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School of Psychology

Exploring the Experiences of Typically Developing Siblings who have a Brother or Sister with Autism Spectrum Condition

by

Kirsty Marie Underwood

Thesis for the degree of Doctorate in Educational Psychology

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<u>ABSTRACT</u>

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EXPLORING THE EXPERIENCES OF TYPICALLY DEVELOPING SIBLINGS WHO HAVE A BROTHER OR SISTER WITH AUTISM SPECTRUM CONDITION

Kirsty Marie Underwood

This thesis explores the experiences of typically developing siblings (TD-Sibs) who have grown up with a brother or sister with Autism Spectrum Condition (ASC). The first chapter presents a systematic review of the literature, using an Interactive Factors Framework (IFF) approach (a framework that is used to guide Educational Psychology practice), to consider TD-Sibs' experiences from a holistic perspective. A total of 22 studies were identified from the systematic search process. The review highlights many inconsistencies in findings, and methodological limitations. Within the sampled research, the quantitative studies tended to focus on potential behavioural, social and emotional difficulties for TD-Sibs, however, there is currently insufficient, consistent evidence to conclude that TD-Sibs, as a group, will experience difficulties in these areas. Through eliciting sibling voice directly, qualitative studies revealed positive aspects for TD-Sibs, as well as, previously unconsidered challenges. The review identifies gaps in the research base and concludes with an IFF diagram to visually represent and synthesise the positive and challenging experiences from the 22 studies as a whole.

The empirical paper explores the views of young adult siblings, who have grown up with a brother or sister with ASC, to gain a greater understanding of their lived experience and how this may interact with their education. Semi-structured interviews were conducted with six participants (aged 19 to 21), and analysed using Interpretative Phenomenological Analysis (IPA). Five super-ordinate themes were identified: Striving to do well; Sense of responsibility; Self-Management; Voice and Acceptance. These exploratory findings identified some positive aspects of being a TD-Sib, however participants predominantly recounted a number of struggles and hidden challenges, which influenced some aspects of their educational experiences. Practical implications and avenues for future research are discussed.

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DECLARATION OF AUTHORSHIP

I, Kirsty Marie Underwood, declare that this thesis titled **'Exploring the Experiences of Typically Developing Siblings who have a Brother or Sister with Autism Spectrum Condition'** and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

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

Signed: ....

Date: ....

x

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A huge thank you to my wonderful friends for your never-ending encouragement, positivity and cheerleading. A special thank you to Niki, Becca, Alys and Anna for being there for the 'final countdown'.

Finally, I would like to say a heartfelt thank you to my family, for the endless support, love and for keeping me going throughout this journey. To my parents, thank you for your constant belief in me, your encouragement and always being there. Thank you to Michael and Peter for your reassurance and positivity. Vicky, thank you for the inspiration and for being you.

This thesis would not have been possible without you all.

Definitions and Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
ASC	Autism Spectrum Condition
ASC-Sib	Sibling with Autism Spectrum Condition
CBCL	Child Behaviour Check List
DS	Down syndrome
ES	Effect Size
EP	Educational Psychologist
F	Female
IFF	Interactive Factors Framework
IPA	Interpretative Phenomenological Analysis
M	Male
PDD	Pervasive Developmental Disorder
SDI	Survey Diagnostic Inventory
SDQ	Strengths and Difficulties Questionnaire
TD-Sib	Typically Developing Sibling of individual with Autism Spectrum Condition

Personal Declaration

Growing up with a sibling with severe autism has provided me with a personal interest and passion in the topic this thesis explores. My professional development as a teacher and now a Trainee Educational Psychologist, has provided further experience with individual cases, and families where there is a child or young person with Autism Spectrum Condition. This has sparked my motivation to research and make sense of the current evidence base, and to better understand how to support siblings, families and the individual with ASC through evidence-based intervention. It is hoped that the exploration of the topic will inspire others to research this relatively underdeveloped area.

Chapter 1:   Exploring the Experiences of Typically Developing Siblings who have a Brother or Sister with Autism Spectrum Condition: A Systematic Review.

1.1   Introduction

This systematic review uses an interactive factors approach to explore the research investigating the experiences of typically developing siblings who have a brother or sister with Autism Spectrum Condition (ASC). The background and context of the review will initially be discussed and key terminology defined. An Interactive Factors Framework (IFF; Fredrickson & Cline, 2009) will then be presented to explore the research from a holistic perspective. The IFF is a way of providing a structured, pictorial representation of thinking around a problem or situation. It is a visual representation of the evidence or presumed factors (affective, cognitive, behavioural, environmental or biological) involved in a situation, and is refined through ongoing analysis of the situation (Annan et al., 2013). As will be discussed, existing literature involving TD-Sibs appears to take a diagnostic approach to examining specific constructs e.g. measuring depression, anxiety or internalising/externalising behaviours of TD-Sibs. Although this is important, it does not consider the range of interacting factors involved when growing up with brother or sister with ASC (e.g. the influence of environmental factors). In this review, an IFF approach is chosen to offer an alternative perspective which explores the possible interacting factors involved in TD-Sibs' experiences. The process of this systematic literature search will be explained and, through application of the IFF approach, results will be described and critically examined.

1.1.1   Background

Due to the shared experience of growing up together over time and the potential endurance that is fostered through family bonds, sibling relationships have been considered as unique and influential in nature (McHale, Updegraff & Feinberg, 2016). A substantial amount of research has been dedicated to exploring how the sibling relationship is affected when one sibling has a disability, as well as considering the wider impact on the siblings concerned. These studies have originated from an area of research that has, historically, focused on the wellbeing of parents (mainly mothers) when there is a child with a disability in the family (Stoneman, 2005).

Studies that have considered the impact on siblings have recruited siblings of children in mixed disability groups (e.g. Giallo & Gavidia-Payne, 2006), with an increased focus on

developmental disabilities (e.g. Hastings, 2007). Meta-analyses of the literature have indicated that a small proportion of siblings experience small negative effects on their psychological functioning (Rossiter & Sharpe, 2001), but have also highlighted the difficulty in drawing clear conclusions due to the inconsistency in research findings. Whilst some studies have found typically developing siblings to experience more emotional and behavioural problems than normative samples (Giallo, Gavidia-Payne, Minett & Kapoor, 2012), others have reported no behavioural problems (Bischoff & Tingstrom, 1991) or highlighted positive psychological growth (Findler & Vardi, 2009). The variability in findings across studies have been attributed to individual family factors or methodological limitations (Hodapp, Glidden & Kaiser, 2005; Stoneman, 2005), which large scale studies have attempted to overcome (Goudie, Havercamp, Jamieson & Sahr, 2013). Nevertheless, it has been suggested that the characteristics (or profiles) associated with specific disabilities may impact on siblings differently (Hodapp et al., 2005) and could, therefore, explain some of the variation in the existing literature.

Researchers have raised particular concerns about typically developing siblings and the overall sibling relationship in families where a child has Autism Spectrum Condition (ASC). This is due to the significant social communication difficulties associated with ASC in contrast to other developmental disabilities (Feiges & Weiss, 2004; Pollard, Barry, Freedman & Kotchick, 2013). Such concerns have informed the current literature review which will focus on this particular area. Nevertheless, the current researcher acknowledges that the grouping of children into specific disabilities is a contentious issue (Timimi, Gardner & McCabe, 2010). It is also recognised that labelling children with diagnostic terminology from a deficit model can be potentially unhelpful when trying to view children labelled with ASC as individuals who have areas of strength. For the purposes of this paper, ASC will be defined as follows.

1.1.2 Definition of Autism

Autism is a complex neurodevelopmental disorder which involves difficulties in multiple areas including social interaction, verbal and non-verbal communication and repetitive behaviour (Kanner, 1943; APA DSM 5, 2013). The way in which these difficulties present varies, which has been reflected through recent changes in the conceptualisation of autism to a 'spectrum disorder', where, previously discrete diagnostic categories (e.g. Pervasive Developmental Disorder—Not Otherwise Specified, Asperger's disorder or syndrome and Autistic disorder) have been withdrawn and combined within the umbrella term 'Autism Spectrum Disorder' (APA DSM 5, 2013; Montgomery et al., 2016). The term 'Autism Spectrum Condition' (ASC) will be used throughout this paper. This acknowledges that, as well as having a diagnosed disability, individuals with ASC have areas of cognitive strength (Baron-Cohen et al., 2009). It has been

suggested that the multi-factorial aspects and continuum on which ASC presents, produces a unique set of positive and negative circumstances which siblings learn to navigate over time (Green, 2013; Orsmond & Seltzer, 2007).

1.1.3   Existing Literature and Theoretical Underpinnings

Previous research involving siblings of individuals with ASC can be divided into two main strands of investigation. One strand addresses the quality of the sibling relationship between the individual with ASC and the typically developing sibling (e.g. Kaminsky & Dewey, 2001; Orsmond, Kuo & Steltzer, 2009). The other strand of research explores typically developing sibling's 'adjustment' when there is a sibling with ASC in the family (Hastings, 2003; Hesse, Danko & Budd, 2013). There appears to be no single definition of 'adjustment' within the literature base. Terms such as 'well-being', 'functioning' and 'psychosocial outcomes' are used interchangeably, as well as reference to different adjustment types (e.g. emotional and behavioural) all encompassed in the blanket term of 'adjustment'. This has been exacerbated by the absence of a specific measure of adjustment, leading to a reliance on using different measurement tools that explore various constructs. For the purposes of this review (and to reflect the similarities amongst the constructs explored), adjustment has been conceptualised as a dominant focus on behaviour that is presented externally (e.g. conduct problems) and internally (e.g. depression and/or anxiety) as well as a consideration of individual self-perceptions (e.g. how individuals view themselves) and social competence (e.g. peer relationships).

The current review acknowledges that these two strands of research are likely to be intrinsically linked when considering sibling experiences (McHale et al., 2016; Petalas, Hastings, Nash, Lloyd & Dowey, 2009). However, this thesis focuses on the holistic experience of TD-Sibs, therefore literature which has focused solely on sibling relationships (e.g. Rivers & Stoneman, 2008) is not included or discussed, whereas studies that have considered the sibling relationship in relation to typically developing siblings' outcomes, adjustment or experiences are considered (e.g. Hastings & Petalas, 2014). The review also incorporates a third strand of more recent research investigating the self-reported experience of being a sibling of an individual with ASC (Petalas, Hastings, Nash, Dowey & Reilly, 2009).

Studies that have investigated sibling adjustment appear to be driven by a theoretical assumption that the presence of an individual with ASC will have a negative impact on the relationships within families and the individual wellbeing of family members. Within the literature, reference has been made to Family Systems Theory as a broad basis for this understanding, which posits that individual family members and the subsystems within families

(e.g. marital partners, parents and siblings) influence functioning and interactions within the family network (Turnball, Turnball, Erwin & Soodak, 2006). As such, having an individual with ASC has been conceptualised as a risk for other family members developing potential difficulties (e.g. anxiety, depression) due to the stress experienced within the family system (Meyer, Ingersoll & Hambrick, 2011). It can be argued, however, that researchers do not have a 'gold standard' for comparison of other family systems to help guide this negative assumption, which has led to largely atheoretical research (McHale et al., 2016; Stoneman, 2005). In fact, McHale et al. (2016) suggest a need to explore theoretically-grounded hypotheses about the development of sibling relationships and the link to individual adjustment through consideration of underlying bio-psycho-social processes.

There is a substantial body of research which explores the role of genetics in the etiology of ASC and the shared behavioural characteristics of ASC among direct family members (Landry & Chouinard, 2016). Referred to as the Broad Autism Phenotype (BAP), researchers have reported cognitive, social, communication and personality characteristics associated with ASC (albeit less pronounced) in typically developing siblings of individuals with ASC (Bolton et al., 1994, Folstein & Rutter, 1977). These characteristics have included difficulties with emotion recognition tasks (Dorris, Espie, Knott & Salt, 2004), planning and attention shifting (Hughes, Plumet & Leboyer, 1999), and social skills and communication (Bolton et al. 1994; Pickles, St Clair & Conti-Ramsden, 2013). Greater expression of the BAP (i.e. demonstrating more characteristics associated with ASC) in typically developing siblings has been found to be associated with more adjustment difficulties (Meyer et al., 2011; Petalas et al., 2012b). In a recent review of the BAP literature involving typically developing siblings, Pisula and Ziegart-Sadowska (2015) stated, "it should be stressed that in the light of BAP research, the majority of brothers and sisters of individuals with ASD develop typically, without displaying autistic traits to a greater extent than the relevant control groups" (p. 13249) and that "the information available at present is insufficient to formulate final conclusions regarding BAP characteristics in siblings of individuals with ASD" (p. 13250). It is likely that the evidence base for BAP is inconclusive because there are currently no standardised criteria for BAP. Therefore, there is a range of characteristics/traits covered across studies, making comparisons between studies difficult (Pisula & Ziegart-Sadowska, 2015; Sucksmith, Roth & Hoekstra, 2011). Since the review highlights that there is variation in developmental outcomes among typically developing siblings, Pisula and Ziegart-Sadowska (2015) suggest it will be important to further explore the role of genetic factors and the contribution of this in developmental trajectories.

Genetics play a role in the etiology of ASC and some findings in the BAP research (e.g. Petalas et al., 2012b) would suggest that siblings' experiences could be affected if they display

these characteristics, however this is not yet fully understood. In line with other researchers (e.g. Giallo & Gavidia-Payne, 2006), this review takes the position that it may be more helpful to consider the range of factors involved in siblings' experiences by acknowledging static variables (e.g. genetics) and exploring dynamic variables (e.g. coping). This is because dynamic variables have the potential for change and could, therefore, provide a route for intervention. This is also consistent with the change in role of Educational Psychologists and the frameworks adopted in practice (Wicks, 2013). This change has involved moving away from a professional approach that has a child-deficit, diagnostic focus (Gillham, 1978) to a collaborative problem-solving approach through assessment, intervention and evaluation (Wicks, 2013). As a result, the EP practice framework (e.g. see The DECP Framework for Assessment and Intervention, 1999) has changed from focusing on the causation of a child or young person's difficulties to understanding the interplay between the different factors or systems around the child or young person (e.g. Bronfenbrenner, 1977).

The current review draws on family systems theory by acknowledging that individuals with ASC should be studied as part of the wider family systems of which siblings are a key and often overlooked aspect. It also draws on Bronfenbrenner's ecosystemic theory (1977), through focusing wider than just the individual typically developing sibling (e.g. characteristics) and exploring how different contexts (home and school) are affected and affect them. Finally, it draws on the Transactional model of development (Sameroff, 2009). This acknowledges that the context in which a young person lives, their culture and circumstances interact with inherited predispositions (e.g. BAP) and that these interacting factors can influence the person's development over time. Sameroff (2010) explains that everything is affecting or being affected by something else (i.e. a transaction) and "the development of the child is a product of the continuous dynamic interactions of the child and the experience provided by his or her social settings" (p. 16). Therefore, within a transactional model, it is acknowledged that although early circumstances matter considerably (e.g. Sroufe, Egeland, Carlson, & Collins, 2005), access to good early intervention such as support in school and advice from other services may make a considerable difference. Understanding typically developing siblings' experiences will help inform any early intervention and support that may be needed for this sibling group.

1.1.4 Previous Systematic Literature Reviews

In line with the previously discussed, mixed disability research, studies exploring the experiences and adjustment of siblings of individuals with ASC have produced inconsistent and inconclusive findings. Some studies have indicated that siblings of children with ASC are more likely to display externalising and internalising problem behaviours (Rodrigue, Geffken & Morgan,

1993; Verte, Roeyers & Buysse, 2003), feelings of loneliness (Angell, Meadan & Stoner, 2012) and low levels of pro-social behaviour and peer difficulties (Hastings 2003); other studies have found positive influences such as an increased self-concept (Macks & Reeve, 2007; Mates, 1990).

Four systematic literature reviews have been conducted, in the past five years, to attempt to draw conclusions and develop an understanding of factors underpinning the inconsistencies presented in the literature base. These have been conducted across a range of disciplines including neurology (Green, 2013), special education (Meadan, Stoner & Angell, 2010) and nursing (Mandleco & Webb, 2015, Smith & Elder, 2010). The reviews have generally concluded that siblings experience positive and negative outcomes depending on individual, family and demographic variables (Green, 2013) but that the influence of these potential predictor variables is inconclusive (Meadan et al., 2010). Two of the reviews suggest a need for intervention (Smith & Elder, 2010; Mandleco and Webb, 2016) but do not detail how this would be approached.

This current systematic review included a quality assessment (Appendix A) of the four previous reviews. The quality checklist produced by the Critical Appraisal Skills Programme (CASP, 2014) was used to identify a number of strengths and limitations of the reviews. Although, three out of four of the reviews attempted to address a clearly focused question and considered appropriate types of papers conducted through a replicable search, the reporting of the results for two of these reviews were not considered sufficiently precise in detail (e.g. Green, 2013; Mandleco & Webb, 2015). For three of the reviews it was difficult to deduce whether the appropriate outcomes had been considered and therefore the applicability and usefulness of the implications to the current review were limited. Interestingly, although Smith and Elder (2010) reported precise results, the review was considered lower in quality due to a lack of clarity around the research question and search process.

In contrast, one review was considered to be of high quality. Meadan et al. (2010) reviewed 12 studies (published between 1997-2008) which investigated the social, emotional and behavioural adjustment of siblings of individuals with ASC. Using a framework derived by Hodapp et al. (2005), the researchers identified key areas of challenge that could explain the inconsistencies in the literature base. Methodological challenges included a wide range of research questions and methodologies used, small sample sizes, an inability to generalise, variation in use of control groups and limited exploration of both genetic and environmental variables. There was also a wide variation in the use of measurement tools (interviews, questionnaires and checklists) and a focus on single informants (mainly mother's views) with little acknowledgement of the sibling perspective. Overall, there was limited information about the experiences and needs of different age groups (including specific transition ages), due to a wide

age range of participant siblings being included within each study. Although studies identified potential risk factors that were associated with adjustment (including gender, birth order, gender of the sibling dyads, social-economic status, family size, maternal stress and family support), the influence of these as potential predictor variables was inconclusive. The authors suggest that the variability in findings imply a need for continued research, so that a comprehensive understanding of the sibling experience can be developed. Since this review, there has been recent qualitative research exploring the sibling experience, which can be considered (e.g. Angell et al., 2012).

1.1.5   Focus of the current review

Although the literature base has increased over time, the research within this field currently presents a limited and somewhat contradictory understanding of the experiences of siblings of individuals with ASC. Stoneman (2005) refers to the term 'scientific inertia'. Indeed, it may be that researchers have continued to study what has previously been studied, using similar approaches, despite the challenges identified by previous systematic reviews.

The current review attempts to draw the available literature together and consider it in a holistic context. This includes exploring the sibling adjustment literature, as well as recent qualitative research investigating self-reported sibling experiences. It is noted that previous reviews have highlighted a reliance on parent-reports of sibling outcomes across studies, with little attention paid to the siblings' views. Therefore, an additional focus of this review is on studies that have directly involved siblings, either through direct measurement or through eliciting the sibling voice. The review is conducted in the field of educational psychology and is particularly interested in the experiences across different contexts (home and school environments), therefore, it includes studies that have used multiple informants (teacher and parents). Finally, the review considers siblings across a wide age range, from 4 to 25 years old. This reflects recent changes to the age range of young people with which Educational Psychologists can be involved (Children's and Families Act, 2014).

Within educational psychology practice, different levels of analysis and their interaction are actively considered when formulating hypotheses, in order to gain a wider view of the child or young person's experience (Monsen & Fredrickson, 2008). One framework that is frequently adopted, when considering this wider holistic perspective, is the Interactive Factors Framework (IFF; Fredrickson & Cline, 2009). This encourages practitioners to explore variables at the levels of biology, cognition (including affect), behaviour and environment (in line with an eco-systemic approach proposed by Bronfenbrenner, 1979). The current review adopts an interactive factors approach to consider the wider sibling experience and potential impact across these different

levels. This is deemed appropriate due to the overlapping and multiple constructs explored in the sibling adjustment research, and the siblings' self-reported experiences.

The overarching objective of this systematic review is to use an interactive factors perspective to explore how the literature has shaped our understanding of the experience of being a typically developing sibling of an individual with ASC.

1.2 Method

1.2.1 Search Strategy

The review used two electronic databases for the literature search, PsycInfo via EBSCO and Web of Science (WoS). The researcher generated search terms (Appendix B) based on the focus of the review, considered key words used in previous reviews and used related terms identified using the thesaurus. An initial search in both databases, following application of limiters (peer-reviewed journals, written in English and exclusion of dissertations) retrieved a total of 363 papers (PsycInfo N =177; WoS N = 186). This was conducted between December 2015 and February 2016. Additional records were found through looking at reference lists from papers in the initial search (N = 4), which resulted in a possible 367 papers to review.

1.2.2 Inclusion and Exclusion Criteria

Titles and abstracts were screened for topic relevance and using the pre-determined inclusion and exclusion criteria (Appendix C). Those which did not meet these criteria (N = 255), were duplicates (N=28) or where full texts could not be accessed (N= 5) were excluded. Full texts were accessed and re-screened using the inclusion and exclusion criteria, and those not eligible were excluded (Appendix C). Following this process (Figure 1; The PRISMA GROUP, 2009), a total of 22 studies were selected for the review. To support clarity, a reference for each study is provided in number form (in brackets) throughout the subsequent sections (Appendix D).
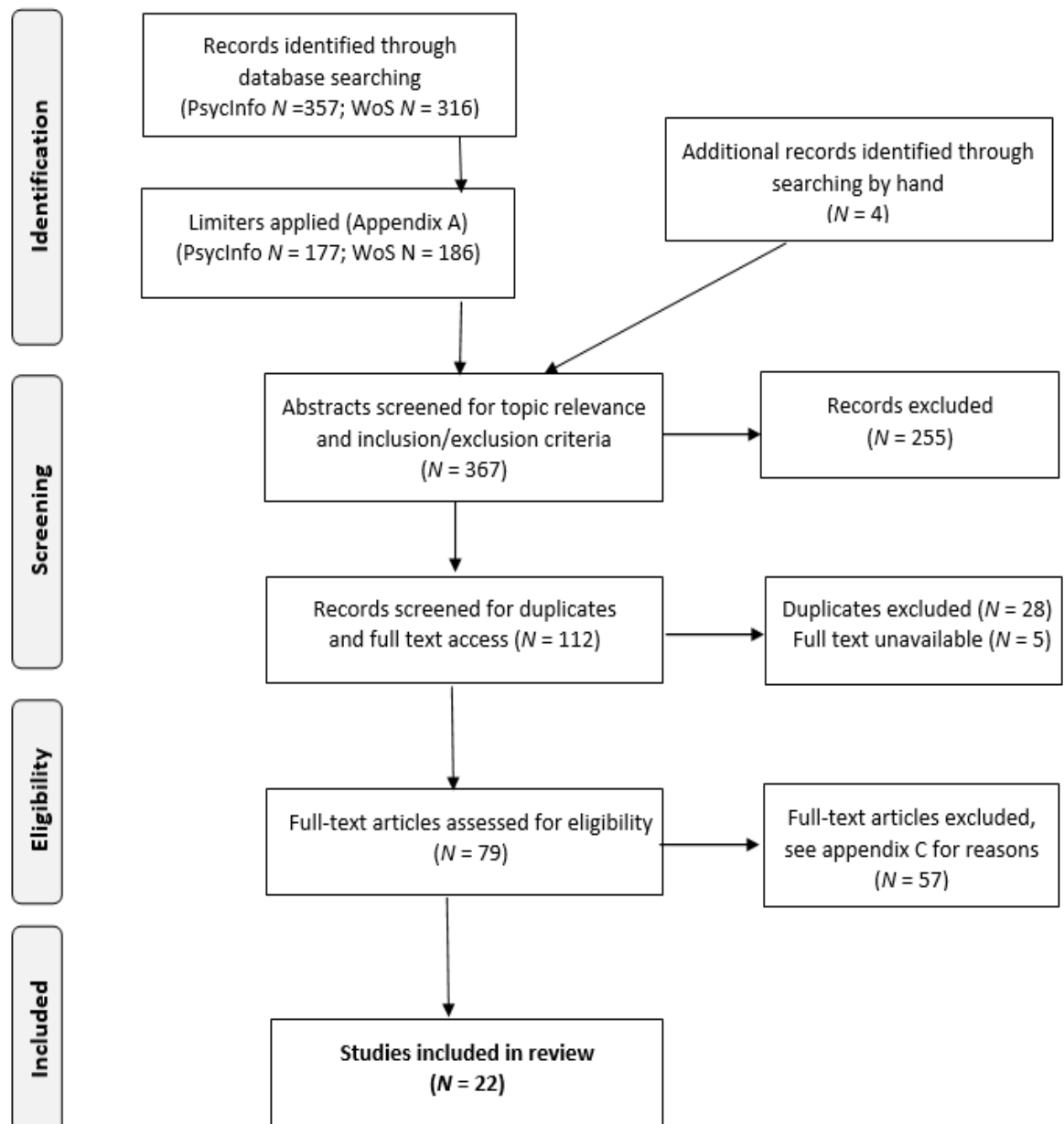
Figure 1: *PRISMA Diagram showing the systematic search process*

1.2.3   Data Extraction

Extracted data from the 22 studies included: descriptive sample data (age and gender); country where the research was conducted; outcome measures (including informants); key findings and limitations. For the remainder of this paper and to further support clarity, typically developing siblings of individuals with ASC will be referred to as TD-Sibs. The siblings diagnosed with ASC will be referred to as ASC-Sibs (who may have a diagnosis of autism, pervasive developmental disorder or high functioning autism). For each study, details about the sample

(including diagnosis), design, measure and findings can be found in Appendix E. Relevant information was also extracted for quality assessments of the studies (Appendix F)

1.2.3.1 Descriptive Summary

Of the 22 selected studies, 15 were quantitative studies, five were qualitative studies and two used mixed methods but quantitatively coded the data (2, 20). All were cross-sectional in design and three were longitudinal (4, 5, 22). Participants ranged in age from 4 to 20 years old, and only one study (2) recruited participants beyond 18 years old. The gender split across these participants were fairly equal. No studies were identified exploring the young adult population (e.g. 16 to 25 years old). The majority of studies did not embed or explicitly discuss an underpinning psychological theory for the research (See Appendix E for data extraction commentary).

1.2.3.2 Quality Assessment: Summary

The seven qualitative studies were assessed using the checklist and accompanying guidance produced by the Critical Appraisal Skills Programme (CASP, 2014). An adapted quantitative checklist was devised based on previous examples of quality assessment checklists (e.g. Hermont et al., 2014). Both checklists were used more qualitatively, in that studies were considered and compared through their areas of strengths and weaknesses, rather than reliance on the overall numerical score each study achieved. This also takes into account research that suggests a numerical system may not be the most useful method for quality analysis of research findings (Booth, Papaioannou & Sutton, 2011). An overview is provided below (see Appendix E for detailed commentary).

1.2.3.3 Quantitative Studies

Overall, the selected quantitative studies provided useful evidence of the different constructs (e.g. externalising and internalising behaviour, self-concept, social competence) to consider when attempting to understand the potential areas of strengths and difficulties for individuals with ASC. The majority of quantitative studies focused on the adjustment of TD-Sibs. Although there was variation in terminology or how variables were operationalised, there was overlap in the constructs measured (e.g. externalising and internalising behaviours) which is reflected in the later results section. The generalisability and sample size of studies was limited by the recruitment methods adopted (e.g. approaching local support groups). Only nine out of the 17 studies discussed a predetermined inclusion and exclusion criteria prior to recruitment. The sample size was rarely justified in studies and there was variation in comparison groups used (e.g. normative data or matched controls). The majority of studies identified potential confounding

variables and discussed ways in which they had been measured, controlled or acknowledged the need to control them in subsequent studies.

This exploration of the quality of the current research highlighted similar challenges in the methodology as Meadan et al. (2010) and indeed this needs to be acknowledged because it makes it difficult to draw conclusions from the findings across the selected studies. A surprising finding is the limited amount of large scale studies amongst the selected studies. This may be due to the exclusion of single informant parent-report studies, which therefore reflects a need for large scale studies that incorporate the sibling view in their measures.

1.2.3.4   Qualitative Studies

Overall, the selected qualitative studies were deemed to be of good quality. All qualitative studies directly explored sibling perceptions and experiences through semi-structured interviews. Three studies (1,2,13) included an example of the interview schedule used and the authors of two other studies provided this when contacted (15,16). The majority of studies clearly stated research aims, used appropriate qualitative methods and provided details of data analysis including credibility checks. Most studies (except number 10) clearly explained their findings, but it is noted that this was a preliminary study which may have limited their depth of analysis and conclusions. Only some studies considered the researcher-participant relationship (11, 15, 16) and only two discussed ethical considerations (15, 16). This is concerning when considering the sensitivity of the topic and the potential power imbalance when adults are interviewing children or young people.

Two studies deemed to be of good quality were conducted by the same authors (15, 16). Both studies used an interpretative phenomenological analysis (IPA) approach to understand the experience of being a sibling of a child with ASC and were perceived as high quality due to the clear and transparent approach to the research. All studies added considerable value to the current review in regards to understanding the wider sibling experience. Interestingly, the absence of qualitative research exploring the perspective of young adult siblings of individuals with ASC is noteworthy when considering how the experience of siblings may differ across the life course.

1.3   Findings

The results of this systematic review have been structured in line with an Interactive Factors Framework approach. Educational Psychologists (EPs) adopt the role of a 'collaborative problem solver' which is central to effective EP practice (British Psychological Society, 2006). When formulating hypotheses about a problem or situation involving a child or young person, the factors across different levels (e.g. affective, cognitive, behavioural, environmental or biological) are considered as well as the interaction between these factors. An IFF provides a structured, visual representation of this thinking around a specific situation. An IFF approach has been taken to structure the findings of the review to consider the different factors, and interactions involved in TD-Sibs' experience of growing up with a brother of sister with ASC. This IFF approach has consisted of two stages. Firstly, sectioning the findings of the identified studies into five different levels: cognition; behaviour; affect; environment and static factors. Secondly, providing an initial visual representation of the findings and potential interactions. This can subsequently be used as a working framework whereby tentative hypotheses change depending on new emerging evidence (Monsen & Fredrickson, 2008). Strengths, limitations and implications of the studies cited are reported within each of these five sections and are also discussed for the overall set of selected studies at the end.

1.3.1   Cognition

Within this cognitive section, the selected studies consider TD-Sibs' academic ability, as well as the thoughts, views and beliefs (cognitions) that the TD-Sibs hold about themselves i.e. their self-concept. Academic outcomes have been measured through quantitative approaches that have either directly assessed individual academic achievement or obtained teacher-reports of TD-Sibs' academic competence. Qualitative interviews have provided an alternative avenue to explore siblings' educational aspirations. Sibling self-concept, however, has only been investigated through a quantitative methodology using sibling-completed questionnaires, with a tendency to rely on one measurement tool.

1.3.1.1   Academic Outcomes

Little attention has been paid to the educational achievement of siblings who have a brother or sister with ASC. Across the 22 identified studies, only one quantitative study (12) directly assessed TD-Sibs academic achievement and this was conducted in 1990. Within this study (14), 33 TD-Sibs completed the Wide Range Achievement Test (WRAT) which measured reading, spelling and arithmetic skills. No significant differences were found when results were

compared to normative data. A control group was not used, however, and there was a considerably large age range of TD-Sibs (5 to 17 years old) within this small sample which may have masked the detection of any potential differences at the various educational stages.

A more recent study, conducted in 2010, recruited TD-Sibs from a narrow age range (aged 6 to 10 years old) and used a control group of siblings of children with no disability (17). The researchers also applied specific recruitment criteria for the ASC-Sib (preschool child diagnosed with ASC, aged between 2 and 5 years old and younger than the TD-Sib), which was the same for the control group (excluding the ASC diagnosis). Instead of directly measuring achievement, primary school teachers were asked to rate the academic competence of TD-Sibs on a five-point measurement scale. No significant differences were found in teacher-reports between the groups, and the mean standard scores for both groups were in the average range. The researchers questioned whether this was due to the small homogenous sample (N=20) that consisted of demographic factors considered to be low risk for negative outcomes. It may also be that any potential impact upon academic outcomes for TD-Sibs is cumulative and, due to the young age of the ASC-Sibs, it would have been helpful to have conducted a follow up study over time.

Semi-structured interviews, which have enabled TD-Sibs to share their own experiences and identify areas for support, have provided initial ideas about the importance of educational attainment for TD-Sibs. Only one qualitative study (1) has elicited these views and indeed this may be because studies have paid little attention to exploring the experience of TD-Sibs across contexts, e.g. home and school environments. The study reported a range of findings from 12 interviews conducted (6 males and 6 female participants) and reported that TD-Sibs tend to desire academic success and that doing well in school was perceived as important to them. Interestingly, older TD-Sibs reported that they were actively involved in their ASC-Sib's education (e.g. attending a parent/teacher conference or helping their ASC-Sib to learn skills). The TD-Sibs in the study were aged between 7 to 15 years old, and in terms of education systems this incorporates both primary and secondary school. It may have been useful to have grouped or recruited TD-Sibs from similar school-age categories to explore whether the views differ across different phases of education.

1.3.1.2   Self-Concept

Across the 22 studies, 6 quantitative studies considered how TD-Sibs perceived themselves and their abilities. Three studies (2, 10, 12) measured self-concept using the Piers-Harris Children's Self-Concept scale (1986) but reported different directions of findings. One study (2) reported no difference in self-concept scores between matched groups (gender, birth order and socio-economic status) of TD-Sibs, siblings of children diagnosed with a learning difficulty and

siblings of children with no disability. Other studies have reported that the TD-Sibs scored significantly higher on this measure (i.e. had a more positive self-concept) when compared to normative data (12) and when using a control group of siblings of children with no disability (10). The latter study (10) reported that TD-Sibs (aged 7 to 17 years old) scored significantly higher on the total self-concept score compared to controls, as well as on sub-scales measuring their views on their own behaviour, intelligence and academic skills. One study (21) used a different measure of self-concept and matched the control group on age, gender, birth order, age-spacing and family size. The participants were also divided into two age groups for analysis: 6 to 11 years old and 12 to 16 years old. In the older age group, female TD-Sibs had a more positive self-concept than female siblings in the matched control group, indicating a potential gender influence. In the studies that have used control groups (e.g. 10, 21), siblings in these control groups scored within the average range, which indicates a genuine comparison increase for TD-Sibs, rather than less positive siblings in the control group. This suggests the TD-Sibs hold a more positive view of themselves than siblings of children with no disability.

In contrast, other studies have used measures of perceived self-competence to explore TD-Sibs' self-perceptions. One study found no difference in TD-Sibs scores on perceived self-competence (e.g. global self-worth) when compared to normative data (20). The study did not use a control group and the sample size was fairly small (N=20) in comparison to the aforementioned studies. Another study (18), which used matched comparison groups, also found no significant differences between TD-Sibs' perceived competence and siblings of children with Down Syndrome (DS) or siblings of children with no disability (controls). One study (22) used regression analysis to investigate predictor variables for TD-Sibs' externalising and internalising behaviour difficulties, and reported that lower feelings of self-competence in TD-Sibs were associated with parent and teacher reported behaviour difficulties, particularly internalising difficulties. This was also maintained over time, across a three-year period.

1.3.1.3 Summary

When all 22 studies in this review are taken into account, it is clear that little attention has been paid to cognitive factors particularly in terms of academic outcome or ability. This may be due to less focus on TD-Sibs educational experiences. From the available evidence, there is no suggestion that TD-Sibs' academic outcomes are adversely affected, however the importance that is placed on good academic achievement (highlighted by study 1) is an area requiring further exploration. In contrast, there has been a substantial focus on TD-Sibs' self-concept yet there is also no evidence that the self-concept of TD-Sibs are negatively affected. The trend in results appears to suggest that TD-Sibs view themselves more positively than siblings of children without

disabilities. It could be that TD-Sibs compare themselves to their ASC-Sib and view their own abilities more favourably. Nevertheless, it could be argued that the pre-determined categories of the quantitative measures used in the aforementioned studies only allowed limited exploration about personal feelings. Future research could consider these feelings in more depth through semi-structured interviews.

1.3.2   Behaviour

This section will consider findings related to internalising and externalising behaviour problems for TD-Sibs and also any findings related to their social behaviour and relationships. Overall, the 22 identified studies are, indeed, dominated by a focus on the behaviour of TD-Sibs. The majority (15 studies) quantitatively investigate the combination of externalising and internalising behaviours using a single measure, mainly the Child Behaviour Check List (CBCL, Achenbach, 1991). Results on this specific measure use parent and/or teacher reports; only one study used an alternative measurement tool to gather TD-Sibs self-reports (7). One study considered behaviour through a biological stress model, and used a direct cortisol measure (9).

1.3.2.1   Internalising and Externalising Behaviour

Out of the 15 studies, seven (3, 6, 8, 17, 18, 19, 21) used the CBCL, three studies (4, 5, 22) used the Survey Diagnostic Inventory (based on the CBCL), and all reported overall scores of externalising and internalising behaviours. Four of these studies used a combination of parent and teacher reports (3, 4, 5, 17) but reported variation in the direction of findings. In the largest study (3), neither teachers nor parents reported inflated levels of behaviour problems in TD-Sibs (N=486). Indeed, TD-Sibs had fewer internalising and fewer externalising behaviour problems when compared to normative data for individuals of the same age. The difference was small as indicated by the small effect sizes for teacher reported (ES = 0.26) and parent reported (ES = 0.13) internalising behaviour problems, as well as teacher reported (ES = 0.32) and parent reported (ES = 0.32) externalising behaviour problems. Another study (17) found no differences in parent reports or teacher reports of TD-Sibs externalising and internalising behaviour when compared to a control group and TD-Sibs scored within the average range. This suggests that TD-Sibs do not experience more behaviour problems than siblings of children with no disability. Although group differences were not significant in the study (17), there were moderate effect sizes for teacher reported internalising behaviour problems (d = .57) and teacher reported total problem behaviours (d = .41), where TD-Sibs scored higher than controls. This tentatively indicates a need to consider the school context more closely and highlights a need for further evidence. Two studies (4, 5), were part of a 3-year longitudinal study that used matched comparison groups of

TD-Sibs, siblings of children with DS and siblings of children with no disability. The initial study (5) found that parents reported significantly more internalising and more externalising behaviour problems for TD-Sibs than the other two groups. Teachers also reported significantly more internalising behaviour problems (5). In the follow up study (4), TD-Sibs continued to have the highest level of parent reported externalising (but not internalising) behaviour problems, and the highest level of teacher reported internalising behaviour problems. Another longitudinal study (22), which used the same groupings, reported a similar trend in parent and teacher reported behaviour problems for TD-Sibs. Taken together, the findings suggest that TD-Sibs may experience more behaviour problems over time than siblings of children with DS or a control group (4, 5, 22).

Studies that have only used parent reports on the CBCL report mixed findings. One study found no differences in reported TD-Sibs behaviour when compared to a control group (6), but another study (21), which used a matched control group, reported more TD-Sibs behaviour problems, particularly for TD-Sibs aged 6 to 11 years old. Other studies (8, 18) have used matched comparison groups of TD-Sibs, siblings of children with DS and siblings of children with no disability. One study (8) reported no significant group differences in behaviour, whereas the other study (18) reported more internalising and externalising behaviour problems for TD-Sibs than the comparison groups. The difference in results may be explained by the context of the sample; families involved in study 18 were part of a large research study, whereas the siblings involved in study 8 had been accessing a sibling support group. In the two studies that reported increased behaviour difficulties for TD-Sibs (18, 21), the mean TD-Sibs group score in both studies were not within the clinical or subclinical range for concern. Considering the mean score, rather than the proportion of TD-Sibs within clinical range can make comparisons across studies difficult. One study (19) considered the proportion of TD-Sibs at risk according to a specified clinical range on the CBCL. Although the mean score of TD-Sibs group fell within average range, 10 TD-Sibs were categorised as falling within a borderline or clinical range for internalising behaviour difficulties and 5 of the same participants were categorised as falling within a clinical and borderline range for externalising behaviour problems (18). Therefore, 40% of the total sample (N = 25) could be considered within the at risk or clinical range for experiencing difficulties.

Five studies (2, 7, 10, 12, 20) used different measurement tools to investigate TD-Sibs behaviour. Of these studies, two (10, 20) used parent reports of TD-Sibs behaviour and found no difference in externalising or internalising behaviour problems compared to normative data (20) or compared to a control group (10). Another study (12) used teacher, as well as parent, reports and found no significant differences in reported behaviour difficulties at home or at school compared to normative data. One study (2), however, used matched comparison groups and

found that parents reported more behaviour problems for TD-Sibs and for siblings of children with a learning difficulty, than siblings of children with no disability. The results from this study could indicate that siblings of children with a disability may be more vulnerable to difficulties than siblings of children with no disability, but this conclusion is tentative due to a reliance on parent reports. Interestingly, in the study, teacher reports were collected but not used due to a low response rate reportedly caused by siblings' reluctance to provide consent for their teachers to complete the measure. Only one study used a measure to gather TD-Sibs self-reports (7). In this study, TD-Sibs reported slightly higher levels of internalising and externalising behaviour problems when compared with normative data. Mean scores were not significantly different and the effect sizes were very small (the majority were below ES= 0.20). Another study (9) considered behaviour through a biological stress model and directly measured the cortisol levels of 22 TD-Sibs (aged between 7 and 17 years old). In this study, there was no difference between cortisol levels of TD-Sibs and cortisol levels of a control group (siblings of children categorised as 'neuro-typical' by researchers). For both groups, the secretion patterns reflected typical patterns expected throughout the day.

Some of the aforementioned studies reported key findings in relation to demographic factors that may affect TD-Sibs behaviour outcomes such as age, gender and family size, however the results are often contradictory and inconclusive. For example, one study reported that older siblings had higher rates of externalising and internalising behaviour problems than younger siblings (18) whilst another study found the same trend in younger siblings (21). Three studies reported there were no gender differences in TD-Sibs externalising and internalising behaviours (7, 12, 18). One study reported that a larger family size (higher number of children in the family) was associated with less behaviour problems, although another study (12) reported no effect of family size on behaviour measures.

1.3.2.2   Social Behaviour and Relationships

Across studies, researchers have considered the amount of friendships TD-Sibs have. Similar to all young people, this has been shown to range from having many friendships (e.g. study 1 described this as being a social butterfly) to feeling socially isolated and lonely (e.g. 1, 2, 15). In one study (2), the researchers quantitatively scored semi-structured interview responses from TD-Sibs (aged between 5 and 20 years old), and compared results to a group of siblings of young people diagnosed with a learning difficulty, and a group of siblings of young people with no disability. 35% of TD-Sibs (N=20) reported feeling 'lonely' or 'rather lonely' and also reported that they had no friends, did not go out to see anybody and preferred to stay at home (often spending time with their ASC-Sib). Some of the mothers of these TD-Sibs also reported that the TD-Sib

appeared lonely. Other sibling groups did not report the same levels of loneliness; 15% of siblings of young people diagnosed with a learning difficulty reported feeling 'rather lonely' and no feelings of loneliness were reported by siblings of young people with no disability. Although study 2 suggests that TD-Sibs may be more vulnerable to social isolation, another study (8), which used a loneliness and social dissatisfaction questionnaire and matched comparison groups, reported low levels of loneliness for TD-Sibs, siblings of children with DS and siblings of children with no disability.

Findings from the selected studies suggest peer relationships may be a particular area of difficulty for TD-Sibs. One study (7), measured self-reported TD-Sibs' scores on the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997). In this study, TD-Sibs (aged between 7 and 17 years) reported elevated peer problems in comparison to UK normative data (not significant but ES = 0.31). Although these levels did not reach significance, 6.7% of TD-Sibs reported peer problems in the 'clinically concerning' range, which is more than four times the expected proportion in the general population (1.5%). Similarly, another study (20) found that TD-sibs perceived themselves as significantly less successful with peer relations (for TD-Sibs aged between 10 to 12 years old) and close relationships (for TD-Sibs aged between 13 to 15 years old) when compared to normative data. Interestingly, this did not extend to other relationships such as relations with parents, which suggests that friendships may be a particular area of concern.

Quantitative studies have investigated whether TD-Sibs' peer difficulties are due TD-Sibs' social competence and social skills (6, 17, 18, 21). Three studies, which measured parent reported social competence, reported no difference between scores for TD-Sibs in comparison to a control group (study 6) or matched comparison groups of siblings of children with DS and siblings of children with no disability (both study 8 and study 18). Another study (21) incorporated self-report measures of TD-Sibs (aged 6 to 16 years old). In comparison to a matched control group, TD-Sibs ascribed more socially skilled behaviour to themselves (i.e. higher perceived social competence) and this trend was particularly evident for female TD-Sibs. Although parent-reports did not mirror this positive impact, there was no difference between TD-Sibs and controls suggesting this was not an area of difficulty. Only one study (17) used both parent and teacher reports. In this study, social skills (cooperation, assertion, self-control and responsibility) of TD-Sibs (aged 6 to 10 years old) were rated in the home and school context. TD-Scores were reported to be within the average range socially and there were no differences between TD-Sibs and a control group. The triangulation of parent, teacher and TD-Sibs self-reported findings suggests that TD-Sibs social skills and social competence are not an area of concern, and may not be contributing to the TD-Sibs reported feelings of loneliness or isolation.

Findings from qualitative studies may suggest that the difficulty in being able to effectively communicate the experience of being a TD-Sib can act as a potential barrier to relationships with others beyond the home context (13, 20). For example, in study 1, researchers concluded that the interviewed TD-Sibs (aged 7 to 15 years old) were socially competent but noted an expressed desire for more friendships, particularly with others who understood. A mixed methods study (2) reported that 55% of TD-Sibs (N =20) had no words to explain 'how' their ASC-Sib was different. The TD-Sibs in this study were aged from 5 to 20 years old, and researchers reported that this was not due to the age or language abilities of the participants but rather they had difficulty explaining the situation. Another study reported that TD-Sibs (aged 10 to 18 years old) expressed difficulties explaining their situation to peers, despite this, 86% of the TD-Sibs (N =22) reported that their friends were aware of their ASC-Sib. In relation to this, one qualitative study (13) reported that TD-Sibs perceived the outside world as somewhat challenging due to the reactions and responses from others (including peers as well as strangers). The same study (13) reported a tension between whether TD-Sibs felt 'allowed' to tell others or not; the researchers suggested that an inability to communicate the TD-Sibs situation resulted in an unawareness of others but also a lack of acknowledgement for the TD-Sibs. In other studies, TD-Sibs have reported challenges associated with negative attitudes from strangers (11, 15, 16) or concerns about introducing friends to their ASC-Sib (11). Of these studies, one (15) also highlighted the importance of open communication in supporting positive relationships for TD-Sibs. Another study (13) reported that TD-Sibs perceived opportunities to discuss and exchange their stories with other siblings in a similar situation as a useful experience.

1.3.2.3   Summary

Although the majority of the 22 studies investigated TD-Sibs internalising and externalising behaviour, it is difficult to form firm conclusions from the aforementioned findings. It may be that some TD-Sibs tend to experience difficulties with behaviour, but the variation in results may reflect the differences in measurement tools used, informants and comparison groups across studies. The findings do indicate the importance of considering behaviour over time and beyond the immediate context, with teacher reports appearing to highlight potential internalising difficulties in the school setting which may not be seen at home. A noteworthy finding was the limited amount of studies that used TD-Sibs self-reports for this measure or the lack of independent observation, which could help triangulate findings.

Peer relationships appear to be an area of difficulty for TD-Sibs, particularly feeling isolated or lonely. However, it may not be the social competence or social skills of TD-Sibs that need consideration and support. Instead, it appears that communication about their current

situation as a TD-Sib can impact on their relationships. This includes whether they should (or are allowed) to speak about their experiences and is perhaps further exacerbated by a perceived limited understanding of others who have not been in similar situations. It appears that some TD-Sibs may find it better to isolate themselves, or spend time with their ASC-Sib, rather than experience social or public exchanges.

1.3.3 Affect

This section will consider findings in relation to the emotional wellbeing of TD-Sibs. Quantitative studies appear to investigate depression and anxiety levels, and use tools that are designed to look for and measure TD-Sibs scores on these specific emotions, e.g. Children's Depression Inventory (CDI, Kovacs, 1983). In qualitative studies, the open-ended structure of interview questions has elicited findings regarding both positive and negative emotions experienced by TD-Sibs in relation to specific events. One study, out of the 22, directly investigated how siblings cope and respond to these emotions.

1.3.3.1 Anxiety and Depression

Across the 17 quantitative studies, four measured depression scores (6, 9, 10, 14) and one of these four additionally measured anxiety scores of TD-Sibs (14). Three of the studies (6, 9, 10) used sibling self-reported scores on the CDI and a control comparison group of siblings of children with no disability. Of these three studies, the study with the largest sample size (N=51) found no significant difference in depression scores between groups (10). One of the other studies (6), recruited TD-Sibs of male ASC-Sibs only (N=22), and found that these TD-Sibs reported significantly higher depression scores than controls. Interestingly, TD-Sibs aged 12 years old and above (categorised as adolescents), had significantly higher scores than those under 12 years old. Although there were no significant gender effects found; the characteristics of the ASC-Sibs (such as being older and the length of time since diagnosis), correlated with depression scores in female TD-Sibs. This could suggest a difference in contributing factors for male or female TD-Sibs depression scores. However, when the most conservative cut off score was applied to TD-Sibs depression scores, only 11 TD-Sibs (N=22) were considered in the 'depressed range', which suggests the proportion of siblings affected may be small. Additionally, there was proportionally more adolescent TD-Sibs than adolescent siblings in the comparison group which may have influenced the results. The remaining study of the three (9) similarly found higher total depression scores for TD-Sibs compared to controls ($\eta p2 = .10$), yet the sample size was also small (N=22) and researcher calculations of post hoc power analysis indicated that N = 43 was needed for adequate power.

The other study (14), which measured both anxiety and depression, found that 36% of TD-Sibs (N= 57) reported depressive symptoms at or above the lowest clinical cut-off score and 8.5% of TD-Sibs reported anxiety symptoms in the clinical range, with sisters (female TD-Sibs) reporting higher levels of symptoms. Nevertheless, these scores were similar to that expected in community samples. The limitations in all the selected studies make it difficult to draw conclusions and suggest there is a need to generate and evaluate further evidence (using larger samples) before concluding that TD-Sibs may be more adversely affected than siblings of children with no disability.

1.3.3.2   Self-Reported Emotions and Coping

A number of studies have explored TD-Sibs emotional responses to experiencing specific, challenging situations related to their home context. One study (19) found that of the TD-Sibs recruited (N=25), 84% reported an aggressive incident (involving their ASC-Sib) as the most common and difficult problem; TD-Sibs reported anger as their most common response to this situation. Qualitative studies have enabled further exploration of TD-Sibs emotions without the constraints of pre-determined categories or standardised questionnaires. During interviews, TD-Sibs have reported feelings of embarrassment (1,15), frustration and anger (15) particularly in situations outside the home context or when their brother or sister with ASC displays challenging behaviour (11). It appears that these feelings are linked to experiences where strangers or peers have displayed negative attitudes or a lack of understanding (15, 16), which can lead to worry for similar future contexts (16). One study (16) discusses an emotional discord for TD-Sibs, in regards to the feelings of embarrassment in social situations, where the TD-Sibs' need to identify with a peer group is challenged by their perception of fairness to their ASC-Sib.

In some studies, TD-Sibs have discussed worries or anxiety for their sibling (e.g. their acceptance) and the future (1). This includes future care plans due to the assumed responsibility they take on as a TD-Sib (16). Indeed, future concerns have been found to be more prevalent for TD-Sibs than siblings of children with intellectual disabilities or no disability (2). When taken together, the emotional and practical challenges experienced by TD-Sibs have been reported to feel emotionally overwhelming (16).

Through qualitative studies, TD-Sibs have also shared their emotional responses from different positive experiences with their ASC-Sibs, for example their enjoyment when spending time with their sibling (13) or their pride in recognition of ASC-Sibs strengths, talents and achievements (1, 2, 15). These studies have used semi-structured interviews to follow TD-Sibs shared discussions, which has enabled information to be elicited about the challenges but also the positive aspects of being a TD-Sib. For example, one study found that only four siblings out of

fourteen did not offer positive experiences regarding the life as an TD-Sibs (where six TD-Sibs were from the same three families). Two studies that used IPA across two different age groups, reported that in both middle childhood and adolescence, TD-Sibs express positive acceptance of their ASC-Sibs. One of these studies (15) reported that there may be some tension with these feelings and a wish for things to be different. The other study reported that TD-Sibs often reflect on the things they have learnt from their ASC-Sib, such as an increased understanding of diversity (16).

Limited consideration has been given to TD-Sibs' coping strategies and responses to their experiences. Interviews have highlighted the importance of TD-Sibs accessing individual private time or isolation (1, 13) and a need for them to compare their responses and feelings with other TD-Sibs in similar situations (13). Indeed, one study has suggested that the emotions experienced by TD-Sibs in challenging situations (e.g. anger, anxiety or frustration) can lead to them withdrawing or remaining silent and guarded (15). One quantitative study (19) directly measured TD-Sibs coping strategies using the KIDCOPE. In response to aggression (the most commonly reported problem) TD-Sibs reported using at least three coping strategies in response; the most frequently reported were emotional regulation and also wishful thinking, followed by social withdrawal, and then distraction. TD-Sibs did not choose self or other blaming as a coping strategy when faced with aggression. This may suggest that TD-Sibs are aware of the feelings that aggressive behaviours elicit, and choose to cope in other ways (19). In fact, findings from qualitative studies suggest that TD-Sibs attempt to establish some kind of level of normality; they accept and adjust to their specific situation and appraise it as their normality (13). Findings have also suggested that TD-Sibs engage in social comparison of other families and siblings and look at their past experiences to appraise their current situation (16).

1.3.3.3   Summary

Generally, studies in this section have tended to capture TD-Sibs emotions and feelings at one point in time and the findings reflect the tool used and particular emotion measured. Quantitative studies have frequently considered maladaptive emotional responses such as anxiety and depression, whilst qualitative studies have enabled further understanding around the events or situations in which strong feelings may occur. Although both negative and positive feelings have been reported, it appears that experiences of intense negative affect may be an issue for a number of TD-Sibs in response to specific situations, however, few studies consider how these siblings cope and respond to such feelings. Future research needs to go beyond identifying TD-Sibs' positive and negative feelings and towards exploring how TD-Sibs respond to these feelings in certain situations.

1.3.4   Environment

This section briefly discusses three factors that have been considered in quantitative and qualitative studies regarding the home environment of TD-Sibs. Studies have reflected on the different access that TD-Sibs may have to their parents due to the understandable but high demands of a sibling with ASC, which may take up more of their available time. The social support available to families has also been considered, particularly the availability for TD-Sibs to speak to others beyond the home context and who else is available to support them. Lastly the potential additional responsibilities placed on TD-Sibs (compared to siblings of children with no disability) has been discussed.

1.3.4.1   Parental Time and Differential Access

TD-Sibs have reported that increased parental attention to their ASC-Sibs is expected and accepted (3) and one study reported that TD-Sibs who were older than ASC-Sibs perceived this to a greater extent, as did female TD-Sibs (20). One quantitative study (22) measured parental differential treatment through a sibling relationship questionnaire, and found that TD-Sibs externalising and internalising behaviour difficulties were linked to perceived parental differential treatment. Indeed, this became more evident over a 3-year period yet, unexpectedly, it was the perception that the TD-Sib was preferred over their ASC-Sib that was predictive of difficulties. An explanation for this finding could be that the tool used was based on sibling relationships rather than a specific measure designed to explore access to parents. It may be useful to employ an observational method to explore this. In interviews with TD-Sibs, there has been discussion of the different daily functioning of everyday life and the restricted family opportunities such as holiday restrictions, an inability to have friends home, a lack of privacy and interference with personal lives as well as the increased demands on parental time (11, 15).

1.3.4.2   Social Support

There is a need for TD-Sibs to talk to others beyond the home context (1), but as previously discussed this can present as a challenge. One study reported that only 35% of TD-Sibs (N = 20) could talk to someone outside the home about their ASC-Sib (2). Another study (6) found that that TD-Sibs who had no one to talk to about having a brother with ASC, scored significantly higher on depression scores. A further study (9) suggests that social support may act as a protective buffer because TD-Sibs total depression scores were, in part, influenced by the availability of social support and accounted for 82% of the variance in scores. Indeed, social support may become more important over time. For example, it has been found that lower levels of social support were associated with parent and teacher-reported externalising and internalising

behaviour problems across a three-year period (22). In this study, teacher-related social support received at time 1 and time 2 was found to be important in protecting against internalising and externalising behaviour difficulties (22). In a different study (9), higher levels of social support from classmates/friends have been associated with lower levels of loneliness and higher academic functioning.

1.3.4.3 Responsibilities

Findings from qualitative studies indicate that TD-Sibs perceive a heightened sense of responsibility and assume a multitude of roles in the family including caregivers, sibling helpers, parent helpers and even rescuers (1). One mixed methods study (20) suggested that although TD-Sibs may express an ability to cope with additional demands, they tend to take on more responsibilities than they can manage. In this study, younger age TD-Sibs reported more feelings of responsibility than older age TD-Sibs, but it may be that older siblings have accepted such feelings as normality. Additionally, female TD-Sibs tended to describe how assumed responsibilities led to the disruption of their daily routines and could feel as though they were bearing a burden (20). It is important to note that these additional responsibilities did not tend to relate to household jobs and domestic chores, but were to do with the multitude of roles that they took on to support their parents or ASC-Sib. These qualitative findings can be triangulated with a quantitative study, which found that although TD-Sibs did not do more domestic housework than controls, they did more caregiving work (6).

1.3.4.4 Summary

It appears from the selected studies that TD-Sibs experience a type of home environment where siblings appreciate and accept the demands placed on their parents, and adopt different roles in which they support their family and sibling. Although their specific family situation becomes the norm, the importance of having somebody outside the home to speak to is a noteworthy finding for school staff and Educational Psychologists (EPs). It may also be important to explore whether TD-Sibs may take on too much responsibility, or are aware of their parent's limited time capacity for them as a result of having an ASC-Sib. The reported benefits for TD-Sibs, when they are able to speak to others outside the home, is a valuable insight when considered alongside the difficulties that have previously been discussed for TD-Sibs in relation to communicating their situations to peers. This has implications for EPs and school staff and indicates that appropriate environmental opportunities to talk (such as in sibling support groups, through peer mentoring, support from Emotional Literacy Support Assistants or teachers) could be very valuable for a number of TD-Sibs.

1.3.5   Fixed Demographic and Family Factors

Although it is beyond the scope of this review to provide a detailed discussion of the various predictor variables, this section provides a brief overview of individual and family factors that have been discussed in the identified studies as potentially influencing the 'adjustment' of TD-Sibs in the sampled studies. Demographic factors cannot be changed, and can be referred to as static or fixed in nature (e.g. gender), whereas some family factors may be changed through ongoing professional support or intervention (e.g. parent wellbeing) but for the purposes of this section they have been considered beyond immediate change.

1.3.5.1   Individual Demographics

Generally, quantitative studies tend to consider individual TD-Sibs' characteristics (e.g. gender and birth order) as potential confounding variables and either gather demographic information and explore this in analysis or control for it within the sample (e.g. using matched experimental and control groups based on age, gender and birth order variables). Despite this, it is difficult to draw any conclusions regarding the differential influence of these factors due to the range of outcomes explored in the selected studies. The key findings from the selected studies in relation to these aspects have been discussed in the relevant, aforementioned sections. However, one study (10) created a scale to consider the cumulative effects of specific demographic factors. This 'risk scale' was positively associated with TD-Sibs academic, social and emotional difficulties, but this was not found to be associated for the control comparison group. High risk factors included being a male TD-Sib, having low socio-economic status, having only one sibling (the ASC-Sib) and being older than the ASC-Sib. The researchers suggest that when the number of these demographic risk factors increase, the likelihood of a negative impact on TD-Sibs also increases (10).

1.3.5.2   Family Characteristics

Consideration has also been given to the characteristics within individual family contexts that may contribute to any impact on TD-Sibs. Two linked quantitative studies (4, 5) identified parental distress as a mediator in the presentation of internalising and externalising behaviour problems in TD-Sibs. Interestingly, this was found to be highest in families of children with ASC when compared to families of children with DS or families with typically developing children (5). During a follow up study three years later, the high level of distress for parents of children with ASC (in comparison to the other groups) had been maintained over time (4). Importantly, another study (14) found that depressive symptoms in mothers were associated with higher levels of

depression and anxiety in TD-Sibs, which suggests this could be a contributing factor to how siblings may cope and respond to their experiences.

The same study also acknowledged a genetic link to ASC through classifying siblings who were considered to be expressing the Broad Autism Phenotype (BAP; conceptualised as showing a genetic predisposition to ASC). The interaction between genetics and environmental elements (stressful life events) were investigated through a diathesis stress model. Findings provided partial support for the model; those TD-Sibs that were identified as expressing the Broad Autism Phenotype had increased levels of depression and anxiety symptoms but only in the presence of a high number of stressful life events. A family history of ASC was also found to be associated with increased depressive symptoms in TD-Sibs. Although this lends support to an interaction between genetics and the environment, the reliability of these conclusions are limited because the measures used to ascertain and categorise genetic elements were brief parent-report questionnaires for TD-Sibs and self-report questionnaires for parents, which were all only completed by mothers.

Findings from qualitative studies indicate that the differential presentation of ASC amongst those siblings diagnosed with the condition presents unique challenges for each family (15). For example, experiencing their ASC-Sibs challenging behaviour and aggression has been discussed as particularly stressful during interviews with TD-Sibs (13 ,16). In one study, TD-Sibs described periods of tantrums, excessive anger and explosiveness (11) and this appears to be perceived as the most negative and challenging aspect during discussions. One mixed methods study (2) compared TD-Sibs to matched groups of siblings of children with intellectual disability and siblings of typically developing children (controls). Interestingly, TD-Sibs experienced more problems with ASC-Sibs disturbing them and breaking things than the other two sibling groups, indicating that this group experience more challenging behaviour to respond to. In another study, increased behaviour problems in ASC-Sibs were found to be associated with lower levels of warmth and more conflict in the sibling relationship, however, the TD-Sibs self-reports of the sibling relationship as well as their own internalising and externalising behaviour were not associated with mother-reported emotion and behaviour problems in ASC-Sibs (7).

1.3.5.3   Summary

Overall, it is important to acknowledge that the experiences and wider impact on TD-Sibs may be influenced by specific TD-Sibs characteristics such as gender or birth order, and/or family characteristics including parental distress, family history and challenging behaviour often associated with ASC. Studies which have tended to explore these variables further have done so to identify those TD-Sibs who may be at an increased risk of negative impact (e.g. of developing

depression). Although it may be interesting to explore and acknowledge these fixed or static factors to identify those at more risk, it may be more helpful to focus on dynamic factors due to the potential of these being utilised to bring about change for TD-Sibs (Giallo & Gavidia-Payne, 2006).

1.4   Discussion

1.4.1   Summary of Findings

This review adopted an adapted version of an IFF approach to structure and compare findings (in the current TD-Sibs literature base) to help further understand the experiences of TD-Sibs from a holistic perspective. Figure two demonstrates an initial IFF to visually represent tentative ideas drawn from the review's findings, as well as possible routes to intervention (see key). Similar to the findings of previous systematic reviews (Meadan et al., 2010), the current review revealed mixed results across the areas explored. Consequently, the proposed IFF is not a definitive model but rather a working framework for ongoing consideration; the levels within the IFF are acknowledged to interact, and the framework is an evolving process whereby tentative hypotheses change depending on the evidence (supportive or non-supportive) that continues to emerge (Monsen & Fredrickson, 2008).

As shown by figure 2, the review has identified a number of factors that reveal both positive and challenging aspects in relation to TD-Sibs experiences. In general, quantitative studies have tended to focus on the potential behaviour, social and emotional difficulties that TD-Sibs may experience. A substantial amount of studies measured levels of depression and/or internalising and externalising behaviours (e.g. 6, 14, 17), but the direction of findings has been mixed. Indeed, there may be some evidence to suggest that TD-Sibs are more vulnerable to these difficulties, particularly when considering the potential role of specific demographic or family factors (e.g. study 10 and 14). Based on findings from this review, there is currently insufficient, consistent evidence to conclude that TD-Sibs as a group will experience difficulties in these areas. The variation in experiences could be explained by the interaction between genetic and environmental factors within contexts (e.g. Bronfenbrenner, 1977; Sameroff, 2009) and as other research has suggested, the presence of BAP characteristics. For example, in line with study 10, research by Meyer et al. (2011) suggests that siblings who display characteristics associated with BAP (e.g. social difficulties) may be less likely to seek social support when needed, and could be more likely to react negatively (e.g. developing depression or anxiety) to having a sibling with ASC or to other stressful life events. The researchers explain that siblings not exhibiting BAP characteristics may be better equipped and find it easier to manage such
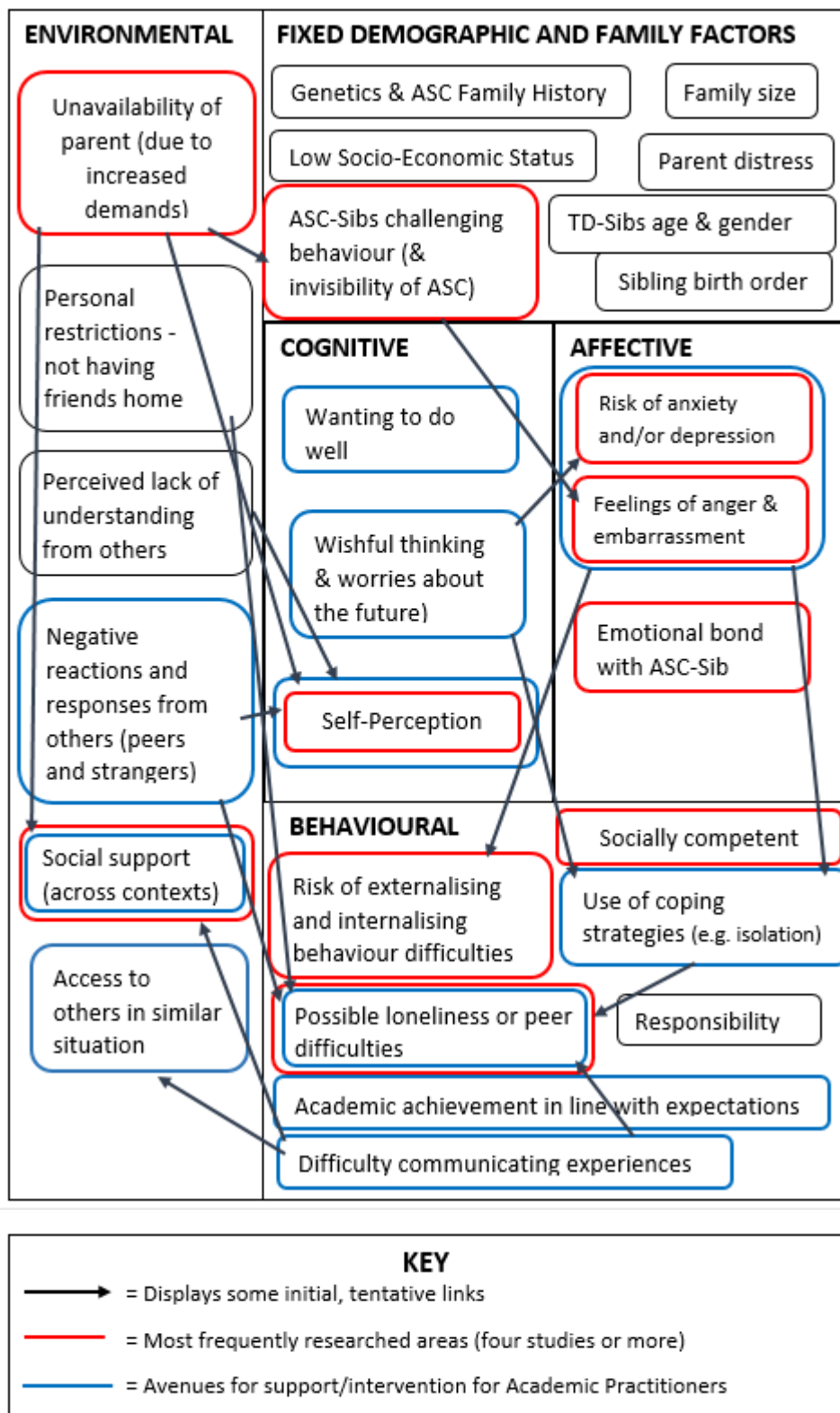
Figure 3: *Interactive Factors Framework approach – initial findings*

experiences. However, these conclusions require further investigation, particularly due to the inconsistency in evidence exploring BAP in TD-Sibs (e.g. Pisula & Ziegart-Sadowska, 2015).

Other reported findings from quantitative studies have been more consistent. Self-concept (10), social competence (8) and academic achievement (12) have been identified as areas where TD-Sibs are comparable (or no different) to other young people (e.g. siblings of children with no disability). Social comparison theory (Festinger, 1954) posits that individuals compare themselves to others in their social environments due to a natural drive to gain accurate appraisal of status, skills and ability. The finding that some TD-Sibs report a more positive self-concept than siblings of individuals without ASC (10,12) may be linked to TD-Sibs perceiving themselves more favourably in comparison to their ASC-Sibs. This mechanism of comparison could serve a self-enhancing function and increase self-esteem (Wills, 1981). Indeed, in relation to the qualitative finding that TD-Sibs perceive it is important to do well and strive to achieve this (12), it may be that comparison leads to an appraisal that ability is fixed (Dweck, 1999) and therefore TD-Sibs may aim to achieve academic grades (i.e. performance goals) to validate or demonstrate competencies (O'Keefe, 2013), relative to their ASC-Sib or peers without a sibling with ASC. These self-enhancement beliefs could have consequences for the achievement goals adopted, the attributions made for failure and the strategies pursued in the face of failure (Dweck, 1999; O'Keefe, 2013), and indeed would be worthy of further investigation.

Further findings from the qualitative studies suggest that negative aspects experienced by TD-Sibs appear to be linked to the presentation of ASC, for example, the invisibility of the condition, aggressive behavioural responses of the ASC-Sib and the negative reactions or lack of understanding from others (11, 13, 15, 16). Similarly, the qualitative studies have revealed other, previously unconsidered, aspects such as TD-Sibs emotional responses to challenging experiences, the multiple roles which TD-Sibs may fulfil, a perceived heightened sense of responsibility and restrictions to parent availability and privacy. In line with the transactional model, these aspects can be considered as dynamic interactions between the TD-Sib and their social settings where each affect the other (Sameroff, 2010). For example, reported feelings of isolation by TD-Sibs (e.g. 2) is likely to be linked to family restrictions within the home context (inability to have friends home and limited availability of parents e.g. 11, 15), as well as perceived challenges about sharing or communicating experiences beyond the home context, which can be exacerbated by TD-Sibs feelings of embarrassment or anger and a lack of effective coping strategies (e.g. isolation) to manage these feelings. Consequently, the importance of understanding the holistic experience of TD-Sibs across the different systems (e.g. school and home) is important to develop an understanding that can inform appropriate intervention. It is also important to note that these studies have highlighted that a TD-Sib's experience is unique and becomes the norm for that

sibling; it is therefore perhaps not helpful or truly reflective to make the experience value laden with a positive or negative label. Instead, it is important to consider if TD-Sibs would benefit from any support with their experiences and what this support may look like.

1.4.2 Strengths

Qualitative studies have provided a richer understanding of TD-Sibs perceived experiences and the balanced approach adopted in semi-structured interviews has facilitated discussion which has provided additional context regarding particular quantitative findings (e.g. social relationships). These studies have also provided further avenues that may be important to explore such as heightened responsibilities, future aspirations and how to enable TD-Sibs to effectively communicate their experiences with others.

There is also a large number of quantitative studies included within this review; together they have formed a useful basis to the research area and highlighted key aspects to be considered for TD-Sibs. The more recent studies included in the review have attempted to overcome some of the previously identified methodological challenges from the previous studies. For example, one study used multi-informants and recruited the largest sample (3) and another acknowledged the absence of TD-Sibs own views and measured self-report data (7). Another recent study, acknowledged the value of incorporating a qualitative aspect into the study and used a mixed-methods design (20). Indeed, it may be that a mixed-methods approach may be of benefit for future research in this area. Certainly, by drawing the findings of quantitative and qualitative studies together in this review, it has allowed a fuller picture of the TD-Sibs experiences to emerge.

1.4.3 Limitations

This review revealed mixed findings regarding the TD-Sibs experience in regards to cognitive, emotional and behavioural aspects. This may be due to the selected studies using a wide range of research questions (e.g. group comparisons studies compared to a TD-Sibs lived experiences), or the methodological challenges that made between-study comparison difficult (e.g. sample size, measurement tools, variation in type of control group). It may also be that TD-Sibs (like their ASC-Sib counterparts) are not a sufficiently homogenous group to be able to contrast with other sibling control groups. Alternatively, a range of other factors may be more important for cognitive, behavioural and emotional outcomes than the experience of being a sibling. Finally, the review used an adapted IFF approach to organise and attempt to understand the different factors in relation to TD-Sibs' holistic experience. A critique of this approach could be

that it attempts to compartmentalise different areas of development in which research studies (or real life cases) do not neatly fit. Furthermore, it could be argued that the interactionist approach can overlook fixed factors which are important, in an attempt to identify routes for change and intervention. Interestingly, Annan et al. (2013) adapted this framework to incorporate an assessment column of next steps, this version would be useful to consider for future research adopting a similar approach. Overall, the traditional IFF acknowledges that factors interact across the domains (or boxes) and that the categories are not distinct. It has been used here as an approach to guide thinking about a complex area of research. It is hoped that this approach is considered as a working framework which can be utilised and adapted as further research emerges.

There are a number of limitations that can be drawn from the body of synthesised research that has been selected for this review. All the studies are cross-sectional in design and, therefore, report on data from only one-time point. Those studies that were longitudinal did not provide interim data between the initial and follow up time point, which was three years later. It is also important to note that the age criteria of participants in selected studies was typically drawn from a relatively large age range (5 to 20 years old) and the majority of individual studies (except a select few of qualitative studies) did not target discrete ranges (e.g. 7-12 years; middle childhood in study 16). This has limited the possibility of trying to understand findings from a developmental trajectory perspective and across key school and transition ages.

Quantitative studies could be critiqued for appearing to be guided by a deficit model assumption i.e. an assumption that there will be potential deficits and difficulties faced by this sibling group. This may have resulted in a potentially leading approach and biased selection of measurement tools where researchers could be considered as 'looking' for difficulties rather than using an alternative wider measure (e.g. the use of a depression measure rather than a neutral measure). There are also a number of quantitative studies which could be critiqued for their selection of informants. For parent reports, most studies recruited mothers. The small number of participating fathers in the research sufficiently reduces an alternative perspective of the TD-Sibs home environment. Similarly, very few studies used TD-Sibs and parent (or teacher) reports of the same measure, which would have helped triangulate results. Furthermore, few studies measured teacher reports, and those that did tended to focus on behaviour rather than wider aspects within the school context. Although the findings do not suggest that TD-Sibs will experience difficulties in school, this review found little and very limited information available regarding the school context, despite most young people spending a significant proportion of their time in school.

1.4.4   Conclusions and Future Research

In an attempt to understand what previous research has indicated about TD-Sibs experience, this systematic review used an IFF approach to consider TD-Sibs experiences from a holistic perspective. In doing so, this paper moves away from the adjustment focus of the previous research, and considers the previous quantitative and qualitative studies in combination, to help further understand the wider experiences of TD-Sibs. The systematic approach utilised clear inclusion and exclusion criteria, a thorough quality assessment and a framework which is used in and guides EP practice. An alternative way of structuring the review (due to the methodological challenges acknowledged in the literature) may have been to use Holdapp's themes (2005), as applied in a previous systematic review (Meaden et al., 2010). However, the potential practical application of an IFF and the evolving evidence-gathering process (which the framework encourages), appears to fit well with the current inconclusive findings in the research area.

It is difficult to draw firm conclusions from the reviewed studies, and instead the findings tend to pose further questions and areas of exploration. Indeed, the mixed findings provide evidence that continued research within this area is needed. Future research should seek to expand the evidence-base by exploring the educational context (schools, college or university) for TD-Sibs, which has been largely overlooked by previous research and therefore omits an important contextual aspect within the TD-Sibs experiences. In the review process, it was noted that no studies could be identified which considered the young adult range (e.g. 18 to 25 years old). Indeed, TD-Sibs self-reports of a heightened sense of responsibility, their adoption of different roles within the family and their concerns about future implications, would be interesting areas to explore with TD-Sibs who are post-adolescence.

As this review demonstrates, qualitative studies using semi-structured interviews have provided a richer picture of the sibling experience and have provided an opportunity for TD-Sibs to communicate their perceived self-support needs. Two of the qualitative studies (considered to be of high quality) have demonstrated it is helpful to explore TD-Sibs experiences within discrete age ranges (15, 16). These same studies also found that in comparison to middle age siblings, adolescent were able to use this process as an opportunity for reflection and appraisal of the past and current experiences (16). No qualitative studies have been conducted with TD-Sibs in the young adult range. Furthermore, the limited available previous evidence regarding TD-Sibs educational experiences lends itself to a wider, open qualitative exploration of the siblings lived experience rather than employment of a quantitative measure using pre-defined categories.

Therefore, the empirical study that follows explores the lived experiences and perceptions of education for typically developing, young adult siblings with a brother or sister with ASC.

1.4.5   Implications for Educational Psychologists

Information written by the UK Sibling Charity, Sibs, suggests that siblings of children and young people with special educational needs or disability (SEND) experience a range of barriers to learning (Sibs, 2015). Indeed, in this same information, the charity offers training to school staff to support them in identifying and reducing barriers for siblings in school. The charity website states:

"Around two pupils in every classroom are at risk for problems with wellbeing and attainment because they have a brother or sister with SEND"

(Sibs, 2016)

Educational Psychologists (EPs) have a role in supporting educational settings to meet the wide ranging needs of the children and young people they support (e.g. Fallon, Woods, & Rooney, 2010). As a scientific practioner, EPs have a duty to disseminate evidence-informed practice and this includes potentially challenging an approach adopted by schools which may not be based in evidence. Despite a substantial literature base, the methodological limitations within the sibling literature and the lack of consideration to a developmental perspective across the life span, means that the experiences of having a sibling with SEND is, as yet, not completely understood. Further, carefully designed research, is required. Given their practical links to primary, secondary and, most recently, college and university settings, EPs may be best placed to do this.

Furthermore, the current review highlighted key aspects worthy of further exploration in relation to the educational context (Figure 2). This included: the perceived importance for TD-Sibs to academically achieve, the role of providing a key adult to faciliate social support from an alternative context, sensitively enabling siblings to communicate their experiences beyond the home context, supporting those siblings who report few (or no) friendships and the management of coping strategies adopted by siblings (e.g. isolation). EPs support young people and schools across areas of cognitive, emotional, social and behavioural functioning, and consider the environmental strategies in place on an individual, small group or wider systemic level. Consequently, EPs may be well suited to support the educational context and self-perceived support needs of siblings (if required), by drawing on the evidence based approaches used across the areas in which they work.

Chapter 2:   Empirical Paper

2.1   Introduction

"A comprehensive understanding of the experience of having a sibling with Autism can be gained from one who actually lives the experience"

(Meadan et al., 2010, p.95)

There is a substantial amount of research that has investigated the potential effect on siblings, when growing up with a brother or sister with Autism. The term 'Autism Spectrum Condition (ASC) will be used throughout this paper to acknowledge that as well as having a diagnosed neurodevelopmental disability (which presents with varying degree of difficulties in the areas of social interaction, repetitive behaviour and verbal and non-verbal communication), these individuals also have areas of strength (Baron-Cohen et al., 2009). Findings from studies that explored outcomes for typically developing siblings (TD-Sibs) with a brother or sister diagnosed with ASC are mixed. Indeed, the empirical evidence explored in the systematic literature review in chapter 1 found inconclusive results in regards to cognitive, emotional and behaviour outcomes for TD-Sibs. Studies have indicated that some TD-Sibs may experience internalising or externalising behaviour problems (Fisman et al., 1996; Fisman, Wolf, Ellison & Freeman, 2000), anxiety or depressive symptoms (Orsmond & Seltzer, 2009) when compared to siblings of children with another disability or siblings of typically developing children. Other studies have reported no behaviour or emotional difficulties (Dempsey, Llorens, Brewton, Mulchandani & Goin-Kochel, 2012; Stampoltzis, Defingou, Antonopoulou, Kouvava & Polychronopoulou, 2014) or have highlighted positive outcomes in sibling's social competence (Kaminsky & Dewey, 2002) or self-concept (Macks & Reeve, 2007). This may be due to methodological limitations such as variation in sample sizes, different types of comparison groups or variation in use of measurement tools (and the associated outcomes). Such issues are beginning to be addressed in large scale, sibling disability research (e.g. Goudie et al., 2013).

It could also be argued that previous quantitative research appears to be guided by a deficit model where there is a focus on the potential difficulties experienced by this sibling group. Petalas et al. (2009) explain that previously posed research questions tend to have a prior assumption that growing up with a sibling with ASC is a stressful journey, which is likely to result in emotional or behavioural difficulties. The research that follows tends to prioritise parent or teacher reports, and has limited direct involvement from the TD-Sibs themselves (Petalas et al., 2009). In reference to the sibling disability research, Stoneman (2005) explains that the

importance of investigating a research question can be reflected in the difficulty of designing and implementing the research to answer it. Indeed, Meadan et al. (2010) state that the inconclusive findings in this area indicate a need for continued research, and, suggest this focus should be on understanding the sibling experience through "hearing the voices" (p.98) of siblings.

2.1.1   Sibling Voice

The systematic literature review in chapter 1 demonstrated how the empirical evidence can begin to shape an understanding of the sibling experience, from a holistic perspective. Indeed, qualitative research eliciting sibling views was found to be valuable in providing a richness of evidence that added to the existing quantitative findings. However, there has been a limited number of qualitative studies in the UK. Masha and Boucher (2006) piloted a qualitative methodology (semi-structured interviews) with this sibling group. Preliminary analysis of the findings indicated that TD-Sibs (aged 11 to 18 years old) gave generally positive reports of their experiences. Challenges were associated with their brother's or sister's aggression (e.g. described as tantrums, anger or explosiveness) and the resulting embarrassment when this occurs in public situations or when dealing with the attitudes of others (including their peers). These siblings also reported difficulties with having their own privacy, having friends to visit at home and the demands on parental time that the situation created. Indeed, due to the pilot approach of this study, conclusions are limited. Although this study was only preliminary, and consisted of 6 participants from three families, similar findings have been reported in more recent studies by Petalas et al. (2009; 2012a).

Petalas et al. (2009; 2012a) adopted a methodological approach of Interpretative Phenomenological Analysis (IPA) to qualitatively investigate sibling experiences. The researchers considered the developmental differences in experiences and used discrete age categories of TD-Sibs who had a brother diagnosed with ASC. In both studies, siblings reported positive experiences such as enjoyment in shared moments, pride at their ASC-Sib's achievements or reflected on the personal skills they had developed (e.g. tolerance). TD-Sibs aged between 9 and 12 years old (pre-adolescent) reported finding their brother's behaviour and the attitudes of others particularly challenging. These experiences were associated with feelings of frustration, anger or embarrassment. Some siblings also reported feeling socially isolated or rejected, and highlighted the need for open communication between family and peers. Adolescent TD-Sibs aged between 14 and 17 years old, similarly reported difficulties in managing their brother's aggressive behaviour, but demonstrated a sense of empathy and reflective thinking by considering their experiences through comparison of the past and present. These siblings also voiced concerns for their brother's future, and some acknowledged an assumed, ongoing responsibility in this. Indeed,

Atkin and Tozer (2014) qualitatively explored the perceptions of adult siblings (aged 25 to 61 years old) and reported a sense of connectedness and personalised commitment which endured through adulthood. The researchers noted that this was sensitive to the context of how adults related and made sense of their past experiences, including their childhood, and their 'sense of duty' within this. The value of a higher level of reflection, and the possible implications of an ongoing perceived responsibility, suggests that older aged siblings may be able to provide a useful, rich insight into the sibling experience.

2.1.2   Transition to Adulthood

Previous qualitative research has not yet investigated the experiences of young adult TD-Sibs, and therefore, has overlooked the transitional period from adolescence to adulthood. Theoretical and empirical understanding of development during this stage of life has changed, so that it is now considered a key period spanning several years of life rather than a brief transition (Tanner & Arnett, 2009). Arnett (2000) introduced the theory of emerging adulthood to describe the extended period of development between adolescence and young adulthood, from ages 18 to 25. Indeed this period is considered to be a critical juncture of human development (Tanner, 2006), an era where life event 'markers' are most likely to occur (Grob, Krings & Bangerter, 2001) and where adults recall the occurrence of their most important life events (Martin & Smyer, 1990). During this period, there is a renegotiation of relationships with parents and independence increases in the areas of finance, living arrangements, romantic relationships and family formations (Cohen, Kasen, Chen, Hartmark & Gordon, 2003). As well as demographic transitions (e.g. finishing education, career, marriage and parenthood), attaining adulthood is associated with the individual's subjective sense of whether they accept responsibility for oneself, make independent decisions and are becoming financially independent (Arnett, 1998, Arnett, 2000). Indeed, Arnett (2007) conceptualises emerging adulthood as a period of development and age of: identity explorations (exploring the type of person they want to be in relationships, work and life); feeling 'in between' (being neither adolescent not adult); instability (frequent changes including those that are involuntary), self-focus (fewer social roles and obligations to others) and possibilities (optimism for the future).

Consequently, the theory reflects a time of relative independence from social roles and normative expectations, where individuals have "left the dependency of childhood and adolescence" but have "not yet entered enduring responsibilities normative in adulthood" (Tanner & Arnett, 2009, p.46). It is a heightened period of change, as well as a time of exploration of different life directions. Some individuals may be less likely to experience this as period of independent exploration due to aspects such as cultural differences, limited opportunities or

personal barriers (Arnett, 2000). Previously reported findings suggest that adult TD-Sibs feel an enduring sense of duty and personalised commitment to their ASC-Sib (Atkin & Tozer, 2014). Indeed, this could have implications for TD-Sibs experiencing the emerging adult period of exploration. Arnett (2007) suggests the transitional age is experienced both positively and negatively, but that there is considerable heterogeneity. Consequently, it "is an especially rich, complex, dynamic period of life to study" (Arnett, 2000, p477) and remains unexplored in TD-Sib research.

Furthermore, this period of development is also relevant to recent changes for Educational Psychology practice. As part of the UK education reforms, Educational Psychologists (EPs) are now required to work with a wider age group including young people aged 16-25 years old (Children's and Families Act, 2014). Indeed, TD-Sibs self-reported challenges with friendships, their emotional responses and perceived responsibility are areas which should be explored within this age group and considered across home and school contexts. As highlighted in the literature review, there is limited consideration to sibling's educational context, despite young people typically spending a significant amount of time in the learning environment. In line with an eco-systemic perspective, a child or young person's development and experience should be considered within the environmental subsystems within which the individual exists (e.g. school and family), as well as the interactions between them (Bronfenbrenner, 1979).

2.1.3   Sibling Experience and Education

Information published by the UK charity, Sibs (n.d.), states that siblings of children with disabilities face barriers to their learning (such as poor concentration, poor pupil-staff relationships and emotional or behavioural problems) which can lead to problems with their attainment and progress. Although there appears to be no cited research evidence accompanying these conclusions, large scale research studies have indicated that the impact on education for siblings should be explored further (Hastings, 2014). For example, Goudie et al. (2013) conducted a retrospective analysis of data from the USA medical expenditure survey and found that siblings of children with disabilities had more parent-reported problems with behaviour at school, completing school work, participating in extra-curricular activities and interpersonal relationships (with parents, other adults and peers). From the recent literature review, only two studies were identified to have explored the educational impact on TD-Sibs. These focused on the academic attainment (Mates, 1990) or academic competence (Quintero & McIntyre, 2010) and have indicated that TD-Sibs academic achievement is in line with expectations. Yet the school environment encompasses more than attainment; indeed, the social, emotional and behavioural aspects within the school experience are areas yet to be considered or explored. Consequently, an

important contextual aspect with sibling experiences has been omitted; this empirical paper attempts to redress this gap.

2.1.4 Study Rationale

There are a number of unanswered questions and unresolved contradictions in the research concerning TD-Sibs. Previous qualitative studies have provided a richer picture of the sibling experience, as well as an opportunity for TD-Sibs to communicate their perceived self-support needs. No qualitative studies have been conducted with TD-Sibs in the young adult range. The current study will therefore use a sample of individuals aged 16 to 25 years old. Furthermore, organisations such as Sibs have made claims such as "children and young people with intellectual and developmental disability overall have a slightly increased risk for problems with wellbeing and educational attainment" (n.d.), yet have provided no supportive evidence of this. There is a need to explore whether these claims can be supported through independent research. It will also be important for educational psychologists, school staff or other relevant professionals to better understand the nature and extent of any difficulties or needs that TD-Sibs may have (if any) in order to make informed judgments about support or intervention. It could be argued that the limited previous research exploring TD-sibs educational experiences lends itself to a wider, open qualitative exploration of the TD-Sibs' lived experience rather than employment of a quantitative measure using pre-defined categories. Therefore, the study will use data from semi-structured interviews in order to make a detailed exploration of how young adults make sense of their experience of being a sibling with ASC and how this interacts with their experiences of education. This will redress the gaps in the existing research base and will also provide detailed and valuable information to assist key adults (such as parents, school staff or EPs) to more fully understand the lived experience of TD-Sibs in order to relate to and support them better.

2.1.5 Research Aims

The aim of the present study is to explore the views of young adult siblings, who have grown up with a brother or sister with ASC, to gain a greater understanding of their lived experiences and how this may interact with their education. The study attempts to address the following research question:

How do typically developing, young adult siblings make sense of their experience growing up with a brother or sister diagnosed with ASC, and how does this interact with their education?

2.2 Method

2.2.1 Methodological approach

Interpretative Phenomenological Analysis (IPA) sits well with the ontological (what we know) and epistemological (how we know) stance of this research. A social constructionist ontological position acknowledges that our interactions with others, and the world around us, influence how we make sense of the world and ourselves (Owen, 1992). Therefore, attitudes and beliefs are influenced by the environment in which we live. From this stance, an individual's reality is based on their construction and views; reality does not exist objectively (Crotty, 1998). The epistemological interpretative approach of this study acknowledges subjective interpretation and social negotiation of participant's events and experiences (Blaikie, 1993). When considering the ontological and epistemological stance of the research, exploring an individual's sense of meaning is important within the context of a lived experience, which is consistent with IPA.

IPA is a phenomenological research methodology, rather than a data analysis method (Smith, Flowers & Larkin, 2009). Phenomenology is the exploration and understanding of human experience; it is a philosophy and a family of research methods (Langdridge, 2007). This family share the basic tenets of phenomenology but are distinct in how they articulate the approach (Smith et al., 2009). IPA was chosen because of its distinct combination of the theoretical perspectives of phenomenology, interpretation (hermeneutics) and idiography (Smith, 2004; Smith et al., 2009). In IPA, phenomenological inquiry occurs as an interpretative process which pursues an idiographic commitment (Smith et al., 2009). This situates participants in their particular contexts, exploring personal perspectives and detailed analysis of divergence and convergence across cases, whilst capturing the richness in each individual's experience (Pietkiewicz & Smith, 2014). Whereas alternative phenomenological approaches, such as Giorgi and Giorgi (2008), aim to develop accounts of commonality in experiences to build a structured picture of a phenomenon. This therefore is more descriptive and does not fit with the interpretative stance of the research.

In this study, IPA seeks to capture richness of experience; growing up with a sibling diagnosed with ASC, and how this experience interacts with their individuals' education. IPA is a phenomenological method that explores an individual's experience from his/her perspective but recognises that the analysis is merely an interpretation of that experience. This approach acknowledges the researcher's own assumptions as well as the interaction between researcher and participant (Willig, 2013). This accepts that other people's worlds are not directly accessible to the researcher. Rather, the researcher is engaged in a 'double hermeneutic' by "trying to make

sense of the participant trying to make sense of what is happening to them" (Smith, Flowers & Larkin, 2009, p3).

Other alternative methods and methodological approaches were considered, but ultimately rejected. Brief consideration was given to grounded theory which sets to generate a theoretical level account of particular experience (or phenomenon), however this tends to focus on achieving a conceptual explanation (theory). Therefore, the nuances and authenticity of individual experiences (which are considered in the small samples encouraged in IPA) are sacrificed in the service of generalisations across a greater number of participants. Similarly, thematic analysis (Braun & Clarke, 2006) was considered as an alternative approach to analysing the data but the groupings and categories that occur in the early stages of thematic analysis somewhat undermine the idiographic focus of participants lived experiences. Furthermore, it can be focused on the frequency of occurring themes rather than their meaning (Alhojailan, 2012), which offers less opportunity to consider TD-Sibs subjective experience and the sense they make of it. Therefore these other approaches do not complement the stance of the research in the same way as IPA. Indeed, there is a growing body of research using IPA that has enabled the voices of under researched groups to be heard (Cassidy, Reynolds, Naylor & De Souza, 2011) including TD-Sibs (e.g. Petalas et al., 2009).

IPA requires a data collection tool that will invite participants to offer a rich, detailed, first person account of their experience. The use of focus groups were briefly considered but rejected because "the presence of multiple voices and the interactional complexity of such events does make it more difficult to infer and develop the phenomenological aspects of IPA" (Smith et al., 2009, p71). They also can result in explanations that elicit attitudes and opinions rather than experiential narratives (Smith et al., 2009). In-depth interviews enable elicitation of stories, thoughts and feelings, as well as an intimate focus on one person's experience (Kvale, 1996). One to one interviews also allow a "rapport to be developed and give participants the space to think, speak and be heard" (Smith et al., 2009, p.57), which may not be possible with focus group dynamics. Semi-structured interviews are an acknowledged tool that captures the richness needed for IPA (Reid, Flowers & Larkin, 2005). They were chosen because they give participants an opportunity to tell their stories whilst directing the interviewer to areas the interviewer may not have considered in their questions (Smith & Osborn, 2003). Structured interviews would not have enabled the researcher to be led by the participant's story, and therefore were not deemed as appropriate for this study.

Shaw (2010) emphasised that the interviewer cannot be completely impartial in their view of the participants' experiences due to their own experiences and knowledge. It is, therefore,

acknowledged that the lens of the current researcher will be influenced by their own personal experience as a sibling of an individual with ASC, as well as their professional role as a Trainee Educational Psychologist. Bracketing (Patton, 1990) or 'epoche' is the attempt to suspend these assumptions, judgements and interpretations that researchers bring to the process, in order to "become fully aware of what is actually before us" (Willig, 2013, p.84). The current researcher was supported to do this though using a semi-structured interview schedule and prompts (that helped maintain reliability), self-interviewing prior to data-collection (to acknowledge own responses), peer supervision (with two other Trainee Educational Psychologists), supervision within the research team and the recording of reflective notes. Data interpretation was facilitated by ongoing researcher-supervisory discussion, as well as discussion with two other Trainee Educational Psychologists. The personal experience of the researcher as a sibling of an individual with ASC was shared with participants during their debrief, it was not shared prior or during their interview.

2.2.2 Participants

The inclusion criteria for recruiting participants was that participants had to be aged between 16 to 25 years old, have a brother or sister with a diagnosis of ASC and live in the same household as their brother or sister (either currently or when growing up). Participants were six typically developing siblings (five females and one male), who had a brother with ASC. Although the sample age range was set at 16-25 years old (a parent consent form, assent form and young person information sheet was available for those aged under 18 years), the six participants were aged between 19 and 21 years old. Three additional individuals expressed interest but could not be contacted further. All six participants were university students (not attending the same university), had lived in the same household as their brother whilst growing up and returned home during weekends or university holidays. Participants were compensated for their time and participation with a £20 Amazon Voucher. Two participants had another TD-Sib in their family. Five participants were older than their brother with ASC. ASC-Sibs were not directly involved in the study but were all males, aged between 15 to 23 years and had a primary diagnosis of ASC. Severity of ASC was categorized as mild (2), moderate (2), severe (1) and very severe (1). This severity scale was intended to provide contextual information rather than a representative measure of ASC severity in their siblings. The four item scale was based on measures adopted by other researchers in studies involving families with an individual diagnosed with ASC (e.g. Gardiner & Iarocci, 2015). One ASC-Sib had a co-morbid condition of ADHD, one had a physical disability with diagnosed learning difficulties and one had epilepsy with diagnosed learning difficulties. Two ASC-Sibs had recently experienced depression.

Table 1: *Participant's Demographic Information*

Pseudonym	Age	Brother's age	ASC Severity
Samantha	20	15	Mild
Olivia	19	16	Mild
Kate	20	23	Severe
Lucy	20	18	Moderate
Robert	21	20	Moderate
Emma	21	19	Very Severe

2.2.3 Interview schedule

Qualitative data was obtained using semi-structured interviews. The interview schedule (Appendix G) was developed through discussions with the researcher and supervisor. As part of the initial development process, the authors of a previous study that used IPA within this population (Petalas et al., 2012a) were contacted. The researchers shared the interview schedule, this was not incorporated for the present research, instead the types of questions asked in relation to their research objective were considered. The interview schedule was first piloted with one sibling whose interview is not included in this analysis (due to her being slightly older than the intended target group). The pilot resulted in some minor changes to the interview format (e.g. the wording of some questions). The semi-structured interviews lasted approximately 60 minutes and involved nine main questions. As the methodological approach adopted is inductive, the questions used were designed as a guide where the interviewer was also guided by the participant's responses. Therefore, supplementary questions or prompts were permitted to arise as deemed helpful or appropriate during each individual interview.

2.2.4 Procedure

Ethical approval was obtained from the University of Southampton Ethics Committee (Appendix H) prior to commencing the participant recruitment process. Provisions, services, support groups, charities and education settings were sent an advert, recruitment letter and invitation letter for participants (Appendix I). Participants were asked to express interest via email. Participants were then provided with an information sheet (Appendix J) and initial demographic form (Appendix K), which was anonymised apart from contact details that were removed on receipt by the researcher. The demographic form was planned to support participant

selection depending on the amount of responses; it was intended that the information provided would be used to identify a balanced sample from those who expressed interest. This was made clear to participants in regards to the incentive being offered. Due to the low response rate, all six participants who expressed interest were selected for interview and sent a consent form (Appendix L). Written consent was obtained from the participating sibling prior to beginning the interview and an additional demographic form was completed (Appendix M). The siblings were encouraged to speak to their family, and their brother with ASC and this was verbally checked before the interview. Participants were given the choice of being interviewed at their home (N = 1) or the research base (N = 5). Interviews were conducted individually, digitally recorded, then transcribed verbatim. Participants were debriefed at the end of the interview (Appendix N) and provided a signature to confirm they had received the voucher. During the debrief, the personal experience of the researcher (i.e. a sibling of an individual with ASC) was shared with the participant.

2.2.5   Data Analysis

Participants interviews were analysed according to guidelines for IPA (Smith, Flowers & Larkin, 2009) as follows:

Table 2: *Data Analysis Process*

Step	Process
1	Reading and re-reading transcript, immersing and familiarising self with the data
2	Initial noting on transcript, highlighting connections, associations and preliminary interpretations of text
3	Exploring and identifying emergent themes
4	Searching for connections across emergent themes. Identifying points of likeness and tentatively grouping initial comments into themes for each interview.
5	Moving to next transcript (repeat steps 1 to 4)
6	Looking for patterns across transcripts. Finalising broader super-ordinate themes, with themes nested within them

Each case (interview transcript) was examined, analysed and interpreted in turn, before considering connections across cases. Each individual transcript was read several times so that the

researcher could become immersed in the data. Notes were made on individual transcripts highlighting preliminary interpretations and emergent themes. Smith et al. (2009) emphasise these steps are guidelines and not prescriptive. It can therefore incorporate different ways of interacting with the data. To limit researcher bias whilst exploring divergent and convergent patterns between cases, the researcher continually returned to the data throughout this stage of the analysis using different ways of checking the data (e.g. colour-coding quotes, post-it notes and using Microsoft Word to 'cut and paste' sections of the transcript to help identify commonalities). Examples of some of these strategies have been included in Appendix O.

When exploring these connections between cases, the researcher considered: how a theme in one case could illuminate the story of another case, which themes were more potent and which themes represented instances of higher order concepts that cases shared (Smith et al., 2009). In line with Pietkiewicz and Smith (2014), emergent themes were dropped at this stage if they did not fit well with the emerging structure or because they had a weak evidential base (transcript evidence). The researcher used different colours allocated for each participant to enable a visual way of ensuring an idiographic perspective was maintained whist identifying patterns across cases to develop super-ordinate themes. Indeed, this colour coding was continued through to final quote selection so that final superordinate themes and emergent themes reflected illustration of shared experiences and individual differences.

For clarity, the findings are presented as super-ordinate themes with subthemes nested within them and illustrated with verbatim quotes from the interviews. For the purposes of confidentiality, pseudonyms have been used throughout this paper. When providing extracts from interviews, ellipsis "…", is used to indicate words omitted to shorten quotes, participant emphasis on a particular word is presented in italics.

2.3   Findings

Five superordinate themes consisting of two or three related subthemes were identified; these are summarised in Figure 3.
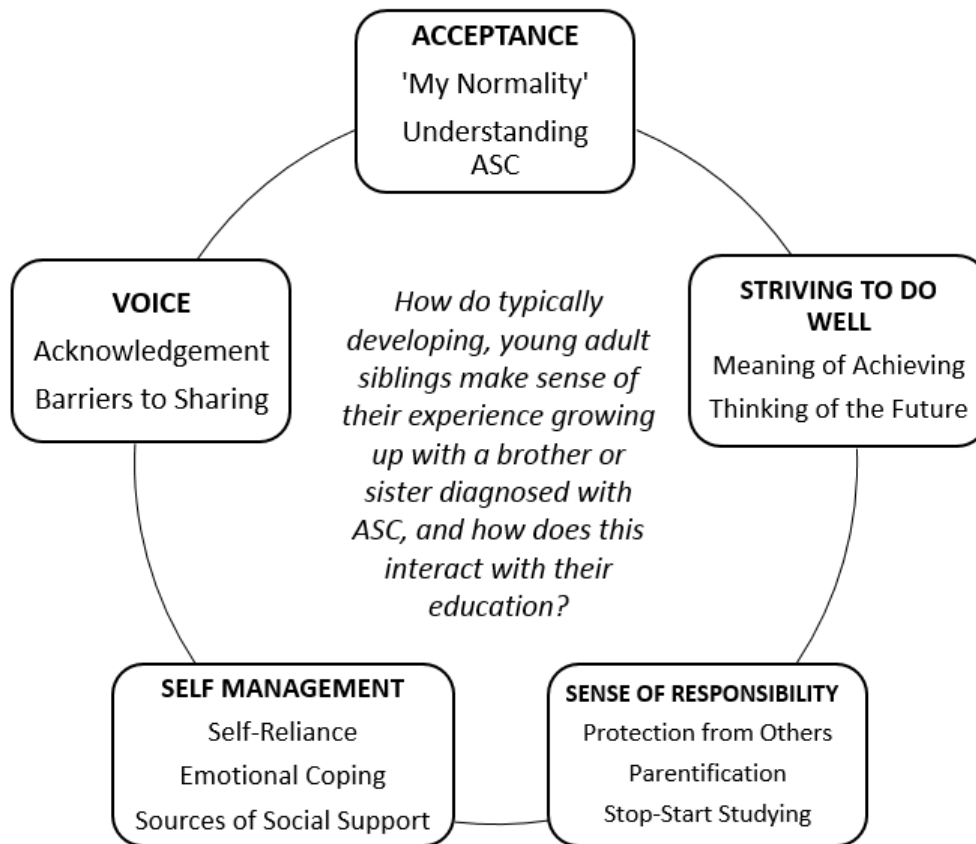
Figure 4: *Visual Representation of Super-ordinate and Subthemes*

2.3.1   Super-ordinate theme: Striving to do well

Educational success was important for participants. They worked hard and had high expectations on themselves to achieve good grades. There was a lack of clarity for participants about where these expectations originated from, but academic achievement appeared to hold some personal value for participants. Their drive was also linked to their thoughts about their future; participants considered their future plans alongside their brother's needs.

2.3.1.1   Subtheme: The Meaning of Achieving

Participants attributed meaning to academically doing well. There was a sense of perfectionism from participants, as well as consideration to where this pressure may have come from. Most participants attributed it to an internal source from themselves, although their responses reflected perceived expectations from others. Some participants referred to the

necessity of working hard, which was linked to their beliefs about their own ability to achieve, as well as whether they viewed ability as 'fixed' or able to change:

> I think I work rather hard, I think. I keep going, try different ways and try. Um, well my friends think I work very hard, but I think I've always sort of naturally been prone to working very hard and dedicating myself to the work. (Olivia, line 263)

Olivia reflects on the effort she puts into achieving; the trying, the different approaches, her friend's perceptions of her, but also how she dedicates her practical (time) and personal resource (herself). Indeed, she later acknowledges, "I've tied, I've managed to tie a chunk of my self-worth to how well I achieved academically", suggesting her continued effort (and subsequent achievement) affects the value she places on herself as an individual. She engages in social comparison of others, including her brother with ASC, whom she has accepted will always be stronger at Mathematics than her ("oh, okay, I'm not quite that good") and this appears to drive her to work harder "not cos it's like 'I have to be better' but 'let's not get shown up'". There appears to be a sense of competition here, as well as an awareness of other's perceptions of her ability in comparison to her brothers.

Similarly, Kate felt "more determined" to achieve as a way of challenging the misconceptions of others:

> …I wanted to show people that just because I had a brother with autism, doesn't mean that I can do – didn't do as well as them, and in actual fact not bigging myself up but I actually did better than them, so it doesn't really – it shows that it doesn't affect it at all. (Kate, line 603)

Kate does not want to be perceived as different or less able due to her sibling experience, and is driven to prove others wrong through demonstrating she is equally (or more) capable than her peers. In contrast, Robert and Lucy experienced a sense of obligation to be the achiever in their families as their sibling could not fulfil that role. Robert explains he was partly influenced by the "…fact that I knew my brother *wasn't* going to so one it was for my parents…" and Lucy talks about experiencing pressure:

> Lucy: I s'pose, like, I wanted to do further stuff because I didn't think he [her brother] would and I knew my parents wanted someone to do it.

> Interviewer: Okay

> Lucy: So I guess I felt more pressure to be the one who, like, did A-levels and went on to university, just because it was unlikely that he was ever gonna do all that, so yeah.

Interviewer: So you 'felt more pressure'?

Lucy: I'm not a very motivated person. I find it hard to do – get myself motivated to do things, so – but it's like, you – you feel other people are depending on you to do it. (Lucy, line 90)

Lucy's discussion implies a lack of choice; the word 'someone' suggests she feels it did not need to be her specifically, but that there was a familial obligation to fulfil which her brother could not. She later discusses how she wanted to leave university in her first year but, after her brother confirmed he was not going, she remained and realised, "Oh, okay, now I have to work even harder."

The value that participants placed on academic achievement could become problematic when siblings experienced (what they perceived as) failure. Kate recalls a time at secondary school where she received a lower grade than expected, "I got a D once, and I was like, 'Oh my God." Kate still struggled to make sense of this, provided possible reasons for what may have happened and described how parental reassurance was needed to help her overcome it. She later adds that she would like to obtain a first class degree, "...personally I want one, cos I've always been at that level where I've had the top grades, so I feel if I let myself down I feel like I'd let my family down as well...". She therefore continues to have a sense of perfectionism within her work ethic. Similarly, Lucy explained that at secondary school, "if I got a B I was upset. If I didn't get an A it wasn't good enough" and then at university, "...I got 65 on my first bit of coursework, and obviously that's a 2:1, and I was really angry with myself. I was like, 'It's not a first. It's not good enough...". She attributed this to a change in motivation which made her consider leaving university. However, her ongoing discussion suggests her current low self-belief in her own ability to achieve at degree level is influencing these thoughts. This has possibly been triggered by her experience of receiving (what she considers as) lower grades. She views her previous achievement as non-deserving, "...I just memorised the mark schemes and I feel like I cheated my way to getting here. I don't feel like I – I earned my place at university at all", and conceptualises attainment as a skill which she has learnt to manipulate by adopting strategies until a point of potential discovery (in this case, university). She engages in social comparison of her peers' ability ("I don't deserve to be here as much as my friends, who are actually clever") and views being 'clever' as a fixed construct which someone does or does not have. Indeed, use of the labels of gifted, talented or clever appear to have resonated with Lucy, "...they'd go, 'Ah yeah, you're gifted and talented. You're really clever,' and I was like, 'I'm really not,'..."; her disagreement with these appear pivotal in her self-doubt. Consequently, the way participants responded or felt when they did not consistently fulfil their high expectations could present difficulties due to how they conceptualised 'achieving' and the value they placed on this.

2.3.1.2   Subtheme: Thinking of the Future

Participants' drive to achieve and be successful extended to their future plans but this was interlinked with concern for their brother's future. The extent of these worries relates to the subsequent super-ordinate theme 'sense of responsibility'. For instance, Samantha (whose mother has taken on the main care-giving role) explains "I think he'll probably, for the foreseeable future, definitely, at least, stay with my mum; be looked after by my mum then. We're really not sure what he's going to do" and her open discussion of possible future routes relayed a sense of security that this was not a concern. In contrast, Olivia shares "But the future, it's not so much mine, I'm more concerned about his really. Cos I think I'm going to be doing ok. God, *my* future is scary enough" and considered how she could help.

For some participants, 'doing well' was related to their sibling experiences, rather than being driven by their own future aspirations:

> I am aware of the fact that in the future that's going to come down to me (pause) so you kind of think about that for future sort of career prospects and things like that you have to bear that in mind um and so it kind of dictates that fact that you do I do feel like um I *need* to do well and get a good job to support him as well as me… (Robert, line 202)

The way in which Robert expresses this suggests he has no choice (e.g. the word 'dictates' and his emphasis on 'need'). He ultimately strives to do well because he feels he has to. Participants' experiences also influenced their future choices of career. Robert's decision to consider post-graduate medicine is linked to having "…grown up with my brother with lots of his medical visits" and "…just generally having someone that needs caring for…". Similarly, Emma describes a discussion about her boyfriend's career choices; "... my mum said, 'well, encourage him to be a doctor, that'd be great. And I said 'why mum, so he can look after [Brother's Name]?' And she was like 'yeah, exactly'. And I was like 'right, okay'." Emma does not feel comfortable with these comments; she perceives them as hints and mirroring past parental comments to herself to have been a doctor. Interestingly, Emma's own choice of career indicates she is still driven by her experiences:

> I'm motivated to do law and go into the legal profession because my parents have always had trouble with getting social services support and just been to court a couple of times. So I was always, if I become a lawyer then I would have the, sort of the power or the expertise to know where they should, who they should talk to and I'd have like the authority to say 'I'm a solicitor, you need to talk to me'. (Emma, line 86)

Although Emma's decision to become a lawyer reflects a move away from parental expectation, she is driven towards a career where "people know definitely what you are". Indeed, the legal profession provides a sense of power for Emma and a way for her to have her say, and make a difference in her family's situation. Kate appears to be similarly motivated. She describes finding ASC "incredibly fascinating" particularly because "they have no idea what causes it". She is driven by a career in further research where she wants to help find cures for diseases:

> I think if I had the ability to cure my brother, I actually think I wouldn't, because I don't know any differently and I wouldn't want to change him, but I think a lot of people would be like, 'Yeah, try and cure him,' but actually I – I wouldn't, but it would be nice if they did find a cure for something like that, or, um, that kids could have it (Kate, line 942)

It is noteworthy that Kate considers a cure for ASC as this could suggest that her brother's needs and her own experiences may be more challenging than she perhaps verbally communicates; it is as if she is trying to reduce the challenges for others who have similar experiences. In this sense, she is driven to "help more people" and make a difference for the future of others.

2.3.2   Super-ordinate theme: Sense of Responsibility

Participants felt a familial responsibility where they tended to adopt a protector or parenting role to support both their brother and their parents. Some participants subconsciously fulfilled these roles, whilst others expressed an awareness that parents required it. This responsibility transferred across home and school contexts for participants who attended the same school as their sibling. Within participants' home environment, the demands caused by this sense of responsibility could feel never-ending, which impacted on siblings' ability to study. This was perhaps experienced as a particularly challenging aspect due to the importance placed on education by these participants.

2.3.2.1   Sub theme: Protecting from Others

Participants adopted a protector role for their sibling, and often intervened to solve peer difficulties or rescue their siblings in social situations. This included directing their friends and teachers or challenging others when comments were made about their sibling.

Despite being bullied herself throughout secondary school, Olivia spoke about how she intervened at school when "more forthright and maybe a little bit more obnoxious" individuals would try and provoke her brother, "So, I'd be like, 'tone it down please'". This protection had extended to her time at University, where she overcame the geographical distance by maintaining

frequent contact with her brother through "basically, any kind of messaging that we can do". Olivia had helped her boyfriend facilitate a small online gaming group to include her brother, and despite not being involved in the game directly, she monitors peer interactions and intervenes when she feels necessary.

> …[I] had a word with [Friend's Name]and [Friend's Name] fessed up instantly. It kind of, it'd been pointed out to him, like 'you've been told before, to have me point it out again'. He was like 'okay, this time he'll remember'. I'm like 'actually treat [Brother's Name] better', so he did. (Olivia, line 724)

It appears that Olivia actively looks out for individuals who she perceives as a threat to her sibling, and confronts them to rescue her brother from the situation. At school, she took a similar approach with her brother's teachers e.g. "If it was a teacher I knew…so, like, 'can you just, he's got this, can you try and be a little more understanding?'". She describes this as "hard" but appears to also find it affirming; she shares the teacher would "just become impressed that it came from a student, that sort of come to say that".

In contrast, Lucy felt this responsibility placed her in a difficult position; she experienced unkind comments about her brother from her peers and describes difficulties with a particular teacher:

> Lucy: There was one teacher who used to make comments about him to me, and she – she was horrible. And I used to, like, get super defensive over it, like if anyone said anything else bad about him, I would, like, be like, 'No, you can't say that. Only I can say that.' Kind of thing, but there was this one teacher who did, and she was horrible, and she used to, like, say it to annoy me.
>
> Interviewer: Could you give me an example, like just tell me a bit about that?
>
> Lucy: Um, yeah, this was in primary school, it was years ago. Um, it was sort of like if some kid was acting up in my class, she'd be like, 'Oh, that's what your brother was like the other day,' and I'd be like, 'It's a little bit different,' you know.   (Lucy, line 236)

Over time, the incident had remained in mind for Lucy. Despite the feelings of embarrassment from the social openness of the classroom, or frustration for the position of responsibility she felt placed in, she continued to defend her brother in this situation.

For other participants, the protective role extended to challenging negative comments about other individuals who have similar needs to their brothers (e.g. ASC). Robert describes such

comments as "a sore subject" and explains "I would call them out on it" referring to his friends. Similarly, Emma recalls the social reactions to a pupil who attended her school:

…she used to sort of wander round by herself on the playground and people just used to watch her as if she was some sort of animal in the zoo. It was horrible. And people were really making fun of her and I would just say well, you know my brother's autistic so I would appreciate if you don't do that anymore. And they'd be really embarrassed but it wouldn't stop them… (Emma, line 304)

Emma's description of a zoo animal indicates the gap she perceives in the general public's understanding of individuals with additional needs. Her comments also reflect her perception that these individuals are vulnerable, may become trapped and require protection from those willing to stand up for them.

2.3.2.2 Sub theme: Parentification

All participants spoke about the additional demands placed on their parents due to their brother's needs; "My mum was massively taken, so it was taking up the burden of looking after an autistic child and any, sort of, extra demands they have" (Samantha). For some this meant "I've not really had to worry about it" (Samantha). Whereas others tended to naturally adopt a parenting role to support their brother; which also involved being a parent supporter "my mum's like my best friend, like a sister more than anything" (Kate), she later adds "She didn't have to tell me, like, 'Go and look after your brother,' or anything like that. I just – I just do that." (Kate).

There was a sense that parents valued this support, and at times could subconsciously place additional demands or requests on some participants. Olivia shares that " …mum really wanted me to go to [Name of University in home city] so I could stay." Similarly, Emma describes an example from a family holiday.

…mum's like oh, well can you take [Brother's Name] and [Sister's Name] and I was quite young, as well, to the pool. It's 10:00pm at night, I don't know what she was thinking, but they were *just* shutting it and [Brother's Name] got stuck up at the top of the slide, and you just hear like lots of screaming, I think [Sister's Name] was there as well, and oh, it was one of those, it's quite a funny story now I can tell people, but it was, yeah, it's one of those things that's stressful at the time, you can't tell [Brother's Name] 'it's closing now', and it was, I think he'd just took off all his clothes and getting naked and [Name] people trying to catch him on the slide. So just stuff like that, and you know I think it's like 'Emma, *you* take them to the pool'. (Emma, line 325)

Emma describes feeling alone, stressed and embarrassed. Her emphasis on 'you' reflects that she felt uncomfortable and is questioning why this was her responsibility to do. Indeed, parent requests could cause a tension between participants feeling obligated but also needing to put themselves first. For Kate and Lucy, this parenting role had involved putting their own feelings aside, in order to support their brother in times of family difficulty. Kate describes explaining her parent's divorce to her brother, whilst coping with her own feelings:

Yeah, so, um, which is a little bit hard to deal with, cos I was going through my own stuff anyway, but then to deal with my brother's as well, um, that – that was a little bit hard, but again I was just – my – I have to help him cos he doesn't understand what's going on.

(Kate, line 810)

Following her Grandad's death, Lucy shares she was requested to "look out" for her brother at school by her parents, "she was like, 'If you see him, can you go and talk to him?' but it was hard because obviously I was upset and I wanted to be with my friends". She also explains, "I was in Year 11 when he was in Year 9 and you can't really go and talk to a load of Year 9s." The tension caused by this parenting role has reached a level of frustration for Lucy. She describes teachers' awareness of her situation as a "hindrance" and explains:

It was helpful that they knew for him, but for me sort of like then they'd be like, 'Ooh, are you not checking on your brother?' and it would be like, 'It's not my responsibility, it's yours, as the people in charge,' you know, 'I wanna get on with my own life,' but yeah. (Lucy, line 613)

2.3.2.3   Subtheme: 'Stop-Start' Studying

For some participants, responsibilities within the home environment could feel relentless; they described there always being something to do, being 'pulled away' from their own tasks or being interrupted by their brother's challenging behaviour. A particularly challenging aspect of this experience was the impact on their home studying. Emma explains, "home wasn't like a peaceful environment. It *still* isn't, actually. Trying to revise at our house is just total chaos." Interestingly, many participants described their approach to home learning as 'stop-start':

It was just the fact that at um at home because of all of his sort of his needs and taking care of him it meant it was very much stop and start on doing things. So when it came to things like homework and studying that was always, you know I would get a little bit done and then there would be an interruption for some reason um and that would keep happening um, and (pause) you know there would always be, there would always be *something* to be done… (Robert, line 333)

Some participants had accepted or relented to this approach "…I would just do it until it was finished really, like however long it took it didn't really – really bother me, but, um, yeah, it did – it was a bit like stop-start, stop-start." Whilst other participants felt frustrated or stressed from the additional pressure these demands placed on them. Emma often takes her brother for a drive so her mother can complete other family chores, she describes the stress this places on her revision time "[sighs] it's just that 'oh we need you to - can you just take him out in the car now?' 'Okay, all right, well, I need to revise this' and it's all about like the timing issue" whereas she describes essays as "less stressful" because it is easier to fit around family requests. Similarly, Olivia explains "it's more when my mum wants me to give her a hand to like try and wake him up or if she has to go out and do something", she adds "It can be a bit 'stop start next' kind of thing. It's fitting everything in. I need to help but also fit everything in (pause) but yeah I think that's it really". Consequently, participants sense of responsibility in supporting their parents and brothers could result in additional pressure and stress to manage their demands across contexts.

2.3.3   Super-ordinate theme: Self-Management

Participants had self-managed their experiences this far. They had learnt a self-reliant approach (which some participants described as independent) where they had quickly learnt to get on with things themselves. During challenging times, this has led to them finding their own ways to cope, with many using physical separation as a way to provide emotional space. Participants also discussed friends and possible sources of social support, although the majority of participants did not tend to draw on this as a resource.

2.3.3.1   Subtheme: Self-Reliance

Participants felt their sibling experiences had made them independent individuals. Kate explains "I think it made me grow up quicker, but actually I'm quite happy about that…It's made me a lot more independent, I think, a lot earlier, and that's really actually quite beneficial for me." However, this appeared more than independence; there was a sense that participants had learnt to be self-reliant as a way of managing their experiences, e.g. "I had to do my own thing look after myself and stuff because they [his parents] had to (pause) sort of focus on my brother" (Robert). This self-reliance was particularly evident in participants' approach to education. Many participants voiced that their parents were unable to help with their home learning. Kate shares, "I didn't really have my mum to do that for me, like to help me." She talks about her mother trying her "hardest but sometimes she'd have to, like, 'I've just got to go and sort your brother out,' and I'd be like, 'Okay, that's fine. I'll try it by myself anyway." Similarly, Robert describes education as "something *I* had to deal with urmm by myself", and this continued throughout his educational journey. He

shares, "…by the time er you know I was in sixth form and then getting on to Uni I was just used to the fact that I was sorting out my own learning and things" which included his further education choices, "…I was at boarding school soo I think my parents just got a phone call and was like 'oh and by the way I'm going off to University to do this'".

A self-reliant approach was reinforced by participants' awareness of their parents' demands, and not wanting to burden them with additional stress. This could become problematic for some participants, where there was a tendency to rely on themselves (rather than seek parental support) which could lead to a point of crisis:

> I think I've always put too much pressure on myself to work hard and then [Brother's Name] got diagnosed with depression and not going to school and stuff and then you just get frustrated with that and it was very difficult because he wasn't always understanding the full emotional implications of it on him or anyone else. But, you kind of feel like, aw, mum and dad are having a hard time sometimes dealing with him, so if I work really really hard, that's something else they've haven't got to worry about. So I worked too hard - I made myself pass out on my desk, I just went too hard. (Olivia, line 306)

2.3.3.2   Subtheme: Emotional Coping through Physical Space

A particularly challenging aspect of participants' experiences were their brothers' behaviours, which were seen to worsen with age and peak at adolescence; participants referred to secondary school being a difficult period. For some participants, it was the inflexibility or "rigidity" (Robert) of their brother's behaviour that was difficult, for others it was the "meltdowns" (Samantha), "anger" (Lucy), "tantrums" (Olivia), "hair-pulling and name-calling" (Kate), which were often seen as "unpredictable" (Emma) or "volatile" (Samantha).

The accumulation of this behaviour could lead to an emotional impact on siblings. Robert shares, "it just kind of wears on you after a while", he later explains, "You know you're trying to get studying done and you're just *tense* and *annoyed* and *tired*"**.** The confrontation and noise experienced during episodes of challenging behaviour provided raw memories for participants. Olivia shares "…there would be like shouting and slamming doors. So, there would kind of be that, and that would make me just want to kind of hide away in a small corner and not listen to anyone". She later explains that the stress accumulates "it's already stressful that people are getting angry and then the added stress that I can't do my work". Lucy describes the "constant yelling" and there is a sense of her feeling powerless, "I'd just be sitting there like, 'Everyone just stop,' and I couldn't do anything". Indeed, Samantha summarises a difficult incident as "I can't

remember where we were going, or what we were doing, but, I know he, he [her brother] wasn't calm when we left".

Participants tried to find their own ways to cope with these feelings and emotions. Most participants explained they needed to physically remove themselves from the situation in order to provide some emotional space. Olivia describes 'hiding away' in her room whilst Samantha implies that the school context provided this separation "when I was at school it was, when I'm at school I can leave that stuff at home and just get on with learning". Similarly, Robert describes boarding school as a place where "I could just get focused on me for a while", he explains that this provided some space and "it was quite nice to just to be *completely* my own person and sort of not have it affect me I guess for a few months".

Indeed, university appeared to provide a route for temporary separation which many participants took advantage of. Olivia explains that she chose a University that was "far enough away to definitely have enough breathing room, otherwise I would want to get like too involved". Robert shares that he decided to "get away from it for a while so that meant when I was applying to university…I applied everywhere in the north and south and nowhere in about three, three hours of home". Lucy describes university providing a route for change:

> Um, I think maybe the – I decided that going to university might have had a slight influence, just because I needed to get out, and it was like, um, 'If I stay here, I'm just gonna stay here and it's gonna be the same forever.' So that kind of like made me leave a little bit. (Lucy, line 919)

2.3.3.3   Subtheme: Sources of Social Support

Participants did not actively seek support for their experiences whilst growing up, but reflected on the importance of connections with key individuals.

Most participants described having a small amount of trusting friendships. However, Emma, Olivia and Samantha had also experienced some bullying, and Lucy and Kate recalled having few friends during their childhood. Participants explained it was difficult to have friends home due to their brother's needs or to celebrate events e.g. "it is a little bit sad that you can't spend the time with him and your friends at the same time" (Kate). Emma describes how she had spent a lot of time with her best friend's family instead, "…most of my childhood memories are at her house or at my other friend's house". Later Emma reflects, "…maybe if I hadn't had my friend that then it would've been a bit of a sad childhood". Olivia felt that she could talk to her friends about her experiences but "it's just like you talk to them about it and you feel like they're there but they can't really do anything". She shares there was a difficult period of time during secondary school

where she "shut down" and "stopped talking to people", but describes a reluctance to seek parent support, "I could go to them for emotional or academic support but I wouldn't really. They had other stuff to deal with." In contrast, Samantha and Emma value having another sibling, because "you always have a friend there" (Emma).

Although participants initially felt they did not need support, there were some contradictions in their discussions which suggested otherwise. Kate's reluctance to seek support appeared to be associated with not wanting to be seen as different; she describes rejecting teachers support when they offered allowances, "I don't want it. I'm no different. I'll do it in the same time as everyone else," and explains, "and I just – I don't like people – like – do you know what I mean? You're like, 'Just leave me to do it by myself, I'm alright.'". Yet when later discussing what is needed to help others with similar experiences, Kate shares, "I think support is a big one, especially when you're younger and you don't understand". Other participants appeared to be unsure about what any support would look like, "I think something could have helped me but I don't know what it would have been" (Lucy) or "…to be honest I'm not sure what they would actually be able to do for support" (Robert). Since starting university, both Robert and Kate had become best friends with individuals who had siblings with similar needs to their brothers:

> We just, like, bonded over that straight away. And you can just talk to her about anything. It's quite…yeah… and it just meant that we could – she understood sometimes how I felt, um, and I understood as well about her. (Kate, line 411)

This shared understanding appears to provide a support mechanism through open discussion and exchanging of experiences.

2.3.4   Super-ordinate theme: Voice

Sibling voice was poignant throughout the six interviews. Each sibling had their own story to tell and perhaps their own motivation for volunteering to participate in the research. For example, Robert spent time after the interview explaining the unfairness of the education system for individuals with additional needs, whereas Kate wanted to speak out and challenge the negative assumptions she felt were frequently made about siblings. Despite these differences, all of the participants appeared passionate about providing a sibling perspective and reflected on this being the first opportunity they had been given to openly discuss their experiences or consider the wider context. Indeed, there was a sense that these siblings wanted to be heard and acknowledged, but that they also typically perceived a risk in voicing their experiences.

2.3.4.1   Subtheme: Acknowledgement

There appeared to be some tension for participants between wanting to be heard but not feeling as though they should be recognised for their experiences. Samantha explains, "its not really about me. Because it's (pause) I'm not my brother". She tends to over-exaggerate as she continues; she laughs about hiding a secret which teachers should be sought out to recognise. This exaggeration could reflect she feels the idea is ridiculous or could be masking her own acceptance that on occasions her experiences can be difficult.

In contrast, Emma describes feeling a lack of recognition from others for her own needs due to being overlooked by her brother's wider difficulties.

> I remember having an argument with my mum during my A level exams and she said well, 'it's not important, I mean, [Brother's Name] can never take them so I don't know why you're stressing' and she just sort of like really downplayed my biggest exams of my life and I was like it really upset me. So yeah, things like that I think is, er well it puts things into perspective. So maybe the (pause) the attention is shifted towards my brother a lot, which is understandable, because he needs the most attention but in times of crisis, he's not an idiot, and he's got a 'no, you can do it you'll be fine', whereas instead of saying 'no, actually it doesn't really matter, your brother can never take them', so sort of *dismissed* which I don't really understand why it was dismissed... (Emma, line 145)

It is as though this was a turning point for Emma in considering a lack of value to her views or own needs. Emma explains that since this moment, she has not voiced her worries about education or her home experiences with her parents or teachers, suggesting this became ingrained in her right to voice her experiences. Interestingly, Emma appears to have found alternative ways to express herself, for example, she discusses writing school essays where she incorporated examples from her home life and considered doing her dissertation in the same topic. This was also found with other participants (e.g. Kate).

Lucy discusses a need for siblings of children with disabilities to be acknowledged in the wider context:

> I remember this one time where, like, they first, like, um, went to this thing all about it, and they came out with all these booklets on, like, siblings, and I was like, 'Okay, I'll read through them,' and I always remember being disappointed because it was just about siblings and their likelihood of having it as well. I remember at that point I really wanted to know what help there would be for me as one without it for that, and I just read through all these books and there wasn't anything, and I kind of got annoyed at that. (Lucy, line 737)

She later adds:

Lucy: …no one ever thinks about anyone else, like around them, like people think of the parents, 'Oh, it must be so hard to have a kid with autism,' um, but no one goes, 'Oh, it must be hard to have a brother or a sister with it,' so yeah.

Interviewer: So what do you think may be helpful for that?

Lucy: I don't really know. Um, it's gonna sound kind of weird, but you know like they have those documentaries to see how people, like, cope with things. Something like that. Like maybe. Just like following a life of the other one, and, like, with several different people just to see how they have it as well.   (Lucy, line 1055)

Lucy is voicing a lack of acknowledgment for her experiences but also for the sibling voice more widely. By choosing a documentary as a possible helpful method, it is as though she wishes to expose the truth by providing an opportunity for others to see all. It appears this is on behalf of herself and others in similar situations but is in contrast to Samantha who jokes about the idea of a hidden secret.

2.3.4.2   Subtheme: Barriers to Sharing

Participants spoke about the responses of others and the feelings of vulnerability after voicing their experiences to others. This was often attributed to a perceived lack of understanding from others who had not lived the same experiences, and could prevent them from sharing their experiences more widely beyond the home environment. Indeed, separating the home and school contexts through closed communication prevented participants having to deal with this. Olivia describes her feelings when sharing her experience with a teacher:

Umm, kinda weird, cos like you can't make eye contact with them to start with, you're like looking over here talking to them. Just sort of looking at a right angle from them. But you, don't know, it feels, it's upsetting, it's upsetting enough to talk about it at home but to talk about it with someone else it kinda feels a bit worse cos it's like you kinda have to go over everything cos at home there's a shared knowledge, you all know what's happened. So that was quite strange and you feel a bit vulnerable as well cos its like I had been keeping it separately but then I wasn't keeping it separately now. So yeah, that was a bit (pause)
                                                                  (Olivia, line 1042)

Olivia describes feeling vulnerable, and exposed by revealing this part of her life. For her, it is private and it appears that she had actively been keeping the school and home contexts

separate. Having a shared knowledge, appears an important factor, and suggests that to truly understand what it is like, you have to have been through it.

Robert expresses concern about others perceptions of him. He worries that he will appear ridiculous to his friends and predicts the magnitude of the problem is likely to be minimised by them even though it is serious:

> …it was also something you don't (pause) you don't really bother talking to your friends about it because for *you* it's an everyday thing and if you did I don't think they could really understand it. It's all these things that seem really *trivial* and you know how much of a problem they can be, not because they're a problem for you and you understand how *ridiculous* it is but you know that's just not going to change like even, like you know telling someone [Brother's Name] can't have such and such because it's not the right sort of cheese sounds like a *ridiculous* thing to say, but we know that is *genuinely* going to be a problem.
>
> (Robert, line 566)

Similarly, Kate describes feeling guilty after talking about her experiences at university with her peers:

> I think it's because people don't actually know the extreme that it can get to, like the pulling the hair, the scratching ... and I felt a bit bad talking about it in the end because it just – it made people a little bit uncomfortable… (Kate, line 859)

Some participants felt that others lack of understanding was due to misconceptions influenced by stereotypes or a biased media portrayal of higher functioning individuals with autism.

> I don't think I would've told people that [about her experiences], unless they were being particularly ignorant about autism in general and I just wanted to shock them [laughs]. That's what I'd usually do, I'd be like 'well, this story', I'd tell a story, then they're like 'right, okay, that's what it is to be, to have an autistic sibling', not 'you take them to a casino and they can remember every card'. (Emma, line 534)

Emma was able to overcome any barriers in communicating her experiences when she was challenging the misconceptions of others. Here, it is interesting that Emma admits to wanting to shock, which suggests that she perceives her reality as shocking to others. This in turn, may be a reason for Emma not regularly sharing her experiences.

2.3.5   Super-ordinate theme: Acceptance

Participants' discussions reflected an ongoing acceptance of having a brother with ASC, which differed in degree across individuals. Their acceptance was linked with conceptualising their experiences as their normality, as well as how participants made sense of, and understood, their brother's condition (ASC).

2.3.5.1   Subtheme: 'My Normality'

Participants described their experiences as their 'normality', acknowledging that although they were likely to be different from others' experiences, it was their norm. Emma shares that it is different for her compared to her mother who had previously experienced a "perfectly normal family and then she can't, well, we don't have that, so I can't really say 'I wish I'd done this, I wish I'd done that', I can't really compare, I don't know any different". Similarly, Kate explains "I'd say most kids haven't had to do that, but for me it's just normal, like so it's not like that bad", and later reflects, "I think it makes you closer, um, because it is – it isn't what people call the norm, really, is it?". Interestingly, Samantha tends to use social comparison to normalise her own experiences; she describes how she explains her brother's challenging behaviour to others, "I don't know, if you go over to anyone's house and their little brother is having a temper tantrum, it's, it's what little brothers' do; it's happening all over the world." Samantha describes she needs an "ulterior version of myself that's going, like, a brother without autism to be able to sort of, to really compare" because for her, her experiences are normal.

Within these discussions, there was a sense of ambivalence. Participants openly discussed the positive aspects of their experiences; they reflected on the closeness of their sibling relationship (Olivia), described shared sibling moments (Kate) and felt they had developed on a personal level through their experiences, e.g. increased tolerance (Samantha), empathy (Emma) and patience (Robert). However, participants also grappled with the challenging aspects, particularly the inequity of parental time and attention. Robert shares, "You can never have any one on one time with your parents or anyone because he always has to be there" and describes how "everyone has to focus on around what works best for [Brother's Name]". He explains that it is difficult to understand, particularly when younger, that your sibling needs "…more sort of attention and they need more time with your parents to sort things out um it can mean that you kind of feel like you're playing second fiddle a lot of the time um (pause)". Indeed, Robert has decided not to have children partly due to the difficulty balancing this focus of attention. Other participants also noted this inequity, but their acceptance of this varied. Lucy shares, "I didn't have my own space, and it was okay for him because he had his bedroom and they built him a den in the loft which he had, and he had my bedroom with my computer". In contrast,

Samantha explains her mother was "very aware of the fact that my sister and I may have been side-lined a little bit, which I've, I've been fine with; I've just accepted."

Consequently, this normality could sometimes disguise the challenges that participants faced. Olivia explains that when individuals are younger "You don't know much different. Like your sibling has always acted like this" therefore "you don't know exactly what has affected you until later when you sit down and analyse it." She states "it's not a good thing or a bad thing, that's just, that's their sibling". Due to this, Olivia emphasises that those surrounding siblings of children with ASC need to have an increased awareness, "You need to be aware of it and *you* might be able to see an effect on them but they can't always see the effect themselves, cos they're just living with how everything is for them".

2.3.5.2 Subtheme: Making Sense of ASC

Participants' understanding of the brother's condition varied between participants, and how they made sense of this was reflected in the way they spoke about their experiences. Participants demonstrated an awareness that challenges associated with their brother's conditions (e.g. aggression, behaviour outbursts, needing a routine) was not their brother's fault. For some participants, there was a level of frustration in their responses that suggested this was still hard to accept at times:

> You know it will be the equivalent of having like mature cheddar over normal cheddar or something and it will just set him off and for the rest of the day he will be in a bad mood and it would make um it would mean that for the rest of the day he will be stubborn and uncooperative and just make everyone's lives *a lot more* difficult… (Robert, line 495)

Robert's frustration with his brother's routines is mirrored in the way he speaks about his experiences; stubborn and co-operative are words loaded with negative connotations, and his own emphasis on the words (in italics) express feelings that this experience is relentless for him. Robert later acknowledges that he "can't get annoyed" with his brother; the way he makes sense of his brother's needs is with an emotion that he feels he should not be allowed to express.

Participants had made sense of ASC based on their own personal experiences with their brother. Consequently, their construct of the condition was dependent on the severity of ASC, how it presented, as well as the characteristics of their sibling:

> I wouldn't see it as a disability at all because he, he has an incredible memory. Like they were reading a book at school, in the class, and a new boy joined, sort of, half way through the term. And he was, sort of, like, what have we, what have we read in this book so far because they

can, sort of, start from the beginning, but they didn't want this boy to be thrown in half way

through the class reading a book. And [Brother's Name] was able to go through it chapter by

chapter, what had happened so far in incredible detail, having just read it once like the rest of

the class. (Samantha, line 754)

Although Samantha and Olivia described their brother's diagnosis as a sense making

moment, there was a consensus among participants that they would have liked further teaching

about the condition and what it meant. Indeed, some participants were still trying to understand it.

Lucy shares "I don't, like, quite understand why he can't do everything everyone else – I mean, I

know why, but it's also like – it's frustrating cos – yeah. It's just cos he's high-functioning, it's like

you can't tell straight away". It appears the invisibility of the condition is particularly challenging for

Lucy to comprehend.

Participants tended to use and extend this understanding through recognising similar needs

in other individuals. They reflected on an increased awareness of tolerance; recognising when

someone was different and accommodating for this. For example, Lucy reflects that she has

purposively included friends in her social group at university who others thought were "weird"

and Samantha explains how her experiences encouraged her to volunteer at a disabled swimming

club. She reflects "I don't know if I'd have done that otherwise".

2.4   Discussion

The present study aimed to explore how typically developing, young adult siblings made

sense of their experience growing up with a brother diagnosed with ASC, and how this interacted

with their education. IPA was used to provide an in depth exploration of participants lived

experiences and perceptions of their education. Five super-ordinate themes were identified.

Participants 'Strived to Do Well', attributing some personal value to achievement by fulfilling their

own and other's expectations through academic and future success. They felt a 'Sense of

Responsibility' which resulted in adopting roles to protect their sibling from others or support

their parents with additional demands. This increased responsibility could at times feel relentless,

particularly when participants tried to study at home. Participants engaged in 'Self-Management'

to adapt to their experiences; they learnt self-reliance, adopted physical separation as an

emotional coping strategy and identified sources of social support (but did not tend to use this).

Although it is acknowledged participants' experiences were idiosyncratic, their sibling 'Voice' was

distinctive. There was tension between being acknowledged and the perceived barriers to sharing

their experiences. Overall, participants portrayed an ongoing 'Acceptance' of their circumstances;

they described their experiences as their normality, and this was linked to how they conceptualised or understood their brother's condition (ASC).

The study identified findings that were in line with previous research. Participants considered some positive shared learning experiences and personal development (Petalas et al., 2012a), but also reflected on the challenges of their sibling experience, such as their brother's challenging behaviour (Mascha & Boucher, 2006), perceived differential parent attention (Stampoltzis et al., 2014) and lack of understanding from the general public (Petalas et al., 2009). Previous studies have recruited child or adolescent TD siblings and, therefore, the present study suggests these themes extend to the young adult age. The study also extends previous qualitative findings by considering a deeper understanding to previous research conclusions. For example, Angell et al. (2012), reported that TD-Siblings worked towards academic success, had a heightened sense of responsibility and adopted a multitude of roles within the family. The present study could suggest that participants place high expectations on themselves to achieve and that this may be linked to the role they see for themselves within their family (e.g. achiever or future care-giver). This could have implications for TD-Siblings' approach to learning in school, their response to experiencing academic feedback and their academic self-concept and their belief in their own ability to achieve (self-efficacy theory; Bandura, 1977).

The finding that participants had a sense of responsibility and adopted a protective role towards their sibling is in line with the research in older adult TD-Sibs. Atkin and Tozer (2014) reported that siblings (aged between 25 to 67 years old) experienced a need to protect their brother or sister with ASC, and, this was seen as an obligated connectedness and adult commitment. Similar to the current study, the authors also found a sense of ambivalence emerged as family relationships changed over time; adult TD siblings accepted a caring role for their brother or sister, but also realised how these responsibilities impacted on their lives. Siblings future aspirations, education and career could be an area requiring further attention.

Participants' emotional responses to aspects of their experiences, their 'stop-start' environment and their need for physical separation, corroborates previous findings regarding siblings expressed emotions (Petalas et al., 2009) and coping strategies (Angell et al., 2012; Ross & Cuskelly, 2006). The emotions which TD-Siblings experience has received little research attention despite the potential future implications for these individuals when such emotional issues are not resolved. Atkin and Tozer (2014) reported that around half of the adult participants they recruited (N=21) had sought counselling as a way of making sense of their past family experiences (which they identified as 'chaotic' or a 'struggle'). The siblings described feelings of recurring anger, low self-esteem or a sense of depression, which could sometimes be triggered by an event (e.g. job

loss), and "caused them to dwell on the past, as a way of explaining the present" (Atkin & Tozer, 2014, p. 231). The ways in which TD-Sibs cope or manage their experiences remains largely unexplored (Ross & Cuskelly, 2006). However, the young adult participants within the current study appeared to have adopted strategies which were not always sustainable (e.g. physical removal) and therefore may not best support their ongoing emotional well-being. Participants were self-reliant perhaps as a way of 'getting on' with things themselves. This seemed to be associated with differential parent attention or not wanting to burden their parents. They were also unlikely to seek (or acknowledge) social support, particularly during secondary school age and older, which contradicts suggestions from previous studies highlighted in the systematic review (Wolf et al., 1998). The balance between when self-reliance could be considered problematic compared to a positive mastered skill is beyond the scope of this discussion. However, the implications this has for providing support to TD-Sibs (i.e. when to intervene and when this may be needed or welcomed) is important to consider and worthy of further research attention.

Previous studies have found TD-Siblings to be socially competent (Kaminsky & Dewey, 2002) but reported feelings of social isolation, rejection and a need for open communication between family and peers (Petalas et al., 2009). In line with previous research, TD-Sibs perceived barriers to sharing their experiences. When peers attended the same school as their ASC-Sib, participants engaged in a number of challenging social exchanges with peers and teachers. This is a novel finding and requires much further consideration. The finding that three out of six of the participants had experienced bullying at school, and all described having few (or a small close circle) of friends is notable and could suggest some social vulnerability for TD-Sibs.

Despite the dominant focus on TD-Sibs externalising behaviour difficulties in the existing TD-Sib literature, participants did not reflect on their own behaviour or share any challenges they had experienced. Instead, and somewhat surprisingly, participants' discussions tended to reflect the intense or perhaps hidden struggles of the TD-Sibs experience, which is in contrast to positive aspects highlighted in previous research with younger TD-Sibs (Petalas et al., 2009; Petalas et al., 2012a). This could be related to the transition from adolescence to adulthood (e.g. leaving home, attending university and wider opportunities) giving further perspective. This also could possibly be due to a cumulative effect over time. This contradiction or difference indicates a need for further research within the adolescent population as well as developmental and longitudinal studies from the early years into adulthood.

2.4.1   Research Strengths

This study gave voice to a TD-Sibs age group that is currently not represented in the research base. The use of an IPA approach enabled the researcher to explore participants' experiences across contexts, identify key themes and consider her own influences and biases through reflexive practice. The study provided an effective and often poignant narrative related to growing up with a brother or sister with ASC. The focus on the educational context, added to the dearth of studies in this area and highlighted avenues for further research.

2.4.2   Research Limitations

There are a number of limitations that should be considered for this study. The findings relate to six participants, who received monetary compensation for their participation. Paid research incentives raise issues of both ethics and bias, which were addressed through supervisory discussion, ethical approval and the planned recruitment process. However as only six participants expressed interest following recruitment, it is acknowledged there could be bias in participant motivation or the verbal responses they chose to give in interviews.
Although the sample size was within the recommended guidelines for IPA (Smith & Osborn, 2007), and generalisation is not an aim of IPA, the sample is limited in representativeness. All participants were university students broadly from the same geographical area and may have been students who value education; therefore, this may not represent the wider population of TD-Sibs as a whole. A particular weakness of the study was the lack of detailed demographic recording of participant information. For example, ethnicity of the participants was not collected and although the interviewer met with all participants, it would not be appropriate to make the assumption that participants would all define themselves as 'White British' simply from appearance. The homogeneity of the sample may also be limited by participant (mostly female and older siblings) and ASC-Sibs characteristics, such as severity of diagnosis, ASC co-morbidity with other conditions and all being male. It is also acknowledged that due to the idiosyncrasy of family experiences when there is a child with additional needs in the family, the grouping of individuals with one diagnosis is not only contentious but may also not be needed.

The interview schedule had a focus on education but the design and style of the interview enabled participants to reflect more widely upon their experiences across contexts. Nevertheless, these questions may have limited participants' responses and missed potential unseen aspects not considered within the interview. On reflection, despite revision after the pilot interview, the wording of some of the questions may have suggested directionality e.g. 'impact'.

2.4.3   Reflexivity

In 'real world research', Robson (2002) states that "the experience and understanding we bring to research, and which we develop during it, are an important ingredient to the research" (p. xi). Throughout this process, from proposal to reporting, I have had a heightened awareness of both my personal experience but also my professional role, and the potential influence this could have on the research. This self-awareness was important in interviews to ensure exploration rather than confirmation of any personal beliefs but also through the journey of analysis. I continually returned to the data, and adopted different approaches (e.g. post-it notes, colour coding) to revisit the data in efforts to ensure the individuals spoke for themselves. Self-awareness was also facilitated through self-reflection, bracketing my emotional reactions and using supervisory discussions throughout key stages to limit potential bias. Although I endeavoured to limit my influence, IPA recognises that there could be different data interpretation from another researcher with different experiences that can unintentionally shape analysis (Creswell, 2007). Consequently, my own experiences cannot be completely 'removed' from the research process but are acknowledged and transparent.

I regard myself as an ethical practitioner and particularly grappled with the assumptions made in previous research that tend to conceptualise having an individual with ASC in the family as a 'risk factor' for family members own development. I want to acknowledge that although these particular findings have tended to highlight some of the struggles of the sibling experience; the purpose is to consider how these experiences could be supported or helped, not judge or apportion a non-existent blame. Diagnosis does not define an individual, and therefore I am aware there are other voices missing when considering a family's context. Indeed, I was driven to tell individual participants stories but felt somewhat restricted by the final development of broader themes due to the wealth of information provided by the six individuals. In terms of further reflexivity, I feel it would have been helpful to have received feedback from a participant to consider their perspectives on the findings, as well as the family members, including their brother or sister with ASC.

2.4.4   Directions for Future Research

The current research (and accompanying systematic review in chapter 1) has taken a broad approach to consider the holistic experience for TD-Sibs. This has suggested there are reasons to further investigate their education and could start with focusing on TD-Sibs who are still in school, which would enable earlier intervention (if needed). It would be beneficial for research to take a narrower focus to explore one aspect in further detail. Future avenues to explore are: the social

experiences of TD-Sibs, and investigating how this differs when siblings attend the same school compared to different schools; investigating the emotional coping and management strategies adopted by TD-Sibs; exploring the relationship between self-reliance and support seeking; and finally further investigating into TD-Sibs perceived support needs. It would also be beneficial for future studies to consider a longitudinal design, to provide a developmental perspective over time.

2.4.5   Practical Implications

Educational psychologists (EPs) can be defined as "scientist-practitioners who utilise for the benefit of children and young people psychological skills, knowledge and understanding through the functions of consultation, assessment, intervention, research and training at organisational, group or individual levels" (Fallon, Woods, & Rooney, 2010, p. 4). EPs meet with the Head Teacher and Special Needs Co-ordinator (SENCo) to negotiate and contract the type of EP work carried out in a specific school. Through discussion and prioritising work across different levels (individual, group and organisational), EPs help support staff to provide an inclusive environment that meets the wide ranging needs of children and young people (Fredrickson & Miller, 2008). As part of inclusive and ethical practice, schools identify, monitor and track vulnerable groups of pupils (who may be 'under the radar') to ensure all pupils are able to access the same opportunities, and consider whether additional support is needed. The findings from this research suggests that TD-Sibs should be acknowledged as a potentially vulnerable group. EPs are committed to evidence based practice and would be well placed to communicate these research findings with schools to encourage preventative thinking around TD-Sibs. A way of doing this would be for EPs to develop an evidence-based checklist to use appropriately with schools and TD-Sibs. This would need to be developed sensitively and be considered in collaboration with the parent views, however it would support early intervention if necessary. A checklist could: a) identify and acknowledge these siblings; b) provide a 'check-in' of the key areas identified by research, incorporating both the positive and potentially challenging aspects; c) open the channels of communication directly with siblings, in a non-threatening manner and d) Consider and elicit the TD-Sibs views about whether they want or need support, and in which areas so that this can be tailored for that individual.

Discussion raised by implementation of this checklist could lead to further implications for EP practice across different levels. On an individual case work level, staff and parent discussion using consultation models that adopt solution-focused thinking, systemic practice and problem-solving (e.g. Kennedy, Fredrickson & Monsen, 2008, Nolan & Moreland, 2014) can be used to encourage an interactionist perspective. This would ensure possibilities for change in the school context are considered, TD-Sibs' agency is acknowledged and the complexity of TD-Sibs lives are

recognised, rather than a within-child focus (Roffey, Williams, Greig & Mackay, 2016). In school, Emotional Literacy Support Assistants (ELSAs) are able to support children to understand and manage their feelings in situations. ELSAs are Teaching Assistants (TAs) that have been trained and are regularly supervised by EPs to deliver interventions focusing on emotional literacy (see Burton, 2008 for further information on the ELSA role). The finding from the current study that TD-Sibs experience a tension between being acknowledged and perceived challenges to sharing their experiences suggest that ELSAs would be well placed to work with TD-Sibs and enable their voices to be heard. Indeed, through this intervention, TD-Sibs would be able to explore and understand their feelings, learn management strategies, reframe situations and be provided with an outlet to share and explore their problems or worries through building a therapeutic relationship (Hills, 2016). This would also support the finding from the current study that TD-Sibs may need support to develop sustainable strategies to manage their feelings and emotions in relation to some of their experiences. In line with this, EPs can incorporate research on TD-Sibs in their ELSA training course (in the ASC training session) and can further support ELSAs through their required termly supervision (Burton, 2008).

On a group level, EPs can support schools in fostering pupils sense of belonging and connectedness with others through helping TAs to facilitate friendship group approaches such as Circle of Friends (e.g. Newton, Taylor & Wilson, 1996). It may be that TD-Sibs would benefit from such groups if they report feelings of isolation or feeling different to their peers. Alternatively, when supporting schools to implement group approaches for students with ASC (such as 'Lego therapy groups' which supports social interactions, see Andras, 2012), EPs could consider involving TD-Sibs or sharing these approaches at home to support TD-Sibs' understanding of ASC and the relationships with their sibling.

On a wider systemic level, the finding that TD-Sibs strive to achieve well has implications for whole school approaches. EPs can support teachers to adopt whole class approaches that encourage growth mindset and learning through mistakes based on the work of Dweck (1999). For TD-Sibs, this will be particularly important to ensure they attribute personal values to their strengths and effort rather than achievement of academic performance goals (Dweck, 2006). Additionally, the skills learnt by TD-Sibs through their experiences such as self-reliance, a recognition of others with additional needs, or helping and wanting to make a difference, could be broadened and built on through providing whole school opportunities such as peer mentoring or peer learning. These approaches have been found to benefit the helpers (TD-Sibs) as much as those being helped (Topping, 2005). EPs may be involved in whole school staff training, supporting others to understand more about ASC and challenging misconceptions to promote good practice in schools. The voice of TD-sibs would be a helpful addition to such training, which

can acknowledge the role of the family whilst also increasing awareness of the potential sense of responsibility TD-Sibs may feel, particularly if attending the same school (as found in this study). Staff may then consider this in their interactions with TD-Sibs which could reduce TD-Sibs need to fulfil a protector role (when attending the same school). TD-Sibs could also be provided with opportunities to access homework clubs or be offered alternative places to study after school, rather than worrying about trying to manage homework in a potentially busy home environment.

Finally, as an applied psychology profession working across the domains of home, school and the community, EPs are well placed to conduct further research in this area. Indeed, EPs could develop a TD-Sibs interest group to encourage discussion, consider further research and inform practice. EPs could then support schools to build on the research evidence, develop understanding and provide appropriate opportunities for TD-Sibs within the school environment. Dissemination of research across the domains in which EPs work, and with parents would help inform and heighten awareness. Sharing it with other TD-Sibs may help TD-Sibs exchange experiences and recognise they are not alone.

2.4.6   Concluding Comments

This research represents an in-depth exploration of the lived experiences and perceptions of education for young adult siblings who have grown up with a brother with ASC. Through sharing their voices and emotive experiences, it is hoped to raise awareness, lead to positive changes in practice and inspire future research into a needed area.

Appendices

Appendix A   **Systematic Reviews Quality Assessment**

Systematic Review Paper	Addressing clearly focused question?	Appropriate types of papers?	Relevant and replicable search?	Quality of papers assessed?	Reasonable combination of results?	Main results clear?	Precise Results?	Applies to population & setting?	Appropriate outcomes considered	Beneficial implications for review	Total rating
Mandleco & Webb, 2016	Yes	Yes	Yes	Yes	Yes	Yes	No	No (DS, Pediatric Nursing)	Can't tell	No	6
Green, 2013	Yes	Yes	Yes	No	Yes	Yes	No	Yes (but neurology)	Can't tell	Some	6
Meadan Stoner & Angell, 2010	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes (but Special Education)	Yes	Yes	10
Smith & Elder, 2010	No	Can't tell	No	No	Yes	Yes	Yes	Yes (but Psychiatric nursing)	Can't tell	No	4

Appendix B   **Search Terms**

1) PsycInfo via EBSCO

Brother* OR sister* OR sibling* OR Sibling relations

AND

Autism Spectrum Disorders OR autis* OR asperger's syndrome OR pervasive developmental disorders

AND

Impact OR experience OR Academic Achievement OR School adjustment OR learning OR Well being

Limiters applied: Peer Reviewed Journal Articles, English Language and Exclude dissertations

2) Web of Science

Brother* OR sister* OR sibling* OR Sibling relations

AND

Autism Spectrum Disorders OR autis* OR asperger's syndrome OR pervasive developmental disorders

AND

Experience OR school impact or wellbeing or psychological adjustment OR outcomes

Limiters applied: English Language, Journal Articles.

Irrelevant categories were also excluded = *GENETICS HEREDITY; REHABILITATION; HEALTH CARE SERVICES; PUBLIC ENVIRONMENTAL OCCUPATIONAL HEALTH; MATHEMATICS; RESEARCH EXPERIMENTAL MEDICINE; REPRODUCTIVE BIOLOGY; AUDIOLOGY SPEECH LANGUAGE PATHOLOGY; ENDOCRINOLOGY METABOLISM; GENERAL INTERNAL MEDICINE; PATHOLOGY; BIOCHEMISTRY MOLECULAR BIOLOGY; SCIENCE TECHNOLOGY OTHER TOPICS; OBSTRETRICS GYNECOLOGY; DEMOGRAPHY; LINGUISTICS; TOXICOLOGY; PHARMACOLOGY PHARMACY; GERIATRICS GERONTOLOGY; MATHEMATICAL COMPUTATIONAL BIOLOGY; IMMUNOLOGY; ONCOLOGY; UROLOGY; RESPITATORY SYSTEM; RADIOLOGY; MEDICAL LABORATORY TECHNOLOGY; SURGERY; PHILOSOPHY; OPTHALMOLOGY; NUTRITION DIETETICS; INFORMATION SCIENCE LIBRARY SCIENCE; ENVIRONMENTAL SCIENCES ECOLOGY; CARDIOVASCULAR SYSTEM CARDIOLOGY; ANATOMY MORPHOLOGY; PHYSIOLOGY; IMAGING SCIENCE PHOTOGRAPHIC TECHNOLOGY; HEMATOLOGY; GASTROENTEROLOGY HEPATOLOGY; DERMATOLOGY; DENTISTRY; CELL BIOLOGY; BUSINESS ECONOMICS; ROBOTICS; RELIGION; GEOGRAPHY; FOOD SCIENCE TECHNOLOGY; CULTURAL STUDIES; BIOTECHNOLOGY APPLIED MICROBIOLOGY; BIOMEDICAL SOCIAL SCIENCES; AUTOMATION CONTOL SYSTEMS; ANTROPOLOGY; ANETHSESOLOGY.*

Appendix C   **Inclusion and Exclusion Criteria**

Study Item	Inclusion Criteria	Exclusion Criteria
Focus of Study	Studies which explored the experiences or impact on sibling life Studies which explored different factors related to holistic experience (biological, affect, behaviour, environment) Studies where siblings directly participated Multirespondent studies including sibling themselves OR respondents across two contexts one of which is school (e.g. parent and teacher report)	Studies investigating the biological or genetic differences between siblings and measuring the risk of typically developing siblings having ASC (including prenatal studies) Intervention studies designed to support siblings with ASC Studies focusing individually on sibling relationship and not wider factors Parent report studies (where parents are the only respondent) Case studies
Participants	Aged from 4 - 25 years old Siblings of an individual with ASC or ASC with additional needs	Pre-school children Sibling of a individual with diagnoses other than ASC Adult studies where age of participants are not clearly shown or where there is 2 or less participants aged 25 and under. Studies exploring the experiences or impact on other family members (e.g. parents not siblings)
Type of Research	Peer reviewed journal articles	Reviews, conferences, unpublished dissertations
Language	Published in English	Published in any language other than English.
Country	Western Countries (North America, Europe or Australia)	Studies not conducted in Western Countries

Reasons for excluding papers for which full text was obtained

79 articles were identified as relevant and retrieved in full text, 57 of these articles were excluded due to the following reasons:

➢ TD-Sibs did not meet inclusion criteria for age (N = 9). Eight of these were adult studies and one was a preschool study. Adult studies which recruited participants from age 25, were examined in detail and those where there were two participants or less in the required age category were excluded.

➢ Articles were summaries, reviews or commentaries (N = 6)

➢ TD-Sibs were not 'typically developing' and had own diagnoses (N = 1)

➢ Articles where the country did not fit inclusion criteria (N = 10)

➢ Articles involving siblings of children with a mixture of disabilities or disabilities other than ASC (N = 10)

➢ Articles which focused on outcomes for the ASC-Sib (N = 4)

➢ Articles detailing single informant studies, using mother-report measures (N = 14)

➢ Articles which investigated TD-Sibs outcomes pre and post intervention e.g. ABA (N= 3)

Appendix D **Identified Studies**

Study number and corresponding author name and publication year

Study Number	Author and Date
1	Angell, Meadan and Stoner (2012)
2	Bagenholm and Gillberg (1991)
3	Dempsey, Llorens, Brewton, Mulchandani and Goin-Kochel (2012)
4	Fisman, Wolf, Ellison and Freeman (2000)
5	Fisman, Wolf, Ellison, Gillis, Freeman and Szatmari (1996)
6	Gold (1993)
7	Hastings and Petalas (2014)
8	Kaminsky and Dewey (2002)
9	Lovell and Wetherell (2016)
10	Macks and Reeve (2007)
11	Mascha and Boucher (2006)
12	Mates (1990)
13	Moyson and Roeyers (2011)
14	Orsmond and Seltzer (2009)
15	Petalas, Hastings, Nash, Dowey and Reilly (2009)
16	Petalas, Hastings, Nash, Reilly and Dowey (2012)
17	Quintero and McIntyre (2010)
18	Rodrigue, Geffken and Morgan (1993)
19	Ross and Cuskelly (2006)
20	Stampoltzis, Defingou, Antonopoulou, Kouvava and Polychronopoulou (2014)
21	Verte, Roeyers and Buysse (2003)
22	Wolf, Fisman, Ellison and Freeman (1998)

Appendix E **Data Extraction Table**

Reference	Country	Sample	Key Outcome Measures	Key findings (effect size provided if reported)	Limitations
(1) Angell, Meadan & Stoner (2012) *Qualitative*	USA	**Informants:** TD siblings **TD-Sibs:** 12 (6M, 6F) 7-15yrs **ASC-Sibs:** 11M, 1F Aged 6-15yrs, Diagnosis: Autism	Semi-structured interviews (interpreted through framework of family systems theory)	TD Siblings strove for academic success, wanting to do well in school & older TD-Sibs were involved in ASC-Sibs education Socially competent but expressed desire for more who understood. Assumed roles of responsible caregivers, sibling helpers, entertainers, aggression rescuers and parent helpers Emotional love, pride & bonds with sibling. Heightened sense of responsibility, concern for ASC-Sib social acceptance and safety, anxiety for future. Embarrassment caused by ASC-Sibs challenging behaviour Coping strategies to broaden personal boundaries (seek support, teaching others) or restriction through isolation	Not generalizable beyond participants Recruitment via ASC support group Age (wide span) Limited family context information
(2) Bagenholm & Gillberg (1991) *Mixed Methods*	Sweden	**Informants:** TD-Sibs & parents 3 groups matched on SES, gender, birth order: **1. TD-Sibs (with ASC-Sibs):** 20 (12M,8F), 5-20yrs	Piers-Harris Children's self-concept scale Rutter Scale (behaviour) Semi structured Interview	No difference in self-concept across three groups. TD-Sibs & Sibs of children with LD had more parent reported behaviour problems than Sibs of children with no disability. Also self-reported that they had to help out more at home. TD-Sibs with ASC Sibs (group 1): - 55% had no words to explain how ASC-Sib was different - 35% could only talk with somebody outside the home about ASC-Sib - 35% reported feeling lonely (appropriate sadness)	Cultural subjectivity Small sample Teacher reports were collected but not used due to low response rate - reluctance from TD-Sibs to consent to this. Not discussed further.

		2. Sibs of children with learning difficulty 3. Sibs of children with no disability **ASC-Sibs:** 20 (16M,4F), 5-12yrs. Diagnosis: Mild, moderate or severe autism		- Had more problems with sibling disturbing them & breaking things than other groups More concerned about ASC-Sib future than other groups	
(3) Dempsey, Llorens, Brewton, Mulchandani & Goin-Kochel (2012) *Quantitative*	USA	**Informants:** Parents, Teachers **TD-Sibs:** 486 (219M, 267F), 6-18yrs **ASC-Sibs:** 486 (418M, 68F), 4-18yrs. Diagnosis: Autism Normative data	Child Behaviour Checklist (CBCL) - Parent & Teacher version	Teachers or parents did not report elevated internalising or externalizing behaviour problems TD-Sibs fewer internalising problems than children of the same age in normative sample. ES suggest difference is small: Parents (0.13); Teachers (0.26). TD-Sibs fewer externalising problems than children of the same age in the normative sample. ES suggest difference is small: Parent (0.32); Teachers (0.32) Low agreement between parent and teacher scoring	Sample from Simons Simplex Collection (SSC) Prior access to support interventions Academic skills, adaptive functioning unexplored Sibling self-report absent No control group
(4) Fisman, Wolf, Ellison & Freeman (2000) *Quantitative*	Canada	**Informants:** Parents, Teachers & Siblings Matched on race, gender, birth order	The Survey Diagnostic Instrument (adapted from CBCL) - Parent & Teacher version	TD-Sibs continued to have highest level of parent-identified externalising problems. High levels of parent-identified internalising problems not maintained at follow up.	Data not reported for the time period between the two study time points No objective observer ratings

	1. TD-Sibs: 42 (16M, 26F). 11-19yrs	Beck Depression Inventory (Parents)	TD-Sibs continued to have highest level of teacher-identified internalising problems (marginally significant effect, p<0.06, compared to controls)	Self-report single measures
	2. 45 Sibs (17M, 28F) of children with DS. 11-19yrs		TD-Sibs had more reported behaviour problems (particularly externalising) over time than sibs of children with DS or controls.	Mother and father perspectives would be useful
	3. 46 Sibs (18M,28F) of children with no disability. 11 -19yrs		For TD-Sibs - high level of parent distress maintained over time; mediator for TD-Sibs behaviour.	
	ASC-Sibs: 35M, 7F, aged 7-21yrs. Diagnosis: PDD			
(5) Fisman, Wolf, Ellison, Gillis, Freeman & Szatmari (1996) *Quantitative* Canada	**Informants:** Parents, Teachers & Siblings **1. TD-Sibs:** 46 (18M, 27F). 8-16yrs	The Survey Diagnostic Instrument (adapted from CBCL) - Parent & Teacher version The Social Support Scale for Children	Parents reported sig. more internalising and externalising difficulties for TD-Sibs than DS or control group. Teachers reported sig. more internalising difficulties (not externalising).	
	2. 45 Sibs (17M, 28F) of children with DS. 8-16 yrs		Controls reported more conflict and less warmth in sib relationship.	
	3. 46 Sibs (18M,27F) of children with no disability. 8-16 yrs (Control group)	Sibling Relationship Questionnaire-Brief Version	Parental distress (highest in PDD group) mediated relationship between group and parental reports of internalising and externalising behaviour.	
	ASC-Sibs: 37M, 8F			

7-18yrs. Diagnosis: PDD

(6) Gold (1993) *Quantitative*	Canada	**Informants:** Parents and siblings **1. TD-Sibs:** 22 (11F,11M), 7-17yrs 2. 34 Sibs of children with no disability **ASC-Sibs:** 22M, Aged 7–17yrs	Children's Depression Inventory (CDI) Child Behavior Checklist (CBCL) (Mothers & Fathers) Questions for Siblings (researcher -constructed)	TD-Sibs scored sig higher on depression than controls Adolescent siblings scored higher than those aged under 12 years. Specific characteristics of the ASC-Sib (older brother, length since diagnosis) correlated with depression in females. No sig. gender effect but suggests difference in contributing factors. TD-Sibs who reported having no one to talk to about having ASC-Sib scored sig. higher on depression. No significant differences in social competence or behaviour problems Sisters did more domestic work than brothers. TD-Sibs did less domestic work than controls, caregiving work approached significance (p<.06)	When most conservative cut off score applied, 50% fall into depressed range (11/22 TD-Sibs) Proportionally more adolescent TD-Sibs than controls (but n.s)
(7) Hastings & Petalas (2014) *Quantitative*	UK	**Informants:** Siblings & Mothers **TD-Sibs:** 94 (47M, 47F) 7-17yrs **ASC-Sibs:** 73M, 21F.	Strengths and Difficulties Questionnaire (SDQ) (Self report) Sibling Relationship Questionnaire (SRQ)	TD-Sibs reported slightly elevated levels of behavior and emotional problems compared with normative. No mean scores were statistically significant and associated effect sizes all very small (all under 0.20 except peer problems 0.31). Although small ES, more than four times (6.7% compared with 1.5%) the expected proportion of	Small sample and associated effect size Sample not representative SDQ as a measure of ASC-Sibs behaviour

		4-17yrs. Diagnosis: PDD, Aspergers, Autism		siblings reported peer problems in the clinically concerning range	
		Normative data			
(8) Kaminsky and Dewey (2002) *Quantitative*	Canada	**Informants:** Siblings and Parents Matched on gender, birth order, age: **1. TD-Sibs:** 30 (Gender NR). 8-18 yrs 2. 30 Sibs of children with DS. 8-18 yrs 3. 30 Sibs of children with no disability. 8-18 yrs. **ASC-Sib:** 8-18yrs Diagnosis: Autism (PDD & Aspergers excluded)	Child Behaviour checklist (CBCL) Social Support Scale for Children (SSSC) Loneliness and Social Dissatisfaction Questionnaire (LSDQ)	No sig. differences in internalising, externalising or total behaviour problems for TD-Sibs, DS or controls. All groups reported low levels of loneliness and high levels of social support (family, friends and teachers) TD-Sibs higher levels of social support from classmates/friends associated with lower levels of loneliness and higher academic functioning (CBCL) No significant results for social competence but sisters of ASC-Sibs reported highest average social competence scores and brothers of ASC-Sibs reported lowest average scores.	Some of participants older than the subject sample used to norm SSSC & LSDQ Large number of participating siblings attended support group 80% of siblings older than ASC-Sibs Gender distribution of sibling dyads not provided.
(9) Lovell and Wetherell (2015) *Quantitative*	UK	**Informants:** Siblings, mothers **1. TD-Sibs:** 22 (45.5% F 55.5% M), 7-17yrs)	Children's Depression Inventory-2 Social Support Scale for Children	No sig differences on social support (all np2= < .10) Groups comparable on basal HPA axis activity; no differences and typical secretion pattern displayed	Caregiver support group Mothers asked to oversee accurate completion of questionnaires

		2. 18 Sibs (53% F, 47% M) of NT children. Mean age 11yrs (Controls) **ASC-Sibs:** 3-21 yrs, Gender NR	Physiological measures	TD-Sibs reported higher depression scores than controls (ηp^2 =.10). Results indicated driven more by emotional (p=.04, ηp^2 =.10) rather than functional problems (non-sig). Total depressive symptoms were in part influenced by availability of social support, along with behavior problems of ASC-Sib (accounted for 82% of the variance in scores on CDI-2). Greater support from family and close friends may act as a buffer	Small sample size - post hoc power analysis suggested N=43 needed for adequate power (to detect moderate ES)
(10) Macks and Reeve (2007) *Quantitative*	USA	**Informants:** Siblings & mothers **TD Siblings:** 51 (21M, 30F) siblings of children with ASC, aged 7-17yrs Control group: Siblings of TD-children: 36 (16M, 20F) 7-17yrs **ASC-Sibs:** 7-17yrs, Gender NR. Diagnoses of Asperger syndrome & PPD excluded	Children's Depression Inventory Short Form (depression) Piers-Harris Children's Self-concept scale (self-concept) Behaviour Assessment Systems for Children-Parent Rating Scale (BASC-PRS) (Ext. & Int. Behaviour)	TD-Sibs scored sig. higher on self-concept (e.g. total score, behaviour, intelligence & academic skills) No significant difference in depression scores No significant difference in parent-reported behaviour Cumulative risk scale of demographic factors created. High risk included being male, low SES, having only one sibling, and being older than the child with ASC. Low risk included being female, high SES, having multiple siblings, and being younger than the child with ASC. For TD-Sibs, sig positive association with TD-Sibs depression scores, sig negative association with self-concept scores & adaptive behaviour. Not found for controls. As number of demographic risk factors increase, negative impact increases.	Small sample Recruited from day school where accessing support Mother reports (not fathers) Need to compare self-report and parent-reports of the same measure
(11) Mascha and Boucher (2006)	UK	**Informants:** TD Siblings	Semi-structured interviews	10 TD-Sibs reported positive aspects of experiences	Pilot study – unable to analyse

Qualitative	**TD-Sibs:** 14 (4M, 10F), 11-18yrs **ASC-Sibs:** 7-20yrs, Gender NR Diagnoses: moderate to low functioning Autism, HFA, Aspergers		ASC-Sib aggression (tantrums, anger, explosiveness) perceived as most negative experience. Felt embarrassed by ASC-Sib behaviour – found public situations, others attitudes & friend introductions particularly challenging Other aspects reported: lack of privacy, inability to have friends home, interference with personal life, demands on parental time, holiday restrictions.	Small sample 6 siblings from 3 families (not independent) Unrepresentative sample
(12) Mates (1990) USA *Quantitative*	**Informants:** TD-Sibs, Parents, Teachers **TD Sibs:** 33 (18M, 15F), 5-17yrs **ASC-Sibs:** 5-17yrs, (gender NR). Diagnosis: mild to moderate Autism Comparison: Normative data	Piers Harris Self Concept scale (Self- Concept) Wide Range Achievement Test (Academic Achievement) The Rutter Questionnaire for Parents (1) and Teachers (2)	Self-Concept: TD-Sibs significantly higher scores than normative data No significant differences in academic achievement (reading, spelling, arithmetic) No significant differences in parent reported home behaviour No significant differences in teacher reported school behaviour No effect of gender or family size on measures	Families received support through TEACCH programme No control group Small sample with wide age range
(13) Moyson and Belgium Roeyers (2011) *Qualitative*	**Informants:** Siblings **TD-Sibs:** 17 (7M, 10F), 6-14yrs	Semi-structured Interviews and focus groups	TD-Sibs accept and adjust to their specific situation Joint sibling activities were important but so was accessing and maintaining private time	Participants contacted via parents All medium/high SES

	ASC-Sibs: 17M, 5-16yrs, Diagnosis: Autism (without LD), mild-moderate impairment		ASC-Sibs behaviour difficult to live with. TD-Sibs looked for ways to cope with aggressive behaviour. Invisibility of ASC is challenging - seemingly 'normal'. Outside world perceived as challenging - being 'allowed' to tell others or not created additional tension. Without sharing this, there was no acknowledgement of situation. Others often did not know about their experiences. Appreciated opportunities to exchange similar experiences.	ASC-Sibs all male Cultural differences
(14) Orsmond and Seltzer (2009) USA *Quantitative*	**Informants:** Mothers and Siblings **TD-Sibs:** 57 (majority female), 12 – 18yrs. **ASC-Sibs:** 40M, 17F 14-21yrs. Diagnosis: Autism	Centre for Epidemiological studies depression scale (CES-D) Revised children's manifest anxiety scale (RCMAS) Life Events Checklist	1/3 (36%) of TD-Sibs reported depressive symptoms at or above the CES clinical cut-off score. 8.5% of siblings reported clinically significant anxiety symptoms. Similar to expected community sample. Scores did not differ significantly whether the sibling currently lived with ASC-Sib or not. Similar to community samples, sisters reported higher levels of depressive and anxiety symptoms than brothers. Brother's reported lower levels of depression and anxiety than community samples. High maternal depression associated with depression and anxiety in TD-Sibs. Partial support for diathesis stress model. BAP associated with higher depression & anxiety scores in presence of high number of stressful life events	Mother reported, brief measures of ASC family history & BAP Sample volunteered for longitudinal, larger study TD-Sibs younger than ASC-Sibs Preliminary study as lacked statistical power to fully test interaction terms due to small sample The study identifies risk, highlights need for intervention but no consideration of what this would look like

(15) Petalas, Hastings, Nash, Dowey & Reilly, (2009) *Qualitative*	UK	**Informants:** Siblings **TD- Sibs:** 8 (3M, 5F), 9-12yrs **ASC-Sibs:** 8M, 8-17yrs, Diagnosis: Autism & LD (3), Aspergers (5) – 1 co-morbid ADHD	Semi- structured interviews	Variation in impact due to unique experience. All reported positive aspects (pride). Daily lives disrupted - parent time, atypical roles, sleep. Experienced frustration, anger, embarrassment and anxiety due to reactions/attitudes of others (peers and strangers). Led to withdrawal, over explaining or remaining silent. Some TD-Sibs felt rejected & socially isolated. Social support seen as important, especially when there is open communication. Expressed positive acceptance but some tension in wanting things to be different.	Recruitment through support agencies All ASC-Sibs male Participant reflection on themes not included
(16) Petalas, Hastings, Nash, Reilly & Dowey (2012) *Qualitative*	UK	**Informants:** Siblings **TD-Sibs:** 12 (6M, 6F) 14-17yrs **ASC-Sibs:** 12M, 4-18yrs, Diagnosis: Autism & LD (9), Aspergers (3) C & ID, 3 Aspergers.	Semi- structured interviews	All reported positive aspects of experiences e.g. tolerance, diversity, shared moments. Appraisal of current circumstances based on past context. Future worries. Assumed responsibility. Difficult to manage ASC-Sib's aggressive behaviour. Experience embarrassment in social situations – emotional discord between acceptance and fairness. Sense of empathy and compassion. Anger, frustration and disappointment at others reactions.	Findings considered in context (geographical location, all male ASC-Sibs) TD-Sibs older than ASC-Sibs 12 fairly large sample for IPA
(17) Quintero & McIntyre (2010) Quantitative	USA	**Informants:** Mothers, Teachers **TD Siblings:** 20 (38.9% M), 6-10yrs	Child Behaviour Checklist (Parent & Teacher) (externalising and internalising behaviour)	No sig. differences in teacher-reported academic competence, both groups within average range No sig. differences in parents and teacher reports of behaviour problems and within average range.	Small homogenous sample with few demographic risk factors Not considered cumulative effects and follow up

		ASC-Sibs: 64.7% M, 2-5yrs. Autism diagnosis	Social Skills Rating System Parent & Teacher Version (Social skills)	But moderate ES for teacher-reported TD-Sibs internalising behaviour problems (d=0.57) and total problem behaviours (d=0.41) – TD-Sibs scored higher than controls but not statistically sig.	Limited information about ASC-Sib (e.g. severity)
		Control group: 23 siblings of TD children (54.5% M)	Academic Competence Subscale	No sig. differences in parent-reported or teacher-reported social skills (co-operation, assertion, self-control responsibility), within average range	
(18) Rodrigue, Geffken, Morgan (1993) *Quantitative*	USA	Informants: Siblings, Mothers and Fathers TD-Sibs: 19 (10F, 9M) Mean age 10.2yrs 20 Sibs (10F, 10M) of children with DS, 11.05yrs 20 sibs (12F, 8M) of children with no disability, 9.5yrs ASC-Sib: 10.98yrs. Diagnosis: Autism & severe developmental disabilities	Child Behaviour Checklist Perceived Competence Scale for Children OR Pictorial Scale of Perceived Competence & Social Acceptance (age-dependent)	TD-Sibs had more mother-reported internalizing and externalizing behaviour problems than sibs of children with DS or sibs of children with no disability. But scores fell within normal range. No sig. differences in perceived self-competence or parent-reported social competence. Older TD-Sibs had higher rates of both internalizing and externalizing behaviours (also found in other groups). Greater marital satisfaction strongly associated with higher levels of sibling perceived competence (e.g. self-esteem)	Families are part of larger research project Groups matched on mental age, gender, birth order, SES, race, family size but limited information regarding sibling groups and background (chronological age range)

(19) Ross & Cuskelly (2006) *Quantitative*	Australia	**Informants:** Siblings & mothers **TD-Sibs:** 25 (19M, 6F), 8-15yrs **ASC-Sibs:** 20M, 5F, 6-16yrs. Diagnosis: Autism Aspergers Normative data	Child Behaviour Checklist (behaviour) KIDCOPE	Mean scores of internalizing and externalizing difficulties within average range. Mothers reported 40% of TD-Sibs had significant behaviour difficulties, predominantly internalising. 84% reported an aggressive incident as most common problem. Anger was the typical response. TD-Sibs used at least three coping strategies for this, most common were emotional regulation and wishful thinking (both reported by 91% of children), followed by social withdrawal (86%); considered to be helpful.	Small unrepresentative sample No control group (aggressive incident may be common for typical sibling dyads) KIDCOPE narrowed identification of problems to one
(20) Stampoltzis, Defingou, Antonopoulou, Kouvava & Polychronopoulou (2014) *Mixed Methods*	Greece	**Informants:** Siblings, mothers, fathers **TD-Sibs:** 22 (20M, 12F). 10-18yrs **ASC-Sibs:** 73% M, 27% F, aged 6 - 26yrs. Normative data	Strengths & Difficulties Questionnaire (behaviour) Sibling Problems Questionnaire Self-Perception Profile for Children & Adolescents Semi-structured interview	Parent-reports indicated no ext. or int. behaviour difficulties. Agreement between mother-father ratings. Younger and middle age TD-Sibs scored sig lower than standard mean scores on peer relations (10-12yrs old) and close friendships (13-15 yrs old). Expressed difficulties explaining situation to peers, 86% reported friend awareness. No difference in perceived global self-worth, behaviour or relations with parents compared to normative data TD-Sibs express ability to cope but tendency to take on more responsibilities than can handle. Daily disruption can evoke feelings of bearing burden and self-doubt.	Limited details about sibling with ASC (e.g. severity, diagnosis) Cultural variability Family factors not explored Small sample No control group

Male TD-Sibs were concerned with sibling's future. Females TD-Sibs perceived differential parent treatment and increased current responsibilities.

Younger TD-Sibs (primary school age) felt more responsible than older age TD-Sibs (secondary school age). TD-Sibs older than ASC-Sib perceived parental differentiation, TD-Sibs younger than ASC-Sib perceived parents had more positive attitude to ASC-Sib.

(21) Verte, Roeyers & Buysse (2003) *Quantitative*	Belgium	**Informants:** Siblings & parents **1.TD-Sibs:** 29 (17M, 12F) 6-16yrs 2. 29 (17M, 12F) siblings of TD children - control group matched on age, gender, birth order, age spacing and family size. **ASC-Sibs:** 28M, 1F. 9-16yrs. Diagnosis: ASD, PDD - HFA	Child Behaviour Checklist (int. & ext. behaviour) Matson Evaluation of Social skills with youngsters Self-Description Questionnaire I & II (Self- Concept)	More parent reported behaviour problems (externalising and internalising) in TD-Sibs than control group. Particularly TD-Sibs aged 6 -11yrs but mean scores did not fall into clinical or subclinical range. TD-Sibs aged 12 to 16 years) had higher perceived social competence and a more positive self-concept than sisters in control group.	ASC-Sibs were part of a semi-residential treatment programme (four nights in treatment centre)
(22) Wolf, Fisman, Ellison & Freeman (1998)	Canada	**Informants:** Siblings, mothers, teachers	The Survey Diagnostic Instrument (int. and ext. behaviour)	TD-Sibs parents reported int. & ext. behaviour difficulties at time 1 and higher levels by time 2. Reported by teachers at time 2. Difficulties related	Absence of observational data

Quantitative	1. **TD-Sibs:** 46 (18M, 28F) 8-16yrs	Self-perception profile for children (Self-competence)	to perception that TD-Sib was parentally preferred over ASC-Sib.	Appropriateness of measure for parent differential treatment
	2. 45 (17M,28F) Sibs of children with DS, 8-16yrs		Low competence predicted internalising difficulties	
	3. 46 (18M,28F) Sibs of TD children, 8-16yrs	Social Support Scale for Children (Perceived support)	Positive effect of social support for all siblings. Lower levels of social support associated with parent and teacher reports of difficulties. Teacher social support important in protecting against behaviour difficulties at time 1 and 2 for TD-Sibs	
	ASC-Sibs: 38M, 8F, 4-18yrs. Diagnosis: PDD	Sibling relationship questionnaire (parental differential treatment)		

Data Extraction Figures

Information extracted from the 22 studies included the study type, descriptive sample data (sibling age and gender), countries where the research was conducted, outcome measures (including informants) and key findings. Additionally, the papers were explored for discussion of an underpinning psychological theory or framework to inform the selected research questions. Relevant -information was also extracted for quality assessments of the studies.

Of the 22 selected studies, 15 were quantitative studies, five were qualitative studies and two used mixed methods but quantitatively coded the data (2, 20). All quantitative papers were cross-sectional in design, three of these were longitudinal (4, 5, 22) and two (4, 5) were part of the same study (pre and post follow up). Research took place in the USA (7), Canada (5), UK (5), Australia (1), Belgium (2), Sweden (1), Greece (1).

Overall 1127 siblings of individuals with ASC were involved in the studies. The gender split across these participants were fairly equal, with 42% male siblings (N=473), 49% female siblings (N=547) and 9% of gender non-disclosed (N=107). Just over half (52%, N=588) of the total 1144 siblings were involved directly, the remaining 48% (N=539) were from multi-respondent studies involving parent and teacher reports. Participants ranged in age from 4 to 20 years old, and only one study (2) recruiting participants beyond 18 years old. No studies were identified exploring the young adult population (e.g. 16 to 25 years old).

Out of the 22 studies, 16 articles did not explicitly discuss an underpinning psychological theory for the research. One study analysed data through 'a family systems lens' (1) whilst others referred to family systems theory but did not provide detail of theoretical assumptions guiding the research questions (19, 22). Two studies appeared to adopt a risk and resiliency framework (4,5), one study applied a diathesis stress model (14).

Appendix F   **Quality Assessments**

F.1   Qualitative Studies

Qualitative Study	Clearly states aims	Appropriate qualitative method	Research design explained	Recruitment details & explained	Data collection explained	Considered researcher-participant relationship	Ethical issues considered	Rigorous data analysis & explanation	Clear statement of findings	Valuable research?	Total rating (out of 10)
(1) Angell, Meadan & Stoner, 2012	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	8
(11) Mascha & Boucher, 2006	Yes	Yes	Yes	Yes	Yes	Yes	No	NR	No	Yes	7
(13) Moyson & Roeyers, 2011	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	8
(15) Petalas, Hastings, Nash, Dowey & Reiley, 2009	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10
(16) Petalas, Hastings, Nash, Reily & Dowey, 2012	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10

F.2 Quantitative Studies

Quantitative Study	Objectives clearly stated	Sample specified and defined	PPs recruitment detailed	Representative Sample	Inc/exc criteria specified & applied	Sample size justified (power/ effect/ variance)	Description of ASC diagnosis, severity, measured (exposure)	Outcome measures clearly defined	Sufficient time frame	Those measuring outcomes blinded	Lost participants detailed (if follow up)	Potential confounding variables comment/ measured/ controlled	Statistical test clearly described (e.g. p-values)
(2) Bagenholm & Gillberg 2011	Yes	Yes	Yes	No	No	NR	Yes	No	N/A	NR	N/A	Yes	Yes
(3) Dempsey et al. 2012	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	N/A	NR	N/A	Yes	Yes
(4) Fisman, Wolf, Ellison & Freeman, 2000	Yes	Yes	Yes	No	Yes	NR	No	Yes	Yes	NR	Yes	Yes	Yes
(5) Fisman, Wolf, Ellison, Gillis, Freeman & Szatmari, 1996	Yes	Yes	Yes	No	Yes	NR	No	Yes	Yes	NR	N/A	Yes	Yes
(6) Gold, 1993	Yes	Yes	Yes	No	Yes	NR	Yes	Yes	N/A	NR	N/A	Yes	Yes
(7) Hastings & Petalas, 2014	Yes	Yes	No	No	No	No	Yes	Yes	N/A	NR	N/A	Yes	Yes
(8) Kaminsky & Dewey, 2002	Yes	Yes	No	No	No	NR	Yes	Yes	N/A	NR	N/A	Yes	Yes

(9) Lovell & Weatherell, 2016	Yes	Yes	Yes	No	Yes	No	No	Yes	N/A	NR	N/A	No	Yes
(10) Macks & Reeve, 2007	Yes	Yes	Yes	No	Yes	NR	Yes	Yes (not detailed)	N/A	NR	N/A	Yes	Yes
(12) Mates, 1990	Yes	Yes	Yes	No	Yes	NR	Yes (not detailed)	Yes	N/A	NR	N/A	No	Yes
(14) Orsmond & Seltzer, 2009	Yes	Yes	Yes	No	Not preapplied	No	Yes (not detailed)	Most except one	N/A	NR	N/A	Yes	Yes
(17) Qunitero & McIntyre, 2010	Yes	Yes	Yes	No	Yes	Yes	No	Yes	N/A	NR	NA	Yes	Yes
(18) Rodrigue, Geffken, Morgan, 1993	Yes	Yes	NR	No	NR	NR	No	Yes	N/A	NR	N/A	Yes	Yes
(19) Ross & Cuskelly, 2006	Yes	Yes	NR	No	NR	NR	Yes	Yes	N/A	NR	N/A	Yes	Yes
(20) Stampoltzis et al, 2014	Yes	Yes	NR	No	NR	NR	No	Yes	N/A	NR	N/A	Yes	Yes
(21) Verte, Roeyers & Buysse (2003)	Yes	Yes	NR	No	NR	NR	Yes	Yes	N/A	NR	N/A	Yes	Yes

| (22) Wolf, Fisman, Ellison & Freeman | Yes | Yes | Yes | No | Yes | NR | Yes | Yes | Yes | NR | Yes (not detailed) | Yes |

Quality Assessment Commentary

The seven qualitative studies were assessed using the checklist and accompanying guidance produced by the Critical Appraisal Skills Programme (CASP). Although studies were given an overall rating out of 10 (see Appendix B) based on the number of checkpoints, the checklist was used more qualitatively as a guide for comparison across the studies. Pre-existing quality assessment tools were not deemed appropriate for non-intervention, cross-sectional quantitative studies. The National Institute of Health (NIH) observational cohort and cross-sectional study tool and the adapted form of the Newcastle Ottawa Scale (Hermont et al., 2014) were jointly considered but instead key ideas from both tools were used to create a checklist to compare certain aspects across studies. It was not appropriate to apply an overall scoring system to this checklist and indeed a numerical system may not be the most useful method for quality analysis of research findings (Booth, Papaioannou & Sutton, 2011). Therefore, like the CASP, it was used more qualitatively to compare strengths and weakness of the selected studies in order to consider their overall quality.

Quantitative Studies

The majority of the quantitative studies focus on the adjustment of siblings with a brother or sister with ASC but the variation in terminology is noteworthy. Across the 11 studies the terms adjustment (13, 19), social adjustment (6), emotional and behavioural adjustment (3, 4, 5, 18), social, behavioural and academic adjustment (17), psychosocial adjustment (8, 10) and psychological adjustment (21) were used. Four further studies referred to psychosocial effects (2), psychophysiological impact (9), psychosocial characteristics (20) and wellbeing (14). Terms were not defined and further variation was added by the way they were operationalised for measurement and tool selection. Generally, however, measurement tools were clearly described and stated the relevant outcome being measured. There was also considerable overlap in the constructs measured (e.g. externalising and internalising behaviours) which is reflected in the later results section.

All 17 papers reporting on quantitative results clearly stated their research aims and specified their sample. However, the generalisability and representativeness of the samples were often limited by the recruitment methods adopted, such as approaching local support groups and early intervention settings or using the data from screening studies. Therefore participants are likely to have been in families already seeking support or looking for support, compared to other families without support who may potentially be more vulnerable. Only 9 out of the 17 studies discussed a predetermined inclusion and exclusion criteria prior to recruitment and it seems that the majority of studies used an opportunity sample based on the number of responses they received to study adverts. Furthermore, the sample size used across studies were rarely justified; only five studies discussed effect sizes and three of these studies (7, 9, 14) identified that their sample size was not sufficient. Consequently, the inconsistencies across the samples recruited make it difficult to compare and draw conclusions across findings.

The majority of studies identified potential confounding variables and discussed ways in which they had been measured, controlled or acknowledged the need to control them in subsequent studies. Interestingly, studies tended to confirm the diagnosis and type of ASC through assessment or parent or sibling reports (e.g. Pervasive Developmental Disorder or Autism) but did not always consider the severity of the condition as an additional variable. The studies which did acknowledge this, provided specific diagnostic information (e.g. study 23 identified the brothers and sisters as having high functioning ASC), used a broad continuum reference from mild to severe (2, 6, 12) or measured the functioning of the individual diagnosed with ASC (e.g. 3). The severity of the condition may vary within the families recruited and this could act an additional confounding variable which many of the selected studies have not considered.

All of the selected studies used a comparison group, but there was variation in the type of comparison data used. Six studies used normative data instead of a control group (3, 7, 12, 14, 19, 20). 11 studies used siblings of typically developing siblings as a control group (2, 4, 5, 6, 8, 9, 10, 17, 18, 19, 22), with five of these studies (3, 5, 6, 9, 20) using an additional comparison group of siblings of children with a different disability (e.g. Down Syndrome or intellectual disability). These studies tended to use matched control groups but there was slight variation in the variables on which siblings were matched. Generally, these tended to include gender and age as well as birth order (4, 5, 8) or socio-economic status (2).

Qualitative Studies

All qualitative studies directly explored sibling perceptions and experiences through semi-structured interviews. Three studies (1,2,13) included an example of the interview schedule used and the authors of two other studies provided this when contacted (15,16). Interviews tended to discuss the experience of being a sibling and growing up with an individual with ASC (including sibling relations), self-identified sibling support needs and sibling knowledge of ASC. This was likely to be particularly useful for building researcher and participant rapport as the studies involved young siblings. The use of interviews helped to explore both the positive and challenging experiences because interviewers are able to respond flexibly to siblings' answers to elicit examples or further enquiry, unlike the rigidity of pre-determined quantitative tools.

The majority of studies clearly stated research aims, used appropriate qualitative methods and provided details of data analysis including credibility checks. It is noted that the level of analytical detail varied; some studies provided a comprehensive step by step approach and others briefly described open coding. Most studies (except number 10) clearly explained their findings, but it is noted that this was a preliminary study which may have limited their depth of analysis and conclusions. Only some studies considered the researcher-participant relationship (11, 15, 16) and only two discussed ethical considerations (15, 16). This is concerning when considering the sensitivity of the topic and the potential power imbalance when adults are interviewing children or young people.

Appendix G **Interview Schedule**

Interview Schedule
Version 3, 06/01/15

ERGO Study ID number: 17370

UNIVERSITY OF
Southampton

Semi-structured Interview Schedule

Project title: Exploring the lived experiences and perceptions of education for siblings of individuals with Autism Spectrum Condition (ASC)

Researcher: Kirsty Underwood, supervised by Dr George Johnson and Dr Klair Norman

Introductory Conversation

a) Warm-up dialogue (introduction, kind of day participant has had)
b) Thanks for participation
c) Request to see signed Consent Form to verify full informed consent to participate
d) Completion of demographic form 2
e) Reminder of research objectives (i.e. to explore siblings views about growing up with a brother/sister with Autism thinking about your school and educational experiences) and approximate duration (i.e. 60 minutes)
f) Reminder that the interview shall be audio-recorded and transcribed verbatim with all personal details anonymised, although write up will include quotes
g) Reminder of right to withdraw consent to participate any time without penalty
h) Reminder of right to decline to answer any questions without explanation
i) Ask if participant has any questions before we begin

NB _____ = name of sibling with ASD

Main Interview Questions

[Reassure participant that there are no right or wrong answers, and that I'm seeking to hear and understand his/her views]

As you know, I am doing a project to try and better understand the experiences of siblings with a brother or sister with Autism Spectrum Condition (ASC).

I'd like to ask you some questions to hear your views about how your school and education experiences may have been influenced by growing up with a brother or sister with ASC.

I'd like us to think and talk about different aspects of your school experiences in relation to this. This includes learning as well as other things such as motivation, friendships and the overall positives and challenges. Does that sound ok? (Pause for answer).

1. If we start by thinking about your learning and achievement at school, tell me a bit about whether your experience as a sibling of a person with ASC may have had any influence on this?

2. *There are lots of things that can affect learning such as motivation, perseverance, confidence, and belief in ourselves. In what ways do you feel your experience with your sibling with ASC impacted (if at all) on things like this?*

3. Tell me about the impact (if any) on your relationships in school?
Prompts: Friendships? Personal relationships? Teacher relationships?

4. Were there any way(s) that your experience with your sibling with ASC made your education and school life more positive and rewarding?

   Prompt: *If yes, can you tell me more about this?*

5. Were there any way(s) that your experience with your sibling with ASC made your education and school life challenging?

   Prompt: *If yes, can you tell me more about this?*

6. How much did you feel you had support and input for your experiences, and by who?

   Prompt: *for parents- how equitable do you feel this was?*

7. In what ways (if any), do you think your experiences affected your career and choices as a learner and young adult?

   Prompts: *parenting, family, future planning, aspirations*

8. What, if anything, do you think is needed in order for siblings of brothers or sisters with ASC to do well in life?

9. Is there anything else you'd like to tell me?

Additional Notes

- Responses to all questions to be explored with appropriate prompts including: "What did you mean....?", "Can you give me more detail...?", "Would you be able to tell me more about...?" "Why do you think that is?" "In what way?"

Follow-up Procedure

1. Administer debriefing Statement
2. Provide participant with Amazon Gift Voucher
3. Request participant's signature
4. Enquire whether participant has any questions about the project at this time
5. Invite participant to contact me at a later date with any questions which may arise
6. Offer to send participant a summary of the research findings upon completion of the project
7. Thank you for participating in the project

Appendix H   **Ethical Approval**

From: ERGO [mailto:ergo@soton.ac.uk]

Sent: 15 January 2016 01:03

To: Underwood K. <ku1g13@soton.ac.uk>

Subject: **Your Ethics Amendment (Ethics ID:18726) has been reviewed and approved**

Submission Number 18726: This email is to confirm that the amendment request to your ethics form (Exploring the lived experiences and perceptions of education for siblings of individuals with ASC (Amendment 1)) has been approved by the Ethics Committee.

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment)

Comments None

Click here to view your submission

ERGO : Ethics and Research Governance Online

http://www.ergo.soton.ac.uk

DO NOT REPLY TO THIS EMAIL

From: ERGO [mailto:ergo@soton.ac.uk]

Sent: 13 October 2015 14:03

To: Underwood K. <ku1g13@soton.ac.uk>

Subject: Your Ethic Submission (Ethics ID:17370) has been reviewed and approved

Submission Number: 17370 Submission Name: Exploring the lived experiences and perceptions of education for siblings of individuals with ASC. This is email is to let you know your submission was approved by the Ethics Committee.

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment)

Comments None

Click here to view your submission

ERGO : Ethics and Research Governance Online

http://www.ergo.soton.ac.uk

Appendix I **Advert, Recruitment and Invitation Letters**

Study Advert
Version 2, 28/09/15
ERGO Study ID number: 17370
Researcher: Kirsty Underwood

Supervisors: Dr George Johnson, Dr Klair Norman

UNIVERSITY OF
Southampton

RESEARCH STUDY:

Are you a sibling of a child or young person with Autism Spectrum Condition (ASC)?

Are you aged between 16 and 25 years old?

Title: Exploring the lived experiences and perceptions of education for siblings of individuals with Autism Spectrum Condition (ASC)

I am doing a research project about the educational experiences of siblings of young people with Autism Spectrum Condition (ASC). The research will involve taking part in an interview, lasting around 60 minutes.

I am interested to hear from typically developing siblings, who are aged between 16–25 years old and have a brother or sister diagnosed with ASC. They must also have lived in the same household as their brother or sister (either currently or previously when growing up). If there is more than one sibling which fits this criteria in a family, both are welcome to participate in the study.

Depending on the volume of responses, not all those who express interest may be asked to participate in this study. However those who are selected, and interviewed will receive a £20 Amazon voucher to thank them for their time and participation in the research.

It is hoped that findings from this research will help us to identify the best way to support families and schools with young people with ASC.

If you are interested, wish to find out more and/or are willing to participate in the project, please contact the researcher for more information about the study. If you are aged 16 or 17 years old (under 18) but would like to participate, please ask your parents to contact the researcher.

Thank you!

Kirsty

Kirsty Underwood, Trainee Educational Psychologist, University of Southampton. Contact: ku1g13@soton.ac.uk

Start/End dates of research: October 2015 – March 2016.

Recruitment letter (provisions, charities & services)

Version 2, 28/09/15

ERGO Study ID number: 17370

UNIVERSITY OF Southampton

Project title: Exploring the lived experiences and perceptions of education for siblings of individuals with Autism Spectrum Condition (ASC)

Dear …………………………………..

My name is Kirsty Underwood and I am a Trainee Educational Psychologist from the University of Southampton. I am currently completing a research project which aims to gain a better understanding of the experiences of siblings who have grown up with a brother of sister with Autism Spectrum Condition (ASC). Particularly, I would like to hear siblings' views about how their school and educational experiences may have been influenced by growing up with a brother or sister with ASC. For example, in their learning, school friendships and the positives and challenging parts of this.

I am looking to carry out my research with siblings of children with ASC and I am hoping that your provision/service/charity may be able to assist me in recruiting participants.

I am interested to hear from typically developing siblings, who are aged between 16–25 years old, and have a brother or sister diagnosed with ASC. They must also have lived in the same household as their brother or sister (either currently or previously when growing up). This study asks siblings to complete two brief demographic questionnaires (which will take approximately 5 minutes to complete) and to take part in an interview, which will last for approximately 60 minutes.

It is hoped that findings from this research will help us to identify the best way to support families and schools with children and young people with ASC.

If you are willing to assist with this recruitment, please could you distribute a letter of invitation (attached) to parents who have a child or young person with ASC. This can be provided to families electronically or in person/by post. You will not be asked to collect any data or provide the contact details of any families.

I will be in contact within the next week to discuss with you this possibility further.

In the meantime, if you have any questions relating to this study please do not hesitate to contact me directly via email (ku1g13@soton.ac.uk). Thank you very much for your time and support,

Best wishes,

Kirsty

Kirsty Underwood

Trainee Educational Psychologist

University of Southampton, Contact: ku1g13@soton.ac.uk

UNIVERSITY OF Southampton

Letter of Invitation: Research Study

Project title: Exploring the lived experiences and perceptions of education for siblings of individuals with Autism Spectrum Condition (ASC)

My name is Kirsty Underwood and I am a Trainee Educational Psychologist from the University of Southampton.

I am doing a research project about the experiences of siblings of young people with Autism Spectrum Condition (ASC). Particularly, I would like to hear siblings' views about how their school and educational experiences may have been influenced by growing up with a brother or sister with ASC. For example, in their learning, school friendships and the positives and challenging parts of this.

This study will involve completing two brief demographic questionnaires (which will take around 5 minutes to complete) and also involves taking part in an interview. The interview asks around nine questions, lasts for approximately 60 minutes and will take place in their preferred location (e.g. at home). The interview will be recorded using a Dictaphone.

I am interested to hear from typically developing siblings who are aged between 16–25 years old and have a brother or sister diagnosed with ASC. They must also have lived in the same household as their brother or sister (either currently or previously when growing up). If there is more than one sibling which fits this criteria in a family, both are welcome to participate in the study.

Depending on the volume of responses, not all those who express interest may be asked to participate in this study. However those who are selected, and interviewed will receive a £20 Amazon voucher to thank them for their time and participation in the research.

If you wish to find out more, are interested in taking part and are…
  ✓ a parent of a young person fitting this criteria **OR**
  ✓ a sibling fitting this criteria, aged between 18 to 25 years

Please contact the researcher (Kirsty Underwood) directly to express your interest via email to ku1g13@soton.ac.uk.

If you are
  ✓ a sibling fitting the criteria, but are aged 16 or 17 years old and wish to find out more
Your parents will be required to contact the researcher on the email above

It is hoped that findings from this research will help us to identify ways to support families and schools with children and young people with ASC.

Thank you!

Kirsty Underwood (Trainee Educational Psychologist, University of Southampton)
Contact: ku1g13@soton.ac.uk

Appendix J   **Participant Information Sheet**

UNIVERSITY OF
Southampton

Project title: Exploring the lived experiences and perceptions of education for siblings of individuals with Autism Spectrum Condition (ASC)

Researcher: Kirsty Underwood, supervised by Dr George Johnson and Dr Klair Norman

I would like to invite you to take part in a research study. Please read this information carefully and should you have any further questions please feel free to contact me. If you are happy to take part in this research, you may wish to discuss the content of this information sheet with your family and your brother or sister with ASC, should you feel this is appropriate.

What is the research project about?

This research is being conducted by Kirsty Underwood, a trainee Educational Psychologist from the University of Southampton. The aim of this study is to gain a better understanding of the experiences of siblings with a brother or sister with Autism Spectrum Condition (ASC). Particularly, I would like to hear siblings' views about how their school and educational experiences may have been influenced by growing up with a brother or sister with ASC. For example, in their learning, school friendships and the positives and challenging parts of this.

Your views and experiences are important to help us identify ways to support siblings and families of young people with ASC. This study particularly considers ways in which schools and education settings could help and support siblings.

Why have you been approached?

In order to participate in this study, the typically developing sibling must be aged between 16 to 25 years of age and have a brother or sister with a diagnosis of ASC. They must also have lived in the same household as their brother or sister (either currently or when growing up). If there is more than one typically developing sibling which fits this criteria in a family, both are welcome to participate in the study. Separate interviews will need to be completed by each sibling.

If I agree to participate, what will I be required to do?

Once you have expressed your interest to participate, you will be requested to complete a brief questionnaire requesting details including your age and gender. Following this, you will be contacted by the researcher who will confirm your participation and ask you to complete a consent form. You will then be asked to take part in an interview with myself, in a location of your preference (e.g. at home). This interview will involve approximately nine questions, will last for about sixty to seventy-five minutes, and will be recorded using a Dictaphone. You will also be asked to complete another brief demographic questionnaire.

Are there any benefits in my taking part?

Depending on the volume of responses, not all those who express interest may be asked to participate in the study. This will be decided using the brief questionnaire information provided. The researcher will confirm with you either way. Those who are selected and consent to take part in the interview, will receive a £20 Amazon voucher to thank them for their time and participation in the research. It is also hoped that findings from this research will help us to understand and identify the best ways to support siblings of children and young people with ASC, their families and their schools.

Are there any risks involved?

Whilst there are no anticipated risks, for some siblings talking about their brother or sister with ASC may elicit feelings of distress or anxiety. Should any participant experience distress at any time during this study, they are free to withdraw without having to give a reason and without their rights being affected in any way.

What will happen to the information provided?

All the information you provide will be treated confidentially. Your personal information will not be released to or viewed by anyone other than the researchers involved in the project. The interview will be recorded, transcribed and stored on a password protected computer. Information will be anonymised after data collection by changing names (e.g. Participant 1). Written results of the study will include quotes from the interview but will not include any information which reveals identifying characteristics or who you are.

What happens if I change my mind?

Participation in the study is voluntary. You have the right to withdraw from the study at any time, without providing an explanation.

Who has reviewed this study?

This study has been reviewed and approved by the University of Southampton, School of Psychology Ethics Committee.

Where can I get more information?

I hope that the experience will be informative and valuable to you. If you have any questions or would like more information, please email Kirsty Underwood at ku1g13@soton.ac.uk.

If you have questions about your rights as a participant in this research, or in the unlikely case of a concern or complaint, 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

What happens next?

If you would like to participate in this research please complete the short questionnaire provided and return it to Kirsty Underwood at ku1g13@soton.ac.uk (it is an electronic form and can be completed on the computer). Following this, the researcher will confirm whether you have been selected to be interviewed and you will be provided with a consent form to complete.

Thank you

Appendix K   Demographic Form 1

Demographic Form 1
Version 2, 28/09/15
ERGO Study ID number: 17370

UNIVERSITY OF
Southampton

Participant Initial Information (1)

Please complete the below information and return to Kirsty Underwood at
ku1g13@soton.ac.uk. This form is electronic and can be completed on a
computer.

About you:

Age (in years): _____

Gender: Male ☐ Female ☐

Are you older or younger than your brother of sister with ASC?   Older ☐ Younger
☐

Do you currently live with your brother or sister with ASC? Yes ☐   No ☐

Did you live with your brother or sister with ASC when you were growing up?

Yes ☐   No ☐

About your brother or sister with Autism Spectrum Condition:

Age (in years): _____

Gender: Male ☐ Female ☐

Has your sibling received a diagnosis of Autism Spectrum Condition: Yes ☐   No
☐

If yes, please indicate the most appropriate level of severity:

Mild ☐   Moderate ☐   Severe ☐   Very Severe ☐

Does your sibling have any additional diagnoses (e.g. ADHD)? Yes ☐   No ☐

Does your sibling live at home? Yes ☐   No ☐

Please provide an email or phone number for which the researcher (Kirsty
Underwood) can contact you on:

_____

This information is being requested to help with participant selection. Your data
will not be shared with anyone outside the research team, and will remain
confidential. It will be made anonymous by removing your contact information. If
you are not chosen to be interviewed, this information will be destroyed. **Please
indicate you have read and understood this, and consent to this information
being used in this way by ticking the box ☐**

Appendix L   **Consent Form**

UNIVERSITY OF Southampton

Project title: Exploring the lived experiences and perceptions of education for siblings of individuals with Autism Spectrum Condition (ASC)

Researcher: Kirsty Underwood, supervised by Dr George Johnson and Dr Klair Norman

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

I have read and understood the participant information sheet (Version 2, 28/09/15) and have had the opportunity to ask questions about the study

I agree to take part in this research project, for the interview to be recorded and for my data to be used for the purpose of this study

I understand that written results of the study will include quotes from the interview but will not include any information which reveals any identifying characteristics (e.g. who you are).

I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected

Name of participant (print name)..

Signature of participant...

Date...

Appendix M   **Demographic Form 2**

Demographic Form 2

Version 2, 28/09/15

UNIVERSITY OF
Southampton

Participant Information (2)

Please indicate how many siblings you have:

One ☐   Two ☐   Three ☐   Four ☐   Five ☐

Please indicate your position in the family (e.g. first born, second born)

1st ☐   2nd ☐   3rd ☐   4th ☐   5th ☐

Please indicate your brother or sister with ASC position in the family ((e.g. first born, second born)

1st ☐   2nd ☐   3rd ☐   4th ☐   5th ☐

Have you attended a sibling support group?

    Currently: Yes ☐   No ☐

    Previously: Yes ☐   No ☐

Please indicate your current living arrangement:

Living with parents/guardian ☐   Home–owner/living independently ☐

University accommodation   ☐   Other   ☐

Please indicate your highest level of education:

School Level ☐   Work–based ☐   Degree ☐   Postgraduate ☐   PHD/Doctorate ☐

Please indicate your employment status:

Student ☐   Employed ☐   Unemployed ☐   Other ☐

Thank you

Appendix N **Debriefing Statement**

Debriefing Statement

Version 2, 28/09/15

UNIVERSITY OF Southampton

Project title: Exploring the lived experiences and perceptions of education for siblings of individuals with Autism Spectrum Condition (ASC)

Researcher: Kirsty Underwood, supervised by Dr George Johnson and Dr Klair Norman

Dear

Thank you for helping with my research project and sharing your experiences with me.

The aim of the research was to help understand the experiences of young people with a brother or sister with Autism Spectrum Condition (ASC). I was particularly interested in talking to you about whether this impacted on your school and education experiences (e.g. your learning and friendships in school).

The research involved typically developing siblings, aged between 16 to 25 years old, who had a brother or sister diagnosed with ASC. It is hoped that findings from this research, will help us identify the best way to support siblings of children with ASC, particularly in school.

The research did not use any deception. The results of this study will not include your name or any other identifying characteristics, but will include quotes from your interview. You may have a summary of the research findings once the project is completed if you wish.

If you have any further questions please contact Kirsty Underwood at ku1g13@soton.ac.uk or my supervisor, George Johnson at George.Johnson@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

Please turn page over

If you have felt affected by any part of this research project and wish to speak to someone about this, please refer to some of the support services listed below:

- Your local GP surgery
- The Samaritans on 08457 90 90 90
- National Autistic Society's Autism helpline on 0808 800 4104
- Sibs: http://www.sibs.org.uk (UK charity supporting siblings of disabled people).
- Contact a family: www.cafamily.org.uk (National charity for families with disabled children) – Helpline: 0808 808 3555
- For those under the age of 18 years old and/or in education, it may be helpful to talk to your Form Tutor, Pastoral Support or Student Support Services within your school or education setting
- For those under the age of 18 years old, it may also be helpful to talk to your parents

Please sign here to show you have read and understood this debriefing statement, and that you have been given your £20 Amazon Gift Voucher.

Signed: _____

Name: _____

Date: _____

If you are under the age of 18, your parents will also receive a copy of this completed debriefing statement. I would also like to thank your parents for their participation in the project and encourage them to contact me if they have any further questions on the contact details provided above.

Thank you!

Kirsty

Appendix O   **Data Analysis Examples**

Self worth

28		he could fixate on his maths work and just run with it,
29		so I was like "oh, okay, I'm not quite that good."
30		Umm…
31		
32	I:	Could you tell me a bit more about that?
33		
34	P1:	Well it never really changed. I dunno, I always knew
35		that was the area that he was better at than me. I think
36		that was it. School, it didn't have that much of an
37		impact, it was more when he joined say my secondary
38		school and I'd feel like I had to look out for him more
39		but that wasn't umm like my personal learning was
40		being affected.
41		
42	I:	Can you explain that a little bit more for me?
43		
44	P1:	Well we did go to the same primary schools, but the
45		way that they organised keeping the juniors and the
46		seniors separate meant that we didn't actually cross
47		over at any point. Cause they kept the sort of the
48		junior school section in one area and the umm, aah
49		can't remember what they're called, the second half,
50		like the key stage three in other areas, I think so that
51		we probably didn't trample the small kids. So I didn't
52		actually see much of him, but I knew like, how they
53		were supporting him in class and what was in place,
54		because yeah, I'd come home and talk about it to
55		mum and dad, but it wasn't until I actually got to

Handwritten annotations:
- Self-concept / ability
- inner thought quote
- fixed
- Has it changed now?
- strengths comparison
- Distinct areas
- minimizing?
- Looking out for sibling (protector)
- own ability / learning
- Look out for him
- separate ages
- Primary school interaction
- Physically Separate
- Out of sight but in mind?
- brother's support
- talks to parents
- Awareness of support

Appendix O

Margin note (left)	Line	Speaker	Text	Margin note (right)

Left margin annotations:

Change in sibling relationship as got older

Reached a mutual point (short, online conversations)

Parents view different to her view. Can lead to her input

Communicator
~ Others views differ

Talking to others as a barrier

Family communication barrier

Transcript:

28   P6:   Umm, um he doesn't interact with people unless

29   they're online really. Um, we didn't get along for –

30   well, we did when we were younger and then

31   when I got older we didn't really get along, and

32   then it's getting to the point where we can

33   communicate online through short comments and

34   things on Facebook, and my parents <u>seem</u> to think

35   that I can talk to him and no one else can. If they

36   want to get something out of him they'll be like,

37   'Ooh, it's better to come from you.' So people

38   seem to think I can do it better than other people

39   can communicating with him.

40

41   I: Okay

42

43   P6:   I don't really know. It's hard to say cause he

44   doesn't really like talking to people that he's

45   related to, so yeah.

46

47   I: Okay

48

49   P6:   He doesn't – yeah, he doesn't really like talking to

50   anyone, but people he knows well he won't really

51   open up to, especially immediate family. He'll talk

52   to, like, other people, but not (us.)

53   contradiction

Right margin annotations:

Relationship has been a journey

online – hidden communication

In the middle – asked to be the go between/ communicator,

Her opinion Not being listened to by others

Lack of conviction – she doesn't feel this

NB: Not percieved as being modest.

Lack of emotional closeness

A family experience not just her

stopping thread of conversation

Mind map 1 — central box: LIVED EXPERIENCES AND PERCEPTIONS OF EDUCATION

- RISKS / vulnerability
- Acknowledgement
- VOICE
- Degree of Acceptance / Self reliance
- Self blame
- Emotional impact
- Social comparison
- 'My Normalising'
- Understanding ASC
- Living with ASC
- Home learning Environment
- Tensions / Non-stop home life
- Day to day!
- Finding an escape route / emotional coping
- Non-stop pressure / home environment
- Impact on personal resource
- Home learning / unpredictable behaviour
- Daily life with ASC
- Keeping reserved
- Burnout
- Emotional impact
- The pressure
- Daily challenges / Fighting
- Non-stop coping
- bier / x-Hook
- Finding an escape route / emotional coping / Self reliance
- Emotional impact / talk
- Inexperience
- Support / Self reliance
- Two similar experience
- Self blame / Not looking / waiting for a future support
- HARDWORKING
- ABILITY
- so / Self-reliance
- Emotional coping
- APPROACH TO EDUCATION / LEARNING / SELF EFFICACY
- Coping with failure
- Striving to do well academically
- EXPECTATIONS
- Future implications / Thinking of the future
- Social connectedness
- Not seeking support
- Friends / bullying
- Future implications
- Lack of understanding
- Rescuing from others
- Delegated Responsibility
- Being a 'Rescuer'
- Non-stop pressure
- Socially
- Non-stop pressure — always something to do

Mind map 2 — central box: How do TD, young adult siblings make sense of their experience growing up with a brother or sister diagnosed with ASC, and how does this interact with their education

- ⑤ SELF MANAGEMENT
  - EMBRACING SELF-RELIANCE
  - support?
  - LEARNING
  - FINDING WAYS TO COPE
  - SOURCES OF SOCIAL SUPPORT
- ① ACADEMICALLY DRIVEN
  - STRIVING TO DO WELL
  - SELF + PARENT EXPECTATIONS
  - THE MEANING OF ACHIEVING
  - EFFICACY / combine?
  - CLEVER AS A CONSTRUCT
  - THINKING OF THE FUTURE
- ② ACCEPTANCE
  - MY NORMALITY
  - LEARNT ACCEPTANCE
  - Ambivalence
  - MAKING SENSE OF ASC
  - Recognising in others
  - The need for support
- ③ HAVING A VOICE
  - ACKNOWLEDGEMENT
  - BARRIERS TO SHARING
  - Lack of understanding
  - vulnerability/weakness
  - Not being able to help
- ④ SENSE OF RESPONSIBILITY
  - IMPACT ON HOME STUDY
  - PARENTIFICATION
  - RESCUING / PROTECTING FROM OTHERS
  - Asking to stay
  - Running / unconscious conscious?
  - From parents / General public

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