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UNIVERSITY OF SOUTHAMPTON

FACULTY OF PSYCHOLOGY

Doctorate in Educational Psychology

Volume 1 of 1

**Understanding the school outcomes for, and experiences of, siblings of children with
autism**

by

Alexandra Gregory

Thesis for the degree of Doctorate in Educational Psychology

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ABSTRACT

FACULTY OF PSYCHOLOGY

Doctorate in Educational Psychology

**UNDERSTANDING THE SCHOOL OUTCOMES FOR, AND EXPERIENCES
OF, SIBLINGS OF CHILDREN WITH AUTISM**

Alexandra Gregory

A systematic literature review was conducted to explore the educational outcomes for, and experiences of, siblings of children on the autism spectrum (autism siblings). Whilst there is a growing body of research on the psychological outcomes for autism siblings, few studies have considered how this might influence the school context. Findings were linked to the Siblings Embedded Systems Framework; school factors, psychological internal challenges and resources, peers and other formal and informal social systems, and personal interpretation of events. Overall, school outcomes and experiences showed large variation, suggesting that some autism siblings are at increased risk of difficulties in the school context, but that autism siblings do not automatically experience challenges in school. Nevertheless, the review highlighted a number of methodological limitations of the evidence-base in this area, including the small body of literature, particularly in the UK, studies of low methodological rigour, such as those employing small sample sizes, and reliance on solely parent-reported outcomes. This limits the conclusions that can be drawn.

The empirical study extended the current literature to explore two school-related outcomes; sense of school belonging and academic self-concept. Using online questionnaires, autism siblings and siblings of typically developing children without autism (typical siblings) aged 11 to 16 years in secondary schools across the UK took part.

Data on sibling wellbeing were also triangulated via self-, parent/carer- and teacher-reports. Relative to typical siblings, autism siblings self-reported significantly lower school belonging and academic self-concept, in addition to significantly lower self, parent- and teacher-reported wellbeing outcomes. Regression models established that sibling-reported internalising and externalising behaviours significantly predicted both school-related outcomes. Sibling group was also a significant predictor in all models, demonstrating that even once demographic variables and sibling wellbeing were controlled, robust sibling group differences were still present. Despite these findings, there was a greater variation in autism siblings' school outcomes compared to typical siblings. Therefore, this study highlights the importance of taking an individualised and person-centred approach to understanding the varying needs of, and providing support to, siblings of children on the autism spectrum.

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Academic Thesis: Declaration of Authorship

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

Understanding the school outcomes and experiences of siblings of children with autism.

I confirm that:

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

Signed: Alexandra Gregory

Date: 04.06.18

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Definitions and Abbreviations

ABA	Applied Behaviour Analysis
ADHD	Attention Deficit Hyperactivity Disorder
APA	American Psychiatric Association
ASC	Autism Spectrum Condition
Autism siblings	Siblings of children with autism
BAP	Broader Autism Phenotype
CASP	Critical Appraisal Skills Programme
CBC	Child Behaviour Checklist
Down's syndrome siblings	Siblings of children with Down's syndrome.
DSM-5	Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition)
DV	Dependent Variable
EAL	English as an Additional Language
ELSA	Emotional Literacy Support Assistant
EP	Educational Psychologist
ERGO	Ethics and Research Governance Online
GCSE	General Certificate of Secondary Education
IV	Independent Variable
IQ	Intelligent Quotient
MALS	Myself-As-A-Learner Scale
MDI	Multiple Deprivation Index/Indices
N	Number of participants
NAS	National Autistic Society
NEET	Not in Education Employment or Training
PCSC	Perceived Competence Scale for Children

Definitions and Abbreviations

PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PSSM	Psychological Sense of School Membership Scale
RQT	Rutter Questionnaire for Teachers
SAICA	Social Adjustment Inventory for Children and Adolescents
SCS	Self-Concept Scale
SDQ	Strengths and Difficulties Questionnaire
SDT	Self-Determination Theory
SEN	Special Educational Needs
SES	Socio-Economic Status
SESF	Siblings Embedded Systems Framework
SPSS	Statistical Package for the Social Sciences
SRS	Social Responsiveness Scale
SSRS	Social Skills Rating System
SSSC	Social Support Scale for Children
TBS	The Belonging Scale
TRF	Teacher Report Form
Typical siblings	Siblings of typically developing siblings
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation
WISC	Wide Range Intelligence Scale for Children
WRAT	Wide Range Achievement Test

Chapter 1 The school outcomes for, and experiences of, siblings of children with autism: A systematic review of the literature.

1.1 Introduction

1.1.1 Siblings of children with disabilities

Disability is defined by the World Health Organisation (WHO, 2018) to include impairments, activity limitations, and participation restrictions, which encompasses both physical and psychological difficulties. From a family systems theory perspective, having an individual with a disability in the family is predicted to have an influence on the subsystems within families, such as parents/carers (referred to hereafter as parents) and siblings (Cox & Paley, 1997; Turnbull, Turnbull, Erwin & Soodak, 2006). Accordingly, researchers have investigated the positive and negative impact on other family members of having a child with a disability in the family. However, historically, in addition to research on the child with autism, research has focused primarily on the psychological outcomes for (e.g. Montes & Halterman, 2007), and personal experiences of (e.g. Gregory, 2017), mothers. Griffiths and Sin (2013) suggested this focus may partly be because services are currently largely designed to meet the needs of primary caregivers and the individual with the disability.

Leder (1994) emphasised the importance of focusing research on sibling relationships, particularly as a reported 80% of Americans have at least one sibling, a figure which is likely to be similar in the UK. Leder highlighted that siblings develop our personalities, learning, and even our career paths, with Leder reporting that many siblings of children with disabilities (referred to hereafter as siblings) enter the helping professions. Barak-Levy, Goldstein and Weinstock (2010) also argued that siblings provide a model for

the development of social skills and future social relations in childhood. For example, Verté, Roeyers and Buysse (2003) suggested that skills such as competition and cooperation are learnt between siblings, which can later ease their acceptance into peer groups. Moreover, as the sibling relationship often outlives that of our parents, and is, therefore, long-lasting, siblings are an important population of interest for developmental psychology.

When a sibling has a disability, relationships may not develop typically and siblings may have to learn to adapt and cope with additional challenges and demands (Griffiths & Sin, 2013). For example, Griffiths and Sin reported that siblings may have to play a significant role in providing care and support for their brother or sister with a disability, which can change the sibling role, but this is often overlooked within support services. Moreover, less attention has been paid to researching the outcomes for, and experiences of, siblings. In practice, this means their needs may be undetected and neglected.

In the existing sibling literature, it has been commonly hypothesised that the impact of having a sibling with a disability will be negative. This has led to a deficit-focused evidence-base focused on identifying mental health problems in siblings. However, findings from individual studies in this area have been inconsistent and contradictory. For example, compared to siblings of typically developing children without a disability (referred to hereafter as typical siblings), some studies have found negative outcomes such as increased levels of problems in interpersonal relationships and psychological wellbeing (Goudie, Havercamp, Jamieson & Sahr, 2013), while other studies have shown positive outcomes such as greater empathy and perspective-taking and less reported conflict between siblings (Stoneman, 2005).

Meta-analytic studies also report inconsistent findings. For example, Rossiter and Sharpe (2001) found a small negative effect for siblings of individuals with ‘mental retardation’, such as in the area of psychological functioning (especially depression). By contrast, a more recent review of siblings of children with intellectual disabilities by

Hastings (2014) concluded that siblings' psychological wellbeing was unaffected overall, although this review was not systematic. In part, these mixed findings may be a result of a number of methodological limitations in the evidence-base, including small sample sizes and lack of control groups, as well as the ranges of ages, disability groups, and outcome measures used in and across studies. Despite these mixed findings, a sub-group of siblings are consistently shown to be at increased risk of psychological difficulties; siblings of children who display challenging behaviour (Neece, Blacher & Baker, 2010; Meyer, Ingersoll & Hambrick, 2011; Petalas, Hastings, Nash, Reilly & Dowey, 2012) and siblings who take on significant caregiving responsibilities (Hannah & Midlarsky, 1985; The Children's Society, 2013).

1.1.2 The Siblings Embedded Systems Framework

The Siblings Embedded Systems Framework (SESF) identifies a range of factors that may account for some of the variation in sibling adjustment (Kovshoff, Cebula, Tsai & Hastings, 2017). In addition to within-sibling factors (e.g. demographics; personal interpretation of events; genetic/psychological internal challenges and resources), Kovshoff et al. also outline factors related to micro and mesosystems (e.g. peers/social systems; school/workplace), exosystems (e.g. media; political and social structures), and macrosystems (e.g. religion; wealth/social class). This framework benefits from exploring the effect of multiple and interacting mechanisms at the individual, family, and wider systems levels on sibling experiences. It also moves beyond a deficit model, to a more holistic, dynamic, and integrated systems approach in which the sibling is viewed as actively, rather than passively, shaping their experiences and outcomes. Figure 1 shows a visual representation of this framework.

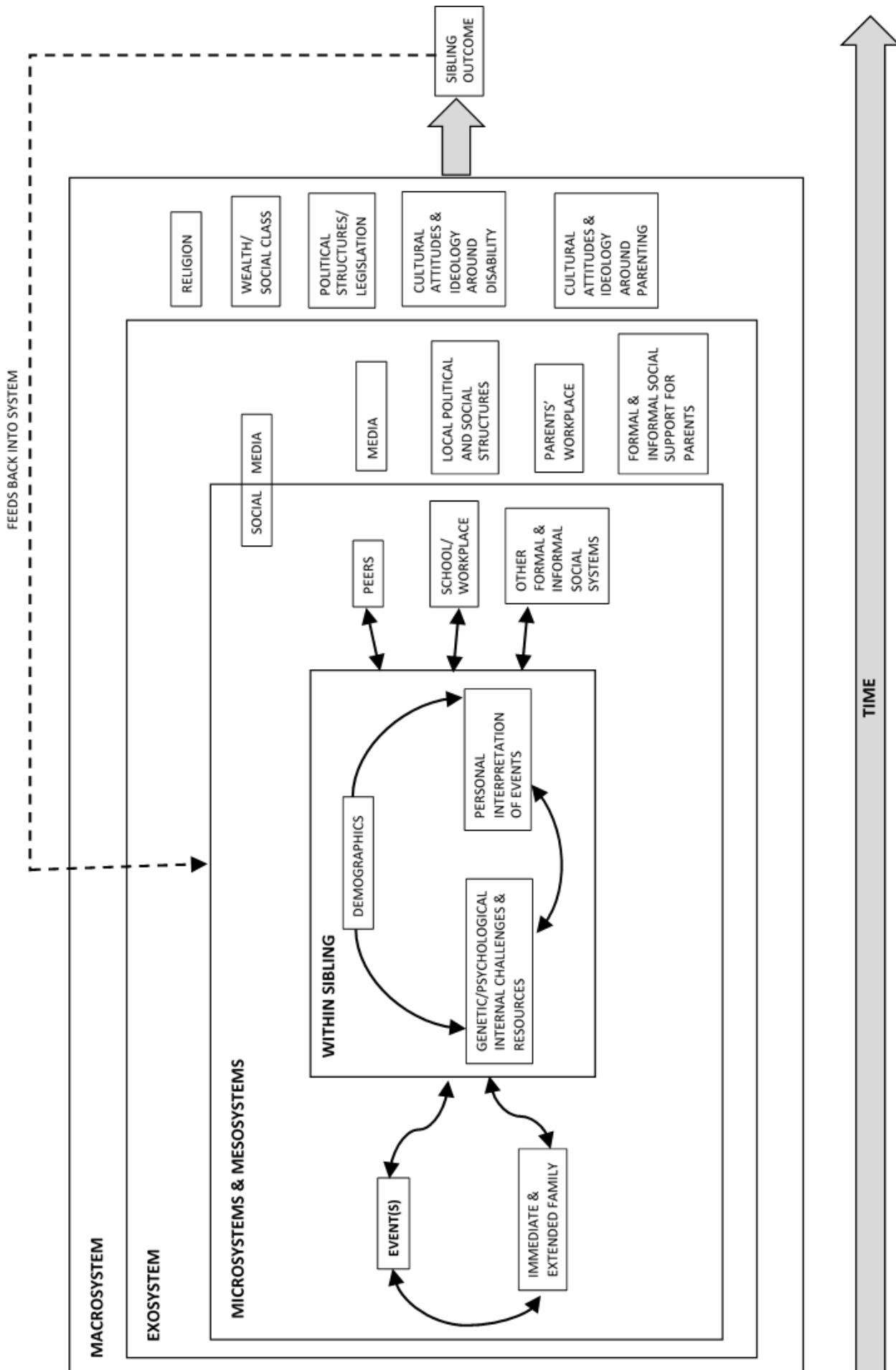


Figure 1. Siblings Embedded Systems Framework.

1.1.3 The school context

To fully understand the potential benefits and challenges of having a sibling with a disability, researchers need to consider a broader set of outcomes than the current, often sole, focus on psychological adjustment. Accordingly, Kovshoff et al.'s (2017) SESF identifies the school context, and the peers/social systems within it, as a wider system influencing sibling outcomes. The school context is particularly significant as, after the home environment, children typically spend the majority of their time there. Like the sibling relationship, school life affects all areas of a child's development, including academic, emotional, social, and physical development (Chien, Tu & Gau, 2017).

Being a sibling to a child with a disability may impact school outcomes and experiences for a number of reasons. For example, parents and siblings in such families are at increased risk for poorer psychological wellbeing, and, in typical siblings at least, researchers have linked child and parental mental health difficulties to poorer child academic outcomes (Scott, Spielmans & Julka, 2004; Child and Young People's Health Outcomes Forum, 2012). Moreover, due to the increased needs of children with disabilities, more parental time, attention and support may be focused on the child with the disability. In typical siblings, researchers have shown that less social support from parents negatively impacts on students' academic achievement (Cutrona, Cole, Colangelo, Assouline & Russel, 1994). The relatively recent promotion on inclusion of children with Special Educational Needs (SEN) in mainstream schools, referred to as deinstitutionalisation by McHale (1986), may mean siblings attend the same school. Due to increased stigma related to disability and mental health (Griffiths & Sin, 2013), this could mean siblings experience adverse reactions from peers, which may affect their school social outcomes. Furthermore, as research has highlighted, siblings may take on increased caregiving responsibilities. Some of these roles may then also blend into the school environment, potentially impacting school outcomes.

Conversely, other literature demonstrates that school may be a protective factor for siblings. For example, in this context, Walton (2016) reported that siblings may be able to escape from the stresses of family life, and Macks and Reeve (2007) argued that siblings can build strong friendships and rely on social support from classmates or teachers. The overcompensation hypothesis suggests that siblings may feel pressure to compensate for the difficulties their sibling with the disability faces (Barak-Levy et al., 2010), which may in turn lead to improved academic outcomes.

Nevertheless, despite the importance of the educational context and various hypotheses about how siblings may be impacted, minimal studies have been dedicated to this area. Nevertheless, The Children's Society (2013) explored the academic outcomes of young carers, in which 50% were caring for a sibling with a health or disability need. Findings showed that young carers had significantly lower attainment at GCSE level and were more likely not to be in employment, education or training (NEET) between ages 16 and 19 than the national average. Goudie et al. (2013) found more problems in siblings' functioning at school compared with a control group, such as behaviour and completing school work, although this was parent- rather than self-reported. However, Dyson (2003) found the academic self-perception of siblings was "well within the normative range" (p. 6).

In a qualitative study, Dyson (2007) used focus group interviews to explore the effects of the inclusion of children with learning disabilities at school on their families. Siblings reported unrealistic expectations from teachers, which perhaps reflects the often undetected needs of siblings. In a study exploring the needs and experiences of siblings of individuals with first-episode psychosis, Sin, Moone, Harris, Scully and Wellman (2012) reported that siblings expressed loneliness and looked to their friends and teachers for emotional support. This again reflects that school, and more specifically social support, may be a protective factor for sibling adjustment. However, siblings also reported feelings of embarrassment, fear of stigma, and lack of understanding, which meant they often kept

their siblings' illness hidden from school and friends and did not invite people back to their homes. These factors may impact on their school social and emotional outcomes. It must be noted, however, that these studies often use mixed disability samples (e.g. Goudie et al., 2013), which cannot account for experiences that may be unique to a particular condition, such as autism.

1.1.4 Autism siblings

Autism Spectrum Condition (ASC) is a lifelong neurodevelopmental disorder first identified by Kanner (1943). The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) defines Autism Spectrum Disorder (ASD) to include persistent difficulties in social communication and interaction and restricted, repetitive patterns of behaviour, interests or activities (American Psychiatric Association (APA), 2013). Although estimates vary, statistics suggest autism affects 1.1% of the general population and is diagnosed more in males (2%) than females (0.3%) (Brugha et al., 2012). As siblings of children with autism (referred to hereafter as autism siblings) are often referred to in the literature to be a sub-group at increased risk for difficulties, there has been growing autism sibling research. Nevertheless, reviews on the psychological outcomes of autism siblings have also found mixed social, emotional and behavioural outcomes (Meadan, Stoner & Angell, 2010; Green, 2013; Aparicio & Minguez, 2015).

Despite this focus on psychological outcomes, there has been limited research into autism siblings' school outcomes and experiences. Compared to other disabilities, autism may bring a unique set of characteristics that lead to increased vulnerability to poorer school outcomes. Firstly, autism is sometimes described as the 'invisible disability', with no observable physical characteristics (Milton, 2012; Hoogsteen & Woodgate, 2013). This could bring the challenge of others doubting that the family member has a disability (Moyson & Roeyers, 2011), which may lead to peers and teachers not recognising sibling needs. Alternatively, this may have the benefit of reduced prejudice and stigma, which may

be protective for social outcomes. Secondly, autism can be associated with challenging behaviour, which can negatively impact siblings' emotional adjustment (Meyer, Ingersoll & Hambrick, 2011). For example, Gorjy, Fielding and Falmer (2017) reported that unpredictable behaviours can lead to high levels of anxiety, external pressure, and instability for siblings. Thirdly, autism-specific social and communication difficulties may impact on sibling relationships and social outcomes at school. Lastly, autism can also be associated with co-occurring conditions, such as learning disabilities (Kim, Szatmari, Bryson, Streiner & Wilson, 2000) or mental health issues such as anxiety (Ghaziuddin, 2002), which could impact siblings. However, these potential risk factors assume the source of any difficulties experienced by the sibling are a function of the child with autism's condition.

Although there are limited studies exploring causal mechanisms, any increased risk of difficulties for autism siblings may, at least in part, be a function of more systemic factors, such as reduced time, attention, and support from parents (Macks & Reeve, 2007; Petalas, Hastings, Nash, Dewey & Reilly, 2009; Benderix & Sivberg, 2007), increased parental expectations (Quintero & McIntyre, 2010), the stress of fulfilling multiple family roles (Stoneman, 2005), resentment of increased responsibilities damaging the sibling bond (Harris & Glasberg, 2012), differential treatment of siblings (McHale & Pawletko, 1992), poorer maternal wellbeing (Quintero & McIntyre, 2010), and higher levels of stress in families of children with autism (Bebko, Konstantareas & Springer, 1987; Weiss, 2002), including in the marital relationship (Rivers & Stoneman, 2003) and parenting (Rao & Beidel, 2009). The pattern of autism inherited in some families also means autism can be more common in siblings (Autism Society, 2018). Siblings may also have subtle traits of autism that do not meet clinical significance, which is known in research as the Broader Autism Phenotype (BAP; Piven, 2001).

1.1.5 Rationale and aim

With regards to autism siblings' school outcomes and experiences, no published systematic reviews are currently available in this area to consolidate this relatively small body of research, relative to siblings' psychological wellbeing. Therefore, the need to synthesise evidence and plan for future research remains a priority. Accordingly, this review specifically aims to answer the following research question: What are the school outcomes for, and experiences of, siblings of children with autism?

1.2 Method

1.2.1 Search strategy

To answer this question, a systematic literature search of studies was conducted using three online electronic databases; PsycINFO, Web of Science and ERIC. Studies were identified through combining the following final search terms/key words generated by the author in October 2017 (with the search commands 'OR' and 'AND' between) to identify; a sample of siblings ("sibling*" OR "brother*" OR "sister*" searched for in the title) of individuals with autism (AND "autis*" OR "asperger*" searched for in the title), and outcomes or experiences related to school (AND "educat*" OR "school*" OR "academ*" OR "class*" OR "learn*" OR "lesson*" OR "attain*" OR "achiev*" OR "atten*" OR "concentrat*" OR "self-concept" OR "belong*"). Asterisks were used at the end of words to retrieve terms with different endings. For example, academ* would find the words academia, academic and academics. Searches were limited to the English language and publication in a peer-reviewed journal.

1.2.2 Inclusion and exclusion criteria

Pre-defined inclusion and exclusion criteria were developed (Table 1) to minimise the possibility of selection bias of studies, and articles were scanned for their relevance against these criteria.

Study item	Inclusion criteria	Exclusion criteria
Type of research	Original/primary research.	Secondary research e.g. discussions, review articles, conference presentations, and blogs.
Publication requirements	Published in a peer-reviewed journal.	Published in a book, case reports, non-peer-reviewed work, and unpublished work e.g. dissertations.
Date	Any year.	N/A.
Language	English language.	Any language other than English.
Participants	A sample of siblings of children with autism. Samples that include the school age range 4 to 19.	Siblings of children with any other disability other than autism. Participants aged below 4 (including the early years) and above 19.
Informants	Siblings, parents/carers, and teachers.	N/A.
Methodology/ study design	Quantitative, qualitative, and mixed methods studies. Quantitative studies: Assessment/measure included specific to school.	Studies that do not report an assessment/measure or aim or interview question specific to school.

	Qualitative studies: Aim or interview question included specific to school.	
Findings/ outcome variables	Studies reporting findings specific to school outcomes or experiences.	Papers that do not include any findings specific to school outcomes or experiences.

Table 1. Literature review exclusion and inclusion criteria.

Given the limited research in this area, the search was not restricted by date or country. Participants were aged 4 to 19 to capture all outcomes and experiences across the school-age range. Quantitative (outcome-related), qualitative (experience-related) and mixed methods research was included so as all studies relevant to school could be captured. Measures had to be specific to the school context or reported by a school teacher, which included findings related to academic attainment, attitudes to learning, peer relations, and school behaviour, but not studies on ‘intelligence’/IQ or ‘cognitive functioning’.

1.2.3 Study selection

The initial searches in each database produced a total of 401 articles (PsycINFO n = 212; ERIC n = 70; Web of Science n = 119). Once duplicates were removed, using the reference management software Mendeley, 229 articles remained. The titles and abstracts of these articles were screened for their relevance against the predetermined inclusion and exclusion criteria. This led to the exclusion of 186 papers. 43 full-text articles were retrieved for a more in-depth review. Following reading these papers, 30 articles were excluded (see Appendix A for exclusion rationales). This led to a total of 13 articles in the current review (10 quantitative, 2 qualitative, and 1 mixed methods). See Figure 1 for the PRISMA recording flow diagram, which shows the paper identification and search/screening process (Moher, Liberati, Tetzlaff & Altman, 2009).

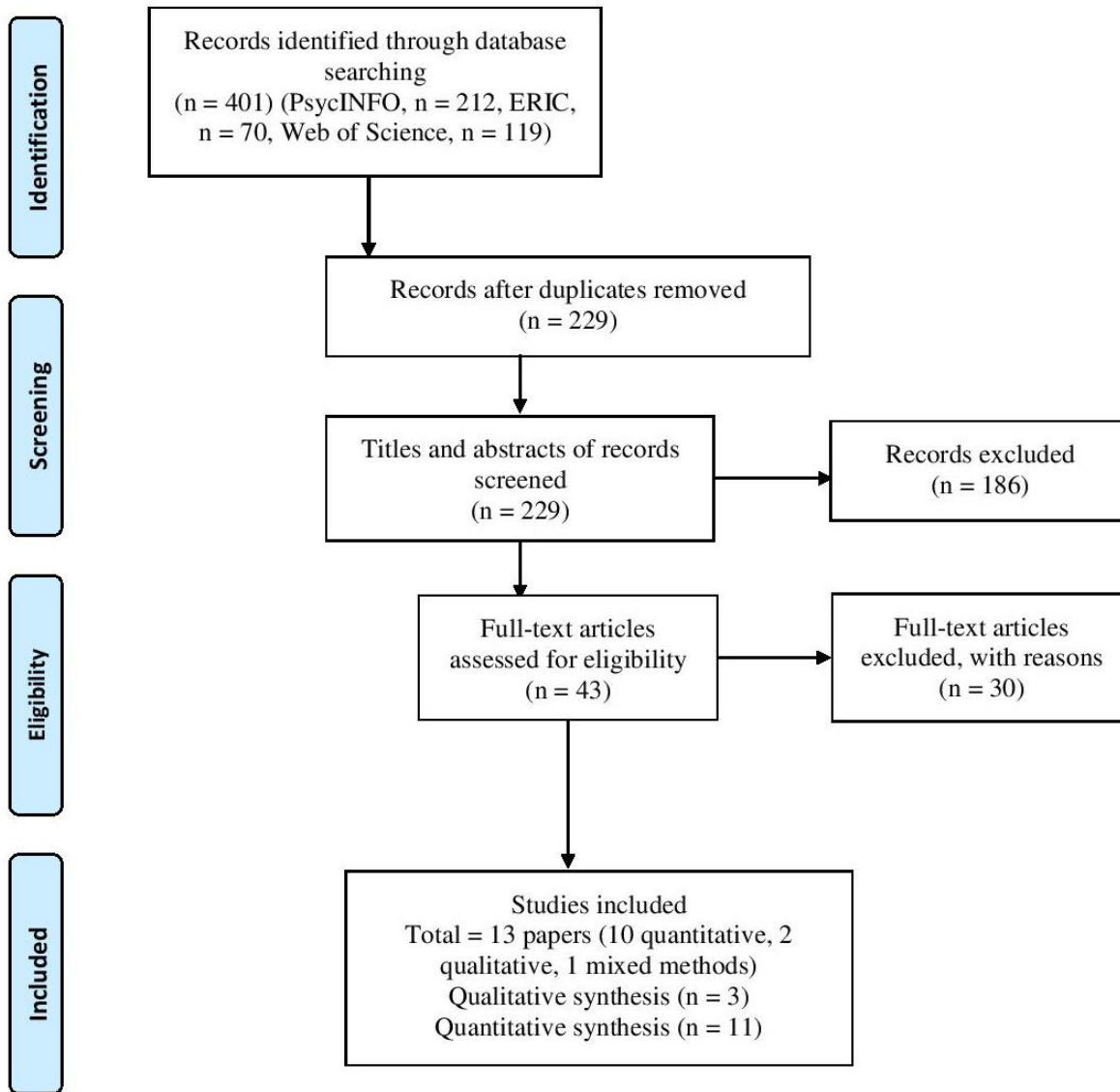


Figure 2. Literature review PRISMA flowchart.

1.2.4 Data extraction

Key data regarding the study characteristics and findings were summarised for the final eligible studies in a data extraction table (Appendix B for quantitative studies and C for qualitative studies). This data included; authors names, study title, year, country, aim, participant information (e.g. sample size, ages and genders), study design, outcome measure for quantitative studies, interview question and/or aim for qualitative studies, and school-specific findings.

1.2.5 Quality assessment

To provide a more objective and rigorous way of evaluating the strengths and weaknesses of the methodology and reporting of eligible studies, studies underwent a quality assessment process. A different quality assessment framework and research checklist was used dependent on the research design. Downs and Black (1998) was used to assess quantitative and mixed methods papers, and the Critical Appraisal Skills Programme (CASP, 2017) was used to assess qualitative papers.

The Downs and Black (1998) research checklist usually consists of 27 items separated into five subscales; reporting, external validity, internal validity - bias, internal validity - confounding (selection bias), and power. As this checklist was created for health intervention studies, a number of adaptations were made to ensure the tool was appropriate to the review question (see Appendix D for the adapted version). For example, questions related to interventions, follow-ups, and randomisation to groups were not applicable to the review, so this led to the removal of items 4, 9, 14, 15, 17, 19, 23, 24 and 26. The wording was changed for items 3, 8, 13, 21 and 22, such as patients to participants (3), interventions to study (8), and making an item specific to the educational context (13). Items 1, 2, 5, 6, 7, 10 and 11 were kept the same. The CASP (2017) checklist consists of 10 items and no adaptations were made to this tool (Appendix E).

Both checklists can be used to numerically score the quality of each study. However, Booth, Papaioannou and Sutton (2012) questioned the usefulness of its scoring in understanding the validity of research findings in individual studies. Therefore, only 'yes' and 'no' responses were given for each item for individual studies, but scores for each item overall were reported in the appendix to assess common strengths and limitations of the evidence-base, along-with a descriptive summary in the results section.

1.3 Results

1.3.1 Study characteristics

The final 13 studies exploring the school outcomes for, and experiences of, autism siblings were published between 1981 and 2017. Studies were from a range of countries nationwide; USA (6), Israel (2), Taiwan (1), Canada (1), Australia (1), Sweden (1), and the UK (1). Autism siblings sample sizes ranged from 11 to 71, with a mean sample size of 35. Collectively, all papers included 482 autism siblings, with a further 543 participants in the control groups (some studies had more than one control group). Overall, 56% of participants were male and 44% were female. The age of siblings ranged from 4 to 19 years.

Studies did not often include main initial aims specific to school, except in Mates (1990), Ben-Yizhak et al. (2011), and Chien et al.'s (2017) studies. Instead, the majority aimed to explore siblings' psychological adjustment more generally. Therefore, measures/outcomes and questions/experiences relevant to school had to be extracted and those unrelated excluded for the purposes of the review. A range of measures were used in the included studies. For quantitative studies including academic school measures/outcomes, three used the Wide Range Achievement Test (WRAT; Jastak & Wilkinson, 1993) (August, Stewart & Tsaim 1981; Ben-Yizhak et al., 2011; Mates, 1990), two used the School Performance subscale of the Child Behaviour Checklist (CBC; Achenbach, 1991) (Barak-Levy et al., 2010; Kaminsky & Dewey, 2002), and one used the Perceived Competence Scale for Children (PCSC; Harter, 1979) (Rodrigue et al., 1993). For studies including emotional and behavioural school measures/outcomes, two used the Teacher Report Form (TRF; Achenbach & Rescorla, 2009) (Nowell, Brewton & Goin-Kochel, 2014; Quintero & McIntyre, 2010), two used the Rutter Questionnaire for Teachers (RQT; Rutter, 1967; Rutter, Tizard & Whitmore, 1970) (Mates, 1990; Bagenholm & Gillberg, 1991), one used the Strengths and Difficulties Questionnaire

(SDQ; Goodman, 1997) (Cebula, 2012), and one used the Piers-Harris Children's Self-Concept Scale (SCS; Piers, 1984) (Macks & Reeve, 2007). For studies including social school outcomes/measures, one used the Social Adjustment Inventory for Children and Adolescents (SAICA; John, Gammon, Prusoff & Warner, 1987) (Chien, Tu & Gau, 2017), one used the Social Support Scale for Children (SSSC; Harter, 1985) (Kaminsky & Dewey, 2002), and one used the Social Skills Rating System (SSRS; Gresham & Elliott, 1990) (Quintero & McIntyre, 2010). All studies were cross-sectional, in which data were collected at one time-point with no follow up.

Regarding the informants for quantitative studies, three used direct attainment measures with the sibling (August et al., 1981; Ben-Yizhak et al., 2011; Mates, 1990) and three used self-report questionnaires (Kaminsky & Dewey, 2002; Macks & Reeve, 2007; Rodrigue et al., 1993). Seven used other informant-based measures, including four parent-report (Barak-Levy et al., 2010; Chien et al., 2017; Kaminsky & Dewey, 2002; Quintero & McIntyre, 2010), and four teacher-report (Cebula, 2012; Mates, 1990; Nowell et al., 2014; Quintero & McIntyre, 2010). For qualitative studies, all three included parent interviews (August et al., 1981; Bagenholm & Gillberg, 1991; Cridland, Jones, Stoyles, Caputi & Magee, 2015). Cridland et al. (2015) was the only study to interview siblings, in addition to the individual with Asperger's, mothers and fathers.

Although the majority of studies had a control group, one measured the impact of an intervention for the child with autism on the autism sibling, so had no control group of typical siblings (Cebula, 2012), another focused on the child with autism and used autism siblings as the control group (Nowell et al., 2014), and a further study did not include a control group at all (Mates, 1990).

1.3.2 Quality assessment: Quantitative studies

Reporting. All 11 studies including quantitative measures clearly described the aims, outcomes to be measured, and participant characteristics. Confounding variables

were only described in five studies, the main findings were only clear in seven studies (and less clear with less recent studies), and estimates of the random variability in the data (such as the inter-quartile range, standard deviation or confidence intervals) were only provided in six studies. Adverse events that may have been a consequence of the research were not reported in any studies, even though questionnaires related to potentially personal and sensitive experiences. Exact probability values and effect sizes were also often not reported.

External validity. Families were usually recruited from specific samples and locations, in which families and siblings self-selected/volunteered for the study. Some siblings and families were unwilling to participate, perhaps because of the potentially personal and sensitive experiences (e.g. Ben-Yizhak et al., 2011; Mates, 1990). Therefore, samples were not representative of all autism siblings. Nevertheless, randomised sampling is more difficult to achieve from this unique population. Moreover, as subjects are born into the autism and typical siblings groups, subjects cannot be randomised to different conditions. No studies reported on the siblings' educational setting, so it cannot be determined whether these contexts were representative. With only one study conducted in UK (Cebula, 2012), the findings of this review may not be generalisable to the UK education system.

Internal validity. Data dredging (analyses that had not been planned at the outset of the study) did not take place in any of the included studies. Nine studies used appropriate statistical tests to assess the main outcomes, with the measures used appearing accurate (valid and reliable). The time frame in which the data were collected from cases and controls was only reported in one study. However, due to the cross-sectional nature of study designs, it can be assumed that data were collected at a similar time point for all participants. As cases and controls were often not recruited from the same schools, participants are likely to have experienced a wide range of educational experiences.

Power. No studies reported power calculations to determine sample size and many had small sample sizes that appeared unlikely to have sufficient power to detect effects.

1.3.3 Quality assessment: Qualitative studies

For the two qualitative studies, the aims and participants were clearly described, and the recruitment strategy and data collection were appropriate. Significantly rigorous data analysis, a clear statement of findings, and ethical issues such as adverse effects were only taken into consideration in one study. The relationship between the researcher and participants was not described in either studies, which could suggest a risk of bias.

1.3.4 Synthesis of findings

Findings were synthesised and organised using the SESF, which provided a useful framework to understand sibling experiences and outcomes. Eight studies reported on academic school outcomes/experiences, which were linked to ‘school factors.’ Five reported on emotional and behavioural school outcomes/experiences, which were linked to ‘psychological internal challenges and resources.’ Four reported on social school outcomes/experiences, which were linked to ‘peers’ and ‘other formal and informal social systems.’ One qualitative study focused on the roles and responsibilities siblings took on in school, which was linked to ‘personal interpretation of events.’

1.3.5 School factors

School factors incorporate findings related to academic achievement. Findings were mixed for autism siblings, with the majority reporting no significant differences (Ben-Yizhak et al., 2011; Chien et al., 2017; Kaminsky & Dewey, 2002; Mates, 1990; Quintero & McIntyre, 2010), but one study reporting increased academic achievement (Rodrigue et al., 1993), and two reporting poorer academic achievement (August et al., 1981; Barak-Levy et al., 2010).

Mates (1990) aimed to explore siblings' adjustment and performance at home and school. With the benefit of using direct assessment measures, Mates used the WRAT to explore academic achievement and found no significant differences related to gender or family size of the siblings, as well as compared to the normative samples. However, this study did not use a control group and had a small sample size of 33 siblings, which became even smaller when divided into the four groups based on their gender and family size. Therefore, this study may not have had sufficient power to detect effects, which may account for the non-significant findings.

Ben-Yizhak et al. (2011) aimed to compare the linguistic abilities of autism siblings and also used the WRAT to explore academic achievement. With the strength of using a control group, they similarly found no significant results in reading, spelling, and arithmetic. As a result, they concluded that participants in the autism siblings group were "typically developing" (p. 757). However, this was also a small sample with which to generalise from, with 19 autism siblings, compared to 13 autism siblings who met BAP criteria, and 38 typical siblings. Again, this study may not have had sufficient power to detect significant findings. Their study was also focused on identifying early markers of risk for the siblings developing ASC, rather than on understanding school experience more broadly.

A mixed methods study conducted by August et al. (1981) aimed to explore the incidence of cognitive disabilities in siblings, with a larger sample of 71 autism siblings and control group of 38 siblings of children with Down's syndrome (Down's syndrome siblings). The WRAT was combined with a parental interview to gain information on academic achievement "concerning the child's academic progress, specifically regarding the need for any special remedial education" (p. 417-418). For autism siblings, 7 out of 11 with a cognitive disability "were receiving special educational remediation for the mentally disabled" (p. 418). Findings were reported that autism siblings had increased difficulties with reading, with two autism siblings demonstrating a specific learning disability in this

area. However, there were no reported statistical tests to compare the findings nor a control group of typical siblings. These two siblings were also said to be in classes for children with ‘learning problems’, compared to one control group participant with a cognitive disability. However, with almost double the number of focus participants than controls, these findings may be misleading. The paper also does not describe the specific questions asked of parents regarding siblings’ academic progress. Moreover, the data for arithmetic and spelling were not reported. Therefore, it is impossible to know whether autism siblings had increased difficulties in these areas or not.

Barak-Levy et al. (2010) aimed to explore the social and emotional adjustment of autism siblings and used the School Performance subscale of the CBC to explore academic achievement. Through parent-report, 37% of siblings performed in the borderline clinical range and 14.8% performed in the clinical range. The authors also stated that “over half of the siblings reportedly have more academic difficulties than the CBC norm” (p. 159). However, findings were not compared to the control group and, again, this was a small sample for quantitative analysis (27 siblings in each condition), which limits the generalisability of findings. Moreover, findings were also based on solely parent-report to assess academic achievement, rather than using direct assessment measures, collecting data from the school, or including teacher-report, which may have higher validity and reliability.

Kaminsky and Dewey (2002) aimed to explore the psychosocial adjustment of autism siblings and similarly used the CBC to assess academic achievement. This study had the strength of using two control groups (typical and Down’s syndrome siblings), which has the potential to show whether any differences are specific to autism, or to more generally being a sibling to someone with a disability. No significant effects were found, but academic achievement was significantly positively correlated with higher levels of social support from classmates. Nevertheless, this study also had a small sample size of 30

children in each group and the academic achievement measure was based on parent-report alone.

Quintero and McIntyre (2010) aimed to examine older autism siblings' psychological adjustment, as well as maternal wellbeing, in families with and without a pre-schooler with autism. The Academic Competence subscale of the SSRS was used to explore academic achievement. Although they found no significant group differences in both parent- and teacher-reports, teacher-reports of academic achievement were significantly related to parent reports of life stress. This suggests factors related to stress may be associated with academic outcomes in autism siblings. A strength of this study was its use of a smaller age range of siblings (6 to 10 years old), but the child with autism was only 2 to 5 years old. Although the study reportedly recruited this age range to minimise variance due to age-related differences and birth order, the effects of being a sibling may be cumulative and more significant over time. For example, challenging behaviours may be typical of the toddler age range and so may not be seen as 'different' at this stage. Moreover, siblings with disabilities or psychiatric disorders were excluded, which is not representative of all siblings. Again, this study also had a small sample of 20 and 23 siblings in the focus and control groups respectively.

A more recent study in Taiwan by Chien et al. (2017) had a specific school aim to examine the school functions in a larger sample of 66 autism siblings, compared to 132 typical siblings, in a study of relatively high methodological quality. The Academic Performance subscale of the SAICA was used to explore academic achievement, but findings between groups were not significantly different. Nevertheless, older age, 'intelligence' (lower full-scale IQ), the siblings' own autistic traits (higher Social Responsiveness Scale (SRS) scores), and higher inattention scores were associated with poorer academic achievement. Moreover, older age, intelligence, and inattentive symptoms predicted poorer academic achievement. The relation between older age and academic achievement may demonstrate the cumulative effect of being a sibling, as suggested

previously. However, on a cautionary note, the inattention measure was not school-specific. Moreover, autism siblings were only included if their sibling with autism was attending mainstream school, and the authors failed to identify the limitation that this is not representative of children who have a sibling with more severe difficulties related to autism who may be attending a specialist school.

Rodrigue et al. (1993) also used two control groups with the aim of examining the psychological adjustment of autism siblings and used the Scholastic Competence subscale of the PCSC to explore academic achievement. Autism siblings had a higher mean score (21.32), compared to Down's syndrome siblings (18.27) and typical siblings (19.50). This may suggest that autism siblings could have higher academic achievement. However, statistical analyses and significance values were not included and except for the table of means, academic achievement was not referred to separately in the results or discussion. Moreover, this measure related to 'perceived' competence, whereas actual academic competence is a different construct and may have produced different findings.

1.3.6 Psychological internal challenges and resources

The psychological internal challenges and resources section incorporates studies exploring emotional and behavioural school outcomes and experiences. This includes findings related to academic self-concept, which involves attitudes to learning and the identity, belief, and self-perception of academic ability (Ommundsen, Haugen & Lund, 2005). In line with the findings for academic achievement, findings for emotional and behavioural constructs were mixed. Regarding academic self-concept, one study found higher scores for autism siblings (Macks & Reeve, 2007) and one found lower scores (Chien et al., 2017). Regarding school behaviour, three studies found no significant differences (Cebula, 2012; Mates, 1990; Quintero & McIntyre, 2010) and one study found poorer school behaviour (Chien et al., 2017).

Macks and Reeve (2007) aimed to explore the psychosocial and emotional adjustment of autism siblings. They explored siblings' academic self-concept specifically using the Self-Concept of Intellectual and School Status subscale of the SCS. 51 autism siblings scored significantly higher, although still in the average range, than the comparison group of 35 typical siblings. This suggests that autism siblings may have a more positive view of their learning. Demographic variables considered to place a child at risk for poorer academic self-concept included being male, coming from a family of low socioeconomic status (SES), only having one sibling, and being older than the child with autism, which may be risk factors for autism siblings. It was also reported that an increase in the number of demographic risk factors had a negative effect on siblings. This study had the strength of exploring siblings' academic self-concept directly through self-report, rather than through their parents, but, again, had the limitation of the control group's small sample size.

In a similar age range, in addition to exploring academic achievement, Chien et al. (2017) also explored siblings' academic self-concept using the Attitudes Towards School-Work subscale of the SAICA. Conversely, they found that autism siblings had poorer academic self-concept, and this was related to lower intelligence, the sibling's own autistic traits, higher inattention and hyperactivity-impulsivity score, and poorer sibling relationship. IQ and poorer sibling relationship significantly predicted academic self-concept. Opposing findings to Macks and Reeve's (2007) study, which assessed the same construct, could be attributed to Chien et al.'s larger sample size, the use of different informants or measures, and/or due to the different educational systems of different countries, which could contribute to the differences in findings in all studies. Moreover, these studies have the limitation of including only a small subscale to measure academic self-concept rather than entire questionnaire measure, which would be more comprehensive.

Regarding autism siblings' school behaviour, a range of measures were used to explore this construct. Bagenholm and Gillberg's (1991) mixed methods study aimed to examine sibling relationships and sibling behaviour difficulties. To assess school behaviour, the RQT was used, but the authors reported that these data were excluded, as a number of siblings did not want their teachers to take part. It would have been interesting to explore why this was the case, as this is a novel finding in itself. Moreover, excluding this data raises the possibility of reporting bias. Nevertheless, the authors instead reported data on "school problems" (p. 295), finding that 20% of autism siblings had 'difficulties' in this area compared to 5% of the control group. It was assumed from the aims of the study that this related to behaviour, although no further detail was given as to what these difficulties specifically entailed. Moreover, 20% only amounted to three siblings, which could have been due to chance, and so these percentages could be considered misleading.

In addition to exploring academic achievement, Mates' (1990) study also explored autism siblings' school behaviour using the RQT. This study found siblings did not perform differently as a result of their gender or family size, but as discussed previously, findings were not compared to a control group. Despite the small sample size, a strength of this study was its use of a teacher-report questionnaire, with a 90% response rate. Teachers were also said to be blind to the child having a sibling with autism, although this, in itself, is curious. Where the sibling had more than one teacher, the language teacher was selected. Although this allows for consistency, this may not be the staff member that knows the child best. Future studies may want to select the siblings' form tutors to increase the validity of findings.

In the only UK study, Cebula (2012) aimed to explore the psychosocial adjustment of autism siblings whose families were using a home-based applied behaviour analysis (ABA) programme. The teacher-reported SDQ, a measure commonly used in the autism siblings research to explore behavioural adjustment and wellbeing, was used to explore school behaviour. No significant group differences were found in either the total score or

any domain/subscale scores, suggesting the ABA intervention did not lead to any observable differences in the siblings' school behaviour. Although this study used a control group, these were still autism siblings (not using ABA), and not comparisons with typical siblings or against norms of the questionnaire. Nevertheless, it was interesting that the siblings' teachers rated siblings significantly lower on conduct problems than the siblings rated themselves. Teachers also rated siblings significantly lower on the hyperactivity domain than the parents rated siblings, and the parents rated siblings significantly lower on the hyperactivity domain than the siblings rated themselves. This suggests the informant used makes a significant difference to findings and needs to be taken into consideration in future studies.

In addition to exploring academic achievement, Quintero and McIntyre (2010) explored autism siblings' school behaviour using the TRF. Compared to families without a pre-schooler with autism, no significant differences were found in overall teacher-reported school behaviour, which may again be influenced by the small sample size. Although not statistically significant, moderate effect sizes were found for autism siblings' internalising (e.g. anxiety, withdrawal or depression) and total problem behaviours in the classroom, with autism siblings demonstrating more behaviour problems than the comparison group. This suggests the possibility of heightened school difficulties for autism siblings, although descriptive statistics were still in the average range. Nevertheless, increased school behaviour problems significantly correlated with mothers' increased reports of life stress and depression, although causation cannot be inferred.

In addition to exploring academic achievement and self-concept, Chien et al.'s (2017) study of high methodological quality also explored school behaviour through the School Behavioural Problems subscale of the SAICA. They found autism siblings to have higher scores, suggestive of increased school behaviour difficulties, which were associated with the child with autism's communication needs and lower IQ, and unaffected siblings' own autistic symptoms, inattentive symptoms, and poorer sibling relationships. Autism

siblings' own autistic traits and inattention and oppositional symptoms predicted worse school behavioural problems.

1.3.7 Peers and other informal and formal social systems

This peers and social systems section incorporates studies exploring social interactions/adjustment, social support, and bullying and teasing school outcomes and experiences. These were reported in four studies and, again, although findings were still mixed, no negative outcomes were reported in this area. Two studies found no significant differences in school social interactions/adjustment (Chien et al., 2017; Quintero & McIntyre, 2010), two found high levels of social support in school (Cridland et al., 2015; Kaminsky & Dewey, 2012), and one found a lack of teasing experiences for autism siblings when compared to the general population and children with autism (Nowell et al., 2014).

In addition to exploring academic achievement and school behaviour, Quintero and McIntyre (2010) explored siblings' school social adjustment through the TRF. They found no significant differences in teacher reports of older siblings' social adjustment in families with and without a child with autism, but, as previously mentioned this study employed a small sample size.

In their much larger sample, in addition to academic outcomes and school behaviour, Chien et al. (2017) explored siblings' school social interactions through the School Social Interactions subscale of the SAICA. Similarly, no significant findings were found compared to the comparison group, suggesting siblings' social skills were in the typical range. Nonetheless, lower school social interaction was associated with more repetitive behaviour and communication needs in the children with autism, the autism siblings' own autistic traits, inattention and hyperactivity symptoms, and poorer sibling relationships. The communication needs of the children with autism, and inattention and oppositional problems of autism siblings, significantly predicted school social interaction.

Chien et al. (2017) hypothesised that inattention may lead siblings to overlook social cues and, therefore, impair their interactions with peers. Again, only parent-reported measures were used.

With the strength of using a self-report measure, in addition to academic achievement, Kaminsky and Dewey (2002) explored siblings' social support in school using the Teachers and Classmates subscale of the SSSC. No significant differences were found. In fact, siblings in all groups consistently reported receiving higher than average levels of social support when compared to the normative sample, with all siblings reporting that they felt 'somewhat' or 'very' supported by teachers and classmates. For both sibling groups, higher levels of social support from classmates was significantly correlated with lower levels of loneliness. For autism siblings specifically, higher levels of social support from classmates was significantly correlated with higher levels of academic functioning.

Social support also emerged in Cridland et al.'s (2015) semi-structured interview study exploring the home and school experiences of adolescents with a younger adolescent brother with autism attending the same school. Siblings reported receiving emotional and practical support from friends in school, which may suggest the protective role of social support. This study benefits from using a qualitative design to explore autism siblings' lived experiences in richer detail than quantitative studies can allow. However, although the sample included 11 participants, only three were autism siblings. Nevertheless, triangulating sibling perspectives to the child with autism, mothers, and fathers is a unique strength of this study.

Nowell et al.'s (2014) study aimed to examine the bullying and teasing experiences among a larger sample of 74 individuals with autism and 68 of their siblings. As not all bullying and teasing experiences are school-specific, only the item 'get teased a lot' from a teacher-reported measure (the TRF) was included (responses included 0 = never, 1 = sometimes, and 2 = often). 40.8% reported teasing in children with autism, which was significantly higher than in autism siblings (7.7%), who were used as a control group with

no comparison to typical siblings. Although the study did not address that autism siblings could potentially be vulnerable to bullying themselves, 7.7% is less than the general population estimates of 8.4% to 23% of children being bullied cited in this study (Bradshaw et al., 2007; Due et al., 2005; Nansel et al., 2001). Therefore, this study suggests that siblings may be protected from such adverse experiences. However, not all teachers took part in the study, which would have led to a smaller sample size from which to draw conclusions. Moreover, teachers may not be aware of all bullying and teasing experiences and these findings are only based on extracting one questionnaire item. Additionally, teasing was not defined, and participants' perceptions and definitions of teasing may differ. For example, teasing may be considered less severe than bullying. There are also different types of bullying and teasing that the study does not differentiate between, such as physical or emotional.

1.3.8 Personal interpretation of events

This section explored the personal interpretation or description of roles and responsibilities that siblings may take on in school, which were reported in Cridland et al.'s (2015) qualitative study with adolescents. Various caregiving roles and responsibilities were reported, including "advocating for their brother with teachers and peers, liaising between the teachers and their parents, managing miscommunications, protecting their brother from bullies, and educating their brother about how to deal with other students" (p. 5), in addition to educating their teachers about autism. The authors concluded that "overall, there were mixed attitudes about undertaking these roles, resulting in some ambiguity about the responsibilities" (p. 5), suggesting benefits and challenges to this. Although some siblings thrived off these protective and educative responsibilities, perhaps interpreting it as the role of a sibling, additional responsibilities may cause pressures that would not be apparent if the siblings attended different schools. It may also be the case that

siblings of any children with disabilities may take on additional roles and responsibilities in the school environment and, therefore, this may not be unique to autism.

1.4 Discussion

Researchers have suggested that autism siblings may be at increased risk for psychological difficulties. However, limited attention has been directed to the school outcomes for, and experiences of, autism siblings. The current paper is novel and unique in that it used a systematic literature search and appraisal to summarise and evaluate this area of research. In total, 13 studies were identified for review, with 11 included in the quantitative synthesis and 3 in the qualitative synthesis (including one mixed methods paper replicated in both syntheses). The findings from the studies were linked to an existing framework, the SESF, which aims to understand the experiences of siblings from a systemic and systematic perspective. With a focus on the school context, the current review considered school factors, psychological internal challenges and resources, peers and social systems, and personal interpretation of events.

Similar to reviews of the psychological wellbeing of autism siblings (e.g. Meadan et al., 2010; Green, 2013; Aparicio & Minguéz, 2015), mixed school outcomes and experiences were found in all areas. Using a risk and resilience model, the presence of differing risk and protective factors may account for this variation in sibling adjustment (Tomeny, Barry & Bader, 2012). Nevertheless, critically, many studies reported no significant differences in school outcomes relative to a control group. This suggests that siblings do not automatically experience adjustment difficulties in school. However, the relatively small body of research and methodological limitations of these studies, such as small sample sizes which may not have had sufficient power to detect effects, make it difficult to draw any firm conclusions.

Regarding school factors related to academic outcomes, studies reporting higher academic achievement for autism siblings (Rodrigue et al, 1993) could perhaps be

explained by the ‘overcompensation hypothesis’. This suggests that autism siblings may ensure they achieve academically at school to overcome any perceived academic difficulties experienced by their sibling with autism (Barak-Levy et al., 2010), such as if they have a co-occurring learning disability. Moreover, Gray’s (1998) argument that autism siblings are often more mature than their peers, due to taking on increased caring responsibilities, may also explain improved academic outcomes. For example, this could lead siblings to be more independent and engaged with their learning.

Conversely, other researchers reporting poorer academic achievement for autism siblings (August et al., 1981; Barak-Levy et al., 2010) replicate The Children’s Society’s (2013) study of young carers. These findings could be explained by anecdotal concerns raised by the Sibs (2018a) charity, such as disrupted sleep impacting on engagement/attention in school, and/or difficulties completing school work at home. However, studies often fail to collect information about, or consider, causal mechanisms in their analyses/designs. Despite these findings, most research in this area found non-significant findings, suggesting academic achievement may not be impacted by having a sibling with autism (Ben-Yizhak et al., 2011; Chien et al., 2017; Kaminsky & Dewey, 2002; Mates, 1990; Quintero & McIntyre, 2010).

Psychological internal challenges and resources reflect findings relating to emotional and behavioural outcomes. Regarding academic-self-concept, studies reporting higher scores for autism siblings (Macks & Reeve, 2007) reflect Dyson’s (2003) study of siblings with learning disabilities. If the child with autism has co-occurring learning difficulties, these findings could be explained by social comparison theory (Festinger, 1954). Perhaps siblings may engage in social comparison to the sibling with autism and perceive themselves as performing better academically. Macks and Reeve (2007) also argued that any increased maturity for autism siblings, leading to improved academic achievement, would, therefore, increase academic self-concept. However, conversely, other researchers have reported poorer academic self-concept for autism siblings (Chien et

al., 2017). This may be explained by the increased risk of poorer psychological wellbeing for autism siblings and potentially shared emotional difficulties with the child with autism, such as anxiety.

Regarding school behaviour, increased difficulties in autism siblings compared to controls (Chien et al., 2017) is similar to those reported for siblings of children with more general disabilities (Goudie et al., 2013). Again, this may highlight the increased risk of poorer psychological wellbeing, which is then reflected in school. An explanation for these behaviour difficulties may include siblings imitating the child with autism's behaviour, if indeed they do display behaviours that challenge, which would occur through observational learning (Bandura, 1977). However, again, most studies found no significant differences in teacher-reported ratings of autism siblings' school behaviour, suggesting adequate behavioural adjustment (Cebula, 2012; Mates, 1990; Quintero & McIntyre, 2010).

Regarding peers and social systems, relating to social outcomes, none of the reviewed studies reported poorer outcomes for autism siblings, including adequate school social interactions/adjustment (Chien et al., 2017; Quintero & McIntyre, 2010) and minimal teasing experiences compared to children with autism and the general population (Nowell et al., 2014). Studies reporting high levels of social support in school (Cridland et al., 2015; Kaminsky & Dewey, 2012) reflect findings by Sin et al.'s (2012) qualitative study of siblings of individuals with psychosis, who looked to their friends and teachers in school for emotional and social support. Perhaps as a result of their sibling experiences, autism siblings may rely more on people in school for support and this may be protective for their social outcomes (Cridland et al., 2015).

Regarding personal interpretation of events, adolescent autism siblings were found to take on increased roles and responsibilities when attending the same school as their sibling with autism (Cridland et al., 2015). Findings regarding the benefits and challenges of this were mixed, but suggest potentially increased difficulties for siblings attending the

same school. Findings suggest siblings may assume some of these responsibilities due to interpreting this as part of their role/identity as a sibling, but also due to pressures from others, such as from teachers and families. This reflects Dyson's (2007) findings of siblings of children with learning disabilities reporting unrealistic expectations from teachers. Siblings may then experience a compounded effect of any pressures/stresses of family life at home in the school environment (Walton, 2016), or have no opportunity to escape daily caregiving responsibilities (McHale, 1986). As taking on additional caregiving responsibilities may put siblings at increased risk of poorer psychological adjustment, this area warrants further research.

1.4.1 Strengths and limitations of the literature

Due to the importance of the educational context for child development, it is promising that research is considering autism siblings' school outcomes and experiences. Strengths of the evidence-base include nearly all studies having control groups of typical siblings, with some using multiple informants, which included a number of teacher-report measures. Chien et al.'s (2017) study appeared to be the most comprehensive to assess school outcomes, with specific school aims and measures that encompassed multiple areas related to school. Moreover, the study had high methodological quality, with a larger sample size to other included studies.

Despite these strengths, there are a number of limitations of the overall evidence-base in this area, which mitigate any conclusions that can be drawn. As only a small body of literature is included in the review, studies were identified with no limit on the date of publication, country of origin, or methodological quality. Including such a wide time span of literature means there are differences in the way in which autism is conceptualised in different studies, as the criteria for autism as a diagnostic category has changed and evolved over time, which may affect the research and conclusions drawn. This also meant that many studies do not reflect more recent educational practice or support in school. In

addition, with a number of studies included with low methodological rigour, unrepresentative samples, and small samples sizes, these factors limit the generalisability of findings. Opportunity sampling is also a limitation of the evidence-base, in which families often self-select to participate and, therefore, may not be representative of all siblings.

Within the included studies in the review, the aims of the research rarely focused specifically on school, but more generally on the psychological adjustment of siblings. Therefore, studies were included with only one school-based measure, subscale, or interview theme, with the additional data not relevant to my review question excluded. The range of different measures used across studies may also be contributing to the mixed findings and lack of consistent conclusions. Many of the findings also rely solely on parent-report which, while important, will only reflect their understanding and perspective of the sibling experience. Moreover, as autism siblings are suggested to be more likely to hide their difficulties from their parents in order not to further burden them (Cridland et al., 2015), these findings may be positively distorted. Further, many studies included participant samples with large age ranges, which may not account for age-related differences in outcomes and experiences, such as findings unique to the adolescent life period. Longitudinal studies may be best placed to explore these differences, alongside an exploration of causal relationships, which the cross-sectional designs of the included studies do not allow. Autism siblings who themselves have diagnoses can also be excluded from studies, which may exclude key information on the sibling experience and is not representative of all siblings. Moreover, these may be the siblings most at-risk and in need of support. Researchers also rarely focus on sub-groups of autism siblings who may be more vulnerable, such as siblings of those who display challenging behaviour or take on significant additional caring roles. Regarding the qualitative research, only three studies were identified. Moreover, two of these reported quantitative outcomes following a

qualitative methodology, which excluded more rich and detailed accounts of the autism sibling school experience.

Lastly, the focus of this review was solely on the school context, rather than other aspects that the SESF invites consideration of, such as sibling ‘demographics’ and aspects within the ‘immediate and extended family’. Alternatively, other models and frameworks were available that would have also been appropriate to discuss the findings of this review. For example, the Interactive Factors Framework (Frederickson & Cline, 2009) also considers interactive factors in different areas, which could have helped synthesise findings into biological, cognitive, behavioural and environmental outcomes. The risk and resilience model (Tomeny, Barry & Bader, 2012) may have also helped organise findings to identify different risk and protective factors.

1.4.2 Future research

Future studies specifically focusing on systematic and interactive factors influencing the sibling experience are needed to provide further evidence in this area. However, school-specific outcomes and experiences, particularly those that go beyond academic achievement, are often neglected in quantitative and qualitative studies. The SESF framework may be used to identify specific areas for future research to explore. To understand more about the psychological internal challenges and resources for autism siblings, more comprehensive measures of academic self-concept are important to include, given their association with achievement and wellbeing (e.g. Marsh & Craven, 2006). Further, researchers should aim to understand more about siblings’ broader experiences in education, such as with regards to their relationships with peers and other social systems and how much they feel a part of their school (e.g. sense of school belonging). More research on siblings’ personal interpretation of events may be achieved via qualitative research and self-reported questionnaires. Future research may also want to consider any benefits or difficulties in school experiences and outcomes when siblings attend the same

school. Finally, the variables that predict school outcomes for siblings, such as demographics and/or wellbeing, will be beneficial to identify risk factors for siblings in terms of their school adjustment.

It is a priority that future studies are of high methodological quality, particularly with larger sample sizes. Inclusion of narrower age ranges would be helpful to identify any age-specific findings. Moreover, designs which exclude siblings with additional needs themselves should be discouraged. In particular, more UK-based studies would also be beneficial to understand the impact of the UK curriculum, examinations, school systems, and academic pressures. Inclusion of school-specific aims and interview questions should elicit more rich and detailed findings related to school outcomes and experiences. Future research would also benefit from triangulating data from siblings, parents, and teachers to gain multiple perspectives and provide a more holistic picture of the sibling experience.

1.4.3 Implications for Educational Psychologists

Although this literature review has not definitively evidenced consistent challenges in the school outcomes and experiences for autism siblings, studies findings poorer outcomes for autism siblings show that some siblings are at increased risk for experiencing difficulties. Moreover, while the Sibs (2018a) charity anecdotally reports increased challenges in school for siblings, this may not yet be evidenced by high quality research. To contribute to the evidence-base, EPs are well placed to conduct further research into autism siblings' school outcomes and experiences. They could then advise schools, charities, and other organisations on such research. It may be particularly helpful to make others aware of research into caregiving responsibilities, particularly when siblings attend the same school, to ensure such roles are minimised. As Sibs (2018b) suggest in their recommendations to schools, EPs could encourage school staff to collect data on how many autism siblings attend their school, so that academic achievement can be explored, in a more ecologically valid context than questionnaire studies, and compared to the wider

school population. EPs could also raise awareness of potential sibling challenges and benefits, as well as signposting for further support (e.g. the Sibs charity) through sibling, parent and/or staff training or workshops. Where a clear need has been identified, EPs could supervise Emotional Literacy Support Assistants (ELSAs) to deliver sibling support groups, which may promote the protective role of social support, or run one-to-one interventions for siblings, such as Sibs Talk (2018c). Taking a family systems theory approach, EPs could also facilitate whole family support groups to promote family functioning.

1.4.4 Conclusion

In conclusion, findings produced a mixed picture of both positive and negative school outcomes and experiences, suggesting some autism siblings may be at increased risk for school difficulties. Nevertheless, many studies found no significant differences related to school factors (e.g. academic outcomes/experiences), psychological internal challenges and resources (e.g. emotional and behavioural outcomes/experiences), peers and social systems (e.g. social outcomes/experiences), and personal interpretation of events. This suggests that autism siblings do not automatically experience difficulties in school as a result of their sibling status. However, mixed findings may be a result of the methodological limitations of the literature, such as small sample sizes. Moreover, the spectrum of autism, differing risk and protective factors, and wide range of interacting factors at play will also be contributing to the findings. Nevertheless, studies with higher methodological quality are needed in this area before any firm conclusions are made. Moreover, as sibling outcomes and experiences appear so varied, it is important that professionals such as EPs utilise a person-centred and individualised approach towards autism siblings and do not assume negative outcomes and experiences. In fact, it may be a beneficial aspect of intervention work to identify the many positives that can be gained from having a sibling on the autism spectrum.

Chapter 2 Academic self-concept and sense of school belonging in adolescent siblings of children with autism.

2.1 Introduction

2.1.1 Autism Spectrum Condition

Autism Spectrum Disorder, also referred to as Autism Spectrum Condition (ASC), is defined in the Diagnostic and Statistical Manual of Mental Disorders as a condition involving difficulties in social communication and interaction, and restricted and repetitive patterns of behaviours, interests or activities (DSM-5; APA, 2013). Approximately 1% of the population are known to be on the autism spectrum (Brugha et al., 2012), and while the exact cause is unknown, research has long suggested a strong genetic and heritable component. For example, correlations of autism among identical twins are significantly higher than in non-identical twins (Colvert et al., 2015) and autism is more common in the siblings of autistic children (Folstein & Piven, 1991). Autism is primarily diagnosed in childhood (Chlebowski, Green, Barton & Fein, 2010), though recent formulations stipulate that impairing symptoms may only surface when environmental demands exceed capacity (DSM-5; APA, 2013).

Given the relatively common prevalence of autism in the general population, and the nature of autism as a spectrum condition of both areas of strength and difficulty, individuals may be impacted both positively and/or negatively by a family member with autism. This is supported by family systems theory, which predicts that having an individual with any additional needs, including autism, in the family will influence family functioning (Cox & Paley, 1997; Turnbull, Turnbull, Erwin & Soodak, 2006). Consistent with this view, researchers have most often focused their attention on exploring the

outcomes and experiences of parents/carers (referred to hereafter as parents), predominately mothers (e.g. Nealy, O'Hare, Powers & Swick, 2012). Historically, this has led to siblings of children on the autism spectrum (autism siblings) being neglected as the focus of research. This is despite more than 80% of the UK population having a sibling, the sibling relationship often being the longest-lasting of family relationships, and sibling relationships often being a source of enjoyment, meaning, and social support (Griffiths & Sin, 2013). Moreover, Rodrigue, Geffken and Morgan (1993) reported the importance of sibling relationships in promoting all areas of a child's development, particularly their social development. When a sibling has a disability, or indeed additional needs, sibling relationships may not develop in the typical fashion. As a result, there may be a change to traditional sibling roles. Therefore, the impact of being an autism sibling is particularly important to study.

2.1.2 Autism siblings research

Autism siblings may have certain characteristics that lead to unique sibling experiences. For example, definitions of autism do not include observable physical characteristics (APA, 2013), with autism being termed as the 'invisible disability' (e.g. Milton, 2012; Hoogsteen & Woodgate, 2013). This may lead to others doubting autism siblings have a family member with a disability (Moyson & Roeyers, 2011), which could lead to reduced stigma, but also others not recognising siblings' needs. Social interaction and communication difficulties may also impact on the sibling relationship and siblings' social development. Many individuals with autism also have co-occurring difficulties, such as learning disabilities or mental health problems such as depression and anxiety (Kim, Szatmari, Bryson, Streiner & Wilson, 2000), which may also impact on sibling relationships and thus outcomes. Some siblings have also been identified to have milder traits of autism that do not meet diagnostic criteria, known as the Broader Autism Phenotype (BAP; Piven, 2001), which may impact sibling outcomes.

Research has primarily focused on the psychological outcomes for autism siblings, but findings of individual studies and reviews have found mixed social, emotional and behavioural outcomes (e.g. Meadan et al., 2010; Green, 2013; Aparicio & Minguéz, 2015). Nonetheless, siblings of children who display challenging behaviour, which can be associated with autism, have been shown to be particularly vulnerable to difficulties (e.g. Neece, Blacher & Baker, 2010; Petalas, Hastings, Nash, Reilly & Dowey, 2012). This may be due to reports of challenging behaviour leading to high levels of anxiety for siblings (Gorjy, Fielding & Falmer, 2017).

Research has also found sibling young carers to have poorer outcomes (e.g. Hannah & Midlarsky, 1985; The Children's Society, 2013). A systemic reason for these difficulties, that does not assume blame on the child with autism's condition, includes increased parental expectations for siblings to provide support in the family (Quintero & McIntyre, 2010). These increased responsibilities can then lead to resentment and the 'role strain' trying to fulfil multiple family roles (Stoneman, 2005). In turn, this can damage the sibling bond (Harris & Glasberg, 2010). Reduced time, attention and support from parents, which is often focused on the child with additional needs, is another factor that may lead to poorer outcomes for siblings (Petalas, Hastings, Nash, Dewey & Reilly, 2009). However, limited studies have explored these causal mechanisms. Moreover, current research into autism siblings can be considered deficit-focused, in which studies often aim to identify mental health problems in siblings.

2.1.3 The school context

To more fully understand the benefits and challenges of being an autism sibling, research needs to consider broader, more systemic outcomes for siblings, in which studies take a more holistic approach to the sibling experience. The Siblings Embedded Systems Framework (SESF) is a model that promotes this through identification of interactive factors that aim to account for the variation in sibling adjustment (Kovshoff, Cebula, Tsai

& Hastings, 2017). This includes school, and the peers/social systems within it, as a context that impacts on outcomes. Experiences and outcomes in the school environment are particularly important to study because siblings spend a large proportion of their time here and school has a large influence on all areas of a child's development. For example, children develop many of their social relationships in school, which helps siblings receive social support from their peers (Macks & Reeve, 2007). Focusing on such dynamic variables can help promote change and adaptation for siblings, as well as identifying areas for intervention that could inform the support siblings receive in school.

Currently, there is limited literature that has sought to evaluate autism siblings' outcomes and experiences in schools. The previous systematic review of this thesis produced mixed findings. Nevertheless, many studies reported no significant findings, such as in the areas of academic achievement (Ben-Yizhak et al, 2011; Chien et al., 2017; Kaminsky & Dewey, 2002; Mates, 1990; Quintero & McIntyre, 2010), school behaviour (Cebula, 2012; Mates, 1990; Quintero & McIntyre, 2010), and school social outcomes (Chien et al, 2017; Quintero & McIntyre, 2010). This suggests that autism siblings do not automatically experience school adjustment difficulties. Many researchers also reported positive outcomes for autism siblings, such as higher academic competence (Rodrigue et al., 1993), academic self-concept (Macks & Reeve, 2007), and social support (Cridland et al., 2015; Kaminsky & Dewey, 2002). In particular, findings related to social outcomes showed a more positive picture. Perhaps autism siblings rely more on social support from their peers, and this is protective for their social outcomes.

Despite these findings, some studies found more negative outcomes for autism siblings, such as poorer academic achievement (August et al., 1981; Barak-Levy et al., 2010), academic self-concept (Chien et al., 2017), and increased school behaviour difficulties (Chien et al., 2017). This suggests that some autism siblings may be at risk of difficulties and therefore vulnerable to poorer outcomes. In addition, qualitative research has shown autism siblings to take on increased roles and responsibilities for their sibling

with autism when they attend the same school (Cridland et al., 2015), which is a risk factor for poorer outcomes.

These mixed findings may be a result of the spectrum of autism, combined with the range of interactive factors that influence sibling outcomes outlined in the SESF, as well as the presence of differing risk and protective factors, which a risk and resilience model would suggest (Tomeny, Barry & Bader, 2012). Additionally, mixed findings may stem from a number of methodological limitations of the evidence-base, including the limited research focused specifically on school, use of a range of ages in single samples, differing outcome measures and comparison groups, and small sample sizes, which make it difficult to draw comparisons between, and conclusion from, published research.

2.1.4 Self-determination theory

Self-determination theory (SDT; Deci & Ryan, 1985) is a psychological theory that can be applied to students in education and provides factors associated with positive school outcomes. Within this theory, Deci and Ryan (1985) state that individuals have three universal and innate needs necessary for their wellbeing, development, and motivation to learn; relatedness, competence, and autonomy. With these three constructs in place, students are said to experience intrinsic motivation, and, therefore, prime learning conditions (Niemic & Ryan, 2009). Alternatively, without feelings of relatedness and competence, Deci and Ryan (1985) suggest this will have negative consequences for learning and development.

Relatedness refers a sense of belonging. With its foundations in attachment theory (Bowlby, 1969), the need to belong incorporates building secure relationships and connections with other people, such as peers, or indeed places, such as school (Baumeister & Leary, 1995). This includes being accepted by others, forming social bonds, and feeling cared for (Griffen & Tyrell, 2007; Maslow, 1970). Through the hierarchy of needs model, Maslow's (1943) theory of human motivation also identifies belonging as a strong

motivational drive and fundamental psychological need. Additionally, the broaden-and-build theory (Fredrickson, 2004) suggests that once we feel secure/a sense of belonging, we are then able to experience positive emotions such as happiness. Fredrickson (2004) states these emotions then broaden our awareness to new opportunities, where we are able to learn, and build skills and resources. Conversely, a low sense of belonging leads to experiences of rejection and exclusion, which can cause feelings of anxiety, depression, grief, jealousy, and loneliness (Frederickson & Dunsmuir, 2009). Therefore, belonging is a crucial component of our wellbeing, which Frederickson and Dunsmuir (2009) also report has implications for engagement with learning and academic progress.

Sense of school belonging (referred to hereafter as school belonging) refers to the extent to which students feel accepted, included, respected and supported in and by their school, and can provide a measure of the quality of school social relations at a whole school level (Goodenow, 1993a). In research, school belonging has been shown to predict a range of school outcomes, such as academic achievement, attendance, motivation and engagement (Goodenow, 1993b), as well as social, emotional and behavioural outcomes (Waters, Cross & Shaw, 2010) (see Chapman, Buckley, Sheehan & Schochet, 2013 for a systematic review). Moreover, research with 12- to 14-year-olds found a predictive link between school belonging and later mental health problems, such as depression and anxiety symptoms (Schochet, Dadds, Ham & Montague, 2006).

Despite the importance of belonging for wellbeing and school outcomes, the previous systematic review in this thesis found no published studies exploring school belonging in autism siblings. As studies previously cited related to siblings' social outcomes in school did not identify increased difficulties, it could be hypothesised that autism siblings' school belonging may not be significantly different to siblings of children who are typically developing (typical siblings). Alternatively, in attempts to reduce burden on their family and the expectation to be the 'healthy' child (Cridland et al., 2015), autism siblings may rely more on their peers and teachers for support and have higher school

belonging than typical siblings. By contrast again, social identity theory, which is an individual's sense of who they are in a group and sense of belonging to the social world (Turner & Tajfel, 1986), may suggest that autism siblings could perceive themselves as 'different' to their peers as a result of not sharing their sibling experience/identity. In which case, this may lead siblings to feel less like they 'belong' to their peers and a lower sense of school belonging.

Niemiec and Ryan (2009) have argued that belongingness alone is insufficient to explain its links with positive school outcomes, such as academic motivation. In addition, SDT postulates that feelings of competence are also needed to produce academic benefits, which refers to an individual's feelings of effectiveness, such as with their learning (Ryan & Deci, 2000). This can be linked to academic self-concept, which is said to be the identity, belief, and self-perception of one's academic ability (Ommundsen, Haugen & Lund, 2005). For example, Burden (1988) identified higher academic self-concept as enjoyment in problem-solving, confidence in a variety of learning situations, careful learning style, and a lack of anxiety. Research has linked higher school belonging to more positive feelings of competence towards school work (McMahon & Wensman, 2009) and academic self-concept (Curtin, Stewart & Ostrove, 2013; Ryan, Stiller & Lynch, 1994). Research has also linked academic self-concept to intrinsic motivation and growth mindset (Dweck, 2008), as well as higher academic achievement (Marsh & Craven, 2006). These are also key elements of the 'competence' component of SDT (Deci, 1971). For example, SDT predicts that the higher the intrinsic motivation, the higher the sense of self-determination. In turn, this increases a students' sense of autonomy, which is the third element of SDT, and refers to self-directed learning (Ryan & Deci, 2000). Therefore, along-with school belonging, academic self-concept also has important implications for sibling outcomes.

Despite the importance of academic self-concept, there is limited research exploring this construct in autism siblings. Studies that have explored a broader and more general

measure of ‘self-concept’, in which academic self-concept was explored through a small subscale, have found contradictory findings. For example, Macks and Reeve (2007) found 51 autism siblings to have significantly higher scores of self-reported academic self-concept when compared to a control group of 35 typical siblings. Conversely, in a larger sample size, Chien et al. (2017) reported poorer attitudes towards school-work (rated by parents) when compared to a control group. Nonetheless, these differences in findings could be due to the different informants and/or measures used, Mack and Reeve’s (2007) smaller sample size for their comparison group, and/or the different educational systems in different countries. However, no studies in the systematic review of this thesis explored academic self-concept in a UK sample, nor utilised a more comprehensive questionnaire focusing solely on this construct.

It could be hypothesised that autism siblings may have higher academic self-concept. For example, Macks and Reeve (2007) suggested that autism siblings may have increased maturity, which may be developed through taking on increased caregiving responsibilities for the child with autism. They argued that this increased maturity would lead to improved academic performance, which would in turn improve academic self-concept. Alternatively, it could be hypothesised that autism siblings may have lower academic self-concept. For example, this may result from the potentially increased risk of poorer psychological wellbeing from factors such as challenging behaviour (e.g. Neece, Blacher & Baker, 2010) and increased caregiving responsibilities (e.g. Hannah & Midlarsky, 1985). Moreover, siblings may share emotional difficulties often linked to autism, such as anxiety, through social learning or due to the siblings’ own traits of autism (Piven, 2001). Such anxiety may generalise to learning, causing lower academic self-concept.

2.1.5 This present study

This current study focused on exploring the school belonging and academic self-concept in a sample of autism siblings, in comparison to typical siblings, in, or leading up

to, adolescence in the secondary school context (school years 7 to 11). Focus on this age period was important for a number of reasons. Primarily, the need to feel competence (e.g. academic self-concept) and relatedness (e.g. belonging) is particularly strong in adolescence. For example, Brechwald and Prinstein (2011) explained that peer relationships become central to the process of an adolescent's self-concept and identity formation. Petalas et al. (2012) reported that adolescence is often characterised by decreased levels of sibling interaction and companionship, and instead siblings rely more on their peers for social support. In turn, strong peer friendships are said to be a mediating factor of successful coping in siblings (Macks & Reeve, 2007; Orsmond & Seltzer, 2007). As the majority of existing research often excludes the voice of the sibling, through a lack of self-reported outcomes, this study explored autism siblings' own perceptions of their school belonging and academic self-concept through self-report questionnaires. Due to the link between school outcomes and wellbeing, and in order to replicate previous research into siblings' psychological outcomes, this study also aimed to explore whether there were any differences in components of wellbeing in autism siblings compared to typical siblings.

This study also aimed to explore the factors that predict sibling school-related outcomes (school belonging and academic self-concept), such as key demographic variables and sibling wellbeing. As research has also identified that the informant used can make a difference to findings related to psychological wellbeing (e.g. Cebula, 2012; De Los Reyes & Kazdin, 2005), and parents have been shown to rate sibling outcomes more negatively than siblings themselves in the autism siblings literature (e.g. Rossiter & Sharpe, 2001), Rodgers et al. (2016) and De Los Reyes and Kazdin (2005) suggest that multiple informants are needed. Moreover, Leach (2014) suggested that a teacher-completed measure would be valuable in future research on school outcomes. Accordingly, this study triangulates information and gains multiple perspectives through a sibling, parent, and teacher measure of wellbeing.

2.2 Method

2.2.1 Design

A cross-sectional quantitative survey research design was employed, in which each participant's data was collected at one time point to gain experiences on a larger-scale. The independent variable (IV) was sibling group (autism siblings or typical siblings) and the dependent variables (DV) were the school-related outcomes (school belonging and academic self-concept).

2.2.2 Approach to statistical analysis

To explore group differences in the school-related outcomes, independent sample t-tests were employed through comparing mean scores on the self-reported academic self-concept and school belonging questionnaires. To explore group differences in wellbeing, independent sample t-tests were employed through comparing mean scores on the self-, parent-, and teacher-reported wellbeing questionnaire. To explore group differences in the proportion of siblings scoring in the 'low' academic self-concept and school belonging questionnaire categories, as well as the 'abnormal' range for wellbeing, chi-squared tests were employed. Following this, hierarchical multiple regression models were used to explore predictors of siblings' school-related outcomes, including sibling group, demographic variables, and self- and parent-reported components of wellbeing (externalising and internalising difficulties) as the IVs, and school belonging and academic self-concept as the DVs.

2.2.3 Data preparation

Data were downloaded from iSurvey and imported into, and analysed with, the Statistical Package for Social Sciences (SPSS Version 24). All data across questionnaires were screened to check for missing items. Nine questionnaire items were missing across 5

participants, which were spread across the parent-reported (items 1, 1, 2, 3, 4, 9) and teacher-reported (items 11, 17, 20) Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997). As the SDQ allows at least three out of five items to be completed per subscale for each participant, and no participant had more than two items per subscale missing, no participants were excluded from the analyses. Instead, the SDQ scoring instructions were followed to score up subscale scores pro-rata for these participants.

2.2.4 Participants

Two groups of participants were recruited for the purposes of this study; autism siblings and typical siblings. Participants were required to be aged 11 to 16 years attending a secondary school in the UK (school years 7 to 11). Please see Table 2 for participant inclusion and exclusion criteria.

Study Item	Inclusion Criteria	Exclusion Criteria
Age	11 to 16 years.	Younger than 11 years or older than 16 years.
School	Attending secondary school (years 7 to 11).	Attending nursery, primary school, sixth form, college, university, or home educated (not in years 7 to 11).
Living	Living in the UK (England, Wales, Scotland and Northern Ireland).	Living outside of the UK.
Autism siblings	Having a sibling with an autism diagnosis of any age.	Having a sibling with any other long-term disability, illness or medical condition.

Typical siblings	Having a sibling who is typically developing without autism of any age.	Having a sibling with an autism diagnosis or intellectual disability.
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Table 2. Participant exclusion and inclusion criteria.

Cohen's (1992) statistical power guidelines were used to determine the sample size necessary for a significance criterion of $p = 0.05$ and a medium effect size for independent t-tests. This recommended an equal sample size of 64 participants in each group. The number of participants varied according to the group/informant. Self-reported academic self-concept, school belonging, and wellbeing data were collected from 65 autism siblings and 57 typical siblings. In addition, wellbeing data were collected from 73 autism siblings' and 67 typical siblings' parents (along-with demographic data), as well as 25 autism siblings' and 12 typical siblings' teachers. All participants were from a range of different areas and schools across the UK. See Table 3 for a summary of participant characteristics, including means (M), standard deviations (SD), and ranges (R).

Group	Autism siblings			Typical siblings		
	M	SD	R	M	SD	R
Age	12.69	1.26	11-15	12.88	1.39	11-16
MDI	3.67	2.61	1-10	3.68	2.37	1-10
Gender	Male N = 27 (37%) Female N = 46 (63%)			Male N = 34 (51%) Female N = 33 (49%)		
EAL status	Yes N = 5 (7%) No N = 68 (93%)			Yes N = 5 (7%) No N = 62 (93%)		
Diagnosis	Yes N = 15 (21%), No N = 58 (79%)			Yes N = 2 (3%) No N = 65 (97%)		

Table 3. Participant characteristics.

2.2.5 Questionnaire measures

Four questionnaires were included in this study; a demographics questionnaire (Appendix F), The Belonging Scale (TBS; Frederickson, Simonds, Evans & Soulsby, 2007) (Appendix G), Myself-As-A-Learner Scale (MALS; Burden, 1998) (Appendix H), and the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) (Appendix I). Questionnaires were made available online through the University of Southampton's iSurvey.

Demographic questionnaire. A demographic questionnaire was constructed for the purposes of this study and completed by all parents. This was used to gather information about the siblings' age and gender, whether they spoke English as an additional language (EAL), any known illnesses, disability or mental health diagnosis (referred to hereafter as sibling disability, based on the WHO (2018) definition of disability), and the child with autism's age and gender. The family post-code was also used to calculate a neighbourhood deprivation score (Multiple Deprivation Index; MDI) (Department for England, 2015; Welsh Government, 2014; Scottish Government, 2016; Northern Ireland Statistics Agency, 2017) (1 = 10% least deprived, 10 = 10% most deprived).

Academic self-concept. To explore academic self-concept, the MALS was self-reported. This is a 20-item questionnaire for children aged 8 to 16 years. The MALS measures children's emotional perceptions and beliefs of themselves as learners and problem-solvers within educational settings. The MALS is standardised on British school children. Example items include 'when I am giving new work to do, I usually feel confident to do it' and 'learning is easy.' Participants rate items on a five-point Likert scale; 5 = 'definitely agree', 4 = 'agree a bit', 3 = 'true half the time', 2 = 'don't agree', 1 = 'strongly disagree'. Scores were reversed for negatively phrased items (items 6, 8, 12, 16, 20), leading to an overall score between 20 and 100. A score between 60 and 82 is

considered average, a score below 60 is representative of 'low' academic self-concept, and a score above 82 is representative of 'high' academic self-concept. The MALS is stated to have strong internal consistency ($\alpha = .85$). Concurrent validity has been established through high correlations of the MALS scores with responses on the multi-dimensional measure of Children's Perception of Control Scale (Connell, 1985). In the current study, the Cronbach's alpha of the measure for this specific sample of siblings was $\alpha = .933$.

Sense of school belonging. To explore autism siblings' school belonging, TBS was self-reported. This is a 12-item questionnaire for children aged 8 to 14 years. TBS was adapted, to be used on a British population of children, from Goodenow's (1993a) 18-item Psychological Sense of School Membership (PSSM) scale, which was designed for American adolescents, TBS measures psychological membership to school, which is the extent to which individuals feel accepted, included, respected and supported at school. Example items include 'I feel really happy at my school' and 'I feel very different from most other kids here.' Participants have to rate items on a three-point Likert scale; 1 = 'no not true', 2 = 'not sure', 3 = 'yes true.' Scores were reversed for negatively phrased items (items 3, 5, 8, 9, 10). Scores are computed and given a mean average score, with final scores ranging from 1-3. Scores below the mid-point (2) are used to identify pupils who have 'low' school belonging. Frederickson et al. (2007) reported high internal consistency reliability ($\alpha = .87$) for TBS. Moderate to strong correlations have been found with all the Harter (1985) self-perception scales. In the current study, the Cronbach's alpha of the measure for this specific sample of siblings was $\alpha = .826$.

Wellbeing. To explore siblings' wellbeing, and identify whether sibling wellbeing predicts school-related outcomes, the SDQ was self-, parent- and teacher-reported. The SDQ is a 25-item measure for use with 4 to 16-year-olds (parent-report) and 11 to 17-year-olds (self-report). The SDQ is a behavioural screening tool that explores the symptoms of common difficulties in siblings and is often used in research as a measure of wellbeing (e.g. White, Connelly, Thompson & Wilson, 2013). Items are separated into five subscales;

conduct problems, emotional symptoms, hyperactivity/inattention, peer relationships, and prosocial behaviour. Example items include ‘I finish the work I’m doing. My attention is good’ and ‘other children or young people pick on or bully me.’ Participants have to rate items on a three-point Likert scale; 0 = not true, 1 = somewhat true, 2 = certainly true. Scores were reversed for negatively phrased items (items 7, 11, 14, 21, 25). Each subscale is given a total score out of 10. Conduct problems and hyperactivity/inattention scores are combined to give a score out of 20 for ‘externalising difficulties’, and emotional symptoms and peer relationships are combined to give a score out of 20 for ‘internalising difficulties’. The total difficulties score combines the externalising and internalising difficulties subscales to give a score out of 40. Total difficulties scores can be categorised in the ‘normal’ (child 0-15, parent 0-13, teacher 0-11), ‘borderline’ (child 16-19, parent 14-16, teacher 12-15) and ‘abnormal’ (child 20-40, parent 17-40, teacher 16-40) ranges. Prosocial scores can also be categorised to fall in the ‘normal’ (6-10), ‘borderline’ (5), and ‘abnormal’ (0-4) ranges. There are currently no standardised categorisations for the ‘externalising’ and ‘internalising’ subscales.

The SDQ has been found to have good psychometric properties (Goodman, 2001). For example, it has good internal reliability, with Cronbach’s Alpha scores above $\alpha = .70$ (Goodman, Meltzer & Bailey, 1998), and criterion validity is also judged to be adequate. In the current study, the Cronbach’s alphas of this measure were $\alpha = .76$ (self-report), $\alpha = .78$ (parent-report), and $\alpha = .81$ (teacher-report).

2.2.6 Procedure

Once ethical approval was obtained from the University of Southampton’s ethical committee (ERGO number 25346, approved 11.08.17), participant recruitment took place from October 2017 until April 2018 using an opt-in consent procedure. Recruitment differed between the two groups. For autism siblings, study adverts (Appendix J) were shared with specialist schools for children with autism, charities such as the National

Autistic Society (NAS, 2018) local branches and Research Autism, on social media e.g. autism parent support groups, and with parents who had attended an autism siblings talk the author runs for families of children with autism. For typical siblings, study adverts (Appendix K) were shared with mainstream secondary schools, on social media e.g. parent groups, through EPNET (an Educational Psychology e-mail forum), word-of-mouth e.g. typical siblings sharing with their friends, and from Educational Psychologists in the author's university and Local Authority.

Parents interested in taking part responded to the study advert via e-mail. Once families were screened against the participant inclusion criteria, parent (Appendix L) and sibling (Appendix M) information sheets were e-mailed, which included links to the online parent (Appendix N) and sibling (Appendix O) consent forms, along-with the questionnaires, and parent (Appendix P) and sibling (Appendix Q) debrief statements. As these forms were broadly similar for each informant and sibling group, examples for the autism siblings group are included in the appendix. Following consent, the parent provided details of the sibling's secondary school and the name of a key member of staff e.g. the sibling's form tutor. The school/Head Teacher was e-mailed an information sheet and consent form to agree to a member of their staff taking part and to send the questionnaire link to the key member of staff. Once written consent from the Head Teacher was obtained, the teacher was e-mailed the teacher information sheet, which included a link to the online consent form, questionnaire, and debrief statement. As an incentive to take part, each family (sibling and parent) and school/teacher who completed the online questionnaires received a £5 Amazon voucher for their time.

2.3 Results

2.3.1 Group differences (t-tests): Analysis plan and data management

To explore whether there were any group differences for school-related or wellbeing outcomes, t-tests were carried out on the total mean scores of the self-reported MALS and TBS, and the total and subscale scores of the self-, parent-, and teacher-reported SDQ questionnaires. The significance level was set to $p = .05$ for all analyses. An online calculator was used to work out effect sizes using Cohen's d (University of Colorado Springs, 2018). Guidelines by Cohen (1992) were followed for the interpretation of the effect size (small effect $r = 0.20$; medium effect $r = 0.50$; large effect $r = 0.80$).

Preliminary analyses were carried on the data separately according to the group (autism siblings or typical siblings) for each total or subscale score for all questionnaires to screen for violations to assumptions for parametric tests. Outliers were assessed by visual inspection of boxplots, normal distribution was assessed by visual inspection of histograms and Normal Q-Q plots, as well as Shapiro-Wilk tests, and homogeneity of variances was assessed by Levene's Test for Equality of Variances. In cases where data were slightly skewed, as Laerd Statistics (2018) reports that the independent-samples t-test is robust to violations of normality, this statistical test was deemed to be appropriate. Additionally, in such cases, a Mann-Whitney U test was planned to 'confirm' the t-test result. In all cases where homogeneity of variances was violated, this is noted, and a t-test statistic with adjusted degrees of freedom (df) is reported that takes this into account.

2.3.2 Group differences (t-tests): Descriptive and test statistics

To explore group differences on all participant questionnaire total scores, the mean (M), standard deviation (SD), range (R), t-test statistics and Cohen's d effect size statistics were calculated for each group (autism and typical siblings), construct (academic self-concept, school belonging, and wellbeing), and informant (self, parent, teacher) and are

included in Table 4. As the number of cases varies for each measure and respondent, the number of participants (N) included in each analysis is also reported.

Group	Autism siblings				Typical siblings			
	N	M	SD	R	N	M	SD	R
School belonging (TBS)								
Sibling	65	2.43/3	0.41	1.50-3	57	2.71/3	0.28	1.92-3
	$t(113) = -4.450, p = < .001, d = .80$							
Academic self-concept (MALS)								
Sibling	65	69.55/100	14.10	37-98	57	78.35/100	12.51	51-99
	$t(120) = -3.622, p = < .001, d = .66$							
Wellbeing (SDQ – total difficulties)								
Sibling	65	13.48/20	6.04	3-29	59	9.59/20	5.57	1-27
	$t(122) = 3.708, p = < .001, d = .67$							
Parent	73	12.10	7.12	1-31	66	7.29	4.73	1-22
	$t(126) = 4.728, p = < .001, d = .80$							
Teacher	25	9.60	8.82	0-35	12	4.83	5.24	0-14
	$t(35) = 1.724, p = .094, d = .66$							
Externalising difficulties (SDQ – conduct problems and hyperactivity/inattention)								
Sibling	65	7.62	4.00	0-20	59	4.83	3.22	0-14
	$t(122) = 4.240, p = < .001, d = .77$							
Parent	73	7.05	4.45	0-19	66	3.89	3.16	0-13
	$t(130) = 4.861, p = < .001, d = .82$							
Teacher	25	6.32	5.49	0-17	12	2.42	2.27	0-6
	$t(35) = 3.051, p = .004, d = .93$							
Internalising difficulties (SDQ – emotional symptoms and peer relationships)								
Sibling	65	5.86	3.60	0-15	59	4.76	3.19	4-10

		$t(122) = 1.791, p = .076, d = .32$							
Parent	73	5.04	3.96	0-17	66	3.39	2.61	0-19	
		$t(126) = 2.922, p = .004, d = .49$							
Teacher	25	3.28	4.29	0-18	12	2.42	3.50	0-9	
		$t(35) = 0.606, p = .548, d = .22$							
Prosocial behaviour (SDQ – prosocial subscale)									
Sibling	65	7.77	1.75	2-8	59	8.14	1.55	4-10	
		$t(122) = -1.231, p = .221, d = .22$							
Parent	73	7.89	2.09	2-10	66	8.42	1.60	1-10	
		$t(133) = -1.699, p = .092, d = .28$							
Teacher	25	7.76	2.28	2-10	12	7.58	2.54	4-10	
		$t(35) = 0.213, p = .833, d = .07$							

Table 4. T-tests results table.

2.3.3 Group differences (t-tests): School-related outcomes

School belonging. There were three outliers in the school belonging data. As these were not extreme, within a moderately large sample size, and still fell in the range of the autism siblings' scores, they were kept in the analysis. Data were slightly positively skewed for the typical siblings group and homogeneity of variances was also violated, so an adjusted t-test statistic was used to take this into account. Overall, autism siblings self-reported significantly lower school belonging than typical siblings, corresponding to a large effect size.

Academic self-concept. The MALS questionnaire data contained no outliers, were normally distributed, and showed homogeneity of variances. Overall, autism siblings self-reported significantly lower academic self-concept than typical siblings, corresponding to a medium effect size.

2.3.4 Group differences (t-tests): Wellbeing outcomes

Total difficulties. Self-reported data contained no outliers, were normally distributed, and showed homogeneity of variances. Parent-reported data contained no outliers and were normally distributed, but homogeneity of variances was violated. Teacher-reported data contained no outliers and showed homogeneity of variances, but data were slightly positively skewed. Siblings and parents in the autism siblings group reported significantly higher total difficulties relative to typical siblings, corresponding to medium and large effect sizes respectively. However, teachers did not report significantly different total difficulties for autism siblings relative to typical siblings (so a Mann-Whitney U test was not deemed necessary), but this corresponded to a medium effect size.

Externalising difficulties. Self-reported data contained no outliers, were normally distributed, and showed homogeneity of variances. Parent- and teacher-reported data contained no outliers, were approximately normally distributed, but homogeneity of variances was violated. Siblings, parents, and teachers all reported the autism siblings group to have significantly higher externalising difficulties relative to typical siblings, all corresponding to large effect sizes.

Internalising difficulties. Self-reported data contained one outlier, but as this was not extreme and in a relatively large sample size, this was kept in the analysis. Data were normally distributed, and showed homogeneity of variances. Parent-reported data contained no outliers and were approximately normally distributed, but homogeneity of variances was violated. Teacher-reported data contained one outlier, but as this was not extreme, this was kept in the analysis. Data were slightly skewed, but showed homogeneity of variance. Parents reported autism siblings to have significantly higher internalising difficulties relative to typical siblings, corresponding to a medium effect size. However, siblings and teachers did not report significantly different internalising difficulties between

autism and typical siblings, corresponding to small effect sizes. Therefore, a Mann-Whitney U test for the teacher-reported analysis was not deemed necessary.

Prosocial behaviour. Self-reported data contained no outliers and showed homogeneity of variances, but were non-normally distributed. Parent-reported data contained no outliers, but were non-normally distributed and homogeneity of variances was violated. Teacher-reported data contained two outliers, but as these were not extreme, they were kept within the analysis. Data were also negatively skewed, but showed homogeneity of variances. No statistically significant group differences were found with regards to self-, parent-, and teacher-reported prosocial behaviour and all effect sizes were small. Therefore, Mann-Whitney U tests were not deemed necessary.

2.3.5 Group differences (chi-squared): Analysis plan and data management

As reporting the mean score of a whole group may neglect siblings that are experiencing the most clinically significant difficulties, and therefore those who may be the most vulnerable and at-risk, the questionnaire cut off values were explored. Chi-squared tests of independence/association were conducted to test whether sibling group was associated with more significant levels of difficulties, as measured by the proportion of siblings with 'low' school belonging and academic self-concept, as well as wellbeing total difficulties (SDQ) categorised in the 'abnormal' range. Assumptions were checked and where analyses had expected counts less than five, as there was 2x2 cross-tabulation, results from the Fisher's Exact test are reported instead. Effect sizes are also reported using the Phi statistic (ϕ). Cohen's (1998) guidelines were followed to interpret the strength of the association/effect size, with .1 representing a weak or small association, .3 representing a moderate correlation, and .5 representing a large correlation.

2.3.6 Group differences (chi-squared): Descriptive and test statistics

To explore group differences in clinical cut off scores on all participants questionnaire measures, the number and percentage of participants who reported ‘low’ school belonging, ‘low’ academic self-concept, and ‘abnormal’ total difficulties, along with the chi-squared test statistics for each sibling group are reported in Table 5.

	Autism siblings	Typical siblings
School belonging (TBS)		
Sibling	N = 8/65 (12.3%)	N = 1/57 (1.8%)
	$p = .036; \phi = .201, p = .026$	
Academic self-concept (MALS)		
Sibling	N = 16/65 (24.6%)	N = 5/57 (8.8%)
	$\chi^2(1) = 5.349, p = .021; \phi = .209, p = .021$	
Wellbeing		
Sibling	N = 13/65 (20%)	N = 3/59 (5%)
	$\chi^2(1) = 6.122, p = .013; \phi = -.222, p = .013$	
Parent	N = 18/73 (25%)	N = 3/66 (5%)
	$\chi^2(1) = 10.932, p = .001; \phi = -.280, p = .001$	
Teacher	N = 7/22 (32%)	N = 0/11 (0%)
	$p = .067; \phi = -.367, p = .035$	

Table 5. Chi-squared analyses.

2.3.7 Group differences (chi-squared): School-related and wellbeing outcomes

School belonging. This analysis did not meet the assumption of having expected counts greater than five so the Fisher’s Exact test was reported. The proportion of autism

siblings who had self-reported low school belonging was significantly higher than typical siblings, corresponding to a small association.

Academic self-concept. All cells met the assumption of having expected counts greater than five. The proportion of autism siblings who had self-reported low academic self-concept was significantly higher than typical siblings, corresponding to a small association.

Wellbeing. All cells in the self- and parent-reported analyses had expected counts greater than five. The teacher-reported analysis did not meet this assumption, with expected counts less than five, so the Fisher's Exact test was reported. The proportion of autism siblings who had self-reported and parent-reported total difficulties in the 'abnormal' range were significantly higher than typical siblings, both corresponding with small associations. Teacher-reported total difficulties were not statistically significant, likely due to the small sample size, but corresponded with a moderate association.

2.3.8 Regression: Analysis plan and data management

Four hierarchical multiple regression analyses, each including two blocks/models, were conducted. Two analyses included school belonging as the DV (analysis 1 and 3) and two included academic self-concept as the DV (analysis 2 and 4). Block/model one (analysis 1 and 2) tested whether the IVs sibling group (autism or typical siblings) or demographic factors (sibling age; gender; disability; EAL; or level of neighbourhood deprivation) predicted school belonging or academic self-concept. Block/model two tested whether the sibling wellbeing (internalising and externalising difficulties) IVs (self-report in analysis 1 and 2 and parent-report in analysis 3 and 4) were significant predictors of school belonging and academic self-concept, in addition to sibling group and demographic variables. Teacher-reported data were excluded from the regression analyses due to the small sample size.

Preliminary analyses were carried out on the data separately according to the regression model to screen for violations to assumptions for parametric tests. The assumptions for all four analyses were met for independence of observations/residuals (as assessed by the Durbin-Watson test for autocorrelation, with statistics ranging from 1.934 to 2.087), linearity between the DV and IVs collectively (tested using a scatterplot), linearity between the DV and each of the IVs individually (tested using partial regression plots), homoscedasticity (tested using scatter plots), multicollinearity (checked through inspection of correlation coefficients, with no IVs having correlations greater than .7, nor VIF scores greater than 10), outliers (assessed using the casewise diagnostics table, with no standardized residuals greater than +3 standard deviations), influential points (checked using Cook's distance values), and normality of standardised residuals (assessed using histograms and P-P plots). The assumption for leverage values was not met. Two participants had leverage values higher than 0.2 (participant 16 and 138 scored between 0.20-0.23). As these did not reach the 'dangerous' level of 0.5 and above, were within a moderate sample size, and the assumptions for outliers and influential points were met, they were kept in the analysis.

2.3.9 Regression: Descriptive and test statistics

The hierarchical multiple regression results are shown in Table 6, which explore the predictors of school belonging and academic self-concept and the variation in the DVs that can be explained by the IVs.

DVs	School belonging	Academic self-concept
IVs	Analysis 1 (model 1)	Analysis 2 (model 1)
	$R^2 = .172, F(6, 113) = 3.911, p = .001$	$R^2 = .152, F(6, 113) = 3.388, p = .004$
Sibling group	$B = 0.264, \beta = .348, p = < .001$	$B = 7.515, \beta = .266, p = .004$

Sibling age	$B = -0.023, \beta = -.077, p = .385$	$B = 0.870, \beta = .077, p = .387$
Sibling gender	$B = -0.050, \beta = -.066, p = .457$	$B = -1.896, \beta = -.067, p = .457$
Sibling disability	$B = 0.095, \beta = .085, p = .350$	$B = 7.047, \beta = .170, p = .066$
Sibling EAL	$B = .047, \beta = .031, p = .725$	$B = 5.771, \beta = -.102, p = .250$
Family MDI	$B = .022, \beta = -.135, p = .125$	$B = -.449, \beta = -.076, p = .394$
	Analysis 1 (model 2)	Analysis 2 (model 2)
	$R^2 = .524$ (R^2 change = .352),	$R^2 = .407$ (R^2 change = .254),
	$F(2, 111) = 40.993, p < .001$	$F(2, 111) = 23.813, p < .001$
Sibling group	$B = 0.134, \beta = .177, p = .015$	$B = 5.120, \beta = .181, p = .025$
Sibling age	$B = -0.030, \beta = -.100, p = .143$	$B = 0.225, \beta = .020, p = .792$
Sibling gender	$B = 0.036, \beta = .047, p = .511$	$B = -1.834, \beta = -.065, p = .417$
Sibling disability	$B = -0.080, \beta = -.072, p = .327$	$B = 0.002, \beta < .001, p = .999$
Sibling EAL	$B = 0.163, \beta = .107, p = .117$	$B = -.607, \beta = -.011, p = .887$
Family MDI	$B = -0.013, \beta = -.082, p = .225$	$B = -0.297, \beta = -.050, p = .506$
Sibling internalising	$B = -0.023, \beta = -.208, p = .007$	$B = -1.874, \beta = -.457, p < .001$
Sibling externalising	$B = -0.055, \beta = -.564, p < .001$	$B = -.679, \beta = -.188, p = .034$
	Analysis 3 (model 2)	Analysis 4 (model 2)
	$R^2 = 0.332$ (R^2 change = .160),	$R^2 = 0.355$ (R^2 change = .203),
	$F(8, 111) = 6.904, p < .001$	$F(8, 111) = 7.641, p < .001$
Sibling group	$B = 0.174, \beta = .230., p = .008$	$B = 5.068, \beta = .180, p = .035$
Sibling age	$B = -0.027, \beta = -.088, p = .275$	$B = 0.436, \beta = .039, p = .624$
Sibling gender	$B = -0.056, \beta = -.073, p = .317$	$B = 4.099, \beta = -.145, p = .078$
Sibling disability	$B = -0.047, \beta = -.043, p = .636$	$B = -1.627, \beta = -.039, p = .657$

Sibling EAL	$B = 0.062, \beta = .041, p = .610$	$B = -2.650, \beta = -.047, p = .553$
Family MDI	$B = -0.012, \beta = -.076, p = .351$	$B = -0.312, \beta = -.053, p = .509$
Parent internalising	$B = -.020, \beta = -.163, p = .088$	$B = -2.103, \beta = -.461, p = < .001$
Parent externalising	$B = -0.033, \beta = -.357, p = < .001$	$B = -.389, \beta = -.112, p = .212$

Table 6. Hierarchical multiple regression analyses

2.3.10 Regression: Predictors of school-related outcomes

School belonging. Results show that analysis 1 (model one), including sibling group and demographic variables, was significant and explained 17.2% of the variance associated with school belonging. Sibling group remained a significant predictor when demographic variables were controlled. Conversely, no demographic variables significantly independently predicted school belonging. In analysis 1 (model 2), the inclusion of self-reported internalising and externalising difficulties to the prediction of school belonging led to a statistically significant increase of 35.2% and this model explained 52.4% of the variance in total. Sibling group remained a significant predictor, as well as sibling-reported internalising and externalising difficulties.

In analysis 3 (model 2), the inclusion of parent-reported internalising and externalising difficulties to model one also led to a statistically significant increase of 16% and explained 33.2% of the variance of school belonging in total. Again, sibling group remained a significant predictor, along-with parent-reported externalising difficulties, but not internalising difficulties. Findings demonstrate that group differences in school belonging remain significant even when demographic variables and sibling wellbeing are controlled for.

Academic self-concept. Results show that analysis 2 (model 1), including sibling group and demographic variables, was significant and explained 15.2% of the variance associated with academic self-concept. Similar to the school belonging results, only sibling

group was a significant predictor in this model. This shows that once demographic variables were controlled, significant sibling group differences remained. In analysis 2 (model 2), the inclusion of self-reported internalising and externalising difficulties to the prediction of academic self-concept led to a statistically significant increase of 25.4% and explained 40.7% of the variance in total. Sibling group remained a significant predictor, along-with sibling-reported internalising and externalising difficulties.

In analysis 4 (model 2), the inclusion of parent-reported internalising and externalising difficulties to model one also led to a statistically significant increase of 35.2% and explained 52% of the variance of school belonging in total. Again, sibling group remained a significant predictor, along-with parent-reported internalising difficulties, but not externalising difficulties. Findings again demonstrate that group differences in academic self-concept remained significant even when demographic variables and sibling wellbeing were controlled.

2.4 Discussion

The present study aimed to explore two school-related outcomes of autism siblings relative to typical siblings (aged 11 to 16) attending secondary schools in the UK (years 7 to 11). In line with self-determination theory, and due to the relative importance of these areas in adolescence, this study specifically focused on feelings of relatedness (through a measure of school belonging) and feelings of competence (through a measure of academic self-concept). In addition, the impact of sibling wellbeing on these two school-related outcomes was also explored. With current limited research into the school outcomes and experiences of autism, particularly in the UK, this is a particularly unique and novel study.

2.4.1 Summary of findings

Autism siblings self-reported their school belonging and academic self-concept significantly lower than typical siblings, with significantly more autism siblings reporting

in the ‘low’ school belonging and academic self-concept categories. In addition, with regards to wellbeing, siblings and parents reported autism siblings’ total difficulties significantly higher than typical siblings, with significantly more autism siblings scoring in the ‘abnormal’ category. When separated into different components, siblings, parents and teachers reported significantly higher externalising behaviours, and parents also reported significantly higher internalising behaviours, in autism siblings. Prosocial behaviour was not significantly different between the two groups. It is interesting to note that the autism siblings group had larger standard deviations and range of scores across all measures, suggesting that these outcomes were also more variable in autism siblings relative to typical siblings. This may be suggestive of the wide spectrum of autism, as well as the presence of differing risk and protective factors in families (Tomeny et al., 2012).

Sibling wellbeing accounted for a significant proportion of variance in siblings’ academic self-concept and school belonging. More specifically, self-reported internalising and externalising behaviours were shown to significantly predict both academic self-concept and school belonging for all siblings. In addition, parent-reported internalising behaviours predicted siblings’ academic self-concept and parent-reported externalising behaviours predicted siblings’ school belonging. Sibling group was also a significant predictor in all models, suggesting robust sibling group differences that were not accounted for by wellbeing or any of the demographic variables measured.

2.4.2 School belonging

Lower school belonging reported by the siblings in the current research contrasts with findings in the systematic literature review of this thesis exploring school social interactions/adjustment, social support, and teasing, which did not find poorer outcomes for autism siblings (e.g. Chien et al., 2017; Kaminsky & Dewey, 2002; Quintero and McIntyre, 2010). This further suggests that school belonging is a unique construct that incorporates more than solely peer support in school, but also support from teachers and

feeling accepted, respected, and included by the overall school culture and ethos (Goodenow, 1993a). Therefore, peer support alone is potentially not protective for school belonging. The contrasting findings may also be explained by previous studies using a larger age range, with siblings aged from 8 years old. This may reiterate the uniqueness and importance of peer relationships and school belonging leading up to and in adolescence (Brechwald & Brinstein, 2011).

Social identity theory (Turner & Tajfel, 1986) may partly explain this finding in adolescence, where siblings may see themselves as ‘different’ to their peers as a result of their sibling status, which may form an important part of their identity. In turn, they may feel less like they ‘belong’ to their ‘typical’ peer group. Moreover, perhaps these findings are reflective of teachers and peers not recognising siblings’ needs. Therefore, siblings may not be receiving the support in school they require, which may impact on their school belonging. Moreover, findings may be explained by research suggesting that families with autism experience increased levels of stigma compared to other disabilities (Gray, 1993; 2002). This may be due to autism being seen as the ‘invisible’ disability (Milton, 2012), possible presence of challenging behaviours, and others’ lack of understanding of the condition (Gray, 1993). As a result, this caused “avoidance, hostile staring and rude comments from others” in some families (Gray, 2002 p. 734). For siblings, this may lead to bullying in school and/or feeling isolated and misunderstood. Additionally, siblings may have their own social difficulties and autism traits (BAP; Piven, 2001), which may impact on their social interactions in school and in turn their school belonging.

2.4.3 Academic self-concept

The finding of significantly lower academic self-concept in autism siblings compared to typical siblings in this present study mirrors findings by Chien et al. (2017), although their study found significantly lower parent-reported, rather than self-reported, academic self-concept. By contrast, these findings are inconsistent with those of Macks and Reeve

(2007) who found higher self-reported academic self-concept scores in their sample.

Again, these mixed findings may reflect the different educational systems in these different countries, or may be a result of methodological limitations, including Mack's and Reeve's (2007) small comparison group sample size, and measurement differences.

Significantly lower academic self-concept for autism siblings could be explained by higher levels of anxiety. For example, lower school belonging scores (Frederickson & Dunsmuir, 2009) and any presenting challenging behaviour of the child with autism (Gorjy, Fielding & Falmer, 2017) are reported to lead to higher levels of anxiety. Moreover, as autism is often associated with co-occurring psychological difficulties such as anxiety (Kim et al., 2000), autism siblings may learn such thoughts, feelings, and behaviours and therefore share these emotional difficulties (Beck, 2011). These anxieties may generalise to areas of self-perception and learning, and therefore autism siblings' academic self-concept. Findings may also reflect the suggestion that autism siblings take on increased caregiving responsibilities in the adolescent life period (Cridland et al., 2015), which has been linked to poorer academic outcomes (The Children's Society, 2013), which is likely to cause lower academic self-concept. However, not all autism siblings are 'young carers' and this was not measured in this study.

2.4.4 Psychological wellbeing

To begin testing the hypothesis of whether these school-related outcomes could be explained by psychological adjustment, group differences were also explored on a measure of wellbeing (the SDQ). Significantly higher self- and parent-reported total difficulties in autism siblings relative to typical siblings, with significantly more autism siblings scoring in the 'clinical' range, replicate studies showing that autism siblings are at increased risk for psychological difficulties (e.g. Hastings 2003). Moreover, these findings specific to the adolescence life period reflect findings of increased difficulties on the SDQ with increasing age (Rodrigue et al., 1993).

Findings showing that autism siblings may be at increased risk of difficulties may be due to the teenage age range being when the first onset of mental health problems are more likely to occur (Mind, 2018; Young Minds, 2018). This could partly be explained by the physical and emotional changes related to puberty. In addition, the Mind (2018) charity states that mental health difficulties can be triggered by academic pressures, such as examinations, which typically increase at secondary school. For autism siblings specifically, the academic pressures of, and biological changes in, adolescence, in addition to some of the potential challenges of being an autism sibling, may lead to increased sensitivity to poorer psychological wellbeing. Moreover, low sense of belonging is said to lead to feelings of anxiety and depression (Frederickson & Dunsmuir, 2009), which may also be contributing bidirectionally to these outcomes.

These significant findings could also be explained by more within-child factors, such as autism traits in the siblings (BAP; Piven, 2001) or the challenging behaviour of the child with autism, which were not measured in this study. More systemic factors may additionally explain these findings, such as increased parental stress and mental health problems in families of children with autism (Bebko, Konstantareas & Springer, 1987; Weiss, 2002), which is likely to affect sibling wellbeing. Findings that autism siblings may take on increased caregiving responsibilities for the child with autism at both home and school in adolescence may also account for wellbeing difficulties (Cridland et al., 2015). This may be driven by increased parental expectations to provide support for the child with autism with increasing age (Quintero & McIntyre, 2010) and increased moral development in adolescence (Kohlberg, 1984), as well as the transition to more independent and responsible adult roles in the teenage years. Despite the explanation, such roles may lead to resentment (Stoneman, 2005) and damage the sibling bond (Harris & Glasberg, 2010), which could impact siblings' wellbeing. Moreover, when autism siblings become overly responsible for other family members, Hooper (2007) termed this 'parentification', which they identified as detrimental to child development.

Findings reporting significantly higher self-, parent-, and teacher-reported externalising difficulties in autism siblings, compared to only parents reporting significantly higher internalising difficulties, may be worthy of note. With hypotheses in the literature that autism siblings are at increased risk of receiving less time and attention from parents (Petalas et al., 2009), due to the additional needs of the child with autism, findings may be explained by the Human Givens model (Griffin & Tyrell, 1998; 2003). This suggests the importance of attention as a fundamental need for us all, so perhaps some autism siblings engage in more externalising behaviours to meet this need. However, this is only speculative.

No significant differences in self- and teacher-reported internalising difficulties between sibling groups may be reflective of the fact that *all* children and young people are at increased risk of internalising difficulties, such as depression and anxiety, in adolescence. Therefore, the differences between groups may be masked and less pronounced. Moreover, as internalising behaviours are more subtle and covert than externalising behaviours, perhaps autism siblings find it harder to self-identify, and therefore self-report, these symptoms in themselves. Nevertheless, parents reported significantly more internalising difficulties in autism siblings. As such internalising difficulties are more common in children with autism (Kim et al., 2000), perhaps parents of autism siblings become more vigilant to these symptoms in all their children.

2.4.5 Predictors of school-related outcomes

Findings that self-reported internalising and externalising behaviours significantly predicted both school belonging and academic self-concept suggests the impact of wellbeing on these school-related outcomes. Findings specific to school belonging reflect research by Waters, Cross and Shaw (2010) who also found links between school belonging and psychological wellbeing. It is likely that this link is bidirectional, with studies also showing predictive links between school belonging and mental health

difficulties in 12 to 14 year olds (Schochet et al., 2006), although this research is not specific to autism siblings.

It is worthy of note that a slightly different pattern of findings emerged in the regression models with the inclusion of parent-reported outcomes, in which only externalising difficulties predicted school belonging and internalising behaviours predicted academic self-concept. Future research on why these links might be apparent would be helpful, although it is plausible that internalising behaviours such as anxiety would be a more significant predictor for siblings' perceptions and anxieties around their learning. Self-reported ratings showing poorer mean scores on all SDQ subscales compared to parents would also contribute to these different findings. Nevertheless, this opposes findings by Rossiter and Sharpe (2001) who found that parents rated sibling outcomes worse than the siblings rated themselves. However, this difference may be accounted for the fact that Rossiter and Sharpe's review was focused on a sample of siblings of children with 'mental retardation' and not just autism. Moreover, they used the full age range of childhood, which reiterates that studies focusing on secondary school-aged siblings may produce unique findings. These findings further echo the importance of the informant used for future research, as well as the importance of exploring the siblings' own perceptions of their adjustment in order to promote a person-centred approach to autism siblings research.

Findings that sibling group significantly predicted both academic self-concept and school belonging in all models suggests robust sibling differences that cannot be fully accounted for by the included demographic variables or sibling wellbeing. This also suggests there may be other factors associated with being an autism sibling that would influence outcomes. This may include areas previously mentioned, such as the presence of challenging behaviour from the child with autism, parental stress and mental health, and, not to mention factors associated with the autism sibling themselves, such as their own autistic traits.

No demographic variables in this study were significant predictors of both school-related outcomes. This contrasts with other research in this area, which has shown that certain demographic variables are associated with increased risk of poorer school outcomes, such as being male and lower socioeconomic status (Macks & Reeve, 2007). Moreover, although more autism siblings had an illness, disability, or mental health diagnosis themselves and the autism sibling sample includes more females, which are interesting findings in themselves, these were not significant independent predictors of outcomes. This indicates that including siblings with additional needs does not necessarily bias the findings in a negative direction. Nevertheless, variables such as gender not emerging as significant independent predictors of outcomes in this study does not necessarily mean that they are not important for school outcomes. For example, this present study only included a neighbourhood deprivation score, and there are several dimensions to a family's SES.

2.4.6 Strengths and limitations

In comparison to other studies in the area of autism siblings' school outcomes, there are a number of strengths of the present study including the sample size, focus on a narrower age range to identify outcomes specific to the secondary school aged-period, inclusion of a control group of typical siblings, focus on a homogenous sample of autism siblings, being a UK-based study, and triangulating self-, parent-, and teacher-reports of wellbeing. Moreover, utilising self-report on all measures gives importance and a voice to autism siblings to reflect on their own thoughts, feelings, and experiences, which promotes a more person-centred approach to this area of research and may be an important aspect of intervention in itself.

Nevertheless, there are a number of limitations of this study that need to be taken into consideration. Regarding recruitment, many autism siblings were recruited from social media parent support groups. This may have led to this sample of participants being more

in need of support. Alternatively, this could lead to families receiving higher levels of support, such as social support and signposting, and instead may be more well-adjusted than those not active on these parenting groups. Moreover, use of a volunteer sample may have led to selection bias, in which only families where the sibling was experiencing difficulties identified this as an important area and therefore volunteered to take part. Alternatively, families experiencing particular difficulties may not have felt they had the time nor capacity to take part and may have been less likely to participate. Either way, these factors may bias the present findings and be a threat to internal validity. In addition, the differing methods of recruitment in both groups may have meant that the samples were not representative. For example, having a small number of Educational Psychologists' children in the typical siblings group may have impacted the findings. A combination of these factors limit the conclusions that can be made.

Other factors that limit the generalisability of findings include the spectrum of autism, likely variety of co-occurring difficulties, and variation in school environments, systems, pressures, and support. Moreover, a range of data was not collected in this study, as previously mentioned, such as parental stress and wellbeing, autism traits in the sibling (BAP), severity of need of the child with autism, such as their levels of challenging behaviour, and demographic information, such as family size and birth order. This may have been helpful because previous research has found siblings' own autism traits (BAP) to be associated with more negative attitudes towards school work and the child with autism's communication needs with the siblings' school behaviour problems (Chien et al. 2017). Therefore, this data may have impacted on findings and would be beneficial for future research to explore. Finally, recruitment of schools/teachers was particularly difficult, due to the number of barriers to taking part, involving separate sequential parent, sibling, Head Teacher, and teacher consent. This led to a small sample size of teachers, which reduced power in these particular analyses.

Regarding the study design, the use of questionnaire measures may have led to social desirability bias. As this seems more likely in the ‘prosocial behaviour’ area, perhaps this accounts for the non-significant findings in this area. Nonetheless, triangulating wellbeing data across siblings, parents, and teachers may have helped to overcome this limitation. However, upon reflection, the SDQ was not the most appropriate measure of wellbeing. Although the SDQ can inform whether autism siblings have increased areas of difficulties, it does not capture positive or enhanced aspects of thriving, so cannot inform whether autism siblings have increased areas of strength. Measures such as the Resiliency Scales (Prince-Embury, 2007), which explore personal strengths (such as optimism and adaptability) as well as vulnerabilities, will be more appropriate for future research to explore this construct. In addition, this promotes a more positive psychology approach to this area of research. Furthermore, in hindsight, the author acknowledges that the MALS has been re-standardised on a larger population to the original standardisation included in this study, with particular reference to the desirability to include norms to incorporate attainment, age, and sex (Norgate, Osborne & Warhurst, 2013).

On reflection, this study could have also collected additional data on the siblings’ particular school experiences, such as whether they attended the same school as the child with autism or not. Finally, as the author is an autism sibling themselves, it is a possibility that their personal connection with this research and own experiences may have biased their interpretation of the findings. However, the quantitative nature of this study minimises subjective interpretation, compared to qualitative research at least.

2.4.7 Future research

There a number of avenues future research needs to explore before findings into autism siblings’ school outcomes and experiences can be generalised. As Leach (2014) suggests, a move is needed in this area from pathology to resilience and a shift in focus from static to more dynamic variables, such as the school-related outcomes included in this

study. Firstly, it would be interesting to explore if these findings are replicated in the primary school phase, or whether they are unique to adolescence. Secondly, this study did not collect data on the academic achievement of autism siblings, which is important to explore. Future research would benefit from comparing the attainment of autism and typical siblings, such as whether there are any differences in their GCSE results. Thirdly, more predictors of school-related outcomes could be explored, such as siblings' own autism symptomology, levels of challenging behaviour of the sibling, or whether or not siblings attend the same school. Fourthly, longitudinal research would be helpful to explore the causal mechanisms behind why some autism siblings are at increased risk of poorer outcomes. Lastly, more qualitative studies are needed in this area of research to explore siblings' school experiences in more depth.

2.4.8 Implications for Educational Psychologists

To support autism siblings, their families, and school staff, this study has a number of implications for EPs in the five core functions of the EP role; training, consultation, assessment, intervention, and research (British Psychological Society, 2018). With regards to training, EPs can raise awareness of the increased risk of wellbeing and school-related difficulties for autism siblings through parent and staff training and workshops, in which siblings and families could be signposted to further support, such as the Sibs charity or young carers. Through consultation, EPs may facilitate parent and staff consultations to problem-solve individual sibling issues. Via assessment, EPs could prompt schools to collect data on the number of autism siblings in their school. As the Sibs charity (2018b) suggest, this will help identify autism siblings as a potentially vulnerable group. Their attainment data can then be compared to the wider school population so that academic progress can be monitored. In casework, TBS and MALS questionnaires could be used assess siblings' needs, or indeed strengths, in these areas. With regards to intervention, these questionnaires could be used as pre- and post- assessment tools to measure progress.

Significant findings in this study also suggest the potential need for EPs to promote, or indeed deliver, or support staff to deliver, intervention work with autism siblings that are identified to experience school-related or wellbeing difficulties. This could involve one-to-one therapeutic work, such as the Sibs Talk school-based intervention (Sibs, 2018a). Nevertheless, although Sibs (2018d) state that “one-to-one support can help a sibling with a specific issue such as anxiety”, the charity also states that “it cannot give a sibling the sense of belonging to a group of other children and young people who ‘get it’”. This suggests the value of setting up sibling support groups in secondary schools, which are evidenced by positive evaluations in research (e.g. Smith & Perry, 2005; Sykes, 2010). Within this, siblings choose to attend and share similar experiences, which may help develop a psychological group identity (Turner & Tajfel, 1986). In turn, this could promote connectedness between siblings and increase their sense of belonging. As Smith and Perry (2005) reported that their support group found significant increases in self-concept, this may additionally benefit siblings’ academic self-concept. Moreover, Macks and Reeve (2007) reported that peer friendships can facilitate positive coping. Therefore, combined with increasing school belonging and academic self-concept, which may be protective factors to build resilience for children and young people, sibling groups may also promote siblings’ wellbeing. This could be combined with promoting more preventative strategies, such as growth mind-set language to develop academic self-concept (Dweck, 2008) and buddy systems and a key adult approach to promote school belonging.

Finally, it is beneficial for EPs to be involved in carrying out further research into the school outcomes of autism siblings or evaluation of sibling interventions in schools, such as Sibs Talk or sibling support groups. EPs may also wish to supervise future Trainee EPs in research to continue to develop this evidence-base. It may also be helpful for EPs to share this research with charities, such as the NAS and Sibs, to inform the support they provide to siblings and promote evidence-based practice.

2.4.9 Conclusion

In conclusion, this study found significantly lower self-reported school belonging and academic self-concept in autism siblings, relative to a comparison group of typical siblings, with significantly more autism siblings scoring in the 'low' categories. In line with SDT, findings suggest that autism siblings are at increased risk of difficulties with regards to feelings of relatedness and competence in a school context. In addition, autism siblings were found to have significantly lower scores on a measure of wellbeing when compared to their typical sibling peers, with significantly more siblings with total difficulties in the 'abnormal' range. This suggests autism siblings may be vulnerable to developing clinically significant difficulties. Wellbeing, as well as sibling group, were significant predictors of both school-related outcomes, but no included demographic variables were significant. Findings suggest the importance of EPs being involved in school-based consultation, assessment, intervention, training, and research roles within this area to support autism siblings' school belonging, academic self-concept, and wellbeing, where individual, group, or whole school needs are identified.

Despite these significant findings, it is important to note that autism siblings' reported experiences were incredibly varied and may be influenced by a wide range of multi-dimensional factors. From my personal perspective as an EP and an autism sibling, I believe EPs should not to assume children and young people are automatically negatively impacted in these areas as a result of being an autism sibling. Alternatively, they should promote a person-centred approach to working with all autism siblings, and indeed all children and young people more generally, in order to gain individual perspectives on their strengths, needs and explanations for difficulties, so that personalised support can be put in place. Moreover, although not yet identified in the evidence-base, promoting the many benefits that can be gained from being an autism sibling may be an important aspect of intervention work.

Appendix A. Literature Review: Excluded Studies After Full-Text Screening

Reference	Rationale for exclusion
Aronson, S. (2009). Am I my brother's keeper? Challenges for the siblings of autistic children. <i>Journal of Infant, Child & Adolescent Psychotherapy</i> , 8(1), 49–56. doi:10.1080/15289160802683450	<p>An article - not an original study. No introduction, method, results or discussion sections.</p> <p>This article highlights some of the issues and challenges facing siblings of autistic children.</p>
Bachraz, V., & Grace, R. (2009). Creating a different kind of normal: parent and child perspectives on sibling relationships when one child in the family has autism spectrum disorder. <i>Contemporary Issues in Early Childhood</i> , 10(4), 317–330. doi:10.2304/ciec.2009.10.4.317	<p>No specific school aim, interview question, or findings.</p> <p>This study aimed to explore the nature of sibling relationships when one child in the family has autism.</p>
Benson, P. R., & Karlof, K. L. (2008). Child, parent, and family predictors of latter adjustment in siblings of children with autism. <i>Research in Autism Spectrum Disorders</i> , 2(4), 583–600. doi:10.1016/j.rasd.2007.12.002	<p>No specific school measure/outcome. SDQ measure, but no teacher-report - not linked specifically to school.</p> <p>This study aimed to assess the adjustment of siblings, with and without a diagnosed non-medical disability or disorder.</p>
Chan, J. Y. N., & Lai, K. Y. C. (2016). Psychological adjustment of siblings of children with autism spectrum disorder in Hong Kong. <i>East Asian Archives of Psychiatry</i> , 26(4), 141–147.	<p>No specific school measure/outcome. SDQ measure, but no teacher-report - not linked specifically to school.</p> <p>This study aimed to explore the psychological adjustment of siblings of children with autism spectrum disorder.</p>
Chien, Y.-L., Chou, M.-C., Chiu, Y.-N., Chou, W.-J., Wu, Y.-Y., Tsai, W.-C., & Gau, S. S.-F. (2017). ADHD-related symptoms and attention profiles in the unaffected siblings of probands with autism spectrum disorder: focus on the subtypes of autism and Asperger's disorder. <i>Molecular Autism</i> , 8(37), 1-12. doi:10.1186/s13229-017-0153-9	<p>No specific school measure/outcome. Attention symptoms and profiles, but not linked specifically to school. Focused on prediction of future ASD traits.</p>

	This study aimed to investigate the ADHD-related traits and attention performance in unaffected siblings of probands with autism and Asperger syndrome, as well as the clinical correlates of ADHD-related traits.
Connell, Z. O., Halloran, M. O., & Doody, O. (2016). Living with a brother who has an Autism Spectrum Disorder: A sister's perspective. <i>British Journal of Learning Disabilities</i> , 44(1), 49–55. doi:10.1111/bld.12109	No specific school aim, interview question, or findings. Also a case study. This study described a sister's experience of growing up with her brother who has ASD.
Dellve, L., Cernerud, L., & Hallberg, L. R.-M. (2000). Harmonizing dilemmas: Siblings of children with DAMP and Asperger syndrome's experiences of coping with their life situations. <i>Scandinavian Journal of Caring Sciences</i> , 14(3), 172–178. doi:10.1080/028393100750018797	No specific school aim, interview question, or findings. Also a mixed sample - not specific to autism. The aim of this study was to describe, from their own perspectives and experiences, how siblings of children with deficits in attention, motor control, and perception (DAMP) and Asperger syndrome cope with their life situations in their families.
Gamliel, I., Yirmiya, N., Jaffe, D. H., Manor, O., & Sigman, M. (2009). Developmental trajectories in siblings of children with autism: Cognition and language from 4 months to 7 years. <i>Journal of Autism and Developmental Disorders</i> , 39(8), 1131–1144. doi:10.1007/s10803-009-0727-2	No specific school measure/outcome reported. The Wide Range Achievement Test was used to identify the Broader Autism Phenotype in siblings, rather than as an outcome measure, and the results of this were not reported (p. 1136). The focus of the study was on cognitive development and receptive and expressive language. The aim of this study was to compare the cognitive and language development of siblings of children with autism to that of siblings of children with typical development.
Gau, S. S.-F., Chou, M.-C., Lee, J.-C., Wong, C.-C., Chou, W.-J., Chen, M.-F., ... Wu, Y.-Y. (2010). Behavioral problems and parenting style among Taiwanese children with autism and their siblings. <i>Psychiatry</i>	No specific school measure/outcome reported.

<p><i>and Clinical Neurosciences</i>, 64(1), 70–78. doi:10.1111/j.1440-1819.2009.02034.x</p>	<p>This study aimed to investigate the behavioural problems and parenting style among children with autism and their siblings in an ethnic Chinese population.</p>
<p>Gillberg, C., Gillberg, I. C., & Steffenburg, S. (1992). Siblings and parents of children with autism: A controlled population-based study. <i>Developmental Medicine & Child Neurology</i>, 34(5), 389–398. doi:10.1111/j.1469-8749.1992.tb11450.x</p>	<p>No specific school measure/outcome. Reading and spelling problems were assessed in a parental interview, but this was not a school specific measure and “only two-thirds of siblings in this group were old enough to attend primary school.” (p. 395).</p> <p>This study aimed to identify the rate of reported neuropsychiatric and cognitive/developmental disorders among siblings and parents of children with autism.</p>
<p>Gold, N. (1993). Depression and social adjustment in siblings of boys with autism. <i>Journal of Autism and Developmental Disorders</i>, 23(1), 147–163. doi:10.1007/BF01066424</p>	<p>No responses specific to school. Closed question asked on school (how important they thought it was to their parents that they do well in school – not important, important, extremely important) but no information on responses/answers to this in the results/discussion.</p> <p>This study aimed to compare siblings of autistic boys and other siblings on measures of depression, social adjustment, and the amount of child care and domestic responsibility the siblings carry within the family.</p>
<p>Gorjy, R. S., Fielding, A., & Falkmer, M. (2017). “It”’s better than it used to be”: Perspectives of adolescent siblings of children with an autism spectrum condition. <i>Child & Family Social Work</i>. doi:10.1111/cfs.12371</p>	<p>No specific school aim or interview question reported.</p> <p>This study aimed to explore how adolescent siblings of children with ASC view their life.</p>
<p>Griffith, G. M., Hastings, R. P., & Petalas, M. A. (2014). Brief report: Fathers’ and mothers’ ratings of behavioral and emotional problems in siblings of children with autism spectrum disorder. <i>Journal of Autism</i></p>	<p>No specific school measure/outcome.</p>

<p><i>and Developmental Disorders</i>, 44(5), 1230–1235. doi:10.1007/s10803-013-1969-6</p>	<p>This study aimed to explore the behavioural adjustment of siblings of children with autism.</p>
<p>Hastings, R. P. (2003). Brief report: Behavioral adjustment of siblings of children with autism. <i>Journal of Autism and Developmental Disorders</i>, 33(1), 99–104. doi:10.1023/A:102229072344</p>	<p>No specific school measure/outcome. Measures on behavioural and social adjustment, but not linked specifically to school.</p> <p>This study aimed to explore the behavioural adjustment of siblings of children with autism and the impact of parental (mother’s) stress.</p>
<p>Hastings, R. P., & Petalas, M. A. (2014). Self-reported behaviour problems and sibling relationship quality by siblings of children with autism spectrum disorder. <i>Child: Care, Health and Development</i>, 40(6), 833–839. doi:10.1111/cch.12131</p>	<p>No specific school measure/outcome. No reference to school specifically.</p> <p>This study aimed to explore behavioural and emotional problems and sibling relationships in siblings of children with autism.</p>
<p>Hastings, R. P., Petalas, M. A., Jones, L., & Totsika, V. (2014). Systems analysis of associations over time between maternal and sibling wellbeing and behavioral and emotional problems of children with autism. <i>Research in Autism Spectrum Disorders</i>, 8(11), 1516–1520. doi:10.1016/j.rasd.2014.07.012</p>	<p>No specific school measure/outcome. SDQ measure, but no teacher-report - not linked specifically to school.</p> <p>This study aimed to extend a systems perspective in autism family research to a triad involving the child with autism, their mother, and a sibling, and also adopted a longitudinal design.</p>
<p>Hwang, S. K., & Charnley, H. (2010a). Honourable sacrifice: a visual ethnography of the family lives of Korean children with autistic siblings. <i>Children & Society</i>, 24(6), 437–448. doi:10.1111/j.1099-0860.2009.00228.x</p>	<p>No specific school aim or interview question reported.</p> <p>The aim of this study was to explore children’s own portrayals of their experiences of living with an autistic sibling.</p>
<p>Hwang, S. K., & Charnley, H. (2010b). Making the familiar strange and making the strange familiar: Understanding Korean children’s experiences of living with an autistic sibling. <i>Disability & Society</i>, 25(5), 579–592. doi:10.1080/09687599.2010.489305</p>	<p>No specific school aim or interview question reported.</p> <p>The aim of this study was to use visual ethnographic methods to explore children’s experiences and perspectives of living with autistic siblings.</p>

<p>McHale, S. M. (1986). Sibling relationships of children with autistic, mentally retarded, and nonhandicapped brothers and sisters. <i>Journal of Autism and Developmental Disorders</i>, 16(4), 399–413. doi:10.1007/BF01531707</p>	<p>Mixed sample. No specific school aim. Data on school interview question/item not reported.</p> <p>Mixed sample of siblings of children with autism and siblings of children who are “mentally retarded” (p. 399).</p> <p>One out of 36 items on the ‘sibling problems questionnaire’ was related to school (“I try to do well in school to make up to my parents for X’s being retarded/autistic”) but data specific to this individual item was not reported. Data related to school experiences not reported separately for the samples.</p> <p>The aim of this study was to explore sibling relationships between children and their handicapped brothers and sisters.</p>
<p>Petalas, M. A., Hastings, R. P., Nash, S., Dowey, A., & Reilly, D. (2009). “I like that he always shows who he is”: The perceptions and experiences of siblings with a brother with autism spectrum disorder. <i>International Journal of Disability, Development and Education</i>, 56(4), 381–399. doi:10.1080/10349120903306715</p>	<p>No specific school aim or interview question.</p> <p>The aim of this study was to investigate the perceptions and lived experiences of typically developing siblings, in middle childhood, who were growing up with a brother with autism.</p>
<p>Petalas, M. A., Hastings, R. P., Nash, S., Reilly, D., & Dowey, A. (2012). The perceptions and experiences of adolescent siblings who have a brother with autism spectrum disorder. <i>Journal of Intellectual and Developmental Disability</i>, 37(4), 303–314. doi:10.3109/13668250.2012.734603</p>	<p>No specific school aim or interview question.</p> <p>The aim of this study was to explore how adolescent siblings growing up with a brother with autism make sense of their unique circumstances and experiences.</p>
<p>Rao, P. A., & Beidel, D. C. (2009). The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. <i>Behavior Modification</i>, 33(4), 437–451. doi:10.1177/0145445509336427</p>	<p>No specific school measure/outcome.</p> <p>A self-concept measure used, but a total score given (does not include subscales e.g. academic) - not linked specifically to school.</p>

	This study aimed to investigate the impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning.
Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. <i>Journal of Autism and Developmental Disorders</i> , 33(4), 383–394. doi:10.1023/A:1025006727395	No specific school measure/outcome. Measures on behavioural and social adjustment (e.g. social support), but not linked specifically to school. The study aimed to study sibling relationships in families with a child with autism.
Rodgers, J. D., Warhol, A., Fox, J. D., McDonald, C. A., Thomeer, M. L., Lopata, C., ... Sheffield, T. (2016). Minimal risk of internalizing problems in typically-developing siblings of children with high-functioning autism spectrum disorder. <i>Journal of Child and Family Studies</i> , 25(8), 2554–2561. doi:10.1007/s10826-016-0407-8	No specific school measure/outcome. This study aimed to examine the anxiety and depression clinical symptom levels in siblings of children with high-functioning autism.
Smith, T., & Perry, A. (2004). A sibling support group for brothers and sisters of children with autism. <i>Journal on Developmental Disabilities</i> , 11(1), 77–88. Retrieved from http://oadd.org/publications/journal-on-developmental-disabilities/	No specific school measure/outcome. This study aimed to examine the effectiveness of a sibling support group for siblings of children with autism.
Stampoltzis, A., Defingou, G., Antonopoulou, K., Kouvava, S., & Polychronopoulou, S. (2014). Psycho-social characteristics of children and adolescents with siblings on the autistic spectrum. <i>European Journal of Special Needs Education</i> , 29(4), 474–490. doi:10.1080/08856257.2014.922811	No specific school measure/outcome. School adjustment is referred to in the abstract and the self-perception questionnaire includes “scholastic competence and achievement” (p. 479), but this is not reported on separately in the results or discussion. No specific school aim either. Social relationships and friendships are referred to, but, again, this was not specific to school. This study aimed to investigate the psych-social characteristics of typically developing children who have siblings with autism and their sibling relationships.

<p>Tomeny, T. S., Barry, T. D., & Bader, S. H. (2012). Are typically-developing siblings of children with an autism spectrum disorder at risk for behavioral, emotional, and social maladjustment? <i>Research in Autism Spectrum Disorders</i>, 6(1), 508–518. doi:10.1016/j.rasd.2011.07.012</p>	<p>No specific school measure/outcome. Measures exploring behavioural, emotional and social adjustment, but not specifically linked to school. Self-concept measure used, but only a total score given (does not include subscales e.g. academic). This study aimed to explore the behavioural, emotional and social adjustment of siblings of children with autism.</p>
<p>Tsai, H.-W. J., Cebula, K., & Fletcher-Watson, S. (2016). Influences on the psychosocial adjustment of siblings of children with autism spectrum disorder in Taiwan and the United Kingdom. <i>Research in Autism Spectrum Disorders</i>, 32, 115–129. doi:10.1016/j.rasd.2016.09.007</p>	<p>No specific school measure/outcome. Measures on peer problems, but not specifically linked to school. Measure on social support includes classmates and teachers, but this data is not reported separately. This study aimed to examine the psychosocial adjustment of typically developing siblings of children with ASD and the extent to which this is impacted by key demographic and psychosocial variables.</p>
<p>Verté, S., Roeyers, H., & Buysse, A. (2003). Behavioural problems, social competence and self-concept in siblings of children with autism. <i>Child: Care, Health and Development</i>, 29(3), 193–205. doi:10.1046/j.1365-2214.2003.00331.x</p>	<p>No specific school measure/outcome. Measures exploring behavioural, social and emotional adjustment, but not specifically linked to school. Self-concept measure included, but only a total score given (does not include subscales e.g. academic). This study aimed to investigate the psychological adjustment of siblings of children with high-functioning autism in comparison with sibling of normally developing children in the domain of behavioural problems, social competence and self-concept.</p>
<p>Wigston, C., Falkmer, M., Vaz, S., Parsons, R., & Falkmer, T. (2017). Participation in extracurricular activities for children with and without</p>	<p>No specific school measure/outcome.</p>

<p>siblings with autism spectrum disorder. <i>Developmental Neurorehabilitation</i>, 20(1), 25–39. doi:10.3109/17518423.2015.1046091</p>	<p>Measures on extra-curricular activities, but this is not linked specifically to school. Results or discussion do not refer to school separately.</p> <p>The aim of this study was to compare the number, frequency, enjoyment and performance in extracurricular activities of siblings of children with autism spectrum disorders to their typically developing peers and to identify differences between actual and desired participation.</p>
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Appendix B. Literature Review: Data Extraction - Quantitative Studies

Author, year, title, country	Study aim	Methodology	Participants	Measures/ outcomes related to school	Findings relevant to school
August, Stewart and Tsai (1981). The incidence of cognitive disabilities in the siblings of autistic children. USA	To examine the incidence of cognitive disabilities in siblings of “autistic probands” (p. 416).	Mixed methods. Direct assessment measure - sibling.	71 siblings of children with autism (36 boys and 35 girls). Control group – 38 siblings of children with Down’s syndrome (20 girls and 18 boys). All aged 4 to 16 years.	Wide Range Achievement Tests (WRAT): Tests of academic/school achievements in reading, spelling and arithmetic skills.	School factors – academic outcomes: <ul style="list-style-type: none"> • 2 siblings demonstrated a specific learning disability in reading. • However, specific results on the WRAT were not reported.
Barak-Levy, Goldstein and Weinstock (2010) Adjustment characteristics of children with autism.	To explore the social and emotional adjustment characteristics and level of behavioural problems of siblings of	Informant-based questionnaire measures. Parent-report.	27 siblings of individuals with autism (12 male, 15 female). 27 siblings with no disabled sibling (12	Child Behaviour checklist: Children’s competency (child activities, social relations, school performance).	School factors – academic outcomes: Parental ratings: <ul style="list-style-type: none"> • 37% borderline clinical range. • 14.8% clinical range. • “Over half of the siblings reportedly have more academic difficulties” than the norms of the questionnaire. Extra-curricular activities not specific to school.

Israel	children with autism.		male, 15 female). Aged 6 to 18.		
Ben-Yizhak, Yirmiya, Seidman, Alon, Lord and Sigman (2011). Pragmatic language and school related linguistic abilities in siblings of children with autism. Israel.	To compare the linguistic abilities e.g. pragmatic language, school achievements, and underlying reading processes of siblings of children with autism to siblings of children with typical development.	Direct assessment measures – sibling.	SIBS-A-BAP: 13 siblings of children with autism who meet Broader Autism Spectrum criteria (3 girls, 10 boys) SIBS-A-TD: 19 typically developing siblings of children with autism (8 girls, 11 boys) SIBS-ToD-TD: 38 siblings of children with typical development (19 girls, 19 boys).	Wide Range Achievement Tests.	School factors – academic outcomes: <ul style="list-style-type: none"> No significant overall group effect for the WRAT reading, spelling, and arithmetic scores – no significant findings.

			Aged 9 to 12 years.		
Cebula (2012) Applied behaviour analysis programs for autism: Sibling psychosocial adjustment during and following intervention use. Scotland, UK	To explore the psychosocial adjustment in siblings of children with autism whose families were using a home-based applied behaviour analysis programme.	Informant-based questionnaire measures. Teacher report.	ABA group: 45 siblings of children with autism (21 male, 24 female). Post-ABA group: 26 siblings of children with autism (15 male, 11 female). Control group: 61 siblings of children with autism not using any intensive interventions. Aged 4 to 16 years.	Teacher report of the strengths and difficulties questionnaire: Behavioural screening.	Psychological internal challenges and resources – behavioural outcomes: <ul style="list-style-type: none"> • No significant group differences found in teacher data either in total score or in any of the domain scores. ABA intervention does not result in differences in scores on the SDQ. • Teachers rated siblings as significantly lower on conduct problems than the siblings themselves did, but did not differ significantly from those of parents. • Teachers rated siblings as significantly lower on the hyperactivity domain than their parents did, with these ratings in turn significantly lower than the siblings' own ratings of their behaviour in this area.
Chien, Tu and Gau (2017)	To compare several scholastic functional	Informant-based questionnaire measures.	66 unaffected siblings of children with autism (35	Social adjustment inventory for children and adolescents	School factors – academic outcomes: <ul style="list-style-type: none"> • Not significantly different from typically developing controls.

School functions in unaffected siblings of youths with autism spectrum disorders.	domains of unaffected siblings to those of ASD and TD youths.	Parent-report.	male, 31 female). 132 typically developing controls (98 male, 34 female). All aged 8 to 19.	(SAICA). Subscales chosen: Academic performance. Attitude towards school work. School social interactions. School behavioural problems.	<ul style="list-style-type: none"> • Older age, lower full-scale IQ, and higher social responsiveness scale (SRS) scores, and higher inattention subscores (SNAO-IV) were associated with worse academic performance. • Older age, lower FSIQ, and inattentive symptoms predicted worse academic performance. • More general inattention deficits, which might increase their difficulties to pay attention to lessons and engage in academic work. <p>Psychological internal challenges and resources – emotional/behavioural outcomes:</p> <p>Attitudes to learning:</p> <ul style="list-style-type: none"> • Unaffected siblings had a poorer attitude towards schoolwork. • Negative attitude towards school work was related to lower full-scale IQ, higher total SRS score, higher inattention and hyperactivity-impulsivity subscore (SNAP-IV), and poor sibling relationship. • Negative attitude toward school-work was significantly predicted by their lower FSIQ and poorer sibling relationships. <p>Behaviour:</p> <ul style="list-style-type: none"> • More severe behavioural problems at school. • School behavioural problems in unaffected siblings were associated with ASD
Taiwan	To identify the possible correlates for impaired school functions in the unaffected siblings.				

					<p>probands' communication deficit (SCQ) and lower FSIQ, and unaffected siblings' higher total SRS score, more ADHD-related symptoms (SNAP-IV), and poorer sibling relationships.</p> <ul style="list-style-type: none"> • Siblings' own autistic traits (higher SRS scores) and inattention and oppositional symptoms predicted worse school behavioural problems. <p>Peers and other formal and informal social systems – social outcomes:</p> <ul style="list-style-type: none"> • Not significantly different. • Worse social interaction at school was associated with more repetitive behaviour and communication deficit (SCQ) of children with autism, higher total SRS score, more ADHD-related symptoms (SNAP-IV), and poorer sibling relationships. • Communication deficits of ASD probands, and inattention and oppositional problems of unaffected siblings predicted social interaction problems at school. <p>In general, maternal education, mother's parenting style, probands' age, the ASD subtype, and the unaffected siblings' gender were not associated with the unaffected siblings' school functions.</p>
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<p>Kaminsky and Dewey (2002)</p> <p>Psychosocial adjustment in siblings of children with autism.</p> <p>Canada</p>	<p>This study investigated psychosocial adjustment in siblings of children with autism compared to siblings of children with Down syndrome and siblings of normally developing children.</p>	<p>Informant-based questionnaire measures.</p> <p>Parent-report.</p> <p>Self-report.</p>	<p>30 siblings of children with autism (15 female, 15 male).</p> <p>30 siblings of children with Down syndrome (15 female, 15 male).</p> <p>30 siblings of children with no known disability (15 female, 15 male).</p> <p>Aged 8 to 18 years</p>	<p>Child Behaviour Checklist (CBC): School performance subscale.</p> <p>Social Support Scale for Children: Teachers and classmates subscales.</p>	<p>School factors – academic outcomes:</p> <ul style="list-style-type: none"> • No significant effects for group or gender on the individual scales of the CBC (which includes school performance). • For autism siblings, higher levels of social support from classmates was significantly correlated with higher levels of academic functioning on the CBC. <p>Peers and other formal and informal social systems – social outcomes:</p> <ul style="list-style-type: none"> • No significant differences found for social support from teachers and classmates. • Siblings in all groups reported that they felt somewhat or very supported by teachers and classmates. • Siblings in every group consistently reported receiving higher average levels of social support than the normative sample. • For all siblings, higher levels of social support from classmates specifically was significantly correlated with lower levels of loneliness. • For autism siblings, higher levels of social support from classmates was significantly correlated with higher levels of academic functioning on the CBC.
<p>Macks & Reeve (2007)</p>	<p>To compare the psychosocial</p>	<p>Informant-based</p>	<p>51 siblings of children with autism (21</p>	<p>Piers-Harris Children’s Self-Concept Scale:</p>	<p>Psychological internal challenges and resources – emotional outcomes:</p>

<p>The adjustment of non-disabled siblings of children with autism.</p> <p>USA</p>	<p>and emotional adjustment of siblings of children with autism and siblings of non-disabled children.</p>	<p>questionnaire measures.</p> <p>Self-report.</p>	<p>male, 30 female).</p> <p>35 siblings of non-disabled children (16 male, 20 female).</p> <p>Aged 7 to 17.</p>	<p>Intellectual and School Status subscale.</p>	<ul style="list-style-type: none"> • The experimental group scored significantly higher than the comparison group on the intellectual and school status subscale. • Comparison group still scored in the average range on these measures. • The demographic variables considered to place a child more at risk for scholastic difficulties includes being a male, coming from a family of low SES, only having one sibling, and being older than the child with autism. • The demographic characteristics found to decrease a child's risk included being female, coming from a family of high SES, having more than one sibling, and being younger than the child with autism. • The presence of a child with autism appears to have an increasingly negative effect on the non-disabled sibling as the number of demographic risk factors increase.
<p>Mates (1990)</p> <p>Siblings of autistic children: Their adjustment and performance at home and in school.</p> <p>USA</p>	<p>To examine the adjustment of siblings of autistic children at home and school.</p>	<p>Direct assessment measures – sibling.</p> <p>Informant-based questionnaire measure.</p>	<p>33 of the oldest school-aged siblings of autistic children (18 male, 15 female).</p> <p>No control group.</p>	<p>Wide Range Achievement Test.</p> <p>Rutter Questionnaire for Teachers.</p>	<p>School factors – academic outcomes:</p> <p>Psychological internal challenges and resources – behavioural outcomes:</p> <ul style="list-style-type: none"> • “Siblings did not perform differently on any of the measures as a nature of their gender or family size.” (p. 549-550). • “In testing for the effect of sex and family size on the dependent variables” (school adjustment, reading achievement, spelling

	To assess whether the gender of the sibling or family size played a significant role in the adjustment of siblings of autistic children.	Teacher-report.	Aged 6 to 17 years.		achievement, and arithmetic achievement), no interaction was found.” (p. 550). <ul style="list-style-type: none"> • “None of the four groups had scores that were significantly different from those of the normative samples on any of the measures.” (p. 550).
Nowell, Brewton and Goin-Kochel (2014) A multi-rater study on being teased among children/ adolescent with autism spectrum disorder and their typically developing siblings: Associations with ASD symptoms.	To examine the teasing experiences among individuals with autism spectrum disorder.	Informant-based questionnaire measures. Teacher-report.	74 individuals with ASD (83.8% male). 68 typically developing siblings (52.9% male). Aged 6 to 18.	Teacher Report Form: Item – ‘get teased a lot’ (response – 0 = never, 1 = sometimes, or 2 = often) to calculate the prevalence of being teased.	Peers and other formal and informal social systems – social outcomes: <ul style="list-style-type: none"> • Teacher reports of being teased for the ASD sample were significantly higher than those in the TD sibling sample. • ASD sample – 40.8% teased. TD sample – 7.7% teased. • Typically developing siblings less likely to be teased than siblings with ASD.

USA					
<p>Quintero and McIntyre (2010)</p> <p>Sibling adjustment and maternal wellbeing: An examination of families with and without a child with an autism spectrum disorder.</p>	<p>To examine sibling social, behavioural, and academic adjustment and maternal wellbeing in families with and without a pre-schooler with autism spectrum disorder.</p>	<p>Informant-based questionnaire measures.</p> <p>Teacher-report.</p> <p>Parent-report.</p>	<p>20 siblings of children with autism (11 male, 9 female).</p> <p>23 siblings of children who are typically developing (10 male, 13 female).</p> <p>Aged 6 to 10 years old.</p>	<p>Teacher Report Form: Behaviour.</p> <p>Social Skills Rating System (SSRS): Academic Competence subscale.</p> <p>Elementary Teacher Version.</p>	<p>School factors – academic outcomes:</p> <ul style="list-style-type: none"> • No significant differences in parent and teacher reports of older siblings’ academic adjustment in families with and without a child with ASD. • Mean standard scores for both groups were in the average range. • Teacher reports of sibling academic competence was significantly related to parent reports of life stress. <p>Psychological internal challenges and resources – behavioural outcomes:</p> <ul style="list-style-type: none"> • No significant differences in teacher reports of older siblings’ behavioural adjustment in families with and without a child with ASD. • Teacher-reported behaviour problems, although not statistically significant, showed moderate effect sizes for sibling internalising (e.g. anxiety, withdrawal or depression) and total problem behaviours in the classroom, with siblings of children with ASD demonstrating more behaviour problems than control siblings, suggesting a possibility of heightened problems at school. Although descriptive statistics suggest they were still in the average range.
USA					

					<ul style="list-style-type: none"> Teacher-reported behaviour problems significantly correlated with mothers' reports of life stress and depression. Teachers rated siblings as having more problem behaviours in families with mothers reporting more life stress and depression. <p>Peers and other formal and informal social systems – social outcomes:</p> <ul style="list-style-type: none"> No significant differences in teacher reports of older siblings' social adjustment in families with and without a child with ASD.
<p>Rodrigue, Geffken and Morgan (1993)</p> <p>Perceived competence and behavioural adjustment of siblings of children with autism.</p> <p>USA.</p>	<p>To examine the psychological adjustment of siblings of autistic children, including self-competence, and social and behavioural functioning.</p>	<p>Informant-based questionnaire measures.</p> <p>Self-report.</p>	<p>19 siblings of severely autistic children (10 female, 9 male).</p> <p>20 siblings of Down syndrome (10 female, 10 male).</p> <p>20 siblings of developmentally normal children (12 female, 8 male).</p> <p>Only mean age reported –</p>	<p>Perceived Competence Scale for Children: Scholastic competence subscale.</p>	<p>School factors – academic outcomes:</p> <ul style="list-style-type: none"> Autism: Mean = 21.31, SD = 3.28; Down: M = 18.27, SD = 3.49; Normal: M = 19.50, SD = 3.66. Analyses for significance are not reported for individual subscales.

Appendix B

			autism - 10.22 years; Down syndrome – 11.05; typically developing – 9.45 years.		
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Appendix C. Literature Review: Data Extraction – Qualitative Studies

Author, year, title, country	Study aim	Methodology	Participants	Questions asked on school	Findings relevant to school
<p>August, Stewart and Tsai (1981).</p> <p>The incidence of cognitive disabilities in the siblings of autistic children.</p> <p>USA</p>	<p>To examine the incidence of cognitive disabilities in siblings of “autistic probands” (p. 416).</p>	<p>Mixed methods</p> <p>Parental interview – information on the development of the sibling.</p>	<p>71 siblings of children with autism (36 boys and 35 girls).</p> <p>Control group – 38 siblings of children with Down’s syndrome (20 girls and 18 boys).</p> <p>All aged 4 to 16 years.</p>	<p>“Information was also requested concerning the child’s academic progress, specifically regarding the need for any special remedial education.” (page 417-418).</p>	<p>School factors – academic outcomes:</p> <ul style="list-style-type: none"> • 7 of the 11 siblings with a cognitive disability “were receiving special educational remediation for the mentally disabled.” (p. 418). • 2 siblings were in classes for children “for the learning disabled”, compared to 1 control group participant with a cognitive disability who was “in a class for the educable mentally disabled.”
<p>Bagenholm and Gillberg (1991).</p> <p>Psychosocial effects on siblings of children with autism and mental retardation: A population-based study</p> <p>Sweden</p>	<p>To examine the sibling relationships.</p> <p>Whether siblings of handicapped children show more behaviour problems.</p>	<p>Semi-structured interviews.</p> <p>Parental interview.</p>	<p>20 participants who had siblings with autism (SA) (12 male, 8 female).</p> <p>20 participants who had siblings with “mental retardation” (SMR) (p. 291) (12 male, 8 female)</p>	<p>“The parent was interviewed in a semi-structured way about the target child’s possible school” “i.e. learning problems.”</p>	<p>Psychological internal challenges and resources – behavioural outcomes:</p> <ul style="list-style-type: none"> • SA: 20% (4 out of 20). • SMR: 15% (3 out of 20). • SFMR: 5% (2 out of 20).

			<p>20 participants who had siblings “free of handicap” (SFH) (p. 291) (12 male, 8 female).</p> <p>Children and young adults aged between 5 to 20. Mean age 10.1 years.</p>		
<p>Cridland, Jones, Stoyles, Caputi and Magee (2015).</p> <p>Families living with ASD: Roles and responsibilities of adolescent sisters.</p> <p>Australia.</p>	<p>This study investigates the experiences of NTD adolescent sisters with a younger, adolescent brother with ASD, paying particular attention to the roles and responsibilities they undertake at school and home.</p>	<p>Semi-structured interview study.</p> <p>Sibling, brother with Aspergers, and parent report.</p>	<p>11 participants from 3 families.</p> <p>3 NTD adolescent sisters attending mainstream school (grades 8 to 11) aged 12 to 17 years (3 female).</p> <p>3 adolescent brothers with Asperger’s syndrome, attending mainstream school (aged 7 to 10). (higher functioning) (3 male).</p> <p>3 mothers and 2 fathers (3 female, 2 male).</p>	<p>Although the study aim is related to school, there are no specific interview questions related to school.</p> <p>Is the way you feel about your brother now different from when he was in primary school?</p>	<p>Personal interpretation of events:</p> <ul style="list-style-type: none"> The sisters were found to undertake various caregiving roles and responsibilities at school, including “advocating for their brother with teachers and peers, liaising between the teachers and their parents, managing miscommunications, protecting their brother from bullies, and educating their brother about how to deal with other students. Overall, there were mixed attitudes about undertaking these roles, resulting in some ambiguity about the responsibilities.” (p. 5).

Appendix D. Literature Review: Quality Assessment: Quantitative Studies

Reporting

Study	Is the hypothesis/aim/objective of the study clearly described?	Are the main outcomes to be measured clearly described in the introduction or methods section?	Are the characteristics of the participants included in the study described?	Are the distributions of principal confounders in each group of subjects to be compared clearly described?	Are the main findings of the study clearly described?	Does the study provide estimates of the random variability in the data for the main outcomes?	Have all important adverse events that may be a consequence of the study been reported?	Have actual probability values been reported (e.g.0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?
TOTAL number of YES responses	11/11	11/11	11/11	5/11	7/11	6/11	0/11	5/11
August, Stewart & Tsai (1981)	YES	YES	YES	NO	NO	NO	NO	NO
Barak-Levy, Goldstein & Weinstock (2010)	YES	YES	YES	NO	NO	NO	NO	NO
Ben-Yizhak, Yirmiya,	YES	YES	YES	YES	YES	YES	NO	YES

Appendix D

Seidman, Alon, Lord & Sigman (2011)								
Cebula (2012)	YES	YES	YES	YES	YES	YES	NO	NO
Chien, Tu & Gau (2017)	YES	YES	YES	NO	YES	YES	NO	YES
Kaminsky & Dewey (2002)	YES	YES	YES	YES	YES	YES	NO	YES
Macks & Reeve (2007)	YES	YES	YES	NO	YES	NO	NO	YES
Mates (1990)	YES	YES	YES	NO	NO	NO	NO	NO
Nowell, Brewton & Goin-Kochel (2014)	YES	YES	YES	NO	YES	NO	NO	NO
Quintero & McIntyre (2010)	YES	YES	YES	YES	YES	YES	NO	YES
Rodrigue, Geffken & Morgan (1993)	YES	YES	YES	YES	NO	YES	NO	NO

External validity

Study	Were the subjects asked to participate in the study representative of the entire population from which they were recruited?	Were the subjects who were prepared to participate in the study representative of the entire population from which they were recruited?	Was the educational setting/context (staff, places, and facilities) where the participants took part representative of the educational setting/context the majority of participants receive?
TOTAL number of YES responses	1/11	0/11	0/11

August, Stewart & Tsai (1981)	YES	NO	Not reported
Barak-Levy, Goldstein & Weinstock (2010)	NO	NO	NO
Ben-Yizhak, Yirmiya, Seidman, Alon, Lord & Sigman (2011)	NO	NO	Not reported
Cebula (2012)	NO	NO	Not reported
Chien, Tu & Gau (2017)	NO	NO	Not reported
Kaminsky & Dewey (2002)	NO	NO	Not reported
Macks & Reeve (2007)	NO	NO	NO
Mates (1990)	NO	NO	Not reported
Nowell, Brewton & Goin-Kochel (2014)	NO	NO	NO
Quintero & McIntyre (2010)	NO	NO	NO
Rodrigue, Geffken & Morgan (1993)	NO	NO	Not reported

Internal validity

	Bias	Confounding (selection bias)
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Appendix D

Study	If any of the results of the study were based on “ data dredging ”, was this made clear?	Were the statistical tests used to assess the main outcomes appropriate?	Were the main outcome measures used accurate (valid and reliable)?	Were the cases and controls (case-control studies) recruited from the same population ?	Were the cases and controls (case-control studies) recruited over the same period of time ?	Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?
TOTAL number of YES responses	N/A	9/11	9/11	1/11	1/11	4/11
August, Stewart & Tsai (1981)	N/A	NO	NO	NO	NO	NO
Barak-Levy, Goldstein & Weinstock (2010)	N/A	NO	Not reported	N/A – need to be from same population.	Not reported	NO
Ben-Yizhak, Yirmiya, Seidman, Alon, Lord & Sigman (2011)	N/A	YES	YES	NO	NO	YES
Cebula (2012)	N/A	YES	YES	NO	Not reported	NO
Chien, Tu & Gau (2017)	N/A	YES	YES	N/A	Not reported	YES
Kaminsky & Dewey (2002)	N/A	YES	YES	NO	Not reported	YES
Macks & Reeve (2007)	N/A	YES	YES	NO	Not reported	NO
Mates (1990)	N/A	YES	YES	N/A	N/A	NO

Nowell, Brewton & Goin-Kochel (2014)	N/A	YES	YES	NO	YES	NO
Quintero & McIntyre (2010)	N/A	YES	YES	NO	Not reported	YES
Rodrigue, Geffken & Morgan (1993)	N/A	YES	YES	YES	Not reported	NO

Power

Study	Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?
TOTAL number of YES responses	1/11. No studies reported power calculations so the author used Cohen's (1992) statistical power guidelines to answer this question.
August, Stewart & Tsai (1981)	Unable to determine
Barak-Levy, Goldstein & Weinstock (2010)	NO
Ben-Yizhak, Yirmiya, Seidman, Alon, Lord & Sigman (2011)	NO
Cebula (2012)	NO
Chien, Tu & Gau (2017)	YES

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Kaminsky & Dewey (2002)	NO
Macks & Reeve (2007)	NO
Mates (1990)	NO
Nowell, Brewton & Goin-Kochel (2014)	NO
Quintero & McIntyre (2010)	NO
Rodrigue, Geffken & Morgan (1993)	NO

Appendix E. Literature Review: Quality Assessment - Qualitative Studies

CASP

Study	Was there a clear statement of the aims of the research?	Is the qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationships between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings ?	How valuable is the research?
TOTAL number of YES responses	2/2	1/2	1/2	2/2	2/2	0/2	1/2	1/2	1/2	1/2
Bagenholm and Gillberg (1991)	YES	NO	NO	YES	YES	NO	NO	NO	NO	NO
Cridland, Jones, Stoyles, Caputi and Magee (2015)	YES	YES	YES	YES	YES	NO	YES	YES	YES	YES

Appendix F. Demographics Questionnaires

DEMOGRAPHIC QUESTIONNAIRE: Parent report on siblings of children with autism (Version 2; 01.06.17)

Study title: Understanding the school experiences of siblings of children with autism.

Researcher: **Alexandra Gregory**

ERGO Study ID number: **25346**

RGO reference number:

Please complete this form on behalf of the sibling who is taking part in this study.

Completed by: _____ (name of participant – parent/carer)

On behalf of: _____ (name of son/daughter who is the sibling)

Information about the target sibling to someone with autism:

Age of your child/the sibling: _____

Gender of your child/the sibling: _____

Family post-code (to calculate a measure of deprivation): _____

Does your child/the sibling have any known illness, disability or mental health diagnosis?

Yes No

If yes, what illness, disability or mental health diagnosis?

Does your child/the sibling speak English as an additional language (EAL)?

Yes No

Information about your child who has autism:

Age of your child with autism: _____

Gender of your child with autism: _____

Thank you for completing this form.

DEMOGRAPHIC QUESTIONNAIRE: Parent report on siblings of typically developing children (Version 2; 01.06.17)

Study title: Understanding the school experiences of siblings of children with autism.

Researcher: **Alexandra Gregory**

ERGO Study ID number: **25346**

RGO reference number:

Please complete this form on behalf of the sibling who is taking part in this research project.

Completed by: _____ (name of participant – parent/carer)

On behalf of: _____ (name of son/daughter who is the sibling)

Information about the target sibling of typically developing children:

Age of your child/the sibling: _____

Gender of your child/the sibling: _____

Family post-code (to calculate a measure of deprivation): _____

Does your child/the sibling have any known illness, disability or mental health diagnosis?

Yes No

If yes, what illness, disability or mental health diagnosis?

Does your child/the sibling speak English as an additional language (EAL)?

Yes No

Information about other siblings in the family:

How many typically developing siblings does your child have? _____

What are their ages and genders? _____

Thank you for completing this form.

Appendix G. The Belonging Scale



THE BELONGING SCALE

Name Date

Age Class Please circle: Male / Female

Read each statement carefully and try to decide how much you agree or disagree with it.
Remember, there are no right or wrong answers.

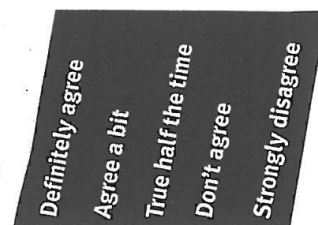
	No not true	Not sure	Yes true
<i>Practice</i> I feel happy drawing pictures.	No	?	Yes

	No not true	Not sure	Yes true
1. I feel really happy at my school.	No	?	Yes
2. People here notice when I'm good at something.	No	?	Yes
3. It is hard for people like me to feel happy here.	No	?	Yes
4. Most teachers at my school like me.	No	?	Yes
5. Sometimes I feel as if I shouldn't be at this school.	No	?	Yes
6. There is an adult in school I can talk to about my problems.	No	?	Yes
7. People at this school are friendly to me.	No	?	Yes
8. Teachers here don't like people like me.	No	?	Yes
9. I feel very different from most other kids here.	No	?	Yes
10. I wish I were in a different school.	No	?	Yes
11. I feel happy being at my school.	No	?	Yes
12. Other kids here like me the way I am.	No	?	Yes



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This measure is part of *Measure of Children's Mental Health and Well-being*.

Appendix H. Myself-As-A-Learner Scale



1. I'm good at doing tests. a b c d e
2. I like having problems to solve. a b c d e
3. When I'm given new work to do, I usually feel confident I can do it. a b c d e
4. Thinking carefully about your work helps you to do it better. a b c d e
5. I'm good at discussing things. a b c d e
6. I need lots of help with my work. a b c d e
7. I like having difficult work to do. a b c d e
8. I get anxious when I have to do new work. a b c d e
9. I think that problem-solving is fun. a b c d e
10. When I get stuck with my work I can usually work out what to do next. a b c d e
11. Learning is easy. a b c d e
12. I'm not very good at solving problems. a b c d e
13. I know the meaning of lots of words. a b c d e
14. I usually think carefully about what I've got to do. a b c d e
15. I know how to solve the problems that I meet. a b c d e
16. I find a lot of schoolwork difficult. a b c d e
17. I'm clever. a b c d e
18. I know how to be a good learner. a b c d e
19. I like using my brain. a b c d e
20. Learning is difficult. a b c d e



Appendix I. Strengths and Difficulties Questionnaire

Strengths and Difficulties Questionnaire

S 11-17

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of how things have been for you over the last six months.

Your Name

Male/Female

Date of Birth.....

	Not True	Somewhat True	Certainly True
I try to be nice to other people. I care about their feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am restless, I cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get a lot of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I usually share with others (food, games, pens etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get very angry and often lose my temper	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am usually on my own. I generally play alone or keep to myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I usually do as I am told	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worry a lot	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have one good friend or more	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I fight a lot. I can make other people do what I want	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other people my age generally like me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am easily distracted, I find it difficult to concentrate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am nervous in new situations. I easily lose confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am often accused of lying or cheating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other children or young people pick on me or bully me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I often volunteer to help others (parents, teachers, children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think before I do things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I take things that are not mine from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get on better with adults than with people my own age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have many fears, I am easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I finish the work I'm doing. My attention is good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you have any other comments or concerns?

Please turn over - there are a few more questions on the other side

Appendix J. Study Advert – Autism Siblings



Study title: Understanding the school experiences of siblings of children with autism.

Do you have a brother or sister with **autism**? And are you in **secondary school** aged 11 to 16 years old? Or do you know anyone that meets this criteria?

If so, **I need you!** 😊

My name is Alexandra Gregory and I am a Trainee Educational Psychologist studying the Doctorate in Educational Psychology at the University of Southampton. I am also a sibling to someone with autism. As part of my course, I am carrying out a thesis/research study that aims to explore the school experiences of siblings of children with autism.

If you are/know a secondary school aged sibling to someone with autism (the child with autism can be any age), I would be really grateful for your participation. Taking part involves completion of online questionnaires with a £5 voucher incentive and will really help to further our understanding in this area.

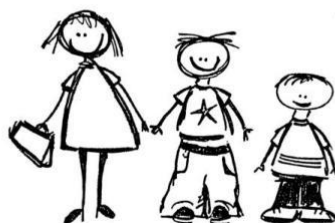
If you would like to find out more about my study and/or would like to take part, please send me an e-mail to ag2g15@soton.ac.uk and I can send you the information sheet and questionnaire link. Look forward to hearing from you!

UNIVERSITY OF
Southampton

Appendix K. Study Advert – Typical Siblings

Version 2; 02.03.18

ERGO study ID number: 25346



Are you at secondary school? Do you have a sibling? And do you want to earn a £5 amazon voucher? Please take part in my research!

My name is Alexandra Gregory and I am a Trainee Educational Psychologist at the University of Southampton. I am currently carrying out a research study where I am looking for **children/young people in secondary school who have at least one typically developing sibling.**

To receive the £5 amazon voucher, yourself and a parent/carer just need to complete an online questionnaire. Additionally, if a key member of staff (e.g. your form tutor) completes a questionnaire, your school will also be given a £5 amazon voucher.

If you fit this criteria and would like to take part, please e-mail me at ag2g15@soton.ac.uk and I can send you the information sheet and the questionnaire link.

Your support would be hugely appreciated, help you reflect on your own school experiences, and further the understanding into the school experiences of siblings. Thanks, Alex

UNIVERSITY OF
Southampton

Appendix L. Parent/Carer Information Sheet – Autism Siblings

PARTICIPANT INFORMATION SHEET: Parents/carers of siblings of children with autism (Version 3; 08.08.17)

Study title: Understanding the school experiences of siblings of children with autism.

Researcher: **Alexandra Gregory**

ERGO Study ID number: **25346**

RGO reference number:

Please read this information carefully before deciding to take part in this research.

What is the research about?

My name is Alexandra Gregory and I am a Trainee Educational Psychologist at the University of Southampton (studying the Doctorate in Educational Psychology). I am requesting your participation in a research study that aims to explore the school experiences of siblings of children with autism. Being a sibling to someone with autism myself has led to my particular interest in this area. I am being supervised by Dr Hanna Kovshoff (Lecturer at the University of Southampton) and Professor Richard Hastings (Professor in Psychology and Education at the University of Warwick).

Why have I been chosen?

This study focuses on two groups of participant siblings; siblings of children with autism and siblings of children who are typically developing without autism (the control group). This study will additionally collect information from a parent/carers and teacher/key member of school staff of each sibling, who will also report on the experiences of the sibling. **You have been chosen as a parent/carers to a sibling of someone with autism.**

What will happen to me if I take part?

If you agree to take part, you can follow the link to the online consent form and questionnaire at the bottom of this information sheet. On the consent form, you will also be asked:

- For the sibling's name, school name and address so a key member of staff at the sibling's school (e.g. their form tutor) can be invited to participate in the study.
- As the sibling (your son/daughter) is under the age of 16, you will need to consent to their involvement in the study.
- If you are happy to be contacted regarding other research projects into siblings.

The parent questionnaires should take no longer than 20 minutes to complete. This includes:

- A demographic form (to be completed on behalf of the sibling) – to collect information on the sibling's age, gender and position in the family etc.
- KIDSCREEN-27 Quality of Life Questionnaire (Ravens-Sieberer et al., 2006; The KIDSCREEN Group Europe, 2006) – to explore the sibling's wellbeing and functioning across physical, emotional, mental, social and behavioural domains.

Appendix L

- Strengths and Difficulties Questionnaire (Goodman et al., 1998) – a behavioural screening questionnaire to explore any conduct problems, emotional symptoms, hyperactivity/inattention, peer relationship problems and prosocial behaviour.

The sibling questionnaires should take no longer than 30 minutes to complete. This includes:

- The KIDSCREEN Quality of Life Questionnaire (as above).
- The Strengths and Difficulties Questionnaires (as above).
- A sense of school belonging questionnaire (Frederickson et al., 2007. Adapted from the Psychological Sense of School Membership Scale - Goodenhow, 1993) – a measure to explore the extent to which an individual feels accepted, included, respected and supported at school.
- The Myself as a Learner Scale (Burden, 1998) – an academic self-concept measure, which is the perception of one's self as a learner and problem-solver.

The teacher questionnaire should take no longer than 5-10 minutes to complete. This includes:

- The Strengths and Difficulties Questionnaires (as above).

All participants will also be asked if there are any further comments you wish to add about the sibling's school experiences.

Are there any benefits in my taking part?

As an incentive to take part, each sibling will be given a £5 amazon or book voucher for their participation. Their school will also be given a £5 amazon or book voucher if their teacher takes part. Taking part will also allow your son/daughter to reflect on their thoughts, feelings and school experiences, as well as be signposted to a charity that provides information and support for siblings and their families on sibling issues (see below). You will also be helping to contribute to the evidence-base into the experiences of siblings of children with autism.

Are there any risks involved?

There are no risks to yourself taking part in this study and there will be a closing debrief activity to help end your participation in the study in a positive frame of mind. However, if you feel concerned about the sibling's experiences and/or wellbeing when completing this questionnaire, I would also like to signpost you to the charity 'Sibs', which provides access to a range of resources and support for siblings of children with disabilities (www.sibs.org.uk; www.youngsibs.org.uk). They also have a specific section for parents on how to support your sibling child/children (www.sibs.org.uk/supporting-young-siblings/parents/). Childline (0800 1111, www.childline.org.uk) also provides a helpline where children can talk about any worries they may have. If worries are significant and distressing, please contact your GP for further support.

Will my participation be confidential?

All data from the questionnaires will be downloaded and saved on a locked password-encrypted drive, which is only accessible to myself. Real names will be translated to a code name so all data is anonymised to protect your identity. I will comply with the Data Protection Act (1998) when handling your data. This involves storage of completed questionnaires for 10 years in line with university regulations.

What happens if I change my mind?

You have the right to withdraw from the study up until 22nd December 2017 once the write up of the study will commence and any data will then be destroyed without your legal rights being affected.

What happens if something goes wrong?

In the unlikely case of concerns or complaints, please inform my project supervisor at the University of Southampton, Dr Hanna Kovshoff (hk@soton.ac.uk). If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 3856, email: fshs-rso@soton.ac.uk.

Where can I get more information?

If you have any further questions after reading this information sheet or after your involvement in the study, please contact myself, Alexandra Gregory at ag2g15@soton.ac.uk.

Taking part

If you are happy to participate, please follow the link to the parent/carer consent form and online questionnaire:

<https://www.isurvey.soton.ac.uk/24180>

Then please pass on the unique sibling information sheet to the sibling, which includes a link to the sibling assent form and online questionnaire.

Appendix N. Parent/Carer Consent Form – Autism Siblings

**ONLINE CONSENT FORM: Parents/carers of siblings of children with autism
(Version 3; 08.08.17)**

Study title: Understanding the school experiences of siblings of children with autism.

Researcher name: **Alexandra Gregory**
ERGO Study ID number: **25346**
RGO reference number:

Dear parent/carers to a sibling of someone with autism,

Welcome to my study on understanding the school experiences of siblings of children with autism. Consenting to take part means you agree with the following statements.

- I have read and understood the information sheet and have had the opportunity to ask questions about the study.
- I agree to take part in this research project (to provide information about the sibling) and for my data to be used for the purpose of this study.
- I understand my participation is voluntary and I may withdraw my involvement at any time up until the write up of the project (22.12.17) without my legal rights being affected.
- I agree for my son/daughter (the sibling) to take part in this research project.
- I agree for my son/daughter's teacher to take part in this research project (to provide information on the sibling).

If you agree with all of these statements, please continue.

Child’s details for the sibling to take part:

Sibling’s name.....

School details for teacher to be invited to take part:

School name:

School address:

School e-mail address (if known):

Name of key member of staff (e.g. form tutor):

OPTIONAL: Would you be happy to be contacted regarding other research projects into siblings of children with autism and therefore consent to the university retaining your personal details on a database (complying with the data protection act), kept separately from the research data detailed above? You can request your details be removed from this database at any time.

Yes No

If yes, please provide an e-mail address we can keep on record.

Appendix P. Parent/Carer Debrief Statement – Autism Siblings

DEBRIEFING STATEMENT: Parents/carers of siblings of children with autism (Version 2; 01.06.17)

Study title: Understanding the school experiences of siblings of children with autism.

The aim of this research was to explore the school experiences of siblings of children with autism. The study has not used deception and the results will not include your name or any other identifying characteristics. A summary of the findings of my thesis can be supplied upon request by contacting myself Alexandra Gregory at ag2g15@soton.ac.uk or my supervisor Dr Hanna Kovshoff at hk@soton.ac.uk (after I leave university from July 2018).

To help you finish this study in a more positive mind-set, I would like you to think about and answer the following question:

What is the most positive thing(s) about school for your child?

Thank you for your participation in this research. Your data will help our understanding of the experiences of siblings of children with autism. If you have any further questions, please do not hesitate to contact me.

Name of parent/carers _____

Signature _____ Date _____

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

If your participation in this study led to any concerns about the sibling of a child with autism, please encourage them to speak to you or a teacher at school they trust. You could refer them to Childline (0800 1111), which is a helpline where children can talk to someone about any worries they may have. You can find further information online at www.childline.org.uk. I would like to signpost you to the Sibs charity (www.sibs.org.uk; www.youngsibs.org.uk), which provides information and support for siblings of those with disabilities (and their families and professionals). If concerns are significant, please refer to your local GP.

Appendix Q. Sibling Debrief Statement – Autism Siblings

Debrief statement: Siblings of children with autism

Version 2; 01.06.17

THE SCHOOL EXPERIENCES OF SIBLINGS OF CHILDREN WITH AUTISM

This study aimed to explore the school experiences of siblings of children with autism. The results of this study will not include your name or any other information that will link back to you. If you would like a summary of the findings of this study, please contact me at ag2g15@soton.ac.uk or my supervisor Hanna at hk@soton.ac.uk.

To help you finish this study in a positive mind-set, I would like you to think about and answer the following question:

What is the most positive thing(s) about school for you?

Thank you so much for taking part in my study. Your information will help us learn more about the experiences of siblings of children with autism. If you have any questions, please feel free to contact me by e-mail.

Name: _____ Date: _____

If you have any questions about your rights in this research, or you feel you have been placed at risk, please contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton. SO17 1BJ. Phone: +442380593856. Email: fshs-rso@soton.ac.uk.

If you found any questions in this study upsetting, speak to a parent/carer, teacher at school that you trust, or your doctor. You can contact myself on ag2g15@soton.ac.uk or the Sibs charity for more information or support (www.sibs.org.uk/contact/ or www.youngsibs.org.uk/get-help/). You could also ring Childline (0800 1111), which is a helpline where people can talk to you about any worries you might have. You can find further information online at www.childline.org.uk.

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