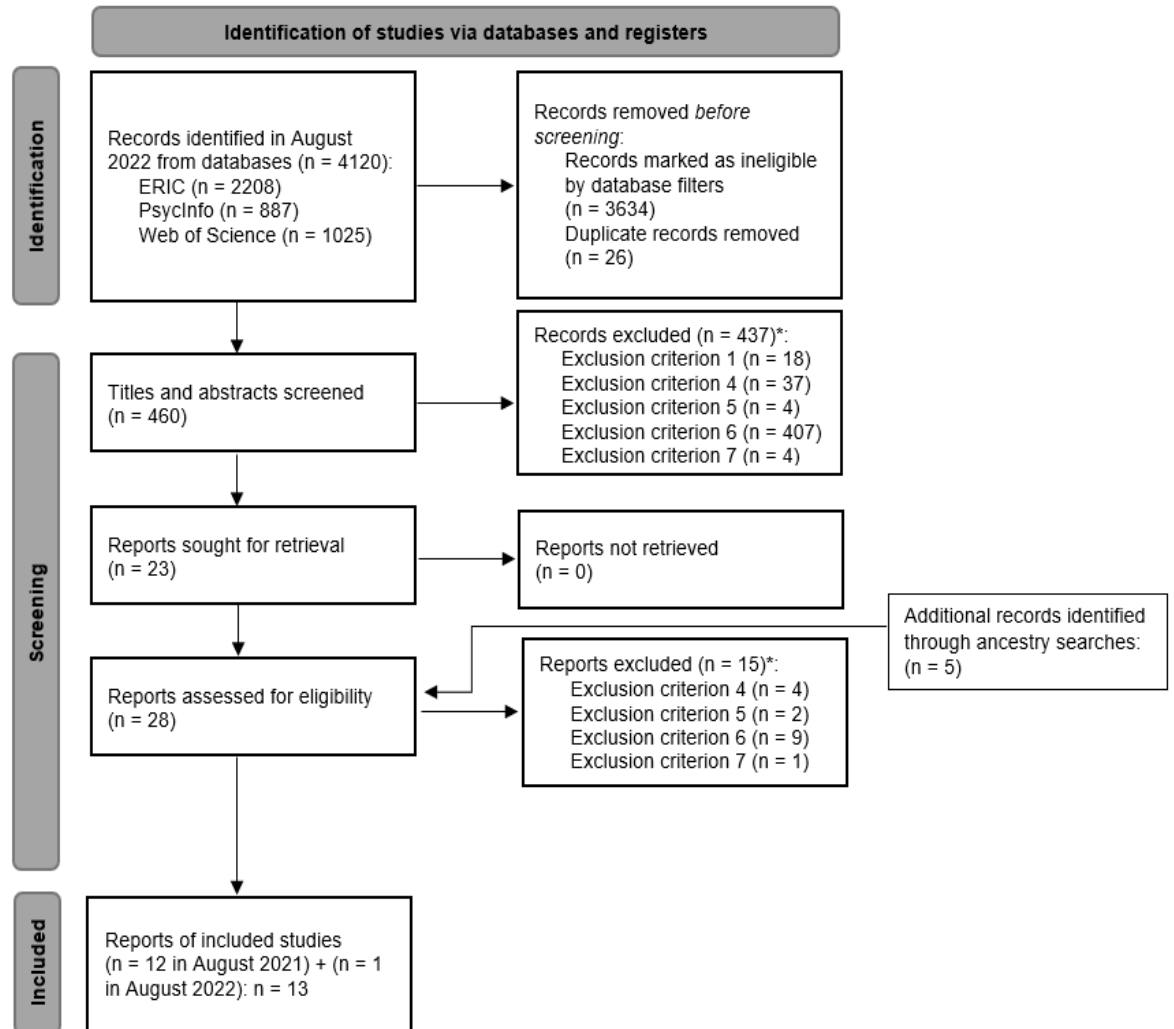
Criteria	Inclusion Criteria	Exclusion Criteria	Rationale
1. Date of publication	The study is published on or after 2000.	The study is published before 2000.	To allow for a sufficient number of relevant studies to be included.
2. Type of Publication	The study is peer reviewed.	The study is not peer reviewed.	To ensure that the research methodology is high quality.
3. Language	The study is published in English.	The study is published in a language different from English.	To ensure that the reviewer is able to understand the research.
4. Participants	a. The participants are students.  b. The participants are described as having autism.	a. The participants are parents, teachers, peers or other professionals.	The review is synthesising views from autistic students about their experiences of mainstream

<sup>1</sup> This search was repeated in July 2023 with the same parameters. Following the identification stage, where searches were filtered and screened for duplication, a total of 559 articles were identified, as opposed to the 460 identified in August 2022. The full search has not been updated and this may therefore have a bearing on the results of the review.

Criteria	Inclusion Criteria	Exclusion Criteria	Rationale
	c. The participants attend /have attended a mainstream secondary school.	b. The participants are not described as having autism. c. The participants have never attended a mainstream secondary school.	secondary school.
5. Setting	The research was conducted in the UK.	The research was conducted in a country other than the UK.	To increase the relevance and generalisability of the findings to students in UK schools.
6. Topic	The research is exploring views on the mainstream secondary school experience.	The research is investigating another topic or evaluating an intervention.	The review is synthesising research exploring views on the mainstream secondary school experience.
7. Study Design	The study has a qualitative element to the design.	The study has a fully quantitative design.	The review is synthesising qualitative literature as this is felt to be the most appropriate design to represent autistic students' views.

Figure 2.1.

*PRISMA Flow Chart (PRISMA flow diagram derived from Page et al. (2021)).*



\*Note. The numbers of articles excluded for each exclusion criterion may exceed the total number of excluded articles as some articles fulfilled more than 1 exclusion criterion.

Table 2.2.

*References for the Included Studies*

Included Studies
<p>Connor, M. (2000). Asperger Syndrome (Autistic Spectrum Disorder) and the Self-Reports of Comprehensive School Students. <i>Educational Psychology in Practice</i>, 16(3), 285–296.  <a href="https://doi.org/http://dx.doi.org/10.1080/713666079">https://doi.org/http://dx.doi.org/10.1080/713666079</a></p>
<p>Costley, D., Emerson, A., Ropar, D., &amp; Sheppard, E. (2021). The Anxiety Caused by Secondary Schools for Autistic Adolescents: In Their Own Words. <i>Education Sciences</i>, 11(11).  <a href="https://doi.org/10.3390/educsci11110726">https://doi.org/10.3390/educsci11110726</a></p>
<p>Dillon, G. V, Underwood, J. D. M., &amp; Freemantle, L. J. (2016). Autism and the UK Secondary School Experience. <i>Focus on Autism and Other Developmental Disabilities</i>, 31(3), 221–230.  <a href="https://doi.org/10.1177/1088357614539833">https://doi.org/10.1177/1088357614539833</a></p>
<p>Fortuna, R. (2014). The Social and Emotional Functioning of Students with an Autistic Spectrum Disorder During the Transition between Primary and Secondary Schools. <i>Support for Learning</i>, 29(2), 177–191.  <a href="https://doi.org/http://dx.doi.org/10.1111/1467-9604.12056">https://doi.org/http://dx.doi.org/10.1111/1467-9604.12056</a></p>
<p>Goodall, C. (2018). “I felt closed in and like I couldn’t breathe”: A qualitative study exploring the mainstream educational experiences of autistic young people. <i>Autism &amp; Developmental Language Impairments</i>, 3 1-16.  <a href="https://doi.org/10.1177/2396941518804407">https://doi.org/10.1177/2396941518804407</a></p>
<p>Goodall, C. (2019). “There Is More Flexibility to Meet My Needs”: Educational Experiences of Autistic Young People in Mainstream and Alternative Education Provision. <i>Support for Learning</i>, 34(1), 4–33.  <a href="http://search.ebscohost.com/login.aspx?direct=true&amp;AuthType=ip,shib&amp;db=eric&amp;AN=EJ1209986&amp;site=ehost-live&amp;scope=site&amp;custid=s8454451">http://search.ebscohost.com/login.aspx?direct=true&amp;AuthType=ip,shib&amp;db=eric&amp;AN=EJ1209986&amp;site=ehost-live&amp;scope=site&amp;custid=s8454451</a></p>
<p>Goodall, C., &amp; MacKenzie, A. (2019). Title: What about My Voice? Autistic Young Girls’ Experiences of Mainstream School. <i>European Journal of Special Needs Education</i>, 34(4), 499–513.  <a href="http://search.ebscohost.com/login.aspx?direct=true&amp;AuthType=ip,shib&amp;db=eric&amp;AN=EJ1222777&amp;site=ehost-live&amp;scope=site&amp;custid=s8454451">http://search.ebscohost.com/login.aspx?direct=true&amp;AuthType=ip,shib&amp;db=eric&amp;AN=EJ1222777&amp;site=ehost-live&amp;scope=site&amp;custid=s8454451</a></p>

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- Humphrey, N., & Lewis, S. (2008). "Make Me Normal": The Views and Experiences of Pupils on the Autistic Spectrum in Mainstream Secondary Schools. *Autism: The International Journal of Research and Practice*, 12(1), 23–46.  
<http://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,shib&db=eric&AN=EJ782106&site=ehost-live&scope=site&custid=s8454451>
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<https://doi.org/10.1177/2396941517706172>
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### **2.3.2 Critical Appraisal of the Studies**

#### ***Weight of Evidence***

The studies were critically appraised for rigour, appropriateness and relevance through Gough's (2007) Weight of Evidence (WoE) framework. This was felt to be a suitable framework for the current review as it has a clear structure and allows for ratings to be assigned, while also enabling flexibility in the criteria used. Each study was evaluated against three independent sets of criteria: methodological rigour (WoE A), appropriateness of design (WoE B), and topic relevance (WoE C), which combined to produce an overall WoE score (WoE D). Table 2.3 demonstrates the WoE scores for each study.

The current review utilised a modified version of the Critical Appraisal Skills Programme (CASP) (Long et al., 2020), to appraise WoE A, recommendations from Fayette and Bond (2018) to appraise WoE B and criteria developed by the reviewer to appraise WoE C. Mean scores from the WoE A, B and C ratings for each study were calculated to produce WoE D scores. Detailed descriptions, rationale and examples of the WoE criteria for each dimension can be found in Appendix C.

Table 2.3.

*WoE Scores*

Study	Methodological Rigour (WoE A)	Appropriateness of Design (WoE B)	Topic Relevance (WoE C)	Overall Weight of Evidence (WoE D)
Connor (2000)	1.4 (low)	1 (low)	2.5 (high)	1.6 (low)
Costley et al. (2021)	2.7 (high)	2 (medium)	2.8 (high)	2.5 (high)
Dillon et al. (2016)	2.4 (high)	1.5 (low)	2.5 (high)	2.1 (medium)
Fortuna (2014)	1.7 (medium)	2 (medium)	1.8 (medium)	1.8 (medium)
Goodall (2018)	2.8 (high)	2.5 (high)	2.5 (high)	2.6 (high)
Goodall (2019)	2.7 (high)	2.5 (high)	2.5 (high)	2.6 (high)
Goodall and MacKenzie (2019)	2.7 (high)	2.5 (high)	2.5 (high)	2.6 (high)
Humphrey and Lewis (2008)	3 (high)	3 (high)	2.5 (high)	2.8 (high)
Makin et al. (2017)	2.6 (high)	1.5 (low)	2.3 (medium)	2.1 (medium)
Myles et al. (2019)	2.4 (high)	1.5 (low)	2.8 (high)	2.2 (medium)

Neal and Frederickson (2016)	2.4 (high)	1.5 (low)	2.3 (medium)	2.1 (medium)
Sproston et al. (2017)	2.8 (high)	1.5 (low)	2.3 (medium)	2.2 (medium)
Tomlinson et al. (2021)	2.7 (high)	3 (high)	2.5 (high)	2.7 (high)

*Note. 1-1.6 (low), 1.7-2.3 (medium), 2.4-3 (high)*

### ***Date and Study Focus***

The date of publication varied between the studies and this was reflected in the scores given for WoE C criterion B. Many core aspects of mainstream secondary schools have remained stable over the last two decades; therefore, it was thought to be relevant to include research dated from 2000. However, given recent developments in understanding, provision and resources around SEN following legislative changes, it was felt that studies published more recently would most accurately reflect the current school experiences for autistic students. Two of the studies were published before 2011 (Connor, 2000; Humphrey & Lewis, 2008), therefore received a low rating as they were felt to be of least relevance to the current time. One study was published between 2011 and 2014, thus received a medium rating (Fortuna, 2014). Though, the remaining studies were all published after 2014, following legislative changes that aimed to promote inclusion, such as the Equality Act (HMG, 2010) and the Children's and Families Act (DfE, 2014),

therefore received high ratings (Costley et al., 2021; Dillon et al., 2016; Goodall, 2018; Goodall, 2019; Goodall & MacKenzie, 2019; Makin et al., 2017; Myles et al., 2019; Neal & Frederickson, 2016; Sproston et al., 2017, Tomlinson et al., 2021).

Each of the studies sought to extend or address a unique gap in the literature base by illuminating the perspectives of autistic students. However, their individual focus and aims were different. In order to consider the potential barriers to students' sense of belonging and psychological wellbeing, it was felt important to include studies that represented views around students' general experiences of mainstream secondary school and gave opportunities for students to reflect on positive aspects as well as those that they found challenging. This allowed the reviewer to contrast the experiences of different students and facilitated a deeper interpretation of the findings with relation to the review question.

Eight of the studies explored students' general experiences of mainstream secondary school, thus received high ratings for WoE C criterion A (Connor, 2000; Costley et al., 2021; Dillon et al., 2016; Goodall, 2018; Goodall, 2019; Goodall & MacKenzie, 2019; Humphrey & Lewis, 2008; Tomlinson et al., 2021). These studies all aimed to elicit views around various aspects of the school experience and identify areas that were particularly positive or negative for autistic students. One study focused on the ways in which students felt included in school (Humphrey & Lewis, 2008) and another sought to identify factors associated with anxiety and stress (Connor, 2000).

A further two studies utilised measures to compare experiences. One study compared the experiences of autistic students with neurotypical students (Dillon et al., 2016) and another study compared autistic students' previous experiences of mainstream education with their current experiences in an Alternative Education Provision (AEP) (Goodall, 2019). Furthermore, two studies focused on specific aspects of the mainstream secondary school experience, thus received medium ratings for this criterion (Myles et al., 2019; Sproston et al., 2017). One study focused on social experiences (Myles et al., 2019) and the other focused on students' experiences around their exclusion from mainstream education (Sproston et al., 2017).

In addition, three studies explored views on the period of transition between primary and secondary school, collecting data from their participants in periods both before and after transition (Fortuna, 2014; Makin et al., 2017; Neal & Frederickson, 2016). The focus of these studies was felt to be less relevant to the current research question, as they were primarily focused around the transitional process rather than general experiences of mainstream secondary school, therefore they received low ratings for WoE C criterion A. Moreover, similar to the aforementioned study (Goodall, 2019), one of these studies sought to compare experiences and utilised their varied participant group to contrast perspectives between students transitioning to mainstream and those transitioning to an AEP (Makin et al., 2017). The second study focused specifically on the students' social and emotional wellbeing across the transitional period (Fortuna, 2014) and the third study

explored views from students who had all experienced positive transitions (Neal & Frederickson, 2016).

### ***Participants***

There was a total of 125 participants across all of the studies, with sample sizes ranging from two to 20 students. Two of the studies (Goodall, 2019; Goodall & MacKenzie, 2019) were carried out as follow-ups to an initial study (Goodall, 2018) and utilised the same study data, therefore their participant numbers did not count towards the overall participant count. However, these studies were considered independently for this review as they analysed responses from separate subgroups of participants within the initial sample and consequently generated some unique themes (see Appendix D for full synthesis of findings). All participants were described as autistic, with the majority of studies referencing formal autism diagnoses (Connor, 2000; Costley et al., 2021; Dillon et al., 2014; Fortuna, 2014; Makin et al., 2017; Myles et al., 2019; Neal & Frederickson, 2016; Sproston et al., 2017; Tomlinson et al., 2021). Participants in one study were also identified as experiencing symptoms of anxiety (Costley et al., 2021). Table 2.4 demonstrates a summary of participant characteristics.

Table 2.4.

*Participant Characteristics*

Study	N	Gender		Age (years)	Current Secondary Education
		Male	Female		
Connor (2000)	16	15	1	11-16	9 mainstreams
Costley et al. (2021)	18	11	7	12-17	2 mainstreams
Dillon et al. (2016)	14	11	3	13 (mean)	1 mainstream
Fortuna (2014)	5	3	2	10-12	2 mainstreams
Goodall (2018)	12	10	2	11-17	AEPs and home schools
Goodall (2019)	(7)	(7)	(0)	(13-16)	(AEPs)
Goodall and MacKenzie (2019)	(2)	(0)	(2)	(11-17)	(Further education college and home school)
Humphrey and Lewis (2008)	20	NA	NA	11-17	4 mainstreams
Makin et al. (2017)	15	13	2	10-12	Various mainstreams
Myles et al. (2019)	8	0	8	12-17	3 mainstreams
Neal and Frederickson (2016)	6	5	1	11-12	5 mainstreams

Sproston et al. (2017)	8	0	8	12-17	PRU and PRU waitlist
Tomlinson et al. (2021)	3	0	3	14-16	1 mainstream

Many of the studies had a mix of male and female participants (Connor, 2000; Costley et al., 2021; Dillon et al., 2016; Fortuna, 2014; Goodall, 2018; Makin et al., 2017; Neal & Frederickson, 2016). The majority of these studies had a male gender bias in their samples, however two suggested that this represented the ratio of autism diagnoses so did not class it as a particular limitation (Goodall, 2018; Neal & Frederickson, 2016). One study had a sample consisting purely of male participants (Goodall, 2019) and another study did not report information on the gender of their participants (Humphrey & Lewis, 2008). However, four studies sought to address the apparent gap in the autism literature illuminating female perspectives and used female only samples (Goodall & MacKenzie, 2019; Myles et al., 2019; Sproston et al., 2017; Tomlinson et al., 2021).

Moreover, all of the participants were aged between 11 and 17 years at the time that the data was collected, though the length and nature of the time they had spent in mainstream secondary school was felt to be an important distinction. This influenced the ratings assigned for WoE C criterion C. Six studies scored highly for WoE C criterion C, as they used samples of students from a range of year groups currently attending mainstream

secondary school (Connor, 2000; Costley et al., 2021; Dillon et al., 2016; Humphrey & Lewis, 2008; Myles et al., 2019; Tomlinson et al., 2021). It was felt that these studies were the most transferable and relevant for the current review as the findings provided insights into various stages of the secondary school experience. The three studies that focused on the period of transition received medium ratings as the students in the post-transition phase of their studies were all in Year 7 and had typically only spent a short while in secondary school by the time of data collection (Fortuna, 2014; Makin et al., 2017; Neal & Frederickson, 2016). The remaining studies received low ratings for this criterion as they included participants who had previously attended mainstream secondary schools, but were currently in an AEP, further education college, Pupil Referral Unit (PRU) or being home schooled (Goodall, 2018; Goodall, 2019; Goodall & MacKenzie, 2019; Sproston et al., 2017). The participants in these studies provided unique insights into the events leading up to the breakdowns in their mainstream experiences which were useful for the current review, though it was felt that the retrospective nature of their accounts may have influenced the accuracy of their recall.

Furthermore, in addition to the samples of autistic students, some of the studies used data from parents/carers and/or teachers to support the findings (Connor, 2000; Dillon et al., 2016; Fortuna, 2014; Makin et al., 2017; Sproston et al., 2017; Tomlinson et al., 2021) (see Appendix A for further details). These studies identified this as a strength of their research design and suggested that triangulating the responses may increase the credibility of

the findings. However, many of the studies found conflicting themes in their analyses between how parents and students felt, with one study suggesting that parental perspectives seemed to be influenced by their own anxieties about their children (Fortuna, 2014). Therefore, it was felt that views from stakeholders were not relevant to the current review. Thus, having additional participants did not influence the WoE ratings and views from stakeholders were not integrated into the current synthesis.

### ***Setting***

However, WoE C ratings were influenced by the education settings that the students currently or had previously attended. It was felt that findings from studies that gained perspectives of students from a range of mainstream secondary schools would be most representative of a typical experience and this was reflected in criterion D. It is acknowledged that qualitative research is not inherently generalisable based on the unique and subjective experiences it reports. However, for the purpose of this synthesis, it was felt important that the research reflected students' experiences across a range of mainstream settings to increase the transferability of the findings and support the recommendations for practice.

Moreover, in two of the studies, all of the participants attended the same school (Dillon et al., 2016; Tomlinson et al., 2021). One of the studies purposely selected their school based on its reputation for "good autism practice" (Tomlinson et al., 2021) and the other discussed the potential

benefits of using participants from a single school for reducing variance between the groups being compared (Dillon et al., 2016). Although the studies justified their sampling approach and one acknowledged the potential limitations associated with it (Dillon et al., 2016), both received low ratings for this criterion. Of the remaining studies, two received medium ratings, as the participants were selected from two secondary schools with similar demographics and training (Costley et al., 2021; Fortuna, 2014). However, the rest of the studies all included students from a range of schools with varied demographics, thus received high ratings (Connor, 2000; Goodall, 2018; Goodall, 2019; Goodall & MacKenzie, 2019; Humphrey & Lewis, 2008; Makin et al., 2017; Myles et al., 2019; Neal & Frederickson, 2016; Sproston et al., 2017).

### ***Design and Data Collection***

All of the included studies had qualitative elements within their designs, with ten employing purely qualitative methodologies (Connor, 2000; Costley et al., 2021; Goodall, 2018; Goodall, 2019; Goodall & MacKenzie, 2019; Humphrey & Lewis, 2008; Myles et al., 2019; Neal & Frederickson, 2016; Sproston et al., 2017; Tomlinson et al., 2021). The remaining three studies had mixed methods designs and discussed ways in which their quantitative data triangulated with the qualitative findings (Dillon et al., 2016; Fortuna, 2014; Makin et al., 2017). Quantitative findings will not be discussed in the current review, but information on the measures can be found in the mapping table (see Table 2.5 in Appendix A).

Each study used slightly different methods to collect qualitative data, though all employed a form of interview with the students. WoE B ratings were influenced by the appropriateness of the methods to enable the students to express their views. WoE B Criterion A was developed around research that suggested semi-structured interviews with additional non-verbal methods may be the most appropriate for students with social communication difficulties (Fayette & Bond, 2018). One study utilised structured interviews with 12 predefined questions (Connor, 2000), therefore received a low rating for this criterion. However, the other studies all collected data through semi-structured interviews, so received medium or high ratings. Furthermore, some of the studies utilised multi-modal aids to support students within the interviews (Costley et al., 2021; Makin et al., 2017; Neal & Frederickson, 2016). Though, only six of the studies used additional qualitative methods, such as photo elicitation, diary accounts and interpretive drawings, to triangulate their findings and received high ratings (Fortuna, 2014; Goodall, 2018; Goodall, 2019; Goodall & MacKenzie, 2019; Humphrey & Lewis, 2008; Tomlinson et al., 2021).

In addition, WoE B Criterion B was guided by research that highlighted the ethical and practical issues around not involving participants with social communication difficulties in decisions about the research process (Fayette & Bond, 2018). For the current review, it was felt particularly important that autistic students were involved in decisions around data collection and reporting to ensure the methods chosen aided participation and findings

accurately reflected their experiences. The majority of studies received low ratings for this criterion, as decisions around data collection were made solely by the researchers (Connor, 2000; Dillon et al., 2016; Fortuna, 2014; Makin et al., 2017; Myles et al., 2019; Neal & Frederickson, 2016; Sproston et al., 2017). The Goodall studies (Goodall, 2018; Goodall, 2019; Goodall & McKenzie, 2019) and Costley et al. (2021) received medium ratings as they used participatory methods by collaborating with autistic individuals to make decisions about the research design, instruments and interview questions. However, only two of the studies received high ratings as they actively involved the participants in decisions around data collection and reporting (Humphrey & Lewis, 2008; Tomlinson et al., 2021). One of the studies involved the students in decisions around recording diary entries and included drawings in their analysis following one student's response (Humphrey & Lewis, 2008). The other study utilised a multiple-case design and analysed responses from each of their participants individually before considering the cross-case themes. They supported each of the students to select the data collection methods that suited their individual communication preferences and checked initial themes with the participants to ensure they accurately reflected their experiences before writing up their findings (Tomlinson et al., 2021).

### ***Analysis***

Furthermore, each study had different theoretical underpinnings. Only two studies explicitly outlined the epistemological assumptions that guided their

research (Humphrey & Lewis, 2008; Sproston et al., 2017). However, eleven of the studies described recognised theoretical frameworks that supported their analyses. Nine used Thematic Analysis (Braun & Clarke, 2006; 2014) (Costley et al., 2021; Goodall, 2018; Goodall, 2019; Goodall & MacKenzie, 2019; Makin et al., 2017; Myles et al., 2019; Neal & Frederickson, 2016; Sproston et al., 2017; Tomlinson et al., 2021), one used Content Analysis (Vaughan et al., 2014) (Dillon et al., 2016) and one used Interpretive Phenomenological Analysis (Smith & Osborn, 2003) (Humphrey & Lewis, 2008). These studies all explained how their themes emerged from the methodology they selected and produced clear statements of findings accordingly, which contributed towards their high WoE A ratings. The remaining two studies did not clearly describe the methods of data analysis they used, nor how their themes derived from their data. These were felt to influence the credibility and trustworthiness of the findings and therefore impacted the WoE A ratings. One study received a low WoE A rating (Connor, 2000), however, the other received a medium rating, on account of the justification they made for their study design and discussion around suggestions for future research (Fortuna, 2014).

### **2.3.3 Findings**

The findings from the included studies were synthesised with an adapted version of Thematic Synthesis (Thomas & Harden, 2008). The stages outlined by the authors were followed to code the texts with reference to the review question and generate descriptive and analytical themes (see

Appendix D for full synthesis of findings). This approach was felt to be appropriate as the current review is inductive and integrative in nature and the included studies varied in richness and were not guided by theories or frameworks. During the coding stage, the findings from each of the research papers were manually analysed and text relevant to the research question was highlighted. This led to the development of initial codes for each study, which were then compared and grouped into descriptive themes according to their meaning. This resulted in the generation of 12 descriptive themes, which were then further analysed and interpreted in light of the review question into four analytical themes: *'feeling unsupported and misunderstood by peers'*, *'experiencing sensory overload in the school environment'*, *'feeling inappropriately supported with academic work'* and *'feeling misjudged and undervalued by teaching staff'* (see Figure 2.2 for thematic map).

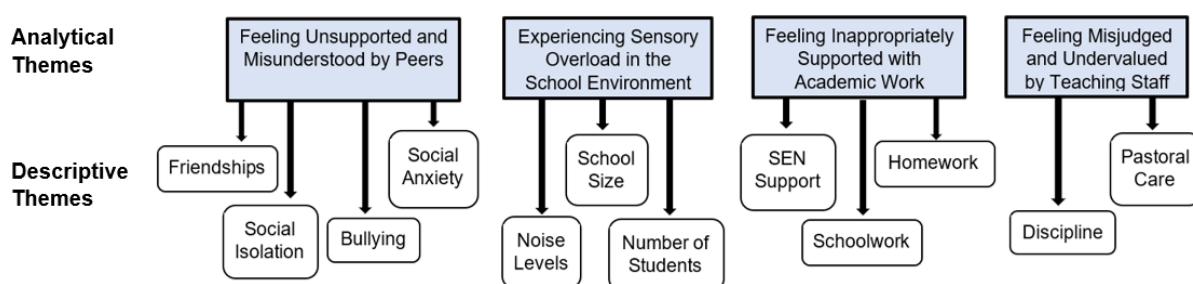
The analytical themes were considered to address the review question in equal weight, as each comprised of views from students in at least 10 of the studies. Additionally, it was not deemed appropriate to exclude any of the studies, as each elicited unique views from autistic students about their lived experiences. However, it was felt to be important that the WoE ratings influenced the relative contribution that each study finding made to the synthesis. Therefore, codes from the studies with high and medium WoE D ratings were grouped first and the descriptive themes created were used to support the coding process for the study with a low WoE D rating. This meant that the codes from the study with the low rating were incorporated into the

descriptive themes, but did not contribute towards their development. Recent research has described the value of using quality appraisal ratings to inform thematic synthesis (Long et al. 2020), therefore this was deemed an appropriate method for the current review.

In addition, throughout the synthesis process, the principle of reflexivity was considered. This was felt to be particularly important when developing analytical themes as it was arguably the most subjective stage of the synthesis. To engage reflexively, the text was continually referred to and participant quotes were reviewed. This allowed the reviewer to consider the extent to which the students' voices were represented by the analytical themes and reflect on the ways in which their own biases and perspectives had influenced the synthesis.

Figure 2.2.

*Thematic Map for Descriptive and Analytical Themes*



### ***Feeling Unsupported and Misunderstood by Peers***

The first analytical theme emerged from findings associated with friendships, social isolation, bullying and social anxiety and was entitled '*feeling unsupported and misunderstood by peers*'.

Some students discussed friendships in a positive regard and suggested that the large number of students in secondary school provided them with new opportunities to make friends for the first time, as well as continuing friendships from primary school (Neal & Frederickson, 2016; Connor, 2000). Students who had been successful in making friends spoke about their preference for having a small number of close friends who were patient, kind, understood them and accepted their needs. They suggested that their friends were able to support them to cope with anxiety in school and helped them feel safe and confident (Connor, 2000; Costley et al., 2021; Dillon et al., 2016; Myles et al., 2019). This demonstrates the value of social support for their psychological wellbeing. However, other students spoke about the difficulties they had experienced with making and maintaining friendships (Costley et al., 2021; Fortuna, 2014; Connor, 2000). One study discussed this with reference to the changes in the social dynamics of the peer group across the secondary school period (Fortuna, 2014).

In addition, many students discussed feelings of social isolation. They described how they felt misunderstood by their peers and were aware of their growing perceived differences, which made it difficult to relate to them

despite their efforts (Connor, 2000; Costley et al., 2021; Goodall, 2018; Goodall & MacKenzie, 2019; Humphrey & Lewis, 2008; Makin et al., 2017; Myles et al., 2019; Tomlinson, 2021). Some students sought ways to fit in with their peers and described strategies they had tried, such as mirroring their behaviour, but suggested that they still felt on the periphery of social groups as they were unable to join in with conversations and did not feel heard or valued (Makin et al., 2017; Myles et al., 2019). Other students discussed feelings of social isolation with reference to peer ignorance about autism, suggesting that their peers did not understand their needs or rejected them on account of their differences (Goodall, 2018; Goodall & MacKenzie, 2019; Tomlinson et al., 2021).

Additionally, some students reported difficulties related to social anxiety. Students experienced anxiety around aspects directly related to peer interaction, such as fearing judgement for getting things wrong or saying the wrong thing in a conversation (Costley et al., 2021; Tomlinson et al., 2021; Myles et al., 2019; Connor, 2000). Some reported specifically struggling in large social groups and attempting to learn hidden social rules to avoid doing or saying the wrong things, which seemed to further contribute towards their feelings of isolation (Myles et al., 2019). Other students reflected on aspects of the social environment more broadly and found the overwhelmingly social nature of mainstream secondary school anxiety-provoking (Goodall, 2018).

Furthermore, some students described how they felt that their differences and support arrangements made them susceptible to being exploited by their peers (Costley et al., 2021; Humphrey & Lewis, 2008; Makin et al., 2017; Goodall, 2019) and many referred to incidents of being physically or verbally bullied (Fortuna, 2014; Goodall, 2018; Goodall, 2019; Goodall & MacKenzie, 2019; Humphrey & Lewis, 2008; Sproston et al., 2017; Connor, 2000). Some of these students explained how they felt further isolated and anxious as a result of bullying (Costley et al., 2021; Humphrey & Lewis, 2008; Goodall & MacKenzie, 2019) and others described how being bullied made them feel angry (Goodall, 2019) and sometimes provoked them to retaliate (Sproston et al., 2017). However, some students reflected on the powerful impact that friends sticking up for them had on their sense of self and emotional wellbeing (Humphrey & Lewis, 2008), demonstrating the protective role that social support can play for psychological wellbeing.

### ***Experiencing Sensory Overload in the School Environment***

The next analytical theme was named '*sensory overload in the school environment*' and encompassed the descriptive themes; 'noise levels', 'school size' and 'number of students'.

Many students referred to the overwhelming auditory environment inside of the classrooms and explained how this distracted them from the lesson, impacted their learning and made it difficult for them to cope in class (Costley et al., 2021; Goodall, 2018; Goodall, 2019; Humphrey & Lewis, 2008; Dillon

et al., 2016; Makin et al., 2017; Sproston et al., 2017; Connor, 2000). Other students reflected on the impact that the overwhelming noise levels had on their anxiety when accessing other areas of school, such as corridors, canteens and playgrounds (Tomlinson et al., 2021; Connor, 2000). One student reflected on how this led to her avoiding shared spaces and added to her feelings of social isolation (Tomlinson et al., 2021).

In addition, while some students reflected on the benefit of having a large school in increasing their access to resources (Neal & Frederickson, 2016), many found the size of the school overwhelming, with those transitioning from primary school describing it as a shock (Fortuna, 2014). Many students experienced anxiety and irritation associated with the constant classroom changes (Goodall, 2018; Goodall, 2019; Goodall & MacKenzie, 2019; Tomlinson et al., 2021; Neal & Frederickson, 2016) and some worried about getting lost and being late for their lessons (Costley et al., 2021; Makin et al., 2017; Neal & Frederickson, 2016). Other students attended small schools or schools with designated small areas for SEN students and identified this as a positive feature of their environment (Dillon et al., 2016; Tomlinson et al., 2021; Myles et al., 2019). One student described feeling safe and supported when they were in this area (Myles et al., 2019).

Furthermore, some students also found the number of students in school overwhelming and benefited from smaller environments where they could develop familiarity with their peers (Dillon et al., 2016). One student reported

that the large school population facilitated new friendships (Neal & Frederickson, 2019). However, others found it challenging and felt it contributed towards their social anxiety (Costley et al., 2021; Myles et al., 2019). Many students also described worries about crowded corridors (Goodall, 2018; Goodall, 2019; Goodall and MacKenzie, 2018; Tomlinson et al., 2021) and students in one study worried about the impact these could have on behaviours, such as, pushing and fighting (Costley et al., 2021). One student also reflected on the impact that large class sizes were having on their access to support within lessons (Sproston et al., 2017).

### ***Feeling Inappropriately Supported with Academic Work***

Another analytical theme was derived from the descriptive themes; 'SEN support', 'homework' and 'schoolwork', and was labelled '*feeling inappropriately supported with academic work*'.

Students in some of the studies described their experiences of SEN support in class (Humphrey & Lewis, 2008; Tomlinson et al., 2021; Dillon et al., 2016; Makin et al., 2017; Sproston et al., 2017). Many of these students reflected on the positive influence that support they deemed appropriate had for reducing bullying, aiding their needs and benefiting the whole class (Humphrey & Lewis, 2008; Tomlinson et al., 2021; Dillon et al., 2016; Sproston et al., 2017). However, some students felt that the support they received was inappropriate (Sproston et al., 2017) and the staff tried to help them too much (Tomlinson et al., 2021). Some suggested that it drew

unwanted attention towards them, which made them feel aware of their differences and contributed towards them being bullied (Humphrey & Lewis, 2008; Tomlinson et al., 2021; Makin et al., 2017).

Furthermore, students also reflected on the academic work that was set for them. Some students felt that the homework they were given was overwhelming and took too much time to complete (Goodall, 2019; Dillon et al., 2016), though felt reluctant to discuss this with their teachers directly (Tomlinson et al., 2021). Additionally, other students spoke about the anxiety they experienced around teachers having extremely high expectations for them and the uniform approach they took to preparing the students for exams, which they felt was inappropriate for their needs (Costley et al., 2021; Tomlinson et al., 2021; Sproston et al., 2017). Students in one study explained that the highly organised structure of the school they attended helped them to plan their work and felt that the variety of lessons they had supported their engagement (Neal & Frederickson, 2016). However, other students found the school structure overwhelming and discussed the difficulties they experienced with planning and organising their work, remembering materials and keeping up in lessons (Makin et al., 2017; Dillon et al., 2016).

### ***Feeling Misjudged and Undervalued by Teaching Staff***

The final analytical theme was generated from descriptive themes related to 'pastoral care' and 'discipline' and was categorised as *'feeling misjudged and undervalued by teaching staff'*.

Some students reported that they felt misunderstood and unsupported by teachers (Goodall, 2019; Myles et al., 2019; Sproston et al., 2017; Makin et al., 2017). Many attributed this to teachers' negative attitudes, lack of knowledge or misconceptions around autism (Goodall, 2018; Goodall & MacKenzie, 2019; Tomlinson et al., 2021; Myles et al., 2019; Sproston et al., 2017). Some students felt they received little attention or interaction from teachers in class (Humphrey & Lewis, 2008; Dillon et al., 2016) and described feeling uncared for and unnoticed (Goodall, 2019; Goodall & MacKenzie, 2019). Though, others described receiving differential treatment on account of their autism (Humphrey & Lewis, 2008) which they felt patronised by, as they felt that staff infantilised them (Tomlinson et al., 2021).

Moreover, students in one study suggested that the inconsistencies between staff attitudes arose from a larger training need as there were few SEN experienced staff in their school (Sproston et al., 2017). Others explained how this was made more difficult by having many different teachers and unfamiliar cover staff (Tomlinson et al., 2021; Sproston et al., 2017).

Conversely, some students described the benefits of having good relationships with trusted staff who they felt supported by (Tomlinson et al.,

2021; Sproston et al., 2017). Students often felt this way about SEN support staff, who they described feeling listened to, valued and understood by (Dillon et al., 2016; Neal & Frederickson, 2016).

Furthermore, many students also felt that teachers did not consider individual needs in their approach to discipline. While some students appreciated the focus on discipline (Neal & Frederickson, 2016), others felt that the methods teachers adopted, such as, periods of isolation, added to their social difficulties by further curtailing their opportunities for interaction with their peers (Goodall, 2018). Some students felt that there was a lack of clear expectations (Costley et al., 2021; Goodall, 2018), which caused them anxiety when teachers were overly strict (Makin et al., 2017) and punished them for things that seemed unfair (Neal & Frederickson, 2016). One student felt that she received no acknowledgement for trying, though was quick to get punished for getting things wrong (Goodall & MacKenzie, 2019) and another described feeling anxious around asking questions after being ridiculed in front of the class for making mistakes (Sproston et al., 2017).

## **2.4 Conclusion and Recommendations**

### **2.4.1 Summary of Findings**

The aim of the current synthesis was to identify themes in qualitative research to address the review question: *‘what are the barriers to autistic students’ sense of belonging and psychological wellbeing in mainstream*

*secondary school?*’ Overall, 12 descriptive themes were identified, which were extrapolated into four analytical themes.

The first analytical theme was conceptualised as ‘*feeling unsupported and misunderstood by peers*’. Students in five of the studies described the positive opportunities secondary school afforded them to make friends, the benefits of their support (Costley et al., 2021; Neal & Frederickson, 2016; Connor, 2000; Dillon et al., 2016) and feelings of safety and confidence in being accepted and understood (Myles et al., 2016). This is consistent with previous research that has highlighted the protective impact a sense of belonging can have on psychological wellbeing (DES, 2019). However, these findings contrasted with the reports from students in nine studies who experienced difficulties making friends (Costley et al., 2021; Fortuna, 2014; Connor, 2000), had growing feelings of perceived difference and felt misunderstood and rejected by their peers (Connor, 2000; Goodall, 2018; Goodall & MacKenzie, 2019; Humphrey & Lewis, 2008; Makin et al., 2017; Myles et al., 2019; Tomlinson et al., 2021). This aligns with research that has highlighted the association between social needs and the development of mental health difficulties (Andrews et al. 2020).

Moreover, students in eight studies referred to bullying (Costley et al., 2021; Fortuna, 2014; Goodall, 2018; Goodall, 2019; Goodall & MacKenzie, 2019; Humphrey & Lewis, 2008; Sproston et al., 2017; Connor, 2000). In line with previous research (Bailey & Baker, 2020; William et al., 2019), some

students felt that their differences made them particularly vulnerable to being bullied (Costley et al., 2021; Humphrey & Lewis, 2008; Makin et al., 2017) and reflected on feelings of isolation, anxiety and anger as a result (Costley et al., 2021; Humphrey & Lewis, 2008; Goodall & MacKenzie, 2019; Goodall, 2019). Some also felt this provoked them to retaliate (Sproston et al., 2017), which provides a possible explanation for some of the “disruptive behaviours” that precede permanent exclusions for autistic students (Graham et al., 2019). These findings also seem consistent with ideas posed by the ‘double empathy problem’ (Milton, 2012) and the suggestion that autistic students receive a disproportionately low level of empathy and understanding from their neurotypical peers. Five studies also referred to feelings of social anxiety, which seemed to contribute further towards students feeling isolated in school (Costley et al., 2021; Tomlinson et al., 2021; Myles et al., 2019; Connor, 2000; Goodall et al., 2018). Overall, findings around this theme seem to demonstrate the protective influence of social support and understanding and the negative impact of social isolation on students’ sense of belonging and psychological wellbeing.

The second analytical theme was understood as ‘*experiencing sensory overload in the school environment*’. Students in three studies had access to small spaces within school designated for SEN students and reported feeling safe and supported (Dylan et al., 2016; Myles et al., 2017; Tomlinson et al., 2021). However, students who did not have these provisions, found the size of the school and number of students overwhelming and reported anxiety

around changing classrooms and getting lost (Costley et al., 2021; Goodall, 2018; Goodall, 2019; Goodall & MacKenzie, 2019; Humphrey & Lewis, 2008; Tomlinson et al., 2021; Neal & Frederickson, 2016; Makin et al., 2017).

Students also described the negative impact of the loud environment on their access to learning and anxiety levels and one student described how experiencing sensory overload resulted in her avoiding shared spaces (Costley et al., 2021; Goodall, 2018; Goodall, 2019; Humphrey & Lewis, 2008; Dillon et al., 2016; Makin et al., 2017; Sproston et al., 2017; Connor, 2000). These findings are consistent with research around executive functioning difficulties associated with autism (Pennington et al., 1997). They also extend research exploring the impact of sensory overload on wellbeing (Iarocci & McDonald, 2006; Remington et al., 2009) by highlighting the negative effect sensory overload can have on social inclusion and belonging through curtailing opportunities for social interaction. These findings therefore highlight how anxiety-provoking the sensory environment can be for autistic students and demonstrate the negative impact this can have on their senses of safety and belonging within the school community.

The third analytical theme was classified as '*feeling inappropriately supported with academic work*'. Students in five of the studies discussed their experiences of SEN support. While appropriate support was felt to be beneficial for learning and wellbeing, when this support was deemed inappropriate, students described standing out from their peers and being bullied, suggesting increased feelings of social isolation (Humphrey & Lewis,

2008; Tomlinson et al., 2021; Dillon et al., 2016; Makin et al., 2017; Sproston et al., 2017). Students in three studies mentioned finding homework particularly difficult and overwhelming (Goodall, 2019; Dillon et al., 2016; Tomlinson et al., 2021), suggesting that this may have been inappropriately differentiated and scaffolded. Additionally, while students in one study described the ways in which they benefited from the structure of their school, students in five studies described the difficulties they experienced in class. They discussed difficulties accessing learning (Dillon et al., 2019), coping with high expectations (Costley et al., 2021; Tomlinson et al., 2021; Sproston et al., 2017) and organisation and planning (Makin et al., 2017), consistent with the Executive Dysfunction Hypothesis (Pennington et al., 1997). Together, these findings demonstrate the negative impact that inappropriate teaching support and inappropriately differentiated and scaffolded work can have on students' sense of belonging and anxiety levels.

The fourth analytical theme was labelled '*feeling misjudged and undervalued by teaching staff*'. Students in four of the studies described feeling misunderstood by teachers (Goodall, 2019; Myles et al., 2019; Sproston et al., 2017; Makin et al., 2017) and many attributed this to the teachers' lack of knowledge around autism (Goodall, 2018; Goodall & MacKenzie, 2019; Tomlinson et al., 2021; Myles et al., 2019; Sproston et al., 2017). Students in six of the studies discussed how this impacted on the way they were treated by teachers (Humphrey & Lewis, 2008) and described feeling uncared for and unnoticed (Humphrey & Lewis, 2008; Dillon et al., 2016; Goodall, 2019;

Goodall & MacKenzie, 2019) or patronised as a result (Tomlinson et al., 2021). Moreover, students in six studies described how their teachers' approaches to discipline felt inappropriate for their needs (Goodall, 2018; Makin et al., 2017; Neal & Frederickson, 2016), anxiety-provoking and demoralising (Costley et al., 2021; Goodall & MacKenzie, 2019; Sproston et al., 2017). This emphasises the negative influence that the teaching approaches can have on students' psychological wellbeing. These findings are consistent with those from previous research, in which autistic students reflected on the impact of teachers not understanding their needs on their sense of belonging in school (Graham et al., 2019). However, students in four of the studies also highlighted the benefits of having trustworthy and supportive staff on their psychological wellbeing, with particular reference to SEN support staff (Tomlinson et al., 2021; Sproston et al., 2017; Dillon et al., 2016; Neal & Frederickson, 2016). Overall, these findings therefore support and extend previous research by illustrating the ways in which teacher-student relationships can influence student wellbeing and emphasising the importance of teacher training around autism.

#### **2.4.2 Strengths and Limitations**

The participant samples within each of the studies varied, with respect to student demographics. Many studies reported male-dominant samples which posed a potential limitation to the transferability of their findings to female students. Some justified their sampling with reference to diagnostic ratios (Goodall, 2018; Neal & Frederickson, 2016). However, research has

suggested that these are not likely to represent the actual number of autistic females in the population (Loomes et al. 2017) and discussed the limitations with underrepresenting females in autism research, with reference to the implications for practice (Shefcyk, 2015). Additionally, research has suggested that some of the difficulties that girls and boys experience in school may be different, for example autistic girls report more difficulties than boys in making friends (Kirkovski et al. 2013). Therefore, it is possible that findings from research with male-dominant samples may not sufficiently capture and represent the views from females in their themes. However, some studies sought to address the gap in the literature and included female-only samples (Goodall & MacKenzie, 2019; Myles et al., 2019; Sproston et al., 2017; Tomlinson et al., 2021). Therefore, for the current review, the variation in samples was felt to be a strength, as the views from a wide range of participants were able to be contrasted and synthesised, which supported the transferability of the current findings.

In addition, one particular strength of the included studies is that the majority used recognised theoretical frameworks to analyse their data and clearly described the processes they went through to generate themes. However, despite the methodological rigour in data analysis, there was great variability between the studies in terms of data collection. Previous research has highlighted the difficulties many autistic students have in communicating their views verbally, with regard to 'alexithymia' (Milosavljevic et al., 2016). This led to recommendations for the use of supplementary non-verbal qualitative

methods and incorporating participant views into decisions around the research (Fayette & Bond, 2018). However, under half of the studies used additional qualitative methods to triangulate their findings (Fortuna, 2014; Goodall, 2018; Goodall, 2019; Goodall & MacKenzie, 2019; Humphrey & Lewis, 2008; Tomlinson et al., 2021) and only two studies included participants in their decisions around data collection and reporting (Humphrey & Lewis, 2008; Tomlinson et al., 2021). This is felt to jeopardise the credibility of the findings overall.

### **2.4.3 Reflexivity**

The principle of reflexivity was considered at various stages throughout the review and a first-person reflexive account is provided below.

Towards the beginning of the review process, I made conscious efforts to unveil the internal motivations that drove my topic selection. This supported me to generate a deeper understanding of my position and biases that may influence decision making. This involved consideration of my role as a psychologist and moral standpoint on issues related to social inclusion, as well as my personal experiences that may have contributed towards the construction of my ethics. This particularly influenced the process of developing the WoE B criteria, as I am passionate about person-centred approaches and eliciting student voice, which I feel led to the development of the extensive criteria.

Furthermore, I feel that my motivation to accurately elicit student voice facilitated the process of analysis, though also at times felt at odds with the interpretive nature of thematic synthesis. Reflexivity was therefore heavily considered through the stages of data analysis and interpretation, particularly when developing the analytical themes. In order to ensure participants' voices were still represented, while not being directly quoted, I returned to the texts repeatedly when naming initial descriptive themes and used participant quotes to actively challenge the assumptions I had made when developing these into analytical themes. This also allowed me to consider the extent to which the interpretations the researchers had made in the papers, as well as their own biases and understanding of autism theory had influenced the way in which I interpreted their findings.

The range of diverse views represented through this synthesis demonstrate the heterogeneity within the population of autistic students who attend mainstream secondary schools. Although I was able to generate themes to describe and analyse the students' views, it is of note that each participant identified with a unique combination of these themes and no two students shared the same set of experiences. This highlights the importance of professionals actively challenging the assumptions they hold that may stem from theory and research that does not represent the unique experiences of the young person they are working with. The process of thematic synthesis has therefore further empowered my position on the importance of actively

seeking out ways to elicit student views and prompted me to reflect on the importance of reflexivity in EP practice.

#### **2.4.4 Recommendations**

##### ***Research***

Future research should seek to address some of the limitations described in the included studies, with regard to gender representation, methods for data collection and participant involvement. It should be emphasised again that autistic students are not a homogenous group. Therefore, student responses should be first considered at an individual level where possible and specific recommendations around 'good practice with autistic students' developed and interpreted tentatively.

Active participant involvement in decision making throughout the research process is thought to be an expressly important feature of research designs with autistic students. One study that received a notably high rating for WoE B supported each participant to choose the data collection methods that suited their personal communication preferences and utilised a multiple-case design to analyse each participant's responses separately before making cross-case comparisons (Tomlinson et al., 2021). This methodology is felt to be particularly appropriate for studies with autistic young people and researchers should consider ways in which this can be incorporated into future studies in this area.

Moreover, the fact that the current review was only able to identify 13 relevant studies suggests that there is an apparent paucity of qualitative research exploring autistic students' perceptions of mainstream secondary schools. The included studies explored various features of the school experience associated with feelings of belonging and psychological wellbeing. However, only one of the studies focused exclusively on students who experienced mental health difficulties (Costley et al., 2021). Previous research has explored views from autistic students who experienced mental health difficulties and identified themes associated with their school experience as contributory factors (Hebron & Humphrey, 2014). Though, future research could develop this further by exploring the qualitative differences between the school experiences of students who experience mental health difficulties with those who do not.

### ***Educational Psychology Practice***

The current synthesis represents views from a range of students related to their unique experiences. It cannot be emphasised enough that autistic students are not a homogenous group, therefore the extent to which any of the current findings can be transferred to an individual student is questionable. However, EPs may wish to view each of the four analytical themes as broad hypotheses to consider within consultations or when working with autistic students who are experiencing difficulties in school, particularly those on the brink of exclusion. In addition, the 12 descriptive themes cover various aspects of the school experience and can be used

creatively by EPs when gathering students' views about school. EPs may wish to create physical resources with pictures or words related to each of the themes that they could use interactively with students, asking them to rank them or identify those they find good and bad about school and elaborate on what these topics mean for them. This type of approach aligns with the 'scientist practitioner' role of the EP by putting the evidence base into practice. Additionally, following the finding that autistic young people often feel misunderstood and misjudged, giving them space and resources to freely express their views about school is likely to be a validating experience, which could act as an intervention in itself.

Ultimately, the findings from the current synthesis revealed that various barriers can exist to a sense of belonging and psychological wellbeing for autistic students in mainstream secondary school. EPs can play important roles in exploring whether any of these barriers exist for students and working with school staff and students to remove them. This may involve recommendations around peer education, reasonable adjustments, differentiation or staff training, though vitally should be considered at an individual level to address the unique needs of each student. It is expected that with these in place, autistic young people would be more able to access appropriate support and experience a true sense of belonging within the school community. It is hoped that this would support their psychological wellbeing and reduce the rising rates of mental health difficulties and permanent exclusions seen over recent years (DfE, 2022b; Graham et al.,

2019; Hebron & Humphrey, 2014). Overall, it is hoped that this review contributes towards the evidence base that informs interventions to improve the mainstream secondary school experience for autistic young people and supports the development of mainstream educational environments where difference is understood and celebrated.



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## **Chapter 3: Empirical Paper**

***“I would be really really sad if I did not have my friends and my worries would be a lot bigger”:***

**The Relationship between Social Support and Anxiety for  
Autistic Students in Mainstream Secondary School**



### **3.1 Abstract**

Anxiety is the most common co-occurring difficulty in autism and many autistic students experience feelings of loneliness. Yet, no known research has explored the relationship between anxiety and social support for autistic students in mainstream secondary school. The current study sought to address this gap and used linear regression to analyse data from 60 autistic students who completed an online survey to measure their levels of social support and anxiety. No significant relationship between the variables was found, which suggests that social support is unlikely to be a protective factor for anxiety, though it was hypothesised that it could aid students to cope with anxiety. Nine students who reported high levels of both social support and anxiety took part in semi-structured interviews to explore this and their responses were analysed with reflexive thematic analysis. Two research questions were posed and themes were identified around key features of social support that helped the students cope with anxiety ('sense of belonging', 'needs being understood' and 'co-regulation') and factors that contributed towards an 'ideal' peer group ('kindness', 'sense of group identity' and 'inclusion'). Findings extend those from previous research and uniquely contribute to the evidence base. Strengths and limitations of the research are discussed, alongside directions for future research and implications for professional practice, teaching, pedagogy and local government guidance. These include recommendations for systemic work to support whole school autism understanding and promote positive autistic social identity.



## **3.2 Introduction**

### **3.2.1 Autism**

Autism Spectrum Disorder/Condition (hereby referred to as 'autism') is a neurodevelopmental difference associated with persistent difficulties in aspects of social communication and interaction, alongside restricted and repetitive behaviours (American Psychiatric Association, 2013). Prevalence research from global and national perspectives have estimated that approximately 1% of the population have an autism diagnosis (Zeidan et al., 2021; Tinsley, 2020). However, this statistic is likely to underrepresent the actual number of autistic people, as research has identified barriers that individuals face to accessing diagnoses and shown that the rates of autism identification continue to exponentially increase (Russell, 2021).

### **3.2.2 Autism and Anxiety**

The number of children and young people experiencing mental health difficulties across the UK has also risen in recent years. A National Health Service (NHS) survey revealed that rates of probable mental health disorders increased from 11% to 17% between 2017 and 2021 (NHS Digital, 2021). Mental health disorders can take various forms, though are generally characterised by emotional difficulties that significantly impact upon an individual's development, daily functioning and access to learning (World Health Organisation, 2019).

The rates of mental health disorders appear to be significantly elevated in neurodivergent populations and research has found that more than 80% of autistic young people experience difficulties with their mental health (Crane et al., 2017). These difficulties often develop as individuals enter adolescence and transition to secondary school (Levy & Perry, 2011). Furthermore, research suggests that the recent events associated with Covid-19 have compounded mental health difficulties for many young people. A survey carried out in January-February 2021 suggested that young people's mental health was increasingly impacted by each of the lockdowns (YoungMinds, 2021). Furthermore, research with autistic young people found that 85% felt their mental health got worse through the pandemic (National Autistic Society, 2020).

Anxiety disorders are found to be the most common co-occurring difficulty in autism, with 40% of young people meeting diagnostic criteria and a further 30-40% experiencing sub-clinical levels that affect their functioning (Simonoff et al., 2008; van Steensel et al., 2011; Vasa et al., 2013). Anxiety disorders are diagnosed when an individual experiences a level of anxiety that is disproportionate to the situation and hinders their normal functioning (American Psychiatric Association, 2017). Research has explored the expression of anxiety in autistic individuals and found that many autistic young people present with 'atypical' symptoms, such as anxiety around routine, specific unusual fears or ritualistic behaviours (Kerns et al., 2014). However, this research found that while these anxieties significantly impact

the daily functioning of autistic young people, the unique presentations may not be recognised by standardised anxiety measures, thus impact on their access to services and support.

One theory proposed to understand the high levels of anxiety experienced by autistic individuals is 'Intolerance of Uncertainty' (IoU) (Buhr & Dugas, 2009). IoU is a trait characterised by an individual's overvaluation of their ability to predict the world, which results in overwhelm when they experience the unexpected (Pellicano & Burr, 2012). Research has revealed significant associations between high levels of IoU, sensory sensitivities and anxiety in autistic children (Boulter et al., 2014; Neil et al., 2016; Osmanağaoğlu et al., 2018). An exploratory model has been proposed to outline the possible pathways related to intolerance of uncertainty and anxiety for autistic individuals (South & Rodgers, 2017). This highlights atypical sensory function, emotion awareness difficulties and rigidity of thought as potential factors common to autistic individuals that increase IoU. It subsequently links increased IoU to heightened anxiety and restricted and repetitive thoughts and behaviours. This provides a promising framework to explain the potential influence of IoU in autism and preliminary evidence has found that interventions to target IoU could be effective in reducing symptoms of anxiety for autistic young people (Rodgers et al., 2017).

### **3.2.3 Autism and Social Support**

In order to receive an autism diagnosis in accordance with the DSM-5, individuals must present with “persistent deficits in social communication and social interaction” (American Psychiatric Association, 2013), which research has associated with ‘Theory of Mind’ impairments (Baron-Cohen, 2000). This suggests that autistic individuals present with markedly different social communication styles, which has prompted the development of interventions designed to target the specific skills that are seen to pose barriers to their integration in mainstream environments (White et al., 2007).

However, viewing social difficulties through a ‘within-person’ lens can be reductionist, as it fails to consider the influence of environmental factors on behaviour and views differences as deficits. This can also lead to an assumption that autistic students do not want friendships or have a “basic desire for aloneness”, as early literature would suggest (Kanner, 1943). Yet, research has found that autistic students desire relationships with their peers, but often report feelings of loneliness that is associated with a low sense of belonging and wellbeing upon transition to secondary school (Goodall, 2018; Hebron, 2018). In school, a sense of belonging has been defined as feeling accepted, valued, included and supported by others (Goodenow, 1993).

Therefore, these findings do not fit with the assumptions made in early literature. Research has also demonstrated the influence of social support and anxiety independently on quality of life for autistic adults of different ages (Bishop-Fitzpatrick et al., 2018; Charlton et al. 2022), which corresponds with

theories that have identified social support as a fundamental human need (Jacobson, 1986). This is also consistent with the suggestions made by Maslow's Hierarchy of Needs (Maslow, 1943), that proposes that a sense of belonging is a fundamental foundation for the development of mental health and self-actualisation.

In addition, more recent research has begun to consider social difficulties more systemically and proposed the 'Double Empathy Problem' (Milton, 2012). This submits that individuals who experience the world differently find it difficult to empathise with each other. For an autistic student in a mainstream school, this may mean that the majority of their peers struggle to understand them, which is likely to pose as a barrier to relationship development. It is therefore possible that the anxiety and low sense of belonging that many autistic students experience is a product of their environment and a general lack of empathy and understanding from their peers in mainstream secondary schools, rather than a within-person factor.

Recent qualitative research has explored this idea through comparing autistic people's experiences of socialising with neurotypical people versus other autistic people and found that difficulties with 'cross-neurotype' understanding and being a minority impacted their sense of belonging (Crompton et al., 2020). Further research has explored autistic young adults' views on 'autism-specific peer support' as a framework to foster a sense of belonging when reflecting on their experiences of mainstream secondary

school (Crompton et al., 2022). However, no known studies to date have investigated the association between social support and anxiety in autistic young people, leaving a significant gap in the literature.

#### **3.2.4 Rationale for the Study**

From a professional perspective, this research is of high relevance and importance to the role of the Educational Psychologist (EP). The findings hold potential to inform systemic work to increase autism understanding and recommendations for strategies to promote support networks for autistic students. Autism is currently the most common need reported on Education Health and Care Plans and the number of autistic students in mainstream schools is rising (DFE, 2022). This suggests that the need for Educational Psychologist (EP) support with autistic students is likely to grow.

In addition, following the recent context of Covid-19, it is probable that mental health services will remain increasingly stretched and more young people will be placed on waiting lists to access support. This highlights the need for early preventative work and understanding around the protective factors for anxiety. Aspects of the EP role, such as, providing in-service training around autism, advocating for the voice of autistic young people and recommending evidence-informed interventions and strategies are therefore arguably more pressing than ever at present.

### **3.2.5 Research Questions**

The aim of the current study is to build on previous research and explore the relationship between social support and anxiety for autistic students in mainstream secondary schools. More specifically, the following research questions (RQs) are proposed:

*RQ1. Could social support be a protective factor for anxiety in autistic students?*

*RQ2. In what ways can social support help autistic students cope with anxiety?*

*RQ3. What contributes towards an ideal peer group for autistic students?*

## **3.3 Methods**

### **3.3.1 Design**

The study adopted a mixed-methods sequential explanatory study design (Creswell et al., 2003), where online survey data were collected and analysed first, before semi-structured interviews and drawing task were undertaken and interpreted. The research is positioned within a critical realist position, which maintains a commitment to seeking truth, while acknowledging that all accounts of knowledge are ultimately dependent on conceptual, contextual and cultural variables. This understanding is described as ‘epistemic relativism’ and highlights the value of methodological pluralism to encourage deep and broad insights (Archer et al., 2016). A

critical realist perspective therefore posits that quantitative and qualitative research can be carried out together to tackle the relative limitations and build upon the strengths of each approach (Shannon-Baker, 2016).

In the research, the surveys allowed for data to be gathered from a large sample of participants who are more likely to represent the wider population of autistic students. However, this did not provide deeper insights into the possible meanings behind results. In contrast, the views elicited from the semi-interviews and drawings had more limited transferability, based on the small sample. However, they counteracted the limitation of using surveys alone by allowing for an in depth exploration of the themes to elucidate the quantitative findings (Ivankova et al., 2006) and inform recommendations. Thus, it was felt that a mixed methods approach was the most appropriate way to answer the current research questions. Previous research exploring autistic students' views on aspects of the mainstream secondary school experience has also utilised mixed methods approaches involving self-report measures and semi-structured interviews to successfully gather data and elicit student views (Dillon et al., 2016; Fortuna, 2014; Makin et al., 2017). This was felt to further justify its use.

The quantitative component of the study addressed the first research question: '*could social support be a protective factor for anxiety in autistic students?*' and the qualitative section addressed the second and third research questions: '*in what ways can social support help autistic students*

*cope with anxiety?’ and ‘what contributes towards an ideal peer group for autistic students?’.*

### **3.3.2 Participants**

No known research has been carried out to investigate the relationship between social support and anxiety. Therefore, a target sample size for the quantitative phase was estimated based on the findings from research exploring the variables more broadly. Various studies exploring autistic students’ views highlight themes around friendships, social isolation and bullying as key challenges of mainstream secondary school that they feel impact their wellbeing (Costley et al., 2021; Fortuna, 2014; Goodall, 2018; Goodall & MacKenzie, 2019; Humphrey & Lewis, 2008; Makin et al., 2017; Myles et al., 2019; Sproston et al., 2017; Tomlinson et al., 2021). Thus, it was hypothesised that there would be a strong relationship between social support and anxiety. However, due to there being no previous research exploring the relationship between these variables directly, a power analysis was calculated based on a moderate effect of .30 (Cohen, 1988). Using 80% power and the traditional significance criterion of .05., the power analysis suggested that at least 85 participants would need to be recruited.

Participants in the survey were 60 autistic students from 24 mainstream secondary schools in the UK who fulfilled the inclusion criteria for the study (see Table 3.1). Eleven of these participants were invited to take part in the interview phase and nine participated in it. Table 3.2 outlines the participant

characteristics for each stage of the study, respectively. Criterion sampling was used throughout the research as a purposive method appropriate for mixed methods designs (Sandelowski, 2000). Participants were selected for the qualitative phase based on their scores from the quantitative measures.

Table 3.1.

*Inclusion Criteria*

Inclusion Criterion	Rationale
1. Students attend mainstream secondary school	Students in Years 7-11 were included as they were currently in compulsory education which constitutes a typical mainstream environment. Those in Year 12 and 13 were asked to reflect on their Year 11 experiences. The potential influence of retrospective recall on the accuracy of accounts for Year 12 and 13 students was acknowledged, though this was felt to be negligible as they were reflecting on recent experiences in education.
2. Students have a diagnosis of autism / self-identify as autistic and are currently on an autism assessment pathway.  Students may have additional diagnoses.	In order to be on a diagnostic pathway, the students had been referred for assessment and undergone initial autism screeners. While the National Institute for Health Care Excellence (NICE) guidelines recommend referral waiting time for assessments to be no longer than three months (NICE, 2017), average NHS waiting times in 2021 were one year (NHS Digital, 2021) and research illuminating health care professionals' experiences suggests that in practice they often exceed two years (Daniels, Coughlan & Duschinsky, 2021) and can be significantly longer for females than males (Dillon et al., 2021). There is also current debate around the validity of self-diagnoses in the autism literature (Sarrett, 2016). For these reasons, it was felt inappropriate to exclude students who were on diagnostic pathways and identified as being autistic.  Anecdotal references were also made to some of the participants having co-occurring diagnoses and this

Inclusion Criterion	Rationale
	also did not warrant exclusion from the study. Recent reviews and meta-analyses have highlighted the high prevalence of co-occurring mental health and psychiatric diagnoses in the autistic population (Lai et al., 2019; Rosen et al., 2018). Therefore, it was felt that including students with co-occurring diagnoses would support recruitment and add to the transferability of the findings.
3. Students are aware of their autism	References to autism were made throughout the research.
4. Students have the capacity to consent to the research and engage independently	Informed consent from students was required for each stage of the research and the research was interested in gathering students' independent views through the survey and interview.

Table 3.2.

*Participant Demographic Information*

Demographic Category		Survey (N=60)	Interview (N=9)
Gender	Female	24 (40%)	3 (33%)
	Male	32 (53%)	5 (56%)
	Non-binary/other	2 (3%)	1 (11%)
	Prefer not to say	2 (3%)	
Chronological Age	Mean (SD)	13.5 (1.6)	13.9 (1.8)
	Range	11-17	11-17
Diagnostic Status	Autism Diagnosis	54 (90%)	9 (100%)
	Self-identification and on diagnostic pathway	6 (10%)	
UK Region	East Anglia	7 (12%)	
	East Midlands (England)	31 (52%)	6 (67%)
	London	2 (3%)	
	Scotland	1 (2%)	
	South East (England)	2 (3%)	1 (11%)
	South West (England)	5 (8%)	
	Wales	2 (3%)	1 (11%)
	West Midlands (England)	10 (17%)	1 (11%)
Number of schools represented		24	7

Demographic Category		Survey (N=60)	Interview (N=9)
Ethnicity*	Any other Asian background	1 (2%)	1 (11%)
	Any other ethnic group	3 (5%)	
	Bangladeshi	1 (2%)	
	Gypsy or Irish Traveller	1 (2%)	
	Indian	1 (2%)	
	Mixed White and African	1 (2%)	
	Mixed White and Asian	1 (2%)	
	Mixed White and Black Caribbean	2 (3%)	1 (11%)
	Pakistani	2 (3%)	
	Prefer not to say	1 (2%)	
	White British	46 (77%)	7 (78%)

*\*Note. The ethnicity options offered in the survey were taken from the agreed list of ethnic groups used in the 2021 census (GOV.UK, 2021).*

*Note. Percentages may not add up to 100 due to rounding.*

### 3.3.3 Procedure

#### ***Recruitment***

Information about the study was initially circulated via email to SENCOs in approximately 90 mainstream secondary schools in Local Authorities in the midlands. The emails detailed the nature of the research (see Appendix F.1)

and included an information sheet (see Appendix F.2). Interest from four schools was received, which accounted for 25 of the total participants.

Secondly, a post was shared via social media platforms and online UK autism support groups (see Appendix F.3). Interest from several parents/carers and young people was gained through this method of recruitment, which accounted for an additional 25 participants.

Finally, due to a male-bias in the sample, the recruitment targeted female participants and emails were sent to 10 female-only mainstream secondary schools in the midlands. Interest from one school was received, which accounted for an additional ten participants. The male-to-female ratio of children meeting diagnostic criteria for autism is estimated to be approximately 3:1 (Loomes et al. 2017). However, research has highlighted the lack of female representation in the research that has informed diagnostic criteria and identified differences in the presentation of autism in females (Dillon et al., 2021). Therefore, autism diagnostic criteria are considered to be biased towards male presentations and it is unclear what the true ratio of autistic females in the population is. With this understanding, the research sought to represent female and male participants as equally as possible.

### ***Survey Phase***

All participants initially completed an online survey which comprised of two measures: the Anxiety Scale for Children – ASD – Child Version (ASC-ASD) (Rodgers et al., 2016) (see Appendix G.1) and an adapted version of the 24-

Item Social Provisions Scale (SPS-24) (Cutrona & Russell, 1987) (see Appendix G.2). Participants completed the surveys either at home or school, depending on their preference, and their responses were pseudonymised and stored securely for analysis. Instructions were presented in the information sheets for the students to complete the surveys independently, though it was advised that a member of staff or parent/carer be present in case they required assistance with interpreting the questions or to provide emotional support if they found any of the questions distressing. At the end of the survey, participants were asked whether they were willing to participate in follow-up interviews.

Internal consistency estimates for both the ASC-ASD and SPS-24 were calculated from the participants' responses. High internal consistency was found for both measures, with Cronbach's alpha scores of .95 for the ASC-ASD and .93 for the SPS-24.

### ***Interview Phase***

Following the quantitative data analysis, the interview schedule was developed. Participants whose survey responses suggested that they were experiencing high levels of both anxiety and perceived social support and were willing to participate in an interview were invited to participate in the interview phase. Participants were interviewed in either a quiet room in their school or online via Zoom (video conferencing platform), depending on their geographical location and personal preference. Each interview began with a

general discussion to build rapport, remind participants about their right to withdraw and give them an opportunity to ask questions. The interviewer then spent around 30 minutes carrying out the semi-structured interview and presenting the ‘ideal peers’ task. The interviews and drawings were then transcribed, interpreted and analysed with reflexive thematic analysis (Braun & Clarke, 2019) and Personal Construct Psychology (Kelly, 1955) (see Appendix H).

### ***Ethical Considerations***

The study was approved by the Research Ethics Committee at University College London (see Appendix E). The ‘high risk’ application detailed information around the proposed study design, data collection and analysis, and attached the recruitment information sheets and consent forms. Approval was also obtained by a UCL Data Protection Officer and a data protection number was issued. Ethical decision making, guided by the British Psychological Society (BPS) Code of Ethics and Conduct (BPS, 2021), was considered throughout the procedure. See Table 3.3 for a full list of the ethical considerations.

Table 3.3.

*Ethical Considerations*

Ethical Consideration	Actions Taken
Awareness of diagnosis	It was stated in the recruitment information for schools (see Appendix F.2) and parent/carers information sheet (see Appendix F.4) that references to autism would be made so the study would not be appropriate for students who were not aware of their autism.
Informed consent	Informed consent for the survey phase was obtained through means of providing online information sheets (see Appendix F.4) and consent forms (see Appendix F.5) to parents. Once parental consent was gained, online participant information sheets (see Appendix F.6) were shared with students, which contained a link to the online survey and an explanation that their assent would be assumed through completion of the survey. Informed consent for the interview phase was obtained through providing information sheets and consent forms to parents (see Appendix F.7 and F.8) and students (see Appendix F.9 and F.10).
Possibility for distress	The information sheets for parents and students detailed the possible risks and benefits of participation. It was advised that a parent/carers or member of school staff be present whilst students completed the survey to provide emotional support if they were to find any questions distressing and for the interviews, the researcher present to provide support and/or seek a trusted adult to support the participant if appropriate. For the online interviews, the researcher had parental contact details in case these were needed.
Privacy and Confidentiality	Information sheets described the means of ensuring privacy and confidentiality to parents/carers and participants. Privacy and confidentiality were upheld through pseudonymising survey responses and storing the data in an access-controlled folder on an encrypted laptop. Following the quantitative analysis and interview phase

Ethical Consideration	Actions Taken
	recruitment, the data was then anonymised and no identifiable data was included in any reports.
Right to withdraw	The information sheets emphasised the right to withdraw from the study up to the point of data analysis. At the end of the survey and interview phases, debriefing information (see Appendix F.11 and F.12) was also provided to explain the purpose of the research, explain why participants were chosen and remind them of their right to withdraw their data.
Deception	The topic and general aims of the study were disclosed to participants in the information sheets and they received debriefs following each research phase. All participants received written debriefs and those who took part in the interviews were also debriefed verbally so that they had an opportunity to ask questions directly and discuss their contribution in more detail. Participants were reminded of their right to withdraw again at this stage.

### 3.3.4 Measures

#### ***Survey Phase***

##### *Anxiety Scale for Children – ASD – Child Version (ASC-ASD)*

Anxiety was measured with the Anxiety Scale for Children – ASD – Child Version (ASC-ASD) (Rodgers et al., 2016). This scale was derived from the Revised Children’s Anxiety and Depression Scale (RCADS, Chorpita et al., 2000) and designed to measure presentations of anxiety in autistic young people. The measure consists of 24 statements that describe different symptoms of anxiety and participants are instructed to rate these on a 4-point

Likert scale of frequency they experience the symptom. Following the guidelines for use, total scores less than 19 indicated likely non-significant anxiety levels and those greater than 24 indicated significant anxiety levels.

The ASC-ASD has been shown to have good validity, through high convergence with other measures of anxiety. Research has found that it is strongly correlated with the Screen for Child Anxiety Related Emotional Disorders (Birmaher et al., 1999) and moderately to strongly correlated with the Spence Child Anxiety Scale (Spence, 1998) (Rodgers et al., 2016; Den Houting et al., 2019). Good reliability has also been evidenced through excellent test-retest scores after one month and high internal consistency, with Cronbach's alpha scores of .94 (Rodgers et al., 2016). This suggests that the ASC-ASD is a well validated and appropriate tool to measure traits of anxiety.

#### *24-Item Social Provisions Scale*

Social support was measured through a version of the 24-Item Social Provisions Scale (SPS-24) (Cutrona & Russell, 1987) adapted to assess peer support for secondary school students. The survey consisted of 24 statements that were each rated by participants on a 4-point Likert scale of agreement. Items were counterbalanced to overcome social desirability effects, with half of the statements being positive and half being negative. Negative items were reversed coded when scoring and higher overall scores indicated that the individual was receiving a higher level of social support. For

this study, scores of 72 and over demonstrated high levels of social support as this would indicate that the participant on average agreed with all of the statements related to feeling socially supported.

The SPS-24 (Cutrona & Russell, 1987) has also received empirical support for validity and reliability. Internal consistency for the measure was found to be strong with Cronbach's alphas of .67 to .76 and support for construct validity was evidenced through moderate to high correlations between the SPS-24 and other measures of social support (Cutrona & Russell, 1987). Further research has found evidence of stability when investigating social support in adolescents, which means that the measure can also be used to assess change over time (Motl et al., 2004). This suggests that SPS-24 is a well-founded and reliable way of measuring social support.

The SPS-24 has not been standardised for use with autistic or adolescent populations, therefore was piloted by a group of four young people (three autistic and one neurotypical) who proposed adaptations to support their understanding. Adaptations were made to reference "peers" in line with the research questions and clarify aspects of the survey and terminology the young people in the pilot indicated were unclear. Additional information was added in the instructions for the survey and clarification of terminology was added in brackets to some of the questions. Although the adaptations made were minimal, it is acknowledged that any adaptation will influence reliability and validity of the measure. However, this was deemed necessary to ensure

that the terminology was accessible for autistic young people, thus supported the internal validity of the study by reducing the influence of potentially ambiguous language on the survey results.

### ***Interview Phase***

Following the sequential explanatory study design (Creswell et al., 2003), the results from the quantitative phase were analysed and interpreted before the qualitative phase was designed. Therefore, the development of RQ2 and RQ3 were informed by the results from the survey.

### ***Semi-Structured Interviews***

Semi-structured interviews were carried out with nine students whose survey responses indicated that they were experiencing clinically elevated levels of anxiety and high levels of social support. Four of the interviews took place in person in quiet rooms in the participants' schools and the remaining five took place online via Zoom. Decisions about the modality of the interviews were made collaboratively with the participants, based on their personal preferences and geographical locations.

The semi-structured interviews were carried out by the researcher, who had a pre-planned set of questions (see Appendix G.3 for interview schedule) that were asked in a conversational manner. This allowed the interviewee to explore issues that were important to them in greater depth (Longhurst, 2003). Semi-structured interviews were felt to be an appropriate method for

the qualitative data collection, based on their use of open questions and flexibility (Kallio et al., 2016). The theoretical flexibility of this approach fitted within a critical realist perspective and allowed for rich data to be gathered about the individual experiences that participants wanted to discuss to avoid participants feeling pressured to discuss topics they found distressing (Barker et al., 2016). The degree of flexibility afforded by the approach also allowed for unplanned clarification questions to be asked and adaptations to be made to make the interview more accessible for participants with communication differences. This is highlighted as an important feature of research designs for studies with autistic participants (Barker et al., 2016; Fayette & Bond, 2018; Tyrrell & Woods, 2020; Zanuttini, 2023).

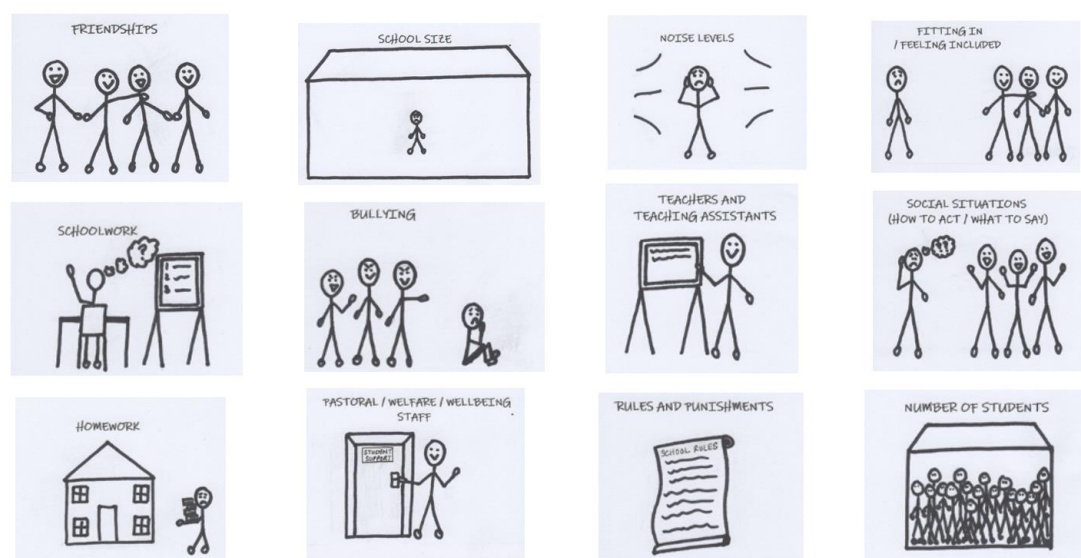
A five-step process, which involved identifying the research questions, retrieving previous knowledge, formulating an initial schedule, piloting and finalising the questions (Kallio et al., 2016) was used to develop the interview schedule. Previous knowledge gained through undertaking a literature review of qualitative research exploring the views from autistic students about the challenges of mainstream secondary school was utilised. This led to the development of 12 cards (see Figure 3.1) which were presented to the students for them to sort into piles of things they found worrying and not worrying about school. Students were given the cards as an additional tool for communication as studies exploring qualitative methods for eliciting autistic students' views about their education have highlighted the importance of utilising both verbal and non-verbal techniques to mitigate power

imbalances (Fayette & Bond, 2018; Tyrrell & Woods, 2020; Zanuttini, 2023).

This also served as a technique to optimise the elicitation of data, which research suggests increases participant comfort, reduces anxiety and supports the development of rapport when interviewing young people with disabilities (Teachman & Gibson, 2013; Tesfaye et al., 2019). From here, questions around the ways in which their peers might support these worries were posed, in line with RQ2. The initial interview schedule was piloted by two autistic young people who offered feedback related to the cards and questions which informed the development of the final schedule.

Figure 3.1.

### *Card Sorting Activity*



### *Drawing the 'Ideal Peer Group'*

The final part of the interview phase consisted of an adapted version of the 'drawing the ideal self' technique (Moran, 2001), where participants were asked to draw or discuss their 'ideal peers' to address RQ3. It was felt important to include an optional drawing component, as research suggests that many autistic people experience alexithymic difficulties with identifying and describing emotions (Milosavljevic et al., 2016) and drawings can elicit constructs that are difficult for many individuals to access verbally (Ravenette, 1988). Drawing techniques have also been utilised by previous research within semi-structured interviews to elicit autistic students' views on their experience of mainstream secondary school (Humphrey & Lewis, 2008; Tomlinson et al., 2021), therefore it was deemed an appropriate approach. However, drawing was presented as optional, based on student preferences, as research has highlighted the importance of actively involving participants in decision making around data collection for research eliciting autistic students' views about their educational experiences (Fayette & Bond, 2018; Tyrrell & Woods, 2020; Zanuttini, 2023).

### **3.3.5 Data Analysis**

#### ***Quantitative Analysis***

Within a statistical software platform, SPSS, perceived social support was entered as the independent variable and anxiety the dependent variable in a linear regression model. The quantitative analysis needed to explore the association between social support and anxiety and a linear regression was chosen as it creates a model from which predictions can be made. Some theoretical rationale was provided from previous research highlighting the impact of social isolation and bullying on wellbeing (Costley et al., 2021; Fortuna, 2014; Goodall, 2018; Goodall & MacKenzie, 2019; Humphrey & Lewis, 2008; Makin et al., 2017; Myles et al., 2019; Sproston et al., 2017; Tomlinson et al., 2021). Linear regression was also felt to be an appropriate method as it estimates the parameters in an equation that can be developed in future research by adding more predictor variables to a multiple regression model.

#### ***Qualitative Analysis***

For the qualitative data, the interviews were transcribed by the researcher and analysed by hand, following the paper outlined by Braun and Clarke for reflexive thematic analysis (Braun & Clarke, 2019). This paper emphasises that reflexive thematic analysis does not involve a rigid, linear set of stages that researchers must follow. However, the broad stages followed for the current review are presented in Table 3.4 for transparency. Full audit trails

that illustrate the application of reflexive thematic analysis, with relation to the quotes, codes, subthemes and themes for RQ2 and RQ3 can be found in Appendices H.2 and H.3.

To enhance the confirmability and dependability of the findings, brief researcher interpretations were fed back to the students during the interview to check that the participants' views were being accurately represented. This involved the researcher paraphrasing and summarising the students' responses to ensure they had been interpreted accurately and encouraging them to provide additional details if appropriate. In addition, when the themes were being reviewed, two post-graduate peers examined the participant quotes, codes and themes to explore the initial researcher interpretations. They also asked questions to review the extent to which these interpretations may have been influenced by the researcher's position and expectations. During this process, the peer reviewers posed questions around the naming and categorisation of codes and themes. These led to reflective discussions that supported the researcher to uncover some underlying assumptions that may have limited the initial analysis. This supported the reviewer to reconsider some of the initial interpretations in light of their position and supported the development of a richer analysis.

Table 3.4.

*Broad Stages of Reflexive Thematic Analysis*

1. Familiarising oneself with the data
2. Generating codes
3. Constructing initial themes
4. Reviewing initial themes
5. Defining and naming themes
6. Producing the report

The principles of Personal Construct Psychology (PCP) (Kelly, 1955; Moran, 2001) were also drawn upon to analyse the participants' comments and drawings associated with the 'ideal peers' activity. PCP is underpinned by the assumption that individuals interpret the world and make predictions about the future by applying 'constructs' or theories they have developed through their life (Moran, 2001). PCP was drawn upon throughout the activity to support the researcher to identify and name the potential constructs the participants held to facilitate a deeper understanding. This was largely communicated through paraphrasing and participant responses further supported the confirmability of the findings.

For the 'ideal peers' activity, participants were first asked to consider their 'non-ideal peers' and then their 'ideal peers'. The questions around their 'non-ideal peers' were included to support the interviewer to identify some of the constructs that the participants held. These were then explored further when they considered the opposing side of the constructs present in the 'ideal peers'. Questions around the 'non-ideal peers' also were also included as a prompt to support students to reflect on how their 'ideal peers' may appear, which may have been a more abstract concept for them. In this way, participant quotes from the 'non-ideal peers' questions were used in the interview to compare and probe further discussion around their 'ideal peers', though were not generally incorporated into the analysis, unless they presented new meaning that was not explored further.

### **3.4 Findings**

#### **3.4.1 Quantitative Analysis**

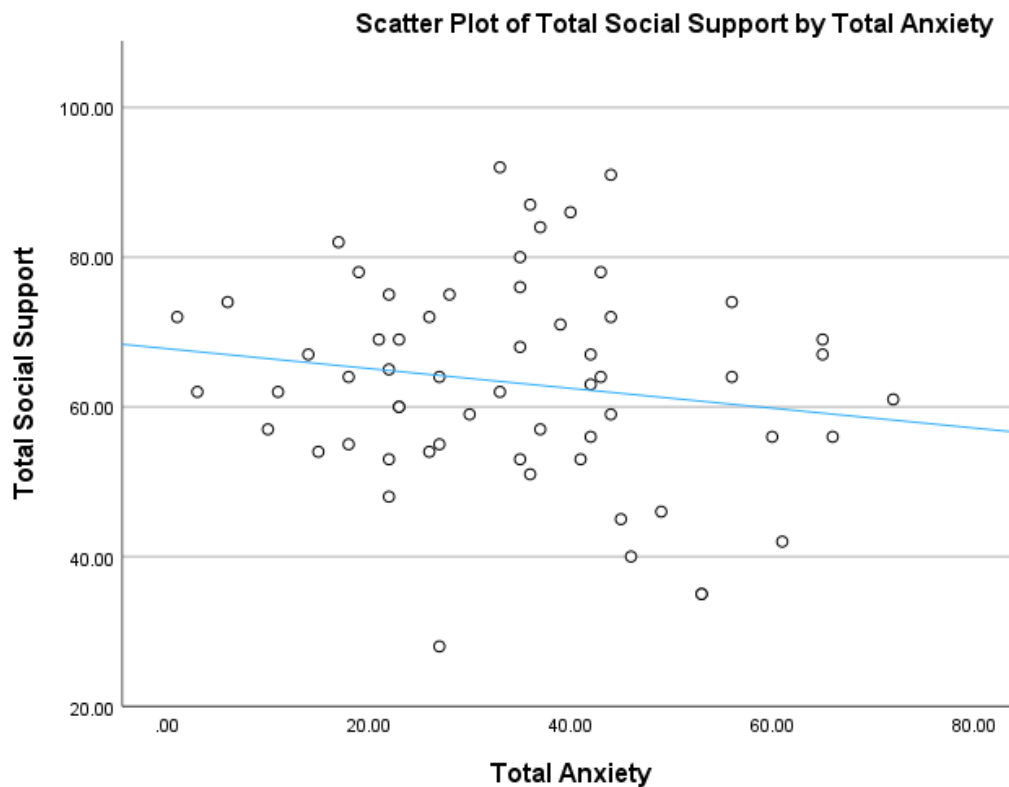
##### ***RQ1. Could social support be a protective factor for anxiety in autistic students?***

To address RQ1, linear regression was used to explore the relationship between the total scores for anxiety and social support calculated from participants' responses to the survey. For anxiety (ASC-ASD), the mean score was 34.81 (SD = 16.25) and range was 71. For social support (SPS-24), the mean score was 63.22 (SD = 13.70) and range was 64.

Social support was entered as the independent variable and anxiety the dependent variable, to investigate the proportion of variance in anxiety explained by social support. The assumptions for linear regression were checked to ensure that appropriate conclusions could be drawn from the results (Field, 2013). The data were normally distributed upon examination of a histogram and the assumption for linearity was assessed by visually examining a scatterplot that did not demonstrate any departures from linearity (see Figure 3.2). An outlier was identified upon this examination and was consequently removed for the remaining analysis. The assumption for homoscedasticity was inspected through plotting the regression standardised residuals and predicted values which demonstrated constant variance of error terms. Normality of error was assessed through examining the histogram of standardised residuals and calculating a Shapiro-Wilk statistic which both indicated normal distribution.

Figure 3.2.

*Scatterplot of the Relationship between Social Support and Anxiety*



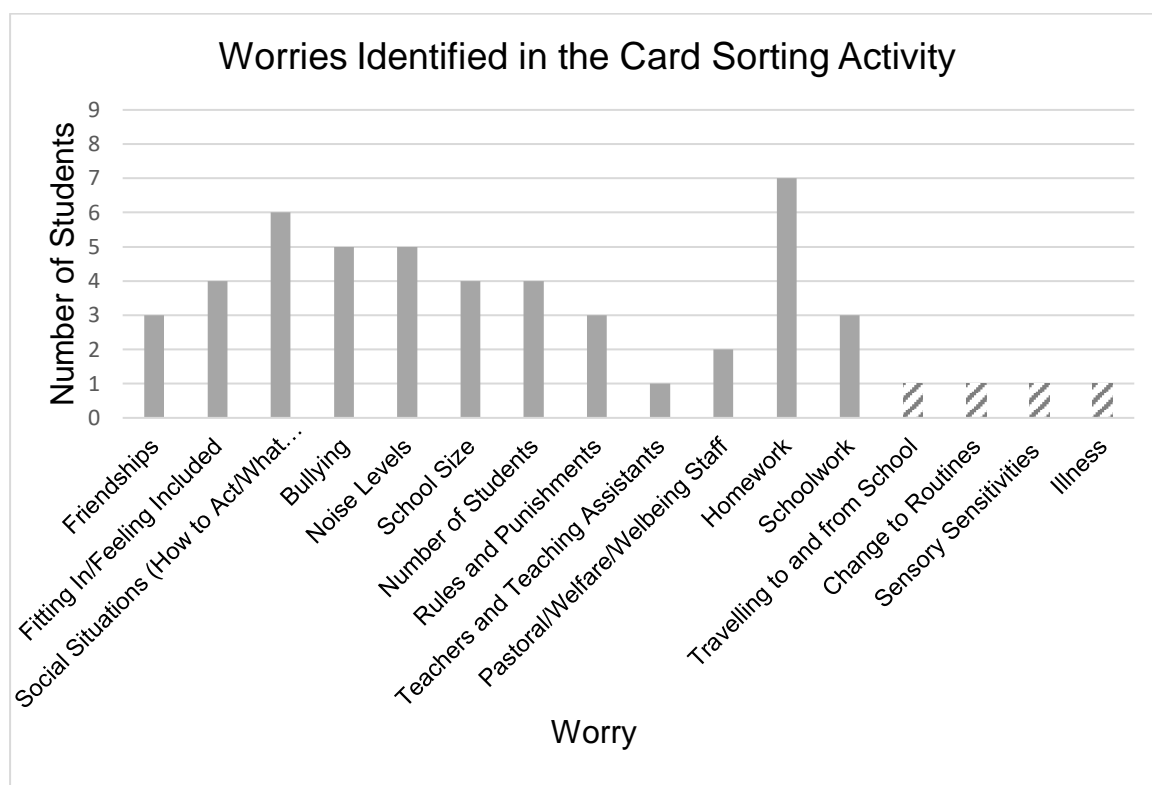
As the core assumptions were met, a linear regression was calculated to predict anxiety based on social support. A non-significant regression coefficient was found ( $F(1, 57) = 0.899, p = .347$ ) with an  $R^2$  of .016 and  $f^2$  of .016. This suggested that there was a small effect size (Cohen, 1988) and a non-significant relationship between the variables. Correlational analyses were also run to explore the relationships between age and social support and age and anxiety. The calculation revealed non-significant relationships between both age and anxiety  $r(57) = .00, p = .982$  and age and social support  $r(57) = .16, p = .235$ .

### **3.4.2 Qualitative Analysis**

The students' responses to the card sorting activity are presented below in Figure 3.3, as a means of illustrating the context of the worries that were referenced through the interviews. Bars with diagonal lines demonstrate additional worries the students identified about their school experience that were not represented by the cards. Themes from the discussions about the cards were not collated as it was not directly relevant for the research questions and previous research has explored this area (for instance, Costley et al., 2021; Fortuna, 2014; Goodall, 2018; Makin et al., 2017; Myles et al., 2019; Sproston et al., 2017; Tomlinson et al., 2021).

Figure 3.3.

*Participant Worries Identified in the Card Sorting Activity*



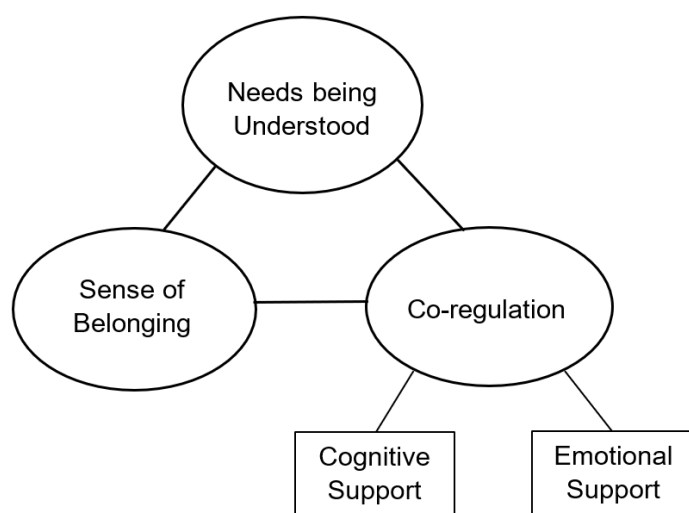
The findings from the reflexive thematic analysis (Braun & Clarke, 2019) are presented in relation to research questions two and three, respectively. For each of the research questions, a thematic map is presented to visually represent the themes before the narrative around each theme is described. In reflexive thematic analysis, a theme is identified as a “pattern of shared meaning” underpinned by a central concept within which multiple facets are brought together (Braun & Clarke, 2019). In this way, each theme is uniquely diverse with different ideas embedded within and subthemes are used

sparingly to identify particularly salient features, as opposed to differing perspectives within a theme.

***RQ2. In what ways can social support help autistic students cope with anxiety?***

Three themes and two subthemes were identified from the students' responses when they were asked about the ways in which social support from their peers helped them cope with their anxieties. The themes were identified as 'Sense of Belonging', 'Needs being Understood' and 'Co-regulation', with subthemes of 'Cognitive Support' and 'Emotional Support' emerging from the 'Co-regulation' theme. The themes are felt to represent unique, yet related variables that each address RQ2. The three themes are therefore positioned beside one another on the thematic map (see Figure 3.4), with interconnecting lines to illustrate the relationships between them.

Figure 3.4.  
*RQ2 Thematic Map*



### 'Sense of Belonging'

The first theme was understood as 'sense of belonging'. In the card sorting activity, almost all of the students identified worries around aspects of the social environment (friendships, fitting in, social situations and bullying). In the interviews, many of the students therefore described how they valued being actively included and accepted by groups of their peers and explained how this supported them to cope with anxieties about saying or doing the wrong things in social situations.

Students identified seemingly small acts, such as, peers playing football with them, sitting with them and listening to them talk about their interests as examples of the ways in which they felt included. Some students described how their friendships were particularly important to them as they felt that the school community was otherwise isolating, explaining that "*without them, I would just be alone to be honest, because no one really likes me like they do*". One student described how the social support he received reassured him that he would have people who could stand up for him if he experienced bullying, thus helped him cope with anxiety about being bullied.

Other students discussed examples of the ways in which social support helped them cope with specific anxieties about the school environment. One student who experienced emotionally based school avoidance, explained how peers texting her to check in and see whether she was going to be in school that day helped her feel valued and reduced her anxiety about

attending. Other students explained that some of their anxieties were common to their peers and spoke about the value of being able to talk about them to peers who could understand and relate to how they may be feeling. One young person expressed this by saying, *“friends tend to have more similar experiences, if I rant to a parent about school work they can understand but don’t have much to empathise with, but if it’s friends and people close to my age and experiences they can be like ‘oh yeah, I definitely know what that’s like’”*.

Some students also spoke about experiencing a sense of belonging in relation to feeling accepted and valued for who they are, which supported them to cope with anxiety about their identity. One student described how the social support he received from his peers helped improve his self-esteem and confidence, by saying, *“that friend has helped me know it’s ok to be yourself and just be who you are”*. Another student spoke about how her friends understood her so well that they thought that she was autistic before she did, which helped her cope with anxiety about openly identifying as autistic.

#### *‘Needs being Understood’*

Furthermore, the next theme was conceptualised as ‘needs being understood’. Almost all of the students referred to specific needs they have in school that cause them anxiety and many described ways in which their peers support these needs. In the card sorting task, the majority of students

identified worries around academic work (schoolwork and homework) and in the interviews, four students described ways in which their peers directly supported the academic needs they experienced. They gave different examples about the ways in which their peers helped them, for instance, offering them direct support in class, prompting them to concentrate and engage with learning or being able to contact them when revising at home. They described that while they still experienced anxiety around some of these needs, the understanding and support received from their peers helped them cope with some of the feelings associated with their anxiety.

Additionally, many students spoke about ways in which their peers advocated for their needs and described how this also helped them cope with their anxiety. For some of the students, this was through seemingly small gestures, for instance, one student said, *"I don't like going by myself to tell teachers what has happened so they go with me"*. However, for others, this involved peers actively identifying their anxiety and acting on their behalf to diffuse the anxiety-provoking situation when they were unable to do so. One student explained, *"if I am agitated and I go a bit non-verbal, my friend the other day as an example told the teacher what I wanted to say, she spoke for me but not in a bad sense, she helped"*. Other students described instances where their peers offered prompts or support with social situations they found anxiety-provoking, for instance, changing the subject of conversation to support their contributions and reduce feelings of discomfort. One student said, *"I think what I need a lot of the time is a prompt because maybe I don't*

*have the confidence to do something myself. I need a prompt and someone to say it's ok to interact with us".* Another student described how she has particular difficulties making friends and explained how her peers support her by explaining her needs to new people and introducing them to one another. She spoke about how this reduced the demands on her to initiate conversations, thus helped her cope with the social anxiety she experiences.

### 'Co-regulation'

The final theme for this research question is defined as 'co-regulation' and consists of subthemes related to 'cognitive support' and 'emotional support'. The term 'co-regulation' relates to attuned peer support that helps students regulate their nervous system in times of stress. This is described as a bidirectional and dynamic process that contributes towards emotional stability for both individuals in the interaction (Butler & Randall, 2013). 'Cognitive support' was conceptualised as peer support that helped students change the thinking that was contributing towards their anxiety. 'Emotional support' was understood as peer support that allowed students to express their emotions and feel listened to.

With regard to 'cognitive support', seven students spoke about their peers offering them advice or coping strategies to manage the physiological symptoms associated with their anxiety, for instance, going for a walk or stepping outside. The value of this support was summarised by one student, who acknowledged, *"I would be really really sad if I did not have my friends*

*and my worries would be a lot bigger*". Some students also described ways in which their peers used techniques to distract them and reduce their levels of worry, for instance, by making them laugh or offering reassuring comments. Additionally, three students gave examples of ways in which their peers used cognitive reframing to help them challenge their thoughts. One student described how this helped him rationalise his worries and explained that *"having someone to talk to helps you put things into perspective and think this isn't actually so bad"*. Another student said this often results in the realisation that, *"a lot of the time those things I was scared of aren't a big deal"*.

Conversely, for 'emotional support', students spoke more about the value of *"having people there to talk to"* and offload their worries to. Some students described this as being particularly comforting when they are in a high state of anxiety directly after incidents have occurred. For instance, one student outlined a recent anxiety-provoking situation and said, *"I was about to have a panic attack and then my friends just came over and helped me up with my stuff and sat with me until I got a little bit better"*. Others explained how their peers offered emotional check-ins when they perceived them to be emotionally dysregulated. One student said, *"they are very good at picking up when I'm not ok"*. Though, all examples outlined more passive approaches to co-regulation than the aforementioned 'cognitive support', as summarised by one student's reflection, *"there's not much they can do to mitigate the issue, but more of a shoulder to cry on"*.

### Summary

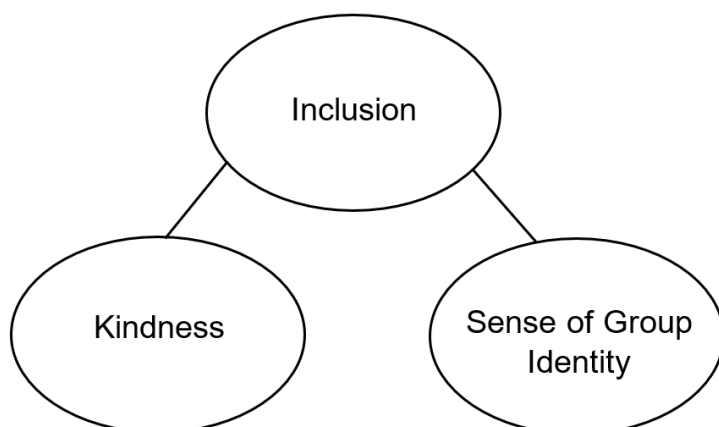
Together, these themes are felt to address RQ2 in a broad and comprehensive manner. The range of responses suggests that there is no single way in which social support helps autistic students cope with anxiety, but rather a combination of factors that are underpinned by central themes. These emphasise the value of the social support and are centred around students experiencing a sense of belonging in the peer group, feeling that their needs are understood and being co-regulated by their peers.

### ***RQ3. What contributes towards an ideal peer group for autistic students?***

Three themes emerged from students' responses to the 'ideal peers' activity. Only one of the students chose to draw for this activity and this illustration is presented within the analysis, alongside discussion around the comments he made and researcher interpretations. In addition, some students reflected upon peers they currently have and others used hypothetical examples, though comments from all students fed into the themes that were derived. These themes were conceptualised as 'inclusion', 'kindness' and 'sense of group identity'. The relationships between these themes are represented hierarchically on the thematic map (see Figure 3.5), with the 'kindness' and 'sense of group identity' themes contributing towards the 'inclusion' theme.

Figure 3.5.

*RQ3 Thematic Map*



*Kindness*

The first theme was identified as ‘kindness’ and views from six students contributed towards it. Within this theme, students spoke about how their ideal peers would be considerate in *“thinking about stuff before they say it”* and act in ways that would make others happy. One student described how this may be delivered through compliments, such as peers commenting on their appearance when they have made the effort to look nice. Others explained that their ‘ideal peers’ would be *“caring”, “understanding and nice towards everyone in the group and other people outside of the group”*.

Four students also spoke about their ‘ideal peers’ being respectful towards others, for instance, *“not picking fights”*, being polite to other students or teachers and letting others talk in conversations. Two students also discussed the ways in which their peers’ humour would be kind. Both of

these students referred to the humour not being centred around targeting other people and one student described this as, *“their humour is not based on them judging other people or making fun of people, not based on someone’s appearance and how they act”*.

Conversely, other students positioned kindness as their peers being available for them when they were experiencing difficulties, such as, low mood or anxiety. One student spoke about how his ideal peers would support his needs *“even if they might not know about autism”*. Others discussed how they would be able to rely on their peers for support in times of need and explained how even seemingly small comments would suffice in reassuring them that their peers were available to support them. One student summarised this by saying, *“the kind of group that would always be there for you no matter what’s happening”*.

### Sense of Group Identity

The second theme was conceptualised as a ‘sense of group identity’ and consisted of views from five students. These students all gave examples about the things their ideal peer group would have in common that would unite them and support their shared identity. For one student, this was based on tangible things, such as sharing food and having the same fashion sense. For others, this was centred around their peers having shared interests and hobbies for instance, one student explained, *“we’re all obsessed with*

*stickers... and we all do sticker trading*". Another student who spoke about her hobbies emphasised, *"this is a really kind of big thing for me"*.

However, another student described how it was not important to her whether her peers had shared interests, but it was more about them sharing ethics and morals. She explained that within her friendship group, *"there is a kind of structure and establishment about what's right and what's wrong that we are all in agreement on"*. Another student also reflected on this idea and explained that it was important to him as he worried that due to the anxiety he experiences around not being accepted, he may go along with what his peers were doing, even if he felt this was wrong. He said, *"I would find it hard to say no to people who were peer pressuring me through fear of either being left out or not accepted"*.

Additionally, two students spoke about how their ideal peer group would contain other neurodivergent people. They described how this would support their peers to understand their needs and anxieties, as they may have experienced similar difficulties themselves, such as sensory sensitivities. One student shared, *"I have a friend in the school who also has autism and she kind of has the same thing as me because she also has the sensitive hearing stuff"*. Another student also spoke about how this understanding could support her to cope with her anxieties through humour. She explained that she found it helpful to laugh about some of her difficulties and felt that

neurotypical people may struggle to understand and misinterpret this as her being *"a really mean person"*.

### Inclusion

The third theme was identified as 'inclusion' and views from five students fed into this theme. These students described their ideal peer group as consisting of a *"variety of people"* and emphasised that their peers would be non-judgemental and *"very open"*. This corresponds with the idea of inclusivity described in the 'kindness' theme. Openness was referenced in relation to students being open and honest about who they are and not pretending to be someone different and also being *"very open to new things and not saying, that's different so it's automatically bad"*. Similarly, two students reflected on how it would be important that they felt comfortable to be themselves and one of these students discussed this with relation to masking behaviours. She described how it would be important that there was at least one peer she had *"known for a really long time or felt one hundred percent stress free around"* so that she could relax in front of them and not need to suppress behaviours she finds comforting. She explicitly spoke about *"masking"* and said, *"there are not that many people I feel relaxed around"*.

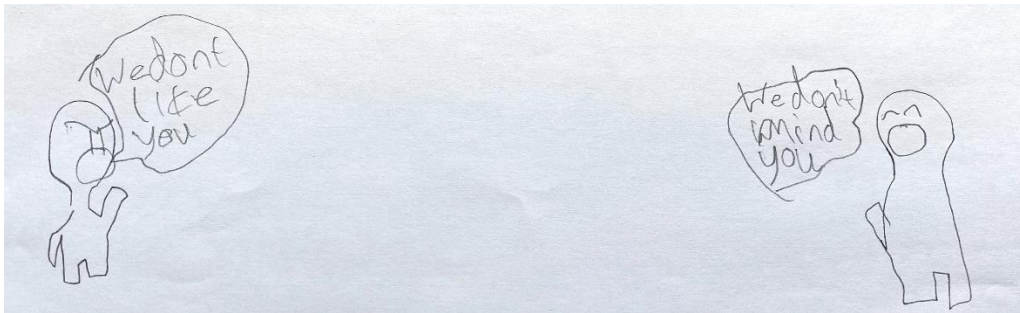
Furthermore, four students spoke about their ideal peers being accepting of different people. One student discussed this with relation to his peers allowing him to join in their football and rugby games, linking to the ideas presented around having common interests in the 'sense of shared identity'

theme. Another student spoke about his ideal peers not only accepting people's differences, but also celebrating them. He explained this as his peers, "*being tolerant and accepting of people's differences and in a way celebrating that and just saying you have different strengths and I have different strengths and just get along*". The idea of celebrating difference was conceptualised as a higher order form of inclusion than simply accepting difference.

However, other students spoke more about peers simply tolerating them. The student who drew his ideal peer group described how his ideal peers would not "*mind*" how he felt or appeared or whether he was similar to or different from them (see Figure 3.6). This image is particularly interesting as it presents the bipolar construct the student holds around what inclusion might look like. His 'non-ideal' peers are presented as an angry character, saying, "*we don't like you*", whereas his 'ideal peers' are shown as a happy character, though, rather than including an opposing statement, such as "*we like you*", he has depicted the character saying, "*we don't mind you*". This was felt to be a particularly powerful quote, demonstrating that in an ideal world for this student, he would not be celebrated or liked, but simply tolerated.

Figure 3.6.

*One Student's Drawings of his 'Non-Ideal Peers' (left) and 'Ideal Peers' (right)*



### Summary

Overall, these findings were felt to answer RQ3 by illuminating a variety of individual responses which were underpinned by central themes. The breadth of responses again demonstrates that autistic students are not a homogenous group, thus, there is not one 'ideal' peer group common to all autistic students. However, the importance of kindness and experiencing a sense of group identity were recognised as common themes across responses. These contributed towards the broader theme of inclusion, therefore, the concept of 'inclusion' is felt to most comprehensively answer the research question.

## **3.5 Discussion**

The aim of the current study was to explore the relationship between social support and anxiety for autistic students in mainstream secondary schools.

Interpretations of the findings related to each research question are presented below, with reference to theory and previous research.

### **3.5.1 Interpretation of the Findings**

#### ***RQ1. Could social support be a protective factor for anxiety in autistic students?***

The quantitative results suggested that social support did not significantly predict variance in anxiety, thus rejected the alternative hypothesis that social support was a protective factor for anxiety. Although no known research has investigated the association between perceived social support and anxiety in autistic students previously, this finding was surprising given that research has found loneliness and fewer friends to be associated with increased anxiety in autistic adults (Mazurek, 2014). It also contrasted with the findings from qualitative research that identified feeling unsupported and misunderstood by peers as key barriers to belonging and psychological wellbeing (Costley et al., 2021; Goodall, 2018; Goodall & MacKenzie, 2019; Humphrey & Lewis, 2008; Makin et al., 2017; Myles et al., 2019; Tomlinson et al., 2021).

It is acknowledged that statistical significance is dependent on sample size (Sullivan & Feinn, 2012) and the current study did not meet the required sample of 85 participants calculated in the power analysis. A small effect size was calculated from the R-squared value, which suggested that there was unlikely to be a meaningful relationship between social support and anxiety.

Though, it is possible that the sample was not large enough to produce a significant result and future research could seek to explore the relationship between social support and anxiety with larger samples of autistic young people. However, it should also be reemphasised that autistic students are not a homogenous group. Therefore, it is possible that the protective role of social support upon anxiety is different for each individual. This would explain the results found in the analysis, though, it remains speculative and RQ2 was devised with the assumption that social support was not a protective factor for anxiety.

To define RQ2, the data from the survey was visually inspected to consider the ways in which social support and anxiety may interact. It was particularly noticeable that a proportion of students reported both high levels of social support and anxiety. This explained the finding that social support was not a protective factor for anxiety. However, previous research has found that autistic students often experience lower levels of school connectedness and higher social isolation than their neurotypical peers and associated this with poorer mental wellbeing outcomes (Goodall, 2018; Hebron, 2018). This suggests that social support is likely to have some positive influence over anxiety. Therefore, RQ2 was posed with the understanding that while social support may not 'protect' students from anxiety, it may support them to cope with it.

***RQ2. In what ways can social support help autistic students cope with anxiety?***

Three main themes emerged from the thematic analysis for RQ2. These were conceptualised as: 'sense of belonging', 'needs being understood' and 'co-regulation', which was further split into subthemes of 'emotional support' and 'cognitive support'.

The first theme was understood as 'sense of belonging'. Within this theme, students spoke about the feelings of isolation they had experienced in school and described how being actively included by their peers supported them to cope with their anxieties about social situations. This aligns with previous qualitative research that has highlighted the positive influence of social support in helping autistic students feel safer and more confident to cope with anxiety in mainstream secondary school (Costley et al., 2021; Dillon et al., 2016; Myles et al., 2019). Difficulties with social communication are part of the diagnostic criteria for autism (American Psychiatric Association, 2013), therefore, it was perhaps unsurprising that a high number of the students reported feeling anxious about social situations. One student described how some of the anxieties he experienced were common to his peers and discussed the value of being able to talk to people who could relate to him. This is consistent with research that has explored sources of social support and identified that those who are socially similar and have faced the same stressors are the most empathetically understanding and best placed to provide effective support (Thoits, 1989).

Furthermore, it was interesting to discover that the support that many students felt they benefitted from was that which led them to feel accepted and valued for their authentic selves. One student reflected on how this helped her feel more comfortable openly identifying as autistic, thus reduced the need for her to mask her autism. This corresponds with research that has found positive autistic social identity to be associated with reduced anxiety in autistic adults and extends the finding to include autistic young people (Cooper et al., 2017). It also relates to recent research into the area of 'autistic burnout', which has been described as a debilitating condition many autistic individuals experience, associated with chronic exhaustion and reduced functioning (Higgins et al., 2021). Research with autistic adults has associated autistic burnout with a lack of empathy from neurotypical people, in line with the Double Empathy Problem (Milton, 2012). This has identified that burnout often occurs following extended periods where individuals mask their autistic traits and behaviours and identified social support as a key factor that facilitates recovery (Mantzas et al., 2022; Mantzas et al., 2022b; Raymaker et al., 2020).

The second theme was conceptualised as 'needs being understood'. In this theme, students discussed their worries about specific difficulties they experienced in school and the ways in which their peers supported them. Some students described how their peers offered direct support to reduce the difficulties they experienced, for instance, assistance with academic work, whereas others outlined ways in which their peers advocated for their needs

when they perceived them to be anxious. This involved peers actively identifying their anxiety and acting on their behalf to reduce the anxiety-provoking situation, for instance, offering prompts in social situations. This finding supports research demonstrating the positive impact of peer understanding on attitudes towards autism (Brosnan & Mills, 2016). It also supports the suggestions made by the Reciprocal Effects Peer Interaction Model (Humphrey & Symes, 2011). This demonstrates how autistic students' social communication difficulties can be further compounded by a lack of understanding and inclusion from their peers, which negatively impacts the social support they receive and their mental wellbeing.

The final theme was defined as 'co-regulation' and was made up of subthemes labelled 'cognitive support' and 'emotional support'. 'Cognitive support' was understood as support that helped students manage their anxiety symptoms and this was often discussed with reference to specific advice, coping strategies or methods of distraction. Some students also spoke about their peers using cognitive reframing to help them challenge their anxious thoughts and rationalise their worries, which is a technique commonly used in cognitive behavioural therapy approaches for young people (Stallard, 2005). Conversely, 'emotional support' was spoken about in relation to peers being available to listen to the students worries and provide a "*shoulder to cry on*" and was felt to be particularly helpful immediately after anxiety-provoking situations. This fits the temporal order of effective social support outlined by previous research, which identified emotional support as

being required in the time of crisis prior to cognitive support (Jacobson, 1986).

Early research into social provisions identified both cognitive and emotional support as fundamental components of social support that individuals need to cope with stressful situations (Caplan, 1964). The findings related to the 'co-regulation' theme therefore suggest that autistic students are no exception and experience this need in the same way as neurotypical people. However, the views presented in the aforementioned themes related to anxieties around social situations suggest that autistic students may have difficulties actively seeking out this support from their peers. This emphasises the value of peers understanding their needs so that they can advocate for them and support them through anxiety-provoking situations.

Additionally, although the themes are categorised independently, they are represented in the thematic map (see Figure 3.3) with interconnecting lines, which demonstrate the reciprocal impact that each theme has on the next. Having their needs understood supported students to experience a sense of belonging and helped their peers co-regulate. In turn, being supported by their peers helped students feel understood and experience a greater sense of belonging. Together, these findings fit within the social model of disability (Oliver, 1996), as they demonstrate the powerful influence of social support on autistic students' ability to cope with anxiety. They also suggest that the anxiety autistic students experience is amplified by their environment and

highlight ways in which small environmental adaptations enable them to cope with their anxiety which was otherwise disabling.

***RQ3. What contributes towards an ideal peer group for autistic students?***

Three main themes also emerged from the thematic analysis for RQ3. These were labelled: 'kindness', 'sense of group identity' and 'inclusion'. These themes were represented hierarchically on the thematic map (see Figure 3.4), as it was felt that the 'kindness' and 'sense of group identity' contributed towards 'inclusion', whilst still retaining sufficient nuances to justify them being themes rather than sub-themes.

The first theme was conceptualised as 'kindness'. In this theme, some students discussed kindness in terms of their peers being considerate, caring and respectful towards others. Some students also described their peers' humour as kind, with it not being centred around targeting specific individuals for how they appear or act. This supports previous research that identified 'minority status' as a key difficulty autistic people faced when socialising with neurotypical people (Crompton et al., 2020). Conversely, other students couched kindness in terms of their peers being reliable and available to comfort them in times of need, akin to the 'emotional support' described within the 'co-regulation' theme for RQ2.

The second theme was understood as 'sense of group identity' and within this theme, students gave examples about different commonalities they

would have with their peers that would contribute towards a shared identity. Some students described having common interests and hobbies, which corresponds with research that has found motivation to engage with special interests to be associated with social contact and subjective wellbeing in autistic individuals (Grove et al., 2018). Another student described having the same ethics and morals as their ideal peers and discussed this in terms of a collective understanding and agreement about what is right and wrong. This comes with the presumption that their peers' views and behaviour would be more foreseeable, therefore links to the suggestions made by the 'Intolerance of Uncertainty' theory that autistic individuals prefer predictability and find it difficult to cope with the unexpected (Buhr & Dugas, 2009; Pellicano & Burr, 2012).

Additionally, two students described how their ideal peer group would contain other neurodivergent students and discussed the value of these peers having a shared understanding about some of the anxieties they experience. This is consistent with research that identified "within-neurotype understanding" as central themes that influenced a sense of belonging and psychological wellbeing for autistic people and explored the idea of autism-specific peer support (Crompton et al., 2020; Crompton et al., 2022). It also supports the aforementioned research around positive autistic social identity (Cooper, Smith & Russell, 2017) and the suggestion that this may reduce instances of 'autistic burnout' following periods of masking (Higgins et al., 2021; Mantzalas et al., 2022; Mantzalas et al., 2022b; Raymaker et al., 2020).

Together with the findings from these studies, this theme provides further evidence for the 'double empathy problem' which suggests that individuals who experience the world differently find it difficult to empathise with one another (Milton, 2012). This positions autistic individuals' 'Theory of Mind' difficulties as a product of them existing in a largely neurotypical society. This theory also therefore suggests that autistic individuals experience a disproportionately low level of empathy from their neurotypical peers, so it is unsurprising that the students expressed a desire for other neurodivergent individuals to be part of their peer group.

The final theme was named 'inclusion' and this was felt to correspond with many of the facets of the 'kindness' and 'sense of group identity' themes. Within this theme, students spoke about their ideal peers being welcoming, non-judgemental and open to different people, which relates to the ideas presented in the 'kindness' theme around peers being considerate of others' feelings. Students also described how this would enable them to be their authentic selves and reduce their need to mask, which research has associated with improved wellbeing for autistic individuals (Cage et al., 2022). This again also relates to the research around 'autistic burnout' and the protective influence of positive autistic social identity on wellbeing (Cooper et al., 2017; Higgins et al., 2021; Mantzalas et al., 2022; Mantzalas et al., 2022b; Raymaker et al., 2020).

Though, interestingly, the ways in which students conceived the idea of 'inclusion' was vastly different. Some students described inclusion in terms of acceptance and one student extended this idea by explaining that his ideal peers actively celebrate difference and focus on strengths. This ideology aligns with the neurodiversity movement that views autistic difference as part of natural variation and rejects ideology behind interventions that seek to 'normalise' autistic individuals (Den Houting, 2019). This also links to the 'needs being understood' theme for RQ2 and supports research demonstrating the positive impact of peer understanding on attitudes towards autism (Brosnan & Mills, 2016). In this way, it also extends findings from previous research that has explored the value of social support from other autistic students (Crompton et al., 2020; Crompton et al., 2022) in suggesting that features of effective peer support are not necessarily unique to autistic peers, but can also be provided by neurotypical peers, provided they understand the autistic student's needs and celebrate their strengths. However, a number of students referenced inclusion in terms of tolerance and one student encapsulated this idea within a drawing of his non-ideal and ideal peer groups next to one another, with the quotes "*we don't like you*" and "*we don't mind you*", respectively (see Figure 3.5). This illustration was a powerful representation, portraying the idea that the student's ideal peers would not necessarily understand or celebrate him, but would simply tolerate him.

The contrast between the ways in which the students conceptualised the idea of inclusion suggested that there were vast differences in the extent to which their strengths and needs were acknowledged and supported by their peers. This links to the Reciprocal Effects Peer Interaction Model, which suggests that a lack of understanding from peers makes social communication more difficult for autistic students, which negatively impacts the social support they receive and their mental wellbeing (Humphrey & Symes, 2011). This finding is of high importance, given the disproportionately high number of autistic young people with mental health difficulties (Crane et al., 2017) and the findings from RQ2 which demonstrate the positive influence peer support can have on mental wellbeing.

### **3.5.2 Reflexivity**

The principle of reflexivity was actively considered throughout the research process. Keeping a reflective journal from the point of developing the first research proposal to writing this empirical paper was a particularly useful tool to facilitate reflexivity. Writing entries in the journal prompted me to keep an active account of the developments in my thought processes that influenced decision making and gave insight into the position I held that underpinned my motivation to undertake the research. This helped to bring the expectations I had for the research into my awareness, which were important to unveil as they influenced the way in which I interpreting and disseminating the findings. Particular consideration was given to my own experience of growing up in a neurodiverse family. This motivated and supported me to engage with a high

level of enthusiasm through each stage of the research process. However, I also remained mindful that the way in which I interpreted the findings was influenced by my own family members' experiences in school. I ensured to actively reflect on this to keep it in my awareness when interpreting the interviews in particular.

Moreover, the diary was used to make reflections following each of the interviews (see Appendix H2), which I revisited to actively review and challenge the assumptions I had made when coding and conceptualising the themes. I found that in attempting to accurately reflect the students' views, many of the initial themes I constructed aligned with the immediate impressions I took from the interviews and often closely reflected participant quotes. While this demonstrated a level of traceability in the data, it indicated that the initial themes represented a superficial understanding of what was discussed and did not embody the complexity of the participants' experiences. At this stage, I found it useful to come away from the data for a short period and revisit the audio recordings to challenge the assumptions I had made and facilitate deeper interpretations of the transcripts. I also found it helpful to review my interpretations with peers, who challenged the assumptions I had made, with understanding of my lived experiences, and suggested different ways I could develop the initial themes. This supported me to reflect on the ways in which my position and expectations had influenced my initial analysis and develop the codes and themes to be more interpretive.

Through the research process, I came to understand that my desire to advocate for autistic young people's voices had initially made me cautious about labelling the themes in my own words, through fear of misrepresenting the students' views. This concern about my position as a researcher influencing the data had made me conscious to stay close to the initial transcripts and led to the development of highly descriptive themes. Once I became aware of this, I was able to return to the transcripts and re-code sections of the data to depict a deeper level of meaning which changed the way I understood the themes. I feel that engaging in this research has further developed my passion for promoting autism understanding through eliciting autistic viewpoints. It has also given me greater insight into the ways in which being raised in a neurodiverse family have influenced my values and how these interact to inform my work as both a researcher and an EP.

### **3.5.3 Strengths, Limitations and Future Research**

The study is considered to have numerous strengths, as well as some limitations that inform suggestions for future research.

#### ***Strengths***

The use of a mixed-methods approach was considered a key strength in enabling the research to explore the relationship between social support and anxiety through different lenses. This fit within the epistemological position of the research and has been identified as an appropriate approach to counterbalance the relative strengths and limitations of quantitative and

qualitative research, respectively (Shannon-Baker, 2016). Some previous studies have utilised mixed methods approaches to explore experiences of autistic students in mainstream education (Dillon et al., 2016; Fortuna, 2014; Makin et al., 2017). However, there has been an overall lack of meaningful participation from autistic individuals in research that has informed autism practice (Fletcher-Watson et al., 2019). There is a tendency for research to utilise neurotypical stakeholder perspectives to illuminate the autistic experience, which has provoked discussion and the development of protocol to promote the inclusion of autistic voices in research (Lebenhagen, 2020; Courchesne et al., 2022). Therefore, eliciting views directly from autistic students is viewed as a significant strength of the current research that should be utilised by future studies to unveil new insights into the lived experiences of autistic students and amplify their voices.

There is also no known research that explores the association between social support and anxiety in autistic students. This is likely to, at least in part, stem from historic misconceptions around autistic individuals having a “basic desire for aloneness” (Kanner, 1943) and the more current position held by deficit-focused autism research carried out by neurotypical researchers that has sought to medicalise autistic differences. The current research, instead, aligns with the social model of disability, which posits that individuals are disabled by their environment not accommodating their needs, rather than a within-person factor (Oliver, 1996). This broadened the scope of the research and allowed for the inclusion of social support as an environmental factor in

exploring the contributors for anxiety. It also provided further justification for the use of a mixed methods approach, as the quantitative phase provided helpful scoping in an otherwise unexplored field. This facilitated the development of a focused qualitative phase that targeted specific research questions.

Moreover, with relation to the sample, female participants made up 40% of the survey participants, which was largely credit to the targeted recruitment drive to female-only schools. This was felt to be a particularly important strength as research has highlighted the general underrepresentation of females in autism research and emphasised the issues this poses with regard to the development of male-biased diagnostic criteria (Dillon et al., 2021). With the understanding that the diagnostic criteria are biased towards male presentations, future research should consider similar approaches of targeted recruitment of autistic females to strive towards equal representation. It is also of note that some students identified with genders other than male or female, which is consistent with research highlighting the representation of gender diversity in the autism community (Lai et al., 2015). Open options for gender identification were presented to the students in the survey and clarification questions were posed to ascertain desired pronouns in the interview. This was recognised by a number of students as a strength of the study, which reinforces the idea that gender identity and diversity should be actively considered and respected in research.

In addition, students also gave feedback that they valued the flexibility afforded to them throughout the interviews. This included a choice over whether the interview was delivered online or in person, which was felt to be an important feature of the study, as research has highlighted the importance of actively involving autistic students in decision making when eliciting their views about their educational experiences (Fayette & Bond, 2018; Tyrrell & Woods, 2020; Zanuttini, 2023). However, the interview approach was consistent across the in-person and online interviews and included flexibility around the verbal and non-verbal communication, which is also recommended when eliciting views from autistic young people and those with disabilities in research (Fayette & Bond, 2018; Tyrrell & Woods, 2020; Zanuttini, 2023; Teachman & Gibson, 2013; Tesfaye et al., 2019). This approach is also advocated in protocols promoting the elicitation of autistic voices in research, that have identified the flexibility of the semi-structured approach and varied response modalities as key tools to facilitate communication (Lebenhagen, 2020; Courchesne et al., 2022). Such protocols should be utilised when designing future qualitative research with autistic young people, though implemented flexibly depending on individual preferences, with the understanding that autistic individuals are not a homogenous group.

### ***Limitations***

With regard to limitations, the sample size for the quantitative phase fell short of the 85 participants required, as identified through the power analysis,

which impacted the likelihood of finding a significant result. This facilitated a discussion around the practical significance of the results, which carried a suggestion that future research with a larger sample size may be warranted.

In addition, while the uses of the ASC-ASD and SPS-24 were justified with relation to previous research, there still exist issues around potential measurement error. High internal consistency estimates were calculated from the participants' responses, however it is possible that the participants misunderstood or misinterpreted the questions consistently across the survey, which would have impacted the quantitative results found. This was less likely to be the case for the ASC-ASD, as it was designed specifically to measure anxiety in autistic young people. However, the SPS-24 was not standardised across autistic populations and was adapted by the researcher for use with autistic young people, which posed greater risks to the validity and reliability of the measure. One way to reduce this potential measurement error would have been for the participants to complete the survey in the presence of a researcher. This would have allowed the participants to ask questions and the researcher to provide clarification to ensure that each participant understood what they were being asked. This approach was not feasible for the present research, given time and resource constraints, though should be considered in future research.

Moreover, with regard to the qualitative research methods, some of the interviews were carried out online. The use of video conferencing software

for research has been criticised due to it inhibiting researchers from perceiving subtle body language cues (Gray et al., 2020). Therefore, this could have posed a barrier to gaining deeper insights in the online interviews and biased the interpretation towards the in-person findings, which future research utilising online methods should consider.

Furthermore, there are also potential issues of trustworthiness in relation to the qualitative analysis. The researcher reflected their interpretations back to the participants through the interviews to check their accuracy and was supported by peers to consider the extent to which their position as a researcher influenced the analysis. However, the final themes and subthemes were not reviewed by the participants. Member checking is not recommended for reflexive thematic analysis, as it does not align with the conceptual and theoretical assumptions of the approach (Braun & Clarke, 2023). However, issues of trustworthiness could have been reduced by recruiting autistic co-researchers to support with the analysis. This participatory approach has been adopted by recent research that has outlined its benefits in supporting the credibility and confirmability of the research findings (Costley et al., 2022). Therefore, future research should seek to employ participatory methods where appropriate and feasible.

### ***Future Research Priorities***

Overall, the current findings support and extend those from previous research by illuminating voices from autistic students that identify features of

effective social support and explore how these can help them cope with anxiety. However, the extent to which effective social support promotes long-term psychological wellbeing and mitigates the development of future serious mental health difficulties for autistic young people remains unclear. Autistic young adults experience disproportionately high levels of mental health difficulties, even when their life outcomes, such as, employment and independence are considered to be 'good' and there remains significantly higher rates of suicidal ideation and behaviour (Gotham et al., 2015; Cassidy et al., 2014; Hirvikoski et al., 2016). Unsurprisingly, understanding autism across the lifespan and the relationship between autism and mental health have been identified as research priorities by the autism community (Roche, Adams & Clark, 2021). Therefore, current findings would be developed by future large-scale longitudinal research exploring the association between secondary school social support and serious mental health difficulties in young autistic adults.

### **3.5.4 Implications for Professional Practice**

Regarding the implications for professional practice, EPs should seek to disseminate the research findings to education settings through training and resources to promote greater autism understanding for both staff and students. EPs generally work across various settings so are ideally placed to share ideas between schools and facilitate working groups of staff to promote positive change. This should be developed on the premise that social support is a fundamental human need that autistic students are not exempt from,

even if they present with social communication difficulties. Though, it should also seek to gain views from autistic students and actively involve them in decision making around the support provided.

One particular avenue for intervention development is around promoting peer understanding and inclusion, as many of the ideas discussed in the themes related to the importance of autistic students feeling understood and valued by their peers. Interventions exist to promote the active inclusion of vulnerable groups of students, such as Circle of Friends, and research has highlighted the positive impact this can have on peer acceptance (Frederickson & Turner, 2003). However, a review of the evidence-base has highlighted implementation differences and methodological weaknesses in some studies evaluating its effectiveness, which make it difficult to understand the true impact of the intervention (Hassani et al., 2021).

Furthermore, other interventions focus on actively promoting social support through peer mentoring. One study described an approach where autistic students formed part of a peer mentoring group, where they acted as both the mentor and mentee (Bradley, 2016). This was developed following research highlighting the positive impact being a mentor can have on wellbeing (Mentoring and Befriending Foundation, 2010) and some promising findings emerged, with regard to self-esteem, inclusion, awareness of support systems and reduced loneliness. This type of intervention could promote co-regulation and support the development of a sense of group

identity, as well as positive autistic social identity for autistic students.

Though the need for close monitoring and evaluation with the students involved in such interventions is paramount.

Moreover, a further role for EPs is to explore the concept of 'true inclusion' with schools and support processes of systemic change to facilitate it. EPs should work with individual schools as partners to gather and analyse views from autistic individuals within their settings. These should be considered at both individual and organisational levels and systematically evaluated with regard to the culture and climate of peer support in their unique settings. EPs are ideally placed to facilitate such projects by drawing upon psychological theories and approaches, such as, systems thinking and Soft Systems Methodology (Checkland, 1981; 1990; Frederickson, 2013) to frame the process and support reflection. This can be used to promote the positive features that already exist within the settings and intervene to address the areas that are identified as requiring further development.

One particular area that warrants consideration from schools is the autistic social identity their autistic students experience. EPs can support schools to consider the factors within their settings that may be inhibiting the development of positive autistic social identity and generate ideas to change these. This would be highly dependent on the individual settings. Though, ideas for strategies that schools could consider might involve students being supported to set up clubs related to their special interests, where they can

meet other students with common interests or specific neurodivergent groups for students who would like to learn more about their own or others' neurodiversity. These types of changes are likely to feel manageable to schools, though would support the development of a more understanding culture, where autistic students are encouraged to be their unique selves.

Together, with the development of EP practice, teaching and pedagogy, the findings from the current study also have the potential to influence local government guidance on best practice for supporting autistic students within mainstream education. In addition, identifying the 'factors associated with pupil wellbeing' and types of approaches that support 'better outcomes for condition-specific needs in mainstream schooling' are currently listed as areas of DfE research interest (DfE, 2018). Therefore, it is hoped that this research could also lead to recognition from the Department for Education (DfE) of the value of social support for autistic students and the importance of continued research in this area.

### **3.5.5 Conclusion**

The current study aimed to explore the relationship between social support and anxiety for autistic students in mainstream secondary school, which no known research has investigated before. The results suggested that while social support is unlikely to be a 'protective factor' for anxiety, effective social support can help students cope with anxiety, which is likely to positively influence their life outcomes. The qualitative findings explored the themes

that can underpin effective social support and gave insight into the features of an 'ideal' peer group. These findings support and extend those from previous research and have implications for EP practice, teaching, pedagogy and local government guidance.

Overall, the findings from the research fit within the social model of disability (Oliver, 1996). They demonstrate the powerful influence social support can have, not only on autistic students' emotional wellbeing, but also on their positive autistic social identity. It is hoped that this research will contribute towards the growing body of evidence supporting the neurodiversity movement. It aims to challenge some of the outdated and unhelpful stereotypes painted in early literature, with the ultimate aim of supporting mental health and life outcomes for autistic people.

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## **Chapter 4: Dissemination and Impact**



## **4.1 Introduction**

This chapter presents a critical reflection of the concepts of evidence-based practice and practice-based research, with respect to the role of the Educational Psychologist (EP). The importance of effective research dissemination is discussed, with reference to different academic and non-academic routes through which research can have an impact. Potential implications for future research, practice and policy are also raised and finally, detailed plans for disseminating this research and evaluating its impact are shared.

## **4.2 Evidence-Based Practice**

In psychology, evidence is viewed as scientific research that can be judged by a community of assessors for its quality (Pring & Thomas, 2004). An evidence base is developed when high quality research around a topic is collated to form a body of knowledge (Hoagwood & Johnson, 2003).

However, when the evidence-based is applied to practice, additional contextual information related to individual and situational factors needs to be considered. Evidence-based practice is therefore considered to be the integration of the best available research with clinical expertise in the application of service delivery (American Psychological Association, 2008).

Evidence-based practice is widely promoted within educational psychology and endorsed by the British Psychological Society (BPS) and Health Care Professions Council (HCPC). The careful application of empirically supported

principles of assessment, formulation and intervention is considered to enhance service-user outcomes and public health (APA, 2008). It is also viewed as a key component of ethical psychological practice, with respect to the responsibility of the psychologist to acquire and apply knowledge and the right of the service-user to make informed-decisions regarding the support they receive (Blease et al., 2016).

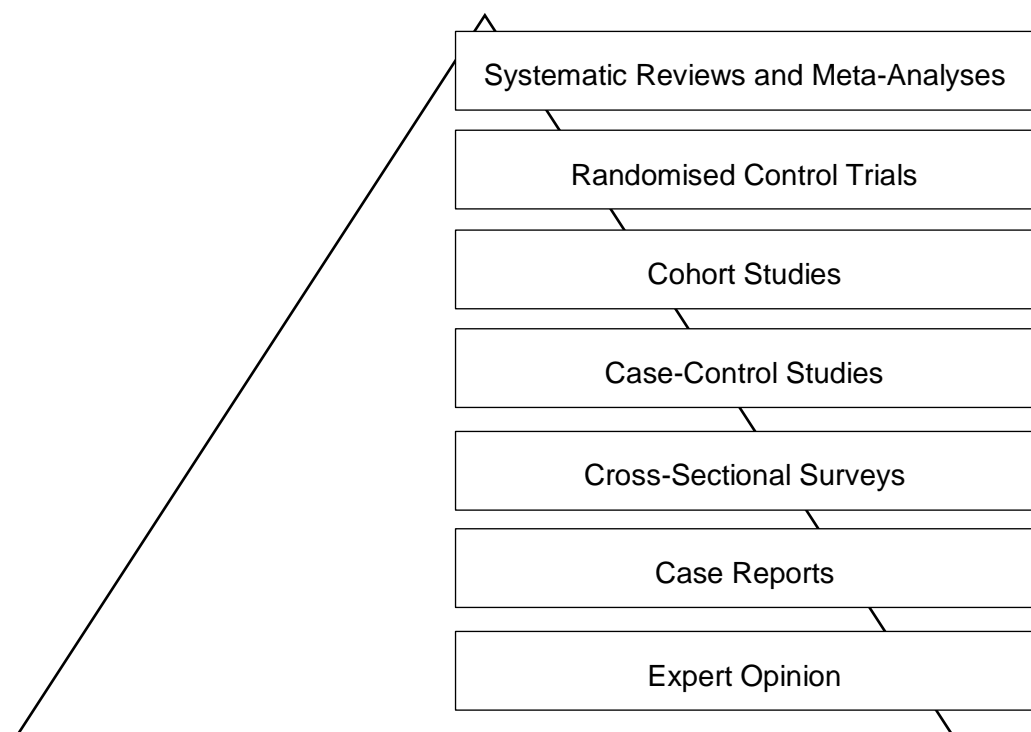
However, a number of limitations to the application of evidence-based practice have been highlighted. These include issues related to the representativeness of clinical samples to the wider population, intervention time and resource demands and a lack of socio-cultural responsiveness (Rousseau & Gunia, 2016; Shernoff et al., 2017). The disparities between highly controlled research conditions and real-world settings have also been criticised, which give rise to issues related to the external validity of research findings (Dunsmuir et al., 2009). Furthermore, it is of note that most research evaluating the effectiveness of interventions considers the shift in group means. However, EPs are often brought into schools to support those who are not responding to support in a typical way, thus considered 'outliers' in the research and require more nuanced approaches (Shaw & Pesci, 2021).

Moreover, evidence-based practice has been criticised for being positioned too far within 'positivist' epistemology, which claim high levels of generalisability from research findings and favours methodological perspectives that are derived from natural sciences, such as Randomised

Control Trials (RCTs) (Webb, 2001). This is reflective in the 'hierarchies of evidence' that have been developed to rank the quality of different types of evidence based on the methodology used within the research (Evans, 2003; Petticrew & Roberts, 2003). Figure 4.1 shows an example of a hierarchy of evidence, adapted from Evans (2003) and Petticrew and Roberts (2003). This demonstrates how hierarchies of evidence typically categorise systematic reviews, meta-analyses and randomised-control trials as research that provides the highest quality of evidence.

Figure 4.1.

*Hierarchy of Evidence, adapted from Evans (2003) and Petticrew and Roberts (2003)*



Hierarchies of evidence generally advocate for the use of rigorous quantitative approaches, while marginalising many qualitative methodologies. The debate about the value of quantitative versus qualitative methods has been present in the field of psychology for a number of decades (Rabinowitz, & Weseen, 2001). Along with methodology, it is often discussed with regard to epistemological differences, stemming from the positivism-idealism debate (Smith, 1983). Thus, the value assigned to research is often associated with the underlying assumptions of the paradigm chosen, rather than the relevance of the approach for the research question (Sale et al., 2002).

However, it has been suggested that considering any single research design as the 'gold standard' of research is reductionist and that the optimal research method for a study should be determined by the type of question being investigated (Evans, 2003). This gave rise to alternative frameworks for considering the high-quality evidence based on the information the research seeks to find (Petticrew & Roberts, 2003). For instance, in research questions seeking to explore participants' views or perspectives from minority communities, qualitative methods would be more appropriate than RCTs. Proposals have also been made around qualitative 'hierarchies of evidence' (Daly et al., 2007). Though, in a similar way, it has been suggested that the appropriateness of qualitative research methodology should be appraised in the context of the review question (Thomas & Harden, 2008). This ratifies contributions to the evidence base from research utilising a range of methodological approaches.

### 4.3 Practice-Based Research

Moreover, in response to some of the limitations discussed for evidence-based practice, arguments in favour of practice-based research have been proposed (Green, 2008; Kratochwill & Shernoff, 2004). Practice-based research is described as a bidirectional process through which psychologists collaborate with researchers to develop contextually relevant evidence that can be applied in practice (Kratochwill et al., 2012). This adds to the knowledge base in a unique way by focusing on the application of research in real-world settings. It also provides information on the structural and contextual factors alongside the processes, which is not possible to ascertain from clinical trials, thus bridges the gap between research and practice (Kratochwill et al., 2012).

To facilitate the process of practice-based research, Falzon et al. (2010) proposed a comprehensive five-step model with prompting questions to support EPs with the evidence searching process. The stages involve: (1) formulating a clear question; (2) searching the literature to find the best available evidence; (3) critically appraising the evidence for validity, accuracy and usefulness; (4) applying the findings, integrating professional expertise and service-user characteristics, culture and preference; (5) evaluating the outcomes and, if necessary, initiating a refined search. This has also given rise to approaches, such as Target Monitoring and Evaluation (Dunsmuir et al., 2009) to facilitate the process of defining, monitoring and evaluating outcomes in response to intervention.

EPs are ideally placed to contribute towards practice-based research, given the time they spend in education settings and the working relationships they develop with schools. EPs also have skills in rapport building and mediation that could particularly facilitate qualitative research. Furthermore, it is likely that school staff will be receptive to engaging with the process, as it aligns with the graduated approach they are accustomed to following, as outlined in the SEND Code of Practice (Department for Education & Department of Health, 2014). This involves engaging in cycles of identifying and assessing need then planning, implementing and reviewing interventions. A similar process would be followed with identifying needs and formulating a research question, navigating the evidence-base to plan and implement an intervention, and reviewing outcomes. Though, it should be emphasised that EPs should not only endeavour to use practice-based research to support their own practice, but also seek to publish articles and disseminate findings to colleagues to support the profession more widely.

#### **4.4 Impact of Research**

Research can contribute towards positive change across various systems and the impact of research should therefore be considered at multiple levels. The UK Economic and Social Research Council (ESRC) defines research impact as the “demonstrable contribution that excellent research makes” to academia, the economy and wider society (ESRC, 2022). It describes three levels through which research can have an impact: (1) ‘instrumental’ - changing legislation and behaviour through policy, practice and service

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development; (2) 'conceptual' – contributing to debates and understanding of policy issues; (3) 'capacity building' – developing technical and personal skills.

When considering research impact, it is important to first identify the relevant stakeholders who may facilitate processes of positive change. This helps to guide decision making around the best methods of dissemination to reach the target audiences. For both the review and empirical paper, the key stakeholders consist of individuals from professional, academic and political fields. The impacts for each of these stakeholders and the levels at which the research is hoped to be received are therefore outlined below.

#### **4.4.1 Academic impact**

Specific ideas for future research topics were proposed in both the review and empirical papers and these hold the potential to have an academic impact in inspiring future studies. However, academic impact is described by the ESRC as the more immediate contribution that research makes to advance scientific methods, theory and application and shift understanding (ESRC, 2022). Therefore, with relation to this thesis, they would be considered to impact the research at a 'conceptual' level (ESRC, 2022), concerning the demonstrable advances the review and empirical papers make to advance research with autistic young people and shift understanding.

## ***Advances to Scientific Methods***

The criteria utilised and developed for the review paper advances research understanding by providing clear guidance on the most appropriate methods for electing views from autistic students. A modified version of the Critical Appraisal Skills Programme (CASP) (Long et al., 2020) was used to appraise methodological rigour, which adds to the limited evidence base for the utility of this coding protocol. In addition, novel criteria to assess the appropriateness of the study designs to elicit autistic students' views were also developed based on the findings from a systematic review (Fayette & Bond, 2018). These highlight the importance of using supplementary non-verbal approaches to facilitate communication and actively involving participants in research decisions. There has been a lack of meaningful participation from autistic individuals in research that has informed autism practice (Fletcher-Watson et al., 2019). Therefore, this is considered to be a particularly important development to promote the use of evidence-based research methods in autism research.

In addition, the empirical paper described an approach to targeted recruitment of autistic females. Research has highlighted that autistic females are significantly underrepresented in autism research and stressed the issues this poses in the development of a male-biased diagnostic criteria (Dillon et al., 2021). This approach therefore advances understanding of methods to target gender inequality in autism research. Together with the criteria used in the review paper, these methods enhance academic

understanding on ways to facilitating meaningful participation from autistic students. This will support the development of more high quality and ethical autism research.

### ***Shifts to Understanding***

Moreover, the review paper enhances autism understanding by presenting a systematic review of the limited research exploring autistic students' views about the challenges of mainstream secondary school. As identified previously, systematic reviews are considered the highest quality research in hierarchies of evidence (Evans, 2003; Petticrew & Roberts, 2003), therefore this has the potential to be highly influential in the academic world. It also demonstrates that the research area is particularly underdeveloped in highlighting the paucity of available research, which provides rationale for the importance of the empirical paper. Moreover, the empirical paper contributes to the evidence base in a unique way and enhances understanding, as no known research has previously explored the association between anxiety and social support for autistic young people in mainstream secondary school. The findings highlight the ways in which social support helps autistic students cope with anxiety, which challenge previous understanding around autistic students having a "basic desire for aloneness" (Kanner, 1943).

The findings from both papers also impact research in contributing towards the debate that advocates for the social model of disability (Oliver, 1996) and the neurodiversity movement. This considers autistic difference as part of

natural variation and challenges deficit-focused, medicalised models (Den Houting, 2019). The extent to which the findings from either paper can be generalised remains notional and is not the aim in qualitative research, given it illuminates unique experiences and autistic students are not a homogenous group. However, they highlight the environmental factors that can positively or negatively impact the mental health and wellbeing of autistic students in mainstream secondary schools. Therefore, they contribute towards understanding by providing evidence against the use of interventions to 'normalise' autistic behaviour and promoting the exploration of initiatives that seek to reduce disabling environments for autistic students.

#### **4.4.2 Professional Impact**

Moreover, EPs work collaboratively with a range of professionals, therefore the professional impact of psychological research expands various services. For both the review and empirical paper, it is felt that the main stakeholders are those working directly with autistic students in mainstream secondary schools and those who hold advisory positions in mainstream secondary schools. These include EPs, teaching staff, autism advisory teachers, mental health support teams, and senior leadership teams. The research impacts professional practice in 'capacity building' (ESCR, 2022), which can span different levels for each of these professionals. The professional impacts of the thesis are therefore considered at both individual and organisational levels.

### ***Individual Level***

The findings from both papers revealed novel insights into the experiences of autistic students in mainstream secondary schools. Therefore, a key impact will be upskilling stakeholders with the knowledge gained to develop their individual practice. For the review paper, this involves understanding of the barriers that can exist to autistic students experiencing a sense of belonging and psychological wellbeing and approaches to eliciting views. For the empirical paper, this will involve insights around autism and anxiety and the value of social support. This challenges assumptions around autistic students not wanting friends. This will also support greater understanding at the practitioner level of the neurodiversity movement (Den Houting, 2019), therefore, prompt professionals to critically review interventions they currently recommend or endorse.

In addition, both papers can be used to develop professional practice related to direct work with autistic students. EPs can utilise the findings from the review paper to consider each of the four analytical themes as potential hypotheses when working with autistic students who are experiencing difficulties with mental health and wellbeing. In addition, the 12 descriptive themes from the review paper cover various aspects of the school experience that were developed into the card sorting activity for the empirical paper. Although the utility of the cards was not explored through the research, the students anecdotally responded well to the activity, which is consistent with findings on the value of supplementary non-verbal methods

when eliciting autistic students' views about education (Fayette & Bond, 2018; Tyrrell & Woods, 2020; Zanuttini, 2023). Therefore, copies of these cards can be shared with professionals to add to a toolkit of resources they can use flexibly when working with autistic students to understand their views about school.

### ***Organisational Level***

Furthermore, a key area that the empirical paper could impact is the evaluation of the school culture and climate with regard to 'true inclusion'. This can particularly impact practice for EPs engaging in systemic work with schools. Knowledge gained from the research supports EPs to be alert to the potential barriers to inclusion that mainstream educational environments may pose for autistic students. It also advocates for EPs to work collaboratively with students, staff and senior leadership teams to identify and challenge these. EPs can utilise psychological theories and approaches, such as, systems thinking and Soft Systems Methodology (Checkland, 1981; 1990; Frederickson, 2013) to frame these processes and support reflection.

The knowledge and understanding gained from systemic work can further influence practice within schools by promoting engagement with interventions to support peer understanding and inclusion. Interventions, such as Circle of Friends (Frederickson & Turner, 2003) and peer mentoring (Bradley, 2018) have been developed for use with autistic students to promote support networks and EPs are ideally placed to work collaboratively with schools to

implement, monitor and evaluate these. This can also extend to impact education around autism more generally for the peer group. This could be delivered by teaching staff, EPs or autism advisory teachers to promote autism understanding at a whole-school level and support the development of mainstream educational environments where difference is understood and celebrated.

#### **4.4.3 Economic and Societal Impact**

Finally, the economic and societal impact is described as the potential benefits research can have to individuals, organisations or nations, in relation to the development of public services and policy (ESRC, 2022). This would be considered an 'instrumental' impact (ESRC, 2022). For the papers in this thesis, this relates to recognition from local government and the DfE and the influence this could have over policy and services for autism.

#### ***Policy Development***

The SEND Code of Practice states that all young people should be supported to communicate their needs and aspirations and contribute towards decisions that influence their outcomes (DfE & DoH, 2014). Increased emphasis is also being placed on schools to actively involve students in decision making related to staff recruitment, curriculum planning and teaching evaluations, through government guidance and awards (HM Government, 2016; UNICEF UK, 2022). However, research suggests that students with special educational needs, particularly social communication differences, are less

likely to be included in these processes (Burnitt & Gunter, 2013; Tyrell & Woods, 2020) and have some of the poorest educational outcomes (Keen, Webster & Ridley, 2016).

The findings from the review paper highlight methods for eliciting student voice in practice that were utilised in the empirical paper. These are consistent with those identified in contemporary reviews of the evidence base (Fayette & Bond, 2018; Tyrrell & Woods, 2020; Zanuttini, 2023). EP service and SEND school policies should integrate these findings to support practice in direct work with autistic students and facilitate them expressing their views. The review paper also identifies aspects of the school environment that can contribute towards poorer outcomes for autistic students. Therefore, the findings have the potential to inform local policy on best practice in supporting autistic students in mainstream education.

Furthermore, identifying the ‘factors associated with pupil wellbeing’ and types of approaches that support ‘better outcomes for condition-specific needs in mainstream schooling’ are current areas of DfE research interest (DfE, 2018). Therefore, it is hoped that the findings from both papers could lead to recognition from the Department for Education (DfE) and the commission of further research in this area.

### ***Service Development***

In addition, it is recognised that autistic young people experience increasingly high levels of mental health difficulties (NHS Digital, 2021). Research

suggests that these are disproportionately higher in autistic than neurotypical young adults, alongside rates of suicidal ideation and behaviour (Gotham et al., 2015; Cassidy et al., 2014; Hirvikoski et al., 2016). Autistic young adults also experience problems accessing mental health support, due to difficulties in evaluating their mental wellbeing or actively seeking help, as well as often experiencing stigma (Coleman-Fountain et al., 2020; Crane et al., 2019). These highlight the need for services to provide early intervention to support mental health outcomes for autistic young people.

The findings from this thesis provide evidence to suggest that secondary schools provide an avenue for early intervention to be delivered. They promote the development of autism-specific support services and additional training in readily available school mental health services, such as Mental Health Support Teams. This training would endorse more proactive approaches to eliciting views from autistic students and evaluating disabling factors within their schools. This would require additional funding from governmental bodies, therefore, recognition from the DfE can be seen as the first step in this process. Though, the ultimate impact of this support would be to improve the mental health of autistic young people through their transition to adulthood by equipping them with skills to evaluate mental health, consider the influence of environmental factors and actively seek support.

## **4.5 Impact Pathways**

Knowledge transfer relates to the integration of psychological theory, research and practice. Lomas (1993) outlined three main forms of knowledge transfer: 'diffusion', 'dissemination', 'implementation'.

### **4.5.1 Diffusion**

Diffusion is described as the process of raising awareness through general publicity, which can target both specialist and non-specialist audiences (Lomas, 1993). For this thesis, the research has mainly been diffused through face-to-face conversations with school staff in consultations, EPs within team meetings and other individuals who have shown an interest. These have raised the awareness of the topics and led to insightful discussions that demonstrate increased interest in the area.

Some of the key findings from Chapters 2 and 3 have also been shared with autistic young people during individual work, particularly through the picture cards produced from Chapter 2 and used in the card sorting activity in Chapter 3. These have been utilised as a tool for eliciting views, through explaining that some other autistic students find these aspects of school difficult and inviting them to consider whether any may be challenging for them. This has supported autistic students to reflect explicitly on their environment, which has increased their own awareness and prompted discussions with school staff to consider ways in which reasonable adjustments could be implemented.

Another pathway for diffusion is through online posts on social media platforms, such as, Twitter, Facebook and Educational Psychology Net. It is intended that some of these platforms will be utilised to diffuse key research findings and related articles, particularly through autism pages and threads. It is hoped that these will invite reflections from different individuals about the topic area and prompt discussion about the practical implications of the research.

#### **4.5.2 Dissemination**

Dissemination is described as knowledge transfer that educates and changes attitudes through sharing research findings with targeted audiences (Lomas, 1993). For this research, this will include publication in academic journals and presentations to both academic and non-academic audiences.

##### ***Academic Journals***

One way to disseminate research is to publish it in journals read by academic professionals in relevant fields. For this thesis, Chapter 2 and Chapter 3 will be prepared as distinct papers that provide unique contributions to the evidence base. For maximum impact to be achieved, it is important that factors, such as, the argument for publication and desired readership are considered so that the most appropriate journals are targeted and the likelihood of acceptance is increased (Belcher, 2009). Each journal has unique requirements regarding the type of research and research topics they publish, according to their foci and audience (Barker et al., 2016). Therefore,

these factors were closely considered when deciding on the most appropriate journals to target.

In addition, it is also important to be aware of the impact factor, which demonstrates the rank of the journal based on the number of times the articles within it are cited. Journals with the highest impact factor are often those that are most widely read and considered to publish the highest quality research (Garfield, 2009). However, journals with high impact factors can be less likely to publish research that does not find statistically significant results, as with the findings from Chapter 3, thus demonstrate publication bias (Easterbrook et al., 1991). In a similar way, these journals may also be more reluctant to publish qualitative research, as this is often developed to generate hypotheses, rather than test them. These factors combine to potentially increase the likelihood of rejection for the research in high impact journals.

In addition, whilst the impact factor provides an indication of the academic impact of the research, the potential practical impact is more difficult to quantify statistically and relates more to the readership of the journal. For instance, practical recommendations in articles published in low impact factor journals targeted at EPs may be more likely to be implemented than those published in high impact factor journals targeted at purely academic communities. Therefore, journals with a range of impact factors and audiences are considered and presented below for the review paper (see

Table 4.1) and empirical paper (see Table 4.2). Similar journals are outlined for both papers, given the similarities between the foci and the relevance of both for education professionals. However, it is felt that the review paper is most relevant for EPs and teaching professions, though the empirical paper may be relevant for broader academic audiences as well. Therefore, the impact factor of the journals considered for the review paper was felt to be less important and the focus was on identifying the most appropriate readership bases. However, for the empirical paper, the impact factor was considered to be more valuable, with the target of reaching a broad academic audience, therefore some more general autism journals are referenced here.

Table 4.1.

*Proposed Journals for Review Paper*

Journal	Impact Factor (2021)	Description and Rationale
Educational Psychology Review	8.2	International journal published quarterly. Publishes peer-reviewed review papers and research-based advice for practitioners. Appropriate to wide readership in educational psychology.
British Journal of Educational Psychology	3.7	British journal published quarterly on behalf of the British Psychological Society for a broad international audience of researchers and practitioners. Publishes peer-reviewed research that contributes towards educational psychological theory and practice. Welcomes rigorous empirical qualitative studies.

Education and Child Psychology	0.89	British journal published quarterly on behalf of the British Psychological Society for an international audience of applied psychologists. Publishes peer-reviewed research related to specific themes that that make a significant and original contribution to the field of educational psychology. Welcomes both qualitative and quantitative studies.
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Table 4.2.

*Proposed Journals for Empirical Paper*

Journal	Impact Factor (2021)	Description and Rationale
Autism	6.7	International journal published 8 times per year by Sage Publications and the National Autistic Society. Publishes peer reviewed research related to improving the quality of life for autistic individuals. Covers a range of areas related to autism, including, education, training and psychological processes.
Journal of Autism and Developmental Disorders	4.3	International journal published monthly. Publishes a range of peer-reviewed research, including articles that seeks to promote wellbeing of autistic individuals and relate to effective care and education.
British Journal of Educational Psychology	3.7	British journal published quarterly on behalf of the British Psychological Society for a broad international audience of researchers and practitioners. Publishes peer-reviewed research that contributes towards educational psychological theory and practice.

Furthermore, titles and abstracts for the submissions of the review and empirical papers are demonstrated in Tables 4.3 and 4.4. The lead researcher will be listed as the first author and the thesis supervisor will be the second author, having contributed towards the development of the thesis and in anticipation of their continued support in working towards publication.

Table 4.3.

*Proposed Title and Abstract for the Review Paper*

Title	The Challenges of Mainstream Secondary School: A Synthesis of Qualitative Views from Autistic Students
Abstract	The current review synthesises research exploring the views from autistic students about their experiences in mainstream education. Autistic students experience significantly higher rates of mental health difficulties compared with their neurotypical peers and are vastly overrepresented in permanent exclusions. Research has identified a low sense of belonging as a common experience among excluded students, however, there remains a relative paucity of research exploring autistic students' perspectives on their educational experiences. It is therefore important to undertake a review of research exploring autistic students' views on what they find particularly challenging about the mainstream secondary school experience in order to identify the potential barriers to their sense of belonging and psychological wellbeing. Thirteen studies were critically appraised in relation to the review question and an adapted version of thematic synthesis was utilised to synthesise the findings. Twelve descriptive themes initially emerged from the data, which were further conceptualised into four analytical themes: 'feeling unsupported and misunderstood by peers', 'experiencing sensory overload in the school environment', 'feeling inappropriately supported with academic work' and 'feeling misjudged and undervalued by teaching staff'. The strengths and limitations of the included studies are discussed with reference to future research and suggestions for developments in Educational Psychology practice.

Table 4.4.

*Proposed Title and Abstract for the Empirical Paper*

Title	<i>"I would be really really sad if I did not have my friends and my worries would be a lot bigger": The Relationship between Social Support and Anxiety for Autistic Students in Mainstream Secondary School</i>
Abstract	Anxiety is the most common co-occurring difficulty in autism and many autistic students experience feelings of loneliness. Yet no known research has explored the relationship between anxiety and social support for autistic students in mainstream secondary school. The current study sought to address this gap and using linear regression to analyse data from 60 autistic students who completed an online survey to measure their levels of social support and anxiety. No significant relationship between the variables was found, which suggests that social support is unlikely to be a protective factor for anxiety, though it was hypothesised that it could aid students to cope with anxiety. Nine students who reported high levels of both social support and anxiety took part in semi-structured interviews to explore this and their responses were analysed with reflexive thematic analysis. Two research questions were posed and three themes emerged within each to outline how social support helped students cope with anxiety and the features of an 'ideal' peer group. Findings extend those from previous research and uniquely contribute to the evidence base. Implications for professional practice, teaching and pedagogy are suggested, alongside ideas for future research and wider dissemination.

***Presentations***

Moreover, another way to disseminate the research is through presentations.

For EPs, the research from Chapter 2 was presented to a Local Authority EP

Service team last year (2022) as the CPD section of a team meeting. This

involved dissemination of the previous research and theory that prompted the

systematic review, as well as the findings from the review itself. It was well

received from colleagues and provided stimulus material for further discussion on potential developments to EP practice, particularly around individual work with autistic students. It is hoped that the findings from Chapter 3 can be shared in a similar manner to the wider service later this year (2023) as CPD. The author has also applied to join an autism special interest group for EPs. This will afford opportunities to share research and ideas with like-minded professionals and contribute towards projects for wider dissemination to influence EP practice and policy. The author also hopes to make contact with researchers in the autism field to discuss their shared interest and seek opportunities to contribute towards future research.

In addition, the findings from this thesis will be presented to trainee EPs (TEPs) and tutors at the UCL research conference for TEPs. This will provide the audience with a current picture of the research base, raise awareness of the neurodiversity movement and encourage ideas for practice. It is also hoped that this will promote wider dissemination with colleagues in a range of EP services, as EPs generally work across various settings so are ideally placed to share ideas between schools and facilitate working groups of staff to promote positive change. Presenting to TEPs also creates a valuable opportunity to influence future research and practice. Therefore, the author also intends to apply to present the research at the DECP conference for TEPs in 2024.

Furthermore, with regard to dissemination to stakeholders, written presentations of the research will be shared via leaflets summarising the rationale, aims and findings from Chapter 3. These will be sent to participating schools and families of the young people involved in the research. The author will also discuss the opportunities to present the findings at Local Authority SENCo forums. It is hoped that these pathways will promote a greater understanding of autism and possible ways to support autistic young people in school.

#### **4.5.3 Implementation**

Furthermore, implementation is described as knowledge transfer that changes service delivery and professional behaviour (Lomas, 1993). This is the ultimate aim from the impact pathways outlined and it is hoped that through disseminating the research, professionals will be inspired to develop their practice. However, it would also be beneficial to deliver training to make the practical implications of the research explicit for EPs, advisory teachers, teaching and leadership staff. This would be designed to share the recommendations for practice from Chapters 2 and 3. Though it would also afford the opportunity to emphasise the importance of gaining views from autistic students and actively involving them in decision making around the support they receive.

## **4.6 Dissemination Timeline**

A carefully considered and planned process is required for disseminating thesis research and transforming it into publishable journal articles (Pollard, 2005). Therefore, a Gantt chart has been developed to outline the dissemination timeline (see Figure 4.2).

### Gantt Chart for Dissemination Timeline

[illegible]

## **4.7 Evaluating the Impact**

Evaluation approaches to assess the impact of research should be considered as interactive and ongoing processes that start from the point of dissemination. It is suggested that best results for evaluation are obtained through a series of approaches, that include, needs assessments, formative evaluations, ongoing process evaluations and summative evaluations (Gaglio & Glasgow, 2017). Therefore, a range of means for evaluating the academic, professional, societal and economic impacts of the research are considered.

With regard to the academic community, the impact of published research can be measured through citation analysis, which involves counting the number of times a paper has been referenced by other research. Higher numbers of references infer the paper has informed more research and can therefore be seen as a quantifiable measure of impact. Though, less formal evaluations can also be obtained from academic communities through feedback at conferences and engagement with online discussion about the findings on relevant forums.

Moreover, for professionals, impact can be measured through evaluation forms distributed when delivering training based on the research. Useful pre and post measures can be incorporated into evaluation forms to explore the changes in understanding or attitude towards autism that the research has generated. Careful consideration would need to be given to developing these forms to identify the relevant foci of the questions. Though, these can be an effective tool to measure impact and understand the potential changes to practice that the professionals foresee, having gained new understanding.

However, the most difficult impact to measure is the societal and economic impact. This is particularly difficult because decisions related to policy and service development are rarely informed by research findings alone and are often taken on the basis of a range of evidence. Therefore, while the research may contribute towards policy and process development, it is hard to determine the exact extent to which it informs the decisions made. Additionally, the timing of the evaluation is challenging for this type of impact. If the evaluation is completed too soon, it may be carried out before the impact has developed and if completed too late, the impact may no longer be traceable. It may therefore be more appropriate to plan for more frequent monitoring approaches to measure social and economic impact, rather than isolated evaluations.

## **4.8 Conclusion**

This chapter has critically evaluated the concepts of evidence-based practice and practice-based research, with respect to the EP role. It has also reflected on the importance of effective research dissemination and the impact that this thesis could have on a range of audiences. Potential implications for future research, practice and policy have been discussed, alongside a plan for dissemination. Finally, different approaches to evaluating the impact of the research on autism understanding, practice and policy have been outlined.

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## **Appendices**



## Appendix A: Mapping the Field

Table 2.5.

### *Summaries of Included Studies*

Study	Aims	Location	Participants (students)	Additional Participants	Design	Methods	Qualitative Analysis	WoE D
Connor (2000)	To identify themes associated with anxiety and stress for the students and highlight areas of management challenge for staff.	England	16 (15 male and 1 female)  Years 7-11 (aged 11-16 years)  From 9 mainstream schools	Special Educational Needs Coordinators	Qualitative design	Structured interviews about their school experience.	Descriptions and summaries of responses for each question.	1.6 (L)
Costley et al. (2021)	To identify the triggers for anxiety in students and gain insight into their experiences and awareness.		18 (11 males and 7 females)  12-17 years old		Qualitative design	Participatory research with a group of autistic co-researchers. Semi-structured interviews.	Thematic analysis (Braun & Clarke, 2014)	2.7 (H)

			From 2 mainstream schools					
Dillon et al. (2016)	To compare the self-reported experiences of autistic students with neurotypical students in areas of social skills, relationships with teaching staff, school functioning and interpersonal ability.	England (West Midlands)	14 (11 male and 3 female)  Mean age 13 years old  From 1 mainstream school	14 individually matched neurotypical controls	Mixed-methods design	Self-report questionnaire and semi-structured interviews.  Quantitative self-reports of social skills, student-teacher relationships, behaviour and emotional wellbeing.	Content analyses (guided by Miles et al., 2014).	2.1 (M)
Fortuna (2014)	To explore the experiences and wellbeing of autistic students and their parents and teachers during the transition from primary to secondary school.	England (East Midlands)	5 (3 male and 2 female).  From end of Year 6 - middle of Year 7 (aged 10-12 years).  From 4 primary and 2 mainstream secondary schools.	Parents and school staff	Mixed-methods design	Questionnaires, 'rate my day' diaries and semi-structured interviews.  Quantitative Likert scale questionnaires and Strengths and Difficulties Questionnaire.	Interview responses and diary entries were coded and summarised.	1.8 (M)

Goodall (2018)	To explore the mainstream educational experiences of autistic students and elicit their views on what could change in schools to better support autistic students.	Northern Ireland	12 (10 male and 2 female).  Aged 11-17 years. 7 in alternative education provisions and 5 home schooled (all previously attended mainstream secondary schools).	Qualitative design.	Semi-structured interviews, participatory methods ('beans and pots' activity and 'diamond ranking' activities) and drawing activities ('good teacher, bad teacher', 'me at school' and 'design your own school' activities).	Thematic analysis (Braun & Clarke, 2014)	2.8 (H)
Goodall (2019)	To explore the educational experiences of autistic students in mainstream school and compare these with their experiences within an alternative education provision.	Northern Ireland	7 (all male)  Aged 13-16 years.  In alternative education provisions (all previously attended mainstream secondary schools).	Qualitative design.	Semi-structured interviews, participatory methods ('beans and pots' activity and 'diamond ranking' activities) and drawing activities ('good teacher, bad teacher', 'me at school' and 'design your own school' activities).	Thematic analysis (Braun & Clarke, 2014)	2.7 (H)

Goodall and MacKenzie (2019)	To explore the experiences of mainstream education from the perspectives of 2 autistic female students.	Northern Ireland	2 (both female).  Aged 16 and 17 years.  1 in a further education college and 1 home schooled (both previously attended mainstream secondary schools).		Qualitative design.	Semi-structured interviews, participatory methods ('beans and pots' activity and 'diamond ranking' activities) and drawing activities ('good teacher, bad teacher', 'me at school' and 'design your own school' activities).	Thematic analysis (Braun & Clarke, 2014)	2.7 (H)
Humphrey and Lewis (2008)	To explore views from autistic students about mainstream education and their inclusion in school to inform practice.	England (North West)	20 (gender information not provided). Aged 11-17 years. From 4 mainstream secondary schools.		Qualitative design.	Semi-structured interviews, diaries and drawings.	Interpretative Phenomenological Analysis (IPA) (Smith & Osborn, 2003)	2.8 (H)
Makin et al. (2017)	To investigate autistic students' experience of transition from primary to	England (near London)	15 (13 male and 2 female) (7 mainstream).	Parents and teachers (from primary and	Mixed-methods design.	Questionnaires and semi-structured interviews. Quantitative measures of IQ,	Thematic analysis (Braun & Clarke, 2006)	2.1 (M)

	secondary school and compare experiences between those transitioning into mainstream and an additional education provision.		From end of Year 6 – start of Year 7 (aged 10-12 years).  From a mixture of schools in 1 Local Authority.	secondary schools)		autism symptomology, sensory profile, anxiety and transition experience.		
Myles et al. (2019)	To explore the social experiences and sense of belonging of female autistic students in mainstream secondary schools.	England (South West)	8 (all female).  Aged 12-17 years. from 3 mainstream secondary schools.		Qualitative design.	Semi-structured interviews.	Thematic analysis (Braun & Clarke, 2006)	2.2 (M)
Neal and Frederickson (2016)	To explore the positive experiences of students' transition to mainstream secondary school and identify the strategies that supported them.	England	6 (5 male and 1 female).  All in Year 7 (aged 11-12 years).  From 5 mainstream secondary schools.		Qualitative design.	Semi-structured interviews.	Thematic analysis (Braun & Clarke, 2006)	2.1 (M)

Sproston et al. (2017)	To explore the experiences of mainstream secondary school and school exclusion from the perspectives of autistic girls.	England (South East)	8 (all female).  Aged 12-17 years.  7 in Pupil Referral Units and 1 awaiting placement in an Alternative Provision (all previously attended mainstream secondary schools).	Parents	Qualitative design.	Semi-structured interviews.	Thematic analysis (Braun & Clarke, 2006)	2.3 (M)
Tomlinson et al. (2021)	To explore the experiences of autistic girls in mainstream secondary school.	England	3 (all female).  Aged 14, 15 and 16 years.  All in mainstream secondary school (which is also a designated centre for students with physical disabilities).	Staff and parents	Qualitative multiple-case design.	Semi-structured interviews, photo elicitation, diaries and drawings.	Thematic analysis (Braun & Clarke, 2006)	2.7 (H)

## Appendix B: Excluded Studies

Table 2.6.

Studies Excluded at Full Article Screening with Reason Codes

Study Reference	Reason Code
Birkett, L., McGrath, L., & Tucker, I. (2022). Muting, Filtering and Transforming Space: Autistic Children's Sensory "Tactics" for Navigating Mainstream School Space Following Transition to Secondary School. <i>Emotion, Space and Society</i> , 42. <a href="https://doi.org/https://dx.doi.org/10.1016/j.emospa.2022.100872">https://doi.org/https://dx.doi.org/10.1016/j.emospa.2022.100872</a>	6
Bottema-Beutel, K., Cuda, J., Kim, S. Y., Crowley, S., & Scanlon, K. (2020). High School Experiences and Support Recommendations of Autistic Youth. <i>Journal of Autism and Developmental Disorders</i> , 50(9), 3397–3412. <a href="https://doi.org/http://dx.doi.org/10.1007/s10803-019-04261-0">https://doi.org/http://dx.doi.org/10.1007/s10803-019-04261-0</a>	5
Bradley, R. (2016). 'Why Single Me Out?' Peer Mentoring, Autism and Inclusion in Mainstream Secondary Schools. <i>British Journal of Special Education</i> , 43(3), 272–288. <a href="https://doi.org/10.1111/1467-8578.12136">https://doi.org/10.1111/1467-8578.12136</a>	6
Browning, J., Osborne, L. A., & Reed, P. (2009). A Qualitative Comparison of Perceived Stress and Coping in Adolescents with and without Autistic Spectrum Disorders as They Approach Leaving School. <i>British Journal of Special Education</i> , 36(1), 36–43. <a href="http://search.ebscohost.com/login.aspx?direct=true&amp;AuthType=ip,s hib&amp;db=eric&amp;AN=EJ833693&amp;site=ehost-live&amp;scope=site&amp;custid=s8454451">http://search.ebscohost.com/login.aspx?direct=true&amp;AuthType=ip,s hib&amp;db=eric&amp;AN=EJ833693&amp;site=ehost-live&amp;scope=site&amp;custid=s8454451</a>	6
Crompton, C. J., Hallett, S., Axbey, H., McAuliffe, C., & Cebula, K. (2022). 'Someone like-minded in a big place': Autistic young adults' attitudes towards autistic peer support in mainstream education. <i>Autism</i> , 13623613221081189. <a href="https://doi.org/10.1177/13623613221081189">https://doi.org/10.1177/13623613221081189</a>	6
Dann, R. (2011). Secondary Transition Experiences for Pupils with Autistic Spectrum Conditions (ASCs). <i>Educational Psychology in Practice</i> , 27(3), 293–312. <a href="http://search.ebscohost.com/login.aspx?direct=true&amp;AuthType=ip,s hib&amp;db=eric&amp;AN=EJ947358&amp;site=ehost-live&amp;scope=site&amp;custid=s8454451">http://search.ebscohost.com/login.aspx?direct=true&amp;AuthType=ip,s hib&amp;db=eric&amp;AN=EJ947358&amp;site=ehost-live&amp;scope=site&amp;custid=s8454451</a>	4c
Emam, M. M. (2014). The Closeness of Fit: Towards an Ecomap for the Inclusion of Pupils with ASD in Mainstream Schools. <i>International Education Studies</i> , 7(3), 112–125. <a href="http://search.ebscohost.com/login.aspx?direct=true&amp;AuthType=ip,s hib&amp;db=eric&amp;AN=EJ1068954&amp;site=ehost-">http://search.ebscohost.com/login.aspx?direct=true&amp;AuthType=ip,s hib&amp;db=eric&amp;AN=EJ1068954&amp;site=ehost-</a>	4b

- Hannah, E. F., & Topping, K. J. (2012). Anxiety Levels in Students with Autism Spectrum Disorder Making the Transition from Primary to Secondary School. *Education and Training in Autism and Developmental Disabilities*, 47(2), 198–209. 6
- Hedges, S. H., Kirby, A. V., Sreckovic, M. A., Kucharczyk, S., Hume, K., & Pace, A. V. (2014). “Falling Through the Cracks”: Challenges for High School Students with Autism Spectrum Disorder. *The High School Journal*, 98(1), 64–82. 5  
<https://doi.org/http://dx.doi.org/10.1353/hsj.2014.0014>
- Humphrey, N., & Lewis, S. (2008). What Does “Inclusion” Mean for Pupils on the Autistic Spectrum in Mainstream Secondary Schools? *Journal of Research in Special Educational Needs*, 8(3), 132–140. 6  
<http://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,s&hib&db=eric&AN=EJ815140&site=ehost-live&scope=site&custid=s8454451>
- Jindal-Snape, D., Douglas, W., Topping, K. J., Kerr, C., & Smith, E. F. (2006). Autistic Spectrum Disorders and Primary-Secondary Transition. *International Journal of Special Education*, 21(2), 18–31. 4c and 6  
<http://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,s&hib&db=eric&AN=EJ843602&site=ehost-live&scope=site&custid=s8454451>
- O’Hagan, S., & Hebron, J. (2017). Perceptions of friendship among adolescents with autism spectrum conditions in a mainstream high school resource provision. *EUROPEAN JOURNAL OF SPECIAL NEEDS EDUCATION*, 32(3), 314–328. 6  
<https://doi.org/10.1080/08856257.2016.1223441>
- Osborne, L. A., & Reed, P. (2011). School Factors Associated with Mainstream Progress in Secondary Education for Included Pupils with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 5(3), 1253–1263. 7  
<https://doi.org/10.1016/j.rasd.2011.01.016>
- Tobias, A. (2009). Supporting Students with Autistic Spectrum Disorder (ASD) at Secondary School: A Parent and Student Perspective. *Educational Psychology in Practice*, 25(2), 151–165. 4c  
<https://doi.org/http://dx.doi.org/10.1080/02667360902905239>
- Waldman, J., McPaul, A., & Jahoda, A. (2022). A Comparison of the Content and Nature of Worries of Autistic and Neurotypical Young People as they Transition from School. *Autism*. 6  
<https://doi.org/10.1177/13623613221111313>
-

## **Appendix C: Weight of Evidence Criteria**

### ***C.1 Weight of Evidence A***

For WoE A, the current review utilised a modified version of the Critical Appraisal Skills Programme (CASP), as reported in Long et al. (2020). The modified version includes a novel question (Question 4) and a novel response option (“somewhat”) in addition to the 10 questions and 3 response options detailed in the original appraisal tool (see Table 2.7). This version was deemed appropriate as the authors emphasise its utility for appraising mixed-quality research in reviews using thematic synthesis.

Based on the suggestions outlined by Long et al. (2020), each study was evaluated against the 11 questions and a response option: “no”, “can’t tell”, “somewhat” or “yes” was given for each question. For the purpose of including scores related to aspects of methodological rigour in the overall WoE D ratings, these categories were given numerical values (1 – “no” and “can’t tell”, 2 – “somewhat”, 3 – “yes”). Although the use of numerical scoring for qualitative reviews has been debated in the literature through suggestions that it promotes “false precision” (Noyes et al., 2018), this approach is felt to be appropriate for the current review as the values correspond with the quality categories (low, medium and high) recommended in the Cochrane guidance for assessing qualitative literature (Noyes et al., 2018): 1-1.6 (low), 1.7-2.3 (medium), 2.4-3 (high) (see Table 2.8 for WoE A ratings).

Note. Questions 1 and 2 have been described as ‘screening questions’ therefore were not included in the overall scores, however an average of the values given for questions 3-11 was calculated to produce an overall WoE A score.

Note. Question 11 was adapted from an open-ended question (“How valuable is the research?”) to a closed-ended question (“Is the research valuable”) to allow for numerical ratings.

Table 2.7.

*Questions Used to Assess WoE A*

1. Was there a clear statement of the aims of the research?
<ul style="list-style-type: none"> <li>- What was the goal of the research</li> <li>- Why it was thought important</li> <li>- Its relevance</li> </ul>
2. Is a qualitative methodology appropriate?
<ul style="list-style-type: none"> <li>- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants</li> <li>- Is qualitative research the right methodology for addressing the research goal</li> </ul>
3. Was the research design appropriate to address the aims of the research?
<ul style="list-style-type: none"> <li>- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)</li> </ul>
4. Are the study's theoretical underpinnings (e.g. ontological and epistemological assumptions; guiding theoretical framework(s)) clear, consistent and conceptually coherent?
<ul style="list-style-type: none"> <li>- To what extent is the paradigm that guides the research project congruent with the methods and methodology, and the way these have been described?</li> <li>- To what extent is there evidence of problematic assumptions about the chosen method of data analysis? e.g. assuming techniques or concepts from other method (e.g. use of data saturation, originating in grounded theory) apply to chosen method (e.g. Braun and Clarke's reflexive thematic analysis) without discussion or justification.</li> <li>- To what extent is there evidence of conceptual clashes or confusion in the paper? e.g. claiming a constructionist approach but then treating participants' accounts as a transparent reporting of their experience and behaviour.</li> </ul>
5. Was the recruitment strategy appropriate to the aims of the research?
<ul style="list-style-type: none"> <li>- If the researcher has explained how the participants were selected</li> <li>- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study</li> <li>- If there are any discussions around recruitment (e.g. why some people chose not to take part)</li> </ul>
6. Was the data collected in a way that addressed the research issue?
<ul style="list-style-type: none"> <li>- If the setting for the data collection was justified</li> <li>- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)</li> <li>- If the researcher has justified the methods chosen</li> </ul>

- 
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
  - If methods were modified during the study. If so, has the researcher explained how and why
  - If the form of data is clear (e.g. tape recordings, video material, notes etc.)
  - If the researcher has discussed saturation of data
- 

7. Has the relationship between researcher and participants been adequately considered?

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions(b) data collection, including sample recruitment and choice of location
  - How the researcher responded to events during the study and whether they considered the implications of any changes in the research design
- 

8. Have ethical issues been taken into consideration?

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
  - If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) If approval has been sought from the ethics committee
- 

9. Was the data analysis sufficiently rigorous?

- If there is an in-depth description of the analysis process
  - If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
  - Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
  - If sufficient data are presented to support the findings
  - To what extent contradictory data are taken into account
  - Whether the researcher critically examined their own role, potential bias and influence during data analysis and selection of data for presentation
- 

10. Is there a clear statement of findings?

- If the findings are explicit
  - If there is adequate discussion of the evidence both for and against the researcher's arguments
  - If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
  - If the findings are discussed in relation to the original research question
-

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11. How valuable is the research?

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature)
  - If they identify new areas where research is necessary
  - If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used
-

Table 2.8.

*WoE A Ratings*

Question		Connor (2000)	Costley et al. (2021)	Dillon et al. (2016)	Fortuna (2014)	Goodall (2018)	Goodall (2019)	Goodall and MacKenzie (2019)	Humphrey and Lewis (2008)	Makin et al. (2017)	Myles et al. (2019)	Neal and Frederickson (2016)	Sproston et al. (2017)	Tomlinson et al. (2021)
1.	Was there a clear statement of the aims of the research?	3	3	3	3	3	3	3	3	3	3	3	3	3
2.	Is a qualitative methodology appropriate?	3	3	3	3	3	3	3	3	3	3	3	3	3
3.	Was the research design appropriate to address the aims of the research?	1	3	2	2	2	2	2	3	2	2	2	2	2
4.	Are the study's theoretical underpinnings (e.g. ontological and epistemological assumptions; guiding theoretical framework(s)) clear, consistent and conceptually coherent?	1	2	3	1	3	3	3	3	3	2	3	3	3
5.	Was the recruitment strategy appropriate to the aims of the research?	3	3	3	3	3	3	3	3	3	3	3	3	3
6.	Was the data collected in a way that addressed the research issue?	2	3	3	2	3	3	3	3	3	3	3	3	3
7.	Has the relationship between researcher and participants been adequately considered?	1	1	2	1	3	3	3	3	1	2	1	3	2

Question		Connor (2000)	Costley et al. (2021)	Dillon et al. (2016)	Fortuna (2014)	Goodall (2018)	Goodall (2019)	Goodall and MacKenzie (2019)	Humphrey and Lewis (2008)	Makin et al. (2017)	Myles et al. (2019)	Neal and Frederickson (2016)	Sproston et al. (2017)	Tomlinson et al. (2021)
8.	Have ethical issues been taken into consideration?	1	3	2	1	3	3	3	3	2	2	1	2	2
9.	Was the data analysis sufficiently rigorous?	1	3	2	1	3	3	3	3	3	2	3	3	3
10.	Is there a clear statement of findings?	1	3	2	1	3	3	3	3	3	3	3	3	3
11.	Is the research valuable?	2	3	3	3	3	2	2	3	3	2	3	3	3
WoE A Rating		1.4 (L)	2.7 (H)	2.4 (H)	1.7 (M)	2.8 (H)	2.7 (H)	2.7 (H)	3 (H)	2.6 (H)	2.4 (H)	2.4 (H)	2.8 (H)	2.7 (H)
<i>Note. 1-1.6 (low), 1.7-2.3 (medium), 2.4-3 (high)</i>														

## ***C.2 Weight of Evidence B***

WoE B ratings reflected the appropriateness of the study design in enabling students to express their views. Despite proposals around qualitative 'hierarchies of evidence' (Daly et al., 2007), research describing methods for thematic synthesis has suggested that reviewers may conceptualise assessments in the context of the review question rather than prioritising particular typologies of evidence (Thomas & Harden, 2008).

For the current review, it is felt that research that facilitated the expression of rich qualitative information and reflected the students' own views was most appropriate for the question. The ratings for WoE B were therefore based on the findings from a systematic literature review exploring the qualitative methods for eliciting student views on their educational experiences (Fayette & Bond, 2018).

Table 2.9.

*WoE B Criteria with Rationale*

Criteria	Weighting		Rationale
A. Qualitative Data	3	Semi-structured interviews triangulated with another type of qualitative data	Fayette and Bond (2018) highlighted the wide use and effectiveness of semi-structured interviews, though suggested supplementary non-verbal qualitative methods may be beneficial to support students with social communication difficulties to express their views.
	2	Semi-structured interviews (including those with multi-modal aids)	
	1	Structured interviews	
B. Student Involvement	3	Participants actively involved in decisions around data collection and/or reporting	Fayette and Bond (2018) reported on the issues with accessibility and power imbalance when students do not play an active role in the research.
	2	Young people involved in decisions around data collection and/or reporting	
		Known stakeholders or professionals involved in decisions around data collection and/or reporting	
	1	Decisions around data collection and reporting made solely by researcher(s)	

Table 2.10.

*WoE B Ratings*

Study	Criteria A Rating	Criteria B Rating	Overall WoE B Rating
Connor (2000)	1	1	1 (low)
Costley et al. (2021)	2	2	2 (medium)
Dillon et al. (2016)	2	1	1.5 (low)
Fortuna (2014)	3	1	2 (medium)
Goodall (2018)	3	2	2.5 (high)
Goodall (2019)	3	2	2.5 (high)
Goodall and MacKenzie (2019)	3	2	2.5 (high)
Humphrey and Lewis (2008)	3	3	3 (high)
Makin et al. (2017)	2	1	1.5 (low)
Myles et al. (2019)	2	1	1.5 (low)
Neal and Frederickson (2016)	2	1	1.5 (low)
Sproston et al. (2017)	2	1	1.5 (low)
Tomlinson et al. (2021)	3	3	3 (high)
<i>Note. 1-1.6 (low), 1.7-2.3 (medium), 2.4-3 (high)</i>			

### C.3 Weight of Evidence C

Table 2.11.

#### WoE C Criteria with Rationale

Criteria		Weighting	Rationale
A. Study Focus	3	Overall experiences of mainstream secondary school	The current review is synthesising views on the overall experiences of autistic students in mainstream secondary schools, therefore studies which focus on a specific feature of the experience or the transition process are less relevant.
	2	A specific feature of the mainstream secondary school experience	
	1	The transition process into mainstream secondary school	
B. Date of Publication	3	Study was published after 2014	This review is interested in the current educational experiences of autistic students. Findings from studies carried out prior to recent legislative changes that have sought to promote inclusion, such as the Equality Act (HMG, 2010) and the Children's and Families Act (DfE, 2014), are likely to be less generalisable to the current experience.
	2	Study was published between 2011 – 2014	
	1	Study was published before 2011	
C. Participants	3	Students from a range of year groups currently in mainstream secondary school	Gathering views from students in a range of year groups gives insight into the overall mainstream secondary school experience. Students from Year 7 are likely to have fewer experiences to draw upon and there may be issues around bias or retrospective recall for students who have left mainstream secondary.
	2	Students from Year 7 (aged 11-12) currently in mainstream secondary school	
	1	Students who have previously attended mainstream secondary school	

Criteria		Weighting	Rationale
D. Setting	3	Students from more than 1 mainstream secondary school with varied demographics	The current review is interested in gathering views from students in a range of mainstream secondary schools.
	2	Students from more than 1 mainstream secondary school with similar demographics	
	1	Students all from 1 mainstream secondary school	

Table 2.12.

*WoE C Ratings*

Study	Criteria A Rating	Criteria B Rating	Criteria C Rating	Criteria D Rating	Overall WoE C Rating
Connor (2000)	3	1	3	3	2.5 (high)
Costley et al. (2021)	3	3	3	2	2.8 (high)
Dillon et al. (2016)	3	3	3	1	2.5 (high)
Fortuna (2014)	1	2	2	2	1.8 (medium)
Goodall (2018)	3	3	1	3	2.5 (high)
Goodall (2019)	3	3	1	3	2.5 (high)
Goodall and MacKenzie (2019)	3	3	1	3	2.5 (high)
Humphrey and Lewis (2008)	3	1	3	3	2.5 (high)
Makin et al. (2017)	1	3	2	3	2.3 (medium)
Myles et al. (2019)	2	3	3	3	2.8 (high)
Neal and Frederickson (2016)	1	3	2	3	2.3 (medium)
Sproston et al. (2017)	2	3	1	3	2.3 (medium)
Tomlinson et al. (2021)	3	3	3	1	2.5 (high)
<i>Note. 1-1.6 (low), 1.7-2.3 (medium), 2.4-3 (high)</i>					

## Appendix D: Full Synthesis of Findings

Table 2.13.

### *Full Synthesis Findings for Each Included Study*

Study	WoE D Rating	Findings	Descriptive Theme	Analytical Theme
Costley et al. (2021)	High	<ul style="list-style-type: none"> <li>• (Friends helping with anxiety)</li> <li>• Difficulties making friends</li> </ul>	Friendships	<i>Feeling Unsupported and Misunderstood by Peers</i>
Neal and Frederickson (2016)	Medium	<ul style="list-style-type: none"> <li>• (Developing more friendships as large number of students)</li> <li>• (Making friends for the first time)</li> </ul>		
Dillon et al. (2016)	Medium	<ul style="list-style-type: none"> <li>• (Having one or a few close friends who provide social and academic support)</li> </ul>		
Fortuna (2014)	Medium	<ul style="list-style-type: none"> <li>• Concerns around making and maintaining friendships</li> <li>• Friendship issues</li> <li>• Peers acting different from how they used to</li> </ul>		
Myles et al. (2019)	Medium	<ul style="list-style-type: none"> <li>• (Having a small number of close friends who understood them and accepted their autism)</li> <li>• (Proximity to friends helped them feel safe and confident)</li> </ul>		
Connor (2000)	Low	<ul style="list-style-type: none"> <li>• Difficulties making friends</li> <li>• (Having friends who they had known for a long time)</li> <li>• (Friends being patient, kind and having shared interests)</li> </ul>		

Study	WoE D Rating	Findings	Descriptive Theme	Analytical Theme
Costley et al. (2021)	High	<ul style="list-style-type: none"> <li>• No one wanting to be around them</li> <li>• Sitting alone</li> </ul>	Social Isolation	
Goodall (2018); Goodall and MacKenzie (2019)	High	<ul style="list-style-type: none"> <li>• No close friends or peers to relate to despite efforts to make friends</li> <li>• Being rejected by peers on account of their disability</li> </ul>		
Goodall and MacKenzie (2019)	High	<ul style="list-style-type: none"> <li>• Peer ignorance about autism</li> </ul>		
Humphrey and Lewis (2008)	High	<ul style="list-style-type: none"> <li>• Not getting along with peers despite trying to make friends</li> </ul>		
Tomlinson et al. (2021)	High	<ul style="list-style-type: none"> <li>• Peers not understanding autism</li> <li>• Growing feelings of perceived difference</li> </ul>		
Makin et al. (2017)	Medium	<ul style="list-style-type: none"> <li>• Feeling aware of their difference and seeking ways to fit in</li> </ul>	Bullying	
Myles et al. (2019)	Medium	<ul style="list-style-type: none"> <li>• Mirroring the behaviour of peers</li> <li>• Being on the periphery of the social group and ignored</li> <li>• Unable to join in with conversations and activities</li> <li>• Not feeling listened to or valued</li> </ul>		
Connor (2000)	Low	<ul style="list-style-type: none"> <li>• Feeling misunderstood by peers</li> </ul>		
Costley et al. (2021)	High	<ul style="list-style-type: none"> <li>• Isolation as a form of bullying</li> <li>• Bullying behaviour</li> <li>• Bullied for attending support unit</li> </ul>		
Goodall (2018)	High	<ul style="list-style-type: none"> <li>• Physical and verbal harassment from peers</li> </ul>		

Study	WoE D Rating	Findings	Descriptive Theme	Analytical Theme
		<ul style="list-style-type: none"> <li>• Fear of being bullied</li> </ul>		
Goodall (2019)		<ul style="list-style-type: none"> <li>• Bullied for being different</li> <li>• Feeling angry when bullied</li> </ul>		
Humphrey and Lewis (2008)	High	<ul style="list-style-type: none"> <li>• Being exploited by peers</li> <li>• Frequent incidents of name calling and physical violence</li> <li>• Increasing feelings of isolation</li> <li>• (Sometimes friends provide support)</li> </ul>		
Fortuna (2014)	Medium	<ul style="list-style-type: none"> <li>• Being bullied by older students</li> </ul>		
Makin et al. (2017)	Medium	<ul style="list-style-type: none"> <li>• Being different making them susceptible to bullying</li> </ul>		
Sproston et al. (2017)	Medium	<ul style="list-style-type: none"> <li>• Social and physical bullying common</li> <li>• Often leading to retaliation</li> </ul>		
Connor (2000)	Low	<ul style="list-style-type: none"> <li>• Being picked on, teased or beat up by peers</li> </ul>		
Costley et al. (2021)	High	<ul style="list-style-type: none"> <li>• Anxiety about not fitting in socially and being judged by other people</li> <li>• Anxiety about negotiating social relationships and not causing offence</li> </ul>	Social Anxiety	
Goodall (2018)	High	<ul style="list-style-type: none"> <li>• Overwhelming intensely social environment</li> </ul>		
Tomlinson et al. (2021)	High	<ul style="list-style-type: none"> <li>• Fearing getting things wrong in front of peers</li> </ul>		

Study	WoE D Rating	Findings	Descriptive Theme	Analytical Theme
Myles et al. (2019)	Medium	<ul style="list-style-type: none"> <li>• Nervous about what to say or do before social interactions</li> <li>• Learning hidden social rules</li> <li>• Struggling in large social groups</li> </ul>		
Connor (2000)	Low	<ul style="list-style-type: none"> <li>• Anxiety about peer interaction</li> </ul>		
Costley et al. (2022)	High	<ul style="list-style-type: none"> <li>• Managing noise and distraction</li> </ul>	Noise Levels	<i>Experiencing Sensory Overload in the School Environment</i>
Goodall (2018); Goodall (2019)	High	<ul style="list-style-type: none"> <li>• Auditory sensory overload</li> </ul>		
Humphrey and Lewis (2008)	High	<ul style="list-style-type: none"> <li>• Noise in classrooms is overwhelming</li> </ul>		
Tomlinson et al. (2021)	High	<ul style="list-style-type: none"> <li>• Overwhelming noise in corridors and canteen</li> </ul>		
Dillon et al. (2016)	Medium	<ul style="list-style-type: none"> <li>• Peers being distracting in class</li> </ul>		
Makin et al. (2017)	Medium	<ul style="list-style-type: none"> <li>• Struggling to cope with noise in classroom</li> </ul>		
Sproston et al. (2017)	Medium	<ul style="list-style-type: none"> <li>• Difficult to learn when lots of noise around</li> </ul>		
Connor (2000)	Low	<ul style="list-style-type: none"> <li>• Lively and noisy classroom</li> <li>• Loud playground environment</li> </ul>		
Costley et al. (2022)	High	<ul style="list-style-type: none"> <li>• Anxiety about the physical space</li> <li>• Getting lost and not being on time</li> </ul>	School Size	

Study	WoE D Rating	Findings	Descriptive Theme	Analytical Theme
Goodall (2018); Goodall (2019); Goodall and MacKenzie (2018)	High	<ul style="list-style-type: none"> <li>• Unpredictability of the environment</li> <li>• Constant changing classrooms is stressful</li> </ul>		
Humphrey and Lewis (2008)	High	<ul style="list-style-type: none"> <li>• Small corridors leading to pushing and shoving</li> </ul>		
Tomlinson et al. (2021)	High	<ul style="list-style-type: none"> <li>• (Designated safe spaces for SEN students)</li> <li>• Anxiety around changing classrooms</li> </ul>		
Dillon et al. (2016)	Medium	<ul style="list-style-type: none"> <li>• (Preference for small school regarding space)</li> </ul>		
Fortuna (2014)	Medium	<ul style="list-style-type: none"> <li>• Large school size is a shock</li> </ul>		
Makin et al. (2017)	Medium	<ul style="list-style-type: none"> <li>• Getting lost due to the size of the school</li> </ul>		
Myles et al. (2019)	Medium	<ul style="list-style-type: none"> <li>• (Small areas in school or clubs help them feel safe and supported)</li> <li>• Size of the school challenging</li> </ul>		
Neal and Frederickson (2016)	Medium	<ul style="list-style-type: none"> <li>• (Increased resources)</li> <li>• (Enjoyed exploring the environment)</li> <li>• Getting lost easily</li> <li>• Changing classes being annoying</li> </ul>		
Costly et al. (2022)	High	<ul style="list-style-type: none"> <li>• Anxiety about the number of people</li> <li>• Crowds, pushing and fighting</li> </ul>	Number of Students	

Study	WoE D Rating	Findings	Descriptive Theme	Analytical Theme
Goodall (2018); Goodall (2019); Goodall and MacKenzie (2018)	High	<ul style="list-style-type: none"> <li>• Busy corridors</li> </ul>		
Tomlinson et al. (2021)	High	<ul style="list-style-type: none"> <li>• Corridors and canteen avoided as crowded and overwhelming</li> </ul>		
Dillon et al. (2016)	Medium	<ul style="list-style-type: none"> <li>• (Preference for small school regarding familiarity with peers)</li> </ul>		
Myles et al. (2019)	Medium	<ul style="list-style-type: none"> <li>• Number of students is challenging</li> </ul>		
Neal and Frederickson (2016)	Medium	<ul style="list-style-type: none"> <li>• (Large school size facilitated new friendships)</li> </ul>		
Sproston et al. (2017)	Medium	<ul style="list-style-type: none"> <li>• Difficulties accessing support due to large class size</li> </ul>		
Humphrey and Lewis (2008)	High	<ul style="list-style-type: none"> <li>• Additional support being very visible in class</li> <li>• (Presence of support staff reduced bullying)</li> </ul>	SEN Support	<i>Feeling Inappropriately Supported with Academic Work</i>
Tomlinson et al. (2021)	High	<ul style="list-style-type: none"> <li>• (Personal accommodations and strategies tailored to individual needs)</li> <li>• (Pupil passport)</li> <li>• Conflict with support staff when perceived to be helping too much</li> <li>• Perceived as different when support staff are present</li> </ul>		
Dillon et al. (2016)	Medium	<ul style="list-style-type: none"> <li>• (Value of additional support networks)</li> <li>• (Benefit of support from educational statement)</li> </ul>		
Makin et al. (2017)	Medium	<ul style="list-style-type: none"> <li>• Support staff making the student more aware of their difference</li> <li>• Being bullied for receiving extra support</li> </ul>		

Study	WoE D Rating	Findings	Descriptive Theme	Analytical Theme
		<ul style="list-style-type: none"> <li>• (Supportive systems and structures in place)</li> </ul>		
Sproston et al. (2017)	Medium	<ul style="list-style-type: none"> <li>• (Support assistants appreciated, benefitting whole class)</li> <li>• Support staff interfering with learning</li> </ul>		
Tomlinson et al. (2021)	High	<ul style="list-style-type: none"> <li>• Struggling with homework and feel cannot communicate this with teachers</li> </ul>	Homework	
Dillon et al. (2016)	Medium	<ul style="list-style-type: none"> <li>• Homework taking up too much time</li> <li>• Not understanding why homework is given</li> </ul>		
Goodall (2019)	Medium	<ul style="list-style-type: none"> <li>• Overwhelming amount of homework</li> </ul>		
Costley et al. (2022)	High	<ul style="list-style-type: none"> <li>• Anxiety about managing the demands of academic work</li> <li>• Pressure to perform</li> <li>• Exam anxiety</li> <li>• Making presentations or answering questions</li> </ul>	Schoolwork	
Tomlinson et al. (2021)	High	<ul style="list-style-type: none"> <li>• Intense stress from exam pressure</li> <li>• Uniform approach to exam preparation</li> </ul>		
Dillon et al. (2016)	Medium	<ul style="list-style-type: none"> <li>• Teachers can digress or move at a pace which is too fast makes learning difficult</li> </ul>		
Makin et al. (2017)	Medium	<ul style="list-style-type: none"> <li>• High demands of the curriculum</li> <li>• Difficulties managing and organising work</li> <li>• Forgetting materials</li> </ul>		

Study	WoE D Rating	Findings	Descriptive Theme	Analytical Theme
Neal and Frederickson (2016)	Medium	<ul style="list-style-type: none"> <li>• (Highly organised structure helps planning work)</li> <li>• (Variety of lessons supports engagement)</li> </ul>	Pastoral Care	<i>Feeling Misjudged and Undervalued by Teaching Staff</i>
Sproston et al. (2017)	Medium	<ul style="list-style-type: none"> <li>• Pressure put on students to achieve</li> </ul>		
Goodall (2018)	High	<ul style="list-style-type: none"> <li>• Feeling misunderstood and unsupported by teachers</li> <li>• Preconceptions and a lack of understanding around autism</li> </ul>		
Goodall (2019)	High	<ul style="list-style-type: none"> <li>• Not feeling cared for by teachers</li> </ul>		
Goodall and MacKenzie (2019)	High	<ul style="list-style-type: none"> <li>• Not being noticed by teachers</li> <li>• Negative attitude towards autism</li> <li>• Teachers caring more about results than students</li> </ul>		
Humphrey and Lewis (2008)	High	<ul style="list-style-type: none"> <li>• Being treated differently by teachers</li> <li>• Receiving little attention from class teacher</li> </ul>		
Tomlinson et al. (2021)	High	<ul style="list-style-type: none"> <li>• Teachers not understanding autism and individual needs</li> <li>• Anxiety around unfamiliar or cover staff</li> <li>• (Benefits of positive relationship with trusted staff)</li> <li>• Lack of autism knowledge and misconceptions</li> </ul>		
Dillon et al. (2016)	Medium	<ul style="list-style-type: none"> <li>• Teachers offering limited student interaction</li> <li>• (Learning support staff listening and understanding)</li> </ul>		
Makin et al. (2017)	Medium	<ul style="list-style-type: none"> <li>• Feeling unsupported by teachers</li> </ul>		

Study	WoE D Rating	Findings	Descriptive Theme	Analytical Theme
Myles et al. (2019)	Medium	<ul style="list-style-type: none"> <li>• Staff speaking to them like a baby when they found out about the diagnosis</li> <li>• Teachers not understanding their needs</li> </ul>		
Neal and Frederickson (2016)	Medium	<ul style="list-style-type: none"> <li>• (Feeling valued and supported by support staff)</li> </ul>		
Sproston et al. (2017)	Medium	<ul style="list-style-type: none"> <li>• (Some teachers offered support and able to build a relationship with them)</li> <li>• Feeling misunderstood by most teachers</li> <li>• Teachers not aware of individual coping strategies</li> <li>• So many different teachers</li> <li>• Few SEN experienced staff</li> </ul>		
Costley et al. (2022)	High	<ul style="list-style-type: none"> <li>• Anxiety about doing the wrong thing, even inadvertently, and getting into trouble</li> <li>• Worries about others breaking the rules and being distracting</li> </ul>	Discipline	
Goodall (2018)	High	<ul style="list-style-type: none"> <li>• Lack of clear expectations from teachers</li> <li>• Opportunities for interaction curtailed by needing to catch up on missed work or being in isolation</li> </ul>		
Goodall and MacKenzie (2019)	High	<ul style="list-style-type: none"> <li>• No reward for engagement</li> <li>• Punishment for trying and getting something wrong</li> </ul>		
Makin et al. (2017)	Medium	<ul style="list-style-type: none"> <li>• Teachers being strict</li> </ul>		
Neal and Frederickson (2016)	Medium	<ul style="list-style-type: none"> <li>• Worries about the focus on discipline</li> <li>• Punishments are unfair at times</li> </ul>		

Study	WoE D Rating	Findings	Descriptive Theme	Analytical Theme
		<ul style="list-style-type: none"> <li>(Preference for the discipline)</li> </ul>		
Sproston et al. (2017)	Medium	<ul style="list-style-type: none"> <li>Being ridiculed in front of the class by teachers for making mistakes</li> <li>Anxiety around asking questions</li> </ul>		
<i>Note. Findings represented in brackets refer to positive comments</i>				

## Appendix E: Ethical Approval

UCL RESEARCH ETHICS COMMITTEE  
OFFICE FOR THE VICE PROVOST RESEARCH



18<sup>th</sup> November 2021

Dr Gavin Morgan  
Division of Psychology and Language Sciences  
UCL

Cc: Megan Exley

Dear Dr Morgan

### **Notification of Ethics Approval with Provisos**

**Project ID/Title: 21373/001: Social Support as a Protective Factor for Anxiety for Autistic Students in Mainstream Secondary School**

I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **18<sup>th</sup> November 2023.**

Approval is subject to the following conditions:

### **Notification of Amendments to the Research**

You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'

<http://ethics.grad.ucl.ac.uk/responsibilities.php>

### **Adverse Event Reporting – Serious and Non-Serious**

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator ([ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Office of the Vice Provost Research, 2 Tavilton Street  
University College London  
Tel: +44 (0)20 7679 8717  
Email: [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)  
<http://ethics.grad.ucl.ac.uk/>

**Final Report**

At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: <https://www.ucl.ac.uk/srs/file/579>
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

**Professor Michael Heinrich**  
**Joint Chair, UCL Research Ethics Committee**

## Appendix F: Information Sheets and Consent Forms

### F.1 Recruitment Email to Schools

 Reply  Reply All  Forward  IM



Thu 17/02/2022 17:11

Exley, Megan

Participation in Research

To

Egress Switch: Unprotected

 You replied to this message on 17/03/2022 14:48.



Hello

I'm Megan Exley, a Trainee Educational Psychologist from UCL and I am contacting you to request participation from students in my doctoral thesis project.

I am looking to recruit autistic students in Years 7-11 with awareness of their autism diagnoses and the project will use surveys and interviews to investigate the relationship between social support and anxiety. The ultimate aim of this research is to increase understanding around autism, therefore participating schools will receive a resource which summarises the findings from the study and presents a range of recommendations. These will include suggestions around how schools might promote social inclusion and support the mental health of autistic students.

I have attached an information sheet which provides more details about the project. Please contact me if you feel any of your students would be keen to participate or you have any further questions.

Many thanks,

Megan

**Megan Exley** (*she/her*) | Trainee Educational Psychologist  
University College London (UCL)

## ***F.2 Information Sheet for Schools***

UCL EDUCATIONAL PSYCHOLOGY GROUP  
RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL  
& HEALTH PSYCHOLOGY



Hello,

I am writing to request your participation in my doctoral thesis research project.

The aim of the research is to investigate whether social support is a protective factor for anxiety for autistic students and to explore their experiences of social support from their peers in mainstream secondary school.

### Background

The rates of mental health disorders, namely anxiety, in autistic students appear to be significantly higher than those of their neurotypical peers. However, no known studies to date have investigated the association between social support and anxiety in autistic young people, leaving a significant gap in the literature. It is felt that researching this topic will increase autism understanding and encourage the development of meaningful strategies to promote support networks for autistic students in mainstream education.

### The Study

Participating students will be sent a short online survey to complete independently related to their experiences of peer support and anxiety. The link to the survey will be at the bottom of the participant information sheet and the survey needs to be completed in a quiet environment where the student is able to focus. The questions will be written in young person-friendly language and should take the students no longer than 15 minutes to complete. It is important that the students respond to the surveys independently, without influence from others, though they may require a trusted adult to sit with them while they complete the survey to support with reading/interpreting the questions.

Following the survey, a small number of students who have expressed a desire to participate in the next phase of the study may be contacted for follow-up interviews with the researcher, Megan. These will need to take place online or in school in a quiet room free from distraction. The interview should take around 30 minutes and will take a semi-structured format and include a short optional drawing task. The interviews will be audio-recorded so that the dialogue can be transcribed for analysis (after which point the audio recording will be securely destroyed). It is not necessary that the student is accompanied by a member of staff for these interviews, however they may wish to have a trusted adult with them for support. If Covid-19 restrictions are in place, the interviews can take place on Microsoft Teams, further information on the modality of the interviews will be circulated nearer to the time.

Please note, the study has received ethical approval UCL REC and the researcher has received full DBS clearance.

## Participants

Potential participants will need to:

- Be in **Year 7, 8, 9, 10, 11, 12 or 13**
- Have either a **formal autism diagnosis** or be on a **diagnostic pathway** and **self-identify** as autistic.
- Have an **awareness** of their autism.
- Have **capacity** to consent to the study and participate independently.

It should also be noted that the study is looking at the relationship between social support and anxiety in students with **different levels of anxiety**. Therefore, all autistic students are welcome to participate, not just those with high anxiety.

## Consent

Before participating in each phase of the research, parents/carers and students will receive information sheets about the study phase and consent forms to sign.

~~SENCOs~~ will be required to identify suitable participants and circulate the information sheets and consent forms.

## Benefits

In exchange for participating in the research, you will receive a resource which summarises the results from study and presents a range of recommendations based on the findings. These recommendations will aim to provide advice and strategies to promote the social inclusion and support the mental health of autistic students within your school.

## Next Steps

If you feel that any of your students would be appropriate to participate in this study, please reply to the researcher, Megan ([megan.exley.20@ucl.ac.uk](mailto:megan.exley.20@ucl.ac.uk)) so that the information sheets and consent forms can be sent to you and circulated with parents/carers.

Thank you very much for reading this information and considering participating in the research.

### ***F.3 Example Recruitment Post on Social Media***

∞★ Research with autistic students in UK  
mainstream secondary schools★∞

Hello! I am Megan, a Trainee Educational Psychologist, and I am currently recruiting participants for my doctoral thesis research. I am looking for autistic students in UK mainstream secondary schools who would be willing to complete a short survey about the social support they receive from peers and their experiences of anxiety.

The views of autistic young people are not always included in research, therefore I am keen to represent as many voices as possible. The ultimate aim of this research is to increase understanding around autism and to support the social inclusion and mental health of autistic young people in mainstream education.

If your child/young person fits the criteria and might be interested in participating, please send me a private message or email me ([megan.exley.20@ucl.ac.uk](mailto:megan.exley.20@ucl.ac.uk)) and I will share more information.

Thank you in advance.

## F.4 Parent/Carer Information Sheet - Survey

UCL EDUCATIONAL PSYCHOLOGY GROUP

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL

& HEALTH PSYCHOLOGY



### Information Sheet for Parents/Carers

UCL Research Ethics Committee Approval ID Number: 21373/001

**Title of Study:** Social Support as a Protective Factor for Anxiety for Autistic Students in Mainstream Secondary School

**Department:** Psychology and Language Sciences

**Name and Contact Details of the Researcher(s):** Megan Exley ([megan.exley.20@ucl.ac.uk](mailto:megan.exley.20@ucl.ac.uk))

**Name and Contact Details of the Principal Researcher:** Dr Gavin Morgan ([gavin.morgan@ucl.ac.uk](mailto:gavin.morgan@ucl.ac.uk))

#### **1. Invitation Paragraph**

Your child is being invited to take part in a research project. Before you decided it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish for your child to take part. Thank you for reading this.

#### **2. What is the project's purpose?**

The aim of the project is to find the relationship between social support and anxiety. We are carrying out this research to try and increase understanding about autism and the importance of peer support, with the ultimate aims of improving the mainstream school experience for autistic students and reducing mental health difficulties. The term 'peers' is understood as the group of students your child is in school with.

#### **3. Why has your child been chosen?**

We are looking to recruit students with autism diagnoses/traits attending mainstream secondary schools to take part in the study.

#### **4. Does my child have to take part?**

It is up to you to decide whether you would like your child to take part. If you do decide that you would like your child to take part, you will need to sign an online consent form (link at the end of this information sheet). Your child will also receive an information sheet and will be able to make their own decision on whether they would like to participate in the research. It should be emphasised that the information sheet your child will receive will refer to autism, so this study is not appropriate for students who are not aware of their neurodiversity.

You can withdraw your child from the research at any time without giving a reason and without it affecting any benefits that they are entitled to. If you decide to withdraw your child, you will be asked what you wish to happen to the data they have provided up to that point.

#### **5. What will happen to my child if they take part?**

Your child will be sent a survey to complete in a quiet place in school/at home which should take no longer than 15 minutes. They will have an adult with them to support them with understanding the questions if they require this.

They will firstly be asked to write down some information about themselves, including their school, year group, name and initials. Their personal responses will not be shared with anyone, including yourselves parents/carers or school, but we will record their personal information in our secure system so that if you or your child changes

their mind and wishes for their data to be removed at any stage in the research up until our analysis in August 2022, we can do so for you.

Next, they will be asked some questions relating to their gender and ethnicity which will be used to see whether the students participating are representative of the wider population in the UK. They will then be asked a range of questions about the peer support they receive and their experience of anxiety.

At the end, they will be asked if they wish to be contacted in the future to take part in an interview with the researcher, Megan. They do not have to participate in this follow-up interview, but if they would like to, they will need to tick a box to indicate this. We may not ask every student who ticks this box to participate in this interview as we will only need around 10 participants for this. If your child is selected to participate, we will send you and your child another information sheet to explain what will be involved and another set of consent forms to sign.

Although we have described the general nature of the tasks that your child will be asked to perform, the full intent of the study will not be explained to them until after they have completed each stage of the study (at which point they may withdraw their data from the study).

**6. What are the possible disadvantages and risks of taking part?**

We do not expect there to be any risks for your child in taking part in this research, however, if your child does find any of the questions distressing, it must be emphasised that their participation is entirely voluntary and they are entitled to stop the survey at any point and withdraw their data from the study at any stage up until data analysis, which will take place in August 2022. There will be a member of staff with them to support them if they do become distressed at any point.

If your child finds it difficult to concentrate for the duration of the survey, we suggest they take a break and returning to the questions when they feel ready.

**7. What are the possible benefits of taking part?**

Whilst there is no immediate benefit for participants in the project, it is hoped that this work will improve understanding around autism and the importance of peer support. After we have analysed the data, we plan to produce a resource for schools that will summarise the research findings and suggest some recommendations that may support autistic students to feel more supported and less anxious in school.

**8. What if something goes wrong?**

If you wish to raise a complaint about the research, this should be sent via email to the Principal Researcher, Gavin Morgan ([gavin.morgan@ucl.ac.uk](mailto:gavin.morgan@ucl.ac.uk)). If you feel your complaint has not been handled to your satisfaction, you can contact the Chair of the UCL Research Ethics Committee – [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk).

**9. Will my child taking part in this project be kept confidential?**

All the information that we collect about your child during the course of the research will be kept strictly confidential. Data with your child's initials will be transferred onto an encrypted laptop and stored in an access-controlled folder. All data will be anonymised following the interviews and no identifiable information will be included in any of the reports.

**10. Limits to confidentiality**

Confidentiality will be respected subject to legal constraints and professional guidelines.

**11. What will happen to the results of the research project?**

The findings from this research will be used in a doctoral thesis, which may become a published article at a later stage. You may opt to receive a copy of this report (option given in consent form). The data will be securely destroyed once the thesis has been approved and no identifiable data will appear in any of the reports or publications.

**12. Local Data Protection Privacy Notice**

**Notice:**

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows: Initials, School, Year Group, Age, Gender and Ethnicity.

The lawful basis that will be used to process your child's personal data are: 'Public task' for personal data and 'Research purposes' for special category data.

*Your child's personal data will be processed so long as it is required for the research project. Your child's data has already been pseudonymised (saved with their initials, age, year group and school so that the researcher was able to contact them to participate in the interview) and will be anonymised (all personal information removed so that no one is able to see which data is yours) after the interviews are written up. The researcher will try to minimise the processing of personal data wherever possible.*

If you are concerned about how your child's personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

**14. Contact for further information**

For more information, please contact the Principal Researcher, Gavin ([gavin.morgan@ucl.ac.uk](mailto:gavin.morgan@ucl.ac.uk)).

Thank you for reading this information sheet and considering your child taking part in this research study.

**Link to online Consent Form:** <https://opinio.ucl.ac.uk/s?s=76200>

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## F.5 Parent/Carer Consent Form – Survey (Opinio version)

### Survey Consent

CONSENT FORM FOR PARENTS/CARERS IN RESEARCH STUDIES - SURVEY

*Please complete this form after you have read the Information Sheet.*

*Title of Study: Social Support as a Protective Factor for Anxiety for Autistic Students in Mainstream Secondary School*

*Department: Psychology and Language Sciences*

*Name and Contact Details of the Researcher(s): Megan Exley (megan.exley.20@ucl.ac.uk)*

*Name and Contact Details of the Principal Researcher: Dr Gavin Morgan (gavin.morgan@ucl.ac.uk)*

*Name and Contact Details of the UCL Data Protection Officer Alexandra Potts: data-protection@ucl.ac.uk*

*This study has been approved by the UCL Research Ethics Committee: Project ID number: 21373/001*

*Thank you for considering to allow your child to take part in this research. If you have any questions arising from the Information Sheet or please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.*

*Please note that consent from both yourself and your child will need to be obtained before they participate in any element of the research. Consent for participation will be signalled by your child's completion of the survey.*

*By selecting each yes option below you are consenting to this element of the study. It will be assumed that unselected options means that you DO NOT consent to that part of the study. By not giving consent for any one element that your child may be deemed ineligible for the study.*

**Q1: Please enter your child's initials**

**Q2: Please enter the name of your child's school**

**Q3: Please select your child's year group**

☐ Year 7   ☐ Year 8   ☐ Year 9   ☐ Year 10   ☐ Year 11   ☐ Year 12   ☐ Year 13

## Consent

**Q4: I confirm that I have read and understood the Information Sheet for the study. I understand what the study will involve and have asked any questions I had. I would like for my child to take part in the survey.**

☐ Yes ☐ No

**Q5: I understand that I will be able to withdraw my child's data up to the point that the data is analysed.**

☐ Yes ☐ No

**Q6: I consent for my child to participate in the study. I understand that their personal information (initials, age, ethnicity, gender, year group and school) will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing and 'research purposes' will be the lawful basis for processing special category data.**

☐ Yes ☐ No

**Q7: I understand that all personal information will remain confidential. Data will be pseudonymised (saved with my child's initials, age, year group and school so that the researcher can contact me if I consent for my child to participate in the interview) in the first instance and then anonymised (all personal information removed so that no one is able to see which data is my child's) once the data has been analysed.**

**I understand that it will not be possible to identify my child in any publications.**

**I understand that confidentiality will be respected subject to legal constraints and professional guidelines.**

☐ Yes ☐ No

**Q8: I understand that my child's information may be subject to review by responsible individuals from the University for monitoring and audit purposes.**

☐ Yes ☐ No

**Q9: I understand that my child's participation is voluntary and that I am free to withdraw them at any time without giving a reason.**

**I understand that if I decide to withdraw, any personal data my child has provided up to that point will be deleted unless I agree otherwise.**

☐ Yes ☐ No

**Q10: I understand the potential risks of participating and the right I have to withdraw my child from the study if they become distressed during the course of the research.**

☐ Yes ☐ No

**Q11: I understand that no promise of benefits has been made, but that the project hopes to contribute towards increasing understanding around autism.**

☐ Yes ☐ No

**Q12: I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.**

☐ Yes ☐ No

**Q13: I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.**

☐ Yes ☐ No

**Q14: I understand that the information my child will submit will be published as a report and I wish to receive a copy of it.**

☐ Yes ☐ No

**Q15: I hereby confirm that I understand why my child have been chosen for this study, as detailed in the Information Sheet.**

☐ Yes ☐ No

**Q16: I am aware of who I should contact if I wish to lodge a complaint.**

☐ Yes ☐ No

**Q17: As a parent/carer, I give permission to the research team to approach my child to ask if they wish to take part in your project.**

☐ Yes ☐ No

**Q18: I would be happy to be contacted to be asked if my child would like to participate in the follow-up interviews**

☐ Yes ☐ No

**Q19: Please type your full name and the date as form of online signature to this consent form.**

## **F.6 Participant Information Sheet – Survey**

UCL EDUCATIONAL PSYCHOLOGY GROUP

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL  
& HEALTH PSYCHOLOGY



### **Participant Information Sheet for Students - Survey**

UCL Research Ethics Committee Approval ID Number: 21373/001

**Title of Study:** Social Support as a Protective Factor for Anxiety for Autistic Students in Mainstream Secondary School

**Department:** Psychology and Language Sciences

**Name and Contact Details of the Researcher(s):** Megan Exley (megan.exley.20@ucl.ac.uk)

**Name and Contact Details of the Principal Researcher:** Dr Gavin Morgan (gavin.morgan@ucl.ac.uk)

#### **1. Invitation Paragraph**

You are being invited to take part in a doctoral research project. Before you decided it is important for you to understand why the research is being done and what it will involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### **2. What is the project's purpose?**

The aim of the project is to find the link between peer support and anxiety. The word 'peers' means the group of students you are at school with. We are carrying out this research to try and increase understanding about autism and the importance of peer support to help teachers make school as good as it can be for students.

#### **3. Why have I been chosen?**

We are looking to find students with autism diagnoses in mainstream secondary schools to take part in the study.

#### **4. Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part, your consent will be assumed through completion of the survey.

You can stop participating in the study at any time without giving a reason. If you decide to stop, you will be asked what you wish to happen to the data you have provided up to that point.

#### **5. What will happen to me if I take part?**

A link to an online survey is given at the bottom of this information sheet. The survey will probably take you about 15 minutes to complete and you will complete it in a quiet room in school or at home on a laptop, device or school computer. An adult will be with you to support with any questions or worries you may have, but it is important that you try to complete the survey as independently as possible.

You will firstly be asked to write down some information about yourself, including your school, year group, name and initials. Your personal responses will not be shared with anyone, including your parents/carers or school, but we will record your personal information in our secure system so that if you change your mind and want your data to be removed at any stage in the research up until our analysis, we can do so for you.

Next, you will be asked some questions about your gender and ethnicity which will be used to see whether the students participating are similar to those in the wider population. You will then be asked questions about how supported you feel by your peers and your levels of worry.

At the end, you will be asked if it would be ok for us to contact you in the future to ask you some more questions about school in an interview in school with the researcher, Megan. You do not have to take part in this follow-up interview, but if you would like to, you will need to tick a box at the end of the survey to say so. We may not ask everyone who ticks this box to participate in this interview as we will only need around 10 participants for this. If you are selected to participate, we will send you another information sheet like this one and a consent form to sign to confirm that you would like to take part.

Although we have described the general nature of the research, the full explanation of the study will not be given to you until after you have completed each stage (at which point, you may ask to remove your data from the study).

**6. What are the possible disadvantages and risks of taking part?**

We do not expect there to be any risks for you in taking part in this research, however, if you do find any of the questions upsetting, please remember that you are allowed to remove your data from the study at any stage up until data analysis, which will take place in August 2022.

If you are finding it difficult to concentrate in the survey, we suggest taking a break and returning to the questions when you feel ready.

**7. What are the possible benefits of taking part?**

Whilst there is no reward for taking part, we hope that this work will improve understanding around autism and the importance of peer support. After we have analysed the data, we plan to give schools some information that will explain what we find and suggest some ways staff may support autistic students to feel happier in school.

**8. What if something goes wrong?**

If you wish to raise a complaint about the research, this should be sent via email to the Principal Researcher, Gavin Morgan ([gavin.morgan@ucl.ac.uk](mailto:gavin.morgan@ucl.ac.uk)). If you feel your complaint has not been handled to your satisfaction, you can contact the Chair of the UCL Research Ethics Committee – [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk).

**9. Will my taking part in this project be kept confidential?**

No one need know that you have taken part in the research nor what you said unless you tell people yourself.

All the information that we collect about you through the research will be kept strictly confidential (private). Data with your initials will be stored on an encrypted laptop in an access-controlled folder and this will be anonymised following the interviews so that people will not be able to tell who the data belongs to. No information linking you personally to any of the findings will be included in the reports produced.

**10. What will happen to the results of the research project?**

The findings from this research will be used in a doctoral thesis, which may become a published report at a later stage. You may ask to receive a copy of this report. The data will be securely destroyed once the research has been submitted and published and no identifiable data will appear in any of the reports or publications.

**11. Local Data Protection Privacy Notice**

**Notice:**

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows: Initials, School, Year Group, Age, Gender and Ethnicity.

The lawful basis that would be used to process your *personal data* will be performance of a task in the public interest.

The lawful basis used to process *special category personal data* will be for scientific and historical research or statistical purposes.

*Your personal data will be processed so long as it is required for the research project. We plan to pseudonymise the data first (save it with your initials, age, year group and school so that the researcher can contact you if you would like to participate in the interview) and then anonymise it (all personal information removed so that no one is able to see which data is yours). The researcher will try to minimise the processing of personal data wherever possible.*

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

**14. Contact for further information**

For more information, please contact the Principal Researcher, Gavin ([gavin.morgan@ucl.ac.uk](mailto:gavin.morgan@ucl.ac.uk)).

You can keep the electronic copy of this information sheet.

**Thank you for reading this information sheet and for considering to take part in this research study.**

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**Link for survey:** <https://opinio.ucl.ac.uk/s?s=75404>

## **F.7 Parent/Carer Information Sheet – Interview**

UCL EDUCATIONAL PSYCHOLOGY GROUP

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL  
& HEALTH PSYCHOLOGY



### **Information Sheet for Parents/Carers**

UCL Research Ethics Committee Approval ID Number: 21373/001

**Title of Study:** Social Support as a Protective Factor for Anxiety for Autistic Students in Mainstream Secondary School

**Department:** Psychology and Language Sciences

**Name and Contact Details of the Researcher(s):** Megan Exley ([megan.exley.20@ucl.ac.uk](mailto:megan.exley.20@ucl.ac.uk))

**Name and Contact Details of the Principal Researcher:** Dr Gavin Morgan ([gavin.morgan@ucl.ac.uk](mailto:gavin.morgan@ucl.ac.uk))

#### **1. Invitation Paragraph**

Your child is being invited to take part in a research project. Before you decided it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish for your child to take part. Thank you for reading this.

#### **2. What is the project's purpose?**

The aim of the project is to find the relationship between social support and anxiety. For these interviews we are interested in finding out about the influence of the peer group (understood as the group of students your child is in school with) and the factors that may contribute towards a supportive peer group. We are carrying out this research to try and increase understanding about autism and the importance of peer support, with the ultimate aim of improving the mainstream school experience for autistic students and reducing mental health difficulties.

#### **3. Why has your child been chosen?**

We are looking to recruit students with autism diagnoses/presentations attending mainstream secondary schools to take part in the study. Your child indicated in the survey that they may like to take part in an interview.

#### **4. Does my child have to take part?**

It is up to you to decide whether you would like your child to take part. If you do decide that you would like your child to take part, you will be asked to sign a consent form. Your child will also receive an information sheet and consent form and will be able to make their own decision on whether they would like to participate in the research.

You can withdraw your child from the research at any time without giving a reason and without it affecting any benefits that they are entitled to. If you decide to withdraw your child, you will be asked what you wish to happen to the data they have provided up to that point.

**5. What will happen to my child if they take part?**

The researcher, Megan will visit your child in school/on Zoom and ask them questions for around 30 minutes. The interview is semi-structured, which means that Megan will have a set of topics that she wishes to discuss but the questions will be asked based off the responses that your child gives and will be delivered in a conversational format. The topics will be centred around how your child feels about their peer group. They will have opportunities to discuss topics in as much or little detail as they feel comfortable with. They will also be asked if they wish to take part in a short drawing task whilst they are in the interview.

Your child is not expected to answer any questions that make them feel uncomfortable and they will be reminded that they can ask to stop the interview at any stage. If you or your child change your minds about participating in the study overall, you can also ask for your data to be removed up until the analysis is complete and the data is anonymised.

Although we have described the general nature of the tasks that your child will be asked to perform, the full intent of the study will not be explained to them until after they have completed the interview, in a written debrief form. At which point, they will be asked to confirm that their data may be used.

**6. Will your child be recorded and how will the recorded media be used?**

The interviews will be audio recorded, with your child's permission and later transcribed by the researcher, Megan. The audio recording of your child's interview will be securely deleted immediately after it is transcribed and the transcript will be used for analysis only and securely deleted immediately after.

Short quotes from the interviews may be included in the write-up of the thesis and any subsequent articles, but consent from your child will be obtained before these are used and they will be anonymised. No identifiable data will be included in the reports. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

**7. What are the possible disadvantages and risks of taking part?**

We do not expect there to be any risks for your child in taking part in this research, however, if they find any of the topics or questions distressing, they will be reminded that their participation is entirely voluntary and they are entitled to stop the interview and withdraw their data from the study at any stage up until the data is analysed, which will take place in August 2022. The researcher, Megan, will support your child if they do become distressed during the interview and will call on a trusted member of school staff for support if necessary.

**8. What are the possible benefits of taking part?**

Whilst there is no immediate benefit for participants in the project, it is hoped that this work will improve understanding around autism and the importance of peer support. After we have analysed the data, we plan to produce a resource for schools that will summarise the research findings and suggest some recommendations that may support autistic students to feel more supported and less anxious in school.

**9. What if something goes wrong?**

If you wish to raise a complaint about the research, this should be sent via email to the Principal Researcher, Gavin Morgan ([gavin.morgan@ucl.ac.uk](mailto:gavin.morgan@ucl.ac.uk)). If you feel your complaint has not been handled to your satisfaction, you can contact the Chair of the UCL Research Ethics Committee – [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk).

**10. Will my child taking part in this project be kept confidential?**

All the information that we collect about your child during the course of the research will be kept strictly confidential. Data with your child's initials will be stored on an encrypted laptop in an access-controlled folder and this will be anonymised following the interviews. School staff may know which students from their setting participated, so may be able to identify any information that the student provides that is specific to their situation. However, direct quotes will only be used with explicit consent from your child and no identifiable information, such as student or school names will be included in any of the reports.

#### **11. Limits to confidentiality**

Confidentiality will be respected subject to legal constraints and professional guidelines.

#### **12. What will happen to the results of the research project?**

The findings from this research will be used in a doctoral thesis, which may become a published article at a later stage. You may opt to receive a copy of this report (option given in consent form). The data will be securely destroyed once the thesis has been approved and no identifiable data will appear in any of the reports or publications.

#### **13. Local Data Protection Privacy Notice**

##### **Notice:**

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows: Initials, School, Year Group, Age, Ethnicity, Gender

The lawful basis that will be used to process your child's personal data are: 'Public task' for personal data and 'Research purposes' for special category data.

*Your child's personal data will be processed so long as it is required for the research project. Your child's data has already been pseudonymised (saved with their initials, age, year group and school so that the researcher was able to contact them to participate in the interview) and will be anonymised (all personal information removed so that no one is able to see which data is yours) after the interviews are written up. The researcher will try to minimise the processing of personal data wherever possible.*

If you are concerned about how your child's personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

#### **14. Contact for further information**

For more information, please contact the Principal Researcher, Gavin ([gavin.morgan@ucl.ac.uk](mailto:gavin.morgan@ucl.ac.uk)).

You will be given a copy of this information sheet and a signed consent form to keep.

**Thank you for reading this information sheet and for considering to take part in this research study.**

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## **F.8 Parent/Carer Consent Form – Interview (Opinio Version)**

### **Interview Consent**

CONSENT FORM FOR PARENTS/CARERS IN RESEARCH STUDIES - INTERVIEW

*Please complete this form after you have read the Information Sheet.*

*Title of Study: Social Support as a Protective Factor for Anxiety for Autistic Students in Mainstream Secondary School*

*Department: Psychology and Language Sciences*

*Name and Contact Details of the Researcher(s): Megan Exley (megan.exley.20@ucl.ac.uk)*

*Name and Contact Details of the Principal Researcher: Dr Gavin Morgan (gavin.morgan@ucl.ac.uk)*

*Name and Contact Details of the UCL Data Protection Officer Alexandra Potts: data-protection@ucl.ac.uk*

*This study has been approved by the UCL Research Ethics Committee: Project ID number: 21373/001*

*Thank you for considering to allow your child to take part in this research. If you have any questions arising from the Information Sheet or please ask the researcher before you decide whether to join in.*

*Please note that consent from both yourself and your child will need to be obtained before they participate in any element of the research. Consent from your child will be obtained before they complete the interview.*

*By selecting each yes option below you are consenting to this element of the study. It will be assumed that unselected options means that you DO NOT consent to that part of the study. By not giving consent for any one element that your child may be deemed ineligible for the study.*

**Q1: Please enter your child's initials.**

**Q2: Please enter the name of your child's school.**

**Q3: Please select your child's year group.**

☐ Year 7   ☐ Year 8   ☐ Year 9   ☐ Year 10   ☐ Year 11   ☐ Year 12   ☐ Year 13

## INTERVIEW

**Q4: I confirm that I have read and understood the Information Sheet for the study. I understand what the study will involve and have asked any questions I had. I consent for my child to take part in the interview.**

☐ Yes ☐ No

**Q5: I understand that I will be able to withdraw my child's data up to the point that the data is analysed (4 weeks after interview).**

☐ Yes ☐ No

**Q6: I understand that my child's personal information (initials, age, ethnicity, gender, year group and school) will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing, and 'research purposes' will be the lawful basis for processing special category data.**

☐ Yes ☐ No

**Q7: I understand that all personal information will remain confidential. Data has been pseudonymised (saved with my child's initials, age, year group and school) and will be anonymised (all personal information removed so that no one is able to see which data is my child's) once the interviews have been transcribed.**

**I understand that confidentiality will be respected subject to legal constraints and professional guidelines.**

☐ Yes ☐ No

**Q8: I understand that my child's information may be subject to review by responsible individuals from the University for monitoring and audit purposes.**

☐ Yes ☐ No

**Q9: I understand that my child's participation is voluntary and that I am free to withdraw them without giving a reason. I understand that if I decide to withdraw, any personal data my child has provided up to that point will be deleted unless I agree otherwise.**

☐ Yes ☐ No

**Q10: I understand the potential risks of participating and the right I have to withdraw my child from the study if they become distressed during the course of the research.**

☐ Yes ☐ No

**Q11: I understand that no promise of benefits has been made, but that the project hopes to contribute towards increasing understanding around autism.**

☐ Yes ☐ No

**Q12: I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.**

☐ Yes ☐ No

**Q13: I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.**

☐ Yes ☐ No

**Q14: I understand that the information my child has submitted will be published as a report and I wish to receive a copy of it. (Yes/No)**

☐ Yes ☐ No

**Q15: I consent to my child's interview being audio recorded and understand that the recordings will be destroyed immediately following transcription.**

☐ Yes ☐ No

**Q16: I hereby confirm that I understand why my child has been chosen for this study, as detailed in the Information Sheet.**

☐ Yes ☐ No

**Q17: I am aware of who I should contact if I wish to lodge a complaint.**

☐ Yes ☐ No

**Q18: As a parent/carer, I give permission to the research team to approach my child to ask if they wish to take part in your project.**

☐ Yes ☐ No

**Q19: Please type your full name and the date as form of online signature to this consent form**

*Thank you for completing this consent form. The researcher, Megan, will be in touch with yourself/your child's school shortly.*

## ***F.9 Participant Information Sheet – Interview***

UCL EDUCATIONAL PSYCHOLOGY GROUP

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL

& HEALTH PSYCHOLOGY



### **Participant Information Sheet for Students - Interview**

UCL Research Ethics Committee Approval ID Number: 21373/001

**Title of Study:** Social Support as a Protective Factor for Anxiety for Autistic Students in Mainstream Secondary Schools

**Department:** Psychology and Language Sciences

**Name and Contact Details of the Researcher(s):** Megan Exley (megan.exley.20@ucl.ac.uk)

**Name and Contact Details of the Principal Researcher:** Dr Gavin Morgan (gavin.morgan@ucl.ac.uk)

#### **1. Invitation Paragraph**

You are being invited to take part in a doctoral research project. Before you decided it is important for you to understand why the research is being done and what it will involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### **2. What is the project's purpose?**

The aim of the project is to find the relationship between social support and anxiety. For these interviews we are interested in finding out about peer groups (the group of students you are at school with) and what makes a supportive peer group. We are carrying out this research to try and increase understanding about autism and the importance of peer support to help teachers make school as good as it can be for students.

#### **3. Why have I been chosen?**

You took part in the survey and suggested that you might like to take part in the interview too.

#### **4. Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and asked to sign a consent form.

You can stop taking part at any time without giving a reason. If you decide to withdraw you will be asked what you wish to happen to the data you have provided up to that point.

#### **5. What will happen to me if I take part?**

The researcher, Megan will visit you in school/call you on Zoom and ask you some questions for around 30 minutes. The interview is semi-structured, which means that Megan will have a set of topics that she wishes to discuss but the questions will be asked based off the responses you give and will be more like a conversation. The topics will be similar to some of those in the survey you completed, though will mostly be based on how you feel about your peer group. You will be able to discuss topics in as much or little detail as you feel comfortable with. You will also be asked if you wish to take part in a short drawing task in the interview.

It is important to understand that you are not expected to answer any questions that make you feel uncomfortable and you can ask to stop the interview at any stage. If you change your mind about participating in the study overall, you can also ask for your data to be removed up until the analysis is complete in August 2022.

Although we have described the general nature of the tasks that you will be asked to perform, the explanation of the study will not be given until after you have completed the interview, where you will receive written information (debrief form) explaining the purpose of the study. At which point, you will be asked to confirm that your data may be used.

**6. Will I be recorded and how will the recorded media be used?**

The interviews will need to be recorded so that they can be later transcribed (written down) by the researcher, Megan and analysed. The audio recording of your interview will be securely deleted immediately after it is transcribed, in August 2022 and the transcript will be used for analysis only and securely deleted immediately after.

Short quotes from the interviews may be included in the write-up of the thesis and any other articles, but these will be anonymised (all identifiable information about you removed) and no identifiable data will be included in the reports. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

**7. What are the possible disadvantages and risks of taking part?**

We do not expect there to be any risks for you in taking part in this research, however, if you find any of the topics or questions upsetting, please remember that your participation is your choice and you are allowed to stop the interview and withdraw your data from the study at any stage up until data analysis, in August 2022. You may have a trusted adult with you through the interview if this would make you feel more comfortable. The researcher, Megan, will also support you if you do become upset during the interview and will ask an adult you know to help if you would like.

**8. What are the possible benefits of taking part?**

Whilst there is no reward for taking part, we hope that this work will improve understanding around autism and the importance of peer support. After we have analysed the data, we plan to make a leaflet for schools that will explain what we find and suggest some ways staff may support autistic students to feel happier in school.

**9. What if something goes wrong?**

If you wish to raise a complaint about the research, this should be sent via email to the Principal Researcher, Gavin Morgan ([gavin.morgan@ucl.ac.uk](mailto:gavin.morgan@ucl.ac.uk)). If you feel your complaint has not been handled to your satisfaction, you can contact the Chair of the UCL Research Ethics Committee – [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk).

**10. Will my taking part in this project be kept confidential?**

No one need know that you have taken part in the research nor what you said unless you tell people yourself.

All the information that we collect about through the research will be kept strictly confidential. Data with your initials will be stored on an encrypted laptop in an access-controlled folder and this will be anonymised following the interviews, so that people will not be able to tell who the data belongs to. No information linking you personally to any of the findings will be included in the reports produced, though the information you provide may be specific to your situation, therefore you will have the right to approve

of any direct quotes used in the write-up before it is published. No identifiable information, such as names or school names will be included in any of the reports.

**11. Limits to confidentiality**

Please note that confidentiality will be maintained as far as it is possible, unless during our conversation I hear anything which makes me worried that someone might be in danger of harm, I might have to inform relevant people of this.

**12. What will happen to the results of the research project?**

The findings from this research will be used in a doctoral thesis, which may become a published article at a later stage. You may ask to receive a copy of this report. The data will be securely destroyed once the thesis has been approved and no identifiable data will appear in any of the reports or publications.

**13. Local Data Protection Privacy Notice**

**Notice:**

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows: Initials, School, Year Group, Age, Gender and Ethnicity.

The lawful basis that would be used to process your *personal data* will be performance of a task in the public interest.

The lawful basis used to process *special category personal data* will be for scientific and historical research or statistical purposes.

*Your personal data will be processed so long as it is required for the research project.* Your data has already been pseudonymised (saved with your initials, age, year group and school so that the researcher was able to contact you to participate in the interview) and will be anonymised (all personal information removed so that no one is able to see which data is yours) after the interviews are written up. The researcher will try to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

**14. Contact for further information**

For more information, please contact the Principal Researcher, Gavin ([gavin.morgan@ucl.ac.uk](mailto:gavin.morgan@ucl.ac.uk)).

**Thank you for reading this information sheet and for considering to take part in this research study.**

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## F.10 Participant Assent Form – Interview

UCL EDUCATIONAL PSYCHOLOGY GROUP  
RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL  
& HEALTH PSYCHOLOGY



### CONSENT FORM FOR STUDENTS IN RESEARCH STUDIES - INTERVIEW

Please complete this form after you have read the Information Sheet.

**Title of Study:** Social Support as a Protective Factor for Anxiety for Autistic Students in Mainstream Secondary School

**Department:** Psychology and Language Sciences

**Name and Contact Details of the Researcher(s):** Megan Exley (megan.exley.20@ucl.ac.uk)

**Name and Contact Details of the Principal Researcher:** Dr Gavin Morgan (gavin.morgan@ucl.ac.uk)

**Name and Contact Details of the UCL Data Protection Officer:** Alexandra Potts [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

This study has been approved by the UCL Research Ethics Committee: Project ID number: 21373/001

Thank you for considering taking part in this research. If you have any questions from the Information Sheet please ask the researcher, Megan before you decide whether to join in.

I confirm that I understand that by ticking each box below I am consenting to this element of the study. I understand that it will be assumed that unticked boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Tick Box
1.	*I confirm that I have read and understood the Information Sheet for the study. I understand what the study will involve and have asked any questions I had. I would like to take part in the interview.	
2.	*I understand that I will be able to withdraw my data up to the point that the data is analysed (in Summer 2022).	
3.	*I consent to participate in the study. I understand that my personal information (initials, age, ethnicity, gender, year group and school) will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing and 'research purposes' will be the lawful basis for processing special category data.	
4.	<p><b>Use of the information for this project only</b></p> <p>*I understand that all personal information will remain confidential. Data has been pseudonymised (saved with my initials, age, year group and school) and will be anonymised (all personal information removed so that no one is able to see which data is mine) once the interviews have been typed up.</p> <p>I understand that it will not be possible to identify me in any publications.</p> <p>I understand that confidentiality will be respected subject to legal constraints and professional guidelines.</p>	
5.	*I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	

6.	*I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.	
7.	I understand the potential risks of participating and the right I have to withdraw from the study if I become distressed during the course of the research.	
8.	I understand that no promise of benefits has been made, but that the project hopes to contribute towards increasing understanding around autism.	
9.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
10.	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	
11.	I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. (Yes/No)	
12.	I consent to my interview being audio recorded and understand that the recordings will be destroyed immediately following transcription.	
13.	I understand why I have been chosen for this study, as detailed in the Information Sheet.	
14.	I am aware of who I should contact if I wish to lodge a complaint.	
15.	I voluntarily agree to take part in this study.	

Name of participant \_\_\_\_\_

Date \_\_\_\_\_

### ***F.11 Survey Debrief Information (Opinio version)***

Thank you for taking part, please read the following information which explains more about the study.

What was this study about?

We designed this study because research has found that lot of autistic students feel anxious in school. We wanted to see whether this anxiety could be linked to the support they get from their peers in school and see whether those who felt more supported by their peers were less anxious. This is why the questions in the survey were about how anxious you feel and how you feel about the support your peers give you.

We hope that researching this topic will help people understand more about autism and help us design some strategies to make autistic students feel happier in school.

We did not give you a full explanation of the study before you took part, because we did not want this to affect the way you answered the questions.

What if I change my mind?

If you want to ask the researcher any further questions or remove your data from the study, please let her know by sending an email to [megan.exley.20@ucl.ac.uk](mailto:megan.exley.20@ucl.ac.uk) before April 2022.

Thank you very much again for reading this information and taking part in the research.

## **F.12 Interview Debrief Form**

UCL EDUCATIONAL PSYCHOLOGY GROUP

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL  
& HEALTH PSYCHOLOGY



### Interview Debrief Form

Thank you for taking part, please read the following information which explains more about the study.

#### What was this study about?

I designed this study because research has found that lot of autistic students feel anxious and I wanted to see whether this could be linked to the support they get from their peers in school. I also wanted to find out how support from peers might help students cope with some of their worries.

I hope that researching this topic will help people understand more about autism and help us design some strategies to make autistic students feel happier in school.

#### Why was I chosen for the interview?

You were chosen to take part in this interview because your responses to the survey suggested that you often feel quite worried, but you also feel quite supported by some of your peers.

I interviewed you and some other students who responded in a similar way to the survey. I plan to see if there are any similarities or differences in your responses to the questions I have asked today.

I did not give you a full explanation of the study before you took part in the interview, because I did not want this to affect the way you answered the questions.

#### What if I change my mind?

If you want to ask the researcher any further questions or remove your data from the study, please let her know by sending an email to [megan.exley.20@ucl.ac.uk](mailto:megan.exley.20@ucl.ac.uk) before August 2022.

Thank you very much again for taking part in the research.

## Appendix G: Measures

### G.1 Anxiety Scale for Children – ASD – Child Version (ASC-ASD)

(Rodgers et al., 2016)

ASC-ASD<sup>®</sup> (Child version)

#### *Anxiety Scale for Children – Autism Spectrum Disorder – Child version (ASC-ASD)<sup>®</sup>*

*Jacqui Rodgers, Sarah Wigham, Helen McConachie, Mark Freeston, Emma Honey, Jeremy Parr  
Newcastle University, Newcastle UK*

Name/ID: \_\_\_\_\_ Date: \_\_\_\_\_ Age: \_\_\_\_\_

Please put a circle around the word that shows how often each of these things happen to you. There are no right, or wrong answers.

1. All of a sudden I feel really scared for no reason at all	Never	Sometimes	Often	Always
2. I worry what other people think of me	Never	Sometimes	Often	Always
3. My heart suddenly starts to beat too quickly for no reason	Never	Sometimes	Often	Always
4. I feel scared when I have to take a test in case I make a mistake	Never	Sometimes	Often	Always
5. I worry people will bump into me or touch me in busy or crowded environments	Never	Sometimes	Often	Always
6. I am afraid of being in crowded places (like shopping centers, the movies, buses, busy playgrounds) in case I am separated from my family	Never	Sometimes	Often	Always
7. I worry that I will do badly at my school work	Never	Sometimes	Often	Always

8. I suddenly feel as if I can't breathe when there is no reason for this	Never	Sometimes	Often	Always
9. I am afraid of new things, or new people or new places	Never	Sometimes	Often	Always
10. I am afraid of entering a room full of people	Never	Sometimes	Often	Always
11. I worry when I go to bed at night because I don't like to be away from my parents/ family	Never	Sometimes	Often	Always
12. When I have a problem I feel shaky	Never	Sometimes	Often	Always
13. I suddenly start to tremble or shake when there is no reason for this	Never	Sometimes	Often	Always
14. When I don't know what will happen, I can't do things	Never	Sometimes	Often	Always
15. I worry when I think I have done poorly at something	Never	Sometimes	Often	Always
16. I always need to be prepared before things happen	Never	Sometimes	Often	Always
17. I feel afraid that I will make a fool of myself in front of people	Never	Sometimes	Often	Always
18. I worry about being away from my parents	Never	Sometimes	Often	Always
19. I worry that something awful will happen to someone in my family	Never	Sometimes	Often	Always
20. I would feel scared if I had to stay away from home overnight because I like to be close to my parents/ family	Never	Sometimes	Often	Always

21. I worry about being in places that are too loud, or too bright or too busy	Never	Sometimes	Often	Always
22. I suddenly become dizzy or faint when there is no reason for this	Never	Sometimes	Often	Always
23. I worry if I don't know what will happen e.g. if plans change	Never	Sometimes	Often	Always
24. I worry that something bad will happen to me	Never	Sometimes	Often	Always

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Jacqui.Rodgers@ncl.ac.uk

**G.2 – Adapted Version of the Social Provisions Scale-24 (Russell & Cutrona, 1987)**

Instructions: For the questions in this section, please think about your relationships with your peers (people you go to school with) at the moment.

Some of these questions may feel like they are asking the same thing, but they are all slightly different so it is important that you try to answer every one of them honestly.

Please show how much you agree with each statement by selecting the appropriate option (strongly disagree, disagree, agree, strongly agree). There are no right or wrong answers.

- 
- 1    There are peers (people I go to school with) I can depend on to help me if I really need it.
- 
- 2    I feel that I do not have close personal relationships with my peers.
- 
- 3    I do not have a peer I can turn to for help when I am stressed.
- 
- 4    There are peers who depend on me for help.
- 
- 5    There are peers who enjoy the same social activities I do.
- 
- 6    My peers do not view me as competent (good at things).
- 
- 7    I feel personally responsible for the wellbeing (safety, comfort and happiness) of one of my peers.
- 
- 8    I feel part of a group of peers who share my attitudes and beliefs.
-

- 
- 9 I do not think my peers respect my skills and abilities.
- 
- 10 If something went wrong, none of my peers would help me.
- 
- 11 I have close relationships with my peers that make me feel secure and improve my wellbeing (safety, comfort and happiness).
- 
- 12 I have a peer I could talk to about important decisions in my life.
- 
- 13 I have relationships with peers where my competence (what I am good at) and skills are recognised.
- 
- 14 None of my peers share my interests and concerns.
- 
- 15 None of my peers really rely on me for their wellbeing (safety, comfort and happiness).
- 
- 16 There is a trustworthy peer I could turn to for advice if I were having problems.
- 
- 17 I feel a strong emotional bond with at least one of my peers.
- 
- 18 I do not have a peer I can depend on for help if I really need it.
- 
- 19 I do not have a peer I feel comfortable talking about problems with.
- 
- 20 There are peers who admire my talents and abilities.
- 
- 21 I lack a feeling of intimacy (closeness) with any of my peers.
- 
- 22 None of my peers like the things that I like.
- 
- 23 There are peers I can count on in an emergency.
- 
- 24 None of my peers need me to care for them.
-

### **G.3 Interview Schedule**

*Introductions, information sheet, consent form and any questions.*

1. First, we are going to look together at these cards which show different things about school that some students find worrying or difficult. I will ask you some questions about the cards, there are no right or wrong answers and please let me know if anything does not make sense.
  - a) Do you get worried about any of these in school?  
*(student sorts cards into piles of often/sometimes/rarely – check for understanding of activity and cards)*
  - b) What do you find worrying about them?  
*(prompt for any not already explained and summarise to check understanding)*
  - c) Is there anything else you find worrying about school?  
*(post-it notes) What do you find worrying about these things?*
2. These questions are about your peers (people you go to school with)
  - a) Is there anything your peers do that helps you cope with any of these worries? *(check for understanding and use card piles as prompts)*
  - b) *Prompt for further information if necessary and summarise what has been said to check understanding.*
3. 'Ideal peer group' drawing task and interpretation.

Finally, I would like you to do an activity where you imagine different peer groups of students in school and draw what they might look like. You don't need to do any writing, just draw and explain to me what you are drawing, there are no right or wrong answers. If you would prefer not to draw, you can just explain what the peer group might be like instead. This is fine too.

- a) Think about a peer group in a school you would not like to go to. Make a quick drawing of these students. What are the students doing? Tell me three things about these students.
- b) Now, think about a peer group at a school you would like to go to. Make a quick drawing of these students. What are the students doing? Tell me three things about these students.
- c) *(Interpret and discuss)*

*Debrief form, questions and thank you.*

## Appendix H: Qualitative Analysis

### *H.1 Extract from a Transcript*

Note. The highlighted text indicates that which was transferred to the table of codes, subthemes and themes for RQ2 (see Appendix H.3 and H.4) to be coded and categorised.

I: my next questions are more around those friendships, so I was wondering, with respect to any of these, is there anything those friends do that helps you cope with any of these worries?

P7: Well, the friends I do have are always there if I need to like rant, they always listen and give me advice and they know how to cheer me up and calm me down, so it's nice having a nice group of friends in school, because with school there's a lot of friends that do come and go but the friendship group I have now is one that I think will stick. It's like the last final one, you know year 10 going into year 11.

I: Yeah, that's really nice, so they sound like they are quite solid friends that are able to help you in various ways? Are there any worries that you think they specifically help you with, there might be a few or not so many?

P7: Well my best friend in the group who's been my best friend since year 6, she tries her best to help me with school work sometimes because she knows that I don't really know much and I struggle and when it comes to loud noises if I need to leave or if I like, well this is another thing, if I am agitated and I go a bit non-verbal, my friend the other day as an example, told the teacher what I wanted to say, she spoke for me but not in a bad sense, she helped and I'm sure they would all do that if I went a bit quiet and yeah... with social situations if I'm getting a bit awkward they will talk and stuff like that.

I: That sounds really good and it sounds like they know you really well so when you do find things difficult and become quite quiet, they speak on behalf of you but because they know what you want to say?

P7: Yeah

I: Yeah, so they really support you in those situations when you may be experiencing shut down, where you're struggling to get your words out or process information?

P7: Yeah

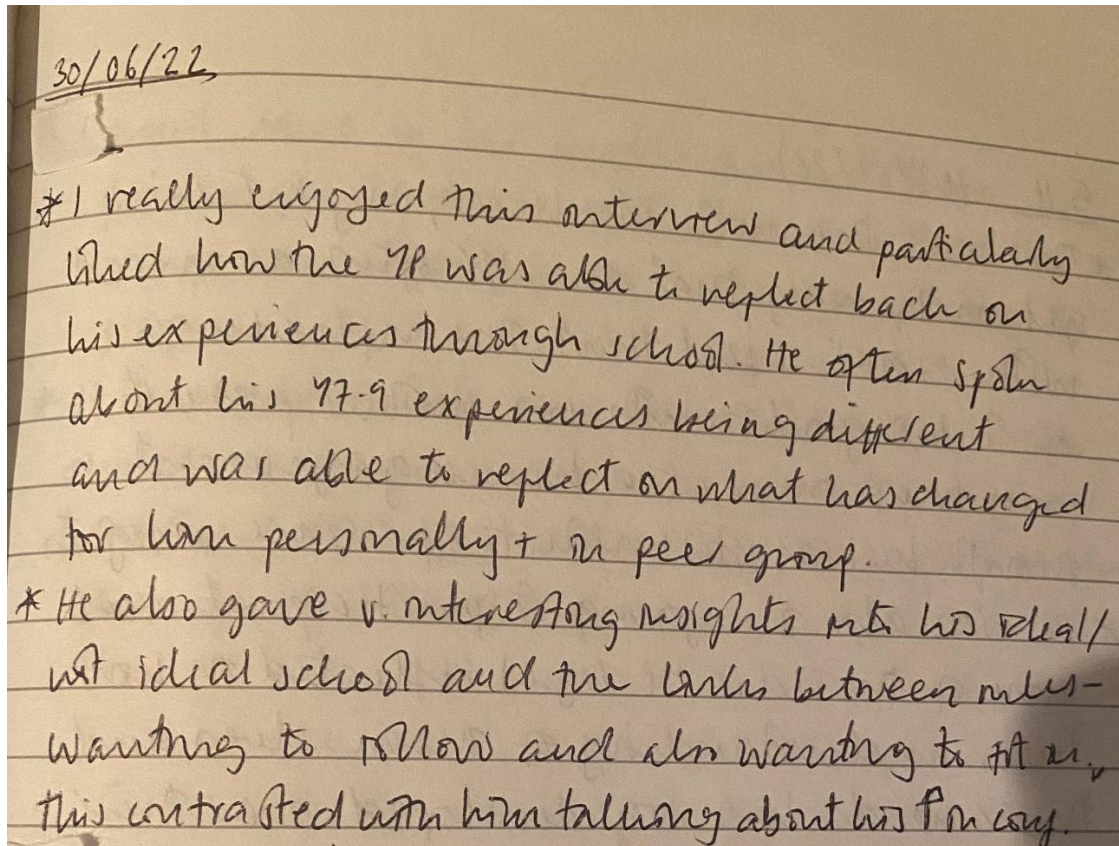
I: So, they are kind of the cards that you were finding worrying, so what about these on the right-hand side, is there any ways that your friends support you with these at all?

P7: Yeah, so with the feeling included, it's kind of like none of us in the friendship group are left out, we always want to see each other, if I'm not in, they text me and ask if I'm coming to school today. There is nothing they do to make me feel like I'm not being included or stuff like that.

## H2 Extracts from Reflective Journal

These extracts demonstrate entries that were recorded in the reflective journal immediately after the interviews with three of the students (participants 5, 6 and 7). I revisited these to actively review and challenge the assumptions I had made when initially coding and generating themes.

### Participant 5 Entry



Participant 6 Entry

(6/17/22)

\* This was a very interesting interview as the 71 was slightly older and very articulate. She discussed how she has learned to manage some of her anxieties and the positive impact her peers have in helping her feel included and make friends. She was particularly keen to talk about her autistic friends and the ways in which they understood her Mtt and humor.

\* She was also keen to talk about the idea of shared morals and understanding of right and wrong.

Participant 7 Entry

[redacted] (08/07/22)  
\* This was a really interesting interview. The YP was again, like P, slightly older so able to reflect on their previous experiences, as well as present. She was articulate with views around teachers not understanding autism

and some of her quotes around this particularly stuck out. She described how her peers were able to help by explaining to staff about her needs.  
\* It was also lovely on a personal level how she thanked me for the research and explained how she felt it was important to support positive change in schools.  
\* She was keen to reflect on her experiences w. EBSA and describe the ways in which her peers helped her cope with anxieties around attending school.

### H3 Initial Audit Trail for RQ2

In the initial analysis, the codes and themes closely represented the participant quotes.

Extract (participant)	Code	Theme
which really helps me get through the day (1)	Getting through the day	Coping
and that gets me through the day (1)		
The thing about having worry is it's never <u>go</u> away I'm always going to have that worry, but the difference between how I was and how I am now is that I now know how to deal with it, how to cope along with it... It's never going to change, I am always going to be walking into a shop and my heart is going to beat faster because it's a changing situation and it's unpredictable and I have no idea what is going to happen, but the difference now is that I now know how to cope with that situation (5)	Coping strategies	
they always listen and give me advice (7)		
I struggle and when it comes to loud noises if I need to leave (7)		Emotional support
They will go for a walk with me and they are very good at picking up when I'm not ok. At the time I am always like 'no I don't need to go on a walk' even though I definitely do so, I don't know, it makes me feel safe (6)	Identifying anxiety	
they know when it's too loud and they say 'do you want to step outside' and remind me to use my timeout card (8)	Encouraging coping strategy?	
they kind of just see when I'm upset if someone has said something to me (8)		
Having people there to talk to and talk at about these kind of things (5)	Someone to talk to about worries	Emotional support
There's not much they can do to mitigate the issue, but more of a shoulder to cry on. Nothing you can do to fix this problem but hey thank you for letting me rant at you for half an hour (5)		
Yeah because if something has happened to me, people could talk to me (1)		
The friends I do have are always there if I need to rant (7)		
to cheer me up and calm me down (7)		Sense of belonging
If I'm upset in school they ask me if I'm ok (8)		
they will sit there and talk to me about what happened (8)		
my friends can say 'oh its ok you can do it' (1)	Reassurance	
I have realised a lot of the time those things I was scared of aren't a big deal (3)		Sense of belonging
In my experience with anxiety, it tends to be a lot of exaggeration and making things seem ten times bigger, so having someone to talk to helps you put things into perspective and think this isn't actually so bad (5)		
They can also make me laugh (1)	Humour	
I know they will be ready to be like 'oh come on you can be with us' (1)	Not being alone	
... and sit there with me (8)		Sense of belonging
if I'm upset about it they do sit there and comfort me (8)		
I will never feel like I won't be able to go with my friends because they don't like me or something like that (1)	Feeling included	

Extract (participant)	Code	Theme
They don't have to have a shared interest but still listening to you (6)		
they know me really well, they thought I was autistic before I did and they just think 'oh that's just X, that's just how X is' (6)		
None of us in the friendship group are left out, we always want to see each other (7)		
if I'm not in <u>they</u> text me and ask if I'm coming to school today (7) (EBSA YP)		
There is nothing they do to make me feel like I'm not being included (7)		
if I did have bullying they could stand up for me (1)	Protection against bullies	
Friends tend to have more similar experiences, if I rant to a parent about school work they can understand but don't have much to empathise with, but if its friends and people close to my age and experiences they can be like 'oh yeah I definitely know what that's like' (5)	Someone to relate to	
can relate with what you're feeling at that time (6)	Shared interests	
play football (2)		
there is always someone that wants to do what you want to do and always someone that has something in common with you (6)	Speaking to staff	Advocate for their needs
I'm still getting bullied they could ask a teacher and they could help and then I know they have done something to help me (1)		
If I am agitated and I go a bit non-verbal, my friend the other day as an example told the teacher what I wanted to say, she spoke for me but not in a bad sense, she helped (7)		
I don't like going by myself to tell teachers what has happened so they go with me. (8)	Standing up against peers	
There was one instance when someone was talking to me about something I was uncomfortable about and I didn't have the confidence to tell him to stop and that friend stepped in and said can you not talk about that (3)		
one of my friends has gone through loads of the school, he's gone around <u>it</u> multiple times before we had to go so he helped me look around and get to know everyone (1)	Familiarising self with school	Orientation
	Familiarising self with people	
Sometimes with work (they help) (2)	Support with schoolwork	Academic support
help me with school work because she knows that I don't really know much (7)		
my friends that are sat next to me prompt me to do my work and write something down (8)	Support with homework	
one of my friends helps me with homework if I get stuck, mainly revision with end of year tests coming up. I know I can message them (8)		
My confidence has grown considerably now (3)	Confidence to be self	Confidence
I can be who I am (3)		

Extract (participant)	Code	Theme
That friend has helped me know it's ok to be yourself and just be who you are (3)		Social Interaction
I think what I need a lot of the time is a prompt because maybe I don't have the confidence to do something myself I need a prompt and someone to say its ok to interact with us. I think that was a big help into why I am more confident now (3)	Prompts	
I don't like making friends so typically I'll let them make friends and then I'll be introduced through them so they've already had a watered-down version of me and then they can have a full on me (6)	Making new friends	
a little bit easier to know what to say with friends (4)	Communication	
With social situations if I'm getting a bit awkward they will talk (7)		

#### ***H4 Final Audit Trail for RQ2***

Following the generation of the initial audit trail, the audio recordings were revisited and the researcher engaged in reflective discussions with peers. This supported the researcher to generate codes and themes that were more interpretive for RQ2.


Extract (participant)	Code	(Sub-theme)	Theme
The thing about having worry is it's never going to go away I'm always going to have that worry, but the difference between how I was and how I am now is that I now know how to deal with it, how to cope along with it... It's never going to change, I am always going to be walking into a shop and my heart is going to beat faster because it's a changing situation and it's unpredictable and I have no idea what is going to happen, but the difference now is that I now know how to cope with that situation (5)	Coping strategies for anxiety provoking situations	Cognitive support	Co-regulation
they always listen and give me advice (7)	Advice		
They will go for a walk with me... at the time I am always like 'no I don't need to go on a walk' even though I definitely do (6)	Coping strategy		
they know when it's too loud and they say 'do you want to step outside' and remind me to use my timeout card (8)			
They can also make me laugh (1)	Positive reframing Humour		
They would use their food to make faces (9)			
to cheer me up (7)			
it makes me really happy and I laugh a lot (9)	Reassurance		
my friends can say 'oh its ok you can do it' (1)			
In my experience with anxiety, it tends to be a lot of exaggeration and making things seem ten times bigger, so having someone to talk to helps you put things into perspective and think this isn't actually so bad (5)	Putting things into perspective Rationalising worries		
I have realised a lot of the time those things I was scared of aren't a big deal (3)	Rationalising thoughts Supporting panic symptoms		
I would be really really sad if I did not have my friends and my worries would be a lot bigger... I would have panic attacks most of the time, I still do but like a lot more and I would just cry a lot because sometimes when I'm really stressed I cry a lot because I feel like I am a disappointment because I overthink a lot (9)			
Having people there to talk to and talk at about these kind of things (5)	Availability to support	Emotional support	
There's not much they can do to mitigate the issue, but more of a shoulder to cry on. Nothing you can do to fix this problem but hey thank you for letting me rant at you for half an hour (5)			
The friends I do have are always there if I need to rant (7)			
Yeah because if something has happened to me, people could talk to me (1)	De-briefing		
they will sit there and talk to me about what happened (8)			

Extract (participant)	Code	(Sub-theme)	Theme
If I'm upset in school they ask me if I'm ok (8)	Emotional check-ins		
And calm me down (7)	Support with regulation		
they kind of just see when I'm upset if someone has said something to me (8)	Emotionally responsive		
if I'm upset about it they do sit there and comfort me (8)			
I was about to have a panic attack and then my friends just came over and helped me up with my stuff and sat with me until I got a little bit better (9)			
they are very good at picking up when I'm not ok (6)	Emotionally perceptive		Sense of belonging
it makes me feel safe (6)	Security		
I know they will be ready to be like 'oh come on you can be with us' (1)	Actively being included		
... and sit there with me (8)	Company		
I will never feel like I won't be able to go with my friends because they don't like me or something like that (1)	Feeling liked and included		
They don't have to have a shared interest but still listening to you (6)	Feeling respected and listened to by others		
they know me really well, they thought I was autistic before I did and they just think 'oh that's just X, that's just how X is' (6)	Feeling accepted for who they are		
That friend has helped me know it's ok to be yourself and just be who you are (3)	Confidence to be self		
My confidence has grown considerably now... I can be who I am (3)			
a little bit easier to know what to say with friends (4)	Knowing what to say		
if I'm not in <u>they</u> text me and ask if I'm coming to school today (7)	Peers wanting you there		
I also am a very generous person and I give my friends food and that makes me happy (9)	Supporting friends		
There is nothing they do to make me feel like I'm not being included (7)	Feeling valued		
without them I would just be alone to be honest because no one really likes me like they do (9)	Include		
if I did have bullying they could stand up for me (1)	Company		
Friends tend to have more similar experiences, if I rant to a parent about school work they can understand but don't have much to empathise with, but if its friends and people close to my age and experiences they can be like 'oh yeah I definitely know what that's like' (5)	Feeling accepted for who they are		
can relate with what you're feeling at that time (6)	Alliance against bullies		
play football (2)	Similar experiences		
	Relate to how feeling		
	Shared interests		

Extract (participant)	Code	(Sub-theme)	Theme
there is always someone that wants to do what you want to do and always someone that has something in common with you (6)	Things in common		
I'm still getting bullied they could ask a teacher and they could help and then I know they have done something to help me (1)	Advocating for needs		Needs being understood
If I am agitated and I go a bit non-verbal, my friend the other day as an example told the teacher what I wanted to say, she spoke for me but not in a bad sense, she helped (7)			
I don't like going by myself to tell teachers what has happened so they go with me (8)	Support with needs		
There was one instance when someone was talking to me about something I was uncomfortable about and I didn't have the confidence to tell him to stop and that friend stepped in and said can you not talk about that (3)	Support in social situations		
With social situations if I'm getting a bit awkward they will talk (7)			
one of my friends has gone through loads of the school, he's gone around it multiple times before we had to go so he helped me look around and get to know everyone (1)	Supporting orientating		
Sometimes with work (they help) (2)	Support with schoolwork		
help me with school work because she knows that I don't really know much (7)			
my friends that are sat next to me prompt me to do my work and write something down (8)	Prompts to engage		
I think what I need a lot of the time is a prompt because maybe I don't have the confidence to do something myself I need a prompt and someone to say it's ok to interact with us. I think that was a big help into why I am more confident now (3)	Prompts to support confidence		
I don't like making friends so typically I'll let them make friends and then I'll be introduced through them so they've already had a watered-down version of me and then they can have a full on me (6)	Support making friends		
one of my friends helps me with homework if I get stuck, mainly revision with end of year tests coming up. I know I can message them (8)	Support with homework		
yesterday I was really stuck and I didn't know what to do and she helped me with my geography homework and she told me what I had to do (9)			

## H.5 Initial Audit Trail for RQ3


In the initial analysis, the codes and themes closely represented the participant quotes.

Extract (participant)	Code	Theme
<p>They don't really mind how I feel and what I look like and stuff like that (1)</p> 	Accepting and celebrating difference	Inclusive
they won't really mind if you're different to them or similar to them (1)		
very open to new things and not like saying that's different so it's automatically bad (3)		
They would be very open and accepting (3)		
being tolerant and accepting of people's differences and in a way celebrating that and just saying you have different strengths and I have different strengths and just get along (3)		
Good to have a mix of people, otherwise it's a bit boring (6)		
Understanding and nice towards everyone in the group and other people outside of the group (7)	Understanding	
one person that I'd known for a really long time or felt 100% stress free around because obviously with masking there are not that many people I feel relaxed around (6)		
Not judging people (3)	Non-judgemental	
being supportive even if they might not know (about autism), just being supportive anyway and very tolerant (3)	Tolerant	
he is very routinely tolerant and not just tolerant but accepting and supportive (3)		
They are really polite, if they teacher is talking they won't talk (1)	Polite	Polite
(not) be rude and annoying (7)		
Playing on PlayStation and playing football and rugby (4)	Shared interests	Commonalities
nice if they had the same interests as that is a really kind of big thing for me (7)		
I really love my friendship group because were not that similar, but we're all fairly smart and all really similar in the things we care about and don't care about so there is a kind of structure and establishment about what's right and what's wrong that we are all in agreement on (6)	Shared views	
Being around the neurodivergent people or mentally ill people is good because everyone has a lot of understanding and we can all laugh about things with people that are similar to you without seeming like a really mean person (6)	Shared neurotype	

Extract (participant)	Code	Theme
cheer me up if there was any homework and to tell you 'you have loads of days to do it, you can try it at school' (1)	Reassuring	Supportive
If there was a student sad they would say 'don't worry about it you can make it through it, don't worry you'll be fine' (1)		
the kind of group that would always be there for you no matter what's happening (7)	Reliable	
supportive, like being there for me (8)		
happy most of the time probably even if there was homework and stuff (1)	Happy	Optimistic
fun and positive people to be around (7)	Positive	
thinking about stuff before they say it (3)	Consideration of others' feelings	Kindness
their humour is not based on them judging people or making fun of people, not based on someone's appearance and how they act (3)	Good humour	
(not) making fun of me or other people, or picking fights with people (7)		
Funny (8)		
we can all laugh about things with people that are similar to you without seeming like a really mean person (8)	Complementary	
simple stuff like 'oh you look nice today' and saying why they look nice, because it might be that they actually put something on in order to look nice (3)		
Friends are very kind... kind and do kind actions (4)	Caring	
A group of nice people to be around (7)		
Caring (8)		
honesty and openness... you have to be honest with yourself (5)	Honest and open	Authentic
comfortable being yourself (5)	Comfortable being self	

### ***H6 Final Audit Trail for RQ3***

Following the generation of the initial audit trail, the audio recordings were revisited and the researcher engaged in reflective discussions with peers. This supported the reviewer to generate codes and themes that were more interpretive for RQ3.

Extract (participant)	Code	(Sub-theme)	Theme
<p>They don't really mind how I feel and what I look like and stuff like that (1)</p> 	Accepting difference		Inclusion
they won't really mind if you're different to them or similar to them (1)			
accepting (3)			
he is very routinely tolerant and not just tolerant but accepting (3)			
being tolerant and accepting of people's differences and in a way celebrating that and just saying you have different strengths and I have different strengths and just get along (3)	Celebrating difference		
Not judging people (3)	Non-judgemental		
Good to have a mix of people, otherwise it's a bit boring (6)	Variety of people		
we have a variety of people (described each friend) (9)			
Having at least one person that I'd known for a really long time or felt 100% stress free around because obviously with masking there are not that many people I feel relaxed around (6)	Not needing to mask		
comfortable being yourself (5)			
very open to new things and not like saying that's different so it's automatically bad (3)	Openness		
They would be very open (3)			
honesty and openness... you have to be honest with yourself (5)			
will include you (9)	Inclusive		
Playing on PlayStation and playing football and rugby (4)	Shared hobbies		Sense of group identity
same favourite colours and same style (9)	Shared fashion		
nice if they had the same interests as that is a really kind of big thing for me (7)	Shared interests		
were all obsessed with stickers... and we all do sticker trading (9)			

Extract (participant)	Code	(Sub-theme)	Theme
I really love my friendship group because were not that similar, but we're all fairly smart and all really similar in the things we care about and don't care about so there is a kind of structure and establishment about what's right and what's wrong that we are all in agreement on (6)	Shared views and morals		
wanting to please people so I would find it hard to say no to people who were peer pressuring me through fear of either being left out or not accepted (3)			
we share thigs for example my stuff (food) and their stuff we usually put it all on a table and share (9)	Sharing food		
we can all laugh about things with people that are similar to you without seeming like a really mean person (6)	Shared humour		
Being around the neurodivergent people or mentally ill people is good because everyone has a lot of understanding and we can all laugh about things with people that are similar to you without seeming like a really mean person (6)	Shared neurotype		
I have a friend in the school who also has autism and she kind of has the same thing as me because she also has the sensitive hearing stuff (9)			Kindness
thinking about stuff before they say it (3)	Considerate		
their humour is not based on them judging people or making fun of people, not based on someone's appearance and how they act (3)	Kind humour		
(not) making fun of me or other people (7)			
simple stuff like 'oh you look nice today' and saying why they look nice, because it might be that they actually put something on in order to look nice (3)	Complementary		
Caring (8)	Caring		
They are really polite, if they teacher is talking they won't talk (1)	Respectful		
(not) picking fights with people (7)			
(not) be rude and annoying (7)			
let you talk (9)			
Friends are very kind... kind and do kind actions (4)	Kindness		
Understanding and nice towards everyone in the group and other people outside of the group (7)	Understanding		
being supportive even if they might not know (about autism), just being supportive anyway and very tolerant (3)	Supportive		
supportive, like being there for me (8)			
cheer me up if there was any homework and to tell you 'you have loads of days to do it, you can try it at school' (1)	Emotional support		
If there was a student sad they would say 'don't worry about it you can make it through it, don't worry you'll be fine' (1)			
the kind of group that would always be there for you no matter what's happening (7)	Reliable		